May 2018

A PHENOMENOLOGICAL LOOK AT THE LIFE HACKING-ENABLED PRACTICES OF INDIVIDUALS WITH MOBILITY AND DEXTERITY IMPAIRMENTS

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ABSTRACT

Human-computer interaction and assistive technology research and practice are replete with examples of mostly non-disabled individuals trying to empower individuals with disabilities through the design and provision of accessible products. This study asks one overarching question: what can these communities learn from the self-driven embodied experiences of individuals with disabilities who address accessibility, impairment, and everyday life concerns for themselves? The goal of this dissertation is to examine the underexplored adaptation, modification, and design-like activities of individuals with mobility and dexterity impairments as well as the implications of these activities for researchers, designers, and individuals with disabilities. This phenomenological study examined the embodied everyday life practices of 16 individuals with mobility and dexterity impairments as well as their efforts to transform disabling practices into enabling ones. Using sensitizing constructs from contemporary social practice theory approaches as described by Andreas Reckwitz and Theodore Schatzki as well as Bruno Latour’s articulation of actor-network theory, this interpretive qualitative research study uncovers different ways participants were dis/enabled and dis/empowered in their daily life practices. Findings point to issues most HCI researchers and professional designers rarely consider in their efforts to study access issues and develop accessible technology, including the impact of the embodied perspectives of mostly non-disabled researchers and designers on the everyday life practices of individuals who live with impairments.
A PHENOMENOLOGICAL LOOK AT THE LIFE HACKING-ENABLED PRACTICES OF
INDIVIDUALS WITH MOBILITY AND DEXTERITY IMPAIRMENTS

by

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Dissertation
Submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Information Science & Technology.

Syracuse University
May 2018
Acknowledgements

First and foremost, I am grateful to God for giving me the courage, strength, and endurance needed to complete this journey. There were many times when I doubted my ability to finish the Ph.D. process. Nevertheless, as I now reflect on my time in the program, I can see a divine tapestry that is better than anything I could have imagined when I started this process in 2009. Second, I want to thank my sixth-grade teacher, Miss. Paula Bright, who played an instrumental role in helping me to see my potential at a time when I could not see it myself. I also want to express my sincere appreciation to my advisor, Jennifer Stromer-Galley, for her support and mentorship over the past five years. I thank my Dad, siblings, and the many dear friends and extended family members who listened to me, laughed with me, and prayed for me throughout this process. Finally, I want to express my gratitude for the Ph.D. process itself. I learned several academic, professional, and life lessons while working on my dissertation that I don’t think I would have learned under any other set of circumstances. I am grateful for the time and opportunities the Ph.D. process has afforded me as well as the relationships forged and refined along the way.
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Chapter 1: Introduction

Problem Statement

Design research and practice enable many individuals with disabilities to access technology, activities, places, and opportunities they would not have access to otherwise.\(^1\) Nevertheless, the exclusion of individuals with disabilities from design as well as the marginalization of their interest and potential contributions to design research lead to instantiations of the values, assumptions, and biases of an ableist society. Although there are exceptions (Anthony, Kim, & Findlater, 2013; Kane, Jayant, Wobbrock, & Ladner, 2009; Meissner et al., 2017), accessible design research and practice framed as empowering to the disability community often does not create room for the voices and experiences of individuals with disabilities to significantly inform design projects, practices, and outcomes. Since most researchers and designers not only are non-disabled members of a society that values non-disabled ways of being but also exercise control over design and research activities, individuals with disabilities rarely shape design or related knowledge about disability and design in ways that significantly benefit them in their daily lives on their terms.

Design and Disability Research

Only a fraction of the general population has a visible disability, and yet most non-disabled people have an opinion about what it means to live with an impairment. There are many well-meaning researchers and design professionals who create, test, and disseminate accessible technology and other artifacts intended to help members of the disability community. Accessible technology design is a popular and undeniably much-needed area of research within the human-

\(^1\) Design research and practice refers specifically to HCI, accessibility, assistive technology, and rehabilitation technology research/practice
computer interaction (HCI) and broader accessibility community. Assistive technology (AT), rehabilitation technology (RT), mainstream products, and technology-related services allow many individuals with disabilities to get an education, secure and maintain employment, and participate in various other daily life activities many non-disabled people may take for granted.\textsuperscript{2} \textsuperscript{3} Nevertheless, many stakeholders who design, manufacture, sell and service products for use by individuals with disabilities or provide services and supports to them are unfamiliar with the experience of disability themselves (Roulstone, 2016). On the surface, this lack of disability identity might seem unimportant, but it sometimes leads to problems for members of the disability community within the context of their daily lives.

Few non-disabled research and design stakeholders acknowledge a well-known reality within the disability studies community: technology and disability are political (Foley & Ferri, 2012; Goggin & Newell, 2003; Roulstone, 2016). As Foley and Ferri (2012) explain, the foundation for the positive claims designers make about technology and disability is taken-for-granted assumptions about what constitutes normal. These assumptions privilege non-disabled "ways of being, which are grounded in normative social, cultural, and economic practices, and, further reified in the design, manufacture, marketing, and implementation of technology" (Foley & Ferri, 2012, p. 194). Inherent in all technology design projects are ideas about what constitutes normal.

\textsuperscript{2} The legal definition of assistive technology according to the Individuals with Disabilities Education Improvement Act of 2004 is "any item, piece of equipment, or product system, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability" (IDEA 2004, Sec. 1401(1)(A). Obviously, AT can be used by adults as well as children and in work or home environments in addition to school environments. The definition provided undergirds the provision of special education services and technology to children with disabilities.

\textsuperscript{3} For this study, rehabilitation technology (RT) and durable medical equipment includes mobility aids (power wheelchairs and other motorized mobility equipment), robotic limbs, cochlear implants, and others primarily high-tech medical interventions that supplement or replace the functional capabilities of an individual with a disability (Albrecht, 1992). AT and RT along with other terms like special education technology, educational technology, instructional technology, and information technology have overlapping meaning, and people use them in different ways (Dell, Newton, & Petroff, 2011). I distinguish AT from RT on purpose because the research literature typically talks about one or the other in isolation.
"normal" ways of operating in society and participating in everyday life activity. Design undergirded by these ideas divide people based on their ability to conform to this socially-constructed notion of normal. As such, technology design represents the current zeitgeist, social constructions, and social imaginations (Roulstone, 2016). Ableist values such as individualism, self-reliance, independence, and competence as well as normative social, cultural, and economic practices guide the design, manufacture, marketing, and implementation of technology (Foley & Ferri, 2012). Design practices that exclude individuals with disabilities, as well as their perspectives and interests, lead to design outcomes that push end-users towards conformity to non-disabled norms and values. These practices do not allow individuals with disabilities to play a role in influencing what is considered normal and, therefore, force them to live life according to standards set and valued by people who may be unfamiliar with the lived experience of having a disability.

Like the practice of technology design, much disability research consists of non-disabled scholars doing their best to faithfully account for the experiences of individuals with disabilities. Non-disabled researchers typically assume expert roles in fields that seemingly champion scientific objectivity yet make critical assumptions about disability and the best ways to address it with little input from people who are familiar with disability from an experiential perspective (Roulstone, 2016). As evidenced by disability research that too often violates the experiences of individuals with disabilities and fails to address their material needs or improve their quality of life (Mercer, 2002; Oliver, 1992), the taken-for-granted values, assumptions, and worldview of people with non-disabled bodies heavily influence the research process and its outcomes. Disability studies scholar Mike Oliver (1992) describes the inextricable link between dominant social understandings about disability and disability research outcomes as follows: "Disability
cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it” (p. 101). The link between the socially-understood meaning of disability and the ableist worldview that gives rise to it has at least four negative implications for disability research. First, and perhaps most importantly, it has led to scholarship that misrepresents and distorts the experiences of individuals with disabilities (Oliver, 1992). We most clearly see this today in the prevalence of accessibility research and practice that relies on static design principles and somewhat rigid approaches intended to increase accessibility and usability (Vanderheiden, 2006) that reduce individual and collective disability experience to something uniform that can be easily understood, quantified, and modeled.

Second, it has led to a persistent power dynamic that structures the relations between mostly non-disabled researchers and participants with disabilities in ways that privilege the researcher’s abilities, knowledge, skills, and interests while giving him or her control over the focus, initiation, and direction of research (Oliver, 1992). We see this play out in several HCI research studies that adopt user-centered design, universal design, and other accessible design techniques, method and approaches (Duff, Irwin, Skye, Sesto, & Wiegmann, 2010; Jayant, 2010; Kane, Bigham, & Wobbrock, 2008; Kane et al., 2009). Despite the use of these labels, the research activities described in these studies exclude individuals with disabilities altogether, place them in advisory or consultative roles, involve them in usability testing sessions only, or leverage them as representative users. Additionally, some HCI researchers leverage non-representative users (e.g., non-disabled individuals) as proxies for members of the target population, which often leads to inaccurate conclusions and missed insights (Sears & Hanson, 2012). The problem with the researcher-driven technology design and testing activities described
is they relegate individuals with disabilities to passive or token forms of participation or exclude them from research activities altogether and thus preclude self-determination or the exercise of personal agency by individuals with disabilities in research activities that may impact their lives.

Thirdly, the influence of an ableist worldview has led to research that attributes disability solely to the individual and ignores social, structural, societal, institutional, and other factors that create problems for individuals with disabilities (Oliver, 1992). In HCI/accessibility research as well as AT/RT design there is a tendency to ignore the aesthetical wishes of end-users or make functionality and ergonomics issues secondary to technology and impairment ones when designing for members of some impairment groups (Roulstone, 2016). Also, despite adult AT abandonment rates are 29.3% (Scherer, 1996), most HCI disability research is intervention-centric (Meissner et al., 2017; Wobbrock & Kientz, 2016). When HCI researchers focus on technology and impairment issues, they often do so based on shared assumptions about the role technology should play in minimizing the effects of impairment (Roulstone, 2016) or maximizing personal independence (Foley & Ferri, 2012). Although some individuals with disabilities may value these goals, the underlying intervention-driven activities carried out by mostly non-disabled researchers leave little room for alternatives or nuance. For instance, some individuals with disabilities may value interdependence over independence and acceptance of alternative ways of being in the world over conformity to standards of normality (Foley & Ferri, 2012). Additionally, individuals with disabilities may allow their current situation to dictate the salience of a value at a given moment. Focusing on impairment and technology without adequately considering the person and context reinforces ableist norms and assumptions because the values and experiences of individuals with disabilities are subordinate to the values mostly non-disabled researchers and designers attribute to them.
Fourth, much disability research has ignored the explanations individuals with disabilities give for the problems they encounter in their daily lives and thus failed to acknowledge or attempt to address their self-defined needs and concerns (Oliver, 1992). This reality is evident in multiple top-down HCI/accessibility research projects that primarily focus on mainstream issues such as interaction with mobile phone devices, interfaces, services, and input modalities (Guerreiro, Nicolau, Jorge, & Goncalves, 2010, 2010; Jayant, 2010; Kane et al., 2009; Ornella & Stephanie, 2006; Wobbrock, Chau, & Myers, 2007) computer input techniques (Saponas, Kelly, Parviz, & Tan, 2009), or touch screen applications and interaction techniques (Duff et al., 2010; Kane et al., 2008). Although their work potentially helps some individuals with disabilities, researcher interests and goals motivate and guide these efforts which may not always align with those of potential end users. The unique and less mainstream technology and everyday life issues that individuals with disabilities encounter are unlikely to draw the attention of some researchers who, in addition to their desire to improve the lives of individuals with disabilities must meet professional goals such as getting published, acquiring tenure, and building a reputation.

Focusing on mainstream or popular issues within their research communities often can be a more rewarding road than researching contextualized problems experienced by individuals or small subgroups within the disability community.

Gaps in the Literature

A significant issue with HCI, AT, and RT research is the common tendency to ignore or overshadow the problem-solving, adaptation, and design-like activities of individuals with disabilities. Several researchers have provided empirical evidence that some individuals with disabilities currently engage in innovative adaptive behavior either independently or collaboratively or possess the capacity to do so (Anthony et al., 2013; Hook, Verbaan, Wright, &
Olivier, 2013; Kane et al., 2009; Meissner et al., 2017; Profita, Stangl, Matuszewksa, Sky, & Kane, 2016). Many of these studies, however, reduce these behaviors to fodder for researcher-led accessible design projects rather than a phenomenon that can inform design practice as well as the way we understand disability and empower those who live with one.

Do-it-Yourself Assistive Technology (DIY-AT) is a new and expanding area of interest within the HCI community. Its goal is to enable the creation and adaptation of assistive technology by non-professionals, including people with disabilities and their families, friends, and caregivers. Scholars enthusiastically advocate for empowered AT adaptation and design activities by members of the disability community as a new potentiality made possible by rapid prototyping tools, 3-D printing, and online communities. Nevertheless, many of these same researchers say that inaccessible Maker tools and limited direct support for individuals with physical impairments make actual participation in DIY-AT projects challenging for those with disabilities (Buehler, Hurst, & Hofmann, 2014; Hook, Verbaan, Durrant, Olivier, & Wright, 2014; Hurst & Kane, 2013; Rajapakse, Brereton, Roe, & Sitbon, 2014). Despite one recent exception (Meissner et al., 2017), research in this space ignores the potential of the current adaptation and innovation activities of individuals with disabilities to inform the future of DIY-AT and the potential implications of these efforts for HCI/accessible design research and practice.

The literature on do-it-yourself (DIY), domestication, prosumption, end-user innovation, and hobbyist hacking pays explicit attention to the adaptation, appropriation, problem-solving, and design-like activities of non-professionals. DIY is all about everyday citizens engaging in

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4 Throughout this dissertation, I will use “consumer-driven” and “bottoms-up” to refer to the design, innovation, and hacker-like activities of non-professionals and everyday citizens. I will use consumer-driven and bottoms-up to refer to several different phenomena including do-it-yourself (DIY), domestication, prosumption, end-user innovation, hacking, hobbyist-hacking, and do-it-yourself assistive technology (DIY-AT) collectively. There are significant differences between these activities that I will parse.
democratic, self-empowered, and self-determined innovation, design, and problem-solving activities usually reserved for professionals (Atkinson, 2006; Hill, 1979; Ratto & Boler, 2014). Domestication research explores personalized ICT consumption behaviors of consumers that often cannot be predicted by designers (Haddon, 2005, 2006; Mallard, 2005). Marketing research on prosumers examines different consumer-driven value creation activities and interrelated producer-consumer value co-creation activities (Kotler, 1986; Xie, Bagozzi, & Troye, 2008). End-user innovation research looks at the trends and tendencies of people and organizations to design what they want and need rather than relying on manufacturers to do it for them (von Hippel, 2005a, 2005b). HCI researchers interested in hobbyist hacking activities have explored phenomena such as IKEA hacking, Arduino hacking, Roomba vacuum cleaner hacking, domestic environment design, technology and electronics hacking, and craft hacking (Buechley, Rosner, Paulos, & Williams, 2009; Kuznetsov & Paulos, 2010; Rosner & Bean, 2009; Wakkary & Maestri, 2007; Wang & Kaye, 2011). The different literature streams mentioned above all examine the self-directed adaptation, appropriation, problem-solving, and design-like activities of everyday consumers themselves. To my knowledge, researchers in these fields have not paid explicit attention to individuals with disabilities who engage in similar behaviors despite evidence suggesting they do (Anthony et al., 2013; George, Binns, Clayden, & Mulley, 1988; Kane et al., 2009; Meissner et al., 2017; Williamson, 2012).

Another gap in the HCI literature is its narrow focus on technology, innovation, and impairment concerns and concurrent lack of consideration for contextual factors or societal assumptions about individuals with disabilities that are often inseparable from usage outcomes. Among other topics and interests, HCI researchers devote much time and attention to the design out in chapter two. Nevertheless, they all have something in common that accessible design does not: non-professionals and everyday citizens initiate and lead them for individually or collectively-determined purposes.
and development of interventions that enhance functional capabilities (Meissner et al., 2017; Wobbrock & Kientz, 2016). A significant portion of HCI literature on accessibility issues seeks to understand the computer use and interaction experiences of individuals with disabilities, design better interfaces for them, and improve their interaction experiences (Lazar, Feng, & Hochheiser, 2017). HCI scholars most often rely on experimental methods, surveys, time diaries, case studies, and similar research methods when conducting disability-related research (Lazar et al., 2017). Most HCI accessibility research focuses on the provision of accessible end-products to individuals with disabilities (Bennett, 2018) instead of the various ways technologies factor into their daily lives. This narrow focus ignores issues such as the stigma associated with AT use (Parette & Scherer, 2004) as well as the way usage amplifies differences between individuals with and without disabilities (Foley & Ferri, 2012; Goggin & Newell, 2003).

Assistive and rehabilitation technology scholars, on the other hand, focus on technology use outcomes primarily in school and workplace contexts, respectively. Assistive technology researchers specifically concentrate on improving the effectiveness of AT in allowing individuals with disabilities to acquire education, work, and life skills, removing barriers to AT access, and maximizing the benefits of AT use (Alper & Raharinirina, 2006; Edyburn, 2000; Maor, Currie, & Drewry, 2011). While these goals have their place and many individuals with disabilities not only value but also strive toward reaching them, researchers rarely look beyond the school and workplace context. For instance, a team of stakeholders along with an extensive amount of training is often available to ensure that students with disabilities reap the benefits assistive technology purportedly offers them, as evidenced in textbooks for educators who work with students who have disabilities (e.g., Dell, Newton, & Petroff, 2011). If you ask adults with conditions like cerebral palsy, many will say that it is nearly impossible to get the same level of
support once post-secondary school ends. Historically, rehabilitation research has focused on the immediate adoption of affordable, safe, and 'suitable' technology that not only increases the independence of individuals with disabilities but also enables them to live a "normal" life despite their impairments (Roulstone, 2016). AT and RT research often places goals like independence, task performance, and productivity above other possible goals and interests that individuals with disabilities may have for themselves. While many individuals with disabilities embrace these same goals, not all of them have access to the needed support outside of the school and workplace contexts. Designing accessible technology that aids individuals with disabilities in these two contexts is important. Nevertheless, designing school and workplace technology outcomes and seeking to improve use outcomes only benefits a subset of the disability community. Those who finish post-secondary school and do not have access to rehabilitation services are largely ignored by AT and RT research communities.

Finally, the field of disability studies has articulated and brought to the fore different epistemological understandings of disability as well as fought for the inclusion of individuals with disabilities in decisions and practices affecting their lives. Two familiar discourses on disability articulated by disability studies scholars are the medical model and social model. The medical model leaves the task of defining and addressing disability issues to the medical industrial complex. It frames disability as an individual deviance, lack, or “personal tragedy” that should be “fixed” or overcome (Corker & Shakespeare, 2002; Mankoff, Hayes, & Kasnitz, 2010; Under the medical model, individuals with disabilities a need to “normalized,” or made to function like a non-disabled person and individual difference is not socially acceptable. The medical model confers authority to “fix” the “problem” of disability to the medical industrial complex.

The social model rejects the authority of the medical industrial complex’s epistemological ordering of disability which both undergirds medical professional interactions with individuals with disabilities and shapes societal perspectives on disability (Mercer, 2002; Rieser, 2006; Roulstone, 2016). According to the social model, a disability is not an attribute of the individual but rather something an individual with an impairment experiences due to living in a world full of physical, social, and structural barriers that limit the opportunities available to him or her.

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The social model, on the other hand, sees impairment and socially constructed ideas about what constitutes disability as two separate things (Barnes, Oliver, & Barton, 2002; Rieser, 2006). While the medical model focuses entirely on the impaired body, early yet still popular articulations of the social model mostly ignore it. Many within the disability studies community and several disability activists celebrate the role the social model has played in shifting the disability conversation away from the body to rights, access, barrier reduction, and other non-impairment factors (Roulstone, 2016). Nevertheless, both the medical and social models suffer from a common limitation: static and one-sided conceptualizations of disability that are not true to the everyday lived experience of individuals with disabilities (Corker & Shakespeare, 2002; Galis, 2011; Roulstone, 2016). Critical disability studies arose in response to the overly socialized concept of disability articulated in the original social model which paid exclusive attention to disability oppression while ignoring the embodied experiences of individuals with disabilities (Roulstone, 2016; Shakespeare, 2006). The medical model focuses exclusively on the body while ignoring other aspects of living with impairments and the social model downplays impairment and the embodied experience of it. Critical disability studies scholars Marian Corker and Tom Shakespeare (2002) argue the one-sided body versus social explanations of the medical and social models, respectively, oversimplify the lived experience of disability, ignore the knowledge individuals with disabilities possess, and fail to capture the diversity of experiences represented within the disability community. Despite past efforts within the disability studies community to make sure research adequately considers the lived experiences of individuals who have impairments (Corker & Shakespeare, 2002; Mankoff et al., 2010; Oliver, 1992) more work is needed to move beyond existing one-sided epistemological explanations of disability such as the medical and social models to more realistic post-structural
ones that delineate the complex network of social relations through and in which people are constituted (Corker & Shakespeare, 2002; Galis, 2011).

**Purpose of this Research**

The purpose of this research is to explore adaptation, problem-solving, and design-like activities from the perspectives of individuals with disabilities within the context of their everyday lives. This study examines the ways individuals with physical impairments manage disability, design, and daily life issues implicated in their everyday practices and related routines. This research uses sensitizing constructs from contemporary social practice theory and actor-network theory approaches to unpack the adaptation, problem-solving, and design-like activities of individuals with mobility and dexterity impairments as well as their related mobility, self-care, recreation, and various other daily life practices. In addition to explicating the practical dimensions of participants' problem-solving and design-like activities, this research seeks to elucidate the constitutive impact of these efforts along with impaired bodies, values, and professionally-designed artifacts on disability and everyday life.

**Research Questions**

When I started this research, I was acutely aware that something was missing from the HCI and accessibility literature: the perspectives of individuals with disabilities who adapt and solve accessibility issues themselves or with support from others. Some HCI studies point to the ability and propensity of some individuals with disabilities to adapt ICT and other interfaces either independently or with assistance (Anthony et al., 2013; Buehler et al., 2015; Hook et al., 2014; Kane et al., 2009). These studies, however, tend to report on the adaptations themselves without exploring the details surrounding them including the activities involved. DIY-AT research purportedly seeks to identify ways to get individuals with disabilities involved in making and
adapting assistive technology. At least one study where researchers secured access to an accessible maker environment and recruited individuals with disabilities for the purpose of getting them involved in DIY-AT activity and identifying lessons for the accessible design community (Meissner et al., 2017). Another study analyzed online forum content describing the self-driven DIY-AT activities of multiple individuals with hearing impairments who customized cochlear implants and hearing aids (Profita et al., 2016). To my knowledge, the HCI community has not paid attention to the embodied adaptation, modification, and design-like activities of multiple individuals with mobility and dexterity impairments, their related embodied daily life practices, or the research and design implications of these activities.

Focusing on the experiences of impaired bodies engaged in individualized problem-solving activities and the practices they enable offers insights into the “problem of people’s embodied relationship to physical artifacts and environments” (Freund, 2001, p. 699). In other words, design, adaptive activity, and daily life practice can serve as sources of disablement or enablement. HCI scholar Paul Dourish defines embodiment as “the property of our engagement in the world that allows us to make it meaningful” and embodied interaction as “the creation, manipulation, and sharing of meaning through engaged interaction with artifacts” (2001, p. 126). The embodied point-of-view often gets excluded from accessible design and HCI design research because of the relative lack of focus on the lived bodily experiences of individuals with disabilities as well as relatively limited attention paid to their adaptation, modification, and design-like activities. The embodied perspective is central to both the interactions researchers and designers foresee and those they cannot foresee. Adaptation, modification, and design-like activity both brings the embodied perspectives of individuals with disabilities to bear on everyday life access issues and configures their practices accordingly. Given the tendency of
HCI research to ignore the adaptation, modification, and design-like activities of individuals with disabilities, my main research question seeks to describe these activities and thus contextualize the related embodied practices of individuals with impairments. My first research question asks how do individuals with mobility or dexterity impairments work alone or with allies (if applicable) to make everyday life practices more accessible? Knowing that various practical, conceptual, motivational, and socio-material considerations circumscribe adaptation, modification, and design-like activity, I divided this main question into four sub-questions. First, I asked what kinds of accessibility-related solutions do participants develop and leverage in their daily life activities? Second, how do participants conceptualize and describe their efforts and solutions? Third, what roles do co-/participants/allies play in their collaborative attempts to make practices accessible? And finally, what material objects, mechanisms, and entities facilitate or impede participant effort to make daily life practices more accessible?

Another goal of this study was to show how impaired bodies and the outcomes of design processes contribute to the lived experience of disability. To do this, I examined the embodied everyday life activities of individuals with physical impairments through the lens of practice theory. According to contemporary social practice theorist Andreas Reckwitz (2002), a practice is the routinized behavior of networked entities consisting of bodily activities, mental activities, the use of objects as well as consideration of the objects themselves, background knowledge (e.g., understanding), competence, states of emotion, and motivational knowledge. Additionally, Latourian actor-network theory describes agency as a capacity realized through human-non-human associations rather than by a human agent independently (Latour, 2005; Orlikowski, 2007). My second research question speaks to this interest: How are individuals with mobility or dexterity impairments disabled or enabled in their daily life practices? Participants' daily life
practices represented instances of professionally designed artifacts, impaired bodies, and organic problem-solving/design-like solutions combining with other practice elements to form the practice-constituting networked entities described by Reckwitz (2002). To unpack how individuals with physical impairments are enabled/disabled in different everyday life situations and contexts, I divided this second main question into two sub-research questions: 2.1 - How do various human and non-human agencies simultaneously constitute everyday practice activities and interact with the mental and bodily activities of individuals with mobility/dexterity impairments?; and 2.2 - How are bodies, minds, objects, and knowledge/know-how implicated in the everyday practice activities of individuals with mobility or dexterity impairments?

The third and final goal of this study was to describe various relational and political issues that circumscribed participants' problem-solving/design-like activities and daily life practices. Individuals with disabilities exhibit diversity in terms of capabilities and interests as do non-disabled DIYers, hackers, and hobbyists. The HCI community has been paying attention to the online and offline activities of hobbyist hackers and DIYers for some time now (Buechley et al., 2009; Kuznetsov & Paulos, 2010; Rosner & Bean, 2009; Wakkary & Maestri, 2007; Wang & Kaye, 2011). Relevant studies examine participation in DIY and maker online communities as well as the use of online platforms for communication and information sharing purposes. The accessibility research community similarly examines the current use of online platforms by non-disabled non-professionals who engage in DIY-AT activities as well as their potential to empower individuals with disabilities to participate in DIY-AT projects (Hook et al., 2013; Hurst & Kane, 2013; Hurst & Tobias, 2011; Leduc-Mills, Dec, & Schimmel, 2013). Excluding some recent exceptions (Meissner et al., 2017; Profita et al., 2016), few researchers have paid explicit attention to the DIY-AT-like content individuals with disabilities post online or its meaning and
significance. One of the things that drove my early interests in my dissertation topic was the existence of online DIY-AT like content on YouTube and a study by Anthony et al. (2013) that sought to derive insights for accessible designers from some of this content.

Several accessible design researchers have published empirical evidence that some individuals with disabilities engage in adaptation, modification, and design like activities (Anthony et al., 2013; Hook et al., 2013; Kane et al., 2009; Meissner et al., 2017; Profita et al., 2016). Unfortunately, many of their studies focus on outcomes and rarely provide details about the nature of adaptation, modification, and design-like activities themselves or the roles individuals with disabilities play in them. As a result, the social activities and values that circumscribe the efforts of individuals with disabilities engaged in activities that are analogous to professional design activities often get overlooked by researchers. This oversight is significant given the nature of research, design, and consumer-driven efforts such as DIY and the sense of helplessness often attributed to individuals with disabilities. According to the medical model of disability, it is assumed that researchers, designers, medical professionals, and other non-disabled members of society are responsible for the well-being of individuals with disabilities (Rieser, 2006). Also, the nature and framing of both professional design and non-professional consumer-driven activities seem to relegate people with impaired bodies to consumers only. To my knowledge, no one has explored alternative social relations afforded by and coinciding with adaptation, modification, and design-like activity by individuals with disabilities.

My third main research question addresses the gap between prevailing and alternative social relations connected to traditional research and design and bottom-up adaptation, modification, and design-like activity by asking how relational aspects of participants' accessibility-related activities and related daily life practices constitute those practices? The first
and second sub-questions attempted to delineate some of the players implicated in participant adaptation, problem-solving, and design-like efforts other than allies who provide direct assistance when and if needed. Sub-question 3.1 asks what groups, entities, and resources do individuals with mobility and dexterity impairments engage in or make use of as it relates to their accessibility projects? Sub-question 3.2 asks who do individuals with mobility and dexterity impairments interact with concerning their accessibility project-enabled practices other than allies? The third sub-question sought to delineate some of the ways various actors other than allies who provided direct assistance to participants factored into their problem-solving/design like projects: 3.3 - What roles do individuals other than allies play in accessibility projects? The fourth sub-question sought to describe participant accounts of how different actors influenced their adaptation, problem-solving, and design-like efforts, configured their practices, and impacted their lived experiences: 3.4 - What meanings do individuals with mobility/dexterity impairments ascribe to the various agencies implicated in their daily life practices?

To access the perspectives, experiences, and insights of individuals who have mobility and dexterity impairments, I decided to conduct in-depth interviews with a few of them. I conducted two sets of interviews with 16 individuals who identified as having a mobility impairment, dexterity impairment, or both. These conversations took place between August 2014 and January 2015. Mobility, communication, and access issues made it difficult to recruit and interview some participants face-to-face, so I also conducted telephone, video chat, and instant messenger interviews.7

7 I discuss the limitations of this approach in chapters three and eight.
Defining Terms

Before outlining the contents of this document, I need to define several terms used throughout this manuscript. The first two are impairment and disability. The term impairment as used here refers specifically to mobility and dexterity impairments of any severity. As per the World Health Organization's (WHO) International Classification of Functioning (ICF), mobility impairments affect the mechanical movement of a person's shoulders, upper arms, wrists, elbows, forearms, hands, fingers, thumbs, hips, thighs, knees, legs, ankles, feet, tarsal, or metatarsal joints (Wood, 1980). Mobility impairments can affect one or more of these limbs (or any part of it/them) on the left, right, or both sides of the body as well as a person's upper extremities, lower extremities, or both. They commonly take the form of partial paralysis, complete paralysis, weakness, fatigue, or stiffness (Wood, 1980). Mobility impairments can impact a person's ability to walk, climb, traverse (terrain), run, reach, lift, sit, stand, or transfer to/from a sitting/standing/recumbent position. Mobility impairments affecting the lower extremities may require a person to use canes, walkers, or wheelchairs. Dexterity impairments typically impact body movement as well as fine and gross motor control associated with tasks such as object manipulation. Dexterity impairments affect fingering, gripping, holding, grasping, and handling abilities (Wood, 1980). Motor and dexterity impairments are not mutually exclusive and can be connected to or implicated in various challenges associated with writing, eating, drinking, bathing, or any other activity of daily living (ADL).

As I alluded to earlier, the term disability can have different meanings depending on who defines it. On a base level, disability includes the experience of having an impairment. Most people link disability to temporary injuries or a formal often longer-term condition such as cerebral palsy, multiple sclerosis, muscular dystrophy, arthritis, or a spinal cord injury. The
social model of disability connects disability to physical and social barriers which minimize opportunities or negatively impact the quality of life of individuals who have impairments relative to people who do not (Goggin, 2009; Rieser, 2006). As it relates to this study, the term disability refers to an experience rather than an attribute of a person. This embodied "experience" includes living with an impairment and all that comes with it as well as the environmental social, political, cultural, and economic, barriers connected to impairment. Rather than equating disability solely to impairment like the medical model or reducing it to a social construct like the social model of disability, I acknowledge that disability is multi-faceted. I view it as inseparable from impairment yet interpreted and understood through different and often contradictory lenses. Most accessibility design research views this construct primarily through the lens of a mostly non-disabled society that values normalcy. For this study, disability refers to the embodied experience of living with an impairment which is simultaneously shaped by bodily characteristics, socially-shaped understandings of impairment, individual lived experience, and practices such as design and policy-making, among others. In this study, I avoid describing disability as a universally defined reality but rather an experience that everyone will likely encounter on some level as they navigate through life.

The third term that needs to be defined here is practice. In the previous section, I provided the theoretical definition of practice according to contemporary practice theorist Andrea Reckwitz. Although that definition is foundational to the analysis presented in chapter six, I will also (and sometimes simultaneously) use this term in a more general sense to refer to the activities a person does within the context of his or her everyday life. Practice in this sense refers to any mundane activity. A few examples include speaking, reading, shopping, cooking, eating, drinking, bathing, household chores, taking care of children, completing career or
education-related tasks, and participating in recreational activities. Practice also includes what some refer to as consumption activities, which occur in the domain of everyday life where people are often free to demonstrate a modicum of creativity at their discretion (de Certeau, Giard, & Mayol, 1998).

In my study, participant practices consisted of daily life activities they engaged in independently, with support from others, or with the aid of assistive technology, rehabilitation technology, or whatever objects one typically need for a given activity (e.g., you need a spoon to eat soup and a saw to cut wood). In this study, I use the term practice to refer to the activities of daily life (ADLs) that necessitated participants' adaptation, design-like, and problem-solving efforts. Activities of daily life included things like consumption behaviors, disability-specific activities such as pain management or transferring to/from mobility equipment, and mundane tasks anyone might engage in regardless of his or her impairment status such as getting dressed or using an electronic device such as a phone or computer. In addition to micro-level consumption and ADL engagement, practices can consist of formal research, design, service provision, decision/policy-making, and similar activities of groups and large entities (Reckwitz, 2002), which this study does not examine.

To close this section, I describe my use of the terms “adaptation,” “modification,” “problem-solving,” and "design-like" activity thus far as well as throughout the first three chapters of this document. I use these terms provisionally to refer to participant efforts to make everyday life practices more accessible. In chapters 4-8, I leverage my participants' vernacular, experiences, and descriptions to make a case for the use of the term life hack to refer to their efforts. Simply stated, a life hack is a clever or non-obvious way to solve an everyday problem

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8 More specifically, “consumption behaviors” refer to the consumption/use of accessible technology, assistive technology, rehabilitation technology, and mainstream consumer products.
Rather than forcing my participant's efforts into an a priori determined category based on my way of seeing the world, I allowed the data to tell me how to categorize the activities they described. I use generic terms such as adaptation, problem-solving, and design-like early on in this dissertation to acknowledge that I inductively labeled, defined, and described the dimensions of these efforts based on the data.

**Key Findings**

This dissertation study uncovered several findings with implications for HCI, accessibility, and disability studies research communities. The first finding is the identification and description of seven different adaptation, modification, and design-like activity types. Participant activities fell into one of two categories (artifact-centered or action-oriented) and six non-mutually exclusive sub-categories. Artifact centered efforts included innovation, modification, bricolage, and repair & maintenance activities while action-oriented efforts included re-appropriation and procedural ones. Second, participant adaptation, modification, and design-like activities (including their ways of labeling and describing them) as well as the self-described motivations, lived experiences, and social interactions they associated with these activities suggest the term *life hack* accurately captures their essence. A life hack is a clever yet non-obvious way to solve a problem or do something and life hackers “operate skillfully and inventively, moderating and adapting tips and schemes” (Potts, 2010, p. 35). Findings point to the myriad of individualized yet ingenious ways participants address physical, social, and political aspects of living with a physical impairment on their terms.

The third significant finding of this study includes experientially-grounded accounts of the roles participants, allies, and other people played in their life hacking efforts. Accessibility research has been known to acknowledge the outcomes of bottom-up adaptation, modification,
and design-like accessibility projects while ignoring the specific roles individuals with disabilities played in the conceptualization and development of those outcomes. Findings from this study describe not only the different roles participants played in their life hacking efforts but also aspects of life hacking and everyday life assistance participants found most valuable when they needed assistance. Their perspectives challenge HCI research community notions of empowerment, assumptions about the contributions individuals with disabilities can make to design-like activities, and medical model assertions about the meaning of disability.

The fourth finding of this study is an explication of the role professional design and life hacking played in either disabling or enabling participants. Instead of focusing on technology, impairment, or both in isolation, this study uncovered how these and other elements of practice form networks that collectively (dis)/enable individuals with motor and dexterity impairments. Disability studies scholars criticize the medical model for reducing disability to impairment while critical disability studies scholars critique the social model for equating disability to social factors and oppression while ignoring the lived embodied experience of impairment (Corker & Shakespeare, 2002). Both critiques highlight the fact that theories of disability often do not capture the diverse and complex lived experiences of individuals who have disabilities. Findings from this study support the recommendations and work of other scholars who say Science and Technology Studies (STS) approaches are needed to fully account for the confluence of design artifact, impairment, social, contextual, and other factors that constitute disability (Galis, 2011; Moser, 2006; Moser & Law, 1999; Schillmeier, 2010). Interestingly, participant lived experiences with impairment as well as their previous adaptation, modification, and design-like activity experiences often made it possible for them to turn disabling networks into enabling ones via life hacking.
The final significant finding of this dissertation is the considerable amount of overlap between critical HCI design and participant life hacking. Inherent in many of the activities and projects participants described were the same social, political, and practical issues taken up in critical design, critical making, post-colonial, and values-oriented design approaches. Participant motivations for their life hacking activities included controlling personal destiny, maintaining economic independence, boosting morale after acquiring a disability, and pursuing interests rarely attributed to individuals with disabilities. These motivations reveal underlying values that not only guided their efforts but also challenged the assumptions of researchers and designers as well as non-disabled people in their lives. Findings point to a fruitful yet unexplored area of inquiry for HCI and accessibility researchers interested in the involvement of individuals with physical impairments in design activities and disability narrative construction.

**Overview**

In this chapter, I have laid the foundation for this study on the adaptation, problem-solving, and design-like activities of individuals with disabilities. In this closing section, I offer an outline of the remaining chapters.

Chapter two serves several purposes. First, it offers descriptions and critiques of the medical, corporate, and social models of disability as well as several different accessible and critical design approaches found in the HCI literature. Second, it describes prominent consumer-driven/bottoms-up approaches to design, problem-solving, and innovation that mostly ignore similar efforts carried out by individuals with disabilities. Third, this chapter explains how existential-phenomenology, as articulated by Maurice Merleau-Ponty, underpinned this research study. Fourth and finally, chapter two introduces constructs from contemporary practice theory approaches articulated by Andreas Reckwitz and Theodore Schatzki as well as by Bruno Latour.
in his actor-network theory approach that guided the theoretical analysis of participant adaptation, problem-solving, and design-like activity-enabled practices in chapter six.

Chapter three describes the recruitment, data collection, and data analysis methods I used to conduct this study. I conducted 32 interviews with 16 individuals who identified as having mobility or dexterity impairments and engaged in adaptation, problem-solving, or design-like activity within 12 months of the data collection period. In addition to the interviews, participants filled out recruitment questionnaires which asked about the general nature and frequency of their adaptation, problem-solving, or design-like behaviors. Secondary data included photos participants allowed me to take, shared with me, or told me I could find online.

Chapter four profiles each participant and offers high-level details about the nature of their impairment(s) and level of independence as well as their adaptation, problem-solving, and design-like experiences. The goal of this chapter is to detail some of the similarities and differences among participants and lay the foundation for later chapters. Chapter five details the different types of adaptation, problem-solving, and design-like activities participants engaged in as well as the practices that necessitated those activities. It also describes participant perspectives on adaptation, problem-solving, and design-like activity meanings, assistance, enablers, impediments, and motivations.

Chapter six provides findings from an analysis of participants' embodied adaptation, problem-solving, and design-like activity-enabled practices through the lens of practice theory and Latourian actor-network theory. For the analysis, I leveraged several sensitizing constructs from different practice theory approaches to parse out and trace the relationships between constituting elements of participants' adaptation, problem-solving, and design-like activity-enabled practices.

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9 I interviewed each participant twice.
enabled practices. This chapter also presents some of the participant-defined agencies implicated in adaptation, problem-solving, and design-like activities and related practices involving assistive technology, rehabilitation technology, mainstream artifacts, and non-disabled individuals.

Chapter seven examines social interactions that circumscribed, enabled, and motivated participant adaptation, problem-solving, and design-like projects. In addition to describing diverse social interactions connected to participants' activities, this chapter delves deeper into how social relationships, other people's assumptions, oppression, and ableism figured into the practice equation and either disabled or enabled participants.

In the eighth and final chapter, I talk about the implications of study findings for the HCI research, accessible design, assistive technology, rehabilitation technology, and disability studies communities. More specifically, I outline several lessons members of these communities can learn from individuals with disabilities who adapt and solve accessibility issues themselves or with support from others. I also discuss the limitations of this study and future research that builds on my findings.
Chapter 2: Literature Review
Disability Models: Deficit Versus Social

Disability and technology are more political than meets the uncritical eye. Both are inherently political in the sense that different groups of people view, understand, and frame them in accordance with their personal experiences and sociocultural background. When thinking about disability and technology, it is critical to consider the experiences and backgrounds of the people speaking as well as implicit assumptions connected to their intentions, experience with disability, or lack thereof. There are various models of disability, and each one has underlying assumptions.

In this document, I will focus specifically on the medical, corporate, and social models of disability. These models typically reveal themselves in everyday language and practices, some of which may seem benign yet have detrimental impacts on the lives of individuals with disabilities. Each one privileges the perspectives of one group of social actors (e.g., medical professionals, product designers, or individuals with disabilities) over another and often support the interests and agenda of the privileged party. When the perspectives of those who supposedly help individuals with disabilities contradict or ignore the perspectives of the people they seek to help, those efforts can easily become unhelpful or even detrimental. Disability models capture this reality.

In his most recent book, UK Disability Studies scholar Alan Roulstone (2016) talked about the aims and impact of professionals in the lives of individuals with disabilities. Citing social work researcher Hugh McLaughlin, Roulstone says professional intervention often leads to generalizations about what constitutes disability, which is evidenced in the use of words like disabled people, service users, patients, etc. by professionals. The use of these terms point to implicit assumptions about the relationships and power relations between professionals and individuals with disabilities (McLaughlin, 2009; Roulstone, 2016). He goes onto say that
assumptions about disability are not only connected to the language professionals use. They are also embedded in disability, rehabilitation, and assistive technology-related professional practices. Interventions in the lives of individuals with disabilities, whether through design, healthcare, or social services are often laden with culturally shaped assumptions about disability and how to deal with it. Assertions about scientific objectivity often serve as a subterfuge that hides implicit and often atheoretical assumptions about disability that influence the provision of products and services to the disability community (Roulstone, 2016).

When referencing McLaughlin’s (2009) assertion about the impact of the language professionals use to talk about individuals with disabilities, Roulstone (2016) says it "points to an incommensurability of life worlds depending on one’s standpoint" (p. 47). Here Roulstone suggests that professionals guided by the medical or other deficit-based models of disability often do not have lived experiences from which to understand life with a disability. Disability models capture the assumptions and perspectives of stakeholders with direct and indirect experience with impairment. Disability models serve as heuristics for understanding different conceptualizations of disability and the supposed roles that both professionals and technology should play in the lives of individuals with disabilities from the perspective of different stakeholders. They also highlight many of the stated and implicit assumptions held by the respective stakeholders. Although there are several models of disability, I will focus on three that are most relevant to this study. I will not go into many specifics about the background and history of these models but rather explain what each one assumes about disability, technology, and professionals as well as the implications of those assumptions in the lives of individuals with disabilities.
Although some would argue the intentionality behind it, the medical model of disability confers life-changing authority onto medical professionals when it comes to any issue related to disability and illness. The medical model not only equates disability with incapability, deficiency, and dependency but also frames individuals who have them as aberrations from the norm of able-bodiedness (Fulcher, 1989; Goggin & Newell, 2003). This mindset is prevalent within the medical industry where professionals work to treat, cure, and reverse anything that deviates from "normal" able-bodiedness. The medical model not only individualizes the problem of disability by blaming it on the person but also over-medicalizes it by ignoring non-impairment issues that create difficulties for individuals with disabilities (Rieser, 2006; Shakespeare, 2006). Additionally, the medical model perpetuates disability constructions that conjure up pity, fear, and patronizing attitudes among non-disabled people (Rieser, 2006), which lead them to either actively discriminate against people with disabilities or force well-meaning but unwanted “help” on them. The medical model’s underlying assumption is that an individual with a disability cannot take responsibility for his or her well-being because of his or her bodily or other impairments. The medical model fosters dependency and undermines the agency of individuals with disabilities. Those who accept its assumptions base decisions that impact the lives of individuals with disabilities on the assessments of typically non-disabled professionals (Rieser, 2006).

Medical model assumptions contribute to the continued prevalence of ableism, or abnormal/normal constructions of people with/without disabilities, respectively, that undergird practices, values, relationships, social interactions, and perceptions of self as well as others (Wolbring, 2008). Ableism is a subtle form of discrimination that is grounded in perceptions and assumptions held by primarily non-disabled people. The systematic subjugation of individuals
with disabilities to political, economic, cultural, or social abasement because of their social status is known as oppression (Charlton, 1998). Both ableism and oppression undermine the psychological and emotional well-being of individuals with impairments, and disabled scholars refer to the psychological internalization of external oppression as “internalized oppression” (Charlton, 1998; Mercer, 2002). Internalized oppression is self-hatred, low self-esteem, frustration, and shame within individuals with disabilities that mirrors their poor, powerless, and degraded status in the ableist world they inhabit (Rieser, 1992; Shakespeare, 2006). Internalized oppression occurs as individuals with impairments grapple with their identity, the low value an ableist society projects onto them, and how to resolve the resulting cognitive dissonance. The relationship between ableism and internalized oppression resulting from the medical model perspective is eerily like the negative experiences of minorities who repeatedly deal with racism in the form of macroaggressions from Whites (Sue et al., 2007). However, ableism and internalized oppression extend beyond social interactions between people with and without disabilities to the multitude of activities and interventions conducted for the “benefit” of people with disabilities based on unquestioned medical model thinking.

The corporate model of disability confers authority on all issues related to disability and illness to professionals and industries that design, create, supply, maintain, and fund interventions meant to address those issues. The corporate disability model esteems scientific knowledge, professionalization, and formal training over the views and perspectives of consumers (Goggin & Newell, 2003). Many accessible technologies and professionals who work with individuals with impairments have medical model understandings of disability inscribed in them and individualize disability just like medical professionals, thus reinforcing negative cultural ideas (Oliver, 1990). People operating under professional and primarily medical model
ideas about disability tend to create scientific knowledge and technological interventions developed specifically for individuals with disabilities in controlled environments removed from the everyday experiences of the intended consumers (Goggin & Newell, 2003). Individuals and institutions operating under corporate model of disability assumptions who provide accessibility-related products and services often frame disability as something to be professionally managed and pay insufficient attention to the social, economic, and other realities many who live with physical impairments face in their everyday lives (Fulcher, 1989; Goggin & Newell, 2003). For them, problem-solving, cost-cutting, and orderly top-down processes rule (De Couvreur & Goossens, 2011). Under these circumstances, designers embed their ableist worldview into the artifacts they design, market, and sell to individuals with disabilities (Foley & Ferri, 2012). These stakeholders can easily ignore the reality of ableism and its link to the embodied assumptions, concepts, and images of disability in corporate and medical models (Goggin & Newell, 2003; Oliver, 1990) and instead allow industry, company, and professional forces to guide their decisions.

There are different opinions on the relationship between the medical and corporate models. For instance, I view them as distinct yet closely related to each other while some scholars collectively label them as deficit or administrative approaches. All deficit/administrative model approaches frame disability as an individual problem curable through rehabilitative medicine or technologies made and distributed by experts who often lack personal lived experience with impairment (Ellis & Kent, 2011; Finkelstein, 1993; Roulstone, 2016). Further, they assume that individuals with disabilities are passive by default and both need and desire interventions that will cure or manage impairment (Rieser, 2006). The products assistive technology, durable medical equipment, and mainstream technologies makers create (e.g.,
wheelchairs, cochlear implants, and contemporary digital communications/media technologies) and the regulated environment surrounding their design, provision, and use give the respective entities de facto ability to manage and regulate the lives of individuals with disabilities. These technologies and the design practices that lead to them can privilege assumed “normal” ways of being that non-disabled stakeholders may take for granted (Foley & Ferri, 2012). For instance, AT itself promotes what is known as “compulsory able-bodiedness” which assumes the goal of technology is to make individuals with disabilities able to approximate the same bodily norms as non-disabled people rather than challenge those norms (Foley & Ferri, 2012). Without careful consideration of underlying assumptions and their downstream impacts, they can effectively limit people with disabilities' aspirations, movement, and access to various parts of the social world (Foley & Ferri, 2012; Goggin & Newell, 2003). In other words, entities that operate under the assumptions of deficit-based models of disability may simultaneously open and limit opportunities, access, and inclusion through their provision of products and services to individuals with impairments (Roulstone, 2016).

The fact that efforts to help or even empower individuals with disabilities can have both intended and unintended consequences in their daily lives is at least partially attributable to different goals and perspectives between members of disability communities and the industries that design, create, maintain, and fund products and services for them. Cultures of practice, professional training, governing bodies, institutions, and economic principles are a few of the forces that shape not only research and professional design practices but also the professionals who participate in them (Roulstone, 2016). In this sort of environment, it is easy and somewhat unavoidable to dismiss the perspectives of people the medical and corporate models frame as
passive, abnormal, incapable, and not responsible for their personal well-being to justify your existence and purpose.

In addition to the various forces that shape professional practice, many professionals themselves have no direct experience with impairment and thus lack perspective when it comes to life with a disability. Power differentials undergirded by ableism and deficit models too often define the relationship between consumers and those who “help” or "serve" them. The power differentials both create and perpetuate the suppression of the voices of individuals with disabilities who often unquestioningly submit and thus give consent to existing power structures (Charlton, 1998). To question the embodied assumptions, concepts, and powerful images in deficit models (Goggin & Newell, 2003; Oliver, 1990) as well as the societal systems and structures that grant third-parties power over the lives of individuals with disabilities is to question deficit-focused constructions of disability and their implications. James Charlton in his popular written work *Nothing About Us Without Us: Disability Oppression and Empowerment* brilliantly captures the impact of politics, economics, and systematic power differentials in the lives of individuals with disabilities:

> In political-economic terms, everyday life is informed by where and how individuals, families, and communities are incorporated into a world system dominated by the few who control the means of production and force. This has been the case for a long time. The logic of this system regulates and explains who survives and prospers, who controls and who is controlled, and, not simply metaphorically, who is on the inside and who is on the outside (of power) (Charlton, 1998, p. 23).

Deficit models of disability and non-disabled people who embrace their underlying assumptions not only give professionals power and privilege over the lives of individuals with disability but also project this dynamic as the only acceptable way. A different way of conceptualizing disability is necessary to interrogate systems of power, prevailing disability constructions, and
the roles professionals and other non-disabled members of society should play in addressing disability issues.

Disability scholar Mike Oliver and disability rights activist James Charlton both link the oppression of individuals with disabilities to Gramsci’s concept of hegemony. Ultimately, deficit approaches are not intentional attempts to disempower, marginalize, or oppress individuals with disabilities but rather byproducts of capitalism as well as the combined influence of power and dominant ideology. Hegemony refers to the propensity of those who rule, control the means of production, or both to instill their ideology in everyone to the point where it is assumed a fact by the masses (Charlton, 1998). Ideology in this sense refers to the values and beliefs that undergird social practices such as medical intervention and the provision of welfare services (Oliver, 1990). As it relates to disability, hegemony and its structural underpinnings (i.e., ideology, culture, the influence of race, gender, and professionals/professions) does several things in capitalist societies like the U.S. First, it defines disability the same way that medical and corporate models do. Second, it assigns a much higher value to “normal” and non-disabled members of society. Third, it gives the medical industrial complex authority over the well-being of individuals with disabilities. Fourth and finally, hegemonic ideology underpins both social policy and most disability-related product and service provision models which too often create dependency instead of reducing it (Oliver, 1990).

Double-speak, blaming the victim, naturalized inferiority, over-medicalization, and ableist non-disabled/normal disabled/abnormal dichotomies all undergird the creation of separate and specialized entities that deal with issues faced by those members of society deemed least able to contribute to it (Charlton, 1998; Oliver, 1990). Further, in capitalist societies that not only have a social safety net but also redistribute economic surplus, hegemony and its structural
underpinnings all inform how redistribution occurs (Oliver, 1990). Hegemony plays a significant role in creating, magnifying, and normalizing ableism as well as the unequal power dynamics between individuals with disabilities and professionals in a capitalist society. First, it transforms individuals with disabilities into commodities in production, exchange, and distribution processes while hiding their resulting dehumanization and exploitation by other [often non-disabled] human beings who profit from this commoditization (Charlton, 1998). Whether intentionally exploitative or not, the medical, rehabilitation technology, and assistive technology industries profit from this arrangement. Second, it gives these same entities the power to exercise domination and control over the lives of individuals with disabilities with little to no consideration of how the structural features of capitalism affect people’s individual experiences with impairment (Oliver, 1990). The reason why the medical and corporate model exclude the perspectives of individuals with disabilities is because hegemonic and capitalist ideologies not only shape how professionals think about disability but also undergird institutionalized professional practices intended to “help” people who have them.

The social model of disability stands in stark opposition to deficit-based models and their assumptions. Its primary underpinning is the idea that disability is not an individualized problem but rather a socially constructed one that makes impairment its foundation (Mercer, 2002). More specifically, social models link impairment to physiological aspects of the individual, including the conditions, functional capacities, and limitations a person possesses from birth, acquires, or develops over time (Goggin, 2009). Disability, on the other hand, occurs whenever someone who has an impairment encounters physical or social barriers which minimize opportunities or negatively impact the quality of life for that person relative to someone who does not have an impairment (Goggin, 2009; Rieser, 2006). According to the social model, the social world not
only defines disability but also provides the necessary elements for its existence (Oliver, 1990). It does not simply say disability has social factors but rather disability is the product of social forces that often influence the lived individual and collective experiences of the disability community yet rarely change based on their experiences. Powerful organizations and institutions constituted in part by dominant cultural perspectives and institutionalized social practices are at the core of most disability definitions. Entities seeking to advance their own self-interests often play a significant role in defining and problematizing disability so they can influence policy decisions to advance their own ends (Albrecht & Levy, 1981; Oliver, 1990). Unfortunately, the underlying biases and moral evaluations about disability often trump the interests and perspectives of people who live with disabilities. The social model represents a self-empowered movement to resist this dynamic and challenge disability constructions based solely on impairment.

In the 1960s, members of the Disability Movement composed of UK organizations controlled by disabled activists who were fed up with profession-driven disability models proffered the social model as an alternative rights-centered construction of disability (Roulstone, 2016). United by the “Nothing About Us Without us” slogan of the international disability rights movement, they advocated for independence, integration, human rights, self-help, and self-determination (Charlton, 1998). The social model affirms the inherent value of individuals with disabilities and society's moral responsibility to address non-impairment issues responsible for the disablement and oppression of individuals with disabilities such as fear, ignorance, prejudice, and discriminatory practices (Rieser, 2006). Designers bring their own assumptions, biases, and understandings to the practice of design. Social model adherents assert that individuals with impairments can and should play a role shaping societal understandings of disability and
technology rather than letting people with no direct experience with impairment control the disability narrative.

Although the social model represents a reconstitution of disability that wrests the construct from non-disabled stakeholders, it does have limitations. These limitations served as one of several related catalysts behind the rise of the critical disability studies perspective in North America (Roulstone, 2016). In its original form, the social model seemed to go too far in politicizing the body while ignoring the significance of impairment in the daily lives of people who have them (Roulstone, 2016; Shakespeare, 2006). Disability constructions based on personal experience are difficult to make when the impaired body does not factor into the disability equation. In its effort to serve as a counter to medicalized and deficit-based models, the social model not only removed impairment from the disability equation but also rejected all the positive benefits many individuals with disabilities derived from medical intervention, particularly those who have degenerative conditions (Shakespeare, 2006). Critics of the original social model argued that by downplaying impairment and realities such as pain and fatigue the social model minimizes the lived experiences of a large segment of the disability community (Roulstone, 2016), which exacerbates the oppression those individuals experience as a result of having a disability in an ableist world. As a result, disability scholars in the 1990s pushed for an alternative social model that created space for people’s individual experiences with impairment (Rieser, 2006; Shakespeare, 2006).

Another issue with the social model is its reformulation of disability as social oppression in a way that demands a person both have an impairment and experience oppression to be considered disabled (Shakespeare, 2006). By defining disability as oppression, the social model frames oppression as the key characteristic of the disability experience. While the homogenous
group of UK-based white male activists with spinal cord injuries who devised the social model (Shakespeare, 2006) and countless other individuals around the world have experienced disability-related oppression, a narrow focus on it ignores impairment related factors in the same way that medical model approaches focus on impairment while excluding social factors. Finally, the social model’s focus on the removal of socially imposed barriers to create enabling environments is overly simplistic and ignores the impracticality of removing all barriers, such as environmental ones (Shakespeare, 2006).

Despite past and present limitations of the social model, it still offers a useful alternative lens to understand the implicit assumptions and discrimination that individuals with disabilities encounter, particularly in the context of design. According to Goggin and Newell (2003), when a group has the economic, institutional, and conceptual independence to reflect on the artifacts they use, it can lead to different knowledge, meaning constructions, and cultural practices that can be compared with popular ones perpetuated by other entities. Tables 1 and 2 summarize many of the assumptions, implications, and limitations of the three primary disability models described in this section. In the next section, I will occasionally refer to these models to identify some of the limitations of many accessible design approaches and their implications for end-users with disabilities.
# Table 1 – Disability Models

<table>
<thead>
<tr>
<th>Medical/Deficit/Individual Model</th>
<th>Corporate Model</th>
<th>Limitations</th>
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<tbody>
<tr>
<td><strong>Assumptions</strong></td>
<td><strong>Implications</strong></td>
<td><strong>Values abled bodies and devalues disabled ones</strong></td>
</tr>
</tbody>
</table>

**Medical/Deficit/Individual Model**
- Disability is:
  - physical incapacity, functional loss, & diminished personal responsibility
  - an individual problem or personal tragedy.
  - 100% attributable to physical impairment
- Doctors, technologists, therapists, and practitioners are responsible for the lives of individuals with disabilities
- The goal of technology is to fix, eliminate, or hide the deficit "problem" through prevention, cure, or rehabilitation

**Implications**
- Justifies/perpetuates/instills:
  - ableism in professions (medical and other) as well as within society
  - differential treatment of people with/without disabilities
- Mindset among individuals with disabilities to overcome rather than embrace who they are as
- Leads to disability oppression

**Limitations**
- Values abled bodies and devalues disabled ones
- Values medical community perspectives while ignoring the lived experiences/preferences of individuals with disabilities
- Diminishes inherent value and worth of individuals with disabilities
- Grossly ignores capabilities of individuals with disabilities
- Medical community controls larger societal disability narrative

**Corporate Model**
- Disability is something manufacturers, service providers, retailers, etc. “manage”
- Scientific knowledge, professionalization, & formal training/education conveys authority
- Professional always knows best
- Doctors, technologists, therapists, and practitioners are responsible for the lives of individuals with disabilities
- Individuals with disabilities are acted upon/targets of other people's actions

**Implications**
- Justifies
  - design, development, and provision of products/services that do not match needs/wants/capabilities of consumers with disabilities
- -assumptions/decisions uninformed by people with disabilities that impact their lives and well-being
- Creates/reinforces unfair power dynamic while patronizing individuals with disabilities
- Market principles, funding bodies, professional associations, etc. guide design, development, and funding of access products and services

**Limitations**
- Values perspectives of design or other professionals with little/no lived experience with impairment
- Marginalizes consumer perspectives, opinions, and experiences
- Assumptions about individual capabilities that do not match consumer’s lived reality
- Ignores how consumers actually use products

**Sources:** Fulcher, 1989; Goggin & Newell, 2003; Newell & Goggin, 2000; Roulstone 2016; Bieling, 2010; Shakespeare, 2006; Rieser 1990
<table>
<thead>
<tr>
<th>Social/Consumer Model</th>
<th>Assumptions</th>
<th>Implications</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| *Disability:         | -is social exclusion while impairment is physical limitation  
                       -is not an individualized problem  
                       -is socially constructed and imposed on top of impairment  
                       -occurs when impairment meets social, structural and environmental barriers in society  
                       *Non-disabled people and organizations oppress individuals with disabilities  
                       *Individuals with disabilities are most qualified to identify and create solutions to the issues they face | *Emphasizes/champions  
                       -rights and wants of consumers with disabilities  
                       -integration of individuals with disabilities into mainstream society  
                       -perspectives of individuals  
                       -theorization on construct of disability  
                       *Places moral and ethical responsibility for addressing disability problem on society  
                       *Removes blame from individuals with disabilities onto society and thus helps to improve their self-esteem and self-confidence | *Ignores impairment/the body and disabling aspects of it  
                       *Equates disability with oppression  
                       *Ignores complexity of disambiguating relationship between impairment (medical) barriers, disability (social) barriers, and their impact  
                       *Implies that universal/barrier-free design is achievable, which it often is not |

Sources: Fulcher, 1989; Goggin & Newell, 2003; Newell & Goggin, 2000; Roulstone 2016; Bieling, 2010; Shakespeare, 2006
Accessibility Research/Accessible Design: User-Centered & Universal Design Approaches

For this dissertation, I adopt Goggin and Newell’s (2003) assertion that design outcomes are both social constructions and “static" artifacts created based on a set of assumptions, values, constraints, and biases. My argument in the introduction to this manuscript was that primarily non-disabled members of design and research communities are susceptible to allowing their unchecked biases, the interests of stakeholders other than individuals with disabilities, and uneven power dynamics to guide their efforts rather than the interests and perspectives of end-users with impairments. Although members of accessibility research and accessible design communities often have the right intentions (e.g., to offer products and services that meet the needs of individuals with disabilities), their actions sometimes fail due to a lack of attention to some of the contextual issues surrounding the consumption of technology and life with a disability.

Design approaches intended to improve the accessibility and usability of artifacts have been a significant concern among scholars and designers within the HCI/accessible computing (Culén, Gasparini, & Hercz, 2010; Glinert & York, 1992; Ladner, 2008; Shneiderman, 1999; Wobbrock, Kane, Gajos, Harada, & Froehlich, 2011), technology and disability (Tobias, 2007; Vanderheiden, 2006), usability (Newell & Gregor, 2000), and disability and rehabilitation (e.g., Iwarsson & Stahl, 2003) communities for the past two decades. Within these communities there are at least three different ways to design for accessibility. First, design “assistive” products made exclusively for individuals with disabilities (e.g., assistive technology). Second, make products accessible to people with and without disabilities (e.g., universal design). Third, create add-on products to make inaccessible objects accessible. Designing products explicitly and specifically for individuals with disabilities can lead to useful and usable products, but may also
stigmatize users and thus negatively impacts usage rates (Parette & Scherer, 2004; Scherer, 1996; Shinohara & Wobbrock, 2011; Vanderheiden, 2006). Additionally, assistive technology reifies the differences between individuals with and without disabilities, thus linking deficit-based assumptions to separate technology for “normal” non-disabled people and individuals with “special needs” (Foley & Ferri, 2012; Goggin & Newell, 2003). Making products and environments that are accessible to anyone and everyone sounds great in theory, but attempts to do so require significant resources and typically fall short of true universality. Although add-on accessibility can successfully make existing products and environments useful and usable to individuals with disabilities, it relegates the needs and interests of those individuals as secondary to those of the average end-user, which some argue is patronizing (Newell, 2008).

The common denominator among these three methods is that end-users differ from the individuals and entities that own and control the means of production. Perhaps with a few notable exceptions, these approaches consist of mostly able-bodied researchers, professionals, or designing things for people who have disabilities. They also seem to ignore that accessibility, like constructions of disability according to the social model, is socially constructed and may have different meanings based on the person and his or her background and immediate circumstances (Charlton, 1998; Goggin & Newell, 2007). Technology made specifically for individuals with an impairment may stigmatize individuals with disabilities and reduce their willingness to use it (Parette & Scherer, 2004). Universally accessible products that must be used with inaccessible ones can still miss the mark. Add-on products may work for someone in environments where there is another person to help him or her use it but limit that same person when no one is around to help.
Below I talk about three broad design paradigms that scholarly and design communities either practice or recommend: user-centered design, universal design, and assistive technology design. In addition to describing some of the core tenets and underlying assumptions of these paradigms, I will discuss their theoretical and practical limitations. I will occasionally make connections between the assumptions, implications, and limitations of each paradigm and the medical, corporate, and social models of disability. By doing so, I will be able to point out inconsistencies between each paradigm's stated intent and actual its impact in the lives of people with physical impairments.

**User-centered design.**

User-centered design (UCD), also known as human-centered design, or user-based design (UBD) in other countries, is a systematic and intentional effort to create systems that fit intended users within a specified context of use. More formally, user-centered design processes not only prioritize the usability and usefulness of design outcomes more than their technological sophistication but also supposedly create room for the needs and abilities of users to influence design activities (Dourish, 2004). Relevant hallmarks of a user-centered approach include taking the needs and capabilities of diverse users into consideration, involving a sample of representative users as active participants in the design and development process, and building personas based on data collected about users to represent them in the design process (Iivari & Iivari, 2006). Human factors and ergonomics are pillar disciplines of modern HCI research and practice (Grudin, 2005) and they primarily deal with making tools, artifacts, and devices usable in workplace settings (Ritter, Baxter, & Churchill, 2014). Many credit Donald Norman and Stephen Draper with first articulating HCI-specific principles of UCD in their 1986 book *User Centered System Design: New Perspectives of Human-Computer Interaction*. According to
them, UCD involved focusing on user needs, conducting both activity/task and general requirements analyses, early testing and evaluation, and iterative design (Ritter et al., 2014). Representative user involvement in many UCD efforts is passive. It aids ideation and system evaluation processes (Ritter et al., 2014) by allowing designers to observe, interview, or model end-users (Iivari & Iivari, 2006). Involvement can also be direct where potential end-users get to play an informative, consultative or participative role in the design effort (Iivari & Iivari, 2006).

There are many different approaches to UCD, and the literature provides several examples of scholars who leverage them in their attempts to address disability and impairment-related issues through design. The three UCD approaches that I will discuss in this document are participatory design, assistive technology co-design, and, empathic design.

**Participatory design.**

Participatory design (PD) in disability/accessibility design contexts is a user-centered design approach that often relies on passive or representative forms of end-user involvement. A PD approach seeks to model the end-users' use context and give them the democratic power to access and exercise control over their design-enabled activities (Dourish, 2004). PD prioritizes what Ivari & Ivari (2006) refer to as work-centeredness, or the shared values, motivations, and interactions among all system or interface users, rather than individual users. Although participatory design approaches involve users in the design process, the overarching motivation is egalitarianism rather than user-centeredness. In other words, the goal of PD is to give all users the same ability to leverage a tool or interface rather than to design it according to each users’ unique specifications. PD is difficult in practice because of the different backgrounds, perspectives, and ways of communicating designers and end-users bring to the table. This reality
can make it difficult for designers to communicate with and understand representative users and vice versa.

While most accessibility-oriented participatory design efforts involve individuals with disabilities in brainstorming, prototyping, or user-testing activities (e.g., Azenkot et al., 2011; Gollner, Bieling, & Joost, 2012; Moffatt, McGrenere, Purves, & Klawe, 2004), some consist of workshops and similar planned events intended to give young people with disabilities a chance to learn about and play an active role in the interaction design process (e.g., Anthony, Prasad, Hurst, & Kuber, 2012). Some scholars recommend using substitute domain experts for end-users to deal with the communicative challenges associated with PD when the intended users have disabilities (Allen, Leung, McGrenere, & Purves, 2008). They argue that field experts not only possess design knowledge but also do not have communication or other impairments. Accessibility focused participatory design approaches may use non-disabled experts as a proxy because working with individuals with disabilities directly “exacerbates” the difficulties target users and system designers have “communicating their ideas given their diverse backgrounds and perspectives” (Allen, Leung, et al., 2008, p. 147). This argument assumes that non-disabled experts possess the ability to understand and translate the needs, capabilities, and interests of people with disabilities into design requirements and their positionalities as non-disabled experts have no bearing on the process or its outcomes. It also reveals a significant limitation of most PD approaches: they have the same potential to frame end-users with disabilities as passive and needy people who cannot address the issues that impact them as medical and corporate disability models.

Sometimes participatory design researchers can be admittedly intentional about using the word *representative* to refer to their use of domain experts as proxies for end users with
disabilities (Allen, Leung, et al., 2008). Nevertheless, their use of domain experts supports the assumed link between disability and diminished personal responsibility, incapacity, and passivity just like the deficit-based models of disability. Some participatory designers have a rehabilitation-oriented perspective on accessibility/design for disability that focuses solely on problematizing and addressing impairment issues with little or no consideration for social, political, and other issues that end-users may face. For example, in one study the researchers selected but later decided against a PD approach to designing digital technologies for people who “suffer” from dementia because their “progressively impairing cognition, personality, behavior…[and] speech” made involving them directly “inappropriate and unethical, as well as of little utility” (Marti & Bannon, 2009, p. 11). I am not dismissing the challenges associated with involving users with disabilities in participatory design efforts or the specific challenges Marti & Bannon faced. Nevertheless, their use of language illustrates an important point. As the following excerpt describing challenges individuals with dementia encounter further reveals, the authors used deficit language that individualized disability and ignored the reality and impact of their ableist mindset:

The social sphere of the individual is jeopardised not only by the impairment of social abilities resulting from global functional impairment of the subject but also by the patients withdrawal from social interaction due to a number of contextual factors ranging from aural and visual ability impairment, institutionalisation and inter- personal disorientation, lack of self-esteem and low motivation (Marti & Bannon, 2009, p. 11).

Notice how the researchers referred to social abilities, global functional impairment, withdrawal from social interaction, aural/visual impairment, interpersonal self-esteem, and low motivation. They link these issues solely to the “patients” without seriously considering the role non-disabled people may play in creating or exacerbating these issues for individuals with dementia. Again, I do not deny the reality that participatory design can be difficult when end users have
communication, physical, or intellectual disabilities. Nevertheless, PD requires flexibility, a willingness to listen, and the ability to reflexively examine one’s positionality as a non-disabled person who likely has demands, goals, and interests that do not match those of the targeted end users. The method will not work unless the people using it are willing to adapt their communication methods or find alternative ways to let potential end-users leverage designers’ capabilities and expertise while sharing their own personal insights. In Marti and Bannon’s study, researchers focused solely on end-user impairments and then substituted end-user involvement with "light observation" and engagement with professional therapists. Perhaps what they deemed “inappropriate,” “unethical,” and “of little utility” served as a subterfuge for their lack of time, resources, inability to adapt, or unwillingness to be self-reflexive. I do not have enough facts about this project to determine whether the issues listed were insurmountable enough to change the direction of the PD effort so drastically. The researchers’ recorded actions, however, suggest that PD approaches are only as flexible and inclusive of end-users with disabilities as the willingness of researchers to check their implicit biases and assumptions about individuals with disabilities as well as their potential contributions to the design process.

**Assistive technology co-design.**

Prescriptively speaking, assistive technology (AT) co-design places AT end-users, their experiences, and their values at the center of the design processes through iterative design and engagement with end-users (De Couvreur, Detand, & Goossens, 2011; De Couvreur & Goossens, 2011). End-user involvement is 100% passive or by proxy. Designers or caregivers lead these "do-it-yourself" design efforts to create innovative interventions that support one individual with a disability and his or her activities. These stakeholders engage the eventual end-user(s) through prototype enabled design testing and evaluation sessions that seek to align end-
user skills and values with properties of the design outcome. Stakeholders other than the person with a disability leverage the prototype to both understand the issues surrounding its use and identify adaptations that will rectify those issues in future iterations (De Couvreur et al., 2011; De Couvreur & Goossens, 2011). While AT co-design supposedly makes the perspectives of all stakeholders central to the effort, "latent perceptions and emotional responses" serve as proxies for the perspectives of end-users rather than their actual input and guidance. AT co-design efforts supposedly involve collaborations with end-users, caretakers, occupational therapists, designers/manufacturers, and other stakeholders (De Couvreur & Goossens, 2011) but individuals with disabilities tend to serve as the target of all other stakeholders' actions rather than active agents in these efforts. Additionally, AT co-design supposedly accounts for the social and emotional needs of consumers (De Couvreur & Goossens, 2011) the corporate disability model ignores. Nevertheless, non-disabled designers and other stakeholders act on behalf of and make decisions for individuals with disabilities and there is no mechanism encouraging researchers to reflect on the different ways that excluding individuals who live with impairments from the process reinforces ableist constructions of disability and further oppresses those who have them. To be fair, co-design outcomes may provide some benefits to potential end-users given the amount of time and energy that other stakeholders devote to understanding their needs and capabilities. Nevertheless, the level of participation in the design process by individuals with disabilities tends to be passive or by proxy only, which means their perspectives and experiences inform design only to the extent that non-disabled designers and co-designers access and translate them into design requirements. Furthermore, although researchers frame co-design as a more user-centered approach to AT innovation, it is marketed to members of rehabilitation and healthcare communities who often think and act in line with deficit disability models. Frequent
use of the word "patient" and the minimization of the potential contributions people with disabilities can make to the design effort by researchers who advocate for AT co-design seem to confirm this orientation.

*Empathic design.*

Empathic design is one of the better user-centered approaches to accessibility/disability design research. Researchers and others who employ an empathic approach work towards developing a personal understanding of the motivations, emotions, mental models, priorities, and struggles of end-users with disabilities and then partner with them during the information creation and design processes (McDonagh et al., 2009). They frame empathic design as an attempt to design with end-users rather than using traditional top-down design methods. Researchers who both use and advocate for this approach believe that respectful curiosity, deep understanding, and the suspension of judgment can lead to better design outcomes for the individuals with disabilities (McDonagh et al., 2009; McDonagh & Thomas, 2010; Strickfaden & Devlieger, 2011b). Intimate trusting relationships create opportunities for designers and potential end-users with disabilities to co-construct knowledge and design genuinely user-centered outcomes (McDonagh et al., 2009). In acknowledgment of the fact that users, in general, often cannot readily articulate what they want or need (Nielson, 2001) empathetic design advocates suggest substituting conversation-centric data collection methods with ethnographic ones. Doing so limits researcher intervention into daily life processes and practices while facilitating the kinds of interactional and relational encounters that foster empathy (Strickfaden & Devlieger, 2011b).

In a study by McDonaugh et al. (2009) the researchers conducted a design research study where they partnered non-disabled college students in an Art and Design program with students with disabilities and asked them to develop assistive artifacts collaboratively. They used
empathic research methods such as ethnography, empathic “modeling,” and shadowing individuals with disabilities in their daily lives. Modelling exercises consisted of non-disabled students using a wheelchair or wearing something that restricted their mobility or dexterity. The co-designers worked together to create non-stigmatizing products that integrated into the lifestyle and personal environment of the designer with a disability. The non-disabled industrial design students were expected to develop empathy and shared understanding with fellow students with disabilities over a relatively short time period. The end-user/co-designer with a disability was free to access and use the Art and Design student’s expertise, hands, tools, and skills. End-user disabilities varied in type and severity and their level of involvement in physical design activities varied accordingly.

Out of all the user-centered design approaches described, empathic design offers the most promise as far as understanding and involving end-users with disabilities in design activities as well as overcoming ableist assumptions that may cloud the judgment of non-disabled stakeholders. Empathic design creates room for non-disabled individuals to identify and reflect on their positionality, engage individuals with disabilities as active contributors to design, and learn about non-technical aspects of the product usage behaviors of end-users.

Despite the potential benefits of empathic design, studies like the one described by McDonaugh et al. are somewhat problematic. Developing empathy for individuals with disabilities and including them as active agents in the design process is time and resource intensive, which may reduce its appeal within professional design communities. Although design studies involving college students with and without disabilities point to the potential of empathic design approaches to lead to useful and usable outcomes made for and by end-users with disabilities, the approach may be impractical for actual designers. Additionally, the empathic
modeling exercises reduced people's experiences with mobility and dexterity impairments to temporary simulations. The simulations may provide some insights into impairment and design-related challenges but not necessarily the lived experience of impairment. In fact, simulations may reinforce ablesit assumptions given their focus on the negative aspects of disability and tendency to overlook how individuals with disabilities successfully navigate their experiences (Mankoff et al., 2010).

The stated goal of empathic design is to design with individuals who have disabilities instead of for them. Its focus on empathy and “the boundaries to a designer’s knowledge and understanding” (McDonagh et al., 2009), however, hints at the potential for parasitic arrangements where the ideas and insights of individuals with disabilities profit non-disabled designers more than themselves. Empathic design’s orientation towards developing a personal understanding and connection with end-user concerns is contrary to traditional design practice, thinking, and values of corporate disability models. The empathic approach is difficult to use when there is significant variation in end-user capabilities, goals, and interests (Newell, Gregor, Morgan, Pullin, & Macaulay, 2011), making it impractical in most commercial contexts where goals such as earning profits and achieving economies of scale rule. Additionally, the word empathy assumes able-bodied designers possess the ability to vicariously identify with the experiences of a person with a disability. Although empathy should be a goal that all accessible designers strive for, in theory, it is much harder to bridge dis/ability divides than existing research studies suggest, particularly in professional design contexts.

Some might argue that all designers should attempt to identify with end users and vicariously experience their feelings, thoughts, and attitudes. The reality of ableism, however, can be a barrier to empathy for non-disabled designers who may unknowingly subscribe to the
assumptions of medical and corporate disability models. Overcoming these assumptions requires prolonged engagement with end-users as well as a commitment to seeing them as people rather than problems. Most technology designers and manufacturers do not have a vested interest in doing this given their professional market-driven interests which I will unpack in a later section.

Additional limitations of user-centered approaches

Disability studies scholars advocate for individuals with disabilities to participate in the design of policies, artifacts, and services in ways that not only move them from the margins to the center but also ensure the outcomes of these processes are genuinely inclusive of what they want and need (Goggin & Newell, 2003). In theory, user-centered design is an excellent way to identify, design, and test interfaces that individuals with disabilities will find usable and useful. The approach, however, often does not go far enough to combat the ableist assumptions designers may have regarding individuals with disabilities. For instance, although the goal is to “involve” end-users, it is easier to do this in research settings than practice ones where people often operate under corporate disability model assumptions. There will always be professional and practical parameters that professional designers must abide by that will impact even the most well-intentioned user-centered design initiative. In these instances, the perspectives of end-users will only inform design to the extent designers allow. Although some user-centered design approaches involve consumers with disabilities as active participants in design activities or at least seek to understand aspects of their lived experiences, they are still top-down and depend on the benevolence of one or more individuals who do not have a disability. In these situations, deficit-based thinking grounded in the background and perspectives of non-disabled designers may still guide the effort to some extent unless those designers make a serious and concerted effort to self-reflect, foster empathy, or both.
Additionally, contrary to the belief of some (e.g., Sandhu, 2000), putting individuals with disabilities at the center of the design process and acting in a patronizing manner towards them are not necessarily mutually exclusive. If individuals with disabilities participate in design activities but do not have the freedom and authority to make design-related project decisions or act on their ideas and interests, then they arguably serve as the means to designer-determined ends. Such arrangements are downright patronizing because they consist of non-disabled people setting the agenda, making all the significant decisions, and relegating disabled partners to a token role while speaking and behaving as if individuals with disabilities play an equal role in these efforts.

Researchers who subscribe to the UCD approaches outlined above seem to recognize the importance and potential of involving persons with disabilities in the design process to some extent. Some HCI accessible technology design studies make notable attempts to integrate end-users with disabilities into design processes as active co-/designers (Azenkot et al., 2011; Gollner et al., 2012; McDonagh et al., 2009; McDonagh & Thomas, 2010; Moffatt et al., 2004; Strickfaden & Devlieger, 2011b). Other HCI studies that focus on designing and testing accessible ICT interfaces put individuals with disabilities in advisory or consultative roles, involve them in usability testing sessions, or recruit them as representative users (Dawe, 2007; Guerreiro, Nicolau, Jorge, & Goncalves, 2010; Kane et al., 2008; Ornella & Stephanie, 2006). Putting individuals with disabilities in more informative or consultative roles, however, can be patronizing. Although some of these researchers say their studies are user-centered and involve individuals with disabilities, the methods section of these studies usually makes it clear who is in charge and thus making the significant decisions. To be fair, research and design practices have an inherent power dynamic that structures the relationship between researchers/designers and
end-users regardless of anyone's disability status. Nevertheless, design research that is genuinely participatory would put the knowledge and resources of the researchers as well as the researchers themselves at the disposal of individuals with disabilities and give them the flexibility to leverage people and resources in ways they deem most beneficial to themselves (Oliver, 1992).

On a different note, designers who are personally unfamiliar with the experience of having a disability are imperfect judges of the needs and wants of individuals who have this experience. Any information that provides some insight into the diverse issues involved in end-users' use of design outcomes can inform their efforts, but may not adequately account for concomitant aspects their experiences. Empathic design can go further than other UCD approaches in uncovering these hidden aspects of the lived experience of disability but require more time, resources, and introspection than most rehabilitation and assistive technologist would be willing to invest. UCD approaches like emphatic design sound great in theory and researchers tend to frame them as promising ways to make more useful and usable products for consumers with disabilities. The truth, however, is that most technology design professionals would not wholeheartedly embrace these approaches because of their misalignment with the interests, goals, funding models, and various other factors that incentivize them to operate based on the dictates of the corporate model of disability.

To be clear, behind any professional designer, researcher, student, or non-disabled person leveraging so-called user-centered design methods are much larger issues that extend beyond the immediate ones they attempt to address. Designers and non-disabled individuals do not oppress individuals with disabilities directly but the political, economic, and cultural dimensions of daily living do (Charlton, 1998). Some UCD methods acknowledge the embodied nature of disability to some extent and try to learn from the perspectives and experiences of those who have them.
Others that are not sensitive to this reality will do little if anything for individuals with disabilities long term. Ideals such as empowerment, human rights, independence, integration, self-help, and self-determination must be central to UCD efforts before they will influence dimensions of disability that impact the economic, political, and social status of the disability community in an ableist society (Charlton, 1998).

UCD can be potentially effective in addressing accessibility and impairment issue. For instance, UCD approaches such as empathic design can help non-disabled design stakeholders to understand some non-impairment-related issues. Historically, the needs of individuals with disabilities and efforts to meet them have been governed by paternalism, or the sense of superiority and control non-disabled people exercise over individuals with disabilities which puts them in a perpetual state of dependency, powerlessness, and degradation (Charlton, 1998). Any research or design effort led by non-disabled people is more likely to oppress than empower individuals with disabilities, regardless of whether the effort includes them, if it does not account for the power relations at play or address the everyday oppression they experience (Charlton, 1998; Oliver, 1990). Despite their potential, all UCD approaches are inherently paternalistic and thus oppressive because the ultimate responsibility for addressing disability-related issues does not belong to individuals with disabilities themselves. Instead, this responsibility must be shared with individuals with disabilities, distributed to them, or exercised on their behalf by non-disabled professionals.

**Universal design.**

Universal design (UD) is an accessibility/disability design approach that seeks to meet the needs of people with and without disabilities equally. Universal Design (UD) originated in the discipline of architecture, but other types of designers have applied its seven core principles in
diveRest of the text...
as a social construction. The second half of the 20th century saw the growth of the Disability Rights Movement which sought to protect the rights and improve the plight of individuals with disabilities in the United States. Although wounded war veterans had somewhat of a voice because of the social development agenda of the United Nations, the same was not true for non-veterans with disabilities (Mathiason, 2010). The Disability Rights Movement that emerged out of this state of affairs sought to secure equal opportunities and rights for disabled persons by lobbying for federal legislation prohibiting discrimination and ensuring the provision of access to education, public spaces, telecommunications, and transportation (Story et al., 1998). Probably one of the most well-known pieces of legislation was the Americans with Disabilities Act (ADA) of 1990, which embodies and puts legal force behind many of the protections envisioned by members of the Disabilities Right Movement.

Products and environments built according to the principles of universal design are inherently flexible and usable by people with and without disabilities. Universal design outcomes either reduce the need for individuals with disabilities to use assistive technology or make it easy to use add-on devices when needed (Vanderheiden, 1998). Within the HCI and accessibility communities, universal design represents a goal that some researchers and designers work towards. In theory, UD approaches make accessibility a primary focus rather than an afterthought. Sometimes designers, however, wait until the end of the design process to apply the principles, thus making the requirements of non-average users an afterthought (Newell, 2008). HCI and accessibility scholars interested in disability and design have applied UD sensitivities in the following ways: 1. As an overarching framework (e.g., Ornella & Stephanie, 2006), 2. As a tool for discussing the findings and implications of user-centered product design efforts by designers (e.g., Jayant, 2010), 3. As a framework for gathering data, understanding everyday
experiences, and identifying potentially useful solutions to accessibility issues (e.g., Kane et al., 2009), and 4. As a framework for designing accessible artifacts (Duff et al., 2010; Saponas et al., 2009). Typically, their research involves prototyping, user testing, and data analysis. The outcomes can be either completely novel or involve new applications of the current state-of-the-art. Researchers tend to apply UD's principles, guidelines, or "theoretical" ideas to diverse design-related projects like the interactions individuals with dexterity, grasp, motor control, hearing, or visual impairments have with mobile phone devices, interfaces, services, and input modalities (Guerreiro, Nicolau, Jorge, & Goncalves, 2010; Guerreiro, Nicolau, Jorge, & Gonçalves, 2010; Jayant, 2010; Kane et al., 2009; Ornella & Stephanie, 2006), computer input techniques for people who have limited use of their hands (Saponas et al., 2009), and touchscreen applications and interaction techniques used by individuals with visual or motor control impairments (e.g., Duff et al., 2010; Kane et al., 2008). Despite the focus on different interaction techniques, technologies, and user populations in these studies, all have the same goal of designing and evaluating technology that is usable by people with and without disabilities.

One of the positives of UD is its focus on flexible and equal access by individuals with and without disabilities. Unlike other design approaches that segregate people with and without disabilities, UD proponents champion inclusion and attempt to consider the needs, abilities, and interests of both parties in mainstream design. UD attempts to bring many of the ideals of the disability rights movement to bear on design. In principle, UD embraces tenets of the social model of disability, including the socially constructed nature of disability and the role of structural and environmental barriers in disabling individuals with impairments. Advocates say that universal design approaches benefit users with and without disabilities alike because the outcomes usually have features that make them easier to use by everyone (Vanderheiden, 1998).
The stigma associated with assistive technology use, which often decreases usage rates among individuals with disabilities (Parette & Scherer, 2004), becomes less of an issue when individuals who have disabilities can access the same technologies as their non-disabled counterparts. Also, universally designed products tend to be less expensive than assistive technologies because of the economies of scale that are easier to achieve with mass-marketed products, which is significant given the higher reported poverty and unemployment rates and lower median incomes of individuals with disabilities compared to the non-disabled population (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2016).

Universal design may seem like the solution everyone has been looking for, but only in theory. Like all things universal, access for everyone is not an easy goal for many reasons. The list of UD principles and guidelines detailed in Tables 3 and 4 below currently serve as the primary means of transmitting UD thinking in addition to visual examples. Each principle and guideline represents a design feature, attribute, or affordance that increases usability. The problem, however, is the lack of corresponding guidance on when and how to translate the universal design principles and guidelines into design requirements. As the list suggests, principles and guidelines alone leave much room for subjective interpretation. The generality of the principles and guidelines poses a problem for anyone who lacks familiarity with them. UD in practice requires multilevel and multi-disciplinary context-specific analyses as well as the development of seamless user, task, environment, and product interrelationships (Sandhu, 2000). The current and persistent lack of a systematic approach to UD and related tools or training (Mankoff et al., 2010) likely reduces the likelihood that the average designer would consider adopting this approach. The lack of tools and training likely explains why there are so few well-known UD exemplars despite the twenty-year history of UD principles.
Another limitation of the principles is the amount of user engagement and testing they demand. The equitable use, flexibility in use, and tolerance for error guidelines likely require a lot of user testing with diverse users. Given non-disabled disability researchers’ history of perpetuating, reproducing, and legitimating the marginalization of individuals with disabilities through segregation, eugenics, and the denial of civil rights (Kitchin, 2000) and other factors, it is often challenging to recruit and include individuals with disabilities in research studies (Mankoff et al., 2010). Therefore, it is often difficult for researchers and designers to recruit the number and variety of potential end-users with impairments needed to test for universal usability. This reality likely serves as a deterrent for many designers because it diminishes their ability to realize the lofty goals of UD.
Table 3 The Principles of Universal Design

<table>
<thead>
<tr>
<th>#</th>
<th>Principle &amp; Guidelines</th>
</tr>
</thead>
</table>
| 1  | **Equitable Use** - The design is useful and marketable to people with diverse abilities.  
Guidelines  
- Provide the same means of use for all users: identical whenever possible; equivalent when not.  
- Avoid segregating or stigmatizing any users.  
- Make provisions for privacy, security, and safety equally available to all users.  
- Make the design appealing to all users. |
| 2  | **Flexibility in Use** - The design accommodates a wide range of individual preferences and abilities.  
Guidelines  
- Provide choice in methods of use.  
- Accommodate right- or left-handed access and use. 2c. Facilitate the user’s accuracy and precision.  
- Provide adaptability to the user’s pace. |
| 3  | **Simple and Intuitive Use** - Use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.  
Guidelines  
- Eliminate unnecessary complexity.  
- Be consistent with user expectations and intuition.  
- Accommodate a wide range of literacy and language skills.  
- Arrange information consistent with its importance.  
- Provide effective prompting and feedback during and after task completion. |
| 4  | **Perceptible Information** - The design communicates necessary information effectively to the user, regardless of ambient conditions or the user’s sensory abilities.  
Guidelines  
- Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information.  
- Maximize “legibility” of essential information.  
- Differentiate elements in ways that can be described (i.e., make it easy to give instructions or directions).  
- Provide compatibility with a variety of techniques or devices used by people with sensory limitations. |
| 5  | **Tolerance for Error** - The design minimizes hazards and the adverse consequences of accidental or unintended actions.  
Guidelines  
- Arrange elements to minimize hazards and errors: most used elements, most accessible; hazardous elements eliminated, isolated, or shielded.  
- Provide warnings of hazards and errors.  
- Provide fail safe features.  
- Discourage unconscious action in tasks that require vigilance. |
Table 4 - The Principles of Universal Design (cont).

<table>
<thead>
<tr>
<th>#</th>
<th>Principle &amp; Guidelines</th>
</tr>
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<tbody>
<tr>
<td>6</td>
<td><strong>Low Physical Effort</strong> - The design can be used efficiently and comfortably and with a</td>
</tr>
<tr>
<td></td>
<td>minimum of fatigue.</td>
</tr>
<tr>
<td></td>
<td><strong>Guidelines</strong></td>
</tr>
<tr>
<td></td>
<td>• Allow user to maintain a neutral body position. 6b. Use reasonable operating forces.</td>
</tr>
<tr>
<td></td>
<td>• Minimize repetitive actions.</td>
</tr>
<tr>
<td></td>
<td>• Minimize sustained physical effort.</td>
</tr>
<tr>
<td>7</td>
<td><strong>Size and Space for Approach and Use</strong> - Appropriate size and space is provided for</td>
</tr>
<tr>
<td></td>
<td>approach, reach, manipulation, and use regardless of user’s body size, posture, or</td>
</tr>
<tr>
<td></td>
<td>mobility.</td>
</tr>
<tr>
<td></td>
<td><strong>Guidelines</strong></td>
</tr>
<tr>
<td></td>
<td>• Provide a clear line of sight to important elements for any seated or standing user.</td>
</tr>
<tr>
<td></td>
<td>7b. Make reach to all components comfortable for any seated or standing user.</td>
</tr>
<tr>
<td></td>
<td>• Accommodate variations in hand and grip size.</td>
</tr>
<tr>
<td></td>
<td>• Provide adequate space for the use of assistive devices or personal assistance</td>
</tr>
</tbody>
</table>

Developed by Bettye Rose Connell, Mike Jones, Ron Mace, Jim Mueller, Abir Mullick, Elaine Ostroff, Jon Sanford, Ed Steinfeld, Molly Story & Gregg Vanderheiden (1997)

Although the outcomes of universal design can be more inclusive of individuals with disabilities than other design paradigms, it replaces user involvement in design processes with the application of principles or the collection of data from users. Designers who apply universal design principles try to integrate features such as functionality, usability, accessibility, and aesthetics within technological and economically feasible limits. Although there are exceptions that come somewhat close to the underlying aim of UD (i.e., Apple products, curb cuts, and Oxo Good Grips), universality is an unachievable goal in most situations. Regardless of their skills and abilities, designers cannot reasonably accommodate the diversity of physical, sensory, motor, and cognitive abilities as well as the diverse cultures, knowledge, and motivations represented within the population (Newell, 2008). Providing access to one group can and often does reduce usability for another (Newell & Gregor, 2000). The unfortunate reality is that UD and similar approaches represent grandiose goals that are impossible to realize in most cases. Besides the practical side of things, designing according to a set of principles rather than engaging end-users and trying to understand their actual activities and capabilities seems to
suggest that static principles and guidelines can adequately account for diversity among and between groups.

UD also fails to empower individuals with disabilities. To an even greater extent than UCD approaches, universal design reduces potential end-users with disabilities to data points that inform the efforts of mostly able-bodied designers. Whereas user-centered approaches attempt to make end-users the central focus, UD substitutes this focus with following guidelines that allegedly lead to usable and useful outcomes. Instead of including individuals with disabilities in design activities, UD approaches mostly engage them to test their UD–informed innovations in either prototype or completed form. So-called accessible web pages that were designed according to accessibility guidelines but are largely or wholly unusable illustrate the risks of principle-driven design (Newell, 2008).

**Assistive Technology Research and Practice Versus Use**

Although assistive technology (AT) is in scope for this dissertation and rehabilitation technology (RT) is not, both approaches to disability and technology have significant areas of overlap. One area of overlap that is particularly important in this study is how the same implicit theory about disability and the best ways to address it undergird both approaches (Roulstone, 2016). While my goal is not to provide a detailed account of rehabilitation research and practice, there are aspects of this approach that apply to assistive technology as well and I will discuss them below.

The 2004 Assistive Technology Act Amendments define assistive technology (AT) as "any piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a [person] with a disability” (Alper & Raharinirina, 2006). Assistive technology devices are meant to help a person with a disability to overcome impairment(s) that impact his/her ability
to move, see, hear, write, communicate, exert motor control, read, do math, or engage in any other bodily or cognitive activity. AT research and practice focuses on making devices explicitly for use by individuals with disabilities in school, work, home, and other everyday contexts. AT has one specific purpose: to put someone with a functional impairment on a level playing field with people who do not to ensure the same educational, vocational, and life opportunities for both parties.

One of the reasons why the accessible technology industry exists and exerts so much influence over the lives of individuals with disabilities is economics. Gary Albrecht, author of the book The Disability Business: Rehabilitation in America defines rehabilitation as both the philosophy and practice of making individuals with impairments able to function to the highest degree physically, socially, and psychologically possible (Albrecht, 1992). In its nascent stages, the rehabilitation industry directed its attention towards making sure that people injured in war or work environments could return to work as soon as possible. It has grown into a complex, multi-stakeholder, multi-billion-dollar industry that simultaneously attempts to help and profit from disability. The rehabilitation industry is responsible for the manufacture and sale of products such as electric wheelchairs, non-motorized mobility equipment, and prosthetic devices, various medical equipment used to treat impairment issues, care facilities, nursing homes, health and wellness services, and other products and services that individuals with disabilities consume.

Somewhat similarly, the AT industry is a major player in addressing impairment concerns through the provision of technology and related services for use in educational contexts. The AT product and service industry simultaneously seeks to help individuals with disabilities and keeps many people employed, which introduces the possibility of multiple and conflicting interests.
Something to notice about the definition of AT is the inclusion of modified and customized items. This definition suggests something that UCD approaches do not: consumption is not limited to passive utilization but also includes adaptation, modification, and design-like activities. This is significant for two reasons. First, since the definition does not attribute these activities to anyone specific, it would be safe to assume that individuals with disabilities can and more than likely do play a role in making assistive technology. Formal AT design research and practice, however, suggests the opposite for arguably disingenuous reasons. In theory, individuals with disabilities should be able to modify and customize AT. Nevertheless, adult AT abandonment rates are 29.3% (Scherer, 1996) and the AT literature often talks about device abandonment resulting from selection processes that exclude individuals with disabilities as well as needs/priorities and device mismatches (Alper & Raharinirina, 2006; Riemer-Reiss & Wacker, 2000; Scherer, 1996). Also, AT literature rarely attributes modification or customization activities to individuals with disabilities despite published HCI/accessibility (Anthony et al., 2013; Buehler et al., 2015; Hook et al., 2013; Kane et al., 2009), historical/societal (Williamson, 2012), disability studies (Goggin & Newell, 2007), and even medical (George et al., 1988) research suggesting the opposite.

The second important thing to note about the definition of AT is that it opens the practice of AT design to researchers and professionals outside of the assistive technology domain as well as non-professionals. The literature is replete with examples of HCI researchers designing, testing, or evaluating the use of assistive technology interfaces (Allen, Leung, et al., 2008; Azenkot et al., 2011; Bigham, Prince, & Ladner, 2008; Brady, Zhong, Morris, & Bigham, 2013; Cherniavsky, Chon, Wobbrock, Ladner, & Riskin, 2009; Duff et al., 2010; Gollner et al., 2012; Guerreiro, Nicolau, Jorge, & Goncalves, 2010; Guerreiro, Nicolau, Jorge, & Gonçalves, 2010;
Kane et al., 2008, 2009; Wei, 2012; Woudstra, Mahmud, & Martens, 2011). A growing number of HCI and accessibility scholars are beginning to explore non-professional assistive technology design, evaluation, and usability testing approaches that are responsive to the needs and interests of individuals with disabilities (Anthony et al., 2013; Branham & Kane, 2015; Buehler et al., 2014; Hofmann et al., 2016; Hook et al., 2014, 2013; Hurst & Kane, 2013; Hurst & Tobias, 2011; Leduc-Mills et al., 2013; Mankoff et al., 2010; Rajapakse et al., 2014). These non-professional "do-it-yourself" approaches and perspectives on AT are particularly critical given the tendency of professionals in the assistive and rehabilitation technology field to focus mostly on impairment and maintain their control over the disability narrative for the sake of self-interest:

The multiple stakeholders in the disability business have their own interests. Human services agencies and industries rely on the construction and maintenance of such social problems as disability to keep them in business, for without recognized and defined social problems, human service agencies would have no reason to exist (Albrecht, 1992, p. 69). Albrecht's reference to social problems does not refer to disability itself, which non-disabled stakeholders often view as a problem embedded in the individual and his or her interactions, but rather the perceived threat of disability to society in the eyes of citizens, groups, or leaders (Albrecht, 1992). Assistive and rehabilitation technology represents big businesses that span multiple industries with various stakeholders who profit off the impairment/disability equivalency of the medical and corporate models of disability. A cadre of players including funding agencies, manufacturers, service providers, and others have positioned themselves to not only address the “problem” of disability but also reap benefits from doing so (Albrecht, 1992; Albrecht & Bury, 2001). This dynamic led to the creation, growth, and survival of institutions that create jobs and earn massive profits by "fixing" a problem they created, defined, and then developed markets to address. For assistive technology industry stakeholders other than consumers, there is little room for alternative approaches to this problem which could take away
their authority and jeopardize the profitability of a system that works well for them while offering some benefits to consumers, albeit at the expense of marginalizing their voices and personal interests.

It is important to ask why AT abandonment rates are nearly 30% despite the existence of entire industries and supporting infrastructures devoted to AT as well as the alleged benefits of this types of technology for individuals with disabilities? Perhaps because of the nature of traditional AT product and service delivery that subordinates the desires and perspectives of consumers with disabilities, who tend to be at the bottom of the economic ladder and often possess little power in these interactions, to the goals and interests of stakeholders who profit from existing product/service deliver models. Indeed, it has been argued that various individuals, interest groups, and large for-profit corporations created the social problem of disability, assumed moral authority to address the problem, and pushed for the favorable healthcare structure that keeps them in business (Albrecht & Bury, 2001). Different stakeholder, institutions, and forces circumscribe AT and its acquisition, use, and disbandment. They include, in addition to consumers and their families, corporations that deal with rehabilitation concerns professionals who provide related services, manufacturers, government agencies, private insurers (e.g., HMOs, PPOs), and public insurers (Medicare and Medicaid). Social, political, and economic factors come into play as well as use contexts such as home, work, school, and social environments. Federal laws like the Assistive Technology Act, the Individuals with Disabilities Education Improvement Act (IDEA), and Section 504 of the Rehabilitation Act as well as state laws and agencies such as the Assistive Technology Act Projects (ATAP) govern various aspects of AT provision and acquisition. Medical, health and human service professionals, family, Individualized Educational Program (IEP) team members, and other stakeholders besides the
person who will use AT all play a role in planning, implementing, facilitating, and evaluating that person’s utilization of AT. Non-disabled stakeholders with varying degrees of AT knowledge all participate in critical AT-related decisions. For instance, insurance companies are powerful stakeholders who serve as intermediaries between AT/RT businesses and consumers who manage the delivery of products and services through their funding policies (Albrecht, 1992).

A significant portion of AT research focuses on its use in school or work contexts. Assistive and rehabilitation technology scholars are often concerned with best practices related to technology and service provision and use. In the 1970s and 1980s much of the research on technology use by students with disabilities focused on the potential of the microcomputer (Woodward & Rieth, 1997). Research and development in assistive/special education technology accelerated starting in the 1980s when scholars began to focus on advancing the quality, availability, and effective use of technology by students with disabilities. Some studies conducted during this time looked explicitly at naturalistic use of AT in school settings (Woodward & Rieth, 1997). Today AT researchers specifically look at the effectiveness of AT in improving or acquiring education, work, and life skills, barriers to AT access, and the benefits of AT use (Alper & Raharinirina, 2006; Edyburn, 2000; Maor et al., 2011). Recent research seems to suggest that AT scholars are concerned with the use and impact of technology in the daily lives of individuals with disabilities. In many of these studies, however, scholars impose their view of effectiveness, barrier, benefit, and acceptable use onto students and the research itself primarily focuses on whether actual use matches their standards. They leave little room for end-user adaptation, modification, or self-determined use because such actions represent deviations rather than meaningful and research-worthy activity.
The impairment-centric orientation of the medical model is noticeable in the AT literature. For instance, Alper and Raharinirina (2006) reviewed 60 empirical studies conducted between 1988 and 2003 and found that scholars often study the use of AT in terms of relationships between variables. Dependent variables include education/work/life skill acquisition, improvement, or management while independent variables include training, pre-AT selection assessments, training material, family involvement, and support. All the dependent variables in these studies were specific to the individual and his or her abilities and ignored other factors that circumscribe AT use. Similarly, a review of 122 peer-reviewed empirical articles published between 2000 and 2006 focused on the use of technology to improve academic skills, AT implementation, academic, non-academic, and employment outcomes associated with AT use, and training professionals to use AT with students who have disabilities (Okolo & Bouck, 2007). Both reviews suggest a methodological individualism inherent in disability research which, like the medical model, reduces all disability-related issues to an individual’s impairment and ignores potential social or other non-impairment related factors (Oliver, 1992). Methodological individualism ignores possible explanations of disability-related issues in ways that marginalize the perspectives and voices of individuals with disabilities who have direct experience with those issues. AT research tends to attribute use factors primarily to the individual and his or her interactions with assistive devices. It also seems to assume that AT development, provision, use, and outcomes are causally linked together without any extraneous variables.

Assistive technology scholarship hints at a supply-push approach to AT provision, which says it is up to the manufacturers and service providers to determine, develop, and provide the right things for consumers with disabilities. An alternative demand-pull approach would base such decisions on the views and desires of consumers with disabilities rather than the experience,
capabilities, and knowledge of the mostly non-disabled professionals involved in AT product and service delivery. Evidence from studies that have explored the actual opinions of AT users seems to support the idea that professionals often ignore or overlook issues that matter to consumers. These studies highlight typical barriers associated with the acquisition, use, and maintenance of AT. AT tends to be prohibitively expensive and overly sophisticated. The high cost and technical know-how required to acquire, use, and maintain devices make them inaccessible to individuals who cannot afford them or do not possess the requisite skills and supporting infrastructure. AT is discriminatory in the sense that the intended user population consists of individuals with disabilities only. Its use in public or social settings often draws unwanted attention from people who do not use or have any familiarity with the device to the user. The stigma factor acts as a disincentive to use AT and an incentive to leverage more inclusive mainstream products (Culén et al., 2010; Gasparini & Culén, 2012; Parette & Scherer, 2004; Shinohara & Wobbrock, 2011; Vanderheiden, 1998, 2006). It is important to note that only two of the sources just cited were published in AT-specific outlets.

End-user perspectives on AT which uncover phenomena such as the role of stigma in adoption behaviors temper the generally optimistic tones of most AT research and practice community members who primarily focus on the positives without exploring social, political, economic, and other factors that circumscribe use. Research that examines use outcomes and gathers the opinions of end-users tend to ignore two relevant facts. First, the AT industry represents a multi-billion-dollar market with stakeholders that include shareholders looking for a return on their investment, paid (mostly non-disabled) professionals, state, federal, private, and other funding agencies, and, most importantly, consumers with disabilities. The positivist orientation of AT research legitimates industry practices by pointing to the benefits of existing
products and the potential benefits of new ones for individuals with disabilities. Positivistic research of this sort tends to focus on the observable, ignore the values different people attach to technology and its use, seek causal explanations for observable phenomena, and assume both the assumptions underpinning research and the methods used to conduct it do not impact outcomes (Oliver, 1992). The second significant issue that AT research rarely accounts for goes back to an argument made earlier in this document. Both technology and disability are political constructs too often defined by those who not only possess the power and authority to do so but also tend to look at disability primarily as deficit. Asking those who have the power to control the disability narrative due to their relation to the means of production and possession of capital (Albrecht, 1992) to rethink their constructions of disability and technology which currently benefit them is not likely to lead to meaningful change. By preventing the desires, values, and capabilities of individuals with disabilities, including their unexpected and innovative ways of using products, from informing the perspectives and practices of the AT research and design communities, they more firmly entrench a supply-push approach to accessibility/disability design at the expense of consumer self-determination and independence.

**What accessibility research and design approaches lack.**

I just described three broad accessibility/disability design paradigms and related research and practice approaches. I critiqued each one with the intention of showing how their underlying constructions of disability and deficit model assumptions shape design practices, outcomes, and use. Some paradigms acknowledge the ability of individuals with disabilities to inform the design process and create opportunities for them to participate in it to some degree. Nevertheless, all the approaches discussed often depend on someone who does not have any lived experience with disability supporting, enabling, empowering, or helping those who do. Individuals with
disabilities are relegated to consumers whose agency is either non-existent or 100% dependent on non-disabled individuals. Even within the human-computer interaction research community where the results of some studies offer evidence that individuals with disabilities engage in assistive technology adaptation activities, researchers tend to make blanket assumptions about the dependency, deference, or both of individuals with disabilities when it comes to making or modifying AT. The other research and professional design communities referenced above do not pay any attention to the self-directed efforts of individuals with disabilities to address accessibility-related issues or see the need to accommodate those who do. Tables 5, 6, and 7 below highlight several limitations of the accessibility/disability design paradigms and approaches discussed in this section.

In the opening sections of this manuscript, I argued that every individual involved in design activities brings his or her knowledge and assumptions about disability to bear on the task and plays a role in influencing the downstream impacts of design outcomes. After talking about the roles that individuals with disabilities play in various design approaches as well as the assumptions other (often non-disabled) stakeholders make about them, I need to add the following caveat. A stakeholder impacts design only to the extent that he or she plays an active role in the design process and possesses the requisite authority and agency to act in his or her individual and collective best interests. The disability/accessibility design approaches discussed in this section all have the same goal of making accessible and usable products for consumption by individuals with disabilities. Nevertheless, they ignore, limit, or dictate the contributions individuals with disabilities can make to the design process. As a result, deficit model ideas about disability and design undergird all related efforts, including those that involve individuals with disabilities in some way. In the next two sections, I will talk about critical design research
and scholarship on bottoms-up/consumer-driven approaches. I will discuss their potential implications for accessible design, individuals with physical impairments, and social understandings about what it means to have a disability. I will primarily focus on research design paradigms that adopt critical stances and socio-cultural movements where consumers engage in more self-directed design-like activities.
### Table 5 - Disability/Accessibility Design Paradigms

<table>
<thead>
<tr>
<th></th>
<th>User-Centered Design</th>
<th>Universal Design</th>
<th>Assistive Technology (AT) / Rehabilitation Technology (RT)</th>
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</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>Prioritize usability and usefulness. Create room for the needs and capabilities of diverse users to influence design</td>
<td>Design environments and technologies that are “usable by all people to the greatest extent possible”</td>
<td>AT: Design/ modify/ customize products that increase, maintain, or improve the functional capabilities of IwDs</td>
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<td></td>
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<td>RT: Design products that help individuals with impairments to function to the highest degree physically, socially, and psychologically possible</td>
</tr>
<tr>
<td><strong>Characteristics</strong></td>
<td>-Consider needs/capabilities of diverse users</td>
<td>-Design for individuals with and without impairments/disabilities</td>
<td>-Design explicitly and exclusively for IwDs</td>
</tr>
<tr>
<td></td>
<td>-Passively/actively/representatively involve end-users in design practices</td>
<td>-Design according to principles and guidelines</td>
<td>-Primarily non-disabled professionals designing artifacts intended to improve the lives of IwDs</td>
</tr>
<tr>
<td><strong>Examples/Approaches</strong></td>
<td>-Participatory design</td>
<td>N/A</td>
<td>-Human-computer interaction research</td>
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<tr>
<td></td>
<td>-Assistive technology co-design</td>
<td></td>
<td>-AT/RT research</td>
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<td></td>
<td>-Empathic design</td>
<td></td>
<td>-AT/RT practice</td>
</tr>
<tr>
<td><strong>Limitations</strong></td>
<td>-Dependent on non-disabled stakeholders</td>
<td>Frames universal access to products and environments as an easily achievable goal but offers little practical guidance on how to achieve it</td>
<td>-Too often ignores/marginalizes the interests and self-directed efforts of IwDs</td>
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<td></td>
<td>-Does not always address the power dynamics between researchers/designers and researched/end-user</td>
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<td></td>
<td>-Somewhat paternalistic since non-disabled people plan, initiate, and guide the effort</td>
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</tbody>
</table>

IwDs=Individuals with disabilities  
AT=Assistive technology  
RT=Rehabilitation technology
<table>
<thead>
<tr>
<th>Description</th>
<th>Role(s) of IwDs</th>
<th>Assumptions about stakeholders /w disabilities</th>
<th>Primary Limitation</th>
<th>Disability Model Parallels</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participatory Design (UCD)</strong></td>
<td>- Passive/ representative involvement in brainstorming/ prototyping/ user-testing activities OR - Domain experts replace IwDs</td>
<td>- Participation in design 100% dependent on others - Impairment precludes participation in design activities</td>
<td>Only as flexible /inclusive of IwD perspectives as non-disabled stakeholders</td>
<td>- Problematize/ address disability/ impairment issues (corporate model) - Links disability to passivity &amp; diminished capacity (medical model)</td>
</tr>
<tr>
<td><strong>AT Co-design (UCD)</strong></td>
<td>- Caregivers serve as proxies/ the actual &quot;co-designers&quot;) - Give feedback during testing/evaluation sessions - &quot;Latent perceptions/ emotional responses&quot; to prototype serve as a proxy for verbal input</td>
<td>- Passive and dependent &quot;patients&quot; - Perspectives reducible to their visible emotions and reactions</td>
<td>“Interactions” with IwDs are passive or mediated</td>
<td>- Links disability to passivity &amp; diminished responsibility (medical model) - May use deficit language (deficit models) - Seemingly values perspectives of IwDs like social model does but marginalizes those perspectives in practice</td>
</tr>
<tr>
<td><strong>Empathic Design (UCD)</strong></td>
<td>- Passive or facilitated involvement in design activities - Partner and co-designer - Source of understanding and target of inquiry</td>
<td>- Active to the extent non-disabled people enable/help them - Perspectives ascertainable via prolonged engagement with them</td>
<td>- Impractical outside of research environments and potentially parasitic</td>
<td>- Involves IwDs &amp; values their perspectives (social model) - Looks beyond impairment / technical factors (social model) - Focuses on capabilities/ contributions thereby attributing agency to IwDs (social model)</td>
</tr>
<tr>
<td><strong>Universal Design</strong></td>
<td>- A data source during prototyping/ user testing/ evaluation sessions</td>
<td>- Needs/ wants/ capabilities reducible to a set of principals</td>
<td>Frames universal access as an easily achievable goal while providing little practical guidance on how to achieve it</td>
<td>- Views IwDs as equal citizens (social model) - Acknowledges disabling effects of environmental, social, and economic barriers (social model) - Assumes IwDs cannot address issues for themselves (medical model) - Problematizes and addresses disability /impairment issues (corporate model)</td>
</tr>
<tr>
<td>Human-Computer Interaction research (AT/RT)</td>
<td>AT/RT design and adaptation activities of researchers/ non-professionals</td>
<td>-Passive/ representative involvement in brainstorming/ prototyping/ user-testing activities -Passive or facilitated involvement in design activities</td>
<td>-Possess potential to participate in design activities but not independently</td>
<td>Limited focus on self-directed AT design/adaptation activities of IwDs</td>
</tr>
<tr>
<td>AT/RT Research (AT/RT)</td>
<td>Researcher-driven efforts to evaluate/ improve usage outcomes in school/ work contexts</td>
<td>-End-users participating in testing/ evaluation sessions -End-users who can provide feedback but cannot inform design</td>
<td>-Perspectives less important than observable/ measurable usage outcomes</td>
<td>Exploration of non-technology/impairment factors is cursory at best</td>
</tr>
<tr>
<td>AT/RT Practice (AT/RT)</td>
<td>Primarily professional market-driven commoditized interventions intended to address functional impairment issues</td>
<td>-A data source during prototyping/ user testing/ evaluation sessions -Someone to simultaneously help and profit from</td>
<td>-Perspectives less important than those of other AT/RT stakeholders -Perspectives less important than observable/ measurable usage outcomes</td>
<td>Typically prioritizes the interests of other AT/RT stakeholders over those of IwDs</td>
</tr>
</tbody>
</table>

IwDs=Individuals with disabilities
AT=Assistive technology
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HCI Critical Design Research Perspectives

The goal of the following is to provide a brief overview of several developments within the HCI research community that could be used to examine accessibility/disability design more critically. Currently, few studies exist in this vein. I will briefly define critical making, critical design, post-colonial computing, and values-oriented-design in addition to discussing some of the strengths and limitations of each. I will primarily focus on potential strengths and weaknesses as it relates to accessibility/disability design issues.

Critical design & critical making.

At their core, critical making and critical design are research-based and artifact-enabled ways of creating knowledge. Anthony Dunne and Fiona Raby coined the term critical design to refer to research that leverages design artifacts to get people to think about their daily lives more critically, particularly as it relates to how the assumptions, values, ideologies, and behavioral norms embedded in design mediate their lives (Bardzell & Bardzell, 2013). Their conceptualization of critical design was grounded in three ideas: 1. Design is ideological, and the ideological leanings of the individuals engaged in the design process inform that process; 2. Most design affirms the social, cultural, technical, and economic expectations of a given ideology; and 3. Design has the potential to challenge or critique a given ideology and its expectations (Dunne & Raby, 2001). Critical design is the embodiment of the third idea, and its goal is to stimulate debate about the cultural and aesthetic role of design artifacts among designers, industry, and end-users (Dunne & Raby, 2001). To achieve this goal, researchers attempt to work with potential design consumers to both interrogate existing design and point to possible alternatives undergirded by different assumptions. Critical design research as articulated by Dunne and Raby (2001) seeks to challenge capitalist ideology and its orientation toward the
status quo, consumer passivity, and the illusion of choice. Critical design depends on an artifact meant to foster critical analysis that does not take things for granted and looks beyond the surface (Bardzell & Bardzell, 2013). Its goal is to intentionally challenge the status quo regarding production and consumption practices as well as the cultural and social assumptions embedded in these practices (Britton & Semaan, 2017). As it relates to accessibility/disability design, a critical design approach could not only engage individuals with disabilities in design-related conversation but also raise the awareness of non-impaired people about disability assumptions that undergird accessible design practices. Critical design's biggest challenge is its relative lack of use within the HCI research community as well as the dearth of guidance on how to apply it (Bardzell & Bardzell, 2013). Despite its intent to create space for user perspectives on design, there are few resources available for researchers interested in leading critical design projects.

Critical making is an STS-informed HCI design research perspective explicated and popularized by University of Toronto Information Professor Matt Ratto. Like critical design, critical making seeks to bridge gaps between the material and conceptual by focusing on the underlying values of design and designers (Ratto, 2011a). According to Ratto, critical making seeks to explore the links between "scholarly research on critical social issues and design methodologies" with the purpose of "furthering critical knowledge through joint material production" (Ratto, 2011b, p. 252). Materially-mediated collaborative technology design activities afford opportunities to examine the societal norms embodied in design and their impact on people's lived experiences. The collaborative process of making artifacts which is central to critical making affords conceptual exploration, reflection, and criticism by active participants in the process (Ratto & Ree, 2012). This process, among other things, uncovers the politics of design and design artifacts (DiSalvo, 2014).
Critical making projects typically consist of three interrelated activities: 1. reviewing the literature for concepts, theories, and ideas that metaphorically map to physical prototypes; 2. collaborative prototype design and build sessions with scholars, students, and stakeholders; and 3. iterative reconfiguration, conversation, and reflection sessions (Ratto, 2011b). Citing STS scholar Bruno Latour, Ratto frames critical making as an attempt to move away from considering design artifacts and the assumptions undergirding them as settled "matters of fact" toward viewing them as unsettled matters of concern that are inherently political (Ratto, 2011a; Ratto & Boler, 2014). As collaborative contributors in critical design projects, stakeholders are free to influence prototype design in ways that support their values, everyday life conditions, and idealized states of reality as opposed to those of professionals. Critical making stakeholders collaboratively and actively "do politics" by making sure design reflects the desires and commitments of a particular social group (DiSalvo, 2014). It is in this sense that critical making is a politically transgressive activity that allows contributors to reflect on the relationship between designers/makers and the artifacts they produce (Ratto & Boler, 2014).

Scholars adopting feminist hacking, Science and Technology Studies (STS), and critical design/making perspectives are beginning to explore technology and the body through critical socio-technical lenses (Britton & Semaan, 2017; Forlano, 2016). They use Haraway’s metaphor of the cyborg to interrogate contentions between normative constructions of gender, race, or dis/ability and materiality, the gendered, racialized, dis/abled body, and personhood (Britton & Semaan, 2017; Forlano, 2016; Forlano & Jungnickel, 2015). They frame hacking as an interrogation of the human/non-human, male/female, and dis/abled dichotomies commonly embedded in technology and sociotechnical systems. Their work highlights the value of post-colonial perspectives (explicated below) that question power, authority, legitimacy, participation,
and intelligibility in top-down design approaches prevalent in professional design processes where practitioners possess significantly more wealth, economic strength, and political influence than end-users (Irani, Vertesi, Dourish, Philip, & Grinter, 2010).

As it relates to disability/accessibility design, critical making holds out the opportunity for individuals with disabilities to play a role in the activity of design as well as the social construction of technology and disability, yet rarely does this occur. Involving individuals with disabilities in critical making projects could potentially empower them to embed their values, perspectives, and wants in design artifacts rather than using products designed by non-disabled people with alternative and potentially conflicting assumptions. Except for Forlano (2016) and Forlano & Jungnickel (2015), there are few exemplars of STS-informed critical making/design projects that I am aware of which include individuals with disabilities in related physical activities or give them the opportunity to reflect on the politics of design. In the case of Forlano's research, she focused on alternative design futures as a person living with diabetes as well as her embodied experiences managing the complex socio-technical network of technologies designed for people with her condition. I would argue that as people living in a world and consuming products that can be inaccessible to them, individuals with disabilities are more likely to reflect on many of the same types of issues that interest members of the critical making research community without outside support from researchers. It just so happens that Laura Forlano is also an academic who wrote about her insights published the findings of her study.

The disability studies community in its conceptualization of the social model of disability already has acknowledged the social and political nature of technology as well as the need for individuals with disabilities to play an active role in shaping its meaning (Goggin & Newell, 2007). DiSalvo (2014) describes critical making as actively ‘materializing the politics of design,’
where end-users determine function, form, practice, and values for themselves through their
design-like activities. Despite the potential to allow individuals with disabilities to play a role in
constructing the form, substance, and meaning of design artifacts as suggested by DiSalvo's
description, critical making is subject to the same limitations as the accessibility/disability design
approaches described earlier in this document. For instance, as evidenced by the current dearth of
critical making studies involving individuals with disabilities, this approach is only as inclusive
as the researchers employing it. Also, the same accessibility challenges that some
disability/accessibility design researchers cite as barriers to the full inclusion of individuals with
disabilities in design activities likely serve as barriers to their inclusion in critical making
projects.

**Postcolonial computing.**

Postcolonial computing is another design research perspective HCI and computer-supported
collaborative work (CSCW) researchers use to interrogate some of the political aspects of design
practice and design artifacts. It is not a specific method or practice but rather a sensitivity to the
power dynamics involved in design practices, notably when the cultures of designers and end-
users differ. Postcolonial computing is a set of tools that afford context-centric and inclusive
interpretations of cultural-technical phenomena (Philip, Irani, & Dourish, 2010). It is grounded in
the uneven balance of power, wealth, economic strength, and political influence which marked
global colonial relationships in the past and still shape geopolitics to this day (Irani et al., 2010).
Postcolonial computing is sensitive to the influence of culture and history on the practice,
outcomes, and impacts of design. It views culture as dynamic and acknowledges the need to pay
attention to colonial history, comparative economic development, and local knowledge
development throughout an IT development project (Irani & Dourish, 2009).
HCI4D researchers adopt postcolonial computing perspectives to interrogate HCI design and development projects intended to "enlighten", civilize", or help "develop" non-westernized nations as well as the forms of power, authority, legitimacy, participation, and intelligibility that mark the underlying cross-cultural engagements (Irani et al., 2010). These scholars begin their work with a basic understanding that all design research and practice is culturally situated and contains power dynamics. As their research progresses, they remain open to alternative practices that not only cede power to members of marginalized groups but also privilege their cultural understandings (Irani et al., 2010). HCI design approaches such as user-centered and universal design explicitly acknowledge the need to include end-users in the design (mostly in passive ways) and account for differences between them. These same approaches, however, rely on the same core set of design, development, and evaluation methods as if they are inherently universal and cross-cultural (Irani et al., 2010). Such approaches are likely to fall short if the goal is to design for individuals from an entirely different culture than researchers or designers.

I would argue that the same sensitivities that HCI researchers who adopt postcolonial computing perspectives bring to HCI4D projects would be beneficial in accessibility/disability design contexts given cultural differences between individuals with and without disabilities. I do not think they would work, however, because of the medical and corporate model of disability assumptions that many HCI researchers embrace. Post-colonial computing proper applies mainly to transnational cross-cultural design projects. HCI researchers rarely talk about disability as a cultural phenomenon and accessibility designers as members of a privileged cultural group. They do not discuss the power dynamics that shape the relationships and interactions between researchers/designers and individuals with disabilities. Except for DIY-AT research, which still does not go far enough in this direction, few HCI researchers question what role others should
play in addressing the concerns individuals with disabilities encounter in their daily lives. The ideals of postcolonial computing seem adaptable to the accessible design context, but only if researchers are willing to acknowledge the cultural, economic, and political inequities between individuals with disabilities and people who try to design things for them as a starting point.

**Values-oriented design.**

The final HCI critical research design approach I want to discuss is values-oriented-perspectives. Technically, all the design research methods discussed in this section focus on values. More specifically, they attempt to either include end-user perspectives in design practices or make the values of designers more explicit to compare, contrast, and integrate them with the values of design end-users during the design process. Value-oriented perspectives assert that the practice of design is not neutral but rather value-laden (JafariNaimi, Nathan, & Hargraves, 2015; Shilton, 2017) and leads to the materialization of social values in design (Shilton, 2012). Researchers who adopt values-oriented approaches define the term *value* differently and thus examine the design process from different angles. HCI and CSCW researchers have defined values as entities that appear in technologies, the conscious or unconscious creations of developers, what designers codify in the features of technology, properties of designers, or properties of users (Shilton, 2017). Several scholars interested in interface design issues have started to explore both the appropriateness of actively incorporating end-user viewpoints into the design of systems and the links between values and design practices (Erickson, Nathan, Jafarinaimi, Knobel, & Ratto, 2012; Shilton, 2017). These and other researchers advocate for sociotechnical design processes that pay explicit attention to values rather than leaving the user to grapple with the downstream impact of designer decisions in their daily lives (Knobel & Bowker, 2011). Shilton (2012) asserts that designers' values not only inform technology planning and development, utility, and
usefulness decisions but also shape the social consequences of these decisions in the lives of users. Knobel & Bowker (2011) point out that values conversations about technology artifacts usually take place after development and while in use. By this time, the onus for rectifying the negative impact of value-related decisions falls entirely on the end-user.

Researchers can perform after-the-fact analyses of the downstream impact of designer values that conflict with users' values, but such analyses ignore the sociotechnical nature of the design process itself. Although we discover the substance and significance of values codified in design by observing their downstream impact in the everyday lives of consumers, the values themselves are determined by people other than consumers. Designers who constantly make decisions as they go about their activities effectively dictate how to address the always changing circumstances that comprise consumers' everyday lives (JafariNaimi et al., 2015). Proper attention to values has the potential to ground design in human life and living (Hargraves & JafariNaimi, 2012; JafariNaimi et al., 2015) and values-oriented perspectives seek to do so by both aligning designer and user values during the design process and understanding how values inform the design process. In theory, values-oriented approaches have the potential to integrate the perspectives of individuals with disabilities into accessibility/disability design processes. In actual practice contexts, these perspectives would be subject to the willingness of design stakeholders to engage the actual perspectives of potential end-users with disabilities. Recruiting individuals with disabilities to participate in research studies is often difficult (Mankoff et al., 2010). Also, as I mentioned when discussing various accessibility/disability design approaches, the nature of researcher engagement with individuals with disabilities tends to be paternalistic and motivated by the goals and interests of the researchers. Value-centered initiatives in the HCI and accessibility community will require a keen sensitivity to the socially constructed nature of
disability as well as the power dynamics that define designer-end-user with disability relationships. Although there is growing interest in valued-centered approaches within the HCI community, its articulation does not yet seem advanced or mainstream enough to begin discussing its application with unique user communities.

**HCI critical design research approaches and accessibility.**

The four critical design research approaches just described represent potential ways the HCI community could reconcile accessibility/disability design practices to the perspectives, needs, and interests of individuals with disabilities. Each approach demands a commitment to critically evaluating the assumptions and biases that undergird design practices and their outcomes. Although these critical research orientations offer the potential to reveal and interrogate some of the politics of accessibility/disability design approaches, I question their ability to empower members of the disability community since they are entirely dependent on the efforts of researchers. Some of these orientations are interrelated, and principles such as user-centeredness, equality, social justice, and self-determination seem common among them. However, since they are dependent on the researcher, most are subject to the same paternalism inherent in UCD approaches. More work is needed to define how these approaches should be utilized and what specific adaptations are needed to actively involve individuals who have disabilities.
Consumption-Driven/Bottoms-Up Approaches

So far in this chapter, I have discussed researcher and professional designer activities. After describing the limitations of four prominent disability/design approaches, I described four researcher-driven critical design research perspectives. Although critical design research represents an opportunity to dig deeper into the social, cultural, economic, and political issues that circumscribe technology design and use, it is entirely dependent on HCI, CSCW, and other researchers and their willingness to acknowledge their complicity in negative constructions of disability and design. The next section discusses several bottoms-up consumer driven approaches to innovation, design, and problem-solving as well as the roles that individuals with disabilities have and could potentially play in them. Several elements of the approaches described in this section manifest themselves in the activities and statements of study participants as evidenced in the analyses presented in chapters 4-7. Unlike most accessible design approaches and critical design research projects, the interest, discretion, and abilities of the individuals who do not own the means of production or benefit directly from academic research endeavors are the drivers of related efforts. As a result, the people engaged in these activities can freely embed their perspectives in design artifacts instead of simply using what is given to them in a predetermined manner.

Domestication, prosumption, & end-user innovation.

Domestication scholarship originated in Europe and anthropology, cultural studies, and media studies have all contributed to its development. Domestication scholars explore the adoption, use, and management of information-communication technologies (ICTs) in household contexts. Topics of interest include looking at how people experience, adjust to, and display ICTs, the role of ICTs in their everyday lives, and the meanings attributed to ICTs (Haddon, 2006).
Researchers in this camp assert that consumers not only appropriate technology and objects for individualized purposes but also make them acceptable and familiar within the context of their everyday environment (Silverstone & Haddon, 1996). Domestication research examines the relationships and interactions individuals have with ICTs in the home environment and views consumption and use activities as the continuation of broader technological innovation lifecycles (Silverstone & Haddon, 1996). User domestication practices are both enabled and constrained by design. Related activities represent not only self-determined innovative use activities on the part of the consumer but also consumption activities enabled and constrained by designer interventions that influence user experiences (Haddon, 2006). Again, some HCI studies point to the ability and propensity of some individuals with disabilities to adapt ICT and other interfaces either independently or with assistance (Anthony et al., 2013; Buehler et al., 2015; Hook et al., 2014; Kane et al., 2009). These studies, however, tend to report on the adaptations themselves without exploring the meanings individuals with disabilities ascribe to them or their significance within the broader innovation context.

At its core, the domestication process is about what people do with new ICTs and research in this space seeks to understand and try to predict this behavior. Activities that designers cannot predict or forecast are known as use drift (Mallard, 2005). Domestication and innovative use researchers articulate examples and frameworks that attempt to categorize some of the unpredictable ways end-users may relate to and interact with ICTs designed by someone else (Haddon, 2005; Mallard, 2005). Researchers and designers who embrace the idea of domestication not only attribute value to the innovative use behaviors of consumers but also seek to understand them within their use and broader innovative design context. This approach balances the structure ICTs impose on consumers with the agency those same consumers exhibit
while using them (Silverstone & Haddon, 1996). Such is not the case in the accessible design approaches described earlier which frame innovation as the work of mostly non-disabled designers, researchers, and teams only and consumption as predictable and formulaic use only.

The connotation of the term "innovation" that undergirds domestication research is subject to limitations. Scholars in this space primarily use qualitative research methods to inquire about past and present domestication activities (Haddon, 2006). Such approaches can miss messy aspects of in-situ domestication activities and the multiple and possibly conflicting issues circumscribing them. Although domestication outcomes can inform professional designers, perhaps there is something to learn from the decision-making and active behaviors that lead to those outcomes as well as their constitution by multiple activities, meanings, and motivations. Categorizations like novel use and use drift do not give enough credit to the fact that the behaviors they represent are more than inputs into an ICT producer's innovation cycle.

Domestication activities are a form of non-professional design and innovation that are valuable in and of themselves given the culturally shaped assumptions people bring to the act of design. Somewhat like disability/accessibility design approaches that seek passive input or after-the-fact feedback from consumers with disabilities, domestication research is bound to the outcomes of professional ICT design practices. It frames innovation and adaptation behavior as a data point for "professional" designers. Looking at similar behaviors by individuals with disabilities would lead to more widespread acknowledgment of their ability to play an active role in addressing their own everyday life concerns. It would also allow research and professional design communities to learn from the self-directed efforts of individuals with disabilities. One limitation to such an approach would be the narrow focus on ICTs or other categories of innovations that already exist and therefore already embody the assumptions and perspectives of the people who
designed them. Domestication is limited to the consumption of extant ICT innovations and therefore may not capture non-ICT consumption and more radical innovation behaviors.

Overall, domestication research tends to frame consumers’ individual and collective activities as post-purchase decisions that should fuel the product innovation and improvement efforts of professional manufacturers, designers, and engineers. Prosumption is a related idea that goes a bit farther in explaining and accounting for some of the motivations behind consumers' post-purchase materially mediated decisions and activities. The term *prosumer* was coined by culture critic and futurist Alvin Toffler in 1980 and represents an amalgamation of the words consumer and producer. It refers to someone who produces some proportion of his or her material goods and services for personal use rather than for exchange (Kotler, 1986).

Prosumption is a marketing term formally defined as consumer-driven value creation activities that consist of the simultaneous production and consumption of outcomes by the same non-professional entity, such as a customer or two bartering partners (Xie, et al., 2008). Prosumption represents a shift from the marketing logic of transaction-based exchanges of tangible resources with embedded value to one where buyers create value for their benefit using "raw" purchased goods, tools, competence, time, money, effort, skill, mental effort, or possibly third-party professional services (Vargo & Lusch, 2004; Wolf & McQuitty, 2011). Two fundamental ideas undergird the concept of co-creation: value-in-use and co-production. Value-in-use is the value determined and created by a consumer during the product consumption and use process. Co-production, on the other hand, is consumer participation in the development of a product through co-design, or distributed production across a producer-consumer value network (Xie, et al., 2008). Co-creation is partially dependent on producer willingness to provide exploitable
affordances, open product designs, and collaboration-based service offerings which consumers can leverage in their value creation and appropriation efforts.

The work of economist and MIT Sloan School of Management Professor Eric Von Hippel is closely related to the prosumption literature. He researches innovation processes distributed among producers and consumers and coined the term *user innovation* to describe a growing phenomenon where users:

…can develop what they want, rather than relying on manufacturers to act as their (often very imperfect) agents. Moreover, individual users do not have to develop everything they need on their own: they can benefit from innovations developed and freely shared by others (von Hippel, 2005a, p. 1).

In the United States alone an estimated 16 million or 5.2% of consumers also innovate (von Hippel, 2017). User innovators include both firms and individuals that derive benefits from making products and services for their consumption (von Hippel, 2005a). Drivers of user innovation include recent advancement in computer and communication technology (von Hippel, 2005b) and something von Hippel (2005a) refers to as information stickiness, or the incremental costs of transferring tacit information about needs and use contexts from the user to producers or “problem solvers” in a usable form. When costs are high, stickiness is high. When costs are low, so is stickiness. As this dissertation study reveals, individuals with disabilities have more knowledge about context variables and how they impact their everyday lives than even the most diligent and thoughtful designers could know or learn. This information is quite sticky because it is hard to transfer from user to producer. When it comes to innovation and problem-solving, user innovators have more accurate information about needs and use contexts than manufacturers and thus stand a better chance of satisfactorily addressing those needs. It is important to note that user innovations benefit producers as well who tend to turn these often-rudimentary consumer
solutions into inputs for their more extensive and better-capitalized innovation efforts (von Hippel, 2005a, 2005b).

Prosumption and user innovation represent a producer-enabled form of domestication that extends beyond ICTs. It acknowledges and includes consumers as part of the value chain rather than looking at consumption and use as a black box. Like empathic design for disability, these approaches have exploitative potential. Paying attention to the ways consumers use and derive value from products as well as the situations circumscribing these behaviors can lead to new or improved products. There is no guarantee, however, that engaged consumers will reap any rewards for their contributions to ideas and inventions the owners of the means of production turn into mass marketed products. Nevertheless, domestication, prosumption, and user innovation go farther than any of the accessibility/disability design approaches in acknowledging the creativity, capability, and agency of consumers. As such, they provide room for consumers to play a role in determining who the user is and what he or she can do. A domestication, presumption, or user innovation-based approach to accessibility/disability design would afford individuals with disabilities the same opportunity to influence both the disability narrative and the technology innovation process via their self-directed efforts.

**Do-it-yourself (DIY) and do-it-yourself assistive technology (DIY-AT).**

Some historians attribute the origins of the do-it-yourself (DIY) movement/ethos to both the end of the 19th century and industrial revolution, which led to a previously unforeseen division between home and work (Atkinson, 2006; Gelber, 1997). An alternative and contested perspective on the historical origins of DIY is that it was a reaction to the post-WWII labor shortage in the 1950s (Atkinson, 2006). In the 1960s, many saw DIY as counter-cultural movement which rejected formal education and its orientation towards de-contextualized
knowledge in favor of self-reliance, self-determination, in-situ learning, and community (Gauntlett, 2013). Throughout its history, the DIY moniker has been used to describe various non-professional activities. For example, the punk and zine DIY culture in the 1970s was noted for its preference for making and distributing homemade alternative cultural content over glossy, professionally produced, and celebrity-oriented forms found in traditional magazines (Gauntlett, 2013). The contested origins and diverse ways people and groups use the term DIY contribute to the lack of an agreed-upon definition.

DIY has been described any democratic or self-empowered creation, maintenance, or repair activity performed by one or more non-professionals who possess the freedom and will to do so (Atkinson, 2006). DIY is not only a set of activities but also a shared ethos. DIY breaks down class, gender, and ability barriers between professionals or those who control the means of production and everyone else. More importantly, DIY enhances people's view of themselves as active agents rather than passive consumers and grants them the ability to codify their meanings and values into their artifacts, environments, and activities. Ratto & Boler, who wrote a foundational book on critical making provided a base definition that describes DIY as both political and practical:

DIY means taking matters into your own hands, not leaving it for others to do it for you. It means making decisions without the gaze of those in power saying what's right and what's wrong, what's allowed and what's not. A decentralized medium of communications alongside ad hoc, leaderless, "cloud-like" social movements, the Internet and DIY seem like the perfect match and a recipe for freedom and democracy (Ratto & Boler, 2014, p. ix).

As a way of thinking and behaving that has political implications, DIY represents both an individual and collective movement away from mass consumerism and industrialization towards cultural production, self-determined labor activities, the empowerment of marginalized groups, democratized technological practices, personalization, and re-appropriation (Hill, 1979;
Tanenbaum, et al., 2013). It is an attitude towards getting things done manifested when a person who can hire someone else to do a task chooses to do it himself or herself instead (Hill, 1979). DIY represents an empowering approach to life that relies on personal skill, ingenuity, hard work, and a desire to demonstrate individual and collective capability. The main idea supporting DIY culture is that experts, businesses, and professionals are not the only ones who can develop solutions and solve problems. Everyday people in the context of everyday life can do things for themselves with more creativity, character, and relevance than experts (Gauntlett, 2013).

Do-it-yourself activities are usually productive, practical, entertaining, or some combination of the three. One or more individuals willfully participate in DIY projects to derive personal, professional, economic, political, material and various other benefits from their activities, outcomes, or both. DIY is about applying labor, effort, ability, and knowledge to raw and semi-raw materials in ways that lead to the production, transformation, or reconstruction of material objects and environments (Wolf & McQuitty, 2011). These materials can come from one or more sources including retail stores, DIY specific retailers such as Home Depot and Auto Zone, or hardware, bargain, and specialty store, the material environment, and a DIYer’s everyday life context (e.g., home, workplace, or school). There is a myriad of activities that people associate with DIY. In fact, a Google or YouTube search for the term “do-it-yourself” will likely return millions of results for activities ranging from home improvement, food preparation gardening, and car maintenance activities to craft, electronics, money-saving, and time-saving projects.

Interestingly, human-computer interaction (HCI) and Computer-Supported Cooperative Work (CSCW) scholars talk about do-it-yourself, hacker, Maker, and end-user innovation cultures, communities, and activities almost interchangeably (Ames et al., 2014; Bardzell,
Bardzell, & Toombs, 2014; Kuznetsov & Paulos, 2010; Lindtner, Hertz, & Dourish, 2014; Tanenbaum, Williams, Desjardins, & Tanenbaum, 2013; Wagenknecht & Korn, 2016). Other researchers in these two research camps talk about DIY in relation to diverse everyday life activities such as hobbies (e.g., crafts) and cooking, (Dalton, Desjardins, & Wakkary, 2014; Rosner, 2010; Rosner & Ryokai, 2010; Tanenbaum et al., 2013; Wang & Kaye, 2011) as well as the use of online platforms that support offline DIY activities (Buechley et al., 2009; Kim & Lee, 2012; Kuznetsov & Paulos, 2010; Rosner & Bean, 2009; Tanenbaum et al., 2013; Torrey, Churchill, & McDonald, 2009).

Unlike most user-centered and AT/RT design approaches that view consumers as users only, DIY and prosumption perspectives acknowledge the agency, capabilities, needs, goals, and wants of non-professionals who possess firsthand knowledge about their daily lives. DIY is primarily consumer-driven where individuals or collectives decide what, when, and how they will entertain themselves, accomplish a task, achieve a goal, or solve a problem. Atkinson (2006), as well as Ratto and Boler's (2014) assertions that DIY is about usurping the authority of professionals, making decisions for oneself, exercising personal agency, and determining the boundary between right and wrong represent everything accessibility/disability design approaches lack. It is no wonder people describe DIY as a democratic movement and DIYers as the exact opposite of passive consumers. DIYers demand and appropriate active roles in design-related activities and control the narrative about who they are, what they can do, and what they deem acceptable.

As I read the literature on HCI approaches to accessibility as a junior Ph.D. student, I was frustrated by the fact that DIY, prosumption, and similar activities were missing, underrepresented, or rarely attributed to individuals with disabilities. As an individual with a
disability with personal experience engaging in adaptation and design-related activities who knows other individuals with disabilities who have similar experiences, I knew there was more to the story. In many ways, this dissertation is my humble attempt to share a perspective on disability and design that is severely lacking in the HCI, assistive technology, and design communities. Ironically, most research that looks at DIY pays attention to non-disabled individuals while mostly ignoring individuals with disabilities. I will delve deeper into this gap in the next section.

**DIY, assistive technology, and “do-it-yourself assistive technology” (DIY-AT).**

Some researchers have in fact explored DIY in the context of accessibility/disability. From a historical perspective, publications like the Toomey J Gazette and the Paralyzed Veterans of America’s Paraplegia News provided first-person accounts of how individuals with severe physical impairments and their families adapted technology and created personalized forms of access in the 1950s and 1960s (Williamson, 2012). In these publications, individuals with disabilities described their everyday lives as well as how they worked alone or with family members and friends to not only tinker with various consumer, rehabilitation, and assistive technology products at their disposal but also modify their homes and everyday household tools. These activities enabled individuals with disabilities and their families in the post-World War II era to adjust to life with a disability in a world that ignored them as well as circumvent the control the rehabilitation industry increasingly exerted over the health and well-being of individuals with disabilities (Williamson, 2012). For them, DIY was a reaction against a growing industry of professionals that either ignored them or looked at them solely through the lens of the medical model. It allowed them to appropriate independence and prove their self-worth to those
who focused solely on addressing their functional impairments and selling them interventions meant to help them "overcome" disability (Williamson, 2012).

Historical analyses like the one presented by Williamson offer concrete evidence that individuals with disabilities and their loved ones have a history of engaging in DIY-like activities. Analyses based solely on literature reviews and archival data, however, can mask many of the intricacies of the phenomena itself and its current implications for accessibility/disability design. The account by Williamson frames DIY by individuals with respiratory polio, paraplegia, and quadriplegia primarily as a coping mechanism. Although he gives the impression that individuals with physical impairments worked alone and with their non-disabled family members and friends, there is no indication of who did what and how. As such, there is no discussion about the way DIY projects both implicated and constituted impaired bodies. Williamson's historical analysis offers valuable insights into the meanings DIYers with disabilities and their families attributed to DIY-like activities and outcomes during the post-WWII era. The research study described in this dissertation explores the specific contributions individuals with physical impairments make to DIY-like activities. Additionally, it examines whether individuals with disabilities make the same kinds of attributions to similar types of activities today as many did during the post-WWII era.

A more recent approach to exploring and advancing DIY in the context of assistive technology is "Do-it-yourself Assistive Technology" or "DIY-AT." DIY-AT originated in the HCI accessible design community and refers to the creation and adaptation of assistive technology by non-professionals, including people with disabilities and their families, friends, and caregivers (Buehler et al., 2014; Hook et al., 2013; Hurst & Tobias, 2011). Scholars recognize the potential benefits of DIY-AT, particularly in the age of emerging technologies.
such as rapid prototyping tools, 3-D printing, and online communities like instructables.com where people share DIY-AT designs and ideas (Hook et al., 2013; Hurst & Kane, 2013; Hurst & Tobias, 2011). Interestingly, few researchers in this space have engaged individuals with disabilities who actively participate in maker activities or framed members of the disability community as producers rather than passive consumers of DIY-AT (Meissner et al., 2017). Much of their research explores various ways to expand access to rapid prototyping tools and making which they believe will lead to more access to expensive yet necessary assistive technology for individuals with disabilities. Some rightly acknowledge that barriers such as inaccessible 3D printers (Buehler et al., 2014) and other rapid prototyping tools (Hurst & Kane, 2013), lack of design expertise (Hook et al., 2014), and lack of needed support (Rajapakse et al., 2014) prevent many individuals with disabilities from using these tools to make and adapt assistive technology.

At its core, DIY-AT is about designing tools and opportunities for individuals with disabilities and their allies to engage in DIY and maker activities. This approach is closely related to the idea of user empowerment, or the development of tools that empower persons with disabilities to create and configure accessibility products to solve their own problems (Glinert & York, 1992; Ladner, 2008). Scholars currently advocating for DIY-AT tend to frame it as the creation of AT devices by non-disabled non-professionals who know and interact with individuals with disabilities rather than individuals with disabilities themselves. Only a few focus on the actual development of tools that make DIY activities more accessible to individuals with disabilities (Hook et al., 2013; Hurst & Kane, 2013). One group of researchers proposed an agenda for identifying ways to support and empower disabled individuals in their DIY AT efforts via the design of interactive technologies and services that allow them to circumvent the social and technical issues that impede their efforts (Hook et al., 2013). They conducted interviews
with six people involved in AT provision, adaptation, and future development activities. Preliminary results suggested that online DIY-AT and maker community collaborations could provide support to individuals interested in DIY-AT activity along with DIY-AT curriculums that teach children how to use rapid prototyping tools (Hook et al., 2013). Only one of the six participants had a disability and made his own DIY-AT. The other interviewees were professional occupational therapists, a medical physics practitioner, and AT developers who work for charities.

Currently, DIY-AT research pays too much attention to what individuals with disabilities could do if provided access to DIY-AT developed by non-disabled people they know personally with technical backgrounds and not enough attention to their current self-directed DIY-AT-like activities (Meissner et al., 2017). In another DIY-AT study, the researchers promoted the idea of getting individuals with disabilities involved in modifying and building assistive technology (Hurst & Tobias, 2011) but seemed to assume individuals with disabilities could not actively participate in these activities on their own. Although they mention empowering users with disabilities, the authors describe their audience as non-engineers who work with persons with disabilities. They explicated the potential of DIY-AT using three practical examples. The first case describes the iterative design of a head pointer that individuals who have severe dexterity impairments could use to paint. The authors say, "…their participants" were "very involved" in the head pointer testing process but their description of the process suggested passive involvement. Although the severity of the participant's impairments limited the degree to which they could participate in the actual design activities, they could have played a more active role in identifying the problem to be addressed and providing input on a solution. Instead, the professor’s frustration as an art teacher with students who could not use their hands defined the
problem-context (painting with severe dexterity impairments). The second case describes the DIY-AT experiences of a non-disabled retired finance professional with an engineering degree who has been “designing and building adaptive technology for 40 years as a hobby” (Hurst & Tobias, 2011, p. 13). This example seems to illustrate a user-centered design project conducted by a non-disabled individual rather than an inclusive DIY-AT project. In the third case, the authors asked four individuals about the modifications they would make to their AT/DME. Asking for input from users in this manner places the focus on them without taking the time to understand what contributions they can make to an actual DIY-AT project. Like many of the design paradigms mentioned earlier in this chapter, the authors seemingly assume that individuals with disabilities are sources of data rather than active agents in accessible design-related processes and projects.

A recent DIY-AT study conducted by Meissner et al. (2017) went farther than most in acknowledging and trying to learn from the experiences of individuals with disabilities. The multi-method study examined the YouTube videos of individuals with physical disabilities who currently engage in an autonomously applied form of “DIY-life hacking” and used the results to inform the development of training and resources that would enable individuals with disabilities to participate in DIY-AT projects using maker technologies. The researchers conducted a thematic analysis of user-generated YouTube videos featuring individuals with disabilities who documented their DIY activities as well as other online data. Findings from this analysis included a list of accessibility issues which researchers attended to during the second phase of the study where they developed accessible maker facilities then recruited, trained, and granted a group of adults with physical impairments both access to maker equipment and the freedom to work on a self-identified project. Although this study goes further than most when it comes to
getting individuals with disabilities involved in DIY-AT, their involvement was still dependent on the efforts of the researchers. Also, while the researchers examined the existing “DIY-life hacking” activities of YouTubers with disabilities, the findings primarily informed their efforts to develop a DIY-AT workshop for individuals with disabilities. The workshop existed in a controlled environment created by the researchers that would be difficult to reproduce outside of a university. While other researchers may run accessible maker initiatives like the one described by Meissner et al., the potential of individuals with disabilities to engage in DIY-AT activity will completely depend on the charity of those researchers as well as workshop design, participant recruitment, and various other choices researchers make.

Although scholars who advocate for DIY-AT recognize the need to empower people with disabilities to get involved in adapting and making AT, current attempts to do so tend to miss the mark in at least one way. For example, although the vision of DIY-AT is to include individuals with disabilities in related physical activity, a recent summit on DIY-AT primarily targeted professional interaction designers, non-professional volunteers, and clinicians who may not have any personal familiarity with the lived experience of disability (Hofmann et al., 2016). Attendees argued about professional and ethical issues related to the use of rapid prototyping tools to create medical prosthetics but entirely excluded potential end-users from the conversation. Similarly, other studies encourage interested parties to learn from people who currently engage in some form of DIY-AT (Hook et al., 2013; Hurst & Kane, 2013), but the findings are typically uninformed or under-informed by the perspectives and experiences of individuals with disabilities who engage in these activities. A small but potentially growing group of scholars attempt to link empowerment to the active involvement of individuals with disabilities in DIY-AT activities, but they tend to focus primarily on maker technology-enabled activities and
ultimately make user empowerment dependent on the planning and training efforts of non-disabled researchers (Meissner et al., 2017). Finally, some scholars praise the potential of online communities like Instructables.com to empower individuals with disabilities through DIY-AT but their studies tend to either focus primarily on related content posted by non-professionals without disabilities or fail to discuss the contributions of individuals with disabilities within these online communities (Hook et al., 2013; Hurst & Kane, 2013; Hurst & Tobias, 2011; Leduc-Mills et al., 2013).

Human-computer interaction scholars have documented the potential fruitfulness of paying more attention to interface accessibility issues encountered by the user in his/her context of use as well as how he or she addresses those issues. Their interest in these in-the-wild interface issues, however, is often limited to how in-situ access problems might inform their research and design activities. Kane, Jayant, Wobbrock, & Ladner (2009) for example conducted a combined interview and diary study to identify mobile phone accessibility problems that people with visual and motor impairments faced and how they adapted inaccessible devices. Adaptation strategies included modifying the device settings, installing access software, customization (i.e., ringtones), utilizing hardware (wrist strap, attached magnifiers, holster bag), multiple devices, and devices with redundant functions. Other strategies included learning to use the device in familiar contexts, relying on memory rather than the device while in public to avoid embarrassment, and using both mainstream and assistive devices, often in combination (Kane et al., 2009). Although this study acknowledged the agency and capabilities of the participants, it still positioned design as something done for people with disabilities rather than by them. The goal of the research was to discover ways to design more accessible and "empowering" mobile devices. This goal is not bad, per se. Accessible design researchers and practitioners should not
only seek to improve accessibility but also pay attention to how consumers create and maintain accessibility for themselves and why. Participants’ adaptive strategies in the Kane, et al. (2009) study were subordinate to the fodder these activities provided to the “professionals” and their accessible design efforts. Like DIY-AT-related studies, the researchers glossed over the capabilities and motivations of disabled DIYers as well as the underlying tensions they ended up resolving via their DIY practices.

**DIY motivations.**

Scholars from different disciplines have discussed and explored the motivations behind DIY and related activities. Three common explanations are consumers who seek to maximize utility, consumer as "dupes" manipulated by mass media and the retail industry, and consumers as postmodern manipulators of symbolic meaning and constructors of identity for self-expression purposes (Williams, 2008). Some DIY-oriented HCI scholars see DIY as a shift away from industrial mass production yet frame it as a set of recreational practices, or practices that are mainly concerned with what STS scholar Rachel Maines defines as "hedonized" technology (Tanenbaum, et al., 2013). Hedonized technology is "any technology that privileges the pleasures of production over the value and/or significance of the products" ((Maines, 2009) in Tanenbaum, et al., 2013, p. 2604). While I agree with the usefulness and applicability of this term to many DIYers, I also agree with Meryl Alper's position that recreation may not be the only DIY motivator for individuals with disabilities (Alper, 2013). One of the problems with recreational and hedonistic explanations of DIY activity like the one given by Tanenbaum et al. (2013) is that it assumes everyone who engages in DIY activity does it for the same reason and there are no contextualized factors to consider. To be fair, other scholars have gone beyond pure pleasure explanations to describe the actual socio-historical context which birthed the DIY movement.
such as growing anti-consumer sentiments, parallel social-historical movements, and newfound desires to express one's creativity (Kuznetsov & Paulos, 2010). However, except for Williamson's historical account, there is scant extant scholarship that probes into the motivations of disabled people who actively participate in DIY projects despite evidence suggesting they do.

**Hackers & hacker culture.**

Hacker culture, or the computer underground, is an identifiable and distributed subculture that exists primarily online. It has a unique cultural capital embodied in its values, esteem for highly specialized skills, information sharing networks, norms, status hierarchies, language, and unifying symbolic meanings (Jordan & Taylor, 1998). The early days of hacker culture was a period of productivity, intellectual inquisitiveness, and innovativeness. Self-identified hackers collectively held the same specific set of principles which formed the epicenter of early hacker culture. The underpinnings for these principles included the exchange of creative brilliance (Nissenbaum, 2004), shared system access and collaborative improvement (Leeson & Coyne, 2005), a belief in the pliable nature of technology and ability to leverage it for "new and unexpected uses" (Jordan & Taylor, 1998, p. 763), and an intellectual curiosity with computers leading to exploration and experimentation (See Levy, 1984 in (Turgeman-Goldschmidt, 2008)). The Hacker Code, or the shared philosophical and ethical standard that has undergirded hackerdom throughout its history, reflects many of these ideals. The Hacker Code has four general principles. The first one is the belief that access to computers and information should be free and unlimited. The second is a belief in the power and potential of computers to improve lives and create art and beauty. Thirdly, hackers had a collectively held mistrust of centralized authority and bureaucracies. Finally, hackers evaluated each other and themselves based on
demonstrated technical skill and merit rather than personal characteristics such as race, age, religion, or socio-economic status (Leeson & Coyne, 2005; Nissenbaum, 2004).

Although there are some enduring ideological elements from its early origins, hacker culture has experienced a shift as far as the types of activities hackers engage in and the non-hacker world’s perceptions of its adherents. The resulting disconnect between identity and perception is partially explainable by the diverse makeup of hacker culture, which is composed of various subgroups that have unique areas of expertise, interests, and behavioral patterns (Turgeman-Goldschmidt, 2008). Each subgroup has a unique sub-culture with distinct values, communication and collaboration channels, motivations for hacking, and means of legitimating members. In current times, however, the term hacker has not only deviated from its original connotation as commonly reflected in the negative vernacular used by the news media and average citizens but also obfuscates diversity among those who hack. As described by Nissenbaum (2004), society used to associate the term hacker with a group of highly skilled and "quirky" individuals whose single-minded focus was to achieve brilliant and innovative technological feats through machine manipulation. Now, people are more likely to link the term to an entire subculture of highly skilled "agents who willfully defy the rules" and collectively represent the online world equivalent of adulterers and property thieves (Nissenbaum, 2004, p. 203). Rather than being associated with a unified group of technological sophisticates with a firm yet benign commitment to the ideals of the Hacker Code, people now view and understand hacker culture as an online contingent of criminals and vandals.

Nowadays, pockets of society view hacking as a set of activities performed by individuals with malicious intent. Many associate hackers with activities such as unauthorized access to electronically stored information, computer systems, and networks, telephone fraud (phreaking),
credit card fraud, mass transit payment system and parking meter rigging, and other forms of fraud committed by electronic component manipulation. When people think about computer hacking, they are most likely to link it to malicious activities they experienced personally or heard about in the media such as password cracking, logic and email bombs, denial-of-service attacks, viruses, and worms. Other criminal activities commonly associated with hacking include electronic vandalism (e.g., defacing a website), national security threats, and the illegally copying and distribution of software or other electronic works with intellectual property rights attached to them (Leeson & Coyne, 2005; Nissenbaum, 2004; Turgeman-Goldschmidt, 2008). In addition to the destructive behaviors attributed to the computer underground, hackers are often demonized as sociopaths, thieves, opportunists, vandals, peeping toms, and terrorists (Nissenbaum, 2004). Although some hackers rightly deserve these labels, many avoid destructive and malicious behaviors. Media and law enforcement portrayals of hackers as criminals (Holt & Kilger, 2008), unfortunately, tend to group both types as one and ignore the diversity among them.

The history of hacker culture suggests that labels and their meanings are often socially constructed and can change over time. Sometimes individuals who are in positions of power or who are the most deviant yet visible social group members can shape how outsiders perceive the group overall. Goggin & Newell (2003) assert that technology is inherently social and political, and the tug-of-war over the meaning hacking and hackers clearly gives credence to this assertion. News media depictions of hackers construct and perpetuate narratives that influence how society views them. These narratives commonly frame hackers as criminals bent on committing unlawful acts against businesses, government entities, and citizens using computers and network technology. These all-inclusive narratives marginalize people who embrace the original tenets
that undergirded early hacker culture but do not engage in the negative behaviors society now associates with hackers (Nissenbaum, 2004). There are hacker subgroups that do not have malicious intentions. They are motivated by a desire to solve complex problems and make society a better place (Leeson & Coyne, 2005; Levy, 1984), and see hacking as acts of scavenging, tinkering, "bricolage," and making creative use of resources (Nikitina, 2012). Nevertheless, in societal discourses, people sometimes group hackers who engage in benign activities with those who hack with ill intent. Also, media narratives regularly associate hacking with computers and network technology due to the history of the practice and centrality of both to the computer underground. Nevertheless, the term has been appropriated by people in offline and hybrid contexts as evidenced by practices such as the hacking of IKEA furniture, Arduinos, Roomba vacuum cleaners, domestic environment, technology and electronics, and crafts (Buechley et al., 2009; Kuznetsov & Paulos, 2010; Rosner & Bean, 2009; Wakkary & Maestri, 2007; Wang & Kaye, 2011). As these diverse activities studied by HCI researchers suggest, hacking often extends beyond the digital world to include offline hobbies, although individual hackers who engage in these activities may still connect and share information via online platforms and within online communities (Buechley et al., 2009; Kuznetsov & Paulos, 2010; Wang & Kaye, 2011).

Social scientists interested in computer hackers and hacker culture have identified certain norms and attitudes that persist across hacker subcultures. Interestingly, these characteristics are not specific to cyber hackers. Researchers have found that technology which facilitates hacking activities, a desire to avoid unwanted attention, knowledge sharing, and mastery all undergird hacker subcultures (Holt & Kilger, 2008). The characteristics just mentioned are consistent within and across subcultures no matter the specific activities, motivations, and ethical
understandings of a specific subculture and the technologies involved in their practices. Two
value-neutral computer hacker labels that focus on the potential of hackers to exploit technology
without reference to the specific ethical nature of the underlying activities are techcraft and
makecraft. Techcraft hacking refers to the consumption of materials and application of
knowledge, existing information, tools, and objects with which one interacts in the context of his
or her everyday life. Makecraft hacking, on the other hand, refers to the use of one's skills to
identify and solve problems or create and use innovative objects and solutions (Holt & Kilger,
2008). Techcraft and Makecraft hackers appropriate value from objects, leverage in-situ
knowledge of what they want and need, or both. They also self-determine the target or intention
of their hacking activities. Engagement in these activities typically entails the simultaneous
utilization and development of skills along with the dissemination of practical know-how across
information sharing networks (Watson & Shove, 2008). Although the 'craft in the techcraft and
makecraft labels refer to the skill, sophistication, and almost magical ability computer hackers
exhibit when appropriating technology for their goals and ends (Holt & Kilger, 2008), the labels
are general enough to capture the offline activities of hacker subcultures that leverage objects
other than computers such as those studied within the HCI research community.

The preceding section outlines several consumer-driven activities with design
implications. The theoretical framing presented in the next section guides the analysis presented
in chapter six. Before I talk about how practice theory informed this analysis, I will describe the
overarching philosophical orientation that guided this study: phenomenology.
Phenomenology and Phenomenological Research

The purpose of this section is to describe the philosophical underpinnings of this dissertation research study. Phenomenology has been described as both a philosophy and a method (Creswell, 2003). Many consider the German philosopher and formally trained mathematician Edmund Husserl (1859-1938) to be the founder of phenomenology who articulated many of its philosophical roots (Dowling & Cooney, 2012). He posited that cognition has its origin in immediate subjective experience and what is evident to humans is restricted to what reveals itself to pure intuition (Husserl, 1964). The motivation for his conceptualization of cognition was his belief that science and mathematics were becoming increasingly abstract and thus disconnected from everyday human experience, understanding, and concerns (Dourish, 2001). The grounding for Husserlian phenomenology is an assertion that certainty is ascertained only through immediate experiences and we should ignore anything outside of those experiences (Groenewald, 2004; Kwant, 1963). In other words, Husserl viewed phenomenology as a primarily descriptive undertaking concerned with psychological acts rather than causal explanations (Husserl, 1964).

Husserl was a student of Franz Brentano, who was one of the first philosophers to assert that consciousness was intentional. For Brentano, intentionality referred to the fact that all human mental activity has a target (Dowling & Cooney, 2012; Groenewald, 2004) and this target can be an external reality (Dourish, 2004). He described intentionality as perception occurring inside the individual rather than an act directed towards some object outside of the individual’s internal conscious experience. For him, consciousness is something projected onto an object by an individual experiencing a phenomenon (Dowling & Cooney, 2012). Brentano said that mental acts such as judgment, belief, meanings, valuations, desires, loves, and hatreds form the core of
intentionality (Groenewald, 2004; Husserl, 1964). The individual who is doing the perceiving does so “in the raw” without premeditation. The intentionality of consciousness suggests that rudimentary mental acts occur as a person intuits one or more things in an almost automatic fashion. Building on the work of Brentano, Husserl saw intentionality as the essential element of consciousness. For him, intentionality meant that humans always direct consciousness towards an object that is not consciousness, per se, but could be a contemplative act of consciousness. Consciousness is therefore intrinsically relational. It is related to objects existing in time and space as well as within itself (Giorgi, 1997). In this sense, consciousness constitutes objects (Holstein & Gubrium, 1994), which transcend both consciousness and consciously lived experience.

Phenomenology according to Husserl is about understanding the essences of lived experience and the meanings people ascribe to it. In other words, phenomenology seeks to understand the relationship between the objects of consciousness, which Husserl referred to as noema and noesis. Noema refers to the one’s perception of an object while noesis refers to a person’s conscious experience of that object (Dourish, 2004). The ways an event occurs in the life-world of people who experience it facilitates an understanding of that event. The relationship between noema and noesis as well as their role in one’s experiences requires the suspension of what Husserl referred to as the natural attitude, or the biases, preconceptions, errors, and prejudices by which both participants and researchers make meaning out of everyday lived experience (Dowling & Cooney, 2012) Another important term coined by Husserl after a debate with Heidegger is the lebenswelt or life world of everyday experience. It refers to the shared and taken-for-granted infrastructural-like understandings and experiences that make up the natural attitude and encompass everyday experience (Dourish, 2001; Dowling & Cooney, 2012).
Phenomenologists seek to deconstruct the perspectives, assumptions, and conceptualizations of lived experiences resulting from a person’s reflection on those experiences (van Manen, 2002). Another way of saying this is that a phenomenologist is interested in the pre-reflective experience of social actors rather than fully developed scientific interpretations and understandings of it. As such, phenomenology seeks to uncover "essences" of human experiences contained within the fleshed out phenomenal descriptions provided by social actors (Creswell, 2003). Husserl used the concept of essences to refer to the essential qualities that make something whatever it appears to be to an individual's consciousness (Todres, 2005). The phenomenologist uncovers essences by looking for elements of an experience that are common across multiple experiences of one or more social actors. Husserl generally assumed that all experiences have essential characteristics that remain constant across variations of the underlying phenomenon (Kvale & Brinkmann, 2009; Todres, 2005).

Edmund Husserl also coined the phrase “back to things themselves” and saw the goal of phenomenology as describing the experiential essences of phenomena (Groenewald, 2004). Although the essences of things in the lived world are not observable, per se, they exist in the sense that they appear in or present themselves to people's consciousness in the moment of a lived experience (Groenewald, 2004; Kvale & Brinkmann, 2009; Pollio, Henley, & Thompson, 1997). Focusing on consciousness, lived experiences, and participants' precise descriptions of them allows the researcher to identify unchanging essential meanings (Kvale & Brinkmann, 2009). Husserl's idea of "getting back to things themselves" is about attempting to uncover the essentials of phenomena as initially experienced. Rather than looking for truth in after-the-fact interpretations by third-parties, Husserl asserted that reality (and thus knowledge) reside within immediate lived-experiences and internal representations of them within human consciousness.
Existential phenomenology.

There are different flavors of phenomenology that build on the work of Husserl. The disciplinary and philosophical orientations of these offshoots differ in distinct ways. Descriptive phenomenological psychology has its roots in Husserlian phenomenology, but it is primarily methods-driven. In phenomenological psychology, the philosophical underpinnings of phenomenology take a back seat to philosophically informed data collection and analysis methods such as description, phenomenological reduction, and uncovering essences (Dowling & Cooney, 2012; Giorgi & Giorgi, 2003). The Dutch (Utrecht) school, on the other hand, combines elements of descriptive and interpretive phenomenology (Dowling & Cooney, 2012). Husserlian phenomenology is experience-and more descriptive and image-provoking while the hermeneutical, interpretive or existential phenomenology of Heidegger and others focuses on the life-world. Both Husserlian phenomenology and existentialism view knowledge as contained in experiences and empiricism rather than in reason and theory. Each one focuses on human lived reality in the context of everyday life. Both also equate human experiences to consciousness, or the relationship between the individual, his or her lived experience in the world, and everything that lived world contains at the time of the experience (Pollio et al., 1997). Phenomenology and existentialism seek to describe human life as lived and experienced by social actors, and both are interested in conscious in-situ experiences. After-the-fact explanations and evaluations are set aside for the sake of the experience itself.

Martin Heidegger (1889-1976) explicitly linked phenomenology to existentialism and focused on the everyday lived experiences of humans rather than essential qualities of conscious experience like Husserl and many of his ilk (Pollio et al., 1997). A critical underpinning of Heidegger’s conceptualization of phenomenology is the idea that while we do not fully grasp the
meaning in our being, a shared ontological characteristic of all humans is our understanding of ourselves as being (Heidegger, 1962). Heidegger believed that mental activity was inextricably linked to a person’s experiences in the world, which differed from Husserl’s idea that the mental and physical are two separate entities. Whereas Husserl asked the epistemological question “how can we know about the world,” Heidegger asked the ontological question “How does the world reveal itself to us through our everyday encounters with it” (Dourish, 2004; Groenewald, 2004). Heidegger’s ontological concerns are central to his concept of ‘Da-sein’/’Dasein’, which is translated as “being-in-the-world,” and refers to the dialogue between a person and the world he or she inhabits (Heidegger, 1962). He went beyond describing essences to understanding how people in their lived world interpret both their practices and themselves (Dowling & Cooney, 2012). Heidegger equated this ability to interpret and understand as fundamental to a person’s simultaneous being in the world and existence as a being of the world (Koch, 1995). Heidegger himself said a being-in-the-world finds meaning by being in the world, which constitutes Da-sein, or the site where being or human existence is disclosed and understood ontologically (Heidegger, 1962). He believed that a person and his or her world co-constitute each other and these two entities form an indissoluble unity (Koch, 1995). For him, the goal of phenomenology was to understand a human’s ability to leverage an indestructible yet modifiable shared cultural background to understand and construct meaning about the world while that same world simultaneously constructs that person and his or her experiences.

Whereas Heideggerian existential phenomenology privileges human beings’ being-in-the-world, existential phenomenologist Maurice Merleau-Ponty (1908-1961) focused his attention on the “primacy of perception” (Merleau-Ponty, 1964, p. xviii). His most developed approach to phenomenology incorporated Husserl’s ideas about perception and Heidegger’s
being-in-the-world orientation (Dourish, 2004; Kockelmans, 1967). He defined phenomenology as the study of essences and asserted the only way to correctly understand people and the world they live in was to start with facts of man and the world (Merleau-Ponty, 1962). Merleau-Ponty said scientific inquiry moves us away from essences to what we can infer from them. He agreed with Husserl’s emphasis on bracketing out the natural attitude to not only describe as-is experiences but also better understand the natural attitude (Merleau-Ponty, 1962). By this, he meant science is an abstraction or representation of lived reality and phenomenology attempts to return to that reality rather than to abstract from it. His view of phenomenology positions science as a construction built on top of the already existent world and our bodily experiences in it (Merleau-Ponty, 1964). Merleau-Ponty also saw the world as existing outside of and before lived experience. Phenomenology, in his estimation, should describe space, time, and the world as we live in them (Merleau-Ponty, 1962).

In *Eye and Mind*, Merleau-Ponty provided insight into how to apply his approach to phenomenology. He argued a painter does not paint with his or her mind but rather by “lending his mind to the world that the artist changes into paintings” (Merleau-Ponty, 1964, p. 161). Merleau-Ponty advocated for a concrete definition of the body to understand how human subjects change one thing into another. He said we need to consider the actual functions of the body and how they work together in the act of making a difference in the world (Merleau-Ponty, 1964). He also described the “enigma” of the human body as an entity that sees and is seen (both by itself and by others) and feels while others can feel it. The body is a visible and moving thing among other things in the world, yet its ability to move and see makes the body a central point encircled by other things (Merleau-Ponty, 1964). Thus, other things are an extension of the self.
although encapsulated in different bodily coverings. The world contains the very elements that make up the body. The body also contains elements of the world.

Merleau-Ponty’s conceptualization of the body suggests that to understand the world and the things in it, we must include the body in our analyses. Excluding the body will lead to an incomplete analysis since the body contains analogs to things outside of itself. Merleau-Ponty reconciled Husserl “philosophy of essences” and interest in perception with Heidegger’s “philosophy of being” and concern with Dasein, respectively, by concerning himself with the body and its role in perception (Dourish, 2001). Ironically, HCI researchers who advocate for critical approaches to design focus on the participation and engagement of end-users in design but seemingly ignore the body and its ability to serve as a lens to understand design. The body as a moving and seeing thing is a point of centrality for all other things, which explains why human presence unveils reality and makes it accessible while human bodies are “an unveiling of the real world” (Kwant, 1963, p. 69).

Fundamentally, Heidegger’s Dasein is about embodiment. A person’s being-in-the-world and the world are inseparable, thus pulling human existence apart from the world is impossible. At the same time, Dasein encounters the world and makes use of artifacts in the world to accomplish tasks and achieve goals. These artifacts do not exist in isolation but are linked to others. The unspoken ways in which we relate to objects and how objects relate to each other in the world has received some attention within the HCI community (Dourish, 2001). Merleau-Ponty similarly saw our existence as inextricably linked to the world and our embodied experiences in it. He did not think extracting original essences from these linkages was possible. According to his logic, the only way to ascertain original essences is to probe into the ties between humans and the world.
Embodiment has a prominent place in Merleau-Ponty’s philosophy of phenomenology, and it takes one of three forms. The first form is the physical human body: body parts, shape, size, and capabilities. The second form of embodiment in Merleau-Ponty's phenomenology is our developed bodily skills and situational responses. The third form of embodiment is the cultural know-how, skills, and understanding we gain through our experiences with the cultural world (Dreyfus, 1998) Notice how all three forms of embodiment involve or enable engaged interaction in and with the world. The body is not something that fades into the background or exists separately from the world it inhabits. Instead, the body facilitates an understanding of itself, which the world acts upon, and the world in which it acts.

*Understanding impaired-bodies-in-the-world through existential phenomenology.*

Scholars have advanced the idea of using Merleau-Ponty’s brand of existential phenomenology as a lens to understand the embodied lived experiences of impaired bodies-in-the-world as well as the ways impaired bodies constitute self while challenging and changing the world (Hockey & Allen-Collinson, 2009; Paterson & Hughes, 1999). This dissertation research study adopted some of the existential-phenomenological ideas espoused by Merleau-Ponty for this purpose. He felt the scientific community needed to stop imposing top-down understandings of the world and instead return to what always precedes understanding: the world as experienced by actual bodies performing physical and speech acts in the real world (Merleau-Ponty, 1964). Such a return was valuable in this study because it opened the door to understand the agency of the impaired body-in-space more deeply and the ways accessibility concerns are embodied and manifested in both design and individualized ways of using the body to complete daily life tasks (Allen, 2004). The linkages between the body and world that Merleau-Ponty described relate to the poly-constructed nature of social practices which I will discuss in the next section.
Merleau-Ponty’s description of the body is particularly relevant to this dissertation research study. Lived-world, the impaired body, and situation come together in ontological relationships of being, which speaks to the why and how behind the individualized adaptation, modification, and design-like activities and related daily life practices of individuals with disabilities. Instead of looking at objects, bodies, and context in isolation, an existential-phenomenological approach like Merleau-Ponty’s facilitates multifaceted understandings that consider the linkages between bodies, objects, agencies, and lived experience. Merleau-Ponty’s view of the body in many ways aligns with the way some practice theorists conceptualize it as outlined in the next section of this document. He used painting as an example of an in-the-moment activity devoid of scientific understandings. He described a painter as a neutral party who both brings his or her body into the world and transforms the world into a painting through vision and movement (Merleau-Ponty, 1964). Vision and movement are bodily functions and, in the case of the painter, the bodily movement makes a difference in the world while vision enables the painter to transform the world. As Merleau-Ponty pointed out, the painter does not need to understand all the inner-working of the body to paint. Nevertheless, the visible world as seen and the artist’s motor capabilities are both intrinsic to the same individual (Merleau-Ponty, 1964). Practice theory approaches commonly describe the body as the crossing point of mental and bodily activity (Reckwitz, 2002). Merleau-Ponty’s attention to the body in his approach to phenomenology affords opportunities to dig into this crossing point as well as the context surrounding it. It sees the crossing point and the context as inseparable and seeks to uncover how the social actor in the world perceives the world as well as him- or herself in it.
Theoretical Framework

This section describes the practice theory framework that guided some of the data analysis for this dissertation study. Scholars have advocated for the use of practice theory approaches with Latour’s ideas around non-human actors (objects) to explore do-it-yourself activities (Shove, Watson, Hand, & Ingram, 2007; Watson & Shove, 2008). This combined approach allows a researcher to analyze the relationship between society and the minutiae daily life activities through the enactment of practices (Pink, 2012). Specifically, Latourian constructs help to unpack the minutiae of practices including the individuals and objects involved in them while social practice theory approaches afford a look at the transformation of practices by the individuals performing them (Pink, 2012). Further, a combined approach allows one to unpack consumption-related daily life practices afforded by consumer retail markets as well as DIY, making, and hacking activities since all of them require the use of material artifacts including tools, equipment, materials, and infrastructures (Røpke, 2009). Scholars advocating for this combined approach believe it would help us to garner new insights about “doing-it-yourself” and social practice. First, it would allow us to understand the role of material objects in forming, transforming, and maintaining practices. Second, it would allow us to see how products and practice assemblages co-evolve. Finally, a combined approach would help us to identify how objects, products, and practice assemblages relate to cycles of production, consumption, and innovation (Shove et al., 2007). Whereas accessibility and HCI research typically frames individuals with disabilities as consumers only, a practice/ANT approach to examining daily life consumption activities reframes consumers as practitioners on the same level as researchers and design professionals. It draws attention to the action of doing rather than possessing and frames
products as things acquired, discarded, and redesigned for purposes of doing and having rather than having only (Røpke, 2009; Shove et al., 2007).

**Practice theory: Foundations.**

This dissertation research study leverages a combined contemporary social practice and STS practice theory approach. In this section, I will discuss some of the origins and underpinnings of the social and STS practice theory perspectives that guided the analysis presented in chapter six. Additionally, I will explain the specific theoretical constructs used in my analyses in chapters three and six of this manuscript.

**Cultural theory.**

Practice theory, or rather, practice approaches represent one of several forms of cultural theories. Others include culturalist, mentalism, textualism, and intersubjectivism. Each one attempts to explain action and conceptualizes the focal point of social phenomena in minds, discourse, and interactions, respectively. Collectively, cultural theories provide nuanced accounts of action that avoid the extremes of purpose-oriented individualism where individual subjective purposes, intentions, and interests both guide behavior and create social order and norm-oriented sociology where collective norms and values guide behavior, which leads to a social order determined by consensus (Reckwitz, 2002). Cultural theories consider and attempt to account for both cognitive and symbolic knowledge rather than linking action to and locating the social in one or the other.

Culturalist mentalism locates the social in the human mind either as symbolic knowledge structures (objectivist perspective) or the sequence of intentional acts in consciousness (subjectivist perspective) (Reckwitz, 2002). Textualism locates symbolic knowledge structures in discourse, communicative acts, or texts. In the poststructuralist/semiotic account of textualism best articulated by Michel Foucault, discourse equates to a series of events occurring outside the
individual (as opposed to in his or her head) where symbolic structures in the form of discursive practice rules become apparent (Foucault, 1972). Though consisting of signs that signify things, discourse does more than leverage signs to refer to the things they represent. Discursive practices also systematically ascribe conceptual meaning to those things (Foucault, 1972).

Intersubjectivists locate the social in speech-facilitated interaction (Reckwitz, 2002). These interactions consist of agents who have minds that refer to and make use of symbolic structures such as rules (Reckwitz, 2002). Intersubjectivism is a process by which actors exchange cultural meanings which they first process in their subjective minds (Reckwitz, 2002). Instead of making minds, texts, or conversations the central focus, practice theory looks at networked and interconnected entities that transcend dualism such as mind/body and individualist/norm-oriented.

**Social theories of practice.**

Practice theory is not a unified agreed-upon framework but rather a collection of theoretical approaches with related philosophical foundations. Social practice theorists view practices as the focal point of social phenomena. For them, the structuring and ordering of practices is an active relational activity rather than something that exists exogenous to practices (Law, 1992). In his theory of structuration, Anthony Giddens conceived of practices as that which is "ordered across space and time," superior to individual experiences, recreated in the activities of human agents, and the focal point of social science research (Giddens, 1984, p. 2). To him, social relations had two characteristics. First, the reproduction of social practices pattern social relations across time and space. Second, practices exhibit 'structural properties' that manifest in the reproduction of practices (Giddens, 1984). Giddens' conceptualization of practice was central to his theory of structuration, which saw social life as recursively constituted by social practice and structure as
both the medium and outcome of reproduced practices (Giddens, 1979). Structure, or rather the structural properties of practices explain why social practices exist across time and space in clearly discernible form and play a role in orienting the behavior of knowledgeable human beings. In other words, humans enact and reproduce social practices by applying a known set of rules (a tacit "practical consciousness") that are inherently social and extend across time and space (Giddens, 1984). In this sense, social structures emerge and transform through the enactment and reproduction of practices. When it comes to human action, these same structures simultaneously enable and constrain it (Giddens, 1984).

Pierre Bourdieu similarly made practices the focal point of scientific inquiry and framed social structure as a verb rather than a noun. He described knowledge as constructed, the social world as a performance, and practices as the acting out of roles that comprise the performance (Bourdieu, 1990). Bourdieu's conceptualization of practice hinged on the idea of habitus. *Habitus*, or "regulated improvisations," is responsible for the production of practices (Bourdieu, 1977) and constitutes them (Bourdieu, 1990). Bourdieu defines habitus as:

...a system of lasting, transposable dispositions which, integrating past experiences, functions at every moment as a matrix of perceptions, appreciations, and actions and makes possible the achievement of infinitely diversified tasks, thanks to the analogical transfers of schemes permitting the solution of similarly shaped problems... (Bourdieu, 1977, pp. 82–83).

This system of "structured, structuring dispositions" (1990, p. 52) and "durable, transposable dispositions (1990, p. 53) known as habitus represent principles which not only generate and organize practices but also remain adaptable. Habitus exists within a dialectical relationship with cognitive and motivational structures which get produced and reproduced repeatedly. Further, it not only is the product of historical practices but also gets reproduced and transformed by them (Bourdieu, 1977). Bourdieu argues that we cannot understand practices by merely examining the
stimuli that seem to trigger them but rather by examining the dialectical relationship embodied in habitus.

Michel de Certeau is a well-known scholar in anthropology who studies the everyday life practices of consumers. He is particularly interested in the activities of consumers navigating, appropriating, and "poaching" in response to systems of power in their everyday lives (de Certeau, 1984; Pink, 2012). de Certeau views everyday life as a site of resistance and appropriation-related activities that infringe on the rights, claims, or duties of systems of power (Pink, 2012). Accordingly, the goal of studies of practice in his view is to understand the situated actions of consumers doing their best to cope with and respond to everyday life demands forced on them (de Certeau, 1984). He describes consumer practices as "productive" endeavors with goal-oriented motivations shared among groups of consumers and unknown to producers or others in positions of power. de Certeau asserts that consumers get constituted through the enactment of practices. Everyday life practices such as moving, communicating, reading, shopping, and cooking can include tactical procedures that make deliberate use of time, the opportunities time presents, and the leeway time affords practitioners (de Certeau, 1984). Practitioners exploit these opportunities by using various information and appropriate objects/products in ways that allow them to one-up systems of power and control.

Social practice theorists Giddens and Bourdieu, anthropologist de Certeau, and contemporary practice theorists Schatzki and Reckwiz, whom I cite throughout this dissertation, frame practices as social phenomena. At its core, social practice theory views practices as central to social phenomena and practitioners are subordinate to practices themselves (Pink, 2012). Contemporary social practice theorists view practices as mediated arrays of human activity facilitated by the attributes of the human body as well as activity, material objects, and shared
practical understanding (Schatzki, 2005). Like Giddens and Bourdieu, contemporary practice theorists not only subordinate practitioners but also the material artifacts, infrastructures, and products involved in the practices or everyday life (Røpke, 2009). For them, meaning and normativity are not found in the individual but instead practices which produce and carry meaning, language, and structure (Pink, 2012). Whether it is the “structural properties” central to Giddens’ structuration theory or Bourdieu’s habitus, social practice theories posit that shared knowledge structures are critical to understanding action. These theories frame tacit knowledge as embedded in shared cognitive and symbolic structures as enabling and constraining forces on the ability of agents to interpret the world and act within it (Reckwitz, 2002). Further, they define the social as all interconnected “embodied, materially-interwoven practices centrally organized around shared practical understandings” (Schatzki, 2005, p. 12). As such, social theories of practice often represent theories of action that cannot fully account for the messiness of everyday life, the role of objects in practices, or the agency of the practitioner by himself or herself.

Contemporary social theoretical approaches see the social as a field of diverse materially-mediated practices governed by shared practical understandings (Schatzki, Knorr-Cetina, & Savigny, 2001). Scholars Theodore Schatzki and Andreas Reckwitz developed a coherent approach to analyze the abstract and largely philosophical concept of practice (Røpke, 2009) which seemed most appropriate for this study given the lucid constructs it offers to anyone interested in analyzing everyday life domestic practices. Practice theory approaches are typically undergirded by one of two key terms: 'practice' (praxis) or 'practices' (praktik). Praxis describes the entirety of human action and views it as a black-box coherent whole. Typically, DIY/consumption scholars who adopt social practice approaches focus on praxis (Shove et al.,
Nevertheless, it is praktik that lends itself to the study and analysis of consumer design-enabled daily life practices.

Reckwitz defines social practices as "routinized type of behaviour" composed of several interconnected elements. The elements are bodily activities, mental activities, both the use of objects and objects themselves, background knowledge (e.g., understanding), know-how, states of emotion, and motivational knowledge (2002, p. 249). Reckwitz describes a practice as something composed of various elements carried by an individual from episode to episode yet irreducible to any one of the elements, including the individual. Human and (sometimes) non-human agents carry the components of practice. Human agents are the source of interconnected mental and bodily action. They are carriers of not only the actual doing involved in practices (bodily activity) but also the understanding, know-how, and desiring practices demand (mental activities). A practice cannot be observed or understood apart from its actual execution. Therefore, practice theorists examine the product of all interconnected elements of practice rather than isolated components.

Most social practice approaches share similar conceptualizations of six social-theoretical concepts that other popular cultural theories do not. These concepts are body, mind, knowledge, routines, structure, individuals, and objects. I will define these and other relevant social practice constructs as well as how I used them in the analysis of participants’ adaptation, modification, and design-like activity-enabled practices in chapter six.

Science and Technology Studies

Unlike social theories of practice and social theories in general, Science and Technology Studies (STS) practice approaches pay attention to objects and humans rather than letting them fade into the background. According to STS scholar Wiebe Bijker, the original goal of STS scholarship
was to find new ways to explore issues such as the risk of nuclear energy, nuclear arms proliferation, and environmental degradation (Bijker, 1997). Today, STS examines the interactions of science and technology as well as social and political theory linkages to technology and innovation (Roulstone, 2016). Some STS scholars who place importance on viewing science as an activity instead of an abstraction have taken an interest in practice theory (Latour, 2005; Law, 1992). Their focus on the link between social theory and technology is particularly relevant for this dissertation which combines social practice theory perspectives with Actor-network theory. Actor-network theory originated in STS as an attempt to adequately account for humans (social), technology (material), and their "recursive intertwining" in practices (Orlikowski, 2007). It is one of many STS post-humanist conceptualizations of both the social and material world that looks at human and non-human actor associations and the actions they afford in the context of everyday life (Latour, 2005; Orlikowski, 2007). Whereas social theories of practice assert that social structure is critical to action, actor-network theory links action to non-human and human actor entanglements. Actor-network theory does not assume the existence of social structure a priori to exploring it (Law, 1992).

Scientific knowledge in an actor-network sense is particularly relevant to this study given the way many HCI and other disability/accessibility design researchers do accessibility research. Knowledge in the actor-network sense is not embodied in research papers and presentations discussing what the researchers discovered through scientific inquiry. Instead, it is the culmination of the physical work that led to the papers and presentations. In the words of distinguished STS scholar John Law, knowledge is:

...the end product of a lot of hard work in which heterogeneous bits and pieces -- test tubes, reagents, organisms, skilled hands, scanning electron microscopes, radiation monitors, other scientists, articles, computer terminals, and all the rest -- that would like to make off on their own are juxtaposed into a patterned network which overcomes their
resistance. In short, it is a material matter but also a matter of organising [sic] and ordering those materials. So this is the actor-network diagnosis of science: that it is a process of "heterogeneous engineering" in which bits and pieces from the social, the technical, the conceptual and the textual are fitted together, and so converted (or "translated") into a set of equally heterogeneous scientific products (Law, 1992, p. 380).

Extending Law's description to the contexts of accessible design and design research points to a significant problem in the approaches discussed earlier. If knowledge production relies on the interactions between the social, technical, conceptual, and textual, then what happens when assumed or archetypical associations do not mirror those that structure people's daily life practices? The knowledge produced may not account for the social, technical, conceptual, and textual realities of end-users' everyday lives. The core claim of actor-network theory is that heterogeneous networks composed of people, machines, and any other natural material imaginable make up the social (Latour, 2005; Law, 1992). These actor-networks manifest in both heterogeneous networks of patterned social relations, and an effect produced by one of these networks (e.g., scientific knowledge, technology innovation, society, organizations, and agents) (Law, 1992).

Social networks are not only the result of human-to-human interactions but also human interactions with non-human material objects entangled in those networks. In these networks, human preferences along with the characteristics, features, and affordances of material objects together impose social order (Law, 1992). There are two significant implications of this dynamic. First, the "social" is not something that exists apart from action. One cannot impose a predetermined social order or the role people and things should play in determining that order (Latour, 2005). Second, social relations and technology shape each other. As STS scholar Winner (1980) notably says, technology can have politics in that they may be designed to produce a specific set of consequences. The material world opposes people through the attributes
of its physical structure and design. Further, technology’s form and function can reflect the interests of designers and determine the actions of users (Latour, 1992) Nevertheless, the actual political impact of technology artifacts must be assessed empirically. Politics at its core is about power, and actor-network theorists assert the mechanics of power cannot be assumed a priori.

This idea was articulated by STS scholars Michel Callon and Bruno Latour as follows:

There are of course macro-actors and micro-actors, but the difference between them is brought about by power relations and the constructions of networks that will elude analysis if we assume a priori that macro-actors are bigger than or superior to micro actors (Callon & Latour, 1981, p. 280).

Actor-network theory analyses do not start with taken-for-granted macrosocial systems and then attempt to explain them. Instead, they focus on the patterning of relationally distributed networks and the various ways power results from these networks. Actor-network theory emphasizes empiricism grounded in actor-networks and their effects, regardless of relative size. Latour argues that many of the assumptions undergirding traditional social science research place artificial limits on the scope of inquiry. These assumptions include the pre-existence of social ties that alert the researcher to concealed social forces (Latour, 2005). In the traditional “sociology of the social” approach, the “social” is the remnant after scholars account for other disciplines such as biology, chemistry, and physics. ANT, on the other hand, sees the social as the product of connections between different scientific disciplines. The social is not a contained domain, discipline, or thing but rather the associations, re-associations, and reassemblings of different domains. Rather than viewing the social as something that a scholar defines or identifies at the beginning of his or her inquiry, Latourian ANT conceptualizes it as something that can only be ascertained in collaboration with social actors after they work through the associations and connections between a set of "controversies" about the composition of the universe. Social actors find themselves immersed in these controversies and must resolve them
before scholarly analysis can take place. By asking the social actors to recount how they settled these controversies and tracing the connections between them, an analyst can guide those actors in "assembling" or defining the social as well as giving it order (Latour, 2005).

There are many different flavors of actor-network theory. Science and Technology practice theorist Bruno Latour's conceptualization of actor-network theory (ANT) frames it as an approach to social science research that does not make many a priori assumptions about what is and is not in scope. ANT is not a theory. It is more of a method or approach to social science research that has the potential to produce rich and insightful theoretical findings and implications. Although ANT is not a formal practice theory approach, it has lucid concepts that afford nuanced understandings of constituent practice components. Objects play essential roles in both the design-like activities and daily life practices of persons with impairments. Latour's framing of ANT describes objects in a way that guided data collection and analysis for this study. I will describe these constructs and their use in the context of this study in chapter six.

STS, actor-network theory, and disability.

This dissertation study is not the first attempt to look at disability issues through STS lenses. Indeed, disability studies scholars disillusioned by the limitations of the medical and social models of disability recognize the value of more critical STS-informed theoretical approaches to disability that integrate the body with material and ideological aspects of life with a disability. Some see STS as one way to bridge body versus society and materiality versus culture divides that are characteristic of modern disability models by linking the disability experience to the socio-material (Galis, 2011). Such an approach shifts disability from an individual or social construction to something produced and reproduced through everyday experiences embedded in socio-material networks. According to actor-network theory, embodied humans, as well as non-
human entities (objects), places, ideas, and realities interact in practice engagement in ways that either enable or disable (Galis, 2011; Schillmeier, 2010). Another way to say this is both human and non-human actors and their capability (or lack thereof) to perform in a specific way not only impact actor-networks but also are constituted by them. ANT does not link dis/ability to impairment, material objects, or culture per se but instead frames it as the product of everyday life networked associations among these entities that can either enable or disable (Galis, 2011; Moser, 2006; Moser & Law, 1999; Schillmeier, 2010). As illustrated in his study of the money practices of blind individuals, Schillmier (2010) believes that we can better understand the abilities and disabilities involved in people's daily life practices by analyzing the relational networks that disable or enable actors entangled in those networks. Dis/ability is a product of the network and its inner workings rather than attributable to any one of its constituent components. Embodiment in this context takes on new meaning: a networked performance composed of a human agent in addition to other human agents, non-human agents, or both (Moser & Law, 1999).

I have already established that end-user with disabilities are often framed as passive outsiders to the production of research and design outcomes. The focus on heterogeneous networks in actor-network theory approaches suggests that agency is something that needs to be examined more thoroughly when it comes to disability. STS scholar Ingunn Moser who has published several articles about the socio-technical ordering of disability describes agency as a potential to act mediated through and realized by multiple actors in a network relationship (Moser, 2006). Researchers and designers are often unaware of the heterogeneous networks that structure the daily life actions of individuals with disabilities. Instead, they focus on their power-laden networked activities which factor into the activities of consumers with disabilities in the
form of research and professional design outcomes that factor into their practices. Looking at the
design-like activities of individuals with disabilities through the lens of a combined social
practice/Latourian ANT framework affords the untangling and elucidation of the networks that
structure the daily life practices of individuals with disabilities and either enable or disable them
as human agents. Rather than looking at design or knowledge-production-like activities,
individuals with impairments, technology, or social interactions in isolation, this study looks at
the local "heterogeneous engineering" activities that allow individuals with disabilities to realize
agency along with other networked human and non-human actors.

Conclusion

In this chapter, I described popular disability models found in the disability studies literature,
HCI accessible design and critical design research approaches, and research on bottoms-
up/consumer-driven appropriation, problem-solving, and design-like activities. I also described
the philosophical and theoretical underpinnings of this study. The next chapter describes the
specific methods used to conduct this study and answer the research questions discussed in
chapter one.
Chapter Three: Methods

The objective of this study was to unpack the adaptation, modification, and design-like activity-enabled daily life practices of individuals with mobility and dexterity impairments. This chapter describes the qualitative approach and methods I used to conduct this inquiry as well as arrive at the findings and conclusions described in later chapters. The first section describes the qualitative research approach used to conduct this study. Later sections describe the participant recruitment, data collection, and data analysis methods.

Characteristics of Qualitative Research

I conducted this dissertation research study using qualitative research methods. The purpose of this section is to describe some of the fundamental attributes of qualitative research. In general, qualitative research is interpretive in its approach, which means the researcher categorizes, organizes, makes interpretations, and draws conclusions about the meaning of data (Creswell, 2003; Lincoln & Denzin, 1994). Interpretivism is one of many philosophical qualitative research perspectives, and its primary underpinning is the belief that interpretation is required to understand how social actors make meaning out of phenomena and events via complex social interaction processes that happen over time and involve history, language, and action (Schwandt, 1994). Phenomenology is one of many perspectives under the interpretivist banner along with hermeneutics, structuralism, semiotics, cultural studies, and variants of cultural studies such as feminism (Lincoln & Denzin, 1994). Although there are exceptions (e.g., descriptive or explanatory studies), qualitative research tends to be interpretive because the goal is for the researcher to make sense of a phenomenon from the perspective of other people and the meanings they bring to it (Lincoln & Denzin, 1994). As with much qualitative research, in general, the study described in this document is interpretive.
The interpretive nature of qualitative research is closely related to another feature of this type of inquiry: the centrality of the researcher. Unlike positivistic methods which use rigid scripts, formal procedures, and validated data collection instruments to supposedly neutralize the researcher’s influence on an inquiry, interpretive researchers embrace the fact that scientific inquiry is dependent on and influenced by the individual(s) conducting it. All researchers make multiple judgment calls throughout the data collection and analysis processes that influence the research. For qualitative researchers, these judgment calls include choosing whether to observe one or more people’s actions and interactions at a given time, including something in his or her field notes, and deciding to ask follow-up questions not included in the interview protocol but pertinent to the conversation. These and other activities require decisions which the researcher, situated in his or her socio-historical context, often makes based on his or her best judgment at a given moment. For instance, the decision to focus on some behaviors, interactions, and participant activities while ignoring others is subjective and will vary based on variables such as the inquirer, his or her alertness, and how much time he or she has spent in the field beforehand. His or her specific training, past experiences, and personal characteristics will influence those decisions to some degree.

In addition to various study design and data collection decisions, the researcher also makes subjective and potentially biased interpretations when analyzing qualitative data. The entire qualitative research enterprise from the design of a study to the production of results and conclusions require several decisions that influence the trajectory and outcome of the research. The influence an investigator has on the qualitative research enterprise does not mean it is entirely subjective. Good qualitative researchers follow rigorous and well-known guidelines, make research plans, and enact measures to maximize the validity and overall quality of the
results. The difference is that quantitative research studies conducted by multiple researchers using the same protocol, data collection procedures, and analysis methods will yield the same or very similar findings. Qualitative research findings, on the other hand, can vary based on the researcher and what he or she brings to the endeavor as a person situated within his or her socio-historical context with personal biases and perspectives on issues.

The social phenomena qualitative researchers study often happens naturally without their intervention. However, as "research instruments" who often interact with social actors and inhabit their natural environment during an investigation, researchers can potentially impact the phenomenon under study. He or she is also subject to unexpected situations that are difficult to predict or prepare for in advance. Although the qualitative researcher makes plans, develops protocols, and makes use of pre-defined scripts, the field brings uncertainties that often cannot be pre-determined as well as challenges that can be difficult to surmount. Qualitative researchers often must exhibit flexibility in the face of this uncertainty. He or she goes into the field with a plan of action but may have to revise or even scrap parts of it when unforeseen circumstances occur.

Again, qualitative scholars make and interpret meanings that social actors bring to a phenomenon. They must demonstrate vigilance in identifying when and how they influence the research process and the results it produces. The qualitative researcher simultaneously interfaces with participants and collects data. In doing so, the researcher encounters individuals who have unique understandings, perspectives, and ways of making meaning, which may differ from his or her understandings, perspectives, and ways of making meaning. The qualitative researcher must account for the fact that his or her worldview bears on the research process and may conflict with the worldview of his or her participants. As a scholar conducting qualitative research, one needs
to both capture authentic representations of participant understandings and disentangle his or her way of interpreting the phenomenon from that of the participants.

Credibility is a vital component of quality qualitative research. Credibility refers to the degree to which the findings resonate with the readers’, participants’, and researcher’s life experiences while still representing one of many possible and plausible interpretations of the data (Corbin & Strauss, 2008). Reflexivity is a common practice within the qualitative research tradition. The goal of this practice is to identify researcher biases and assumptions as well as relevant aspects of his or her background that may influence the research process and his or her interpretations of participant meanings (Carlson, 2010). It consists of systematically reflecting on and writing about who the researcher is and how his or her biography shapes the study (Creswell, 2003; Lincoln & Denzin, 1994). Reflexivity acknowledges that all researchers have biases, values, and interests and seeks to make them transparent to the intended audiences.

In addition to executing qualitative procedures in accordance with their accepted use, qualitative researchers engage in member checking to maximize the credibility of study findings. Member checking is the process of returning analyzed data to the participants to find out if they see themselves and their way of seeing the world in the researcher’s interpretations. Its purpose is to assess and validate the trustworthiness of results as well as to ensure the researcher’s voice does not overpower the participants’ (Birt, Scott, Cavers, Campbell, & Walter, 2016; Carlson, 2010). Member checking allows the researcher to determine whether participants’ way of seeing the world matched the way he or she understood and explicated it in the analysis chapters. I will talk about the specific reflexivity and member checking procedures for this study later in this chapter.
Self as researcher.

Self-awareness is an important and necessary aspect of qualitative research given its interpretive nature. Both research participants and researchers engage in meaning-making throughout the research process. As the data collection and analysis instrument, the researcher frequently makes interpretations shaped by his or her personal history, biography, gender, social class, race, ethnicity (Lincoln & Denzin, 1994), and, in the case of this study, impairment status. In qualitative race and ethnic research, "race and ethnicity, as mediated through insider status, is constructed and becomes a central dynamic" (De Andrade, 2000, p. 271). Similarly, I entered the field knowing that my status as an individual with a cerebral palsy conducting disability research would not only help me to secure insider status with participants but also shape the study in unique ways. My personal experiences living with impairments give me a different perspective than scholars conducting disability research who are able-bodied. My experiences shaped how I interpreted and made meaning out of my participants’ experiences. In this section, I talk about my background and experiences as well as how both motivated and likely impacted this dissertation research study.

I have a mix of spastic diplegia and dyskinetic cerebral palsy. Spastic CP, which results from motor cortex damage during the early stages of development produces muscle stiffness and tightness (“What is Cerebral Palsy,” n.d.). Damage to the basal ganglia during development, on the other hand, leads to dyskinetic CP, which causes involuntary body movements (“What is Cerebral Palsy,” n.d.). I have significant impairment in both of my legs which impacts my walking abilities. I also have dexterity and speech impediments. There are different types of CP, and people who have it can have vastly different experiences. For instance, although some individuals with diplegia have impaired walking abilities, others cannot walk at all. Some with
diplegia who can walk may have an irregular gait pattern while others may not have any visible mobility issues. Diplegia can impact one or both legs and may impact one's upper extremities as well, but usually to a less significant and noticeable extent. I walk with an irregular gait, and my right knee goes inward toward my left leg like a pair of scissors when I take a step. I have lived with this condition all my life. Moreover, I have met others who have spastic diplegia as well as other forms of CP.

My educational career started in a school specifically for individuals with disabilities. In the second grade, my teachers and parents decided to “mainstream” me. The transition was challenging because, for the first time, I was noticeably and somewhat awkwardly different from my peers. In addition to the apparent difference in physical ability, I had to wear a hockey helmet to protect my head if I fell. I had to use various assistive technologies which simultaneously helped me to complete my work and led to stigmatization among my peers. Some of the encounters I had with peers and teachers were grounded in ableist ideas which highlighted and reinforced the differences between us. During most of my time as a primary and secondary education student, I experienced what Rieser (2006) refers to as internalized oppression or a negative view a person with a disability has about himself which creates feelings of low self-esteem and further reinforces the low value that non-disabled people sometimes attribute to individuals with disabilities. To be fair, I also had positive experiences with teachers and peers who saw my potential and looked beyond my impairments. However, for a long time, I did not value myself as a person with a disability. At the time, I was not aware that there was a connection between the low sense of self-worth and the social interactions I had with others as an individual with a disability in an ableist society.
I was unfamiliar with the social model of disability until I started graduate school. The social model distinguishes disability from impairment. It links impairment to a person's cognitive and physical capabilities while framing disability as a limitation or loss of opportunity due to physical and social structures in society (Rieser, 2006). The first time I read about the social model, it did not resonate with me right away. I was still holding on to socially shaped negative perceptions of disability and some internalized oppression. As a United Cerebral Palsy intern in 2015, I wrote a blog post about my elementary and secondary educational experiences as an individual with CP, and I used the social model as a lens to interpret those experiences. Writing this article made me realize that people who did not value abled and disabled bodies the same shaped certain aspects of my childhood and young adult experiences. I internalized some of these negative perceptions and allowed them to color the way I saw myself. I admit that I am not a purist when it comes to the social model. Personally, I view impairment as one of many aspects of the disability experience along with socio-cultural factors. Nevertheless, I wholeheartedly embrace the social model as an alternative lens to view disability and understand certain things from the perspective of people who live with impairment. I see it as a framework that can be used to identify and interrogate ableist assumptions held by the media and society about people with disabilities.

The inspiration for this study started with a personal acknowledgment of my tendency to find ways to circumvent impairment related challenges. Over the years, I have developed ways of buttoning shirt buttons, signing and submitting documents, cooking, carrying bulky or heavy things, carrying or moving dishes around in my kitchen, taking photographs, and completing various other tasks that are difficult because of my mobility and motor control limitations. I enjoy finding individualized ways to do activities, and I attribute my interest to my parents. As a
child, I spent many hours watching my Dad fix cars and work on home improvement projects. My mother, on the other hand, conceptualized and made the first adaptation I ever used. It was a makeshift button hook which consisted of a safety-pin attached to a rubber band. As a high school student, I had to wear a shirt and tie to work. One day after buttoning the top button on my shirt for about the 50th time, my mother clipped a safety pin onto a rubber band and showed me how to use it like a button-hook. This adaptation worked well for me for a while. I ran into an issue, however, whenever I misplaced the button hook or the rubber band broke. My dexterity issues make it difficult for me to open and close a safety pin. One day after spending almost 30 minutes trying to attach a safety pin to a rubber band after the previous band popped, I looked in the medicine cabinet hoping to find another solution. After a few minutes of rummaging, I found a package of bobby pins. Within two minutes I figured out a bobby pin worked better for me than safety pins because they are easier to grasp in my hand and manipulate given their longer length. I could replace a broken rubber band within seconds without having to worry about poking my fingers with a sharp metal object. Also, the longer length of the bobby pin made it easier to feed and pull through the button holes on my shirts. I have been using the same solution since my junior year of high school.

I knew that I wanted to conduct accessibility research when I started graduate school, but it took some time to identify my niche. During the first four years of my matriculation, I read dozens of papers written by accessibility and HCI scholars. Most of them had one thing in common: the researchers did not seem to have any first-hand experience living with impairment. To be fair, the only way to know if someone has a disability is for that person to disclose it. Perhaps more of the scholars I read had disabilities than I realized. Maybe some of those scholars chose not to disclose their impairment status. Nevertheless, the more I read, the more I realized
their work rarely included the voices of the people they studied. Instead, it tended to describe what they did for individuals with disabilities by designing or testing the usability of new assistive technology.

As discussed throughout this dissertation, the scholarship on disability and design too often marginalizes rather than empowers individuals with disabilities. UK disability studies scholars like Mike Oliver (1992) highlight the need for disability research to take a less positivistic approach. He explains there is an inherent individualism in positivist research which reduces all phenomena to the individual without consideration of social factors involved. Disability research that is positivistic tends to assume the problems individuals with disabilities face are solely due to their impairments while ignoring social, structural, societal, and institutional forces (Oliver, 1992). As a corollary, the conclusions disability researchers reach about the problems people with disabilities face rarely match what individuals with disabilities identify as problems.

Whether intentional or unintentional, disability researchers often ignore the real self-defined needs of people who live with impairments because of their orientation towards individualism. As a person with a disability who also had some experience leveraging homemade accessibility solutions, I wondered why accessibility scholarship did not pay much attention to the adaptation, modification, and design-like activity of individuals with disabilities. When I modified the homemade button hook that my mother devised for me to increase its usability, I not only appropriated more independence but also began to act on the reality that I could find a way to do just about anything I needed to do despite my impairments. I cannot say that I fully understood the scope of what this event meant at the time, but it was significant. My mother could have easily purchased a button-hook from the store, however, asking for help, struggling to
do a task independently, and then learning how to do something for myself was more valuable than using a store-bought product. The button hook and other adaptations taught me to think outside of the box and try multiple avenues. I discovered that I did not always need to buy a pre-made solution. I realized that I was quite capable despite my physical impairments. With time, I learned that I was not the only individual with a disability who adapts. Throughout my life, I have known and seen other people who live with physical impairments and find ways to adapt. As I read the works of HCI and accessibility scholars as a junior Ph.D. student, I wondered why they did not include the perspectives of individuals with disabilities who engaged in adaptation, modification, and design-like activities. I also wondered what these perspectives might add to conversations about accessible design and disability.

Although the experience of disability is not identical for all people who live with impairment, shared experiences and understandings sometimes exist. As someone who has experienced both impairment and disability, I started this study feeling like I would be able to relate to my participants on a level that would be difficult if I was not personally familiar with impairment and disability. I believe that having a noticeable disability made it somewhat easier for me to build rapport and earn the trust of some study participants. However, I also entered the field with a mild degree of fear because of my speech impediment. Sometimes others have a difficult time understanding my speech. I thought it might become an issue during some of the interviews, which it did, but not in a significant way. Whenever participants had trouble understanding something I said, they would usually ask me to repeat it. Slowing down and repeating my words always resolved misunderstandings.

The shared understandings I mentioned a moment ago simultaneously made it easier to build rapport and made reflexivity more crucial. For instance, some of my participants also had
 However, the type and nature of our impairments, as well as our individual experiences with CP were not always the same. Nevertheless, sometimes it was tempting to project my experiences and understandings onto participants who identified with aspects of my experiences and understandings. I had to continually remind myself of this throughout the study, particularly with participants who had CP. For example, one participant shared several personal stories and experiences that resonated with me during our interviews. At times during our first interview, I found myself wanting to draw conclusions and make assumptions based on similarities between our experiences and ways of seeing things. Some of this tendency could be attributable to the fact that he was my first interviewee. After that interview, I reviewed the transcript and realized I needed to resist the urge to state commonalities between his experiences and mine. Instead, I needed to stick to simple follow-up questions that would give him a chance to explain things from his perspective in more detail.

As a scholar conducting disability research, I felt like I had an obligation to bracket my meanings as much as possible to avoid distorting the perspectives of my participants. As an individual with a disability talking to other people with disabilities about a topic that is personally meaningful and significant, reflexivity required some work. I maintained a journal during the data collection and analysis phases of the research. I documented many of my ideas, interpretations, biases, and assumptions in this journal. I did most of my writing while reviewing the interview transcripts and working on the initial rounds of coding. I also jotted down some thoughts in between participant interviews and during later stages of the analysis process. I revisited this journal several times during the process to make sure that I separated my biases and personal experiences from those of my participants. Writing down my interpretations during
different phases of the research allowed me to identify where I may have gone too far in an assertion or possibly missed the import of a participant’s comment.

The journal not only helped me to formulate follow-up questions for the second interview with each participant but also served as a record of what I believed, assumed, and took for granted while in the field. It was most useful when it was time to describe the essences of adaptation, modification, and design-like activity from the perspective of my participants. For instance, I tried to describe and give a name to the phenomena on multiple occasions. After reading these entries a few times, I realized I needed to pay more attention to what my participants said about their activities overall during both interviews instead of trying to label and define the phenomena based on their responses to one or two interview questions. The one regret I have is that I did not write in my journal every day. Sometimes I would wait a few days to write about various topics and ended up forgetting what I initially wanted to hash out on paper. Also, the journal was informal. I wrote entries in MS Word, Atlas.ti's memo manager, and the notes feature on my computer. I tried to date and categorize each entry, but some of the categories did not make sense after a few months.

**Why Mobility and Dexterity Impairments**

I decided to focus on mobility and dexterity impairments for a couple of reasons. First, my personal experiences as an individual with both types of impairments was a factor. I have not only experienced challenges and barriers related to my physical impairments but also leveraged personalized adaptations to address them. I have always known others with physical disabilities who did the same thing. It was natural for me to want to engage others with physical disabilities given my personal experiences and interactions with others like me.
The second reason why I decided to focus on mobility and dexterity impairments was the tendency of popular disability models to make impairment the basis for determining ab/normality and the value people in each category possess within a capitalist economy (Oliver, 1990). Medical and corporate disability models frame individuals with disabilities as aberrations from the norm that must be "fixed" via rehabilitative science, technology, and the work of non-disabled professionals (Ellis & Kent, 2011; Finkelstein, 1993; Fulcher, 1989; Goggin & Newell, 2003; Roulstone, 2016). Although the same could be said for vision, hearing, cognitive, and other capabilities, independent and skillful use of the body (particularly the hands) are undoubtedly central to adaptation, modification, design, and similar activities. According to deficit disability models, reduced ability to do the same things a non-disabled designer, maker, or DIYer can do excludes individuals with disabilities from participating in these activities. Much of the HCI and DIY literature seems to validate this assertion since it often relegates individuals with disabilities to the role of passive consumer of design outcomes. It seemed fitting to talk to individuals with physical impairments who engage in adaptation, modification, and design-like activity given the assumed connection between impairment and passive consumption undergirding deficit disability models. I could have included individuals with hearing and visual impairments as well but decided their lived experiences and everyday accessibility issues were too distinct from those of individuals with mobility and dexterity impairments to derive any meaningful findings across participants.

**Recruitment: Strategy**

**Identifying potential participants.**

A common barrier disability researchers often encounter is finding and recruiting members of the target population. Researchers, and particularly non-disabled ones, historically have done a poor
job of accurately representing participants with disabilities and considering their interests, opinions, wishes, and aspirations in the design, conduct, and reporting of research (Kitchin, 2000; Oliver, 1992). As a result, individuals with disabilities can be hesitant or unwilling to participate in research studies because of possible misrepresentation and exploitation. In general, sampling in qualitative research is purposively and conceptually driven (Huberman & Miles, 1994). Phenomenologists tend to advocate for the selection of participants who have experienced the phenomenon studied (Creswell, 2007; Groenewald, 2004; Hycner, 1985). For this study, I used multiple strategies to identify and recruit participants to not only find individuals with disabilities who have adaptation, modification, and design-like activity experience but also combat the recruitment challenges associated with disability research.

One strategy that researchers use to gain access to individuals with disabilities is through gatekeepers or facilitators (Cameron & Murphy, 2007; Nind, 2009). This approach entails collaborating with stakeholders from one or more organizations that have access to members of the population researchers are interested in studying. Collaborating includes giving gatekeepers information about the study and asking them to recommend, contact, or distribute information to people who might be interested in the research topic and willing to participate (Nind, 2009). I used this strategy in hopes of identifying people with mobility and dexterity impairments who also engage in adaptation, modification, and design-like activities. I reached out to local organizations that work with individuals who have mobility, dexterity, and other types of impairments. These organizations included SUNY Upstate Medical Center-Physical Medicine and Rehabilitation in Syracuse, NY, ARISE Independent Living center in Syracuse, NY, a disability rights organization in Central New York, and a meetup group in Connecticut for people with multiple sclerosis.
One of the first potential gatekeepers I contacted was the president of Disabled in Action (DIA) of Greater Syracuse. DIA is a civil rights advocacy group run by and for individuals with disabilities. After my initial meeting with the president, I decided to become a member. I started attending meetings in July 2014 and still go occasionally. The group meets monthly to discuss pertinent access, civil rights, insurance funding stipulations, and other issues that impact individuals in Syracuse who have disabilities. I decided to join the group for four reasons. First, to learn more about the different issues the group addresses. Second, to see if there were any opportunities for me to get involved beyond attending the monthly meetings. Third, to build as much rapport as possible before asking people to participate in my study. Fourth and finally, to avoid taking my gatekeeper’s graciousness for granted or engaging in exploitative research practices which valued my goals over the interests over those of the organization and its members. Getting involved long-term was my way of investing in causes that were salient to members of the organization instead of focusing on my research agenda only. Once I obtained IRB approval for my recruitment materials, I gave each DIA member a copy of the recruitment flyer. During the August 2014 meeting, I briefly described the study, passed out recruitment flyers, and answered questions.

The gate-keeper strategy alone did not yield the number of people I needed to recruit. In addition to the gate-keeper strategy, researchers who study disability and design related issues often use multiple recruitment methods (Allen, McGrenere, & Purves, 2008; Bingham et al., 2008; Brady et al., 2013; Grammenos, Kartakis, Adami, & Stephanidis, 2008; Guerreiro, Nicolau, Jorge, & Goncalves, 2010; Kane et al., 2008, 2009; Ornella & Stephanie, 2006; Orpwood et al., 2010; Woudstra et al., 2011). In addition to asking gate-keeper to identify and distribute recruitment materials to potential participants, researchers commonly reach out to people in their
social networks. Variations of this method include reaching out to participants from previous studies (Dawe, 2007; Kane et al., 2009) and distributing recruitment messages via relevant e-mail distribution lists (Brady et al., 2013; Kane et al., 2009; Ornella & Stephanie, 2006; Shinohara & Wobbrock, 2011).

In addition to identifying and contacting gate-keepers, I reached out to people in my social networks to ask for the names and contact information of individuals who might be interested in participating in the study. I contacted friends and colleagues with and without disabilities. Some personal contacts with disabilities expressed interest in participating. Others connected me to people in their social networks. I also reached out to the director of Syracuse University’s Disability Cultural Center (DCC) who not only distributed a short blurb about my study to several of her professional contacts but also sent an email on two disability studies listservs.

I found more participants online via message board forums, YouTube, and Facebook. I frequently visited the Wheelchairjunkie.com (WJC.com) online forum as a lurker from June 2013 until the start of this study. The forum no longer exists as of July 2017, but the person who started it is a rehab technology industry icon, manager at a large power chair solutions company, and advocate for consumers with disabilities. He is a wheelchair user himself and often provided free expert technical advice to forum members regarding their mobility equipment. WCJ.com was not exclusively devoted to adaptation, modification, and design-like activity, but there was an “everything mobility” sub-forum on the site where contributors asked questions and engaged in asynchronous conversations about many different topics. Popular discussion subjects included accessibility products, technology, everyday life issues, and adaptation, modification, and design-like activity. Some of the projects and ideas members discussed on the “Everything
Mobility” sub-forum exemplified the types of adaptation, modification, and design-like activity and related practices this dissertation research study unpacks. I reached out to the owner of the forum to ask for permission to join the forum, start a thread about my study, and send recruitment materials to specific members. After obtaining permission, I posted a message on the Everything Mobility sub-forum to introduce myself to the community. During the week of November 8th, 2014, I sent emails to specific members who posted adaptation, modification, and design-like activity-related content to the forum between July 2011 and July 2013. I used this time frame because it coincided with the data collection period for a different but related study exploring the online adaptation, modification, and design-like activity-related content of individuals with disabilities (Robinson, in-progress).

Throughout 2013 and 2014, I subscribed to several YouTube channels featuring individuals with disabilities engaging in or talking about adaptation, modification, and design-like activity-related activities. By the fall of 2014, I found more than 450 videos posted by more than 40 contributors. I created a spreadsheet with video topic, channel, and publisher information for most of these videos. The spreadsheet made it easy to identify YouTubers with disabilities who have adaptation, modification, and design-like content on their channels. During the second week of November in 2014, I reached out to several publishers on my spreadsheet to recruit some of them. I targeted channels featuring someone with a mobility or dexterity impairment who posted at least one video about an individualized tools, tactics, and ways of dealing with accessibility, impairment, and everyday life issues. I reached out to approximately 30 of the YouTubers on my list. I sent YouTube inbox messages to 28 contributors and emails to the remaining ones. Unfortunately, using the YouTube inbox feature may have lowered the response rate. After sending messages to several people, I did some experimenting and discovered how
difficult it was to retrieve YouTube inbox messages. Although I included my personal contact information in each message, I am not sure if the message itself was easily retrievable by all recipients. Sometimes contributors post their email addresses on their channel. Unfortunately, I had already sent 28 of the 30 messages via YouTube’s built-in messaging platform before I realized the issue with the inbox feature.

I also attended a Meet-Up group to find more potential participants. Meetup.com is a website that helps people with shared interests to find each other and connect offline, often in a group setting. Group organizers post meeting details such as purpose, location, and time on Meetup.com website. The main Meetup.com page for the MS support group I attended (THIS-ability) had an explicit statement saying that anyone could join. Interested individuals had to create an account on the meetup.com website to RSVP for future events and get on the group's mailing list. I reached out to the THIS-ability group organizer on September 29th, 2014 and he called me within a couple of days. During the phone conversation, I told him about the study, and he invited me to the next meeting in Hartford, Connecticut on October 7, 2014. The group was composed of mostly middle-aged adults with multiple sclerosis. I could not distribute recruitment information after the meeting because I submitted revisions to the IRB protocol the week before and I was still waiting for to get them approved. I kept in contact with the group's organizer and sent the recruitment materials to him once the IRB approved my modified protocol.

The final method I used to find and recruit participants was snowball sampling. This method consists of asking study participants to either refer other people who might be interested in the study and eligible to participate or provide information that will help the researcher identify other people who may be interested and eligible to participate (Babbie, 2012). I will
describe exactly how I used snowball sampling later in this chapter when I discuss participation incentives. I have just described the different ways that I identified potential research participants. In the next section, I will explain the screening protocol I used to select actual participants.

**Screening: Inclusion & exclusion criteria.**

Identifying and contacting individuals with mobility and dexterity impairments was only the first step in the recruitment process. Next, I had to screen everyone who responded to the recruitment materials to determine their eligibility to participate in the study and the nature of their adaptation, modification, and design-like activity experiences. I used inclusion and exclusion criteria to identify who to ask to participate in the study. There were three primary requirements for inclusion in this dissertation research study:

1. The individual must have a dexterity impairment, mobility impairment, or both
2. The individual must have engaged in adaptation, modification, and design-like activities within the last 6-12 months.
3. The individual must be willing to discuss specific adaptation, modification, and design-like activities with me.

I also had exclusion criteria, and anyone who expressed interest the study but met any of the following conditions did not receive an invitation to participate in the study:

1. The individual did not have dexterity or mobility related difficulties
2. The individual adapted, modified, or made things for someone who has a dexterity or mobility impairment but not for him/herself
3. The individual is younger than 18 years of age
4. The individual is unwilling to talk about his or her adaptation, modification, and design-like activities and outcomes.

5. The individual’s adaptation, modification, and design-like activities have nothing to do with mobility or dexterity issues.

The second and fifth elements are worth explaining. Several accessibility researchers focus on a related phenomenon known as “DIY AT” (Hook et al., 2014, 2013; Hurst & Tobias, 2011) which pays an inordinate amount of attention to the efforts of non-disabled individuals to adapt and make assistive technology for individuals with disabilities. In at least one instance, I had to turn away a non-disabled caregiver who engaged in adaptation, modification, and design-like activity for someone with a disability and expressed interest in the study. While I did ask participants if I could interview someone who played a role in their adaptation, modification, and design-like projects, all my participants were people with disabilities who also played a role in these projects.

I added the fifth exclusion to limit participation to people who had in-scope impairments. I did not exclude people with non-mobility or dexterity impairments (i.e., vision impairment) if they also had a mobility or dexterity impairment and at least some of their adaptation, modification, and design-like activities allowed them to address related issues. Including individuals with out-of-scope impairments seemed like mixing two distinct groups of people who may engage in adaptation, modification, and design-like activities for different reasons. For example, I assumed the accessibility, impairment, and everyday life issues someone who has a learning disability might face would not be comparable to those faced by someone who has a physical impairment. Therefore, it seemed logical to exclude individuals who have learning disabilities from the study unless they also had a mobility or dexterity impairment. This criterion
was ineffective in one instance, and I ended up dropping a participant from the study after the data collection phase. He had a visual impairment and severe back issues that he claimed affected his mobility. During our interviews, I realized that nearly all the adaptation, modification, and design-like activities we discussed were specific to his visual impairment and had nothing to do with mobility.

I embedded the inclusion criteria in the recruitment materials. Sometimes interested individuals asked questions or shared information about themselves when responding to the recruitment materials that raised a red flag. I always followed up on these issues to kindly let people know if something could or did make them ineligible to participate. My conversations with gatekeepers and personal contacts always included an explanation of what made someone eligible or ineligible to participate in the study. The questionnaire described in the next section afforded further screening of interested individuals as well as the selection of participants from the pool of people identified using the recruitment methods described earlier.

**Recruitment questionnaire.**

I distributed a questionnaire to everyone who reviewed the recruitment materials, expressed an interest in participating in the study, and did not trigger any red flags during the initial contact stage. The questionnaire allowed me to find out and document whether each respondent met the inclusion criteria. I also used it to identify the general types of adaptation, modification, and design-like activities each person engaged in as well as his or her specific impairment(s) and general level of independence. Additionally, the questionnaire had an item that asked the respondent about his or her preferred interview channel. I used completed questionnaires to select potential participants from the pool of individuals who expressed an interest in participating. I reached out to everyone who completed the survey and met the inclusion criteria
and asked them to participate. Responses from recruited individuals also enabled me to adapt the interview protocol for each participant which I will discuss later when I describe phase II of the data collection process. Diagram 3.1 below depicts the entire recruitment process, including the role of the questionnaire in screening interested potential participants.

![Diagram 3.1 - Recruitment Process](image)

**Figure 1 - Recruitment Process**

The initial and subsequent launch of the questionnaire was somewhat unsuccessful, and I had to revise it twice. The first version was paper-based, and some of the questions were confusing.

After deciding to recruit participants via online channels in addition to offline ones, I needed a way to distribute the questionnaire virtually. A web-based Qualtrics version seemed like the best way to do this. Once the IRB approved a slightly revised Qualtrics version of the recruitment
questionnaire, I added a link to it in the recruitment emails I sent to people after they expressed an interest in participating in the study. The paper version of the questionnaire was not eliminated but rather made available upon request for anyone who needed or preferred it. The recruitment email with the link to the Qualtrics-based questionnaire had one sentence telling each potential participant that he or she could request the paper version at any time.

Several people expressed an interest in participating in this study, but a smaller number completed the recruitment questionnaire. One individual who expressed interest was kind enough to offer unsolicited feedback to me about the questionnaire. Although I asked for feedback from colleagues before launching the questionnaire, I could have done more to make sure the language used would be accessible to a non-academic audience. The unofficial informant also said the questionnaire more than likely conveyed the wrong message and people may have perceived it as a crafty attempt to steal their ideas. I was initially hesitant to act on her advice because I did not want to modify the IRB protocol again. After several weeks of waning interest as evidenced by several incomplete questionnaires, however, I knew she was right and decided to amend the protocol again.

I tried to make the revised version of the questionnaire shorter and more straightforward. After several rounds of editing, I ended up getting rid of the Qualtrics versions of the questionnaire and incorporating the most important questions into the initial contact email. I simplified the questions by focusing on one primary idea for each one and being less tautological in my use of synonyms. The revised email asked potential participants to reply with their responses to the questions if interested in participating.
Participant incentive structure.

Initially, I did not offer participation incentives to participants. I incorrectly assumed people would find the topic interesting enough to volunteer their time without incentives. I also did not have funding set aside to provide incentives, and I wanted to avoid paying out-of-pocket if possible. However, I later realized participating in this study required a significant time commitment, and it was incorrect to assume people would invest their time without an incentive. After struggling for weeks to recruit people and reviewing several studies conducted by accessibility researchers (e.g., (Branham & Kane, 2015; Kane et al., 2009; Oh & Findlater, 2013; Shinohara & Wobbrock, 2011), I decided to revise my IRB protocol so I could offer a token of appreciation to my participants. Everyone who participated (excluding co-participant allies) received either an Amazon.com gift code via email or a physical gift card. Three participants requested physical brick-and-mortar store gift cards instead of Amazon gift codes, and I accommodated their requests. I revised my IRB protocol in late-September of 2014 so that I could start offering incentives to participants. I had successfully recruited one person before deciding to give tokens of appreciation. I informed him of the change once the IRB approved it. He received the same token of appreciation as everyone else who participated in the study.

I offered everyone a $10 or $25 gift code/card, depending on the number of interviews the participant completed. Participants were eligible to receive a $10 gift code/card if they completed one interview and then decided to stop participating in the study. Participants who completed both interviews received a gift code/card equal to $25. All study participants completed both interviews. Participants who referred another person who also participated in the study he or she received an additional $10 on his or her gift code/card. I described the token of appreciation and referral incentives in the recruitment materials, initial contact email, and
informed consent letter. Each participant received his or her $25 or $35 gift code/card within 24-48 hours of completing the second interview. Most received their $25 or $35 gift code/card within 8 hours of completing the second interview.

As alluded to in the preceding paragraph, I asked recruited participants to consider referring other potential participants to me, and offered an additional incentive for doing so. This technique is known as snowball sampling, and it is most useful when members of the target population are difficult to locate. It entails asking each interviewee or participant to suggest other people or provide information that will help the researcher identify additional participants (Babbie, 2012). Given some of the difficulties involved in recruiting individuals with disabilities, snowball sampling seemed like an excellent way to find additional participants. I assumed that people would be more willing to participate if someone they already knew told them about the study. I also figured previous participants already understood the purpose of the research as well as the type of people I sought so they would be able to identify individuals within their social networks who met the inclusion criteria. Snowball sampling does not necessarily have to include incentives, but it seemed like an excellent way to gain access to the population of interest and to thank informants for their help. Any participant in the study who referred at least one other eligible individual who also decided to participate in the study received an additional $10 added to his or her gift code/card. Image 2 and diagram 1 below depict the incentive system used for this study.
Figure 2 - Participant Incentive Structure

1. Participant completes 1st interview
   - $10

2. Participant completes 2nd interview
   - $15

3. Participant refers someone who a) meets screening criteria and b) completes 1st interview
   - $10

Participant receives gift code/card
- $10 for one completed interview
- $10 + (n*$10) for one completed interview and n successful referrals
- $25 for two completed interviews
- $25 + (n*$10) for two successful interviews and n successful referrals
Diagram 1- Participant Incentive Structure
I needed a way to keep track of referrals that protected everyone’s identity. Every participant received a referral coupon with a randomly generated four-digit number on it after completing his or her first interview. Figure 3 below shows a sample referral coupon. The randomly generated four-digit code allowed me to keep track of who made a referral without asking participants to disclose personal information about each other. I created a referral coupon template in Excel which generated a random number every time I opened the file or edited any cell on the spreadsheet. For each participant, I opened the template, copied and pasted the random number as text, saved the referral certificate as a .xls file with the participant's ID in the file name, and emailed a copy of the file to him or her. I kept track of participant names, IDs, and referral codes in a password-protected Excel workbook. I told participants to give their referral code to everyone they referred to me. The recruitment questionnaire had an item which asked for the referral code of the person who told the respondent about the study.

![Referral Coupon](image)

*Figure 3 - Sample Referral Coupon*
Participants

Table 8 below shows the participant yield for each recruitment channel, including the number of people referred by other study participants. Twenty-eight people responded to the recruitment materials and began working on the screening questionnaire. Seventeen or 61% of the 28 people who expressed an interest completed the questionnaire and met the inclusion criteria. I removed one person from the study after interviewing him because most of his adaptation, modification, and design-like activities enabled him to address visual impairment issues rather than mobility or dexterity-related ones.

Seventeen subjects (11 males, six females) between the ages of 19 and 72 with a mean age of 39.9 years old participated in this study. Although some research suggests the optimal number of participants in a phenomenological study is less than 10 (Morse, 1994), others give a range of 5-25 (Creswell, 2007; Polkinghorne, 1989). All participants lived in the U.S. (Northeast-6, Midwest-5, Southeast-1, Southwest-1, West-1, Northwest-1, South-1) and had mobility impairments, dexterity impairments, or both. Interviewees included individuals who engaged in adaptation, modification, and design-like activities independently as well as those who worked with spouses, family members, or caregivers because they could not independently perform the physical tasks that making or using an adaptation, modification, or design-like project outcome demanded. Including individuals who collaboratively engaged in adaptation, modification, and design-like activities afforded insights into the different contributions people with disabilities bring to these efforts. One participant’s husband who helped her with adaptation, modification, and design-like activity-related tasks and projects also participated in a separate 45-minute interview.
### Table 8 - Recruitment Method Yields

<table>
<thead>
<tr>
<th>Channel</th>
<th># Respondents/Interested People</th>
<th># Incomplete Questionnaires/People Excluded</th>
<th># Recruited &amp; Interviewed</th>
<th># Excluded from Analysis</th>
<th># Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listserv</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Facebook</td>
<td>4</td>
<td>-</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Gatekeeper</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Personal contacts</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Referral</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Meetup Group</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>WCJ.com</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>YouTube</td>
<td>6</td>
<td>2</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>11</td>
<td>17</td>
<td>1</td>
<td>16</td>
</tr>
</tbody>
</table>

**Participant interview platforms.**

There were four types of interviewees distinguishable by the method used to recruit them and the medium they selected for the interviews. Individuals recruited offline through personal contacts and gatekeeper organizations usually participated in face-to-face interviews. I allowed the individuals I recruited through online channels to choose between Skype, telephone, or instant-messenger facilitated interviews. It would have been preferable to conduct all interviews face-to-face given the richness of this communication channel. Location differences, however, made traveling to each participant and conducting two face-to-face interviews impractical. Also, some participants preferred computer-mediated channels. Thirty-five percent of interviewees (6) chose face-to-face interviews. The first interview lasted an average of one hour and twenty-six minutes while the second lasted an average of one hour and five minutes. I conducted these face-to-face
interviews in locations that participants suggested such as their homes, workplaces, and schools. These interviews allowed me to not only talk to the participants about the environment surrounding some of their daily life challenges and practice activities but also see some of their adaptation, modification, and design-like activity outcomes in person. In a few instances, I took pictures of participants’ physical adaptation, modification, and design-like activity outcomes or ways of doing things. Additionally, face-to-face interviews made it easier to engage and build rapport with participants, particularly when they invited me into their personal spaces.

**Table 9 - Interview Platforms Used**

<table>
<thead>
<tr>
<th>Interview Platform</th>
<th># Participants</th>
<th>% Total</th>
<th>Avg. length of Interview #1 (hrs:mins)</th>
<th>Avg. length of Interview #2 (hrs:mins)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-Face</td>
<td>6</td>
<td>35%</td>
<td>1:26</td>
<td>1:05</td>
</tr>
<tr>
<td>Instant Messenger</td>
<td>5</td>
<td>29%</td>
<td>1:36*</td>
<td>1:16**</td>
</tr>
<tr>
<td>Video Chat</td>
<td>3</td>
<td>18%</td>
<td>1:42</td>
<td>1:12</td>
</tr>
<tr>
<td>Phone</td>
<td>3</td>
<td>18%</td>
<td>0:54</td>
<td>0:40</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>17</strong></td>
<td><strong>100%</strong></td>
<td><strong>1:16</strong></td>
<td><strong>1:04</strong></td>
</tr>
</tbody>
</table>

*Includes extended interview for one participant who had computer issues

**Excludes participant who could not finish second interview because of computer issues

Eighteen percent of interviewees (3) participated in video chat facilitated interviews, and another eighteen percent agreed to telephone interviews. The interview protocol for the video chat and telephone interviews were shorter than the face-to-face protocol but longer than the instant messenger one. The brevity of the video and voice interview protocols seemed warranted given the mental and physical energy that each one required. For video chat and telephone conversations, participants had to coordinate a time and find a physical space where they could do each interview. Participants who selected one of these channels essentially took time out of their personal lives and interacted with me while they were in their homes, offices, and other
private spaces. Unlike face-to-face interviews, video chat and telephone-mediated ones depended on properly functioning ICTs.

Participants who opted for video chat platforms used Skype or Google Hangouts. The average time for the first video chat interview was one hour and forty-two minutes while the average for the second was one hour and twelve minutes. Using video chat platforms can introduce potentially time-consuming and frustrating challenges. I had to reschedule my first interview with one participant because I had issues with Google Hangouts. I also had to call one participant instead of video chatting with him because of last-minute technical difficulties with the FaceTime application on his iPad. Nevertheless, seeing participants while conversing with them made it easier to build rapport and interpret nonverbal cues such as smiles and sighs.

The first and second telephone mediated interviews lasted an average of fifty-four and forty minutes, respectively. Telephone interviews lacked some of the richness of the face-to-face and video chat interviews. For instance, I could not read participants' facial expressions, which made it more challenging to connect with them. Unlike face-to-face and video chat conversations which afford visual and audio interaction, the telephone limited our interactions to voice-only communication. I have a speech impairment which sometimes made it difficult for participants to understand me. Although the impairment was not a significant challenge in any of the interviews, I had to repeat myself more during the telephone conversations. Telephone interviewees likely had to listen more actively and ask me to repeat or clarify something I said more often than face-to-face and video chat interviewees. However, in telephone-mediated interviews, participants were free to explain things in detail, provide numerous examples, and respond to follow-up questions without the added challenges of dealing with video chat platforms, meeting in person or coding and decoding messages in written text.
Twenty-nine percent of participants (5) requested instant messenger-facilitated interviews. IM platforms included Google Chat, Citrix GoToMeeting, and Facebook Messenger. The first instant messenger interview lasted an average of one hour and thirty-six minutes while the second one lasted one hour and sixteen minutes on average. One participant had computer issues during both interviews which extended the length of our first conversation and shortened the length of the second. The averages listed in table 9 above includes the extended time of the first interview and excludes the shortened time of the second. Some participants had motor and dexterity control limitations which probably made instant messenger interviews time-consuming for them. However, at least one participant who opted for instant messenger interviews was also non-verbal. IM was the best medium for her out of the available options because it did not require speaking. Instant messenger interviews allowed participants to substitute talking with written text while video chat and face-to-face interviews combined voice communication with the ability to make gestures and use body language if necessary. However, instant messenger facilitated interviews demanded time, energy, dexterity, motor control, and manual effort in the form of using a keyboard to type.

I modified the interview protocol for the instant messenger interviews to reduce the demands instant messenger facilitated conversations placed on participants. The instant messenger interview protocol was shorter than the other three protocols. I asked fewer conversational questions intended to elicit lengthy responses and probed less often. I assumed participants would prefer to give shorter responses and decided to ask more questions that were specific and to the point. IM platform questions were intended to evoke short yet meaningful responses. The most significant drawbacks to the instant messenger interviews were the terseness of participant responses and the limited ability to probe on salient points. Instant messenger
conversations are not as fluid as voice conversations because each conversant is coding and decoding messages via a chat interface. Unlike verbal communication, which is instantaneous and does not demand any additional mechanics beyond speaking, IM-facilitated conversations require mechanical movement in the form of typing (unless a person is using voice recognition or some other alternative input interface).

Instant messenger-facilitated interviews tended to lack the depth and breadth of the interviews conducted using other platforms. Participant responses were terse and prepared within 10-30 seconds or longer. I tried to respect participants' time by keeping the length of the interviews short. Although most participants agreed to continue chatting beyond the allotted 45-60 minutes allotted, it was still difficult to build rapport during these short, mediated conversations. One of the corollary outcomes of IM-facilitated interviews was short already-transcribed conversations with very few details. Many of the examples and descriptions provided by IM participants lacked the richness of those provided by participants who opted for one of the other three interview channels. Some of the answers IM interviewees provided lacked details that would have been useful during the analysis. I should mention that besides minor punctuation issues, I did not edit my written conversations with participants I interviewed via instant messenger. Conversations snippets quoted in the analysis chapters consist of participants’ original words with clarifying notes from me in [brackets] when needed.

Data Collection

Phase I recruitment questionnaire.

This study had three data collection phases: recruitment screening, an initial interview, and an exit interview. Phase one started in August 2014 and continued until early January 2015. During phase one, prospective participants completed a recruitment questionnaire which asked general
questions about the person’s adaptation, modification, and design-like activity experience, impairment, and level of independence. I created both Qualtrics and MS Word versions of the questionnaire. I sent the Qualtrics version to potential participants after they contacted me via email and expressed interest in the study. I told prospective participants they could request the MS Word version in my response email which included a link to the Qualtrics version. Once an individual completed recruitment questionnaire, I reviewed their responses to make sure the person met the inclusion criteria. If someone completed the questionnaire and met the inclusion criteria, I invited him or her to participate and set up the initial interview.

I used each participant’s answers on the recruitment questionnaire to adapt the original phase II interview protocol. I paid attention to the types of practices respondents said their adaptation, modification, and design-like activities enabled them to do, details about their impairment, and how often they asked for assistance in their daily lives. I altered questions for each phase II interview protocol to ask participants about their answers to relevant recruitment questionnaire prompts. For participants recruited via YouTube and online forums, I reviewed some of their adaptation, modification, and design-like activity-related online content before the first interview and altered a couple of protocol items to make sure that we discussed this content as well. Appendix A lists the items on the original recruitment questionnaires and their purpose.

**Phases II and III: Participant interviews.**

Scholars caution researchers conducting phenomenological research to allow the essence of the phenomena to emerge from rich descriptions rather than presupposing them (Groenewald, 2004). Some also recommend multiple interviews with participants to elicit a richer and more nuanced account of the phenomenon from each participant (Creswell, 2007; Smith & Fowler, 2009). The second and third phases of data collection consisted of separate semi-structured interviews.
Separating the interviews into two phases instead of conducting one extended interview had several benefits. First, it allowed me to review the transcript from the first conversation with a participant and identify aspects of his or her adaptation, modification, and design-like activities and the practices they enable to discuss further. Second, it gave me the opportunity to formulate follow-up questions that I did not ask or consider during the first interview. Third, it gave the participant an opportunity to reflect on the topic and provide additional experiences or clarifying details during our second interview. Finally, conducting two interviews instead of one changed the nature of the demands I asked participants to meet. Instead of asking them for two or more hours of their time in one sitting, I requested two separate 45-minute to one-hour interviews. Although the average length of time I spent with participants turned out to be two-and-a-half hours, which was a bit longer than expected, I distributed it over two sessions which reduced time participants needed to devote to a single interview session.

I used semi-structured interview protocols for the phase I and II interviews for two primary purposes: to make sure that we covered high priority topics and to keep the conversation from going too far afield. As often as possible, I refrained from asking questions from the protocol and instead allowed participants to talk without interrupting them. Some participants needed fewer prompts than others, and I tended to rely on the protocols more with participants who spoke less. Whenever I asked questions, I tried to follow the guidance of phenomenological researchers who suggest avoiding asking ‘why.’ "Why" questions shift the conversation away from describing experiences to confirming hypotheticals or theoretical assertions (Pollio et al., 1997). Although I kept these questions to a minimum, there were times when I used them to get the interviewee to provide more details. Participants who naturally talked more tended to cover different aspects of their adaptation, modification, and design-like
activity without being prompted to do so, especially during the first interview. The types of questions these participants ran with included the following: 1. Are there aspects of your daily life that you find challenging?; 2. Do you have adaptive practices or tools for dealing with these [challenging] aspects of your life?; and 3. Walk me through a typical day for you from the time you get out of bed until the time you go to sleep? In full disclosure, I only used the first question above with all participants regardless of the interview platform. The second question was for non-instant messenger interviewees only and the third one for face-to-face interviewees only. However, irrespective of the platform, questions like these encouraged some participants to share things about their experiences and insights that I touched on in the interview protocol as well as subjects I had no intentions of covering but found insightful and relevant to the conversation.

**Phase II initial interview.**

The second phase of data collection consisted of a semi-structured introduction interview intended to elicit descriptions of participants’ adaptation, modification, and design-like activity and related daily life practices. The phase always started with a check to ensure the participant completed the informed consent procedure. I sent a link to the Qualtrics-based informed consent survey 12-24 hours before the first session to give participants a chance to read and ask questions at their leisure. Before starting the interview, I would confirm whether the individual I was about to interview had given consent and give them a chance to do so if they had not already. Next, I briefly described the research and tried to give the person a sense of what to expect during the interview. I asked for their permission to record the session and then started the discussion. Some questions asked participants to expand on recruitment questionnaire responses. At times, I would ask them to expand on life hacking-enabled practices they alluded to in their questionnaire responses but had not yet mentioned during the interview. I also inquired about the different
types of assistance they received in their daily lives. We often discussed problem-solving approaches and the role of allies and co-participants in adaptation, modification, and design-like projects. Another major topic we discussed was discovering and sharing adaptation, modification, and design-like activity experiences as well as any social interactions connected to those experiences. I usually asked follow-up questions throughout the interview, but sometimes I reserved one or two of them for the end of our session.

As I mentioned earlier, the phase II interview protocol questions factored into the conversation differently based on the interviewee and his or her willingness to talk without being prompted to do so. Once the interview ended, I told the participant about the referral system and answered his or her questions, if applicable. Initial interviews lasted approximately one hour and sixteen minutes on average across all interview platforms (see table 9 above). I conducted the first phase II interview on September 18, 2014, and the final one on January 24, 2015. Appendix B lists each phase II initial interview protocol question and its purpose by topic and platform.

**Phase III exit interview.**

Next, I conducted a second semi-structured interview with each participant during the third data collection phase. This conversation tended to be a bit more structured than the first one for all participants. I asked additional questions and sought clarification and elaboration on points mentioned during our first discussion. After the first interview, I would review the transcription or audio recording to identify salient points to probe on during the exit interview. In the same way questionnaire responses shaped some of the phase II interview protocol questions, the initial interview conversation informed the phase III interview protocol questions. For instance, when I reviewed the transcripts or audio recording of our first conversation, I always listed all the adaptation, modification, and design-like activities/outcomes a participant talked about during
our conversation. I usually started the exit interview by naming most if not all the adaptation, modification, and design-like activities and outcomes we discussed previously. I also used details participants shared about their adaptation, modification, and design-like activity experiences during the first interview to frame some of my questions for the second one. I primarily used the exit interview to dig into the labels and meanings participants attributed to their adaptation, modification, and design-like activities as well as their related collaboration and sharing activities. Exit interviews lasted approximately one hour and four minutes on average across all interview platforms (see table 9 above). Appendix C lists all the phase II exit interview questions and their purpose by topic and platform.

**Phase III: Co-participant interview**

One participant allowed me to interview an ally who assisted with many of her adaptation, modification, and design-like projects. I interviewed the participant’s husband after interviewing her twice. The purpose of interviewing both individuals independently was to reduce the chances of one person influencing the other and increase the likelihood that both parties would be open and transparent with me. I asked questions intended to elicit the co-participant’s accounts of their collaborative adaptation, modification, and design-like activity experiences. Although I prepared and utilized a semi-structured interview, my conversation with the co-participant primarily consisted of me listening to him and following up with a protocol question twice. He covered almost everything in the protocol without being prompted to do so.

As the person who did a lot of the physical labor that went into developing the participant’s adaptation, modification, and design-like activity outcomes, the co-participant shared new and different details about their collaborative efforts. Descriptions provided by the co-participant supplemented those provided by his wife. I did not regard data collected from the
co-participant as more authoritative than what my participant said during our interviews. Instead, the co-participant interview uncovered different dimensions of the participant’s level of independence and adaptation, modification, and design-like activities as well as the nature of their collaborative projects. Appendix D lists all the phase III exit interview questions and their purpose by topic and platform. Image 3 below depicts all the data collection phases described in this section.
Image 3: Study Procedure with Data Collection Phases
Data sources.

One data source for this dissertation research study was questionnaire response data. Questionnaire responses from all actual and potential study participants informed both the selection of participants and phase II interview questions. The interviews led to the production of the second data source, interview transcripts. There was no need to transcribe the instant messenger-facilitated interviews since they were already in text form. I audio recorded all participant and co-participant face-to-face, telephone, and video chat interviews with a Sony digital audio recorder.

I transcribed one phase I face-to-face interview and then hired and paid a transcriptionist. It took me a long time to transcribe my first interview and hiring a transcriptionist allowed me to use my time reviewing and analyzing the data instead of spending inordinate amounts of time transcribing audio recordings. The second benefit was practicality. Although the transcription process can both aid analysis, shape future data collection, and expose the researcher to the terminology each participant uses, carefully reading the transcripts provided the same benefits. I read, annotated, and took notes on the interview transcripts while moving forward with data collection. I would not have been able to do this within a reasonable amount of time without hiring a transcriptionist. Additionally, I would not have been able to transcribe each participant’s phase II interview before conducting the exit interview without a long delay between both events. The third benefit was the ability to include more people in the study. Data collection started with the August 2014 release of the paper-based survey questionnaire and ended with the final phase II interview on January 24, 2015. Since I could record an interview, submit it to my transcriptionists, and receive the transcription within 1-2 weeks, it was easier to plan, schedule, and conduct more interviews within the five-month data collection period.
I supplemented interview transcripts with a third data source: photos of participants' adaptation, modification, and design-like activities, outcomes, and everyday environment(s). Initially, I planned to require adaptation, modification, and design-like activity walkthroughs from all face-to-face participants which I was going to video record. However, I later decided to drop the walkthroughs and ask for photographs instead. I decided against walkthroughs because they would have placed additional demands on participants and there was no guarantee the demonstrations would have told me anything about the phenomenon of adaptation, modification, and design-like activity by individuals with disabilities. Also, asking participants to demonstrate something seemed too intrusive and subject to the Hawthorne effect, or the tendency of humans to alter their behavior when they know someone is observing them (Adair, 1984). Although walkthroughs might have uncovered aspects of adaptation, modification, and design-like activity that I could have probed on in the interviews, the additional demand it would have placed on participants was not worth the potential benefit. I asked all participants to share pictures of their adaptation, modification, and design-like activity outcomes but made doing so optional. I also asked if I could take pictures of specific adaptation, modification, and design-like activity outcomes when I visited participants' home or office to conduct interviews. I did not obtain many pictures from participants. Nevertheless, the photos I did receive or take serve as visuals in the analysis chapters later in this document.

The fourth data source was my field notes which I maintained throughout the data collection and analysis process. My field notes served several purposes. First, I recorded notes, observations, pertinent reminders, and reflections in my field notes. Sometimes I took notes on participants, interview settings, salient statements made during interviews, participant adaptation, modification, and design-like activity outcomes, and insights and thoughts that came to mind as I
analyzed the data. I also recorded things I wanted to revisit with participants during the second interview, ideas, and my own biases, reflections, challenges, frustrations, and role and impact as a research instrument. My field notes proved valuable when talking to participants during the first and second interviews as well as during data analysis and manuscript writing.

The fifth data source was secondary data which I found before the study started or co-/participants shared with me. I built a database of YouTube content creators with disabilities who had adaptation, modification, and design-like activity content on their channels before this study started. Sometimes I referred to information in that database when talking to participants I recruited on YouTube. I usually searched for photographs, instruction manuals, how-to guides, YouTube videos, Pinterest posts, public Facebook groups, online forums, tool and product descriptions, companies, and organizations mentioned by co-/participants or implicated in their adaptation, modification, and design-like activities. I also collected resources related to disability and impairment from gate-keepers. Whenever possible, I used secondary data sources to develop more informed questions or describe things participants mentioned during the interviews. If participants referred me to their Facebook page or other social media accounts, I asked for permission to use adaptation, modification, and design-like activity outcome photos in this dissertation if I saw them.

The sixth and final source of data was existing literature on hacker culture. I reviewed these literature streams to understand and explain the activities, associated meanings, and motivations of hackers. I used the literature I found to talk about some of the parallels between participant adaptation, modification, and design-like activity and hacker culture. Tables 10, 11, and 12 shows how each data source informed the research questions.
<table>
<thead>
<tr>
<th>Research Question</th>
<th>Recruitment Questionnaire</th>
<th>Participant Interview Transcripts</th>
<th>Co-Participant Interview Transcripts</th>
<th>Photos</th>
<th>Field Notes</th>
<th>Secondary Data</th>
<th>Extant Hacker Literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How do individuals with mobility or dexterity impairments work alone or with allies (if applicable) to make everyday life practices more accessible? (Empirical)</td>
<td>basic profile /w participants' adaptation/ modification/ design-like activities, practices, and general level of independence</td>
<td>discuss adaptation/ modification/ design-like activities, practices, and related accessibility/ impairment related concerns</td>
<td>perspective of someone involved in participant's adaptation/ modification/ design-like activities efforts</td>
<td>n/a</td>
<td>list/descriptions of similarities/differences among participants and adaptation/ modification/ design-like activities</td>
<td>illustrations of aspects of co-participants' adaptation/ modification/ design-like activity efforts</td>
<td>n/a</td>
</tr>
<tr>
<td>1.1 What kinds of accessibility-related solutions do participants develop and leverage in their daily life activities?</td>
<td>identify different types of practices that necessitated participant adaptation/ modification/ design-like activities</td>
<td>discuss participant adaptation/ modification/ design-like activities and practices</td>
<td>n/a</td>
<td>n/a</td>
<td>record emergent thoughts about adaptation/ modification/ design-like activity-related themes and insights throughout study</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>1.2 How do participants conceptualize and describe their efforts and solutions?</td>
<td>n/a</td>
<td>discover how participants labeled and framed their adaptation/ modification/ design-like activities efforts</td>
<td>n/a</td>
<td>n/a</td>
<td>keep track of similarities/ differences in ways of discussing/ framing adaptation/ modification/ design-like activity</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>1.3 What roles do co-participants/ allies play in their collaborative attempts to make practices accessible?</td>
<td>discover how much assistance participants needed /w adaptation/ modification/ design-like activities and practices</td>
<td>discover different roles co-participants played in practices and adaptation/ modification/ design-like activities</td>
<td>supplement participant accounts of effort distribution /w account of co-participant</td>
<td>n/a</td>
<td>keep track of similarities/ differences in ways co-participants framed collaborative adaptation/ modification/ design-like activities</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>---------------------------------------------------</td>
<td>---------------------------------------------------</td>
<td>---------------------------------------------------</td>
<td>n/a</td>
<td>review resources co-participants mentioned or shared during interviews (e.g., photographs, instruction manuals, how-to guides, YouTube videos, social media, tool and product descriptions, companies, and organizations etc.)</td>
<td>n/a</td>
<td></td>
</tr>
</tbody>
</table>

| 1.4 What material objects, mechanisms, and entities facilitate or impede participant effort to make daily life practices more accessible? | n/a | give participants opportunity to disclose what enabled/impeded their ability to engage in adaptation/ modification/ design-like activities | supplement participant accounts of adaptation/ modification/ design-like activity facilitators/impediments with co-participant account | n/a | n/a | n/a |
### Table 11 - Purpose/Use of Data Source (RQ2)

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Recruitment Questionnaire</th>
<th>Participant Interview Transcripts</th>
<th>Co-Participant Interview Transcripts</th>
<th>Photos</th>
<th>Field Notes</th>
<th>Secondary Data</th>
<th>Extant Hacker Literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. How are individuals with mobility or dexterity impairments disabled or enabled in their daily life practices? (Theoretical)</td>
<td>identify participants' impairment(s)</td>
<td>ask participants about adaptation/ modification/ design-like activities and practices. Capture participant descriptions of their adaptation/ modification/ design-like activity outcomes and related practices</td>
<td>supplement participant accounts of their adaptation/ modification/ design-like activity efforts and outcomes with co-participant accounts</td>
<td>offer visual examples of adaptation/ modification/ design-like activity and practice theory-related findings</td>
<td>record practice theory-related insights discovered throughout study</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>2.1 How do various human and non-human agencies simultaneously constitute everyday practice activities and interact with the mental and bodily activities of individuals with mobility/dexterity impairments?</td>
<td>n/a</td>
<td>look for evidence of practice theory elements</td>
<td>n/a</td>
<td>review photos for evidence of adaptation/ modification/ design-like activity outcome features/affordances and other aspects that support practice-related aspects of co-/participant accounts</td>
<td>record significant statements from co-/participants and emergent insights about constitutive elements of adaptation/ modification/ design-like activity-enabled practices</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Question</td>
<td>Action 1</td>
<td>Action 2</td>
<td>Action 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.2 How are bodies, minds, objects, and knowledge/know-how implicated in the everyday practice activities of individuals with mobility or dexterity impairments?</td>
<td>discover nature of participants' impairments (used to formulate additional questions)</td>
<td>identify who/what participants attributed agency to when talking about their adaptation/modification/design-like activities/outcomes and related practices. Tag instances of practice theory constructs in data</td>
<td>review transcripts for supporting/additional evidence of practice theory elements to supplement participants' accounts</td>
<td>examine photos for confirmatory evidence of interconnections among practice theory elements</td>
<td>delineate/describe relations among practice theory elements and various human and non-human agents co-participants associated with adaptation/modification/design-like activity and related practices</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>
**Table 12 - Purpose/Use of Data Source (RQ3)**

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Recruitment Questionnaire</th>
<th>Participant Interview Transcripts</th>
<th>Co-Participant Interview Transcripts</th>
<th>Photos</th>
<th>Field Notes</th>
<th>Secondary Data</th>
<th>Extant Hacker Literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 How do relational aspects of participants’ accessibility-related activities and related daily life practices constitute those practices?</td>
<td>n/a</td>
<td>discuss people, entities, groups, resources, etc. implicated in participants’ their accounts of their adaptation/ modification/ design-like activity efforts</td>
<td>supplement participant accounts with co-participant accounts of people, entities, groups, resources, etc. implicated</td>
<td>n/a</td>
<td>n/a</td>
<td>supplement co-participant accounts of social aspects of adaptation/ modification/ design-like activity with details about the people, entities, groups, etc. they mentioned</td>
<td>identify themes, ideas, and mindsets common among hackers to be used in analysis</td>
</tr>
<tr>
<td>3.1 What groups, entities, and resources do individuals with mobility and dexterity impairments engage in or make use of as it relates to their accessibility projects?</td>
<td>n/a</td>
<td>identify people, places, resources, etc. participants mentioned and linked to their adaptation/ modification/ design-like activities</td>
<td>supplement participant accounts of people, places, resources, etc. implicated in their adaptation/ modification/ design-like activities with those included in co-participant accounts of those activities</td>
<td>n/a</td>
<td>n/a</td>
<td>look up the people, places, resources, etc. co-participants mentioned using the Internet. Ask participant additional questions and provide examples in the analysis write-up</td>
<td>n/a</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Section</th>
<th>Question</th>
<th>Task 1</th>
<th>Task 2</th>
<th>Task 3</th>
<th>Task 4</th>
<th>Task 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.2</td>
<td>Who do individuals with mobility and dexterity impairments interact with concerning their accessibility project-enabled practices other than allies?</td>
<td>n/a</td>
<td>identify people who played a role in participants' adaptation/ modification/ design-like activity efforts other than co-participants</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>3.3</td>
<td>What roles do individuals other than allies play in accessibility projects?</td>
<td>n/a</td>
<td>identify people other than co-participant who motivated/ discouraged co-participants, shaped I adaptation/ modification/ design-like projects, or had a impact on participants' lives as individuals who get involved in these projects</td>
<td>n/a</td>
<td>n/a</td>
<td>delineate and describe the specific roles people other than co- participants played in adaptation/ modification/ design-like project efforts</td>
</tr>
<tr>
<td>3.4</td>
<td>What meanings do individuals with mobility/dexterity impairments ascribe to the various agencies implicated in their daily life practices?</td>
<td>n/a</td>
<td>identify meaning and motivations participants attributed to people, objects, and actions associated with their adaptation/ modification/ design-like activity efforts</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>
Data Analysis

The study described in this dissertation is phenomenological primarily from a philosophical perspective. By this, I mean it is underpinned by phenomenological ideas from the existential tradition. More specifically, existential phenomenology views everyday life as the source of ontological understanding (Heidegger, 1962) and the body as a necessary entity to understand the world and the lived experience of someone in it (Merleau-Ponty, 1964). Although I followed popular phenomenological guidance to analyze some of the data, it is important to note that my study explored multiple dimensions of adaptation, modification, and design-like activity. The common thread among these dimensions was the centrality of the phenomenon, impaired bodies, lived experiences, and everyday life. In the words of Groenewald, I focused on the lived experiences of my participants with the issue researched (adaptation, modification, and design-like activity) (Groenewald, 2004). I always attempted to bracket out my personal views and preconceptions and often delineated appropriate units of meaning and then clustered them to form themes (Hycner, 1985). However, the data analysis process varied based on the research question I tried to answer.

For this study, I used inductive coding methods as my primary analytic tool. Coding is one aspect of qualitative data analysis that consists of assigning a word or phrase to a portion of text that captures its summative meaning, salience, essence, or evocativeness (Saldaña, 2013). The researcher/analyst generates and assigns these codes with the intent of symbolizing and attributing meaning to data for later stages of the analysis such as pattern detection, categorization, and theory building (Saldaña, 2013). Content analysis seeks to derive and describe the meaning of text (Krippendorff, 1980). Qualitative content analysis methods represent systematic ways of describing the meaning of text by applying a pre-determined set of
codes, often derived from existing literature, to related parts of the text to aid in description (Saldaña, 2013). Inductive codes, on the other hand, come from the text itself. An inductive code is a word or short phrase from the actual language used by participants and recorded in qualitative data such as interview transcripts (Saldaña, 2013). Inductive coding also goes by the name of in vivo coding, and it is particularly useful in studies that seek to give voice to the research participants (Saldaña, 2013).

I conducted four separate analyses of recruitment questionnaires and transcribed co-participant interviews. I also constructed short biographies for each participant. I used Hycner’s simplified phenomenological interview analysis process and took field notes to develop a complete picture of the phenomenon grounded in its context (Hycner, 1985). Hycner’s (1985) method consists of investigating the constituent elements of a phenomenon while keeping the context of the overall phenomenon in view. The purpose of this analysis was purely phenomenological and thus warranted use of Hycner’s method. The goal was to identify and describe the essence of participant adaptation, modification, and design-like activity from the perspective of participants. A second analysis was deductive and involved looking for evidence of practice theory constructs in the interview transcripts and then fleshing out the relationships between those constructs. I essentially conducted a content analysis leveraging several sensitizing constructs that are common across practice theory perspectives as well as others that are unique to Latourian Actor-Network Theory. This method allowed me to describe the interactions between objects, impaired bodies, and various human and non-human agencies that constituted participant’s daily life practices and product consumption activities. The third analysis allowed me to identify and delineate the adaptation, modification, and design-like activity categories discussed in chapter five. I used a combination of content analysis and
eclectic coding for this task. For the content analysis, I used constructs developed by an ICT domestication researcher to describe different types of innovative ICT use by consumers (Haddon, 2005). The chosen constructs could be applied to the innovative use of other types of technology as well, including many participant adaptation, modification, and design-like activities that involved the creation or modification of objects. Additional inductively-derived codes allowed me to categorize adaptation, modification, and design-like activities that did not fit into pre-defined ones and flesh out the details of all categories. For the fourth analysis, I used an eclectic coding scheme to identify and describe social aspects of adaptation, modification, and design-like activities evident in participant descriptions of their related efforts and the practices that necessitated them. Eclectic coding allowed me to use several different coding methods without restrictions on what could emerge from the data. My selection of coding methods afforded the emergence of participant voices, salient topics, and eventually, meta-codes that captured diverse social aspects of adaptation, modification, and design-like activity. Table 13 below provides a summary of the different analysis procedures by chapter and topic.

I combined both interview transcripts for each participant into one file before conducting the analyses described in this section. I used both Atlas.ti and Microsoft Excel to do the analyses. I primarily used Atlas.ti to conduct first cycle coding and Excel to conduct second cycle coding and identify themes. While Atlas.ti made it easier for me to both organize the data and keep all my analytical memos in one place, the volume and diversity of codes generated during the first cycle made using Atlas.ti or further analysis challenging. In hindsight and after reviewing several YouTube videos on this subject, I realize I could have completed second cycle coding using Atlas.ti, and it probably would have been more efficient. Nevertheless, Excel allowed me to
extract codes and quotations specific to one topic and organize, group, label, and display data in ways that facilitated the analyses.

**Table 13 - Data Analysis Goals and Approaches**

<table>
<thead>
<tr>
<th>Chapter 4: Participant Profiles</th>
<th>Chapter 5: Participant Adaptation, Modification, &amp; Design-Like Activity</th>
<th>Chapter 6: Adapt/Mod/Design-Like Activity -Enabled Practices</th>
<th>Chapter 7: The Sociality of Participant Adapt/Mod/Design-Like Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal:</strong></td>
<td><strong>Coding Methods</strong></td>
<td><strong>Coding Methods</strong></td>
<td><strong>Coding Methods</strong></td>
</tr>
<tr>
<td>Describe participants and general characteristics about them and their unique adapt/mod/design-like activities</td>
<td>Attribute</td>
<td>Hypothesis, Descriptive, Axial</td>
<td>Hypothesis, Descriptive, Process, Axial</td>
</tr>
<tr>
<td>Define and categorize participant adapt/mod/design-like activities</td>
<td>Hypothesis, Descriptive, Axial</td>
<td>Identify essences of participant adapt/mod/design-like activities and enabled practices</td>
<td>Identify/describe adapt/mod/design-like activity-related social negotiations and interactions</td>
</tr>
<tr>
<td>Identify essences of participant adapt/mod/design-like activities and enabled practices</td>
<td>Identify participants’ daily life practices involving adapt/mod/design-like activity outcomes through the lens of practice theory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Examine participants’ daily life practices involving adapt/mod/design-like activity outcomes through the lens of practice theory</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Participant profiles.**

One of the first things I did to the transcribed interviews and participant recruitment questionnaires after importing them into Atlas.ti was to content analyze them to identify and code characteristics about the participants. Attribute coding entails logging demographic and other significant participant characteristics for later management and reference (Saldaña, 2013). Common attribute coding categories included age, gender, ethnicity, and interview time frame (date/time). Additionally, I tagged impairment type, formal disability, date of impairment/disability onset, participant geographic location, interview format (F2F, phone, video chat, IM), and setting for face-to-face interviews. I used the data I tagged with these attribute codes to construct each participant profile in chapter four. I did not ask participants about their race and age during the data collection phase although most of them disclosed these details without me.
asking. I reached out to participants who did not share these details during the data collection phase eight months after it ended.

I content analyzed the transcribed interviews to identify, code, group, and explicate participants’ adaptation, modification, and design-like activity. First, I identified participant descriptions of adaptation, modification, and design-like activities they created or leveraged. Data analysis consisted of both inductive and deductive coding. I used four constructs from Haddon's Types of Innovation framework as deductive codes to capture the different types of adaptation, modification, and design-like activities that involved objects. Haddon’s framework is specific to ICTs and the adaptation, modification, and design-like activities participants discussed either transcended technology types or did not involve objects at all. However, as table 14 below illustrates, certain constructs from this framework can be used to describe other forms of technology-enabled innovations without losing their meaning. The grounding for the framework is consumer/user creativity as exemplified in the innovative ways people use ICTs in their daily lives (Haddon, 2005). The focus on ICTs makes sense given the fact that domestication researchers focus specifically on the adoption and use of ICTs in people’s daily lives. Nevertheless, this framework categorizes some of the ways potential users may relate to and interact with ICTs as well as how innovative use fits into the broader innovation landscape (Haddon, 2005). It accounts for the reality that all users are not the same and the activities of those who innovate are commensurate with their capabilities, skills, and interests.

Haddon's framework categorizes ICT design/redesign/use activities into four levels. The first level consists of highly technical projects and people such as skilled technical hobbyists who historically worked on early microcomputer projects and devised innovations that we now refer to as hacks. The second level includes hobbyists who participate in new practices and new ICT-
enabled activities such as early radio broadcasters who used ham radios. The third level includes people with less technical expertise who do things such as add content to public or personal web pages. Like the second level, the fourth is practice/activity oriented. Unlike the second, the fourth includes non-technical hobbyists. Example level four ICT-enabled practices and activities include using the telephone, and much later SMS messaging for social purposes back when few people regarded them as social tools (Haddon, 2005).
<table>
<thead>
<tr>
<th>Level</th>
<th>Category</th>
<th>Definition</th>
<th>Core Activity</th>
<th>Required Technical Skills</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Redesign</strong></td>
<td>Re-designing ICTs, improving existing applications</td>
<td>Technical Manipulation</td>
<td>High</td>
<td>Hobbyists, users, designers, game modders, lead users&quot;</td>
</tr>
<tr>
<td></td>
<td><strong>Design</strong></td>
<td>Designing ICTs, developing new applications.</td>
<td></td>
<td></td>
<td>Designer/user, early hackers, open source software developers</td>
</tr>
<tr>
<td>2</td>
<td><strong>New Practices</strong></td>
<td>Developing new practices using ICTs, creating new content or establishing new patterns of interaction</td>
<td>Practices/Activities</td>
<td>Moderate to High</td>
<td>Early ham-radio operators (playing music over the airwaves before radio broadcasting was popular), Machinima film producers</td>
</tr>
<tr>
<td>3</td>
<td>Content Creation</td>
<td>Design activities such as the website content creation and placement as well as website design</td>
<td>Technical Manipulation</td>
<td>Low to Moderate</td>
<td>Creators of personal home pages, club/association web pages prepared by members</td>
</tr>
<tr>
<td>4</td>
<td><strong>Pattern of Use</strong></td>
<td>The emergence of new patterns of use or new practices within the wider public or subgroups of it</td>
<td>Practices/Activities</td>
<td>Low</td>
<td>Early adopters of telephone for social purposes; social practices emerging around SMS/text messaging</td>
</tr>
</tbody>
</table>

**Bolded** constructs influenced initial coding
I derived adaptation, modification, and design-like activity categories by first identifying each instance of an activity or an outcome of that activity in the data. Next, I coded instances using the design, redesign, new practices, and pattern of use from the Types of Innovation framework (content analysis). Next I inductively derived and defined new constructs for a subset of the remaining adaptation, modification, and design-like activity instances that did not fit into the predetermined categories. I tagged the remaining instances with these new codes. The category definition work consisted of axial coding or describing the properties of each adaptation, modification, and design-like activity category, delineating subcategories, and describing the relations between categories and sub-categories (Saldaña, 2013). Axial coding happened throughout both coding processes. I refined construct names and definitions based on characteristics of the coded instances such as the activities, tools, objects, and skills involved. I refined the definitions of the predetermined constructs multiple times while applying them to the data as well as after I finished the content analysis and inductive coding processes. I developed working definitions of the inductively derived codes based on the subset of instances used to derive them. I refined the definitions after tagging the remaining instances. This process led to the adaptation, modification, and design-like activity categories and definitions defined in chapter five.

**Essences of participant adaptation, modification, and design-like activity.**

The purpose of this analysis was to uncover the essences of adaptation, modification, and design-like activity and the practices they configured. I used the first three steps of Hyner’s simplified phenomenological interview data analysis process. This process entails investigating the constituent components of a phenomenon without divorcing them from the overall phenomenon to identify its essential features and relationships (Groenewald, 2004). The five steps are:
1. Bracketing and phenomenological reduction

2. Delineating units of meaning

3. Clustering units of meaning to form themes

4. Summarizing each interview, validation, and modification (where needed)

5. Extracting general and unique themes from all interviews and making a composite summary

The first step involved identifying and bracketing out my suppositions and interpretations to the best of my ability to see the world through the eyes of my participants. I followed Groenewald’s suggestion to repeatedly listen to each interview to both become familiar with the words the interviewee uses and gain an overall picture of him or her (Groenewald, 2004). As I mentioned earlier, I read each phase II interview transcript before the phase III interview. After both interviews, I read the phase transcripts for each participant and recorded field notes along the way. Field notes included verbatim quotes and terms the participants used when talking about their adaptation, modification, and design-like activities as well as unique aspects of their efforts. I also constructed 2-5 sentence mini-descriptions of each participant after reading his or her interview transcripts.

Delineating units of meaning refers to extracting or isolating statements that seem to elucidate the phenomenon (Groenewald, 2004). It requires both subjective judgment calls in selecting and weighting appropriate units of meaning and intentional bracketing on the part of the researcher. I conducted this step using Atlas.ti. My first cycle of coding was eclectic and consisted of descriptive, values, and versus coding. The descriptive codes captured different topics related to adaptation, modification, and design-like activity. Value codes reflected participants’ values, attitudes, and beliefs related to adaptation, modification, and design-like
activity, disability, and daily life. Versus codes identified conflicts and multiple ways participants saw or described the same thing (Saldaña, 2013). During first cycle coding, I tagged words, phrases, sentences, and paragraphs in the interview transcripts that seemed to illuminate different aspects of adaptation, modification, and design-like activity. Next, I reviewed the tagged content and inductively derived my codes using one of the combined interview transcripts. When I coded a new transcript, I simultaneously used my existing codes and derived new ones. At times, I returned to previously coded interviews to apply newer codes that more accurately described something about the phenomena. After coding three full interviews, I had several codes that I used consistently for the remainder of the first cycle coding process. However, there were times when I had to update my coding frame and revisit previously analyzed interviews because of the emergence of a new code. I also did some in vivo coding during the first cycle process to capture words and phrases that offered insight into participants’ worldview and ways of talking about their adaptation, modification, and design-like activities. To do this, I looked for words and phrases that caught my attention such as metaphors, similes, evocative word choices, and ironic, witty, and repetitive statements (Saldaña, 2013).

After coding all the combined interview transcriptions, I reviewed all my codes to delete redundancies, combine related topics, and begin defining some of the coded units of meaning. I used both the memo writing and code manager features in Atlas.ti for this process. I would look at quotations for a given code and jot down any preliminary themes. Next, I engaged in second-cycle process coding which consisted of looking across participants to identify the essences (Saldaña, 2013). To do this, I exported all my codes along with the tagged portions of the interview transcripts to Excel where I developed meta-codes for similarly coded data. In some cases, I developed new codes that better captured related snippets from the interviews. In other
instances, I refined or expanded one or more of the first-cycle codes. The resultant pattern codes captured themes and explanations in the data which I turned into statements and then expanded on in the analysis presented in chapter five.

**Participant adaptation, modification, and design-like activity-enabled practices.**

The purpose of the practice theory analysis was to explore the how and why behind participant adaptation, modification, and design-like activity and the practices it enabled from a theoretical perspective. For this analysis, I used deductively-derived and process codes. I used sensitizing constructs from contemporary practice theory approaches articulated by Andreas Reckwitz and Theodore Schatzki as well as constructs specific to Latourian actor-network theory to guide the analysis. I applied these codes to segments of interview transcripts where participants described different practices. Table 15 lists and describes the practice theory constructs that guided this part of the analysis. Additionally, I tagged all co-/participant action in the data using process codes, or gerunds (-ing words). Process coding captures both observable action (such as eating) and conceptual action (such as wrestling with something) (Saldaña, 2013). Process coding allowed me to analyze the ongoing adaptation, modification, and design-like activity-related actions and interactions co-/participants took in response to problems (e.g., practice breakdowns or accessibility issues) to reach a goal or handle a problem (Corbin & Strauss, 2008; Saldaña, 2013).
After using Atlas.ti to code practice-related words, phrases, and sentences in the transcripts, I downloaded my codes and quotations into Excel to conduct further analysis. I used spreadsheets to organize, sort, and group the quotations. Next, I used axial coding to describe both how each practice theory construct fitted the quotations used to tag them and the different relationships between the constructs and associated quotations. To facilitate axial coding, I grouped process codes for related adaptation, modification, and design-like activity-enabled

<table>
<thead>
<tr>
<th>Construct</th>
<th>Description</th>
<th>Source</th>
</tr>
</thead>
</table>
| Body           | -Carrier of social practices  
-Site where physical and mental activity occur  
-Co-agent in meeting demands practices place on practitioner/agents  
-End' result of previous practice performances                                                                 | (Reckwitz, 2002; Schatzki, 2005)             |
| Bodily Activity| -Routinized movement and utilization demands placed on all human bodies that engage in a practice (i.e., you must press keys to type on a keyboard and it is somewhat expected that most people type with their fingers) | (Reckwitz, 2002; Schatzki, 2005)             |
| Knowledge      | -Historically and culturally shaped intentionality (understanding/desiring)  
-Tacit or formal knowledge embodied in humans or embedded in objects  
-The interconnection between understanding, desiring, and interpreting with bodily activity and the other elements of practice | (Reckwitz, 2002)                            |
| Individual     | -Human agent who serves as the crossing point for bodily and mental activities/performances  
-Carries and “takes over” mental bodily activity  
-Agent who "Takes over" routinized bodily activity | (Reckwitz, 2002; Schatzki, 2005)             |
| Object         | -Co-agent/practitioner in meeting practice demands  
-Non-human material agents that make a difference in human action | (Latour, 2005)                              |
| Agency         | -What human and non-human agents co-contribute to acts of doing  
-Self-described accounts of who/what makes the social actor act  
-That which produces action and change  
-Anything that "makes a difference in the course of some other agent's actions" is an actor with agency | Latour, 2005                                 |
activities to reconstruct the practices those activities comprised. Doing so made it easier to compare, contrast, and describe actions related to specific practice constructs such as body and bodily activity. The analysis presented in chapter six of this dissertation fleshes out the connections between practice theory constructs for groups of adaptation, modification, and design-like activity-enabled practices. The interactions among practice theory elements as revealed by this analysis provide insights into why participants engage in adaptation, modification, and design-like activity and how this activity configures their daily life practices.

**The sociality of participant adaptation, modification, and design-like activity.**

Chapter seven presents various social aspects of adaptation, modification, and design-like activity discovered during the data analysis process. This part of the analysis consisted of several steps, beginning with a review of the descriptive and in-vivo codes I applied to the data during first cycle coding. While reviewing the codes, I discovered several social topics that I downloaded into an Excel spreadsheet along with the related quotations. Once again, I developed pattern codes for similar topics by either developing new codes that better captured related snippets from the interviews or refining the first-cycle codes. I took the resultant pattern codes and used the participant explanations to which they referred to describe the various social influences and relationships participants connected to their adaptation, modification, and design-like activity efforts.

**Steps taken to maximize research quality.**

Some researchers use the term *validity* to refer to how accurately the explanations in a qualitative research study fit participant descriptions of the phenomenon. Others use the term *credibility* to describe trustworthy and believable findings that reflect participants’ researchers, and readers’ experiences of a phenomenon but represent only one of many ways to interpret the data (Corbin
Regardless of the term used, I followed two widely accepted approaches to ensure the interpretations and findings described in this document represent participants’ way of understanding their adaptation, modification, and design-like activities and related practices. This section describes the two approaches used for this study.

Qualitative researchers can miss the mark when it comes to ensuring the credibility of findings by imposing their personal biases, beliefs, and assumptions throughout the inquiry process. One way to combat against this is journaling or writing memos where the researcher records his or her reactions and feelings throughout the data collection and analysis processes (Carlson, 2010; Corbin & Strauss, 2008). Keeping a record of thoughts and feelings allows the researcher to practice reflexivity and identify potential instances when his or her ways of seeing and understanding the world may differ from the way participants see and describe it. As I mentioned earlier in this chapter, I recorded many of my thoughts, opinions, and interpretations in a journal during the data collection and nascent stages of the data analysis phase. I also wrote several analytical memos during the data analysis phase where I sometimes recorded my assumptions, ways of seeing things, and potential differences between my interpretations and what participants said. I revisited my journal and analytical memos throughout the analysis process, sometimes adding to what I said previously after further reflection. The journal entries and memos were particularly useful when analyzing the data and writing up the results. Both made it easier for me to remain aware of my biases and assumptions and bracket them out of the analysis. The final chapter of this document has a section where I talk about some of the limitations of this study. In this section, I will reflect on what did and did not go well as well as what I will do differently in future research endeavors (Carlson, 2010).
Another way that I tried to enhance the credibility of my findings was through member checking. Member checking involves returning analyzed data to participants to assess and validate the trustworthiness of results (Birt et al., 2016; Carlson, 2010). In other words, member checking ensures the voice of the participants and the researcher are harmonious. The purpose of member checking is to give participants the chance to confirm whether the analysis accurately reflects their experiences. Participants usually receive the opportunity to offer corrections, clarifications, elaborations, or request deletions (Carlson, 2010). Some researchers return interview transcripts to participants for their review while others send polished parts of their analyses. For this study, I sent chapters five through seven to participants along with their specific profile from chapter four. Each participant received an email with copies of his or her profile and chapters six through eight in their entirety. A copy of the member checking email sent to each participant and be found in appendix E. I gave participants approximately six weeks to respond to the email.

Conclusion
In this chapter, I described the recruitment, data collection, and data analysis methods used in this study. My goal was to make my choice and use of methods transparent to the reader of this document. In the following four chapters, I will present the results of my study. Chapter four describes each study participant and gives a broad overview of his or her adaptation, modification, and design-like activity experiences. Chapter five describes the different types of adaptation, modification, and design-like activities participants discussed as well as the phenomenological essences of these activities. Chapter six looks at participants’ adaptation, modification, and design-like activity-enabled practices through the lens of practice theory. Lastly, chapter seven describes several social dimensions of participants’ adaptation, modification, and design-like activities.
Chapter 4: Participant Profiles

Background

This chapter provides brief descriptions of everyone who participated in this study. The purpose of these profiles is to give the reader a sense of who was behind participant adaptation, modification, and design-like activity as well as the practices that necessitated them. This chapter serves as a backdrop for the analyses presented in later chapters.

The profiles below describe each participant and highlight certain aspects of his or her history as an individual with a disability who engages in adaptation, modification, and design-like activity. I recruited seventeen subjects (11 males, six females) between the ages of 19 and 72 with a mean age of 39.9 years old to participate in this study. I removed one subject from the study after his second interview because his adaptation, modification, and design-like activities had more to do with his visual impairment and back issues rather than dexterity or mobility limitations. All 16 participants who met the inclusion criteria lived in the United States (Northeast-6, Midwest-5, Southeast-1, Southwest-1, West-1, Northwest-1, South-1) and had disabilities that affected their mobility, dexterity, or both.

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10 All participant and co-participant names are pseudonyms.
Table 16 - Participant Demographics

<table>
<thead>
<tr>
<th>Name*</th>
<th>Sex</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Impairment Type***</th>
<th>Daily Assistance Needs</th>
<th>Interview Format</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arnold</td>
<td>M</td>
<td>50-64</td>
<td>Native American</td>
<td>Mobility</td>
<td>Sometimes</td>
<td>Phone</td>
</tr>
<tr>
<td>Cecil</td>
<td>M</td>
<td>40-49</td>
<td>Black/African American</td>
<td>Mobility</td>
<td>Not Very Often</td>
<td>F2F</td>
</tr>
<tr>
<td>Deanna</td>
<td>F</td>
<td>18-29</td>
<td>Black/African American</td>
<td>Both</td>
<td>Often</td>
<td>F2F</td>
</tr>
<tr>
<td>Dominic</td>
<td>M</td>
<td>18-29</td>
<td>White/Caucasian</td>
<td>Dexterity</td>
<td>Sometimes</td>
<td>IM</td>
</tr>
<tr>
<td>Erin</td>
<td>F</td>
<td>30-39</td>
<td>White/Caucasian</td>
<td>Both</td>
<td>Very Often</td>
<td>IM</td>
</tr>
<tr>
<td>Grant</td>
<td>M</td>
<td>40-49</td>
<td>White/Caucasian</td>
<td>Both</td>
<td>Often</td>
<td>IM</td>
</tr>
<tr>
<td>Kimberly</td>
<td>F</td>
<td>30-39</td>
<td>Unknown</td>
<td>Both</td>
<td>Very Often</td>
<td>IM</td>
</tr>
<tr>
<td>Leon</td>
<td>M</td>
<td>40-49</td>
<td>Black/African American</td>
<td>Both</td>
<td>Not Very Often</td>
<td>F2F</td>
</tr>
<tr>
<td>Neil</td>
<td>M</td>
<td>18-29</td>
<td>Unknown</td>
<td>Both</td>
<td>Sometimes</td>
<td>F2F</td>
</tr>
<tr>
<td>Ross</td>
<td>M</td>
<td>40-49</td>
<td>White/Caucasian</td>
<td>Mobility</td>
<td>Sometimes</td>
<td>F2F</td>
</tr>
<tr>
<td>Samantha</td>
<td>F</td>
<td>18-29</td>
<td>White/Caucasian</td>
<td>Both</td>
<td>Sometimes</td>
<td>Phone</td>
</tr>
<tr>
<td>Scott</td>
<td>M</td>
<td>65-80</td>
<td>White/Caucasian</td>
<td>Both</td>
<td>Often</td>
<td>Phone</td>
</tr>
<tr>
<td>Sheila**</td>
<td>F</td>
<td>65-80</td>
<td>White/Caucasian</td>
<td>Both</td>
<td>Often</td>
<td>F2F</td>
</tr>
<tr>
<td>Stuart</td>
<td>M</td>
<td>30-39</td>
<td>White/Caucasian</td>
<td>Both</td>
<td>Very Often</td>
<td>Video Chat</td>
</tr>
<tr>
<td>Tabitha</td>
<td>F</td>
<td>18-29</td>
<td>Black/African American</td>
<td>Mobility</td>
<td>Sometimes</td>
<td>IM</td>
</tr>
<tr>
<td>Wallace</td>
<td>M</td>
<td>30-39</td>
<td>White/Caucasian</td>
<td>Both</td>
<td>Very Often</td>
<td>Video Chat</td>
</tr>
</tbody>
</table>

*Participants’ real names are not used in this study.
** Spouse, caregiver, or another ally also interviewed.
***See Tables 17 and 18 for more detailed disability and impairment information

Profiles

Arnold

- Type of interview: Telephone
- Disability: T-5 Paraplegia (Incomplete)
- Impairment(s): Mobility
- Length of time participant has lived with disability: Since March 2010
- Onset of disability: Botched surgical procedure after an injury sustained while cutting down a tree. The botched procedure resulted in his spinal cord injury.
- Participant Description: Arnold is a 50-64-year-old Native-American male who lives in the Northeast. He does not have any motor control from the chest down, but he does have some sensation in that region. Arnold's upper body is fully functional. He uses a power chair for mobility.
- Co-Participant Description: N/A
Adaptation/modification/design-like activity background: Arnold was a DIYer long before his spinal cord injury. After his injury, he joined a Makerspace where he regularly made tools that enabled him to engage in a variety of activities in his daily life. He also made tools that allowed him to use the Makerspace equipment from a seated position in his wheelchair. Arnold’s injury forced him to call professionals for some automotive, home, and other maintenance tasks he could do on his own before his injury. He found it frustrating that he no longer could do tasks that used to be easy for him to do.

Nature of most adaptation/modification/design-like activity: Making things, using objects for alternative/multiple purposes, repairing and maintaining accessibility equipment.

Type of practices adaptation/modification/design-like activity enables: Adaptive rock climbing, operating Makerspace equipment, picking up items on the floor, cleaning pool

Key quote(s): 1. "I would say I’ve developed at least half a dozen to a dozen different solutions to problems that I’ve had. A lot of it is I see something, I figure out what I need to do and I’ll make whatever it is I need. Sometimes it’s just something very simple." 2. "One of the things that I have to do is try to figure out what can I do to make stuff work for me." 3. “That’s part of the whole maker [movement] thing is you make it the first time and you say, OK, this is good, this is good, that’s not so great; let me see what I can do to fix that better."

Cecil

Type of interview: Face-to-Face
Disability: Cerebral Palsy
Impairment(s): Mobility
Length of time participant has lived with disability: Entire life
Onset of disability: Congenital (at birth)
Participant Description: Cecil is a 40-49-year-old African-American male from the Midwest. Cecil has a manual chair and a power chair. He lost the ability to use crutches when a vehicle struck and injured him the year before our interview. Cecil had both a helper and a friend who assisted him with laundry, cooking, and other daily life tasks a couple of times each week. He often performed these tasks himself but utilized the assistance when it was available to him.
Co-Participant Description: N/A
Adaptation/modification/design-like activity background: Cecil “had to learn how to adapt” once he became a "young man" who lived on his own. He has spent over half of his life coming up with individualized solutions and ways of doing things.
Nature of most adaptation/modification/design-like activity: Unique ways of completing tasks and relying on individualized procedures to do tasks
Type of practices adaptation/modification/design-like activity enables: Moving items from one place to another, chores, cooking, going up or down stairs, and maintaining mobility
Key quote(s): 1. "…just move and let me do it how I do it. I’ll get it done." 2. "[Coming up with individualized solutions and ways of doing things] That’s an everyday process."

Deanna

Type of interview: Face-to-Face
Disability: Tuberculosis (TB)
Impairment(s): Mobility and dexterity
Length of time participant has lived with disability: Since she was eight months-old
Onset of disability: Stroke
Participant Description: Deanna is an 18-29-year-old African-American female who lives in the Midwest. She had a stroke when she was eight-months-old. Deanna has not been able to use her left arm or hand since the stroke and experiences some dexterity-related challenges. She also has a minor speech impediment.
Co-Participant Description: Deanna’s father found and acquired various products that she re-appropriated in her daily life practices.
Adaptation/modification/design-like activity background: Deanna relied on her parents a lot when she was younger but sought more independence as she got older. Deanna was engaged to be married when I interviewed her. She was keen on figuring out ways to do things independently for the sake of her future family.
Nature of most adaptation/modification/design-like activity: Relying on individualized procedures to do tasks, re-appropriating objects for alternative/multiple purposes
Type of practices adaptation/modification/design-like activity enables: Chores, reaching objects, dressing, bathing
Key quote(s): 1. "Let me try. If I need help, of course I’ll ask somebody, but I don’t want others to say, ‘let me do this [for you]; I see you struggling.’ Let me try first. Then if I need help I’ll ask you." 2. "…let me try it before I ask because I don’t like everybody doing everything for me."

Dominic
Type of Interview: Instant Messenger (Facebook)
Disability: Cerebral Palsy (CP) and scoliosis
Impairment: Dexterity (primarily) and mobility
Length of time participant has lived with disability: Entire life
Onset of disability: Congenital (at birth)
Participant Description: Dominic is an 18-29-year-old white male who lives in the Midwest. CP affects the left side of his body and primarily manifests itself in intermittent left-hand numbness. Dominic has other conditions that cause physical pain: scoliosis, two herniated disks in his back, arthritis, "bad knees", a "bad leg", and a torn rotator. He described these conditions as the "side effects" of CP.
Co-Participant Description: N/A
Adaptation/modification/design-like activity background: Unknown
Nature of most adaptation/modification/design-like activity: Modifying/fixing objects and relying on individualized procedures to do tasks
Type of practices adaptation/modification/design-like activity enables: Using computers, carrying objects, driving
Key Quotes: 1. "I'll be damned if I let something as trivial as a numb hand stop me." 2. "pretty much anything a healthy person can do, I can do it just taking another path." 3. "My fiancé tells me I'm too stubborn to let anything or anyone keep me from doing what needs done [sic]."
### Table 17 - Participant Disability/Impairment Details

<table>
<thead>
<tr>
<th>Name</th>
<th>Impairment Type</th>
<th>Disability</th>
<th>Cause</th>
<th>Onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arnold</td>
<td>Mobility</td>
<td>T-5 Paraplegia (Incomplete SCI)</td>
<td>Failed surgical procedure</td>
<td>March 2010</td>
</tr>
<tr>
<td>Cecil</td>
<td>Mobility</td>
<td>Cerebral Palsy</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Deanna</td>
<td>Both</td>
<td>Tuberculosis (TB)</td>
<td>Stroke/Exposure to TB</td>
<td>Eight months old</td>
</tr>
<tr>
<td>Dominic</td>
<td>Dexterity</td>
<td>Cerebral Palsy</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Erin</td>
<td>Both</td>
<td>Cerebral Palsy</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Grant</td>
<td>Both</td>
<td>C4 Quadriplegia (Incomplete SCI)</td>
<td>Wakeboarding accident</td>
<td>April 2010</td>
</tr>
<tr>
<td>Kimberly</td>
<td>Both</td>
<td>Cerebral Palsy</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Leon</td>
<td>Both</td>
<td>Cerebral Palsy</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Neil</td>
<td>Both</td>
<td>Cerebral Palsy</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Ross</td>
<td>Mobility</td>
<td>Arthrogryposis</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Samantha</td>
<td>Both</td>
<td>Common Variable Immunodeficiency</td>
<td>Unknown</td>
<td>Toddler</td>
</tr>
<tr>
<td>Scott</td>
<td>Both</td>
<td>Multiple Sclerosis</td>
<td>Unknown</td>
<td>20 years ago</td>
</tr>
<tr>
<td>Sheila</td>
<td>Both</td>
<td>Arthrogryposis</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Stuart</td>
<td>Both</td>
<td>C5/C6 Quadriplegia (Complete SCI)</td>
<td>Traumatic injury (Rugby)</td>
<td>19 years old</td>
</tr>
<tr>
<td>Tabitha</td>
<td>Mobility</td>
<td>Cerebral Palsy</td>
<td>Congenital</td>
<td>Birth</td>
</tr>
<tr>
<td>Wallace</td>
<td>Both</td>
<td>C1-2 Quadriplegia (Complete SCI)</td>
<td>Traumatic injury (Bad fall)</td>
<td>March 1997</td>
</tr>
</tbody>
</table>

**Erin**

- Type of interview: Instant Messenger (Facebook and Google Hangouts)
- Disability: Cerebral Palsy
- Impairment(s): Mobility and Dexterity
- Length of time participant has lived with disability: Entire life
- Onset of disability: Congenital (at birth)
- Participant Description: Erin is a 30-39-year-old female who lives in the Western region of the United States. She uses a power wheelchair and has very limited use of her hands. She is also nonverbal and uses a letter board to spell what she wants to say to people who are physically present. Erin had personal care assistants who helped her with various activities of daily life at the time of our interviews.
- Co-Participant Description: Erin's parents modified things for her when she was younger. She has worked with family members, aides, and others to modify various objects she uses in her daily life practices.
- Adaptation/modification/design-like activity background: Erin said she engaged in this type of activity most of her life.
• Nature of most adaptation/modification/design-like activity: Combining two or more objects to make something useful, making/modifying things, and re-appropriating objects for alternative/multiple purposes
• Type of practices adaptation/modification/design-like activity enables: Communication, arts and craft activities, sex and disability advocacy work
• Key quote(s): 1. "Ha! I just ignore [anything that tries to stop me from doing something] and do what I want to anyway." 2. "We always had the attitude that if something pre-made wouldn’t work, we would just adapt it."
<table>
<thead>
<tr>
<th>Name/ Abbreviation</th>
<th>Description/Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
</tr>
<tr>
<td>Complete spinal cord injury</td>
<td>No motor function or sensation below level of injury</td>
</tr>
<tr>
<td>Spinal cord</td>
<td>The pathway for motor and sensory information that travels between the brain and the body. This information enters and leaves the spinal cord via spinal roots.</td>
</tr>
<tr>
<td>Incomplete spinal cord injury</td>
<td>Absence of some movement or sensation below level of injury</td>
</tr>
<tr>
<td>C</td>
<td>Cervical level of spinal cord (throat area) which contains eight total cervical nerve roots. Seven of these roots (C2-C7) rest just below a corresponding C2-C7 vertebra. C8 exists between the C7 and T1 vertebra and C1 rests between the skull and C1 vertebra.</td>
</tr>
<tr>
<td>T</td>
<td>Thoracic level of spinal cord (torso/middle of body) which contains 12 nerve roots which rest below each respective vertebra</td>
</tr>
<tr>
<td>L</td>
<td>Lumbar level of spinal cord (lower back) which contains 5 nerve roots which rest below each respective vertebra</td>
</tr>
<tr>
<td>Congenital</td>
<td>Birth-related</td>
</tr>
<tr>
<td>Paralysis</td>
<td>Loss or impairment of the ability move or feel anything in one part of the body</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>Loss of the ability to move and/or feel anything in the upper extremities (arms/hands) and lower extremities (legs/feet) due to a cervical level injury to the spinal cord</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>Loss of the ability to move and/or feel anything in the lower extremities (legs/feet) due to a thoracic or lumbar level spinal cord injury</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>Sideways curvature of the spine</td>
</tr>
<tr>
<td>Cerebral Palsy (CP)</td>
<td>Group of neurological conditions resulting from non-progressive brain injury that occurs during or soon after birth. Often affects body movement, muscle control, and balance.</td>
</tr>
<tr>
<td>Diplegia</td>
<td>CP-related impairment that affects legs. May affect both arms as well, but to a lesser extent</td>
</tr>
</tbody>
</table>

11 (Kirshblum et al., 2011)
12 Ibid.
13 Ibid.
14 Ibid.
15 Ibid.
16 Ibid.
17 Ibid.
18 Ibid.
19 (“Scoliosis | Define Scoliosis at Dictionary.com,” n.d.)
20 (“Definition of Cerebral Palsy,” n.d.)
21 (Kent, Ruth M., 2013)
22 (“What is Cerebral Palsy,” n.d.)
<table>
<thead>
<tr>
<th>Name/ Abbreviation</th>
<th>Description/Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemiplegia&lt;sup&gt;23&lt;/sup&gt;</td>
<td>CP-related impairment that affects one side of the body such as the left arm/hand and leg/foot</td>
</tr>
<tr>
<td>Spasticity&lt;sup&gt;24&lt;/sup&gt;</td>
<td>Continuous muscle tone that results in tightness, stiffness, and awkward movement. Spasticity can affect the legs or legs and arms (diplegia), one side of the body such as the left arm and left leg (hemiplegia), or all four limbs (quagriplegia)</td>
</tr>
<tr>
<td>Arthrogryposis multiplex congenital (Arthrogryposis)&lt;sup&gt;25 26&lt;/sup&gt;</td>
<td>Congenital fixation of a joint in either an extended or contracted state. Often associated with muscle weakness</td>
</tr>
<tr>
<td>Common Variable Immune Deficiency (CVID)&lt;sup&gt;27 28&lt;/sup&gt;</td>
<td>An immune system impairing condition that makes one highly susceptible to sickness and infections. CVID has a variety of possible comorbid conditions and rheumatoid arthritis is one of them. Rheumatoid arthritis is a condition that causes chronic and abnormal joint inflammation and the symptoms include hand and/or foot joint pain, swelling, and stiffness.</td>
</tr>
<tr>
<td>Multiple Sclerosis (MS)&lt;sup&gt;29 30&lt;/sup&gt;</td>
<td>A chronic and unpredictable immune-mediated process in which the immune cells are sensitized to attack the central nervous system consisting of the brain, spinal cord and optic nerves. MS symptoms may include blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, and blindness and more. Symptoms may be intermittent or persist and worsen over time.</td>
</tr>
</tbody>
</table>

**Grant**

- Type of interview: Instant Messenger (Citrix GoToMeeting)
- Disability: Quadriplegia
- Impairment(s): Mobility and Dexterity
- Length of time participant has lived with disability: Since April 2000
- Onset of disability: Wakeboarding accident which led to a C4 spinal cord injury
- Participant Description: Grant is a 40-49-year-old male who lives in the Southwest. He is paralyzed from the shoulders down and has limited to no use of his hands. Grant can move his shoulders and biceps, but he does not have functioning triceps. Although he cannot consciously grasp or pinch objects, his hands are usually closed tightly, which makes it possible to push items into his palm and under his fingers. Grant uses a power chair to get around and drives a modified van. His wife assists

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<sup>23</sup> Ibid.
<sup>24</sup> (“Cerebral Palsy Information Page: National Institute of Neurological Disorders and Stroke (NINDS),” n.d.)
<sup>25</sup> (“Medical Definition of Arthrogryposis,” n.d.)
<sup>26</sup> (Meissner et al., 2017)
<sup>27</sup> (Genetics Home Reference, n.d.)
<sup>28</sup> (Reference, n.d.)
<sup>29</sup> (“Definition of MS,” n.d.)
<sup>30</sup> (“Multiple Sclerosis FAQs,” n.d.)
him with some of his activities of daily life such as dressing, cooking, and getting on his bike.

- **Co-Participant Description**: Grant's wife assisted him with some of his projects. He would design something in his head or on the computer, and then his wife would turn the plan into a tangible reality. When a project required expertise that his wife did not possess, Grant hired a group of fabricators to make what he designed.

- **Adaptation/modification/design-like activity background**: Grant was good with tools and did things around the house before his injury. He made his first object modification as an individual with a disability immediately after his injury while he was still in the hospital.

- **Nature of most adaptation/modification/design-like activity**: Modifying objects, relying on individualized procedures to do tasks, and re-appropriating objects for alternative/multiple purposes

- **Type of practices adaptation/modification/design-like activity enables**: Self-care activities, using electronics, manipulating objects, opening and closing doors

- **Key quote(s)**: 1. "I will rarely look at a product only for its intended use. I'm constantly thinking outside the box on those items." 2. "Before my injury I always felt there was nothing that I could not do. Now, I still feel that there is nothing that I cannot do, but it does come down to whether I am willing to put forth the effort and money to get it done."

**Kimberly**

- **Type of interview**: Instant Messenger (Facebook)
- **Disability**: Cerebral Palsy
- **Impairment(s)**: Mobility and Dexterity
- **Length of time participant has lived with disability**: Entire life
- **Onset of disability**: Congenital (at birth)
- **Participant Description**: Kimberly is a 30-39-year-old female from the Midwest. She owned a power chair but was using a medical transport chair to get around in her home when our conversations took place. Kimberly's power chair needed some adjustments because it made her back hurt. She used the transport chair to give her back some relief until the power chair refitting. Kimberly cannot do certain activities of daily living because she cannot stand and use her hands at the same time. She received 12 hours of state-funded assistance every day at the time of our interviews.

- **Co-Participant Description**: Kimberly's assistants help her as needed. She did not provide many details about the type of adaptation/modification/design-like project help her assistants provided.

- **Adaptation/modification/design-like activity background**: All her life

- **Nature of most adaptation/modification/design-like activity**: Unique ways of completing tasks and using objects for alternative/multiple purposes.

- **Type of practices adaptation/modification/design-like activity enables**: Maintaining mobility, writing, bathing

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31 Kimberly had issues with her computer during both interviews. She submitted responses to questions from the second interview via email. Asking questions via email was not ideal, but it was the only option that seemed to work for her. Her responses to the five questions were terse. I sent a follow-up email to her a few months after our interviews to find out her ethnicity and ask a few clarifying questions but she did not respond.
Key quote(s): 1. "Necessity is the mother of invention." 2. "I'm sure you know this, but with CP, you kind of have to [engage in adaptive behaviors]."

Leon
- Type of interview: Face-to-Face
- Disability: Cerebral Palsy
- Impairment(s): Mobility and Dexterity
- Length of time participant has lived with disability: Entire life
- Onset of disability: Congenital (at birth)
- Participant Description: Leon is a 40-49-year-old African-American male from the Midwest. Cerebral palsy primarily affects his mobility, but he has some dexterity challenges as well. He uses one cane/crutch to walk and tends to drag one foot behind him as he ambulates. Leon's dexterity impairment makes it difficult for him to type rapidly or manipulate tiny objects.
- Co-Participant Description: N/A
- Adaptation/modification/design-like activity background: All his life
- Nature of most adaptation/modification/design-like activity: Unique task completion procedures and re-appropriating objects for alternative/multiple purposes
- Type of practices adaptation/modification/design-like activity enables: Moving objects from one place to another, playing sports, working on a computer, reaching items
- Key quote(s): 1. "I think people look at you and first off they think can he do this? I hate when people look at you and they assume oh, this poor kid. ‘How long have you had CP? Are you sure you can do this? Are you sure you can do that? Do you need help?’ I’m like don’t assume that I can’t do something. The people just look and they automatically feel sorry for you. I feel sorry for the people who automatically feel sorry for me because there’s more than one way to skin a cat I’ve been told. I make it. It might not be your way, but I make it." 2. "There’s a way around everything to me."

Neil
- Type of interview: Face-to-Face
- Disability: Cerebral Palsy
- Impairment(s): Mobility and Dexterity
- Length of time participant has lived with disability: Entire life
- Onset of disability: Congenital (at birth)
- Participant Description: Neil is an 18-29-year-old male who lives in the Northeast. He has difficulties using his left hand and experiences occasional tremors. He has reduced accuracy and limited fine motor control with his right hand. Additionally, his fine motor control decreases the further his limbs are from his body. Neil uses a power chair to get around outside of his apartment. He often uses crutches inside his apartment and when he needs to walk short distances. Neil has a condition called strabismus, which manifests itself in involuntary eye movement. He described it as a muscle imbalance that causes one eye to go off to one side. Neil’s strabismus creates

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32 I sent a follow-up email to Neil a few months after our interviews to find out his ethnicity but he did not respond.
problems with fatigue, headaches, and difficulty focusing while reading, writing, and typing.

- Co-Participant Description: N/A
- Adaptation/modification/design-like activity background: Neil said he engaged in this type of activity all his life.
- Nature of most adaptation/modification/design-like activity: Using individualized procedures to do activities and leveraging products for multiple/alternative purposes
- Type of practices adaptation/modification/design-like activity enables: Preparing food, communicating, doing chores, writing/typing, going in/out of doors, moving bulky or heavy objects
- Key quote(s): 1. "I guess I probably do like thousands [of] small adaptations a day. I just don't notice." 2. "I try multiple avenues [when trying to adapt or find a way to do something]. I think it came from building Legos [as a child]."

Ross

- Type of interview: Face-to-Face
- Disability: Arthrogryposis
- Impairment(s): Mobility
- Length of time participant has lived with disability: Entire life
- Onset of disability: Congenital (at birth)
- Participant Description: Ross is a 40-49-year-old white male who lives in the Northeast. The formal name of his disability is arthrogryposis multiplex congenita. He was born with hip contractures which his doctors mistook for a breached birth. They broke his legs to "bring them down" and then put him in a body cast. As a child, Ross wore braces that extended from his feet up to his chest. Although the braces allowed him to walk with crutches, they were uncomfortable and slowed down his mobility. As a teenager, Ross stopped wearing braces and switched to a manual wheelchair. Ross' gluteus minimums muscle is flat, so he cannot stand erect. He can stand on his legs, but only if he is holding on to something. Also, scar tissue limits his range of motion and prevents him from spreading his legs very wide. Ross' mother not only did therapeutics with him when he was a child but also found ways for him to do activities of daily life. In addition to having a disability, Ross identifies as a gay man. He struggled with his sexual orientation as a teenager but later found strength in embracing both his disability and sexual identities.\(^{33}\)

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\(^{33}\) My interviews with Ross were thought-provoking and somewhat less structured than others. I did not have to ask many questions. Ross had a lot to say about the construct of disability and his experiences as a gay man with a disability, specifically. He had answered several of my questions before I had a chance to ask them. There was much content from our interviews that did not make it into the analyses. Ross had a colorful yet genuine way of expressing himself. He hated the idea of normalization and commonly described himself as a "non-conformist." At one point, he explained why he was a non-conformist: "I'm not going to conform to what's expected. 'Oh, it's inappropriate.' Don't fucking tell me. Right there, you might as well say, 'Oh, you can't.' I don't like that. It's the nonconformity. It's the rebelliousness. I'm going to rebel against the doctors that told my mom to institutionalize me. I have been rebelling against them since the beginning of my existence because I refuse to be marginalized. I refuse to be limited and delineated by your opinion." Ross tended to combine non-conformity with humor in ways that he knew would offend some people. He described a lot of his jokes as irreverent and inappropriate. Ross uses profanity quite often and occasionally makes "cripple jokes" that others sometimes found offensive. However, he did not intentionally try to offend people but rather joked around because it was his way of dealing with life’s frustrations.
• Co-Participant Description: Ross' mother helped him to figure out ways to do mundane practice activities as a child, but he found ways to do these things for himself as an adult.
• Adaptation/modification/design-like activity background: All his life. Since he was a child, Ross always "sought to participate" in all aspects of life.
• Nature of most adaptation/modification/design-like activity: Unique ways of completing tasks, relying on individualized procedures to do tasks, and using objects for alternative/multiple purposes
• Type of practices adaptation/modification/design-like activity enables: Recreational activities, carrying objects, moving objects from one place to another, transferring to/from wheelchair, maintaining mobility, self-care activities
• Key quote(s): 1. "It's about having the say, being the cause in the matter of my life, having say in what I do and what I don't do. Not having my body tell me what I can and cannot do, not having the opinion of others tell me what I can and cannot do, not letting myself tell me what I can and cannot do. I often have to push myself." 2. “Whether you have a disability or not, you go out into the world and you figure out ways, whether it's ways to talk to a girl so you could date, or a guy, or ways to employ yourself, figuring out shit. That's what life is. It's figuring out shit”

Samantha
• Type of interview: Telephone
• Disability: Common Variable Immune Deficiency (CVID)
• Impairment(s): Dexterity and Mobility
• Length of time participant has lived with disability: Since a toddler
• Onset of disability: Unknown
• Participant Description: Samantha is an 18-29-year-old white female who lives in the Northeast. In addition to Common Variable Immune Deficiency (CVID), Samantha experiences comorbid conditions such as intermittent hand numbness, chronic back pain, spine damage, and fatigue. Although she did not describe her autoimmune disorder in detail, one of its common manifestations is rheumatoid arthritis. Two of the symptoms of rheumatoid arthritis are numbness and reduced grip strength. Samantha linked the numbness she experiences to her autoimmune disorder and said it made tasks such as manipulating small or delicate items difficult at times. Samantha’s back pain prevents her from sitting for extended periods of time. It is also hard for her to bend down or lift her arms high, which makes reaching and lifting challenging.
• Co-Participant Description: N/A
• Adaptation/modification/design-like activity background: Since high school (approx. 10 years)
• Nature of most adaptation/modification/design-like activity: Relying on individualized procedures to do tasks, re-appropriating objects for alternative/multiple purposes, and combining two or more objects to make something useful.
• Type of practices adaptation/modification/design-like activity enables: Writing/typing, arts and crafts activities, carrying objects, bathing, using computers, reaching objects
Key quote(s): 1. "[At one point in high school] I didn’t really want to rely on people as much, or I was just worrying that people weren’t as happy to help. " 2. "I don’t like to admit it, but sometimes I’ll force myself [to do things without asking for help], and then I kind of get hurt."

Scott

- Type of interview: Telephone
- Disability: Multiple Sclerosis (MS)
- Impairment(s): Mobility and Dexterity
- Length of time participant has lived with disability: 20+ Years
- Onset of disability: Unknown
- Participant Description: Scott is a 65-80-year-old white male from the northeast. MS is a progressive condition and Scott started experiencing its effects in 1994. The effects Scott experiences include muscle atrophy, reduced hand strength, and impaired mobility. Scott once used canes, but he eventually lost the ability to maintain his balance. At the time of our interviews, he used a power chair most of the time. He also uses a walker. When he was not in his power chair. Scott has a hard time getting up after bending down. The progression of his MS has accelerated since 2013 and impacted his ability to engage in certain physical activities he once enjoyed. Scott sometimes asks his wife to help him with daily life tasks such as getting dressed and putting on his socks and shoes.

- Co-Participant Description: N/A
- Adaptation/modification/design-like activity background: Scott always enjoyed working with his hands and doing do-it-yourself (DIY) projects. Both before and after the onset of MS, Scott acquired experience and a repertoire of tools that made making and modifying things as an individual with M.S. easy and enjoyable.
- Nature of most adaptation/modification/design-like activity: Unique task completion procedures, combining two or more objects to make something useful, and making things
- Type of practices adaptation/modification/design-like activity enables: Maintaining mobility, carrying objects from one place to another, reaching and manipulating objects
- Key quote(s): 1. "I was always a do-it-yourselfer, and I always liked doing stuff. So, for me it was fun." 2. "I was never afraid to pick up some tools and try something, so I never needed anybody else to show me how to do certain things. I was a quick study for a lot of things. And being a dentist I always worked with my hands, so it was kind of natural for me to do these things." 3. "If I had the same issues with my dexterity that I do now when I was younger, I probably would not have done a lot of the things that I did. I probably would have been more frustrated in trying to do it and finding it may be more difficult than I wanted to deal with."
Sheila

• Type of interview: Face-to-Face
• Disability: Arthrogryposis
• Impairment(s): Mobility and Dexterity
• Length of time participant has lived with disability: Entire life
• Onset of disability: Congenital (at birth)
• Participant Description: Sheila is a 65-80-year-old white female who lives in the Northeast region of the United States. She uses a power wheelchair. Sheila could walk on crutches for much of her life but had to stop using them because she started falling more frequently once she reached her sixties. She cannot transfer to and from her wheelchair independently. Sheila has short arms which makes it difficult to reach objects that are not close to her body. She cannot reach her head, which makes grooming activities such as combing her hair challenging. Sheila also cannot do house cleaning tasks, although she possessed the ability to do some of them when she was younger. Sheila's husband assisted her with many of the ADLs she could not do independently.

• Co-Participant Description: Sheila's husband Jack constructed many of the adaptation, modification, and design-like activity outcomes she leveraged in her daily life practices. He also maintained and repaired her wheelchairs and other mobility equipment. Although Jack did not state his exact profession, he referred to several construction and renovation jobs he did in the past. He added an addition to their home and renovated commercial office space by himself. Jack's ability to fix and make things eliminated the need to purchase expensive adaptive equipment for Sheila. The two of them often worked together to develop useful adaptation/modification/design/like activity outcomes. Sheila would make suggestions and offer input and Jack constructed solutions based on her guidance and feedback. Jack played a critical role in making sure that Sheila was not dependent on entities or people who would not look out for her best interests as an individual with a disability.

• Adaptation/Modification/Design-like activity background: Sheila began figuring out individualized ways to do things as a child and continued doing so throughout her life. Jack and Sheila have worked together to make daily life activities more accessible to her throughout their marriage.

• Nature of most adaptation/modification/design-like activity: Making or modifying things, combining two or more objects to make something useful, repairing/maintaining accessibility equipment, and unique ways of completing tasks.

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34 I interviewed Sheila and her husband Jack separately so that both individuals would feel free to share whatever he or she wanted without the other person interjecting. I conducted both interviews with Sheila in her office. I spoke to Jack in their home while Sheila was in another room. Jack performed a lot of the physical labor that went into creating many of Sheila’s life hacks. However, Sheila was not a passive consumer of Jack’s efforts. It was clear from my conversations with both of them that Sheila and Jack worked together to figure out what would allow Sheila to be as independent as possible. Sheila said her mother had a profound influence on her. Sheila’s mother lived during a time when women faced a lot of workplace discrimination. She wanted to become a manager in a male-dominated work environment, and she eventually did. Sheila looked up to her mother because of her accomplishments in the face of discrimination. During our interviews, she called herself a fighter and said she had a family full of fighters like her mother.
Type of practices adaptation/modification/design-like activity enables: Childcare, self-care activities, maintaining mobility, opening and closing doors, working on a computer, office tasks, eating, chores, reaching objects

Key quote(s): 1. "I never really, I just never really thought of myself as just being a person with a disability who couldn't have a life and who couldn't live normally like everyone else." 2. [Jack] "As life went on, we just did things as we needed them, and it's hard to think of things, because it was just part of living and nothing really special to us." 3. [Jack] "My mantra is with duct tape and wire coat hangers you can save the world." 4. "I don't know. People tell me I've always been kind of a go-getter."

Stuart

Type of interview: Video Chat (Google Hangouts)
Disability: C5-C6 Complete Quadriplegia
Impairment(s): Mobility and Dexterity
Length of time participant has lived with disability: Since age 19
Onset of disability: Competitive rugby accident which led to a spinal cord injury
Participant Description: Stuart is a 30-39-year-old white male who lives in the northwest. He is completely paralyzed from the chest down. Stuart has a hard time grabbing and manipulating objects. Activities such as pulling something out of his wallet are challenging without assistance or the use of a tool. Stuart's hands tend to stay closed, but his left index finger often sticks out. He uses universal handcuffs with rod-like poking tools to grasp and manipulate objects. People who have impaired or no hand function often use universal handcuffs. They are splints a person wears on his or her hand or arm. The user can insert eating, writing, or other utensils into the part of the cuff that wraps around the hand. The cuff enables the user to manipulate the utensil using open or closed handed wrist movements. The pokers that Stuart use serve as his fingers for different tasks. They are attached to the handcuffs in such a way that Stuart can leverage them to grab, type, text, grip, poke, and perform various other object manipulation tasks. Stuart's mother lives next door to him and helps him with daily life tasks when he asks for it.

Co-Participant Description: Stuart's mother and other relatives have helped him to modify and utilize objects that allow him to engage in certain daily life practices.

Adaptation/modification/design-like activity background: Engaged in adaptation/modification/design/like activity increasingly more with time after his injury

Nature of most adaptation/modification/design-like activity: Combining two or more objects to make something useful, relying on individualized procedures to do tasks,

35 Stuart admitted that adapting and doing things for himself was not automatic for him. He grew up receiving help from others as an individual without a disability and the same way of operating carried over into life with quadriplegia. Stuart admitted that he was more likely to engage in adaptation, modification, or design-like activity to do things he liked to do and rely on others to do the things he was either indifferent about or did not want to do. He said his mom always supported his independence, but never pushed him to be independent. For instance, she fed him for one to two years after his injury even though he possessed the ability to do it himself. One of his caregivers, on the other hand, encouraged him to identify and silence a side of himself that always wanted to take the quickest and easiest way (e.g., asking for help when he should not). He said the caregiver showed him “tough brotherly love” by refusing to do things for him that he could do himself.
re-appropriating objects for alternative/multiple purposes, and making/modifying objects

- **Type of practices adaptation/modification/design-like activity enables:** Recreational activities, eating and drinking, retrieving objects, using electronics, reaching objects

- **Key quote(s):** 1. "I went a long time without feeding myself [post-SCI], even though I could move my arms, even though I could do it. I like that quick, easy way of doing things and for probably a year or even maybe two when I first got injured, my mom was feeding me a lot of my meals. It still happens on occasion, when I have tacos or something that’s really messy. Maybe sometimes I’m just not feeling well or I’m feeling incredibly lazy, I’ll ask my mom for help for feeding me. But for the most part I eat my own meals with a fork and do my own thing. I don’t require a lot of help. Especially if I’m with friends… There are times when I have the ladies feed me, but that’s another story right there. There are things that have changed as I’ve grown and I’ve wanted more independence. There are people in my life that have helped me do that. One of my caregivers used to try to push me to be more independent, so it’s had an influence on my life from having them help me out."

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**Tabitha**

- **Type of interview:** Instant Messenger (Google Hangouts)
- **Disability:** Cerebral Palsy (Spastic Diplegia) and Scoliosis
- **Impairment(s):** Mobility
- **Length of time participant has lived with disability:** Entire life
- **Onset of disability:** Congenital (at birth)
- **Participant Description:** Tabitha is an 18-29-year-old African-American female from the Southeast. Cerebral palsy affects both of her legs, and she uses a manual wheelchair for mobility. On top of having CP and scoliosis, Tabitha is short. Her height makes it difficult for her to reach things above her head that are beyond her grasp.
- **Co-Participant Description:** Tabitha's step-father made a homemade wheelchair ramp that enables her to get in and out of her home. In the past, Tabitha's step-father also purchased products for her that she leveraged in her daily life practices.
- **Adaptation/modification/design-like activity background:** Since she started living by herself 15 years ago.
- **Nature of most adaptation/modification/design-like activity:** Relying on individualized procedures to do tasks, re-appropriating objects for alternative/multiple purposes
- **Type of practices adaptation/modification/design-like activity enables:** Reaching objects, carrying objects, cooking, going in and out of doors, transferring to/from wheelchair
- **Key quote(s):** 1. “The benefits [of adapting and finding ways to do things] for me is a sense of achievement, being able to say I did it, and not letting anything stop me so to speak. Because just because it has to be done differently doesn't mean it can't be done." 2. "I have a lot of disabled friends and we discuss different ways we do things."
Wallace

- Type of interview: Video Chat (Skype)
- Disability: C1-C2 Quadriplegia
- Impairment(s): Mobility and Dexterity
- Length of time participant has lived with disability: Since March 1997
- Onset of disability: Bad fall that resulted in a spinal cord injury
- Participant Description: Wallace is a 30-39-year-old white male from the southeast. Wallace cannot use his hands or his legs. He relies on a ventilator to breathe and possesses the ability to breathe independently for approximately four hours. In addition to his ventilator, Wallace uses a machine called the Cough Assist, which clears congestion-causing secretions in his lungs. The machine connects to Wallace’s tracheostomy tube. Caregivers and family members operate the machine when he gets congested. Wallace also experiences involuntary spasms. Wallace’s injury is complete, which means he does not have sensation or motor control below his level of injury. He also has autonomic dysreflexia, which he described as "a quadriplegic’s way of getting signals that there’s a pain." In other words, Wallace's body cannot discern temperature, sweat, or send pain signals from an impacted area of his body to his brain. Instead of feeling pain, Wallace’s blood pressure rises, and he gets head rushes when there is pain below his level of injury or if his bladder is full. Wallace cannot be alone for an extended amount of time because of his respiratory challenges. He has a team of caregivers who help him with most of his activities of daily living. In addition to his parents, Wallace received 40 hours of nurse care per week and had several paid personal care assistants at the time of our interviews.

- Co-Participant Description: Wallace's caregivers and family members work with him on adaptation/modification/design/like activity projects that make daily life activities more accessible.

- Adaptation/modification/design-like activity background. Wallace was a math major in college, and he linked his adaptation/modification/design/like activity background to his love of problem-solving. The first time he worked with others to make an everyday life task more accessible occurred soon after his injury. Once he left the rehabilitation center, he worked with his caregivers to figure out a better way to use his respiratory equipment that suited his needs and their availability.

- Nature of most adaptation/modification/design-like activity: Combining two or more objects to make something useful, making things, unique task completion procedures, re-appropriating objects for alternative/multiple purposes

- Type of practices adaptation/modification/design-like activity enables: Health and self-care activities, recreational activities, using computers, drinking liquids

- Key quote(s): 1. "My master’s degree is in entrepreneurship and the mindset of an entrepreneur is just a problem-solving mentality. If you see a need, if there’s..."
something that’s not working right, do something to fix it and make it better." 2. "We [Wallace and his caregivers] just do the best solution." 3. "Also, each situation is probably a little different, so you’re going to have to learn the situation and try to make adaptations and modifications that better suit your needs. That’s been the mindset that we’ve always had." 4. "I have two primary paid caregivers that I’m really close with and I talk a lot with. They also have the ability to think outside the box a little bit."

Participant Activities: An Initial Look

This chapter offered brief descriptions of the 16 individuals who participated in this study. Although each person's adaptation/modification/design-like activities, background, related daily life practices, and assistance needs differed, there were frequently repeated themes across participants. For instance, participants like Arnold, Scott, and Sheila and her husband engaged in several adaptation/modification/design-like activities that involved making, modifying and fixing things. Cecil, Leon, Neil, and Deanna, on the other hand, often utilized individualized routines and task completion procedures. The specific adaptation/modification/design-like activities participants described were unique to the individual and his or her everyday life context. However, each one enabled participants to do tasks in their daily lives on their terms. The next chapter of this dissertation will take a closer look at the different adaptation/modification/design-like activities participants described and the daily life practices their efforts allowed them to do.

Researchers interested in DIY-AT often talk about empowering people with disabilities to adapt assistive technology. For the most part, DIY-AT research studies either have more participants who are non-disabled than individuals with disabilities (Hook et al., 2014, 2013; Hurst & Kane, 2013) or exclude the perspectives of individuals with disabilities altogether (Hofmann et al., 2016). Therefore, non-disabled people who adapt things for individuals with disabilities inform findings significantly more than
individuals with disabilities who have first-hand experience living with an impairment. Some rightly acknowledge that barriers such as inaccessible 3D printers (Buehler et al., 2014) and other rapid prototyping tools (Hurst & Kane, 2013), lack of design expertise (Hook et al., 2013), and lack of needed support (Rajapakse et al., 2014) prevent many individuals with disabilities from using these tools to make and modify assistive technology. However, in these studies, individuals with disabilities are usually underrepresented or their perspectives do not inform the findings in any significant way. Instead, they get relegated to the status of beneficiaries of researcher and therapists’ efforts to make their activities more accessible rather than informants who have something to add to the DIY-AT conversation.

The profiles in this chapter suggest not all individuals with disabilities frame their adaptation/modification/design-like activities the same way. Perhaps DIY-AT's narrow focus on Maker activities excludes other types of adaptation, modification, and design-like activities that empower individuals with disabilities. Interested accessibility researchers may be missing out on the perspectives of individuals with disabilities who engage in slightly different forms of DIY-AT because of the narrow scope of their studies. Relatedly, some accessibility scholars commonly link the provision of more accessible rapid prototyping tools to more individuals with physical impairments creating, modifying, and enhancing assistive technology (Buehler et al., 2014; Hurst & Kane, 2013). Perhaps more accessible maker tools would motivate more interest in DIY-AT. Grant, Arnold, and Scott's profiles, however, suggest the length of time a person has engaged in these activities and lived with an impairment as well as pre-impairment involvement in maker projects may be additional factors that enable some individuals
with disabilities to participate in DIY-AT activities. Arnold created homemade tools that enabled him to use rapid prototyping and other maker equipment, which seems to support Hurst & Kane's assertion. However, Grant, Scott, Sheila, and her husband Jack made objects that did not require access to this equipment or a Makerspace.

Finally, key quotes from participants about themselves and their adaptation/modification/design-like activities suggest that attitude and internalized beliefs may also influence whether an individual with a disability will engage in certain types of adaptation, modification, and design-like activities. In other words, people with disabilities are not monolithic. There can be personal, social, and contextual factors that make a person inclined to engage in adaptation, modification, and design-like activities in addition to technological ones. This chapter highlights a few personal and contextual factors surrounding participants’ adaptation, modification, and design-like activities. Other chapters will examine these and other participant-identified factors that may make someone with an impairment more inclined to engage in adaptation, modification, and design-like activities.

A major takeaway from the profiles in this chapter is that sometimes individuals with disabilities adapt in diverse ways. Buehler et al. (2015), Kane et al. (2009), and Profita, Stangl, Matuszewska, Sky, & Kane (2016) offer empirical evidence that people with disabilities make, modify, and adapt artifacts according to their needs and preferences. The profiles in this chapter highlight generic types of participant adaptation, modification, and design-like activities as well as details about each interviewee and the daily life contexts surrounding their activities. Despite the difference between participants and the contexts surrounding their efforts, each one found ways to align their
capabilities, needs, preferences, and available resources so they could do things in their lives. With few exceptions, co-/participants did not wait for someone to make tools or other resources for them. Regardless of their impairment(s), daily life activities, or current level of independence, participants found ways to do whatever they wanted or needed to do either independently or with assistance from someone they knew. In this sense, adaptation, modification, and design-like activities were the means participants used to pursue whatever ends they found salient.

Conclusion

The next three chapters will examine both the adaptation, modification, and design-like activity and activity-enabled practice themes found in the data across participants in greater depth. More specifically, chapter five will explicate the ways co-/participant made everyday life more accessible and amenable to participants' goals, capabilities, and needs as well as some of the meanings, motivations, enablers, and impediments they linked to their efforts. Chapter six will look at participant adaptation, modification, and design-like activities and related daily life practices through the lens of practice theory to identify the ways that various actors and agencies disabled or enabled participants. Finally, chapter seven will examine participants' adaptation, modification, and design-like activity-related social interactions including the different online platforms, offline communities, and people who factored into their efforts.
Chapter 5: Participant Adaptation, Modification, and Design-Like Activity or “Life Hacks”

The purpose of this chapter is to answer my first research question: How do individuals with mobility dexterity impairments and their co-participants, if applicable, make everyday life practices more accessible? Accessibility in the framework of this study refers to the ability of someone who lives with physical impairments that affect his or her movement or dexterity to participate in an everyday life practice. This chapter is the first of three that both explores participant adaptation, modification, and design-like activity efforts and unpacks how those efforts empowered them in their daily life practices. More specifically, each section in this chapter addresses one dimension of how and why interviewees worked individually or with others to develop and implement solutions intended to make everyday life practices more accessible within the context of their daily lives. The analyses presented in this chapter answer four research sub-questions. First, I summarize participants’ daily life practices as well as the types of adaptation, modification, and design-like activity outcomes that allowed them to engage in these practices (RQ 1.1). Next, I describe how participants conceptualize their adaptation, modification, and design-like activities and outcomes (RQ 1.2). Thirdly, I talk about the roles participants and co-participants play in adaptation, modification, and design-like activity efforts and the daily life practices they enable (RQ 1.3). I also discuss the general motivations participants attribute to their adaptation, modification, and design-like activity efforts. I compare some of the findings in this section to literature on accessibility-related adaptations, hacking, and hacker culture to justify the appropriateness of the term life hack to characterize the adaptation, modification, and
design-like activities individuals with disabilities engage in to productively configure their practices. In the final section, I describe different factors that participants felt either facilitated or impeded their adaptation, modification, and design-like activity efforts or those of other individuals with impairments (RQ 1.4).

Everyone selected to participate in this study admitted to using homemade artifacts, possessing individualized ways of completing tasks, leveraging unique object interaction methods, or engaging in other adaptive behaviors. Each participant filled out a recruitment questionnaire and indicated he or she had at least one example of an adaptation, modification, and design-like activity that made it possible to participate in a daily life task. As explained later in this chapter, I use the term life hack to capture the various adaptive activities and outcomes participants leveraged to engage in daily life practices despite accessibility, impairment, technological, social, economic, or other challenges. A life hack is a clever yet non-obvious way to solve a problem or do something and life hackers “operate skillfully and inventively, moderating and adapting tips and schemes” (Potts, 2010, p. 35). Life hacking allowed participants to engage in daily life practices such as cooking, grooming, recreational activities, personal mobility maintenance, and many others. Each life hack served as the bridge between a participant’s needs or intentions and his or her successful performance of a practice task when one or more of the challenges mentioned earlier made performance challenging or less than ideal. Thus, I apply this term to characterize the practices I learned about from my participants. Life hack situates my participants as active agents in altering their lifeworld so that it accommodated their distinct capabilities. The following section
describes the different daily life practices participants engaged in and the nature of the life hacks that made engagement possible.

**Daily Life Practices and Related Life Hacks**

From this point on the term *life hack* will be used to refer to any participants’ adaptation, modification, and design-like activities and activity outcomes that enabled them to engage in a daily life practice activity. The next major section of this chapter will justify the use of this term. Remaining results chapters will provide additional justifications. I content analyzed two interview transcripts from my sixteen study participants and identified 283 different life hacks that enabled 18 categories of daily life practice activities. Table 19 below lists these 18 categories of daily life practices participant life hacks enabled them to do. The seven most common types of activities were: 1. manipulating or reaching something with hands or feet; 2. carrying or moving something or someone; 3. moving and controlling the body; 4. Doing household tasks such as chores; 5. Working with computers and mobile devices; 6. Participating in sports and recreational activities; and 7. Performing activities of daily life such as bathing.

It is important to note that many of the practices participants did via their life hacks were not directly related to impairment. Some of their life hacking efforts allowed them to do tasks they enjoyed or derived personal satisfaction from doing. Examples include sports and recreational activities, hobbies and interests, and working in a Makerspace. For example, Stuart and Leon described life hacks that allowed them to lift weights and play baseball, respectively, while Ross had personalized ways of getting on a horse to go horseback riding. Erin, Stuart, and Samantha created or modified artifacts that allowed them to paint, play video games, and knit, respectively. Erin said she modified
sex toys as part of her sex and disability advocacy efforts. Finally, Arnold made tools that allowed him to use the equipment in the Makerspace he joined. Mobility and dexterity impairment limitations did not stop these participants from engaging in activities that demand physical exertion, fine motor control, or standing. Impairment also did not prevent interviewees like Erin from finding ways to engage in sexual activity. This is significant given past research suggesting society values heteronormative ideas about sex and tends to view individuals with disabilities as asexual as a result (Esmail, Darry, Walter, & Knupp, 2010). Later sections will explore participant practice variety more deeply, but the implications of the different practices participants engaged in as well as the life hacks that enabled them to do so extended beyond the activities themselves. Each participant told his or her individual story about what it means to live with impairment through his or her life hacking and daily life practice activities. By making life decisions for themselves and then figuring out ways to act on them, participants often challenged norms regarding disability and assumptions about what individuals who have physical impairments can do. The categories listed in table 1 suggest that life hacks allowed participants to do tasks that impairment or related issues made difficult for them as well as engage in activities that people might not link to people who live with mobility or dexterity impairments.
<table>
<thead>
<tr>
<th>Practice Category</th>
<th>Examples of Participant Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manipulation &amp; Reach</td>
<td>Manipulating objects with hands or feet (e.g., pressing buttons, using foot pedals, changing baby diapers, etc.), reaching an object or person such as a baby, accessing something in a cabinet or beyond one's reach</td>
</tr>
<tr>
<td>Carrying &amp; Moving</td>
<td>Carrying objects (e.g., plates, cups, groceries, etc.) or babies/children, carrying items while using mobility equipment, carrying items up/down stairs, moving something heavy or bulky</td>
</tr>
<tr>
<td>Bodily Control &amp; Movement</td>
<td>Going up/down stairs, body positioning, transferring to/from surfaces (e.g., wheelchair, vehicle, toilet, bed, a horse)</td>
</tr>
<tr>
<td>Household Tasks</td>
<td>Home maintenance, laundry, folding/hanging clothes, cleaning floors, washing windows, etc.</td>
</tr>
<tr>
<td>Computers &amp; Mobile Devices</td>
<td>Using computer hardware/accessories (keyboard, mouse, headset, monitor, etc.), using computer operating system and software, using mobile devices, interacting with digital content, web design</td>
</tr>
<tr>
<td>Sports &amp; Recreation</td>
<td>Bowling, lifting weights, exercising, rock/mountain climbing, horseback riding, swimming</td>
</tr>
<tr>
<td>ADLs</td>
<td>Bathing, brushing teeth, combing/brushing hair, dressing, Toileting</td>
</tr>
<tr>
<td>Mobility Equipment &amp; Accessories</td>
<td>Maintaining, repairing, and using mobility equipment (e.g., power wheelchairs), utilizing mobility equipment accessories</td>
</tr>
<tr>
<td>Health</td>
<td>Pain and pressure management, energy maintenance, skin care, using medical devices</td>
</tr>
<tr>
<td>Doors</td>
<td>Opening, closing, entering, exiting</td>
</tr>
<tr>
<td>Writing &amp; Typing</td>
<td>Handwriting, typing on a keyboard</td>
</tr>
<tr>
<td>Hobbies &amp; Interests</td>
<td>Arts &amp; crafts, video games, sex and disability</td>
</tr>
<tr>
<td>Eating &amp; Drinking</td>
<td>Eating, drinking, feeding a baby or child</td>
</tr>
<tr>
<td>Making/ Maker activities</td>
<td>Acquiring materials, using tools/equipment to make or modify artifacts, cleaning up after using Makerspace tools/equipment</td>
</tr>
<tr>
<td>Mobility</td>
<td>Ambulating/getting around, using mobility equipment, navigating in inaccessible spaces</td>
</tr>
<tr>
<td>Communication</td>
<td>Verbal communication, non-verbal communication</td>
</tr>
<tr>
<td>Planning Activities</td>
<td>Managing space, managing finances</td>
</tr>
<tr>
<td>Automobiles</td>
<td>Driving, DIY automotive repair</td>
</tr>
</tbody>
</table>
Altogether, I identified six types of life hacks: 1. Innovations, 2. Modifications, 3. Bricolage, 4. Repair/maintenance, 5. Re-appropriations, and 6. Procedures. Four of these were artifact-centered activities, and two were action-centered. These categories were inductively derived from the data. Table 20 defines the categories and types of life hacks and provides an example of each one from the data.

Artifact-centered participant life hacks resulted in new, modified, or repaired objects as well as amalgamations of multiple otherwise disparate objects. These life hacks led to tangible outcomes that did not previously exist or did not exist in the same form and with the same function as the original object(s). They also include do-it-yourself maintenance and repair activities. Artifact-centered life hacking activities include the following: 1. Creating something from scratch (innovation); 2. Altering existing artifacts (modification); 3. Repairing/maintaining durable medical equipment and accessibility products, and 4. Combining two or more objects to create something that is functionally distinct from the original components (bricolage). Participants and allies, if applicable, created, changed, repaired, maintained, and culled together artifacts that participants could leverage in their daily life practices. The level of sophistication varied by person, underlying practice, and practice context. Each artifact-centered life hack outcome was unique in the sense that its conceptualization and creation was participant-inspired and a participant or a participant-ally pair created it.
### Table 20 - Types of Participant Life Hacks and Life Hacking Activities

<table>
<thead>
<tr>
<th>Life Hack Category &amp; Description</th>
<th>Life Hack Type</th>
<th>Life Hack Description</th>
<th>Associated Activities</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Artifact-Centered:</td>
<td>Innovation</td>
<td>Creating artifacts that did not exist previously or did not exist in the same form</td>
<td>Making, installing, building, inventing, designing, machining, and creating</td>
<td>Scott made a window lever extension that allowed him to reach the lever to open &amp; close windows in his home without bending down</td>
</tr>
<tr>
<td></td>
<td>Modification</td>
<td>Altering, adjusting and customizing existing artifacts or environments</td>
<td>Reusing, repurposing, recycling, covering, attaching, changing, adding</td>
<td>Sheila's husband bent her spoon so she could use it to eat independently</td>
</tr>
<tr>
<td></td>
<td>Bricolage</td>
<td>Concatenating otherwise disparate artifacts into something useful</td>
<td>Combining, piecing together, connecting, putting together</td>
<td>Samantha added a hollowed-out ink pen to yarn to make it easier to grip and manipulate while knitting</td>
</tr>
<tr>
<td></td>
<td>Repair/Maintenance</td>
<td>Fixing or maintaining artifacts</td>
<td>Repair, maintain, overhaul, re-assemble, replace</td>
<td>Arnold overhauled an old power chair that was in disrepair</td>
</tr>
<tr>
<td>Action-Oriented:</td>
<td>Re-Appropriation</td>
<td>Interacting with objects in new or slightly modified ways</td>
<td>Leveraging, adapting, using</td>
<td>Leon turned a shirt into a &quot;tourniquet&quot; he used to carry his baby niece while using his cane-crutch to walk</td>
</tr>
<tr>
<td></td>
<td>Procedure</td>
<td>Accomplishing a task in a unique or unconventional manner</td>
<td>Varies based on the practice</td>
<td>Ross climbed out of the window and onto the roof of his car to mount a horse</td>
</tr>
</tbody>
</table>

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Action-oriented participant life hacks took the form of participant-centered routines, ways of doing things, and object interaction patterns that made daily life practices more accessible and amenable to participants’ capabilities and goals. Action-oriented life hacks included unique participant-centered object interaction methods (re-appropriation) and individualized methods of doing activities (procedures). Although some action-oriented life hacks involved artifacts, they were not the primary focus. The participants' interactions with objects and what he or she accomplished with them were more important than the artifacts themselves. In other words, the actor and object become what Latour (2005) refers to as an actor-network rather than two separate entities. These actor-networks could accomplish what neither the participant nor the object could independently. Participants’ individualized adaptive behaviors were as essential to the actor-network as the objects he or she utilized. To be clear, participants and all their artifact-centered life hack outcomes formed actor-networks as well. The next chapter explores the role of participant-design outcome and participant-life hack outcome actor-networks in participants’ daily life practices.

Artifact-centered life hacks.

An artifact-centered life hack always results in a tangible outcome that participants can leverage in their daily life practices. The life hack is the outcome, and the related activities are distinct from the practice tasks the outcome enables the participant to do. Artifact-centered life hacks are the result of productive physical activities performed on one or more objects or inputs. Although the outcomes may be integral to allowing the participant to engage in a practice and the design and development of this type of life hack is usually informed by in-situ practice engagement, making an artifact-centered life hack is not the same as leveraging it to do a practice activity.\textsuperscript{37}

\textsuperscript{37} The last sentence of this paragraph will make more sense after reading the subsection on action-oriented life hacks.
As the name suggests, an innovation life hack outcome is a new artifact or digital solution. A participant uses this outcome in the context of a daily life practice to make the underlying activity possible or easier. The outcome of an innovation life hack makes the physical demands of a practice activity more complimentary to the participant's goals, desires, capabilities, and needs. Activities such as installing, building, inventing, designing, machining, and creating result in innovation life hack outcomes. The efforts that go into this type of life hack include thinking and acting like an inventor, product designer, manufacturer, or some combination of the three. Sometimes the physical effort involved in this type of life hack is distributed among the participant and one or more other people (e.g., a co-participant or ally), particularly when the participant lacks the requisite dexterity, mobility, or other physical capabilities to develop a solution. For instance, if a project required the assembly of raw materials and the participant could not perform this task, he or she would look to an ally or co-participant for assistance. While most innovation life hack outcomes took the form of tangible objects, some consisted of digital resources such as Wallace’s small computer programs known as macros.

An innovation life hack is not the same as a modification life hack, which the next subsection will define. Developing an innovation life hack outcome, however, may require the modification of raw materials and other inputs. An innovation is not the same as adding or installing a commercially made accessory to an existing product (e.g., purchasing and attaching a mobile device holder to a wheelchair to make it easier to use an iPad). An innovation life hack requires some ingenuity and planning on the part of the participant and a co-participant, if applicable. It also requires productive labor that turns inputs into outputs. Unlike commercially available products, a participant or participant and ally (if applicable) devises, plans, and
develops an innovation life hack from scratch. The outcome of the effort cannot be purchased by other people unless the participant decides to sell it. Additionally, professionals such as builders, electricians, assistive technology manufacturers, etc. probably would not make the same solution in the same way given the resources at each one's disposal, although they might like or acknowledge the value of the idea.

Scott’s window lever extension is one example of an innovation life hack outcome. He has six-foot long windows in his home, and the position of the lever forced him to bend down to open and close them. Bending down is hard for Scott because of M.S. One day he went to Home Depot and asked a sales associate if the window manufacturer sold an extension pole. After finding out the company did not make one, Scott decided to create his own:

Scott: I bought some PVC pipe. I cut it so that it would fit over the handle and I made a “T” at the very end of it with another piece of PVC, and I use that to open the window. I have a long extension that I can turn so I don’t have to bend down to open the window. So, I go in and I’m looking and I tried to figure out what I could use. They didn't have an answer for me, so I tried something and it works.
Me: Scott, in that instance, the PVC piping, did you cut that or did you have it cut while you were at Home Depot?
Scott: I cut that at that point.
Me: You said that it fits over the lever. You didn't have to attach it; you just slide it over the lever and that’s it?
Scott: I had to cut a specific hole in the T section of the PVC piping to fit over the handle, and I played with it for a while. I had to modify the PVC so it would fit over the handle in a certain way with a hole in it that allowed me to put pressure on it.
Me: How did you modify the PVC?
Scott: They have a T section. On the round side of the T, I cut a big channel so that I could fit it over the handle of the window, and then I cut a little hole in the other side of it that the end of the handle would pop through that so that it would grab onto it. Then I had to add a little because it was banging into the wood. It was just a matter of playing with it for a while; just trying it and modifying it and keep on trying it. [Telephone interviewee]

Another example of an innovation life hack outcome was Arnold’s mill stick which he used to operate the milling machines in his Makerspace from his wheelchair. He described the mill stick as follows:
One of the first things I had to invent was what I call my mill stick, which is a three-foot length of one by that I have a notch and a hole cut in one end of it. The notch is something that allows me to reach up and work the power switch, which is up at the top of the mill. Then there’s a hole that fits over the crank to change the motor speed. [Telephone interviewee]

Arnold used the verb *invent* to describe his actions which led to the development of his mill stick. Scott did not use the same word, but both participants did invent something they leveraged in their everyday life activities. Both participants made something that did not exist beforehand in the form needed. They used machines and tools to turn raw materials (PVC pipe and wood) into items they could use to reach something they otherwise had trouble accessing or could not access at all. Both innovation life hack outcomes were grounded in the participants’ awareness of their capabilities, needs, and preferences. Scott had trouble bending down and knew he needed something long that would allow him to access the window while sitting. Arnold used a wheelchair and knew he needed something that would enable him to reach and access the controls on the milling machines without standing. Arnold had a strong desire to use the equipment in the Makerspace while Scott was determined to find what he needed. Both men had the foresight and capability to plan and make something they did not have access to in the form they needed it.

*Modification.*

A modification life hack outcome is an artifact or environment that a participant and ally, if applicable, changed in some way to make it useful and usable. Modification life hack outcomes resulted from making alterations to existing artifacts. The participant may have purchased, found, salvaged, previously used, or received the object from someone else. He or she then figured out how to make it fit his or her physical capabilities as well as the context of the daily
life activity. Most artifact modification efforts made the underlying object more usable or useful to the participant as he or she engaged in an activity.

Modification activities include reusing, repurposing, recycling, bending, covering, attaching, changing the form, or adding something to an object. These actions led to a change in an object that made its features and affordances both usable and useful to the participant doing a practice activity. Some artifact modification outcomes enabled participants to engage in a non-ICT related form of usage drift, which refers to product utilization that deviates from the expectations of commercial designers and developers and makes it difficult for them to predict consumer ICT use (Haddon, 2005).

Sheila's baby bassinette was an example of a modification life hack outcome. While their son was still an infant, Sheila and her husband Jack modified a bassinette so that she would be able to simultaneously use her wheelchair and transport their son around their home. Sheila's need to use a wheelchair and her short arms made safely carrying their infant son challenging. After purchasing a reclining baby seat that turned into a bed, they modified it to make it easier for Sheila to use from her wheelchair. Jack added wheels to the seat so that it rolled. This addition allowed Sheila to move their son as she rolled around the house in her wheelchair. The life hack consisted of purchasing a product and then adding something to it to give it an additional affordance that had utilitarian value.

A second example of a modification life hack outcome was Arnold's rental vehicle tailgate closer. The day before our second interview, Arnold made a reacher stick that allowed him to close the tailgate door on a recently rented van. He had to rent a van after a mechanic accidentally drove his adapted van into a garage bay door. Arnold described the issue he was having with the tailgate as follows:
When I got the [rental] van I found that it doesn’t have an electric lift on the tailgate. I got the tailgate open; I can’t reach it, so I got a bar of metal to hook into it to make a reacher stick to grab the tailgate and pull it down to where I can close it.

Arnold explained exactly how he made the tailgate reacher stick later in the conversation:

Yesterday, when I needed to make that hook to pull the tailgate down, I went down [to the Makerspace] and looked in the scrap bin and I found that somebody had a broken bar clamp that they were throwing out. I fished it out of the trash, cut the head off it and used that bar of steel as what I made the hook out of, because that to me is a lot more reasonable than trying to go out and find a new piece of steel to use. It wasn’t originally intended to be used as a thing to grab the door with. I just said, ‘what can I turn into a tool to reach up and grab the door?’” [Telephone interviewee]

A third modification life hack outcome was Grant's adapted car audio controllers. Grant cannot grasp objects with his hands which made turning the round knobs and pushing buttons on the radio in his adapted van difficult. He used a product called Sugru to modify the shape of the knobs and buttons to make them easier to use:

Me: Are there specific materials beside zip ties and Velcro that you like to use when you are creating a DIY solution?
Grant: Sugru is a moldable silicone that sticks well and is easy to form into different shapes. I use that a lot on the buttons in my van. But I almost always go to Velcro and zip ties first.
Me: How might you use Sugru on the buttons with your van? Do you use it to repair broken buttons or to make buttons easier to use?
Grant: Easier
Me: So maybe to change the shape of a button?
Grant: Right. I have a lot of round knobs, so I use it to create a cone that sticks off the round. I can hit the cone to turn the knob. I also use it to build up certain buttons that I push more than others. Like my favorite radio station.
Me: so almost like an extension or lever?
Grant: Yes. [IM interviewee]

While Arnold modified a piece of scrap metal to turn it into something he could use, both Grant and Sheila engaged in usage drift which consisted of changing the original design of objects to use them in their daily life activities adaptively. In all three instances, the participants took something that already existed and altered it to suit their needs and preferences. The outcomes of
their modification life hacks strengthened and enhanced the link between their capabilities and
the objects they used for the underlying practice tasks.

_Bricolage._

A bricolage life hack outcome is an amalgamation of two or more different objects. The
underlying life hack activities result in a single entity that is more useful and usable than the
constituent artifacts. Bricolage life hacks resemble hacker-like acts of scavenging, tinkering, or
making creative use of resources (Nikitina, 2012). The outcomes of bricolage life hacks allow
participants to leverage the components, features, or affordances of one or more supplanted
objects in a daily life practice. Associated activities include combining, piecing together,
connecting, and putting together. A bricolage life hack can be something as simple as adding
LED lights to the bottom of a wheelchair and footplate so the user can see at night (Stuart). It can
also be as complex as making a baby bottle warmer out of aluminum foil, a low-powered heating
unit, and pre-made baby bottles full of milk (Sheila and Jack). No matter the complexity,
bricolage life hacks bring together multiple objects in ways that are useful and usable to a
participant engaging in a daily life practice.

Samantha's yarn holders represent one example of a bricolage life hack. She took an ink
pen, removed its contents, and fed her knitting yarn through the ends of the hollowed-out writing
utensil. It was difficult for her to manipulate the yarn with her bare hands whenever they went
numb, and this life hack outcome made it easier for her to continue knitting during those times.
By adding the hollowed-out pen to the yarn, she gave herself a rigid interface that allowed her to
manipulate the yarn despite her reduced dexterity.

Grant's electric toothbrush life hack outcome was another example of bricolage. Grant
has limited use of his hands, and he needed a way to hold and use his electric toothbrush without
dropping it. His solution was to buy a billiard hand brace and add it to the toothbrush. The original intended use of the brace was to make playing billiards easier and more accessible for individuals with limited or no hand grip. He attached the brace to his toothbrush in a way that allowed him to hold and control it despite his hand impairment.

Stuart worked with allies to implement a bricolage life hack so that he could use a product. He has limited dexterity and uses universal cuffs with pokers attached as an alternative to using his fingers. The bricolage life hack described in the following excerpt reveals what Stuart, his mom, and uncle did to make his Xbox controller accessible so he could play video games:

I should bring up, too, that I have an Xbox 360. My mom came up with this idea of wrapping the Velcro around a pillow, in the center of this pillow and then putting the pillow on my lap and using these hand thingies [universal cuffs and pokers] to be able to hit the buttons. And I came up with the idea of breaking a regular burnable CD. I broke those and I created larger shapes and connected them with Velcro to the buttons that I pressed. That gave me a larger space to work with when I needed to press buttons. Because when they’re small, the buttons are the size of the end of [the] tips [of the pokers] and it’s hard to accurately hit the buttons...Then on the controller my uncle helped me wire in a mouse trigger, where I have my right trigger, which is often used for turbo or shooting. I have it connected to the controller and I place the mouthpiece in my mouth and I use my tongue to press on the button, so that I can play games better than I would be able to. Otherwise, I wouldn’t be able to use turbo or I might not even be able to shoot. It would just be really frustrating to even try. [Video-chat interviewee]

Stuart and his family attached objects to one another (e.g., secured the controller to the pillow with Velcro), changed the form of the joystick (e.g., replaced buttons with broken CD pieces), and added something to the controller (e.g., the mouth trigger). Each item added to the controller made it possible for Stuart to access and manipulate its features and affordances with his given capabilities. The same was true for Grant’s toothbrush life hack and Samantha’s yarn holders. The amalgamations participants created had everything they needed to successfully productively manipulate the constituent objects despite hand numbness, limited dexterity, and limited grip.
Image 1 - Stuart’s modified Xbox controller

Image 2 - Stuart’s universal cuffs and pokers
Repair & maintenance.

A repair & maintenance life hack consists of non-professional or "do-it-yourself" repair and maintenance activities. Sometimes these efforts are intended to circumvent formal repair and maintenance channels, especially when it comes to servicing durable medical equipment or assistive technology. Co-participants who repaired and maintained equipment usually had horror stories about past experiences with professionals who typically do these tasks for people with disabilities. Their life hacks obviated the need to deal with professionals which saved participants money, prevented headaches, or both. Repair & maintenance life hack activities included fixing, maintaining, or overhauling equipment. They also included efforts to reassemble or replace equipment parts and accessories. The underlying equipment included power chairs, other durable medical equipment, and various artifacts around the home or office. Co-participants often attributed their repair and maintenance capabilities to experience, technical knowledge, advice from others, or service referrals.

Repair and maintenance life hacks usually enabled participants to address an issue related to mobility, accessibility, technology, or service providers which prevented them from engaging in a daily life activity and using artifacts. Arnold mentioned two different maintenance/repair life hacks that enabled him to keep an old power chair working. One consisted of overhauling a chair by taking it completely apart, replacing the motors, rewiring the chair's electronics, and then putting the whole thing back together. Another one consisted of upgrading the joystick pod as described in the following excerpt:

My latest thing is the push-stick pod I had to do some reverse engineering on. If you go on eBay to look for pods, there’s two styles, one with a speed potentiometer knob and one without, where they want you to change speed with this pushbutton setup that is clumsy. I said, gee, they look almost identical and I bought some of the cheap ones without the knob. The cheap ones without the knob are 50-100 bucks. With a knob, they’re about $250. Opened them up and found, gee, on the board there’s three holes that
say pod module. Did some reverse engineering, electronic poking around and found that, gee, I can fill one hole and put in $10 worth of parts and turn my $100 pod into the $250 pod. That was one of my latest things. [Telephone interviewee]

Sheila's husband Jack similarly performed do-it-yourself maintenance and repair tasks when there was an issue with her power chair. Once he repaired the control box on when it stopped working:

Me: I know Sheila told me the control box on her power chair, if she ever had any issue with it, you would literally take it apart and fix it...
Jack: Yeah. Oh, did she tell you about that?
Me: Yep.
Jack: The first chair she had?
Me: Yeah, how you used to literally take it apart?
Jack: Yeah. She was having problems and it wasn’t operating properly, so we called the dealer where we got it from, and they said we can get you a new one for two hundred dollars or a used one for ninety. We didn’t have the money, so I took the bottom off, and I looked at it, and there were just two hemispheres, and a pentameter that went this way [points left with right index finger] or that way [points right with left index finger], a lot simpler than it is now. I blew the thing out, and dusted it, and cleaned it, put it back together, and never had another problem. I said I’ll keep my two hundred bucks. [Face-to-face interviewee]

Sheila, her husband Jack, and Arnold avoided going to professionals by maintaining, upgrading, and repairing durable medical equipment themselves. These and other examples suggest that repair and maintenance life hacks consisted of addressing mobility equipment needs (and wants) without going to a third party or paying for expensive and sometimes unnecessary parts and services. Also, Jack and Arnold's knowledge and expertise with electronics and mechanics enabled them to figure out the underlying issues and how to address them. Arnold had a mobility impairment but still possessed the upper body movement and hand dexterity needed to work on his mobility equipment. Sheila, on the other hand, relied on her husband Jack's physical capabilities to keep her power chair working. A later section will examine the roles participants played in life hacking efforts when they worked with a co-participant or ally.
**Action-oriented life hacks.**

Unlike object-centered life hacks, action-oriented ones are inseparable from daily life practice activities. Participants enacted action-oriented life hacks as they interacted with practice artifacts or performed practice tasks. Unlike object-centered life hacks which often resulted in a tangible outcome that a participant leveraged to participate in some activity in his or her life, these involved changing the activity itself, certain aspects of it, or the way the participant did it. In other words, action-oriented life hacks consist of activities the participant does while performing a practice task. An action-oriented life hack does not exist in any observable form until a participant enacts it. Therefore, an understanding of what the participant needs to do a given practice task manifests itself in the actual doing of the practice task rather than the design and development of a life hack outcome.

**Re-appropriation.**

A re-appropriation life hack is an instance of an individualized human-to-artifact interaction that makes an artifact more useful or usable to a participant engaging in a daily life practice. Re-appropriation life hack activities often involve leveraging common practice objects and the body in innovative ways. Sometimes re-appropriation life hacks co-occur with artifact-centered or procedural life hacks. For instance, someone may not only use a common object in a unique way but also employ an individualized procedure to complete a practice tasks that requires the same object. A re-appropriation differs from the more standardized interaction method most other people would use to complete the same practice task.

The mark of many re-appropriation life hacks is the opportunistic use of whatever is available to someone as he or she attempts to participate in a daily life practice activity. They often involve extracting as much value from the objects at one's disposal as possible. The ways
participants utilized the underlying objects would often differ from the original intended purpose as defined by the designers. Re-appropriation life hacks most distinctly resemble the idea of information-communication technology (ICT) usage drift. Usage drift occurs when consumers utilize information-communication technologies in ways that product designers and developers could not predict during the design and development process (Mallard, 2005). Re-appropriation life hacks similarly consisted of participants utilizing objects for purposes and intentions that deviated from convention or socially accepted human-to-artifact interaction methods. Some re-appropriation life hacks also required the use of modification outcomes, albeit in unique and opportunistic ways.

Leon's baby carrier was a good example of a re-appropriation life hack. It involved using a sweater to carry his baby niece while walking with his cane-crutch. He described the life hack as follows:

I made a little I don’t know what you call it. It was like a tourniquet or something where I just tied it on her, put the sleeves together, tied it together, wrapped her in it, and I could lift her up that way and take her different places in the house. [Face-to-face interviewee]

Most people carry children in one or both arms and wear sweaters to keep them warm. Leon leveraged a sweater for an altogether different purpose: to carry his young niece.

Kimberly's creative use of a medical transport chair and household furniture was another example of a re-appropriation life hack. At the time of our interviews, Kimberly was having some issues with her power chair. Her re-appropriation life hack consisted of leveraging both a manual medical transport wheelchair and strategically arranged furniture to get around in her home until she got her power chair refitted. Unlike most manual wheelchairs which have 20+ inch tires, a medical transport chair typically has 8-12” back wheels and 6-8” front wheels. With wheels that small, a transport chair does not provide the affordances needed to grab the wheels
propel oneself. Family members or caregivers typically push a person around in a transport chair. Kimberly explained how she leveraged this piece of durable medical equipment and objects in her living space as follows: "My manual [transport] wheelchair doesn't have [regular-sized] wheels, so I have the furniture arranged so that I can grab onto it and propel myself with my hands" [IM interviewee]. Most people would not consider household furniture a mobility aid or attempt to use a transport chair to get around independently. By leveraging the furniture and its arrangement as well as the chair, Kimberly pushed and pulled herself around her living space independently. She actively and uniquely leveraged a piece of durable medical equipment intended for passive use by interfacing with the furniture in her environment.

**Procedures.**

Procedural life hacks are individualized methods participants used in their daily life practices to get things done. They include tips, tricks, and shortcuts participants leveraged to exploit a set of circumstances and do whatever they wanted or needed to do. Although procedures are not artifact-centered, objects do factor into many of them since they either are required to do the underlying activity or offer useful affordances that enable the participant to utilize his or her individualized procedures. Procedural life hacks are participant-centric task completion steps that are unique to his or her capabilities. Participants enacted the same procedure every time they wanted to do the underlying daily life activity. Many procedural life hacks are grounded in an individual’s specific capabilities and environment as well as the situational factors surrounding a given practice activity. Most procedural life hacks obviate the need to ask for help and thus reduce participants' dependence on other people. Sometimes they include a specific role for an ally or other person assisting the participant. Procedural life hack-enabled tasks often differ from the ways that most non-disabled individuals do the same daily life tasks. They represent the ways
participants figured out how to do things in their daily lives using the physical capabilities they possess.

To reiterate, most procedures involve artifacts. These objects, however, are common to the underlying practice activity, regularly utilized by the participant, or both. What made some procedural life hacks unique was that participants leveraged common objects in multiple and unrelated everyday practices. For example, Scott uses a walker for mobility purposes inside of his home. In addition to using it as a mobility aid, he leveraged his walker as a carrying tool. Scott would place a plate of food on the walker seat and then use the mobility device to move himself and the plate from one spot to another. Eventually, he added something to the seat of his walker to make this way of carrying food less prone to messy spills. This bricolage life hack consisted of attaching mesh netting around the seat of the walker to catch a plate in case it slid around on the seat. Doing so minimized the chances of dropping food on the floor. However, even before hacking the walker itself, Scott used it as both a mobility aid and a carrying tool. He exploited the walker's natural affordances to carry food to and from his dining room table independently while simultaneously using it to walk. The mesh net he added to the seat made his procedure less messy.

Neil had several procedural life hacks that involved leveraging the objects in his environment, parts of his body, or both. For instance, he regularly used crutches to get around in his apartment, but it was hard to do certain tasks in the kitchen while simultaneously using them. Neil had a way of cutting and paring food that obviated the need to rest his body weight on his crutches while using the knife: "[W]henever I would pare something, and I needed to be standing up at the table I’d typically use a table as support for balance. So, I lean against it excessively" [Face-to-face interviewee]. Neil also had motor control issues that made using both
hands in a coordinated fashion difficult. To deal with this, he used his right hand “excessively” and avoided using the left one when possible. For example, if he needed to cut the food he was eating, he used the fork to do it to circumvent using a knife in one hand and a fork in the other. Neil also had a unique way of buttoning his shirt that allowed him to use his right hand only. He used his right thumb to push a button into a hole while holding the edge of the shirt with the other fingers on his right hand. These procedures involved taking advantage of objects and environmental affordances as well as certain body parts that were readily available and easier to use.

Participants who utilized procedures tended to describe a series of steps they used to complete practice tasks. These repeated courses of action allowed participants to leverage the physical capabilities they possessed to do activities, albeit in individualized ways. For example, despite being a wheelchair user, Cecil never felt limited by stairs because of his procedural life hacks for steps. They allowed him to go up and down stairs if there was no ramp or elevator. Going down was a two-step process that consisted of sitting down on the first step and scooting down the stairs one step at a time. Ascending the stairs was a two-step process as well which involved sitting on a step and then lifting himself up onto the next one. Rather than using his feet and legs to walk up and down a flight of stairs, Cecil relied on a procedure that allowed him to scoot up or down using his arms, legs, and bottom.

Leon shared a procedural life hack that allowed him to safely remove items from his oven. He uses a cane-crutch to walk and has balance issues. It is hard for Leon to simultaneously hold on to his cane-crutch and lift something heavy out of the oven without falling and possibly burning himself. Leon regularly used the following procedure to take an item out the oven: 1. pull a kitchen chair close to the oven; 2. take the item out of the oven and place it in the seat of
the chair. After removing the item from the oven, he either 3a. moved it from the chair to the stovetop or 3b. transferred the dish to a second chair; 4. pushed the chair to the table, and 5. lifted the dish from the seat of the chair to the table. The first two steps in Leon's procedure allowed him to hold his cane-crutch with one hand while pulling the item out of the oven. The remaining steps enabled him to move the item to the desired location while walking with the cane-crutch. The re-appropriated chair served as a stable yet mobile surface that could support the weight of a heavy dish. It offered affordances that made Leon's procedural life hack possible. He always used the chair as a resting place for a heavy item and sometimes used it as a tool to transport the item from the oven to the table as well. The chair was one of many objects involved in Leon’s execution of his individualized procedure to move a dish from the oven to his kitchen table.

**Additional insights on the six types of life hacks.**

As the preceding section reveals, artifact-centered and action-oriented life hacks are not mutually exclusive. Sometimes participants used life hacks from both categories to accomplish one practice task or multiple tasks that constituted the same practice. Also, some action-oriented life hacks have both re-appropriation and procedural components. To distinguish one life hack from another, I had to disentangle the different actions and objects participants mentioned in their description of a practice activity and the life hack that enabled them to do it. For instance, Leon's description of how he removed dishes from his oven and moved them to his kitchen table consisted of a set of steps. Embedded in those steps was a reference to a re-appropriated kitchen chair which he described as one of the pieces of furniture he used to transport plates and cups from one spot in his kitchen to another at a different point in our conversations. Also, Kimberly re-appropriated a transport chair and the furniture in her home for alternative purposes but also
utilized a procedure that consisted of grabbing the items in her environment and pushing or pulling against them to get the chair to move.

The object-centered and action-oriented distinction is an important one. Typically, studies that acknowledge the life hack-like activities of individuals with disabilities focus on the artifact-centered activities performed on assistive technologies, mobile phones, and other artifacts (Anthony et al., 2013; Kane et al., 2009). Findings from this dissertation research study reveal that individuals with physical impairments may change and adapt their actions and ways of performing them in addition to the physical artifacts they use. Scholars who are interested in accessible design should always consider the fact that individuals with disabilities may be able to adapt in multiple and diverse ways. Also, the distinction between object-centered and action-oriented makes it clear that professionally-designed artifacts are not always primary enablers. Sometimes professionally-designed products served as inputs into life hacking activities. These inputs were useful only to the extent that participants could leverage them as needed. Whether participants modified, repaired, or created an assemblage of objects or simply used a product as-is, they determined usability and usefulness. Some life hacks commonly resulted in productive forms of usage drift, which allowed participants to engage in daily life practices in ways they could not do otherwise.

Life hacking activity can potentially tell designers things that are hard to uncover via surveys, usability tests, or controlled research settings. However, some of these insights are best understood when they are also grounded in a solid understanding of the different reasons why individuals with disabilities life hack. Some of these reasons are related to the socially constructed nature of disability as well as the roles that people with and without disabilities play in the design and development of different products and services. The next two sections of this
chapter will delve into various aspects of life hacking, accessible design, and the implications of each from the perspectives of study participants.

Participant Perspectives: Conceptualizing Disability, Design, and Life Hacks

In the opening section of this chapter, the term *life hack* was said to embody the different adaptation, modification, and design-like activities that allowed participants to engage in daily life practice activities despite accessibility or impairment related challenges. The participant-centric orientation adopted in this section is meaningful given the way persons with disabilities are excluded from the process of design and often viewed within society. Participants’ life hacking activity contradicts many of the assumptions that undergird common disability models which influence the provision of products and services to the disability community as well as societal understandings about (dis)ability. The purpose of this section is to illustrate some of the benefits of examining participant life hacking from their perspective as well as what those insights can add to designer, researcher, and societal understandings about disability.

There are three primary disability models: medical, corporate, and social. Each one informs how a society’s institutions and people understand, view, and treat people with disabilities. The *medical model* frames individuals with disabilities as incapable, deficient, and needy and makes no distinction between disability and impairment (Fulcher, 1989; Goggin & Newell, 2003). The medical model assumes that people with impairments cannot take responsibility for their well-being. Somewhat related to the medical model, the *deficit model* sees disability as an individual problem *curable* through rehabilitative medicine or technologies made and distributed by experts who often lack personal lived experience with impairment (Ellis & Kent, 2011). Both the medical deficit models support the corporate model, and they are prominent in industries that provide products and services to members of the disability
community. The corporate model esteem scientific knowledge, professionalization, and formal training over the views and perspectives of individuals with disabilities (Goggin & Newell, 2003). According to Goggin and Newell, people who perpetuate professional and primarily medical model ideas create both scientific knowledge and technologies developed specifically for individuals with disabilities in controlled environments removed from their everyday experiences (Goggin & Newell, 2003).

Individuals and institutions operating under corporate model assumptions frame disability as something to be professionally managed with little or no regard for the social, economic, and other realities many who live with physical impairments face in their everyday lives (Fulcher, 1989; Goggin & Newell, 2003). Relatedly, they tend to ignore the reality of disablism, or everyday discrimination against people with disabilities, and its link to the embodied assumptions, concepts, and powerful images in the corporate and medical models (Goggin & Newell, 2003; Oliver, 1990). The products assistive technology and durable medical equipment makers create for individuals with disabilities (e.g., the wheelchair, cochlear implant, and contemporary digital communications/media technologies) and the regulated environment in which they operate give these entities access to manage and regulate the lives of individuals with disabilities. Without careful consideration of the downstream impacts of their decisions, they can effectively limit people with disabilities’ aspirations, movement, and access to various parts of the social world (Goggin & Newell, 2003). In other words, organizations that operate under the assumptions of the corporate model may produce products and services for individuals with impairments that disable them by further excluding them from mainstream social and economic life. The social meanings people attach to an impairment determine whether they become individual or social problems. Impairment becomes a social problem when the social actors who
fight to shape policy do so out of their biases, self-interests, and moral evaluations (Albrecht & Levy, 1981). Disability is embedded in the physical and social structures we take for granted as a society (Goggin & Newell, 2003). When the in-situ experience of impairment does not inform decisions that impact the lives of people who live with impairment, there is a greater chance those decisions will limit and oppress rather than empower and help (Oliver, 1990).

The social-constructionist view of disability stands in opposition to medical and corporate disability models and related terminology. It is underpinned by the idea that disability is not an individualized problem but rather a socially constructed one that makes impairment its foundation (Mercer, 2002). The social constructionist view also acknowledges that individuals with impairments should play a role shaping societal understandings about disability and related issues. One of the reasons why it is important to consider the language that participants used to describe their life hacks and themselves is to understand design, technology, and disability from their perspective as people who live with impairments. When a group has the economic, institutional, and conceptual independence to reflect on the artifacts they use, it can lead to different knowledge, group constructions, and cultural practices that can be compared to prevailing ones perpetuated by other entities (Goggin & Newell, 2003). As the remaining sections of this chapter and later ones affirm, life hacking does afford a degree of independence from the individuals and institutions that make products and provide services for people with impairments as well as non-disabled people in general who operate under naive assumptions about disability.

Most approaches to accessibility and design in general either exclude consumers with impairments or include them only to generate, test, and validate what professionals make. Ironically, participants' life hacking activities often had design-like qualities. The same
individuals who conceptualized and developed life hacks also used the outcomes of their efforts. Looking at participant terminology provides insights into what the purpose and goal of design should be from the situationally-grounded perspective of people who live with physical impairments. It also affords experientially-grounded insights into the lived experience of impairment as well as the downstream impacts of decisions that are uninformed or under-informed by their perspectives. Some disability studies scholars say that phenomenological examinations of people’s live experiences with impairment may help to reconcile social (social model) and biological (medical model) aspects of impairment (Mercer, 2002). Others stand behind the idea “Nothing for us Without Us”, or that political-economic and cultural systems must recognize and include the experiential knowledge of people with disabilities in decision-making processes that affect their lives (Charlton, 1998). The life hacking activity of individuals with impairments represents one context where design, the lived experience of impairment, and experiential knowledge of people who have impairments coalesce in productive and insightful ways.

Oliver described how capitalist societies produced the medical model of disability. He explained the benefit of examining disability and economic production as follows: “the nature of disability can only be understood by using a model which takes account of both changes in the mode of production and the mode of thought as well as the relationship between them” (Oliver, 1990, p. 32). These ways of understanding are not possible by people who are oblivious or unsympathetic to the socio-cultural factors surrounding disability and attribute disability to the individual only (Oliver, 1990). Participants in this dissertation research study did not talk about disability just in terms of impairment. In line with the social model of disability, they talked about economic, social, political, and other barriers that society builds on top of impairment
which contribute to the experience of being disabled (Mercer, 2002). Examining how participants label and conceptualize their life hacking activities affords a look at disability, design, and accessibility-related concerns from a perspective that often gets excluded from decision-making conversations. It also affords what Goggin (2008) refers to as the “two-sided logic of innovation,” or “the sustained, genuine interaction between different users, different notions of ability, disability and impairment, and the processes of design” (p. 7) afforded by participation in these processes.

Study participants often made comments that illuminated different aspects of their life hacking behaviors as well as what those behaviors meant to them. The goal of this section is to explicate common characteristics of their life hacking efforts from their vantage-point. The following presents an analysis of the terminology participants used to characterize their efforts as well the motivations behind their life hacks.

**Participant terminology.**

Participants used several different terms to refer to either their efforts or the outcomes of those efforts. Examples include adapting/adaptation; "homemade accessibility"; modifying/modifications; life/lifestyle hacks; recycling/repurposing/reusing; "self-developed tools"; strategies; techniques; tactics; ways of doing; and "what you need type solution." One or more participants used these terms either when asked to label their behaviors or while describing their efforts. Although the examples listed mean different things, all of them fall into the same two categories described earlier: artifact-centered and action-centered.

Artifact-centered terms typically included those participants used to describe something they made, modified, repaired, or assembled for use in a daily life practice. Participant terms and phrases like modification, recycle/repurpose, "self-developed tools," homemade accessibility,"
“energy adaptation,” tactics, and "what you need type solution" all fit neatly into this group. Action-oriented terms often referred to ways of adapting oneself, one's actions, or both to get something done. Participant used terms and phrases like "adaptive tools," "developed way," way to be independent, "responding to a need," “strategies,” “techniques,” and “ways” with action-oriented connotations rather than artifact-centered ones. Other terms like “adapt/adaptation,” “do-it-yourself,” and “life/lifestyle hack” fell into either category depending on who used it and how. Appendix F lists and common terms and how participants used them to describe their adaptation, modification, and design-like activities as well as the outcomes of those activities.

Participants and allies, if applicable, tended to use activity-oriented terms to capture their methods of doing daily life activities as well as the essence of all their life hacking efforts. They used these terms to refer to procedural life hacks that enabled them to manage energy levels as a busy college student (Neil), complete grooming tasks independently (Deanna), or use the body in distinct ways to perform a task such as moving firewood while walking on all fours (Ross). They also used these terms to describe themselves, other individuals with disabilities, or life hacking in general. For instance, Stuart [Video-Chat interviewee], Ross [Face-to-Face interviewee], and Sheila's husband Jack [Face-to-Face interviewee] referred to their efforts as "how we manage, how we do things," ways "I've chosen or managed or found to go about it," ways of "just respond[ing] to what’s in front of you," respectively. These descriptions link life hacking to intentional and productive ways of getting something done that are grounded in one's lived experience. Participant definitions also suggest they saw their efforts as a necessary and practical part of life for an individual with a disability. This latter assertion was stated more explicitly by Kimberly who said, “with CP, you kind of have to [adapt]” [IM interviewee].
Artifact-centric terms and corresponding definitions captured what participants and allies, if applicable, did to artifacts or the built environment to make them usable in their everyday life practices. For instance, Samantha [Telephone interviewee] labeled her efforts "homemade accessibility" which consisted of "create[ing] or alter[ing] something to make it work for you."

Many of Grant and his wife's artifact-centered outcomes consisted of "changing my environment...to make it possible or easier for me to interact with it." A few of Arnold's activities consisted of "recycling," "reusing," or "repurposing" something. He provided the following example to illustrate what these terms meant: "It may have been made for something else; let’s see if I can make it work for whatever task I’m trying to accomplish" [Telephone interviewee].

Participants also used artifact-centered terms to refer to the tangible outcomes of their efforts. Stuart described each one of his "what you need type solutions" as "a certain something [that] I have to create it [sic] to get the needs met that I’m looking for" [Video-Chat interviewee].

Wallace [Video-chat interviewee] similarly described the modifications he and his caregivers utilized in his daily practices as "customized and personal to my situation." These descriptions suggest that life hacking activities include not only making artifacts useful and usable but also figuring out how to leverage objects for purposes other than the one the original designers had in mind. This latter assertion is best summed up in Grant's approach to addressing issues in his daily life, " I will rarely look at it, [a] product only for its intended use. I'm constantly thinking outside the box on those items" [IM interviewee].

Some of the terms and definitions participants used to describe their efforts fell into both life hack categories. Terms were classified as both when more than one respondent used it and usage varied by participant and context. For example, Scott, and Sheila used the word adapt to refer to instances of using an object for a unique purpose. On the other hand, Erin, Dominic,
Neil, Tabitha, and Ross used the same word to refer to instances of doing a task in a unique way or matching physical capabilities with everyday life demands. Similarly, Erin viewed the term "do-it-yourself" as a reference to doing something differently while Sheila, Tabitha, Neil, and Scott linked the same term to an artifact one creates, makes, uses, or adapts without the help of a professional.

Only one participant used the term life hack, but the way he defined it was both action-oriented and object-centered. In one instance, Leon described a life hack as "whatever you can find to help you." This description was the capstone of a larger description of his approach to addressing accessibility and impairment issues:

I think when you have something like what we have, cerebral palsy, I don’t think there’s any specific thing that I use. Anything that’s around that I can handle, like if it’s something I can lift or I can put it in, it could be a wagon, it could be a basket, it could be a bag, it could be a chair, it could be a piece a furniture. It could be anything that if I could push it or pull it, or pick it up. I used to use, like if I had a book bag, I would put stuff in book bags and take it to places, or just anything that I could handle that I could use, I would use. Again, they’re life hacks; whatever you can find to help you, that’s what I would use. [Face-to-face interviewee]

In the excerpt, Leon referred to a life hack as “whatever” met his need at a given moment. His references to objects in the excerpt touch on the object-centered aspect of life hacking. However, during other parts of our conversation he described this same term as "capable ways of doing things in life in general", "adapting life to the way that you live", and "adapting life to make it more accessible for yourself." The "capable ways of doing things" description resembles action-oriented procedural adaptations. The "adapting life to the way you want to live" and "adapting life to make it more accessible for yourself" descriptions both hint at the necessity of adapting, generally, for individuals with disabilities, which is characteristic of several activity-centered descriptions.
Why “life hacking?”

One of the issues I encountered while conducting this study was how to label the phenomenon in a way that was faithful to the participants’ experiences and efforts. Earlier I mentioned the importance of giving individuals who live with impairments a voice in all decisions that affect their lives. I also talked about how discrimination against people with impairments and their marginalization within society often results from them not having a voice in the social shaping of society’s understanding of disability. In this section, I explain how participant conceptualization of their adaptation-related activities justifies the use of the term life hack in this document.

Scholars in the accessibility community commonly use the word adaptation to refer to attempts to overcome accessibility challenges or make design artifacts more accessible in everyday life contexts (Anthony et al., 2013; Kane et al., 2009). Thomas Moran, a popular figure in the human-computer interaction community, used the term adaptive design to refer to consumers realizing usefulness and deriving satisfaction from resources at hand by fitting them into the patterns of their everyday life (2002). Moran’s definition captures many of the artifact-centered co-/participant efforts described earlier in this chapter. However, the terminology and definitions participants used to describe their efforts extended beyond technology, accessibility, and the material resources at their immediate disposal. Participants often used terms and definitions that attributed agency and self-determination to themselves. Later sections of this chapter will examine these two characteristics of participant efforts in greater detail. For now, it is important to point out that participant definitions of terms like "ways to be independent," "strategies," "techniques," "adapt," do-it-yourself," and "life hack" had multiple layers. Some participant efforts did involve leveraging objects to realize usefulness and derive satisfaction, as suggested by Arnold’s definition of the terms recycle, repurpose, and reuse. Others, such as
Stuart’s definition of adaptive tools and Neil’s definition of adapt, focused on action-oriented activities more than technology or other kinds of artifacts. Similarly, Grant, Samantha, and Leon explicitly linked their activities to accessibility-related concerns while participants like Sheila, Tabitha, and Deanna explicitly linked their efforts to living and doing things independently. At their core, participant conceptualizations made it clear that the way the accessibility and HCI communities talk about adaptations may not capture the different types of related activities performed by individuals with physical impairments. Overall, participant efforts were more purposeful, emergent, and practice-oriented than deterministic and technology-dependent. However, scholars who talk about adaptations tend to pay more attention to technology issues than the interdependent ways of leveraging it and other artifacts for self-determined purposes. Since the term adaptation, as accessibility and HCI scholars commonly use it, ignores some of the activities and undervalues the intentions of individuals with disabilities who engage in related activities, I decided to look for a more accurate term to describe participants’ efforts.

Danny O’Brien coined the term *life hack* in 2004 to describe how programmers use technology to maximize productivity, increase efficiency, and manage information overload (Potts, 2010). Over time, however, the use of this term has expanded beyond knowledge work in the information age to almost any activity a person does in his or her daily life from cooking, cleaning, and exercising to DIY automobile repair, interpersonal relationships, and health maintenance. Foundationally speaking, a life hack is a clever yet non-obvious way to solve a problem or do something and life hackers “operate skillfully and inventively, moderating and adapting tips and schemes” (Potts, 2010, p. 35). In the following three sub-sections and the next two chapters, I will advance several arguments justifying the use of this term in this manuscript.
Again, later sections of this chapter address the motivations behind participant life hacking efforts such as a desire for independence, self-determination, and greater agency. Interestingly, some computer hackers describe themselves as individuals who undertake projects or build products because they derive a sense of pleasure from doing so (Levy, 1984). On one level, hacking is political, and practitioners engage in it to undermine institutions that seek to control the Internet (Nissenbaum, 2004), make society a better place to live (Leeson & Coyne, 2005), and secure and wield power over computer systems (Jordan & Taylor, 1998). On another level, hackers do what they do to show off their technological prowess (Turgeman-Goldschmidt, 2008) and accomplish what others cannot do with technology (Jordan & Taylor, 1998). Hackers direct their efforts towards constructive goals that have both real-world implications and personal value. Hacking may involve engaging in intentionally subversive activities, but hackers also value using their skills and knowledge to exploit computer systems simply for the sake of doing so or because of the fame and notoriety they earn as a result. Central to the activities of hackers is a sense of pride derived from their creative inventiveness with technology and their skillful and inventive ways of using it for collectively-determined ends.

Although the sophistication of participants’ life hacks varied, all of them were individual expressions of ingenuity as well as demonstrations of skill and inventiveness. Potts (2010) asserts that life hacking, or everyday problem-solving, represents unpredictable ways that people demonstrate creative inventiveness in different everyday life contexts. Unlike computer hackers who seek to impress others by their technical skills, take overt political stances, or both, participants sought to “hack” their everyday lives by finding and leveraging unique ways of addressing barriers or exploiting opportunities, albeit in personally creative ways. The
terminology and related definitions they used to describe their efforts suggest life hacking was just as valuable to many of them as accomplishing the daily life practices that necessitated a life hack solution. Therefore, participant efforts not only allowed them to solve everyday life problems but also accomplish goals and derive personal satisfaction from doing so. The ways participants defined and conceptualized their efforts suggests that although accessibility, technology, and available resources factored into their efforts, there was also a personal value component that researchers guided by Moran's narrow conceptualization of adaptive design can easily miss. Participants did more than fit artifacts into the pattern of their daily lives. They actively managed their daily lives by skillfully using their impaired bodies and exploiting various artifacts at their disposal in self-determined and personally satisfying ways. Participant life hacks were non-obvious in the sense that most non-disabled researchers and designers probably would have not have imagined or replicated them in their efforts to help individuals with disabilities through design. They were also somewhat subversive in the sense that participants appropriated social practice activities and artifacts as needed instead of conforming to well-known standards of using the body and leveraging design artifacts.

The LIFE in life hacking.

This dissertation study is phenomenological in that it seeks to both understand how human beings experience their lived world and garner insights about some phenomenon of interest that are grounded in an understanding of those experiences (Todres, 2005; van Manen, 2002). At its core, phenomenology examines “how we perceive, experience, and act in the world around us” (Dourish, 2004, p. 21). For this study, the phenomenon of interest is emergent forms of addressing issues with accessibility or impairment-related implications in the context of everyday life, and the analyses focus on the different ways individuals with physical impairments
experience and respond to them. Temporal, spatial, social, technological, political, economic, and other conditions circumscribed each participants’ daily life practices and ways of engaging in them. Many of these variables varied across instances, person, time, and situation. Nevertheless, these emergent activities always took place within the context of the everyday and the collection of participant practices which made them necessary. Life hacking activity was the result of co-/participants' physical bodies engaging in physical or speech acts in the real world (Merleau-Ponty, 1964). As such, life hacking and practice activity afford a phenomenal view of the world from the perspectives of bodies in the world experiencing and responding to it.

The word life in the context of this study refers to both the context of life hacking activity and the whole of everyday lived experience. It includes the temporal, spatial, social, cultural, technological, political, and other factors that constitute daily life for each participant. Contemporary understanding of life hacking as tips and tricks that increase personal efficiency and productivity may apply to some participants' life efforts. However, life hack as it is used in this study acknowledges the fact that related activities intertwine with a participant’s practices and co-constitute his or her lived experiences in several ways that vary depending on the situation, context, person, and other factors. Life hacking occurs in the everyday world as it is experienced by an individual rather than how it is understood and theorized by scholars or designers. Life hacking is grounded in the contextualized circumstances and experiential realities of daily life and, as later sections of this document reveal, many participant life hacks represent in-situ responses to reality and the circumstances that constitute it. The life in the term life hack acknowledges the embodied nature of life hacking and life hacking as a phenomenon that occurs in real time and real space. The word embodied here means co-/participants possess and act through a physical manifestation in the world known as the body (Dourish, 2004). In this sense,
the term *life hack* means more than a tip or trick that helps a person achieve a goal or accomplish a task. Instead, it serves as a phenomenon entangled in the embodied experiences, actions, and responses of individuals with disabilities as they encounter various accessibility, impairment, design, social, cultural, political, and other issues during their practice engagements. Life hacking stands in stark contrast to usability testing, surveys, and controlled experiments that seek to re-create or mimic interaction experiences and then learn from them. The activities described in this dissertation occurred in the laboratory of daily life where design artifacts, participants, and the circumstances of the life as usual met and sometimes clashed. Life hacking in this sense represents the ways participants perceived, experienced, and acted in real time within the laboratory of their individual yet routine daily lives.

*Leon’s definition of life hacking and participant efforts.*

One interviewee used the term *life hack* explicitly and defined it in a way that captures several aspects of participant behavior overall. Although only one participant explicitly used this term, the way he defined it captured several aspects of the projects and activities described by all 16 participants. Leon defined this term in four different ways:

Me: You mentioned your basket and your red wagon. Are there specific materials, things, or objects that you like to use when you're doing something? You mentioned the wagon and you mentioned the basket. Are there other things that you tend to go to often to do things?

Leon: I think when you have something like what we have, cerebral palsy, I don’t think there’s any specific thing that I use. Anything that’s around that I can handle, like if it’s something I can lift or I can put it in, it could be a wagon, it could be a basket, it could be a bag, it could be a chair, it could be a piece a furniture. It could be anything that if I could push it or pull it, or pick it up. I used to use, like if I had a book bag, I would put stuff in book bags and take it to places, or just anything that I could handle that I could use, I would use. Again, it’s life hacks; *whatever you can find to help you*, that’s what I would use. [Face-to-face interviewee]
Me: I want to go back to something else you said last time. You said you don’t like using the term ‘disability’ but ‘capability.’ Can you explain how did that come about? How did you decide that you liked capability?
Leon: Because a disability to me means you can’t do anything for yourself. You can’t comb your hair. You can’t brush your teeth. You can’t walk. You can’t talk. There are capable ways of doing things in life in general. People that if you don’t have let’s say a funnel to use to pour sugar in something, I’ll get some aluminum foil and make my own funnel. You find ways to make life hacks. That is what I call them. [Face-to-face interviewee]

Me: I like that you used the term ‘life hack,’ and I really like that term. If you had to define that, how would you define life hack?
Leon: Adapting life to the way that you live.
Me: Adapting life to the way that you live?
Leon: Or adapting life to make it more accessible for yourself, and that’s with anybody. If a fat person—excuse me for that—but if a fat person can’t get in the car (I’ve seen many fat people trying to get into a small car), they make their way in it. I don’t know how, but they make their way in it. It’s just like me. If I can’t get somewhere, it might look strange but I do it. We all do get by in life somehow. [Face-to-face interviewee]

Regardless of the way other participants labeled and defined their efforts and the specific actions involved, all efforts fit into one or more parts of Leon's four-part definition of life hack. The "whatever you can find to help you" phrase from the first excerpt includes project inputs, any artifacts co-/participants modified, repaired, or patched together into an assemblage, and the various object and environmental affordances they leveraged in their practices. The "whatever" one leverages to either make a solution or do a practice activity part of his definition points to the practicality aspect of life hacking.

The "capable ways of doing things in life" descriptor in the second excerpt above captures all participant-centric interactions with objects (re-appropriation) and procedural life hacks as well as the link between life hacking and daily life. Action-oriented solutions seek to create a better fit between participant capabilities and the physical demands a practice places on all practitioners. Whereas someone without a mobility or dexterity impairment might complete a task in a relatively uniform way, activity-centered solutions represent "capable" yet unique
“ways of doing” the same activity with an impairment. Unlike artifact-centered outcomes, activity-oriented solutions are inseparable from a task, the individual doing it, and the artifacts the task requires, if applicable. Action-oriented solutions represent ways of simultaneously addressing accessibility and impairment issues and engaging in a daily life practice activity. Whereas the description of a life hack in Leon's first quote captures artifact-centered efforts, the descriptor in the second excerpt is complementary to the definition of activity-oriented efforts. "Capable ways of doing" are re-appropriations and procedures that enable participants to engage in everyday activities. They entail modifying aspects of the practice rather than the artifacts used to do them.

The two excerpts from Leon's third definition of a life hack, "adapting life to the way you want to live" and "adapting life to make it more accessible for yourself," apply to artifact-centered and activity-centered solutions. Both types of “adaptations” enabled participants to engage in the practices they either wanted or needed to do in the face of accessibility or impairment-related issues. The generality of the phrase "adapting life" makes it applicable to multiple goals including improved accessibility, reduced impact of impairment-related issues, and changes in the way a person lives and does things in his or her life. Adapting life to make it fit the way a person wants to live seems like a rather broad definition. As such, it can include the non-technology related and more personal aspects of life hacking. Later sections will examine these ancillary aspects of life hacking in more detail, but suffice it to say that Leon's definition captures a dimension of these activities the accessibility community's conceptualization of adaptations does not.
Disability models versus the lived experience of impairment.

As a construct that is socially shaped by different stakeholders with different interests and goals, disability is inherently political. People who live with impairments, non-disabled individuals, family members of people with disabilities, policymakers, assistive technology manufacturers, medical professionals, educators, and several other individuals and groups play a role in the way society understands disability. The social meanings that people attach to some physical and cognitive impairments allow powerful groups to define them as social problems and then position themselves as part of the solution, sometimes for their benefit or personal gain. These groups not only possess the power needed to influence social policy but all operate based on their biases, self-interests, and moral evaluations (Oliver, 1986, 1990).

Unfortunately, some of the policies these entities push for have the appearance of benefitting individuals with disabilities but instead marginalize and exclude them. Academia, entire industries, and other capitalist institutions that have the power to influence disability-related social policy sometimes end up further excluding individuals with disabilities from mainstream social and economic life in ways that serve their self-interest. For instance, personal tragedy theory individualizes the problems associated with disability in a way that blames the individual and ignores the social and economic structures that create and reinforce many of those problems (Oliver, 1986). When institutions that possess the ability to influence policy perpetuate the personal tragedy theory rather than critically thinking about disability and its social shaping, they reify their role as entities that do things to, for, and on behalf of disabled people while doing very little to improve the quality of life and social status of the disability community (Oliver, 1986, 1990). There is little or no incentive for most entities that fill these roles to empower
individuals with disabilities to do things for themselves because doing so undermines social and economic policies that undergird their business models and reason for existing.

Different approaches to design that consider diverse needs and different abilities tend to have the same overall goal of making sure that individuals with disabilities can use artifacts and physical spaces. However, scholars and designers who champion and push for accessible design and empowering people with disabilities tend to subjugate those people to the position of beneficiaries rather than self-empowered agents. One example of this is the accessibility research community’s current push for do-it-yourself assistive technology or DIY-AT (Hook et al., 2014, 2013; Hurst & Kane, 2013; Hurst & Tobias, 2011; Leduc-Mills et al., 2013). The vision of DIY-AT is to include individuals with disabilities in efforts to make and modify assistive technology. However, the number of people from the target population represented in their studies is usually small or zero, and research findings often privilege the perspectives of non-disabled individuals who work with or provide products and services to members of the disability community rather than those who live with an impairment. Thus, people with power, influence, and resources who may not have any first-hand experiences with physical impairment conduct research, make decisions, direct initiatives, and draw conclusions with real-world implications about the best way to empower people who do live with one. There is minimal direct engagement with the people DIY-AT is supposed to benefit. Therefore, these scholars publish the results of their research and perhaps try to shape policy without critically examining how their efforts may affect the people they intend to help in the context of their daily lives.

Dominant deficit disability models make it easy for well-meaning people to position themselves as best able to help people with disabilities to overcome accessibility and impairment-related limitations. However, it is important to examine the social, cultural, and
economic factors that limit and disenfranchise people with disabilities in their daily lives in addition to technology-related ones. Otherwise, scholarly and other communities that could potentially play a role in foregrounding society’s understanding of disability and different approaches to design in people's real-life experiences instead create an echo chamber where the views and perspectives of the people they want to help take a back seat to their goals and agendas.

While some participants engaged in life hacking and daily life practices independently, others needed varying degrees of assistance from family members, friends, and others. When asked how often they sought assistance from other people in their daily lives, 13% participants said not very often, 38% said sometimes, and 50% said often or very often. Unsurprisingly, most of the individuals who did not need much assistance with daily life tasks also did not need much life hacking assistance. The next section focuses specifically on participants who needed help with both everyday activities and life hacking efforts. More specifically, I talk about assistance exclusively in the context of life hacking and everyday practices with the goal of illustrating how design and empowerment informed by the insights, perspectives, needs, and capabilities of a person who lives with an impairment looks. The following analysis uses interview data from one co-participant and several participants to delineate the different roles that each party played in life hacking activities. The findings suggest that one can access a consumer-driven model of disability that contradicts the personal tragedy theory by examining how participants work with co-participant and allies to life hack and engage in daily life practice activities. The different forms of aid participants described as well as their roles in these collaborative efforts allowed them to empower themselves even when they did not possess all the physical capabilities needed to do so independently.
Participant perspectives: Co-participant/ally roles in practices.

Both Sheila and Grant relied on their spouses primarily to help them with physical tasks they could not accomplish independently. Both typically had to rely on their significant other or someone else for assistance with tasks they could not do independently and did not have a life hack which made the task easier or more accessible. For instance, both Sheila and Grant relied on their spouses to prepare food for them and assist with wheelchair transfers because of mobility, dexterity, and upper body motor control limitations. The different life hacks both individuals used reduced their dependence on others but did not eliminate it. Grant encapsulated this dynamic perfectly while describing his daily routine:

[Near beginning of the first interview]

Me: On the recruitment questionnaire, you said that you ask people for assistance with daily activities often. What types of things do you ask for assistance with?
Grant: Mainly my wife. Since we both work at home. She is my primary helper. She helps me dress completely. Makes my breakfast and coffee. Fixes me a snack. Puts me on my bike. Picks up anything I drop.

[Near end of the first interview]

Grant: I have done things like make my software company 100% paperless. I use the new app to take pictures of checks so that I don't have to go to the bank. I should say that my kids take pictures of those checks for me. I have a particular cup and bought a refrigerator that has water on the door so I can get my own water throughout the day. That used to be a point of contention between me and my wife. I used to have a voice recognition telephone that my wife had to charge every night. I have since moved to this USB microphone and a typical headset. I have changed the door handles and added ropes, such that I can open and close every door without help around the house. I have installed motion sensing light switches. I bought a Samsung TV that I can control with my smartphone. In short, once I am dressed up for the day, I really don't need help from anyone until I'm ready to go to bed at night.
Me: So, you have made it so you only need help getting dressed and getting ready for bed?
Grant: 99%. [IM interviewee]

During other parts of our conversation, Grant admitted that at times he ran into unexpected obstacles which forced him to either wait for someone to come along and assist him or decide not to do the underlying tasks. For the most part, Grant could get through his day without his
wife by leveraging different life hacks. Sheila similarly relied on her husband Jack for tasks such as cooking, transportation, and some of the housework while doing almost everything else in her day using her physical capabilities and individualized life hacks. As a busy grandmother, employee, and disability rights advocate, Sheila sometimes encountered unexpected obstacles, and Jack was her primary go-to person in those situations. Otherwise, life hacking enabled Sheila to maintain her independence with minimal to no assistance from others.

*Image 3* - *Sheila’s adaptive dressing table and adapted comb*
Other participants were a bit more dependent on the people in their lives and either required or requested assistance with more of their everyday activities than Sheila and Grant. These individuals had dedicated help from family members and other caregivers such as personal aides and state-funded nurses or assistants. Kimberly, Erin, and Wallace sought to do things without assistance whenever possible, and they worked with others to devise and make some of their life hacks with that motivation in mind. Nevertheless, these participants needed help with many or all daily life practices. As an individual with quadriplegia who does not have any feeling or movement in his body from the neck down, Wallace was the least independent.
participant in this study. At the beginning of our first interview, he said there were only two activities he could do independently: operate his wheelchair via a sip-and-puff interface and use voice recognition software to control his computer, respectively. Erin had limited use of her hands and was nonverbal. She needed help with most activities of daily life.

Stuart worked part-time in a local grocery store and lived an active life outside of his home but often depended on his mother, caregivers, and strangers with tasks such as eating, health management, dressing, and reaching or retrieving objects. Unlike most participants, Stuart admitted that sometimes he sought assistance from others for tasks that he could do independently simply because of the convenience it afforded him. For instance, he possessed the ability to feed himself and had tools that made dressing and undressing easier but sometimes asked for help with these tasks when he did not feel like doing them.

**Participants perspectives: Participant roles in life hacking projects.**

A fascinating discovery about co-participant and ally life hacking efforts is that most participants framed themselves as active agents in these collective endeavors regardless of the type, degree, or frequency of assistance they received from others. Participants who worked with an ally to life hack had a similar way of describing their contribution to those efforts, which suggested they were more than passive beneficiaries of other people's work. For participants like Sheila who had limited use of her arms and hands, their life hack contributions rarely included physical activities such as assembling parts or manipulating objects. Nevertheless, they typically did not view their contributions as distinct from their allies'. They rarely said parents, nurses, friends, or spouses adapted or modified something for them. For example, when asked how she and her husband discovered or made life hack solutions, Sheila said, “We kind of did it together” [Face-to-face interviewee]. When describing the role that his wife played in their life hacking efforts, Jack
said, “Mostly her role is [to say] that’ll work or that won’t work. I had to brainstorm, but she came up with ideas as we went. I did all the doing, but basically I’d have the brainstorms and say let’s do this, and [she’d say] this doesn’t work” [Face-to-face interviewee]. Whenever they hacked something for Sheila, they would discuss the underlying issue and then Jack would brainstorm ways to turn their ideas into something tangible. He also did all the physical labor required to make the solution. Sheila held veto power when it came to determining whether a life hack worked for her. Sheila’s input regularly informed Jim’s physical efforts, and he was always open to her suggestions and feedback. Although Jack completed all the physical activities, Sheila and her husband both framed their life hacking activities as collaborative efforts. Neither one of them described life hacking as something Jack performed and Sheila benefitted from but rather something they did together to “figure something out” (Sheila) and “respond to a need or what’s in front of you” (Jack).

When someone else played a significant role in their life hacking efforts, Wallace, Grant, and Erin used the pronouns "we" to frame it as a collaborative effort, "I" to denote their individual contribution to the project, or "we" and "I" to distinguish who contributed what. For instance, Grant once went to a marine shop where someone made a wheelchair chest strap for him. As with many of his life hacks, Grant told the individual what he wanted, and the store employee made the strap according to his specifications. Grant described this episode as follows: "I went to a Marine shop and worked with a guy who does all of the ropes for sailboats. I had him build me a chest strap design that I can put on myself and tighten" [IM interviewee]. Wallace similarly described different life hacks as collaborative efforts and purposefully used pronouns that included him in the activity. For instance, when talking about a simple trick his
caregivers used to make sure he did not overheat while sitting in the sun, Wallace used the word "we" to describe it:

I had a nurse that was experienced enough to know that we needed to bring a spray bottle that we could fill with water to keep cool and spray open skin, spray people in the face and whatever. We did that. We were used to doing that with me if I’m going to be sitting out in the sun for an extended period of time. [Video-chat interviewee]

While Wallace used "we" to suggest that he had a say in the utilization of life hacks, Erin used the word "I" to refer to artifact-centered design activities. For instance, one of her life hacks allowed her to use her head to point to objects on her letter-board instead of her hands. Erin is nonverbal and has limited use of her hands, and this solution accounted for her physical limitations. In the following excerpt, it is apparent that Erin initially attributed the development of her laser pointer life hack to herself:

Me: What was the biggest challenge with your old communication system?
Erin: Fatigue! I would get tired quickly and I have so much to say
Me: okay. Yeah, that must have been a lot of pointing!
Erin: Yes
Me: - Will your video show me how you made your new system? [The participant shared a link to a YouTube demonstration video earlier in the conversation]
Erin: No I velcrowed [sic] a laser pointer to a visor and hook it up to a battery pack.
Me: so now you point using your head?
Erin: Yes.
Me: Cool! Okay, one final question. On the questionnaire, you said that you have worked with others to develop DIY solutions. Who did you work with and how did these individuals assist you?
Erin: My friend who do[es] electric work hooked up my laser to the battery pack. [IM interviewee]

Notice how Erin initially said she attached the laser pointer to the visor and then connected it to a battery pack but later indicated her friend played a role in this effort. In the examples presented above, Sheila, Grant, Wallace, and Erin all framed their contributions as essential to the combined effort. While sometimes acknowledging that other people helped, they claimed some responsibility for the conceptualization, development, and use of their life hacks. While these
participants often did not take part in the physical labor involved in object-centered life hacking, the efforts to construct, make, repair, or modify objects centered around them. Each participant played a vital role in the underlying activities and shaped the outcome in distinct ways by default. These participants did not possess the physical capabilities needed to strap a laser to a head visor, build a custom-made chest strap, or attach a yardstick to a comb. Nevertheless, they shaped these efforts by defining what they wanted, providing feedback, and lending their awareness of the underlying practice context as well as their capabilities, needs, and desires to these joint efforts.

Both participant and co-participant contributed knowledge and capability to life hacking projects. The former contributed an intimate awareness of self and practice context while the co-participant possessed the ability to turn all the inputs into outcomes. To be sure, there was overlap between the knowledge each actor contributed. For example, although Grant relied on others to do the physical labor, he understood and often pre-planned how those individuals should design what he asked them to make. On the other hand, Sheila understood certain things about her needs, wants, and practice contexts, but she relied on her husband Jack to devise and design something that would work for her based on her input. Jack was not ignorant of his wife's capabilities, needs, and preferences and yet he actively listened to her feedback. Participants and co-participants made different contributions to life hacking projects, and yet interviewees framed these joint activities as collaborative rather than carried out by a single actor alone. Also, unlike a lot of third-party design and development efforts, participant and co-participant life hacking projects were always directed towards one common end: to allow a specific person with a disability to do an activity given the unique circumstances of that person’s daily life.
Participant perspectives: Life hacking motivations.

This section examines the personal and often hidden benefits participants derived from their life hacking activities and how these benefits further justify the use of the term *life hack* in this research study. One cannot fully understand what participants' life hacking efforts meant to them beyond the obvious advantages of making things more accessible and having the freedom to engage in certain practices without looking at the different motivations behind them. This section describes some of the less obvious reasons why participants engage in life hacking activities from their perspective. The examination reveals that besides participating in various daily life practices, interviewees engaged in life hacking activities to control their destiny, derive economic benefits, reap therapeutic benefits, pursue hobbies or personal interests, and demonstrate their capabilities to others.

Controlling destiny.

Some participants engaged in life hacking activities because they either wanted to avoid feeling limited and helpless or desired as much independence as possible. Once Ross walked on all fours along an inaccessible trail leaving his wheelchair behind because he wanted to enjoy the hike with his significant other. Although he was initially hesitant to do so out of fear of what others on the hike would think, he decided to do it because he did not want to feel "limited." After admitting that sometimes engaged in life hacking activity because of the positive attention it brought him, Ross linked the hiking procedural life hack to self-determination and wanting to enjoy an activity with his significant other:

I was in Nova Scotia with my mom and my boyfriend Kevin at the time, and I wanted to go on this hike with him, and there were stairs. It was a looping trail, so we left the wheelchair and I walked on all fours. Again, that decision to do that publicly is awkward. There's where I could have been disabled, not the fact that I couldn't do it, but I could have limited myself because of the social perceptions; and it is somewhat, not so much embarrassing; it's humbling -- that's the better word -- for me to choose to get out, and I
chose. But in the end, it was empowering, because, again, people thought it was amazing. I didn't do it in that case; I did it because I was frustrated, because I wanted to do what I wanted to do. I didn't want to be limited. I think he wanted to go on that particular trail, and I don't like to not be able -- you know. [Face-to-face interviewee]

Ross mentioned other episodes where life hacking gave him the freedom to choose what he wanted to do instead of being "limited." Deanna [Face-to-Face interviewee], on the other hand, often found herself fighting for independence and freedom from her sometimes overprotective parents. Her life hacks allowed her to avoid feeling "helpless," a state she equated with not having the freedom to try to do simple things like make her bed or bathe herself without someone barging in to help her. Like Deanna, Samantha sometimes life hacked to avoid asking for help or receiving unwanted assistance. Ten years before our interviews, an "anti-accommodation" teacher in high school told Samantha that she would not make it in the real world if she could not do things on her own. This teacher's comment made Samantha less willing to ask for help and more prone to do things for herself. Her life hacking efforts represented one way she sought independence and avoided reliance on others. Tabitha somewhat similarly derived intrinsic value from doing things for herself. She lived alone and admitted that it was "always scary not only for the person but [also] for their parents" [IM interviewee]. Nevertheless, when asked about the personal benefits of life hacking, Tabitha mentioned, "a sense of achievement, being able to say I did it, and not letting anything stop me so to speak."

Ross, Deanna, Samantha, and Tabitha all saw their life hacking efforts as something that allowed them to avoid feeling limited by their disability or overly dependent on others for assistance with everyday activities. One or more of their life hacks were intended to maximize their independence, personal agency, or both and they framed their efforts as such. One of the motivations behind their life hacking efforts was the independence and personal freedom they gained from doing so. Life hacking enabled them to do the things they wanted and needed to do,
albeit in unique and individualized ways, and thus maximize how much control they had over their personal destinies.

**Economic freedom.**

Sheila and her husband provided economic justifications for certain life hacks or life hacking in general. Both said they engaged in these activities to avoid paying for goods and services they deemed too expensive. Sheila and her husband echoed very similar sentiments regarding the cost of "adaptive equipment." Jack said they did not look at or consider accessibility products already on the market before attempting to life hack because they knew buying something would be too expensive. Sheila had both Medicare and supplemental insurance at the time of our interviews, and she did not want Medicaid although it would have covered the cost of a lot of potentially useful equipment. Both Sheila and Jack admitted they were not wealthy people. She had qualms about getting Medicaid, however, because she felt both public insurance providers and the durable medical equipment (DME) industry "leave people with disabilities at the[ir] mercy" [Face-to-face interviewee]. Sheila equated having Medicare to becoming "dependent on the system," and although she met the age requirement to receive it, she wanted to avoid getting it until she did not have a choice. When I asked why, she responded, "I don’t want to go on Medicaid until I absolutely have to because that’s when you become poor. You have to spend down [your assets]." Again, Sheila and Jack were not wealthy. Nevertheless, despite the benefits associated with Medicaid, getting it would have forced them to give up some control over their finances, which they were unwilling to do. As a result, Sheila and Jack decided to forego Medicaid and work together to make whatever she needed.

Sheila and Jack referred to their life hacking efforts as the "cheaper way." When describing their adapted comb, power chair control box repair/maintenance life hack, or other
solutions, Jack often emphasized how economical it was to do these things. From an economic perspective, it was more desirable to develop homemade solutions than to subscribe to Medicaid, which would have paid for costly DME the couple could not afford out-of-pocket. Doing so gave them more control over their finances.

*Morale & therapeutic benefits.*

Arnold [Telephone interviewee] explicitly said life hacking had "therapeutic value" and helped with personal "morale." Neil [Face-to-Face Interviewee] echoed a similar sentiment, although he did not use the same words to express it. As an individual who was not born with a disability, Arnold was vocal about the challenges he experienced while adjusting to life with a spinal cord injury. He thought it was somewhat easier for individuals who lived with a disability their entire lives because they were "less frustrated and annoyed" by their condition than people like him who know life with and without a disability. He went on to say this about the benefits he derived from his life hacking activities as an individual with paraplegia:

> I think that making stuff, one, it helps you solve your own challenges because there’s an awful lot of stuff out there, but they don’t make anything that does what I need. Also, just for the morale or therapeutic value it’s good.

Me: You also mentioned the morale and therapeutic value of making things. Sticking with people with disabilities, can you go back to that?...
Arnold: Whereas somebody like me who’s a spinal cord injury person, it was like yesterday I could do all this cool stuff and I didn’t think too much about, OK, I’ve got to go climb that ladder. I climbed the ladder, or I’d go out and chop wood all day or whatever. Then, suddenly, here you are and you’re stuck in this chair and your body doesn’t work anymore. It’s tremendously frustrating because of all the things that you can sit there and say I could have done that yesterday; I can’t do it today. Just being able to find something that you can still do is really helpful, as opposed to just being stuck in a chair not doing anything. [Telephone interviewee]

Arnold engaged in life hacking activities because of the "morale" and "therapeutic value" he derived from doing something he enjoyed and still possessed the ability to do as a person with
paraplegia. As the excerpt above reveals, having a disability represented a loss in capability and the inability to do certain activities that were once easy for him. Working in a Makerspace environment and developing artifact-centered life hacks made life with a disability more enjoyable because doing so resembled the different activities he could do before the onset of paraplegia.

Unlike Arnold, Neil was born with a disability. Nevertheless, he also found a sense of comfort in life hacking, and specifically, using individualized procedures to do everyday practices. For Neil, the source of frustration necessitating therapeutic relief was not his disability but rather his interactions with people who did not have a disability. Neil had parents, family members, and other people in his life who did not value his life hacks and sought to normalize him as much as possible. As the following excerpt reveals, the people around Neil made life hacking a risky yet necessary activity for him whenever he was in their presence:

There’s a lot of resistance in my family, on the outside of like, ‘you’re doing it wrong,’ or, ‘do you need help?’ If they see me doing something slightly differently, they try to rush over. That’s made me a bit more self-conscious about it, but I still need to do those subtle adaptations. I guess, more for comfort than actual efficiency. Like necessary adaptations, I may pass on because of getting yelled at. [Face-to-face interviewee]

The "subtle adaptations" Neil did for "comfort" rather than "efficiency" were therapeutic in nature since they allowed him to cope with awkward social dynamics. When Neil found himself in the presence of people who did not appreciate his life hacks, he engaged in related activities that allowed him to manage certain aspects of cerebral palsy that affected his physical comfort without drawing too much attention to himself. In doing so, Neil could achieve a relative degree of physical and emotional peace despite his proximity to non-disabled individuals who were hostile to his procedural life hacks. Adapting gave him the freedom to take care of his physical needs while minimizing the chances of negative reactions from others.
Both Arnold and Neil made statements suggesting they life hacked to cope with challenging, awkward, or unfamiliar situations. Whether the challenge was adjusting to life with a disability or managing impairment related issues around people who were keen on normalization, life hacking made it easier to cope. They derived conciliatory benefits from their life hacking efforts which made their respective situations easier to accept and manage.

**Hobbies & personal interests.**

Participants were also motivated to life hack by a desire to participate in hobbies and pursue personal interests. Several life hacks were developed specifically so participants could take part in arts and crafts, recreational, or other leisure activities. Arnold's homemade adaptive rock climbing equipment, Samantha's yarn holders for knitting, and Erin's head paintbrush represent a few examples of life hack outcomes participants devised and made to pursue hobbies and personal interests. Some participants explicitly linked their propensity to life hack to their desire to enjoy extracurricular activities. For Scott, making and modifying things was a hobby. In addition to addressing accessibility and impairment related issues in his everyday life, he also made and modified artifacts because it was "fun, "relaxing," and "satisfying." Scott's background as a dentist who enjoyed working with his hands before the onset of MS did not disappear as his condition progressed. Instead, his related pre-impairment experiences equipped him with confidence and skills that made artifact-centered life hacking activities easier for him than they would have been otherwise. As the next excerpt reveals, acquiring the skills needed to make, modify, and adapt artifacts before the onset of M.S. and subsequent gradual deterioration of his dexterity made him more willing to keep life hacking despite the challenges associated with doing so:

I think acquiring [M.S.] later in life may be the easiest way to develop all the [necessary] skills. Because if I [had] the same issues with my dexterity that I do now when I was
younger, I probably would not have done a lot of the things that I did. I probably would have been more frustrated in trying to do it and finding it may be more difficult than I wanted to deal with. I’m just basing that on my now, because in the last couple of years, my disability has increased dramatically. I find that my mental desire to do these things exists, but my physical ability to do them doesn't, so I don’t undertake as much now as I used to do in the past. [Telephone interviewee]

Other participants engaged in life hacking efforts because of their desire to participate in sports, recreation, and related extracurricular activities. For instance, Stuart was an avid weight lifter, and he was preparing to climb a mountain around the time of our discussions. Arnold was an adaptive rock climber and made some of the adaptive equipment he used to climb. Ross had tried several different extracurricular activities in his life including bowling, skating, racquetball, adaptive dancing, and horseback riding. Stuart acquired quadriplegia later in life while Ross lived with arthrogryposis since birth. Nevertheless, both pursued interests that were physical in nature and sometimes required capabilities they lacked. Both developed and utilized procedural life hacks that matched their capabilities to the physical demands of each practice or adapted and leveraged objects with features and affordances that supplemented their physical limitations.

*Demonstrating capability & proving oneself.*

The last major motivation behind participant life hacking activities was a desire to demonstrate one's capabilities or prove oneself. Participants who were motivated by this desire tended to encounter people or situations that challenged their capacity to live the way they wanted or accomplish specific tasks because of their physical impairments. Whether it was a reaction to limitations imposed on them by others or self-driven, participants wanted to prove they could do whatever they resolved to do and life hacking enabled many of them to do so. When asked what she valued most about life hacking, Tabitha explained, "The benefit for me is a sense of achievement, being able to say I did it, and not letting anything stop me so to speak." [IM
This same desire to feel a sense of accomplishment was evident in one of Scott's justifications for his life hacking activities: "Usually I look and I’ll see these things on the market, and sometimes I think I could do it better myself" [Telephone interviewee]. For Scott, making something that was better than a product he could buy in the store motivated him want to create something instead of buying a product someone else made.

Other participants were more extrinsically motivated and sometimes directed their efforts towards proving others wrong. For these individuals, it was important to prove what they could do to others, and some of their life hacks enabled them to do so. For example, Leon said he often ran into people who doubted his capabilities once they realized he had cerebral palsy. More specifically, during his job searches, interviewers would ask questions about his ability to perform the responsibilities and wonder whether he would need help performing the duties of the position. He explained that many times the questions were coupled with assumptions and unwanted pity. As the following excerpt reveals, people's reactions to Leon made him want to prove them wrong, and he found unique ways to show them what he could do when given the opportunity:

Leon: The people just look and they automatically feel sorry for you. I feel sorry for the people who automatically feel sorry for me because there’s more than one way to skin a cat I’ve been told. I make it. It might not be your way, but I make it.
Me: When you run into people who make those assumptions, do you have a way of interacting with or dealing with those people?
Leon: My thing of it is I’m not a person who likes a lot of confrontation. I will if I have to, but my thing of it is I’ll show you better than I can tell. My favorite saying and I love it: actions speak louder than words. [Face-to-face interviewee]

Life hacking allowed Leon to show others what he could do via his actions. Dominic [IM Interviewee] did the same thing with a former boss who "viewed disabled people as lesser [sic] than him." Dominic once worked a retail job that involved independently moving crates weighing up to 120-pound without a hand truck, pallet driver, or similar tool. Dominic said his
boss would not make exceptions for anyone regardless of their impairment status. This policy coupled with his supervisor's negative attitude towards individuals with disabilities made Dominic feel like he “had something to prove.” He figured out a way to carry the crates independently which consisted of using his "good hand" to support the weight of the crate and his "bad arm" to "guide it." By using a personalized procedure to carry the heavy crates, Dominic said he was proving his ability to do what a "healthy" non-disabled person could do to his boss.

Deanna described her parents as protective several times during our interviews and related several instances when she felt the need to prove her abilities to them in hopes of getting them to loosen their grip. Despite being engaged, Deanna had to deal with parents who were reluctant to grant her the freedom to do things for herself. At one point, her father verbally acknowledged the fact that he and his wife would not always be around to do things for her but also reaffirmed their commitment to making sure that she was “taken care of” while they were around to help her. It was against this backdrop that Deanna explained her propensity to leverage re-appropriation and procedural life hacks that afforded her some independence from her parents and allowed her to demonstrate what she could do. As the following quote explains, she connected her life hacking propensity to a desire to prove her ability to live an independent life away from her parents:

I’m trying to prove to them or show to them. I don’t have to prove nothing, but I want to show them that I’ll be OK. We’re going to be OK. Whoever I’m with at the time. Me and Cecil, we’re going to be OK. We’ll find a way. [Face-to-face interviewee]

Tabitha, Scott, Leon, Dominic, and Deanna all connected life hacking to proving something. Whether their goal was to feel a sense of achievement and self-actualization or to demonstrate their capabilities as individuals with disabilities to others, life hacking enabled them to do so.

\[^{38}\text{Deanna and Cecil were engaged at the time of this study.}\]
Participants motivated by a sense of achievement or self-actualization said opportunities to do something they liked or never tried before motivated them to life hack. Everyone who sought to prove others wrong engaged in life hacking activities to show others what they already knew about themselves.

A summary of participant motivations to life hack.

Life hacking allowed participants to identify and pursue whatever mattered to them at any given moment, whether it was participating in a practice activity, achieving a personal goal, or successfully demonstrating their capabilities to people who doubted or limited them. All life hacks had a practical benefit tied to the underlying daily life practice a participant wanted to do. However, as the preceding section reveals, practical life hacking activity also had intrinsic meaning and personal significance to many participants in the same way that hackers derive pleasure and fulfillment from their escapades with computer systems and networks. Efforts to control destiny, demonstrate personal capability, and prove oneself via life hacking speak to personal, social, and political issues that drove some participants to figure out ways to make and do things for themselves instead of relying on professionals or other third-parties. Even participants like Deanna and Leon who said some of their life hacks represented attempts to prove others wrong about their capabilities confirm that participants derived internal satisfaction and validation from their efforts.

Life hacks that enabled participants to control their destiny and pursue certain hobbies and personal interests also allowed them to engage in activities that people do not always associate individuals with disabilities. Interestingly, hackers see themselves as adventurers and frame their practices as instances of breaking boundaries, shattering conventions, and doing the impossible (Turgeman-Goldschmidt, 2008). Most participants did not use this type of language
to talk about their life hacks or the practices they enabled. However, the feedback and opposition participants faced from the people in their lives in response to their efforts confirm that some of them life hacked out of a desire to do what others tried to restrict them from doing or said they could not do. In this sense, their efforts were also mini acts of resistance and pushing the envelope that afforded them some control over their lives as well as the ability to make decisions for themselves. Participants like Neil and Arnold who derived therapeutic benefits from life hacking provide further evidence that life hacking has unseen intrinsic value that can make it easier to deal with certain aspects of living with an impairment. Both participants said they found a unique sense of comfort in the act of life hacking and their related efforts allowed them to realize it.

The motivations outlined in this section not only elucidate some of the drivers behind life hacking but also reveal something about the nature of these activities. The motivations behind participant life hacks included both the accomplishment of practical goals and the realization of social, economic, and intrinsic benefits. These benefits included the freedom to exercise agency, self-determination, and personal responsibility. Participants’ life hacking efforts offered a counter-narrative to medical and corporate models that frame individuals with disabilities as passive needy, and dependent targets of other people’s efforts. As with hackers, participants in this study had complex motivations that extended beyond each instance of engaging in an activity to the entirety of his or her lived experiences and identity as a person who lives with an impairment. Life hacking allowed them to self-actualize despite the physical, social, and other barriers that stood in their way. Participants constructed a narrative about disability where they were both self-empowered and self-determined as evidenced by the fact that they actively
engaged in the affairs of their daily lives and resisted people and circumstances that restricted them from doing so on their terms.

**Participant perspectives: Life hacking enablers and impediments.**

It was hard to identify one main thing that either enabled or prevented participants from life hacking in the context of their daily lives because of the differences between individuals and their life hacking tendencies. Nevertheless, some participants did mention analogous life hacking enablers and impediments. For instance, those who worked alone or with a co-participant to make or modify artifacts said certain materials and tools enabled their artifact-centered life hacking projects while those who had a long history of engaging in do-it-yourself or similar activities felt like their previous experiences helped them. Participants who sought to leverage or modify existing objects said at least one of their life hacks did not materialize or failed at some point because the underlying design artifacts were either poorly designed or too rigid for them to modify or change. Others found that the physical demands life hacking projects or life hacking-enabled practices required conflicted with the physical capabilities they possessed and thus prevented them from developing or using life hack outcomes. Finally, some participants' personal experiences and insights suggested that individuals with disabilities are less likely to find ways to life hack and do things for themselves if other people constantly do things for them instead of letting them try to do those things for themselves.

**Enabler #1: Materials.**

Life hacking, as defined by Leon, sometimes involves leveraging whatever one can find to help himself or herself in a situation. Participants shared many different life hacks, and it would be impossible to succinctly describe what the word "whatever" included for all interviewees or set boundaries around what someone could use in his or her life hacking efforts. Nevertheless,
interview transcripts contained five material objects commonly used in life hacking activities and life hack-enabled practices across multiple participants. For instance, Samantha, Stuart, Tabitha, Scott, and Arnold all used grabber tools or reaching aids to access items on the floor, in cabinets, or on shelves. The most commonly mentioned life hack raw material was tape. Samantha, Erin, Sheila's husband Jack, and Neil all said they used tape (most often duct tape) to create, fix, or modify something. Erin used medical tape to make adapted sex toys while Jack used black electrical tape to make a prototype of the adapted comb Sheila uses to do her hair. Other examples of tape-enabled life hacks include the following:

Samantha: I tend to attach handles to things, because I have a hard time carrying things like books and stuff. When I was a kid, I started making stuff with duct tape, so I make duct tape handles for my stuff... [Telephone interviewee]

Me: Are there other materials that you like to use when you are creating, adapting, or modifying things?
Erin: I sometimes ductape [sic] tools for art to my hands. For example, a carving needle for ceramics was once ductapped [sic] to my hand. So, I guess ductape [sic] would be another tool for adaptation. [IM interviewee]

Me: Are there specific materials that you like to use to make your own adaptations? We joked earlier about using duct tape. Do you like duct tape or anything else, or have you used discernment, too, to do certain things or to adapt certain things?
Neil: Duct tape is really just for when something breaks. [Face-to-face interviewee]

Me: ...what types of materials do you tend to use a lot for stuff like that?
Jack: Well, duct tape mostly. My mantra is with duct tape and wire coat hangers you can save the world. [Face-to-face interviewee]

Erin, Grant, and Stuart all said they used Velcro for at least one life hacking project. In addition to using Velcro, Grant and Stuart also had an affinity for using zip ties. Both received assistance from others with their Velcro and zip tie life hacks. Near the start of our first interview, Grant stated, "Velcro and zip ties get a lot of use around here" [IM interviewee]. He later explained
how he and his wife used zip ties to keep his feet from slipping off the pedals of his wheelchair: "I now have a zipped tight loop on all of my shoes and then zip tied that loop to my foot pedals each day, and cut them off each night." Stuart, on the other hand, used zip ties to prevent the wires on his power chair from moving. He also used them to attach his backpack to the back of his wheelchair.

Sugru is a moldable glue-like substance that turns into rubber within 24 hours. It permanently adheres to almost anything, including glass, metal, wood, and plastic (“About Sugru,” 2017). Sugru enables consumers to make, fix, or enhance objects however they would like (“About Sugru,” 2017; Sugru, 2014).

Both Grant and Stuart used Sugru to modify artifacts so they would be more accessible and usable to them despite their dexterity challenges. Grant used this product to modify the radio controls in his adapted van:
Me: Are there specific materials beside zip ties and Velcro that you like to use when you are creating a DIY solution?
Grant: Sugru is a moldable silicon that sticks well and is easy to form into different shapes. I use that a lot on the buttons in my van. But I almost always go to Velcro and zip ties first.
Me: How might you use Sugru on the buttons with your van? Do you use it to repair broken buttons or to make buttons easier to use?
Grant: Easier
Me: So maybe to change the shape of a button?
Grant: Right. I have a lot of ground knobs, so I use it to create a Cohen [sic] that sticks off the round. I can hit the Cohen to turn the knob. I also use it to build up certain buttons that I push more than others. Like my favorite radio station. [IM interviewee]

Stuart similarly used Sugru to change the shape and size of different interfaces as well as to make small repairs to his wheelchair:

Stuart: ...I use the Sugru for little modifications. Sometimes it’s making a button bigger or fixing a little problem on my wheelchair, things like that.
Me: Can you give me an example of something you might fix on your chair with Sugru?
Stuart: Say part of my chair is falling off and I don’t have any way to stick it back down I might use some Sugru. I just use it for little things. I use it like anybody else would use it. I don’t know if that’s considered…or not. [Video-chat interviewee]

Sugru, tape, Velcro, zip ties, and reaching tools were common items that two or more participants or co-/participant/ally pairs utilized in their life hack projects. Participants had other materials they liked to use as well, but these five items were popular across multiple interviewees. One of the takeaways from their utilization of these materials can be summed up by Stuart’s explanation of how he uses Sugru. Although their life hacks were accessibility or impairment related, they used these items like anybody would. In other words, they leveraged do-it-yourself materials with multiple potential uses for individualized projects which happened to be accessibility related. The flexibility of these materials made them useful to the participant regardless of the specific project. These five materials were regular everyday items. Except for Sugru, which is a newer product that some people may not know about, these items can be found in most people’s homes or purchased at most hardware, department, and thrift stores. Assistive
technology specific or accessibility branded products did not empower participants. Instead, common items that most people have easy access to and use in various do-it-yourself projects also enabled participants who live with physical impairments to life hack and perform practice activities. Proponents of DIY-AT and similar efforts should keep in mind that providing access to rapid-prototyping tools is not the only way to empower individuals with disabilities to make, modify, and adapt assistive equipment. Just like non-disabled DIYers, sometimes participants only needed tape, Velcro, zip ties, glue, access to objects with useful affordances, and a little ingenuity.

**Enabler #2: Previous related experiences.**

Every participant had unique life hacking histories and experiences that shaped subsequent projects. Some participants’ journeys as individuals with physical impairments who engage in life hacking activities suggest that life hacking not only is learned, perfected, and carried out over time but also builds on past experiences and insights. For instance, Kimberly, Neil, Samantha, Ross, Sheila, and Arnold all had procedural life hacks that allowed them to organize their personal space in a manner that made it easier to access what they need independently or use their mobility equipment in cramped quarters. Their solutions evolved over time. Once they figured out which organization procedures worked for them, they continued to use them. Sometimes participants framed their life hacks as the culmination of related knowledge and past experiences. Kimberly [IM interviewee] said most of her "mods" were the result of trial and error. Ross originally used a cardboard box for his wood carrying life hack then switched to a skateboard and finally figured out a way to slide wood across the floor on a towel. Both Arnold and Scott were avid DIYers before the onset of disability, and both said their previous
experience factored into their post-impairment life hacking efforts. When describing how his
pre-MS do-it-yourself experiences factored into his recent life hacking efforts, Scott said:

    Everything I’ve done before makes it easier to keep on going and doing this stuff, 
because I have the tools, I have the experience to do this stuff, so it made it easy for me to say I’m not going to stop doing this stuff. [Telephone interviewee]

Before the onset of Wallace's spinal cord injury, he loved problem-solving and majored in math
as an undergraduate student. After his injury, he earned a Master's degree in entrepreneurship
and linked his educational pursuits to his post-spinal cord injury life hacking efforts:

    Wallace: My master’s degree is in entrepreneurship and the mindset of an entrepreneur is just a problem-solving mentality. If you see a need, if there’s something that’s not working right, do something to fix it and make it better. As far as actually entrepreneurship, if there’s a major need that’s not being fulfilled in the marketplace and you know of a way to fulfill that, then there you go.

    Wallace: I think [adapting is] just a problem-solving mentality. You just, you have a problem and you figure out its solution, and that’s really just all there is to it. When I was in undergrad at the University of Florida, my entrepreneurship professor invited me to come in and talk about the entrepreneurial mindset. That’s basically it’s just a problem-solving mentality because first, you must recognize a need that needs to be solved or a problem that needs to be solved for many people. Obviously the bigger the problem or the more people you can help with it, potentially the more successful the business can be. Entrepreneurs routinely run into problem after problem after problem with starting a business. You run into roadblocks. Have you ever heard the expression that ‘a smooth sea never made a skillful sailor?’

    Me: I have not but I like that one. I like that.
    Wallace: You can’t adjust which direction the wind is blowing, but you can adjust your sails for that wind. So, you can start out one direction as an entrepreneur, then you must adjust and go a different direction to go with whichever way the wind is blowing your business so to speak. That can apply in different aspects of life, but I like that saying. [Video-chat interviewee]

Several participants explicitly stated or implied that past experiences prepared them for future
ones when it came to their life hacking projects. They learned and tried things in the past that
informed future life hacking activities and related daily life practices. Each experience seemed to
build on earlier ones and prepared the participant for future projects. Participants who lived part
of their life without a physical impairment often built on their pre-disability experiences when they life hacked. They felt like certain things they had learned before the onset of impairment gave them the knowledge, experience, and mentality to life hack with an impairment.

**Enabler #3: Tools.**

The final life hacking facilitator mentioned by multiple participants was tools. Participants leveraged and, in one case, created tools that enabled them to make, modify, and utilize the artifact-centered life hacks they leveraged in their daily life activities. These tools allowed them to either conceptualize or plan artifact-centered life hack outcomes or to do the physical work required to make them. Grant sometimes used Power Point, Google 3-D Sketchup, and Microsoft Paint to plan and design his life hack solutions. He also used these programs to "[get] all of the bugs worked out" of his designs before passing them along to his wife or a group of professional fabricators he sometimes hired to execute his plans [IM Interviewee]. Grant used these tools to define what he wanted and then relied on assistance from other people to turn his plans into an actual life hack solution.

Unlike Grant, Scott possessed the ability to do the physical labor that his object-centered life hacks required. Scott was formerly a dentist, and he always enjoyed working with his hands. At one point in our discussion, he explained that he had a history of using tools to fix and make things: "I used to do a lot of handiwork around my house for many years, I was never afraid to pick up some tools and try something" [Telephone interviewee]. However, as his M.S. symptoms progressed, Scott was losing the hand strength these activities demanded. In fact, at the time of our interviews, he was not as active around the house as he was a few years before because of his hand strength and mobility issues. Nevertheless, he had recently bought a tool that allowed him
to continue some of his life hacking activities. After describing the towel-rack grab bars he recently installed in his bathroom, Scott explained how the tool he purchased helped him:

Scott: What I also have done is I bought a power screwdriver. I’m losing the strength in my hands to put in a screw, so I bought a power screwdriver to help me if I do any work like that around my house.
Me: Is it more like a drill type or is it just a screwdriver with power? You know they have different kinds. They have the kind that’s just barely a power screwdriver.
Scott: It's just like a drill but it’s much lighter weight. It’s much smaller than a regular drill, so it’s something that I can hold. It’s light enough for me to hold. I never have to worry about dropping it. [Telephone interviewee]

Like Scott, Arnold did the physical work his life hacking activities demanded sans assistance from others. Arnold was an active member of a Makerspace where he created several of his artifact-centered life hacks using fabrication, heavy metal machining, welding, woodworking, and other types of equipment. One of the challenges Arnold faced when he became a member of the Makerspace was that the design of some of the equipment prevented a person who could not stand from using it. As a power chair user with T-5 paraplegia, standing was not an option for Arnold. To address this challenge and empower himself, Arnold created several tools that allowed him to use different pieces of equipment while sitting in his wheelchair. These tools included a 'mill stick” with custom cut holes which allowed him to reach and work the controls on the top of the CNC milling machine and "lathe mirrors” with magnetic bases which provided him with an angled view of the lathe's work surface [Telephone Interviewee]. Just like Scott's power screwdriver/drill, the tools Arnold made and used enabled him to create and modify things despite impairment and accessibility related challenges. The only difference was that Scott leveraged an already-made tool designed by someone else while Arnold cut, drilled, and assembled his tools.
Image 6 - Lathe from Arnold’s Makerspace

Image 7 - CNC Milling machine from Arnold’s Makerspace
Impediment #1: Artifact design.

One of the primary barriers to life hacking was the design of already existing artifacts. In the same way that the inaccessibility of the equipment in Arnold's Makerspace initially excluded him from using it, other participants encountered artifacts that were poorly designed or inflexible which prevented them from doing what they wanted or needed to do with them. It is important to point out that life hacking activities rarely consisted of conforming to the guidelines of intended use set by designers. Therefore, "inaccessible," "poorly designed," and "inflexible" sometimes described whether an artifact allowed a participant to accomplish what he or she wanted to accomplish rather than its general usability and usefulness. It is also worth noting that although some participants leveraged the same materials (e.g., tape, zip ties, Sugru, etc.) in their life hacking projects, they typically adopted a pragmatic approach to life hacking, meaning whatever artifact they had access to that worked simply worked. However, sometimes inputs participants thought would work did not.

Samantha and Ross both described life hacks that initially failed because of the quality of the raw inputs they used to make each one. Samantha duct taped small cups to the legs of her sewing machine so that she could adjust the height and relieve pressure on her back when needed. The cups were not as sturdy as she thought and they broke eventually. Samantha stopped using her sewing machine once the cups broke. Ross initially used a cardboard box to slide firewood across his kitchen and living room floor while walking on all fours. The box eventually ripped, and he had to find something stronger to use. Samantha and Ross both used objects that were not durable enough to handle the demands of the underlying tasks and they either revised or scrapped their life hacks as a result.
Designs that were inflexible also negatively impacted participants' life hacking efforts but in a slightly different way than flimsy inputs. Whereas flimsy inputs led to practice activity breakdowns, inflexible design prevented participants from engaging in a practice activity altogether. For instance, a barrier that once prevented Neil from life hacking was the "constraints of [a] design." For him and others, objects were designed in ways that afforded a certain kind of use and did not allow much deviation from intended use. When asked to provide an example of a design constraint that prevented him from life hacking and using something, Neil talked about his attempt to modify a video game controller:

Neil: I really wanted to play videogames, but the controller was just not set up. No matter how I would want to use it, I wouldn’t be able to use some of the buttons like the left button, because the way they’ve designed the control.
Me: So, in that case you couldn’t adapt it?
Neil: Yeah, I couldn’t adapt it, even though now I know people do adapt it. [Face-to-face interviewee]

Sheila and her husband Jack provided another example of an inflexible artifact that precluded a needed life hack. They were looking for a new accessible van around the time of our first interview. Jack and Sheila purchased and attached an after-market wheelchair ramp to the side sliding door of their previous vehicle. Chrysler made a change to the design of its latest models which prevented Jack from doing the same thing to a newer van:

The thing that happened was that Chrysler, specifically, and the others [van manufacturers] all followed in afterwards, had gone to this thing they call stow-and-go seating. The center seats would fold down to the floors. Well, that floor won’t hold a wheelchair. It’s not strong enough. Our ’06 Caravan that’s out there, the side door on it is thirty-and-a-half inches open width. Nobody makes them that wide anymore—twenty-eight, twenty-eight and a half, that’s it, and narrower—because in my research, I think I probably hit every mini-van manufacturer there is, and the widest I found was twenty-eight and a half. The result of that problem is that the company, PVI, Prairie View Industries, doesn’t make the ramp anymore because there’s no market for it anymore because it won’t fit in the door. So, we’re SOL, totally, so we had to buy a modified van, and that’s what people are stuck with now. [Face-to-face interviewee]
Participants often leveraged the form, features, and affordances of artifacts or added new ones via life hacking to make daily life practices more accessible. Properties such as durability and changeability made it possible for participants and co-participants to use objects as needed in their projects. Objects that did not possess these qualities either resulted in ineffective life hacks or prevented participants from life hacking and participating in practice activities altogether. One takeaway from participants’ experiences with design artifacts is that usage drift is something designers interested in accessibility issues should keep in mind and perhaps make room for when possible. A top-down approach to technology design and regulation should perhaps make room for bottoms-up situational modifications that people who live with impairments and their allies, if applicable, can do to technology without fear of voided warranty agreements or other punitive actions.

**Impediment #2: Required physical capability.**

In some instances, participants’ physical capabilities impeded their ability to life hack. Life hacking usually enabled participants to do daily life activities using the physical capabilities they possessed despite their mobility or dexterity related challenges. In addition to daily life practices, making and using life hack also placed physical demands on the body that participants could not always meet because of impairment related issues. Sometimes impairment prevented participants from hacking objects and practices as needed. Their attempts to make or use life hacks failed because they could not do the physical activity doing so required. For instance, Ross, who walks on his hands or all-fours because his legs cannot support all his bodyweight, once tried to figure out a way to roller-skate independently. Despite having the upper body strength to support all his body weight on his hands and arms, Ross could not mimic the movements people typically make
on roller skates. He could not replicate the same lower-body motions of someone who skates using his upper body:

I’ve always sought to participate, and it was just like, okay, my friends were going roller skating, and I wanted to go, but I couldn't. I'd tried. My sister used to roller skate, too, though, so I tried putting the roller skates on my hands, because I would prefer to be independent and do something independently and actually do it fully, by myself, but I could never get enough lean. The roller skate would be on my hands, and I would stand in a handstand, and I even tried with my feet, pushing off, or my sister would try to tell me how they move their ankles or their feet to [brief tangent on tap dancing] ... Anyway, I tried doing it by myself, but that never worked. I tried leaning a little further this way [forward], in a handstand. I tried to lean my butt over that way [behind him] because that's how you roller skate: you kind of lean forward and you kind of push back; but the only thing I did was flip over. I would flip over and land on my ass and be like, 'Oh, that ain't gonna work.' Finally, I just gave in to the fact that I would need help, so my friends would hold my feet. [Face-to-face interviewee]

As stated earlier, several participants saw tools as life hack enablers. While certain tools made it possible for participants to make, modify, and repair artifacts, other pieces of equipment had the opposite effect because a participant lacked the physical capability needed to use them. In juxtaposition to the lightweight drill that he purchased and used, Scott had other tools that he could not use any longer because of the rapid progression of Multiple Sclerosis:

Me: Have you ever faced things that maybe impeded or made it difficult to do these things? Have you ever run into rules or policies or procedures that made it harder for you to do it yourself?
Scott: No. My dexterity has been affecting what I would do. It just gets harder for me to use my hands as the years have gone by. The MS has caused the muscles to atrophy and it just makes it more difficult for me to grab instruments, so I haven't really been as active in the past probably two years as I have been in all the years before. [Telephone interviewee]

Participants’ physical capabilities sometimes prevented them from doing a daily life practice activity while simultaneously motivating them to life hack in some way. When someone's physical abilities did not match the demands a life hacking project or solution demanded, they either found an alternative solution or did not do anything. Since Ross could not create an individualized way of skating that allowed him to mimic leg and feet movements with his arms
and hands, he could not skate independently and had to rely on others for help. Scott, however, stopped making as many artifact-centered life hacks as he once did because he no longer had the physical ability to hold and use the required tools.

Impediment #3: Lack of motivation.

This final life hack impediment category was a lack of motivation. Whether talking about themselves or other individuals with disabilities, some participants stated that someone with a disability must have a motivation to address the accessibility and impairment related issues he or she encounters. Interestingly, participants who mentioned this impediment commonly linked it to a tendency to rely on other people too much. For instance, Stuart was not particularly active when it came to life hacking and admitted that he sometimes relied on his Mom and others to do simple tasks for him that he could have figured out a way to do himself. At one point, he candidly explained that life hacking and doing things for himself required him to make a conscious effort to stop relying on others. Sometimes he did not try to life hack or find alternative ways to do things because he had other people who would readily do those things for him:

Part of my nature growing up was to be kind of lazy; I’ll be honest. I remember being able to be independent, but instead I could ask someone else to do it. That was my character. If someone was around me I’d be like, ‘go turn off the light,’ instead of doing it myself. It’s not engrained in me a whole lot now, but I can see that part of me that still exists today. If I’ve got somebody around it’s much easier just to say, even though I can do it, something in my mind just says have them do it. I must recognize that I’m doing that in order to do it myself and sometimes I don’t catch it. I do it the easiest way, instead of maybe what I should be doing in doing it myself. It’s like a mind game that I play with having quadriplegia as well, because my whole life is dependent on other people and me doing things for myself isn’t as common as someone doing things for me. Sometimes it’s easier just to say, ‘would you do that for me?’ even though I can do it. Ultimately, it comes down to whatever I’m probably asking would take me longer than it would take the other person and sometimes I just like the easy way. [Video chat interviewee]
Stuart saw in himself what some participants saw in other individuals with disabilities. Sheila thought that programs like Medicaid conditioned people with disabilities to be less self-reliant and less likely to figure out individualized ways to do things. In other words, she felt like these programs not only discouraged some individuals with disabilities from life hacking but also made them overly dependent on their insurance provider:

Me: Have you ever been in any groups, whether online or in person, groups where people have discussed or shared or mentioned their own adaptations?
Sheila: No, you know, I haven't. I think a lot of people depend on professionals to figure out something for them.
Me: Why do you think that is?
Sheila: Maybe because they’ve been conditioned to think that way. Maybe they just don’t sit there and figure out maybe I could do this, and this would be better than getting this other piece of equipment. If you're on Medicaid, Medicaid will buy a lot of equipment for you. They’re stingy in a lot of ways with some stuff, but it’s certain medical products, which makes me angry. But they will buy some adaptations for you so you don’t have to figure them out. I had to figure them out because we’d be paying privately. And besides, I just didn't think it was necessary for a lot of it. Or a couple of times I did get something and it didn't work, so it was waste. [Face-to-face interviewee]

Sheila and Stuart reiterated the same idea: people or entities that are there to help individuals with disabilities can sometimes demotivate them from figuring things out for themselves. However, unlike Stuart, Sheila intentionally minimized the extent to which she had to ask others, including her husband in many respects, for assistance with impairment-related issues so that she could maintain her independence. She was willing to forego certain benefits associated with assistance for the sake of her independence. In fact, her desire to be independent was one of the things that motivated her and her husband to life hack. Stuart, on the other hand, developed a tendency to take the "easiest way" because his Mom and others always did things for him while he was growing up instead of letting him figure them out for himself. Part of the reason why he was willing to let others address impairment-related issues for him was he grew up allowing them to take care of non-impairment related ones.
Ross related a story that poignantly illustrates how some participants saw too much assistance from others as a life hacking impediment that made individuals with disabilities overly dependent on others. He shared a story from his teenage years about an encounter he had with a young man with an unknown disability. The young man could not put on his clothes (including his underwear) independently. Ross attributed his lack of independence in this area to his mother's tendency to help him instead of letting him "struggle" and eventually learn how to do it himself:

I remember at summer camp -- I don't know if I told you this -- but there was this young man. He was maybe 14. He was a little portly, and I don't know if he had cerebral palsy, I don't know what his condition was, but he walked, but he was just different. But he was also limited. And I remember one time he told the camp counselor, 'You've got to put my underwear on,' and all of us looked at him like, 'You can't put your own underwear on?' I said to him, 'Who puts your underwear on at home?' and he goes, 'My mom.' I looked at him, and there he was naked, because we had showered, and he had hair and everything, and I thought I would not want my mom looking at my junk! You are pubescent! Now, granted I didn't have all this articulation about it, but I know internally that was the experience, like, 'Dude! I would not want my mom dealing with my personals at this point in my life. At this point I want independence of that.' So, I remember telling him, looking at his body and thinking, 'Why shouldn't you be able to put on your own underwear? I don't understand,' realizing that because his mom always did it is why he never learned how. [Face-to-face interviewee]

Ross, Sheila, and Stuart's comments all support an idea discussed earlier: life hacking is both learned and developed as a person encounters challenges and figures out how to address them. When other individuals or entities are always there to deliver individuals with disabilities from impairment related difficulties, they not only rob them of opportunities to learn how to life hack but also demotivate them from trying. This finding suggests that life hacking has psychological implications as well as practical, social, and economic ones. Participant efforts extended beyond the immediate practice situation that excluded them. They also influenced the way they saw themselves and other individuals with disabilities in the world. Those who frequently participated in life hacking related efforts tended to view themselves as people who solved
problems themselves rather than depending on others to do it for them. Participants and other individuals with impairments they knew who were less prone to life hack typically did not feel the need to do so because other people always stepped in to take care of things for them.

**Participant perspectives on life hacking: Key takeaways.**

Although tools, equipment infrastructure, and support may make DIY-AT, life hacking, and similar activities more accessible to individuals with disabilities, the findings from this chapter suggest those gestures alone are not what enabled and motivated participants. It is equally important that individuals with disabilities see themselves as people who can participate in life hacking projects. Some of that confidence comes from having opportunities to try, fail, and learn from mistakes and grows as individuals with impairments take a more significant stake in the decisions and concerns that impact their daily lives. Designers, researchers, service organizations, various entities that serve the disability community, family members, friends, and others who provide various forms of assistance to individuals with disabilities need to understand something: not all help is beneficial. An earlier sub-section on co-participants illustrates what beneficial help looked like for participants and chapter 8 will unpack the distinction between meaningful and unbeneﬁcial help more. I bring this point up here because there is an inextricable link between the social shaping of collective understandings of disability and technology and the roles individuals play in the social shaping process. When designers, researchers, and society perpetuate deﬁcit model ideas, then it is easier to justify forms of assistance that do not empower but rather create and reinforce dependency. However, when people with disabilities receive the opportunity to try, struggle, and succeed or fail based on their efforts and contributions, then it changes the narrative. No longer is disability a problem that third-parties need to cure. Instead, individuals who live with impairment become people who have ample opportunities to be
creative, make decisions for themselves, and determine the best way to address various issues they encounter in their daily lives if they choose to do so. When individuals with disabilities have the chance to exercise their creativity, practice self-determination, and determine who, when, and how others will assist them there is a greater chance they will exhibit behaviors that challenge medical and corporate model assertions. Further, they can leverage their capabilities and experiential knowledge of life with an impairment in ways that designers and researchers cannot due to their positionality as well as the resource and other practical constraints imposed on them.

Sheila, Stuart, Ross, and Sheila's insights all support the idea that active participation in life hacking activities benefits individuals with disabilities psychologically and motivates them to continue life hacking. Individuals and entities that provide products, services, and various forms of help to individuals with disabilities should consider the potential psychological and image construction aspects of life hacking in their efforts to help and empower. To do so, they must look beyond products and services to both the people using them and the role they play in shaping the dialogue on disability. They must see life hacking and DIY-AT as forms of self-empowerment that allow individuals with disabilities to not only match objects to usage contexts but also influence the way people in society view and relate to them. Finally, they must adopt a broader view of empowerment that is informed by what individuals with disabilities can learn to do for themselves and consider providing forms of assistance that help them along this path instead of creating or reinforcing dependency.

**Conclusion**

In this chapter, I explained how participants both addressed impairment-related issues in the context of their daily life practices and managed their quality of life for themselves via life
hacking. The first major contribution is an explanation of the different types of life hacks participants described (innovations, modifications, repair/maintenance, bricolage, re-appropriations, and procedures) as well as the various practices their life hacks enabled them to do. Participant life hacking efforts and outcomes represent analogs to the types of activities and artifacts that professional designers, R&D teams, and researchers typically take responsibility for on behalf of individuals with disabilities. There was one major difference with study participants, however: the same people who leveraged life hacks in the context of their daily lives often played an active role in conceptualizing, developing, and testing them.

The second contribution of this chapter is an understanding of life hacking grounded in the perspectives of people engage in related activities. Most studies that acknowledge or explore the adaptation activities of individuals with disabilities focus exclusively on accessibility, technology, and available resources to figure out how to better design accessible technology. While this approach has some merit, it ignores other factors that constitute a person’s practice contexts as well as his or her experiential knowledge of these factors. To identify the factors explicated in this chapter, I examined how co-/participants conceptualized their efforts overall and framed their individual contributions. I also identified the motivations, enablers, and impediments participants linked to their efforts. First, I analyzed the terminology co-/participants used to describe their life hacks and then compared extant literature on hackers to the language co-/participants used. In addition to justifying the use of the term life hack in this study, I explicated how related efforts consist of diverse physical activities with outcomes that have both practical value and personal meaning to participants. The value and meaning participants attributed to their efforts were somewhat comparable to the benefits computer hackers derive
from their activities, yet each project addressed specific practical, social, economic, and other realities that constituted their lived experiences.

As mentioned in the preceding paragraph, this chapter also examined the reasons why individuals with impairments in this study engaged in life hacking activity from their perspective. Existing studies tend to focus on the ways DIY-AT could potentially empower individuals with disabilities. These ways include providing either greater access to assistive technologies that meet the needs of individuals with disabilities (Hook et al., 2014; Hurst & Kane, 2013) or more accessible rapid prototyping tools that people with physical impairments can use to make and modify assistive technology for themselves (Buehler et al., 2015, 2014). Although these forms of empowerment could prove meaningful to some individuals with disabilities, they are largely uninformed by the way people with disabilities who currently engage in DIY-AT-like activities empower themselves or the motivations behind their efforts. Therefore, these studies frame individuals with disabilities as people who benefit from DIY-AT because of the efforts of researchers and non-disabled non-professionals. The examination of participant motivations presented in this chapter suggests that participants played an active role in life hacking. In addition to making it possible to use technology and engage in everyday life practices on their terms, participants life hacked to control their destiny, take control of their finances and other aspects of their lives, manage psychological aspects of living with a disability, pursue personal interests, and demonstrate their capabilities to people who doubted them. These motivations point to the importance of social, cultural, and economic factors as well as self-actualization goals and the desire to live a self-determined life to individuals with disabilities. DIY-AT and other initiatives meant to empower individuals with disabilities must consider these
and other factors from the perspective of people who live with impairments to make sure empowerment happens on their terms rather than someone else's.

The fourth and final major contribution of this chapter is an explanation of the factors that enable and impede life hacking from the perspectives of individuals with disabilities who do it. In addition to talking about the potential benefits of DIY-AT to individuals with disabilities, accessibility scholars commonly discuss the current barriers. DIY-AT seeks to get non-professionals involved in efforts to make, modify, and repair assistive technology by taking advantage of the expanding availability of rapid prototyping tools. DIY-AT facilitators and barriers tend to be connected to the use of these tools. For instance, common facilitators cited in the literature include the availability of rapid prototyping tools, 3-D printing, and online communities such as instructables.com where people share DIY-AT designs and ideas (Hook et al., 2013; Hurst & Kane, 2013; Hurst & Tobias, 2011). The barriers scholars often mention include inaccessible 3D printers (Buehler et al., 2014) and other rapid prototyping tools (Hurst & Kane, 2013), lack of design expertise (Hook et al., 2013), and lack of infrastructure and needed guidance (Rajapakse et al., 2014). Many of the underlying studies that mention barriers and facilitators include zero or only a few individuals with disabilities as research participants. All the participants in this dissertation research study live with physical impairments. Findings from this study suggest that factors such as life hacking-related experiences, the adaptability of objects, and personal motivation to find solutions to accessibility and impairment related issues may make some individuals with disabilities more willing and able to participate in life hacking-related projects than others. These and other enablers and impediments have little to do with access to rapid prototyping tools and equipment. They highlight some of the less obvious yet meaningful considerations that researchers who say want to see more people with disabilities
involved in fitting assistive technology into their daily life practices may miss or ignore if they
do not adequately engage with individuals who live with impairment and already engage in more
self-directed forms of DIY-AT.

All findings from this chapter suggest that one's perspective influences the way he or she
understands disability, shapes the way society views it, and approaches either professional design
or non-professional life hacking-related activities. People without disabilities, or the able-bodied,
can have good intentions yet lack perspective on the lived experiences, practice activity contexts,
intentions, capabilities, and needs of people who possess rich experiential knowledge of life with
an impairment. People who live with impairments, on the other hand, may lack access to either
formal or commoditized means of production and the social capital needed to influence policies
and certain decisions that impact their daily lives. They do, however, possess experiential
knowledge of the circumstances and issues that constitute their daily lives as well as first-hand
awareness of the downstream implications of decisions that factor into their lived experiences.
This chapter examined how this awareness and experiential knowledge combines with the
knowledge and capabilities of co-/participants in different life hacking projects. Further, this
chapter provides insight into the social construction of disability by examining consumer
conceptualizations of disability connected to and enabled by the life hacking activities of
individuals with disabilities.

The preceding chapter described various aspects of life hacking from the perspective of
participants. The next chapter will take a closer look at life hacking and the everyday life
practice activities it enables through the lens of practice theory. More specifically, chapter six
will examine how objects, life hacks, impaired human bodies, and standard bodily activities both
configured and enabled participants’ practice activities.
Chapter 6 - Life Hacking and Everyday Life Activities through the Lens of Practice Theory

In this chapter, I answer the following research question: How are individuals with mobility or dexterity impairments disabled or enabled in their daily life practices? To answer this larger question, I respond to two sub-questions intended to unpack participant practices enabled by their life hacking activity: How do various human and non-human agencies simultaneously constitute everyday practice activities and interact with the mental and bodily activities of individuals with mobility/dexterity impairments? (RQ 2.1); and How are bodies, minds, objects, and knowledge/know-how implicated in the everyday practice activities of individuals with mobility or dexterity impairments? (RQ 2.2). The phrase life hack-enabled refers to activities participants did using a practice artifact they made, modified, or repaired (artifact-centered life hack) or unique interaction methods and task procedures (activity-oriented life hack). The analyses below unpack participants’ life hacking-enabled practices and describe the various entities and agencies implicated in their accounts of these practices. I used several sensitizing constructs from different practice theory approaches to parse out and trace the relationships between constituting elements of participants’ life hack-enabled practices. This opening section introduces the theoretical constructs referenced in chapter two to orient the reader my use them in the analyses presented later in the chapter.

A Re-introduction to Practice Theory and Latourian Actor-Network Theory

The body and bodily activity are two distinct practice theory constructs that bear on both daily life practices and life hacking activity. It is important to distinguish how these two constructs relate to everyday practices and life hacking since they both constitute the body as a practice construct and inform how one uses the body in practice engagements. Bodily activity refers to material demands placed on the body that dictate movement and use (Schatzki, 2005). One way
to view this construct is to see it as the set of physical demands a given activity forces the body to do. They represent the required human physical effort that anyone engaging in the practice must exert. Bodily activities are social in the sense that every practitioner engaged in the same practice performs them and the repetition of these bodily activity performances by multiple actors over time constitute the practice as well as all bodies that become entangled in it (Schatzki, 2005). Activities such as using a basic coffee maker, washing dishes, walking, and driving a wheelchair all place a unique set of physical demands on the person doing them. There are elements of every practice that are not only common to the practice itself but also carried by human agents from one performance to the next. One of those elements is routinized bodily activity. The ways of using and moving the body a practice activity requires are as essential to that activity as the human performing it. Even if an individual possesses the know-how, will, and tools to accomplish a task, it will remain unaccomplished unless the possessor carries out the required activities in a productive manner. The same goes for every person who engages in that activity regardless of the specific individual or context. Shared ways of using and moving the body not only inform specific practice engagements but also provide evidence of the practice itself.

Participants knew and often described the ways an activity required the people doing it to use their bodies. They also knew which required movements non-disabled individuals could perform that were difficult or impossible for them to perform. Additionally, participants described distinct ways of moving and using their impaired bodies when talking about how they leveraged life hacks in their practices. In some instances, multiple individuals with similar impairments described almost identical life hack-enabled ways of using the body, leveraging artifacts, or both, which provided unique and unexpected evidence of life hack-enabled practice
structure. Structure refers to the heterogeneous networks of practice elements that endure over time and similarly enable or constrain the everyday activities of multiple participants (Schatzki, 2001, 2005).

The human body has a unique role in practices as one of the primary constitutive elements. Schatzki (2005) refers to the body as an entity which carries and performs a routinized way of doing a task requiring both physical and mental activity. He describes it as the culmination of several instances of training and using the body to perform a practice in a specific way. As the carrier of social practice, the human body not only serves as the site where bodily and mental activity occurs but also brings both functional limitations and capabilities into practice engagements. In the case of the study participants, life hacks often relieved tensions between functionally impaired bodies and the ways of using the body different practices demanded. Sometimes participants successfully matched their functional capabilities to the requirements a practice activity placed on the body via unique ways of using their functional capabilities, existing objects, and their immediate physical environment to accomplish a task. Participants also developed and leveraged object-centered life hacks in ways that allowed them to capitalize on the functional capabilities they possessed as well as the affordances the life hack offered.

Objects played a role in participant everyday practices in addition to participant-actors themselves. The roles that objects played is important to consider from an accessible design standpoint. Latour (2005) describes objects and humans as co-agents that together constitute daily life practices and make a difference in the human actor’s course of action. He asserts that when the elements of practice come together in a specific episode (i.e., one instance of a person washing the dishes, doing laundry, etc.) objects have just as much agency as the human actor and
shape the episode just as much. In fact, both actors come together to form what is known as an actor-network which works as a single entity to do the underlying practice activities (Latour, 2005; Orlikowski, 2007). While human agents are the unique crossing point of the bodily and mental activities that constitute practice, objects give a permanence to practices which extends across multiple episodes (Latour, 2005). Objects in this sense link one episode of engaging in a specific practice activity to all other instances of doing that same activity. The participant's body and the objects they use to engage in a practice activity are two essential elements that contribute to the actual doing of the practice.

Although all human bodies are in a constant state of flux and can be trained to do what we want and need them to do, impairment can make it harder to perform physical tasks using the body or limit the extent to which the body can adjust to the demands forced on it. For example, a person who breaks his or her arm may not be able to use the broken limb to the same extent that he or she could use it before the injury. The person may figure out ways to do a task using the broken arm, but his or her impairment will likely negatively impact task performance. Most professionally designed artifacts, in contrast to the human body, have a rigidity and fixity to them that signifies how to use them. Life hacking changes the equation for daily life practice activities by making provision for the rigidity of design artifacts, various factors that circumscribe their design and use in practices, and impaired human bodies. Life hacking that involves the use of objects in participant-centric ways (re-appropriations and procedural life hacks) or the creation, modification, or repair of artifacts changes the actor-network dynamic as well as the interaction among all the elements that constitute both the practice and the person engaging in it. Dis/ability changes meaning in the context of practices. Unlike deficit model accounts that link disability to impairment while ignoring other disablers or social model
accounts that seem to ignore the impaired body and instead focus on social and political
disablers, practice theory frames the person as one of several networked entities that can be
enabled or disabled depending on the configuration of practice elements. Life hacking is all
about creating productive networked arrangements that simultaneously account for deficit and
social models of disability concerns.

Latour's perspectives on objects and agency relate to this study in one other way. Both
the human and non-human actors in a practice engagement act, but only one of them can
overtake. This concept of “overtaking” refers to the exclusive capability of the human actor to
control the multiple human and non-human agencies that factor into each practice engagement.
As stated earlier, both human and non-human actors have agency. Nevertheless, action cannot be
attributed entirely to the human agent or the object(s) involved in a practice activity. Rather, an
action is a compilation of multiple and distinct agencies that a human agent takes over (Latour,
2005). Agency is the network-enabled capacity for a human agent to act realized through
associations with diverse actors, including non-human ones (Latour, 2005; Orlikowski, 2007).
For instance, an object may constrain or prevent an individual from using it effectively in the
same way that a shovel with a short handle makes the practice of digging a hole less efficient. On
the other hand, an object and its affordances may enable a human agent to do what he or she
could not do otherwise in the same way a jackhammer makes breaking up concrete possible and
durable medical equipment such as a wheelchair or crutches make mobility possible for someone
who does not possess the ability to walk. Although objects make a difference in human action
(i.e., have agency), they do not act alone and cannot go against the structures that not only shape
a practice but also impact each instance of a practice engagement. Human agents, on the other
hand, possess the unique ability to co-opt the elements of practice as well as the multiple
agencies acting on him or her. This ability to co-opt, however, cannot be realized without the non-human agents that co-perform practice activities and co-create productive arrangements that enable the overtaking process.

Design artifacts and the ways of using the body an activity demands persist across all instances of a person engaging in a practice as well as among people engaging in the same practice. Nevertheless, any human agent can either support or contradict practice structures when he or she engages in the underlying practice activity. Overtaking refers to the ability of the human agent as one of many essential elements that not only constitute but also are constituted by practices to act in ways that either align with prevailing social norms or contradict them.

Keeping in mind that socially shaped ways of acting or using something can be at odds with a person’s functional capabilities, artifact-centered life hack outcomes contributed agency by allowing participants to enact and overtake practice elements when it would have been challenging or impossible to do so otherwise.

Participants in this study developed and used life hacks that enabled them to engage in everyday life practices. The body, life hacks, and various agencies configured these practices in distinct ways. Additionally, participant practical knowledge and awareness of their bodies, capabilities, and the circumstances surrounding their practice engagements played a role in enabling them to enact and overtake practice elements. The body shaped life hack-enabled practices in three primary ways. The most common way was for functional limitations and attributes of a participant's body to clash with the demands daily life activities placed on practitioner bodies. These conflicts made participation in the underlying activities difficult, inefficient, or even impossible, save for the participant's life hack. The second way the body shaped life hack-enabled practices was that participant bodies and bodily movements played a
central role in making a life hack or using it for practice-related purposes. Functional limitations, design, or both sometimes impeded or precluded participants from participating in day-to-day practice activities or doing them independently. In response, these individuals leveraged existing functional capabilities, unique ways of using the body, alternative parts of the body, or some combination of the three to manage these impediments. Thirdly, the bodies of non-disabled allies (when applicable) played a role in life hacking efforts. Some participants worked with allies to make, modify, and repair artifacts. These collaborative efforts enabled participants to manage whatever impeded them from engaging in daily life activities. A few needed assistance from co-participants or allies to use some of their life hacks as well. The functional capabilities of a spouse, caregiver, friend, or other ally allowed him or her to contribute to life hacking projects and help enable the participant in his or her practices.

Many practice artifacts consisted of objects participants made, modified, or repaired individually or with assistance from another person. Others included design artifacts the participant used as-is, but in ways that were unique to him or her. Life hacks enabled participants to exploit objects, object affordances, things in their environment, parts of the body, or the whole body in ways that were productive. The resulting actor-networks bridged the gap between the ways of using the body practices demanded and the physical capabilities participants possessed. Life hacks influenced and often enabled human agents, whom Reckitz (2002) described as the crossing point of bodily and mental routines, to perform a given practice. As with all practices, objects, human bodies, individual will, and know-how (mental activity) all co-constituted specific acts of engaging in a practice. Both activity-centered and object-centered life hacks played unique roles in enabling participants to overtake practice elements in specific acts of doing a given practice activity. Both types changed the dynamics among constituent practice
elements and influenced the human-non-human networked effort by allowing the human agent to overtake using his or her capabilities. Nevertheless, it was only within the context of practice engagements that embedded human/non-human actor-networks exercised agency in ways that were productive and meaningful to the participant. Participant could overtake the constitutive elements of practice in specific engagement episodes only when life hacking activities or outcomes co-contributed agency to the effort along with the participant.

The life hacks described below represent instantiations of participant negotiations between the ways of moving and using the body a practice required of them and what they could physically do with their bodies. These negotiations enabled the participants to reconcile gaps between functional capability and the bodily activity associated with a practice. Participants (and in some instances, allies) were not only aware of these gaps but also possessed and leveraged, among other things, the self-awareness, know-how, and desire needed to figure out how to close them (Schatzki, 2005). This gap-closing effort included not only the conceptualization and development of each life hack but also an analog to Schatzki’s concept of "taking over" the elements of practice co-enabled by participant life hacks. This process included leveraging the body, objects, or both in unique ways within the practice context the participant faced. A human agent takes over the body, bodily and mental activity, object(s), and other practice elements in localized acts of doing. As the analysis below reveals, participants could take over the constitutive elements of practice (including those belonging to the social sphere) because their embodied knowledge and life hacks allowed them to form a productive actor-network with other practice actors and thus close the gap between required ways of using the body and his or her physical capabilities.
One way to describe a few of the life hacks analyzed below is the view them as de Certeauian tactics. Tactics are deliberate actions by an individual human agent who lacks the will, power, and location necessary for autonomy (de Certeau, 1984 Kindle version. loc 695, section 3). Strategies, on the other hand, are opportune manipulations of power relationships by an individual or entity with power (de Certeau, 1984 Kindle version. loc 695, section 3). The original designers who created many of the objects that co-constituted participants’ daily life practices made those objects for a specific purpose or use. Standards, rules, and social norms dictated the form and governed the use of these products and consumers were expected to follow them. Standards, rules, and norms also governed certain everyday practices participants engaged in that did not involve the use of objects. When participants encountered gaps between rules they were expected to follow and their physical capabilities or preferred way of doing things, they purposefully employed tactics that enabled them to use objects in unique ways that worked for them despite the reified assumptions designers, developers, and other entities made regarding the end-users. Participant-life hack actor-networks played the same role in closing the gaps between recommended socially shaped ways of using objects and the body to accomplish a task and ways of using both that were more agreeable to participants. Life hacks played a critical role in closing the gaps between required ways of using the body and physical capability. In other words, life hacks sometimes allowed participants to subvert self-identified practice barriers and do things their way instead.

The Role of Life Hacks in Closing Demand-Capability and Demand-Intention Gaps

Study participants faced everyday life situations that placed six different types of demands on the body: 1. Managing personal mobility while carrying something; 2. Controlling the body, bodily movements, or both; 3. Manipulating objects; 4. Reaching or retrieving something; 5.
Transporting objects up or down stairs; and 6. Completing tasks that require one’s legs, feet, or both. In each situation, there was a gap between the required ways of using the body that the underlying practice activity demanded and the functional capabilities the participant possessed or felt most comfortable using. Many times, participants couched required bodily activity in their descriptions of what they could not do or why they needed a life hack. For each life hack description provided by participants, an effort was made to highlight the underlying daily life practice activity as well as the demands that it placed on the participant’s body. The following sections describe the six demand categories using exemplars to illustrate how objects, life hacks, participants’ impaired bodies, and bodily activity both configured the underlying practice activity and turned disabling practices into enabling ones.

**Managing personal mobility while carrying something.**

Some everyday life practice activities require people to simultaneously move their body and a separate entity such as an object or small child from one location to another. For study participants with mobility impairments, functional limitations, mobility methods, characteristics of their bodies, or a combination of these factors made the dual task of independently moving self and another entity difficult to accomplish. This section illustrates a few examples of how life hacking impacted the demand-capability gap between participant capabilities and required ways of using the body to manage personal mobility while simultaneously moving another entity.

The first example came from Leon, who devised and leveraged multiple activity-oriented life hacks that allowed him to transport dishes, food, and drinks around his kitchen independently. Leon walks with the aid of a forearm crutch. He drags his right foot when he walks and uses his forearm crutch for additional support and stability on the left side of his body. Leon described his forearm crutch as both a cane and a crutch or a “cane-crutch.” At least four
different times during our interviews, he admitted that balance issues made tripping or falling a persistent and potentially dangerous risk for him in his daily life. Leon’s cane-crutch has a forearm cuff and a handle near the middle of the cane. Slipping his arm into the cuff, holding on to the handle, and leaning his weight on the cane to walk reduces the risk of losing his balance. While the handle plays a role in increasing his stability, the downside to holding on to it to walk is that he only has one free hand to do other things. Among other activities, the cane-crutch precludes Leon from leveraging both hands to hold and transport a plate, cup, or both while walking. Instead of simultaneously walking with his forearm cane-crutch and carrying dishes in his hands, Leon devised and utilized three different life hacks to make this daily life activity more manageable. For one of these life hacks, he made use of counter space to move items around his kitchen:

…when I lived by myself; if I needed to carry something and it was too heavy, because I have a hard time walking and carrying plates and things like that. So, if I have a lot of counter space, I use the counter to take my plate or cup. [Face-to-face interviewee]

Leon leveraged fixtures and furniture in his kitchen to make the task of moving a plate or cup possible for him. His life hack consisted of leveraging an immobile object in his environment (the counter) to replace parts of the task he could not perform. Carrying an object typically demands consistent and measured support of that object's weight. A person carrying a plate in his or her hands cannot let go until he or she places it on a solid flat surface. Simultaneously walking and carrying something like a plate or cup consists of two distinct but intertwined sets of physical activities that require specific and somewhat precise body movements. Performing these movements was difficult for Leon since the demands one task placed on his body conflicted with both the ways of using his body the other task (walking) demanded as well as his functional capabilities. Again, walking with the cane-crutch required the use of a hand which otherwise
would be free to hold and secure an object as he ambulated. Leon used the counter surface to separate three tasks: 1. supporting the weight of a plate/cup/etc.; 2. moving this item; and 3. ambulating. As such, the countertop played a role in his effort to “carry” an item around his kitchen. In the act of taking a plate to the table, he offloaded the task of supporting the weight of the object to the countertop while he focused on moving the item and himself, albeit in a contextually-convenient way. Using the fixture in this way allowed him to keep one hand on the handle of his forearm crutch and use his free hand to hold and slide the plate or cup across the countertop without spilling anything. The countertops allowed him to slide the plate or container a few feet and walk with his forearm crutch. If Leon took his hand off a dish that he was sliding along the countertop, it would not fall to the ground because a stationary flat fixture supported its weight.

Leon was not the only participant who had trouble carrying something and using mobility equipment at the same time. Progressive muscle atrophy increased Scott’s reliance on his walker to get around in his home. Using a walker made it difficult for Scott to carry plates to his kitchen table. One of his life hacks included modifying and leveraging his walker to make this task easier:

Scott: On my walker, what I’ve done to make my life easier, if I’m in the kitchen, and I want to take a plate and bring it to the table I can’t carry it because I need to use the walker. So, I put the plate on the seat of the walker, but the problem there is that a lot of times [the plate] will slide, so I put mesh netting around the walker around the seat area. So, if it slides, it slides into mesh netting. That’s one of the things that I’ve done to make my life easier.
Me: So the mesh netting, does it keep [the plate] from sliding or does it catch it if it does slide?
Scott: It catches it if it does slide. [Telephone interviewee]

From the beginning of this life hack's evolution, Scott used the seat of the walker as a surface to hold and support the weight of a plate as he used his walker. He would put a plate of food on the
walker seat and then use the mobility device to ambulate as he would in any other context. A person carrying a plate holds it securely in his or her hands so that it does not fall. The person also does his or her best to prevent sudden and dramatic movements that could lead to spills, which is commonly achieved by holding the plate securely in one or both hands and walking with caution. Scott’s Walker made provision for this demand carrying a plate places on the human body. The mesh netting that Scott added to his walker obviated the need to secure the plate in his hands. It also made sudden movements less risky since the added affordance caught the plate if it slid around on the seat. The seat and mesh netting together both supported and quarantined the plate so that Scott could focus solely on mobility. The walker served as both a mobility aid and an interface that allowed him to move the plate using the functional capabilities he possessed. It allowed him to integrate the practice activity of carrying his food to the table with the practice of walking in a way that leveraged personal capabilities as well as object affordances.

The third example comes from Ross who devised a unique way to transport firewood that bridged the gap between his functional capabilities and the demands the task placed on his body. Ross has a wood burning stove in his home and keeps a supply of covered wood outside the back door in his kitchen. His spouse typically brings several pieces of wood into the house for him so that he does not have to worry about doing it. Sometimes, however, when Ross spends most of his day at home alone, and it is cold outside, he ends up depleting the supply of wood in the house before his husband gets home. When this happens, he must restock the supply of wood inside his home independently. Carrying wood usually requires standing, walking, lifting, supporting the weight of one or more individual pieces of wood, and balance. Ross could not use his body to perform these constituent activities because of his disability. Although he uses a
manual wheelchair outside of his home, Ross often walks on all fours when he is inside of his home. His life hack, which consisted of leveraging objects for purposes other than most people, made it possible for him to move himself and the firewood from his back porch to his living room using his preferred mobility method:

So, I folded a towel in half, and then what I do is put that just inside the doorway, and then I open the back door -- because the wood's right there off the back -- ...So I select the wood I'm going to use, and I usually try to get a variety. If I'm just starting a fire, and I literally need all the wood, I select three or four pieces to start, and then I get the bigger ones, and gradually get bigger ones. I may have to do two or three trips. I load them onto the towel, then I climb back into the house, and then I pull the towel and close the door...so then I'll just pull. I'll be on all fours, and I'll slide the towel a little bit, and sometimes I can scoot. I don't move it and then move me; I can actually move it and me, just drag it through...and then drag it over [to the fireplace in the living room], and then I unload it onto a wood rack that keeps it off the ground. I may bring in two or three loads...That's how I use the towel. I just drag it around. [Face-to-face interviewee]

Before getting into the details of Ross’ life hack-enabled practice activity, it is worth noting that he tried different materials before figuring out a towel was ideal for the task. In earlier iterations of this artifact-centered life hack outcome, he used a cardboard box by itself as well as a cardboard box with a skateboard. He eventually replaced the box and skateboard with a towel because of the qualities of the latter. Although a person can use a towel for multiple purposes, it is most often used to absorb moisture from something or someone. A towel possesses certain qualities that made it useful to Ross in a way that it might not be helpful to the average non-disabled person. The towel was not only stronger than the box but also could be folded and resized. It also did not scratch the linoleum floors in his house. These qualities made it possible for Ross to stack pieces of wood on top of the towel and then simultaneously pull the edge of the towel and himself at the same time. Ross’ knowledge of his abilities and the things he learned from previous iterations of this life hack informed his selection and use of the towel to move the wood.
Whereas the task of carrying the wood placed demands on Ross’ body that he could not meet, his way of transporting the wood with the cloth towel allowed him to use his unique mobility technique while leveraging his upper body strength. Over the course of his life, Ross developed his body in ways that made this life hack possible. When describing his upper body strength and ability to do things such as pull something as heavy as a towel with multiple pieces of wood on top of it, he said, "I developed my body out of using it just in normal life." Ross’ previous daily life practice experiences allowed him to develop upper body strength and practical know-how he leveraged in various other practice contexts that followed. Instead of supporting the weight of the wood with his body, Ross offloaded this task to the floor. The linoleum floor and towel made it possible for him to drag the pile of firewood as he ambulated on all fours through the kitchen and to the fireplace in his living room. A carpeted floor would have resulted in more friction, making it harder for him to pull the towel across the floor. He leveraged the attributes of the floor and the durability of the towel as well as his developed physical capabilities and ability to figure out a way to move the wood without standing, walking, and constantly supporting the weight of the wood, which he could not do simultaneously.

**Actor-network-enabled “carrying” practices.**

Each human-non-human network reconciled the gap between what moving or carrying something while walking demanded from the body and what each participant could physically do given the nature and extent of his mobility challenges. Leon and the countertop formed an actor-network that allowed him to offload the tasks of supporting the weight of the dish or cup and thus prevent it from falling on the ground. The counter provided a surface that Leon could slide a cup/plate along or allow it to rest motionless if he needed to take his hands off the item at any time. Since the counter supported the weight of the item, he could rest it on the counter without
worrying about it falling to the ground. While the original designers of Scott’s walker included many of the affordances he utilized to move a plate of food around his kitchen, he added one more that helped transform the walker into a more productive agent in the actor-network. The Scott-and-walker actor-network moved the plate of food leveraging both Scott's abilities and the walker's affordances. For instance, the wheels made it easy to move the walker, the handles gave Scott something to hold on to as he walked, and the seat supported the weight of the plate so that Scott did not have to do so. Like Leon with the counter, Scott offloaded certain demands to the one object he could leverage while walking (i.e., his walker). In his case, he offloaded two demands the underlying task place on practitioners’ bodies to the walker seat: holding a plate with at least one hand and supporting its weight. Offloading these demands to the walker in this way, however, created another problem: the plate could easily slide off the edge of the seat. Scott improved his life hack by installing mesh netting around the seat. The mesh netting acted as a protective boundary that prevented the plate from sliding off the edge of the seat, thus making the walker a more productive agent in the networked endeavor.

Ross, the towel, and the linoleum floor formed a tri-actor-network that collectively constituted the task of independently transporting wood. This complex actor-network made it possible for Ross to "take over" the social practice of carrying wood (and all that it entails) despite his unique method of ambulating. The floor, towel, and human agent each contributed something to the joint effort and made it possible for Ross to do something that would have been difficult otherwise. The towel served as a dual interface between the human agent and the wood as well as the floor and the wood. The first interface replaced the demand to hold and carry the wood in one's arms, hands, or both. The towel served as a flexible but strong surface that Ross could interact with to move the wood without physically carrying it. The towel kept the wood
pieces together so the human agent could move several pieces at once. It also gave him something to grab and pull at a comfortable pace as he "walked" on all fours. The second interface between the floor and the wood made it easier for Ross to pull the wood. The manageable amount of friction between the towel and the linoleum floor made it possible to slide the towel without damaging either agent. Ross supplied the power needed to move the wood, albeit, by leveraging learned and developed way of using his upper body strength. The tri-actor-network together allowed Ross to act on his desire to move the wood without damaging the floor despite his mobility method and the gap between his method and the ways of using the body transporting wood typically requires.

Mobility equipment, individualized mobility methods, environmental affordances, common objects, or some combination of these things made it possible for participants to move items from one place to another. The life hack-enabled “carrying” practices described represent a few exemplars of the various ways participants developed and used a solution, leveraged ordinary objects, and/or used their bodies in unique ways to manage personal mobility while moving an object. Each life hack bridged the gap between participants’ capabilities and the physical demands of the task, albeit in different ways. The one common element is that the human and non-human actors in each actor-network shared the demands that moving something from one spot to another placed on the human body. Environmental and object affordances, object features, and participant capabilities and mobility behaviors combined in productive ways when life hacks changed the nature of the task of carrying or moving something. Participants shared the burden this task typically placed on a human agent with an artifact-centered life hack, everyday object, or environmental fixture, which allowed him or her to focus more on mobility and less on carrying. By relying on artifact-centered life hacks as co-agents, participants could
play productive roles in actor networks that not only shared the demands of the task but also made participants effective at enacting and overtaking practice elements despite their mobility challenges.

**Controlling the body and its movement.**

Most everyday life activities that involve the body require a measure of restraint, controlled movement, or both. Unlike life hacks that enabled participants to manage personal mobility while carrying something, this group of life hacks gave them the ability to move or not move one part of the body (e.g., foot or hand) in a specific way. By leveraging these life hacks, participants could exercise more control over a body part or use their bodies in the precise ways that daily life practice activities demanded. Most of the time these life hacks were necessary because functional impairment made restrained movement, controlled movement, or both impossible for the participant to demonstrate independently.

Grant uses a power chair to get around, and he has complete paralysis from the shoulders down. His lack of control over his lower extremities conflicted with certain demands that using his power chair placed on the bodies of all users. The wheelchair did not have foot or leg straps and driving over bumps or uneven surfaces sometimes caused Grant’s feet to fall off the pedals. Since Grant lacked motor control from the shoulders down, he not only needed help placing his feet on the pedals of his wheelchair but also could not keep them in place if a hill or bump caused his feet to fall off the pedals. Asking someone to help him in those situations was inconvenient, to say the least, and made him unnecessarily dependent on others. During one of our instant messenger interviews, Grant described an action-oriented life hack he leveraged to keep his feet in place on the footrest so they would not fall off the pedals when he was away from his home and family:
…using zip ties to keep my feet on my foot pedals. I tried a dozen different solutions to keep my feet there and nothing worked sufficiently. I now have a zipped tight [sic] loop on all of my shoes and then zip tied that loop to my foot pedals. Each day, and cut them off each night [sic]. [IM interviewee]

Grant's wife zip-tied his shoes to his footrests every day because he has upper extremity motor control issues as well. She added zip tie loops to all his shoes which she secured to the chair every morning with another zip tie. Each day his wife threaded a new zip tie through each shoe loop and around part of the footrest. Once she closed and tightened each zip tie, Grant’s feet remained on the footrests of his wheelchair for the rest of the day. He could not take his feet off the pedals until his wife or someone else cut off the zip ties. Grant’s life hack consisted of using a utilitarian object in an individualized way. It closed the gap between the demands his power chair placed on his body and his functional capabilities. Grant, the zip tie, and his procedural use of it together made it possible to limit leg and foot movement. This life hack allowed him to perform a functional activity he could not do on his own: keeping his feet on the pedals.

Arnold does not have any motor control from his chest down because of paraplegia. As a result, he cannot move his lower body to relieve pressure on his legs or reposition his feet on his wheelchair footrest. For individuals who use wheelchairs, these tasks are essential for preventing painful sores resulting from continuous pressure on the legs and buttocks. Arnold broke his leg when he injured his spinal cord in 2010, and had to wear a cast for a while as a result. He started using a product he learned about in rehab to make it easier to move his leg independently. After his leg had healed and his doctors removed the cast, the loss of motor control resulting from his spinal cord injury rendered him permanently unable to move his legs independently. The product he leveraged while he wore the cast was so useful to him that he continued using it after his leg healed, the cast was removed, and rehab ended. He even contacted the product’s designer to suggest ways to improve it based on his experiences:
My initial injury, part of it was a broken leg. In rehab, they gave me a thing they called a cast handle to put around my splint and help me move my leg around. I thought it was really great, so I said, ‘give me another one for the other leg, even though my other leg is not broken.’ Essentially, they're two Velcro straps. One goes around your leg just above the knee and one just above the ankle. Then they’ve got some webbing straps that run in between them, and it gives you a handle that you can reach down and grab to move your foot around for pressure relief or to reposition it on your footrest without having to try to get your hands up underneath your leg and grab your clothing to pull your leg to the desired position. When the initial pair started to wear out, I went online and ordered another pair. I left a nice review on Amazon...I said they’re great the way they are, but there are things you could do to make them, to me, a better product. He has been working slowly on incorporating those. I’m working right now with the latest version of them. They were made with just one version of it that allowed the buckles to be in one position on one leg and a different place on the other leg. Because they were facing the same direction, that makes sense. I said it would be better if you made a left one and a right one so that you can get the buckles in the best place on both legs. He’s done that. [Telephone interviewee]

If Arnold did not have access to the leg/case handles, he would have to either get his hands underneath his thigh or grab and pull the legs of his trousers to move his lower extremities around. Arnold continued using the leg/cast handles when his leg healed because they made these everyday life movements easier. Although he did not develop or modify the product, it still counts as a re-appropriation life hack because of his usage drift, or product use that varies from what designers expected or envisioned when they made it (Mallard, 2005). Arnold used a product designed specifically for people with leg casts as a tool that enabled him to address functional impairment related challenges resulting from his spinal cord injury. He could do so because he dealt with many of the same functional impairment issues without the cast that he did while wearing it. For instance, Arnold did not regain the ability to move, control, stand, or walk on his legs once doctors removed his cast. He continued using the leg/cast handles to do what his functional impairment prevented him from doing even though he no longer wore a cast.
**Actor-network-enabled movement and control-related practices.**

Participants like Grant and Arnold leveraged existing objects to move and control their legs and feet. These participants had functional limitations which prevented them from moving their lower extremities or using them in controlled ways. Their life hacks consisted of re-appropriating ordinary objects for specific purposes in their practice activities. Those objects served as co-agents in actor-networks that made it possible for participants to move and control their lower extremities in the ways specific practices demanded. As co-agents, these objects either replaced or supplemented functional capabilities the human agents lacked because of impairment.

Object affordances such as strength, flexibility, and dispensability made zip ties the ideal non-human agent in the Grant-zip-tie actor network. Grant’s way of leveraging zip ties to restrict foot and leg movement that he could not control independently bridged the demand-capability gap. As a non-disabled individual who made it possible for Grant to use this life hack, Grant's wife factored into the underlying actor-network as well as the zip ties and his shoes. Grant's wife attached the loops to his shoes and secured his shoes to his wheelchair with a zip tie (object) daily. The shoes Grant wore on his feet had an interface (the loop) that made it possible to secure them to the wheelchair pedals. Therefore, securing a shoe to a pedal also meant securing one of Grant's feet to the pedal. Grant and the fastened zip ties (object) kept his legs and feet (body) in the proper position and prevented his feet from sliding off the pedals. These two actors together prevented unwanted movement and thus allowed Grant to maintain his independence during extended amounts of time away from his family. While Grant had to place his feet on the footrest with assistance from his wife at the beginning of each day, the fastened zip ties kept them there with no additional effort on his part. When he sat in the chair with his legs in front of him, the zip ties held his lower extremities in position. All actors made a difference in the way Grant used
his wheelchair. Grant, his wife, the zip ties, his shoes, and the wheelchair (which did not have leg straps) all made the task of enacting and overtaking practice elements associated with using a wheelchair safer and more convenient. For instance, Grant said that aside from getting help from his wife with dressing and undressing, he goes through his day without having to ask anyone for help. This desire for independence factors into his wheelchair usage practices. The footrest life hack enabled the enactment of desire, accepted ways of using a wheelchair, his wheelchair, and functional impairment by enhancing his ability to keep his feet on the pedals.

Arnold and the leg handles formed an actor-network that made leg movement possible despite his loss of lower extremity motor control. The actor-network bridged the gap between Arnold's functional limitations and his desire to independently use his body in his daily life despite his functional limitations. Specifically, the actor-network changed the way Arnold moved his legs. The non-human agent enabled Arnold to move and control his lower extremities using his hands and arms. Affordances such as the Velcro strap, webbing straps, and handles made moving and controlling his legs with his arms and hands productive and efficient. Arnold and the leg handle formed an actor-network that made independent leg movement possible, albeit through an interface that allowed him to convert upper body movement into lower body movement. In other words, the actor-network made the task productive by enabling Arnold to use the upper body capabilities he possessed instead of forcing him to rely on lower extremity movement and control capabilities he did not possess. The features and affordances of the leg handle matched Arnold's functional abilities and allowed him to accomplish what a non-disabled person could do without this product: move his or her lower extremities. Arnold and the leg handles co-constituted several instances of practices involving leg movement and as a result, Arnold developed insights on the quality and effectiveness of the product. His feedback to the
product's designer was grounded in several episodes of working with and through it in his daily life practices in ways the original designer did not foresee. His guidance addressed not only the features and affordances of the leg handles but also its performance as a co-agent in his everyday life practices. He gave the designer suggestions stemming from contextualized use of the product as both an individual with a broken leg and a spinal cord injury survivor who lacks lower extremity motor control. The challenges he faced while using the product in the context of his daily life practices also influenced the feedback he gave the designer. Arnold's utilization of the leg lifter in his practices hints at the potential of life hack-enabled practices to give consumers with disabilities unique insights into how product designers can make their products more accessible and universally useful.

**Manipulating objects.**

Manipulation life hacks made it possible for participants to utilize objects, object features, and object affordances to accomplish tasks in their daily lives. The term “manipulation” refers to both what the life hack enabled the participant to do as well as what the participant/ally did to make or modify an object for personal use. Although some of these life hacks consisted of making or modifying objects to fit the participant’s functional capabilities, others consisted of utilizing existing objects in unique ways to do something. Manipulation life hacks were common when participants’ functional impairments made it difficult or impossible for them to utilize various objects they encountered or wanted to use in their everyday practices. The object manipulations described below made it possible for them to engage in specific activities of daily life such as eating & drinking, dressing, and participating in recreational activities. Some also enabled participants to leverage objects such as mobility equipment and computers.
Quadriplegia significantly limits Stuart’s motor control and dexterity, which makes it difficult for him to use his hands to do certain tasks. For the most part, both of his hands stay closed, and he cannot do certain tasks that most non-disabled individuals can do with their hands. Quadriplegia often precludes him from doing daily life activities that demand the use of his fingers to grip, pull, etc. without his life hacks. One such life hack involved leveraging his universal cuffs and pokers in a unique way. A universal cuff is a common accessibility product that consists of a strap with Velcro that wraps around a person's hand and two horizontally aligned holes on the palm side that serve as a holder for everyday life tools such as silverware, writing utensils, and toothbrushes. Stuart's "pokers" are bluish-green rods that he leverages along with the cuff as makeshift fingers. During our video chat interview, he demonstrated how he used the slots as holders for his pokers. On both hands, a rod protruded from the holes on each cuff and extended across his palm. Both rods were a bit longer than the width of Stuart’s hand which allowed him to use the ends as artificial fingers. The actor-network, which consisted of the cuffs, pokers, and Stuart, could do what the human actor could not do independently. The network combined Stuart's limited motor control and capability to interact with objects using alternative methods with the affordances non-human agents provided.

Sheila’s short arms, dexterity challenges, and inability to raise her arm to her mouth precluded her from eating independently with regular silverware. One of her artifact-centered life hack was silverware that her husband Jack modified in a way that allowed the resulting actor-network to bridge the gap between Sheila's capabilities and the demands using unmodified silverware placed on her body. For instance, Jack bent the handle of a soup spoon at an angle that obviated the
need for her to lift the spoon all the way to her mouth. The modification allowed Sheila to raise
the spoon to a height that was comfortable for her and put the contents into her mouth.

A spinal cord injury left Wallace with complete paraplegia from the neck down, which
means he cannot experience sensations or move his body below his neck. He relies on caregivers
for help with most daily life activities because he cannot use his hands. Wallace needs to drink
water throughout the day for health reasons, and he uses a catheter that his caregivers clean twice
daily. While he relies on his caregivers for bladder care, Wallace leverages a life hack that allows
him to independently drink water without using his hands. In the excerpt below, Wallace
explained how his caregivers took an object used by non-disabled individuals for recreational
and military purposes and modified it so that he could independently drink water when he
wanted without assistance.

Wallace: I don’t know if you can see it. See the black straw sitting on top of the white
straw here?
Me: Yes, I do.
Wallace: That’s a camel back. That’s a camel back drinking system, which we fill it up
with water and I can drink all night long. …

Me: I have one more follow-up question from last time. Your Camel Back drinking
system, is that something you created or is that something you bought off the shelf or is it
something you adapted?
Wallace: I think it fits both of your questions. It’s designed for camping, hiking, bicycle
riding, the military and all these different people. They usually use like a small backpack.
It’s a drinking system. I guess you’d call it a bladder that you fill up with water and then
a three-foot hose or something. I think you can see it, the black thing on top with the
white straw. That’s my Camel Back. The black one is the military one. I wanted
something to be less discrete, but most of them are bright blue. You can buy it off the
shelf. It started to become a little bit more common knowledge among wheelchair users,
but my friend [friend’s name], the one that I was helping with the computer stuff, she
learned about the Camel Back probably 15 years ago. She got me my first one so that I
could drink independently and we just figured out a way to attach it to my wheelchair and
attach it to my sip and puff [an assistive technology interface that allows someone to use
his or her breath to operate a switch controlled device by inhaling and exhaling into a
tube], so that I could drink without having to ask somebody for a drink of water.
Me: What did you use to attach it to your chair?
Wallace: I think we used cable ties. I’m not entirely sure how it’s attached in the back.
think it’s using cable ties in the back, also, but up here to get it properly positioned on top of my sip and puff, to where I could actually get to it, we use a couple of small cable ties and strap it on tight with the cable ties. [Video-chat interviewee]

Wallace used the Camelback drinking system in a way designers likely did not foresee. The intended users of the drinking system were combat military personnel, but Wallace leveraged it to address challenges related to his spinal cord injury. This life hack, which is another example of Mallard's (2005) concept of usage drift, consisted of modifying a commercial product in such a way that Wallace not only could attach it to his wheelchair but also leverage its features to accomplish something his motor movement and control challenges made impossible otherwise.

The setup allowed Wallace to both take the drinking system with him wherever he went and easily access the drinking straw without assistance. His caregivers’ physical ability to attach the system to Wallace's wheelchair and adjust it for his use made up for the fact that he could not use his hands to manipulate, position, or access the straw by himself. They also created affordances (e.g., straw attached to other wheelchair accessories and positioned near his mouth) that enabled him to leverage the features of the drinking system without using his hands.

**Manipulation/exploitation – recreational activities.**

Stuart played video games (sometimes competitively) before his spinal cord injury, but after his injury, he found it difficult to operate the controller with his fingers. He wanted to continue playing and competing with other people, which demanded hand coordination and adroitness [dexterity]. One of his artifact-centered life hacks was an Xbox video game controller that his mom and uncle helped him to modify. Stuart leveraged this life hack to bridge the gap between the physical abilities gaming required and his capabilities. Video game controllers like the Xbox 360’s have small buttons that demand adroitness. Although Stuart could use the pokers inserted into the pockets of his universal cuff to press the buttons on the controller, the size of the buttons
made it difficult to manipulate them with the accuracy and skill that playing well demanded.

Additionally, the Xbox 360 controller has an ergonomic design that is meant to make the dual tasks of holding it while pressing buttons seamless. Stuart, however, could not hold the controller in his hands the way the original game console designers intended. As a result, he had a difficult time manipulating the buttons on the controller. The following excerpt from my interviews with Stuart describes how he leveraged multiple controller modifications to access all its functions:

I should bring up, too, that I have an Xbox 360. My mom came up with this idea of wrapping the Velcro around a pillow, in the center of this pillow and then putting the pillow on my lap and using these hand thingies [universal cuffs with pokers] to be able to hit the buttons. And I came up with the idea of breaking a regular burnable CD. I broke those, and I created larger shapes and connected them with Velcro to the buttons that I pressed. That gave me a larger space to work with when I needed to press buttons. Because when they’re small, the buttons are the size of the end of my tips, and it’s hard to accurately hit the buttons. You know I can’t let my friends beat me in FIFA soccer when I’m playing them, right? I’ve got to play my best. Then on the controller my uncle helped me wire in a mou[th] trigger, where I have my right trigger, which is often used for turbo or shooting. I have it connected to the controller, and I place the mouthpiece in my mouth, and I use my tongue to press on the button, so that I can play games better than I would be able to. Otherwise, I wouldn’t be able to use turbo, or I might not even be able to shoot. It would just be really frustrating to even try. [Video-chat interviewee]

The three modifications Stuart, his mom, and uncle made to the Xbox controller enabled him to interact with it in a way that worked for him given his functional impairments. He could use the modified controller to perform all the actions the gaming system afforded despite having limited use of his hands. The modifications provided affordances that made using the controller easier and productive for Stuart. These affordances enabled him to keep the controller in the same position, press buttons accurately, and use an alternative interaction technique to press buttons that were not easy to manipulate with his handcuff and pokers.

Samantha described an object manipulation life hack that she leveraged in one of her recreational practices. One of the effects of Common Variable Immunodeficiency for her is
 temporary hand numbness, which makes it difficult to use her fingers to complete tasks requiring adroitness. As described in the next excerpt, Samantha discovered and adopted an artifact-centered life hack that made knitting accessible when her hand numbness flared up:

As I mentioned, I make a lot of stuff, like crafts and stuff, and I was having issues holding onto the yarn. It was too small, and I was trying to make a hat, I think. One of the Pinterest things had a picture where someone put a hollow pen around it [the yarn], and it made it so you could hold onto the pen, and then the yarn would just come out the other end, so I was able to do that, and I got that from Pinterest. [Telephone interviewee]

Hand numbness and the resulting reduction in manual dexterity made interacting with soft and thin materials like yarn challenging. By adding a solid cylindrical object to the yarn, Samantha changed the way she interfaced with the yarn. The empty pen shell acted as an alternative interface that was easier for her to hold and manipulate with her hands whenever she experienced numbness. The size of the pen and its solid round structure gave Samantha something larger and easier to grasp with her fingers than the yarn itself. She leveraged the pen to bridge the gap between the adroitness that working with soft and small materials demanded and what she could reasonably do with her hands when she experienced numbness.

Arnold developed and leveraged life hacks that made it possible for him to develop other artifact-centered life hack outcomes. Arnold is an active member of a Makerspace near his hometown. He does not have any motor control at or beneath his diaphragm due to a spinal cord injury. Arnold cannot use his legs and therefore utilizes a power chair for mobility. The inability to stand made it difficult for him to use certain pieces of equipment in the Makerspace. For instance, all the milling machines have overhead power and motor speed controls. A milling machine shapes solid pieces of metal or wood by cutting off excess material. One of the manipulation life hacks Arnold developed enabled him to independently operate the power switch and speed control knob on the milling machines while sitting in his wheelchair:
…we have a sharp CNC milling machine. I was learning how to use it. One of the first things I had to invent was what I call my mill stick, which is a three-foot length of one by that I have a notch and a hole cut in one end of it. The notch is something that allows me to reach up and work the power switch, which is up at the top of the mill. Then there’s a hole that fits over the crank to change the motor speed.

One of my other tools that’s almost doing a very similar thing is what I call my mill stick, where in order to use some of the mills at the [name of makerspace] I have to be able to reach the power switch that’s way over my head and also adjust the speed on one of them. I got a piece of board that was maybe a couple [of] inches wide and an inch thick and about three feet long. I cut a notch in one end that will fit over the power switch and drilled a hole that will stick over the speed adjusting knob. [Telephone interviewee]

Unlike most participants who utilize manipulation life hacks, Arnold does not have a dexterity impairment. Instead, his mobility issues and the design of the milling machines co-created a gap between the physical activities required to manipulate the milling machine controls and Arnold's physical ability to access and manipulate them. Arnold and his mill stick innovation formed an actor-network that bridged the gap between the demands the mill placed on all users and Arnold's physical capabilities. Together the two actors could reach and operate the milling machine controllers while Arnold sat in his wheelchair. An individual who can stand has easy access to the top of the machines. The life hack did not eliminate the need to operate the power switch and speed control knob on the upper part of the machine. It did, however, enable Arnold to access the controls as if he were standing on his feet and using his hands without physically doing so. The main difference between Arnold's life hack-enabled method and the way a non-disabled person would do it was that he leveraged the mill stick as an interface between his hand and the machine. The length of the mill stick made it possible for him to "reach" what typically could only be accessed by someone who is standing. The hole and notch in the stick also made it possible for Arnold to turn the speed dial and flip the power switch, respectively from a distance.
**Manipulation/exploitation – operating input interfaces.**

Some participants made and leveraged homemade mobility equipment add-ons when functional limitation prevented them from using professionally designed equipment interfaces. For instance, fine motor control issues made it difficult for Sheila to use the joystick on her power chair with the accuracy and precision the task demanded. More specifically, it takes hand and finger coordination [dexterity] to apply the right amount of pressure to the joystick and operate a power chair safely. Arthrogryposis reduces Sheila’s fine motor control, particularly when she does not have anything to rest her wrist on while using her hand. Whenever she got a new power chair her husband Jack would immediately add a wrist platform to the joystick's control box. Jack provided specifics about how he made the add-on during our interview. First, he stacked several pieces of cardboard on top of each other and wrapped black electrical tape around the stack. Next, he attached the wrapped-up pieces of cardboard to the back of the control box of her power chair joystick. During an interview with Sheila, she explained how important it was to add the platform to her newest power chair and the role it played in her mobility and other daily life practices: “I had to be able to rest my hand on something to have the fine motor skill” [Face-to-Face Interviewee]. The homemade wrist platform add-on makes it possible for her to effectively coordinate her finger and hand movements and thus operate the joystick in a more fluid and controlled manner than she could without it.

Wallace cannot use his hands at all, and he needs assistance from others with most of his daily life activities. The only part of Wallace's body that he can control independently is his mouth. His caregivers made a power chair add-on that he leveraged to use his computer without assistance. This life hack outcome made up for the fact that Wallace could not use his hands to type, control a mouse, put on a headset, or adjust the headset if it was uncomfortable on his head.
Wallace had other wheelchair add-ons like the one for his headset. All his life hacks bridged gaps between Wallace's functional capabilities and the demand to manipulate objects with one's hands inherent in the underlying daily life activity. The headset add-on made it possible for him to control his computer hands-free with his voice. Wallace used this life hack outcome along with several self-programmed computer macros that allowed him to use voice commands instead of the keyboard and mouse. The headset add-on consisted of his allies attaching his computer headset to his wheelchair in a way that made it accessible to him on-demand:

I don’t know if you can see, but the way we tipped my microphone from my computer. That’s actually a headset. It’s designed to go on my head, but the problem is, for the most part, I don’t want that on my head that long. If I’m on my computer for 12 hours overnight, I can’t take that headset off if it hurts or if it slips when I tilt back. Again, we just modified how we wear it basically, put it around my neck like a necklace and then extend it up and then strap it to my sip-and-puff so that it will stay. When I tilt back, the microphone won’t slip back by my ear to where I can’t use it. It will remain in a place where I can access it. So I guess that’s another example of how we’ve taken an existing product and we use it a little differently. [Video-chat interviewee]

Wallace also utilized an unmodified commercially-available power chair accessory. A sip-and-puff joystick controller interface allowed him to operate his power chair with his mouth instead of using his hand to move a standard joystick. His caregivers took advantage of the position of the sip-and-puff straw by attaching the headset microphone to it so that it was near Wallace's mouth. Instead of wearing the headset on his head, he wore it around his neck like a necklace. His caregivers extended the microphone and attached it to the sip-and-puff straw with a hair scrunchie. Since the sip-and-puff interface was stationary and the straw was positioned relatively close to Wallace’s mouth, the microphone was always positioned for use and therefore independently accessible. The sip-and-puff interface, drinking system straw, and headset microphone remained within range for Wallace to use even when he tilted his chair back. He did
not have to worry about adjusting the headset on his head or repositioning it once his caregivers set it up for him.

**Actor-network-enabled object manipulation-related practices.**

Participants who leveraged object manipulation life hacks had upper or lower body motor control limitations, reduced dexterity, or similar functional limitations which prevented them from using their arms and hands in the precise ways a given task demanded. Design factors and socially shaped ways of using artifacts clashed with each participant's functional capabilities and severely limited his or her ability to use a given artifact to complete a task without assistance or a more accessible alternative to the artifact. Object manipulation life hacks made it possible for participants to access, utilize, and manipulate objects to accomplish tasks by changing the way they interacted with those objects.

Both Stuart and Sheila described life hacks that consisted of leveraging or slightly modifying everyday items for use as tools. Stuart leveraged an assistive technology together with a common dollar-store item to pull down his shirt and retrieve his wallet independently. Stuart, his universal handcuffs, and the rods he utilized with the cuffs formed an actor-network that collectively manipulated his clothing and accessories, allowing him to dress independently despite his quadriplegia-related dexterity and motor control difficulties. This actor-network bridged the gap between demands such as pinching the edge of a shirt, the sides of a wallet, or its contents and the fact that Stuart has limited use of his hands. The handcuffs and rods provided him with makeshift "fingers" he could operate like real ones. As a result, the human agent (Stuart) could overtake the physical demands of dressing, physical objects (i.e., his shirt and wallet), his desire to move towards greater independence, and know-how involved in acts of dressing resulting from post pre- and post-spinal cord injury experiences. Sheila and the bent
spoon formed an actor-network that merged the former’s physical capabilities together with the latter's structure and shape. This actor-network made using a soup spoon accessible and productive for Sheila by reducing the distance between the eating utensil and her mouth. Similarly, Stuart's handcuffs and pokers made interacting with his clothes easier in specific instances of getting dressed.

Wallace and Samantha both leveraged life hacks that consisted of re-appropriating objects for their self-determined practices. Wallace, his drinking system, wheelchair, sip-and-puff switch interface, and the cable ties that held the system in place formed a multi-agent actor-network. All these actors constituted Wallace's drinking activities and limited his dependence on his caregivers to them setting up and maintaining the system. Samantha and the hollow pen she sometimes leveraged while knitting formed an actor-network that empowered her to meet the manual dexterity demands the activity placed on her. Samantha's dexterity difficulties were not constant, and the actor-network enabled her to overtake the constituent practice elements of her knitting practices when she experienced the hand numbness associated with her condition. While Samantha brought know-how, will, experience, and creativity to bear on the practice of knitting, the non-human actor (hollow pen) provided a simple yet effective alternative interface she could use to manipulate the yarn when she experienced hand numbness.

Arnold and Stuart's life hacks consisted of significantly modifying objects so they could leverage them in their recreational practices. Their life hacks allowed them to bring, among other things, their pre-injury experiences and know-how to bear on the activities they enjoyed doing before their injuries and wanted to continue doing afterward. Arnold has an extensive history of making, modifying, and repairing things that started long before his spinal cord injury. Arnold and the mill stick formed an actor-network that made practice elements such as the desire to
utilize Makerspace equipment independently, his pre- and post-injury experiences as a DIYer, the fact that he sat in a wheelchair, and the design of the milling machines productive even though the mills were inaccessible to wheelchair users. The mill stick contributed to Arnold's efforts by allowing him to access and manipulate what was otherwise out of his reach. The length of the stick allowed him to access the controls on top of the mills while the notch and hole enabled him to turn the mill on and off and change the speed, respectively.

Similarly, Stuart leveraged a customized artifact that allowed him to access otherwise inaccessible object features. The out-of-the-box design of his Xbox controller and the demands its design places on users clashed with Stuart's ability to access and press all the buttons at will as an individual with complete paralysis from the chest down and limited use of his hands. Stuart and his modified controller formed an actor-network that collectively manipulated the controller’s buttons and other features in ways that would not be possible without both actors. The actor-network accounted for both Stuart's functional limitations and the inaccessible features of the original unmodified controller. It also allowed him to both participate in a hobby he enjoyed and to competitively play against other people.

Both Sheila and Wallace leveraged life hacks that caregivers attached to their power chairs. Sheila and the homemade control box platform comprised an actor-network that made it easier and safer for Sheila to overtake practice elements that constitute using a wheelchair by distributing the required physical activities between the human and non-human actors. The non-human actor (the cardboard platform) was custom-made for Sheila and the realities she faced as an individual who had difficulty controlling the arm and hand she uses to drive her power chair. The shape and placement of the platform as well as its constant availability as an add-on accessory combined with Sheila's strong desire for independence, short arms, limited dexterity,
and limited upper extremity motor control and made it possible to drive the power chair without fear of crashing. The platform positioned her hand within reach of the joystick and provided the support she needed to avoid making sudden or disjointed hand movements. The platform essentially took on physical activities that Sheila could not do while allowing her to concentrate on the ones she could do. Wallace's computer headset add-on similarly obviated the need to do physical tasks that he could not perform by shifting those tasks to the non-human agents and their networked arrangement with the human agent. Wallace, and the power chair, headset, sip-and-puff straw, and scrunchie all played a part in enabling his computer use. By placing the headset around Wallace's neck and positioning the microphone close to his mouth, the resulting actor-network accounted for the fact that Wallace could not independently grab, control, or change the position of the headset and microphone. It obviated the need for him to do activities the practice of using a computer headset requires which he cannot do independently. Wallace could independently overtake will, desire, technical know-how, the headset, his computer (including its features, affordances, and accessibility options), and the physical demands using a computer place on the body because objects attached to his power chair made his headset accessible to him.

All manipulation life hacks bridged gaps between the expected ways of using one’s upper extremities that utilizing objects in a specific fashion demanded and the functional capabilities participants possessed. They made enacting and overtaking practice elements (particularly objects necessary for the practice regardless of the practitioner) in individual acts of doing practice activities possible. Object manipulation life hacks closed the demand-capability gap by allowing the participant to do practice tasks and use the underlying objects with the physical capabilities they possessed instead of forcing them to use capabilities they did not possess.
Several study participants described life hacks that enabled them to manage the demands that activities such as reaching, grabbing, and pulling placed on their bodies. Each participants’ functional limitations made these tasks difficult or impossible, and they leveraged life hacks to bridge the gap between their capabilities and the demands a given task placed on the body. Tabitha has spastic diplegia, which is a form of cerebral palsy that affects a person’s lower extremities (e.g. legs) only rather than his or her upper extremities or both. She uses a wheelchair and cannot stand. One of her life hacks consisted of using an assistive tool marketed to individuals with disabilities to reach items from her wheelchair:

Well, my house is not accessible at all, so I have quite a few techniques to reach things. When it comes to reaching things, I'm known to use a broom to reach and knock down what I need, or getting out of my chair and up on a counter...also my step-father came across this contraption that I call "the grabber" that if I can't do the other two things I'd just grab that and it picks things up and I reach them with ease. [IM interviewee]

An important thing to point out is that Tabitha explicitly attributed agency to the grabber tool when she said, “it picks things up.” Tabitha lived alone in a home that she described as inaccessible. As an individual who actively seeks "to continue to live as independently and productively as possible," sometimes she had to leverage objects in ways that were useful to her. For instance, one of the issues Tabitha ran into living in an inaccessible home included sometimes wanting to retrieve an object in a cabinet or on top of something tall and being unable to reach it from her wheelchair. She leveraged her "grabber" tool or an ordinary broom to retrieve items. While a broom is a common cleaning tool present in many households, the grabber is a multi-purpose tool often marketed to individuals with physical disabilities. Tabitha used these objects to extend her reach and thus eliminate the need to stand to reach items in her kitchen. Tabitha was not the only participant who used something like a tool to access items
beyond her reach. Leon [Face-to-Face interviewee] did the same thing when he needed to access something in a kitchen cabinet. The only difference was that he used his cane crutch instead of a broom or grabber tool. Samantha, who has severe spine damage and experiences chronic back pain, also uses a broom to access and retrieve items beyond her reach. The back pain made it difficult for her to lift her arms above her head, which complicated the task of reaching and retrieving different items on shelves at her place of employment. Somewhat like Tabitha and Leon, Samantha [Telephone interviewee] sometimes used a broom to reach and move files or other items closer to her body so that she could retrieve them without extending her arms all the way. Although she used the broom in a slightly different way than Leon and Tabitha, Samantha leveraged it to achieve the same goal: to access something beyond her reach independently.

Tabitha, Leon, and Samantha leveraged brooms, cane-crutches, and other objects to either extend their reach or reduce the amount of reaching they had to do to access something beyond their reach. Tabitha and Leon both leveraged brooms to not only make the job of accessing items beyond their reach easier but also exchange the task of reaching up to retrieve the desired item with knocking the item onto the floor and then picking it up. The broom extended both participants’ reach beyond the length of his or her arm. It also changed the retrieval task from one requiring a person to grab something above his or her head to one where the participants reached down to retrieve it from the floor. Unlike Leon and Tabitha, Samantha used a broom to pull desired items closer to her and thus reduce the length she had to reach out her arms to access and retrieve it.

Tabitha's grabber tool extended her reach like the broom did, but instead of knocking the item onto the floor, she used the grabber to retrieve it. According to Tabitha, she did not pick up the item but her grabber did. The tool had a lever-controlled hand-like interface that Tabitha
could close and open by pulling and releasing the tool’s handle. Positioning the claw-like interface over an item and pulling the handle secured the object in the claw and allowed her to pull it towards her body. Once the item was within reach, she could access it with her other hand or place it on her lap.

Sheila leveraged a homemade life hack outcome that exchanged the act of extending her arms straight out to reach into a file cabinet to rotating a desktop alternative that positioned her files close to her body. The length of Sheila’s arms makes it difficult for her to reach items unless they are close to her body. Sheila and her husband Jack developed an artifact-centered life hack outcome that she used at work to address reaching-related difficulties associated with retrieving items from a traditional file cabinet. Jack constructed a different type of filing cabinet that minimized the amount of required reaching. Jack described the form of this file cabinet life hack as well as what it offered that traditional file cabinets did not in the following excerpt:

I also made her a rotary file cabinet. It was on a lazy Susan base so it would rotate, and it had four slots, if you will, about bing, bing, bing, bing [models a four-sided object with hands and taps each side as he says "bing"], so that she could turn it and have access to her files instead of trying to operate a drawer, which wouldn’t work because she couldn’t get to the back of the drawer, and they weren’t getting her any sideways drawers like they have now. [Face-to-face interviewee]

Traditional file cabinets are stationary units with long pull-out drawers. While items in the front part of the drawer might have been somewhat accessible to Sheila, elements farther back were beyond her reach. Instead of having two or more long drawers stacked on top of each other, the lazy Susan file cabinet consisted of a desktop-sized rotating base with four slots. Sheila could turn the base to access each slot. Instead of reaching into a long drawer that was partially or wholly beyond her reach or asking someone to retrieve items from the drawer for her, she could turn the base and bring the contents of each drawer within her reach. This life hack transformed
an activity that typically required a person to fully extend his or her arm into one accomplishable by rotating a base.

**Actor-network-enabled reach & retrieval-related practices.**

Reach and retrieval life hacks bridged the gap between the degree to which an everyday task required the average person to extend his or her arms to access something with his or her hand and participants' ability to access and retrieve something desired. Life hacks that enabled participants to reach or retrieve something in their environment involved leveraging: 1. the features of existing or homemade objects to access something beyond reach; or 2. alternative ways of using the body and interacting with objects.

Tabitha, Leon, and Samantha each formed actor-networks with their artifact-centered life hack outcomes. Each human-non-human entity facilitated the overtaking of physical capabilities, functional limitation, desire [e.g., to retrieve something independently], and movement necessary to reach an object that was beyond the length of his or her extended arm. These actor-networks combined each participant's physical limitations and capabilities with the form, length, and rigidity of the broom, cane, and reacher tool. Both agents in each actor-network contributed something to the collaborative effort to make it productive. The length and rigidity of the broom, cane, and reacher made it possible to access objects from a distance while the human actors leveraged those tools to move desired objects within arm’s reach. Whether the participant used the tool to move or retrieve something desired, each long rigid non-human agent neutralized the impact of human agent's limited ability to reach and retrieve something far from his or her body. These non-human agents made up for the fact that Tabitha sat in a wheelchair and she was short, Samantha had back issues, and Leon used a cane-crutch for mobility and could not reach very high because of his height. In Leon's case, his life hack solution was not impairment-related as
much as it was height and reach related. Professionally-designed equipment intended to support mobility played a role in helping Leon achieve a non-mobility related goal. All the participant-tool actor-networks described in this section bridged the demand-capability gap by allowing the participant to access objects they could not reach with their hands.

Sheila and the lazy Susan file cabinet formed an actor-network that leveraged her body as it was rather than placing demands on her that she could not meet because of her functional limitation. Rather than forcing her to extend her arm, which Sheila could not do, the lazy Susan life hack solution replaced that task with one that she could do independently. The design of the solution made the overtaking process doable for her given her functional capabilities because it transformed the practice itself. It made filing and accessing papers independent of the traditional file cabinet that requires a user to reach into long drawers. The Lazy Susan filing system brought files to Sheila instead of forcing her to retrieve them from deep inside a drawer.

**Transporting objects up a flight of stairs.**

Stair-related life hacks were primarily action-oriented and each one enabled participants with mobility challenges to carry items up or down stairs. Participants who described stair life hacks had a mobility impairment that forced them to either find a unique way to deal with stairs or avoid them altogether at least once in their lives. Participants leveraged material resources and environmental affordances to make the task of independently moving themselves and objects from one floor to another possible.

Cecil described several life hacks that enabled him to move items up or down stairs during our interviews. For each one, he leveraged the same underlying techniques to ascend or descend stairs. Cecil utilizes both a power chair and manual wheelchair for mobility. Although he used crutches for most of his life, a 2014 automobile accident left him unable to walk with
crutches. Cecil uses elevators to go to different floors in buildings if one is available and operational. Before his accident, however, Cecil had two procedural life hacks that enabled him to go up and down stairs when he did not have access to an elevator. He continued using one of these methods after the accident. It consists of sitting on the first step of a flight of stairs with his legs in front of him and feet resting on a lower step. He then inches up or down the stairs one step at a time. This technique served as the foundation for another procedural life hack that allowed Cecil to move items up and down a flight of stairs, as explained in the excerpt below:

Cecil: If I had steps and I wanted to go downstairs to get some clothes or something, I’d just take a basket down, put the clothes inside, sit on the step, and bring it.
Me: What kind of basket, a clothes basket?
Cecil: Yeah.
Me: So you would go one step at a time and drag the basket?
Cecil: Back up, yeah. To get the basket down there I just toss it down there and retrieve it once I get down the stairs.
Me: When you go up, do you drag the basket in front of you or behind you?
Cecil: On the side of me. Like I’m sitting here right now [legs hanging off the front of his wheelchair seat cushion with feet flat on the footrests], as I move up my body up each step, I bring the basket up with me.
Me: If you were taking a load of clothes up a flight of stairs, how long might it take you to do that, a few minutes, a minute?
Cecil: It would take me a while, depending on how many steps. [Face-to-face interviewee]

Although Cecil used the basket to carry clothes, which aligns with its originally intended purpose, he also leveraged it to carry other “somethings” up and down stairs. Cecil's stair-climbing procedure (described earlier) facilitates his way of taking items up a set of stairs. As he moved his body up the stairs one step at a time while remaining in a seated position, he brought the basket of items alongside his body. Each step played a dual role in this life hack-enabled practice. It supported Cecil's body weight, gave him a surface to sit on, and supported both the combined weight of his body and the clothes basket. Each step gave him a platform that he could climb and then sit on until he was ready to ascend the next one. Each step also gave him a place
to rest the clothes basket while he was moving his body to the next step. Individuals who can walk up a flight of stairs will typically bear their body weight as well as the weight of an object they are carrying. Since people who do not have mobility impairments can stand and use their lower extremities to climb stairs, they bear all this weight on both their feet and legs. Cecil cannot bear his body weight on his legs alone. His way of using the stairs to move himself and the basket bridged the gap between what the task of carrying something up a flight of stairs demanded and his physical capabilities. Sitting on his bottom and scooting up the stairs allowed Cecil to ascend the stairs without bearing much weight on his legs. He offloaded a task demand he could not complete to the stairs while using the physical capabilities he did possess and his personalized stair climbing methods to climb the stairs with the basket of clothes. Cecil not only used his body in an individualized way but also leveraged each step on the flight of stairs.

Leon did not provide many details about how he climbed stairs in general. It is possible that he used his cane-crutch, the railing, or both. Leon did, however, describe a dilemma he once faced when he wanted to carry several items upstairs to his apartment, but could not simultaneously walk and carry the items in his hands:

Leon: Just when I used to live in an apartment that had stairs, you had to have stairs to go up to the bedroom and the bathroom. One day I had stuff downstairs that I wanted to take upstairs, so I just put it in a Hefty trash bag and pulled it up the stairs. I might have put holes in the bag pulling it up the stairs, but I got it up.
Me: How many stairs were there?
Leon: I’d say about 18. [Face-to-face interviewee]

As the exchange above reveals, Leon offloaded the tasks of holding and carrying each item to the trash bag. He substituted carrying items in his hands while ascending stairs with pulling the weight of the articles using a trash bag. When describing this episode, Leon did not say his mobility impairment prevented him from bringing each item upstairs individually. He said he wanted to bring everything upstairs in one trip to minimize the time and overall effort the task
involved. His trash bag re-appropriation life hack enabled him to do the task in a way that was more desirable and efficient for him. The bag made it possible for him to ascend the stairs the same way he always did while carrying more items than he could otherwise.

**Actor-network-enabled practices related to carrying items up a flight of stairs.**

The examples just outlined and several others show how different life hacks and participants formed actor-networks that collectively bridged the demand-capability gap associated with carrying items up several steps. The actor-network in Cecil's life hack-enabled practice consisted of Cecil, the steps, and a clothes basket. The actor-network combined Cecil's physical capabilities and learned ways of managing stairs with environmental affordances and the size and shape of the clothes basket. Practice elements such as Cecil's upper body strength, ability to use his hands and arms to raise and lower most of his body weight, past experiences dealing with stairs, the stairs themselves, and the clothes basket all constituted the practice of carrying multiple items upstairs in a way that was productive. Leon and the trash bag formed an actor-network that collectively constituted and shared the tasks of carrying and moving multiple items up a flight of stairs. The bag not only kept each item from falling but also allowed Leon to simultaneously use his hands and arms to hold the rail or cane-crutch and pull the items while ascending the stairs. As Leon held on to and pulled the bag, it supported the weight of the objects it contained. While pulling the bag required physical effort on Leon's part, it was also easier for him than simultaneously ascending the stairs and carrying all the items or making multiple trips up and down the stairs for each item. The gap in this scenario existed between the way Leon wanted to carry the objects upstairs and what he was physically capable of doing on stairs as an individual who needs to hold on to something to ambulate independently. The trash bag transformed the task of carrying everything into a one-handed effort. The actor-network shared
the demands that carrying items upstairs normally place on a person's body in a way that made it possible for Leon to use one hand instead of both to move the items, which complemented his stair climbing procedure. The bag held the items while Leon pulled the bag and ascended the steps himself.

It is worth noting the prominence of will and desire in the practices described in this section. Both Cecil and Leon's life hacks enabled them to independently accomplish daily life tasks or accomplish them in desired ways despite the demand-capability gap created by their mobility impairments and the presence of stairs. Both leveraged environmental affordances as well as mundane objects to ascend or descend stairs while holding on to something. Whether it was the handrail or the steps themselves, objects in their environment played a role in practice constituting actor-networks. They were empowered to take over practice elements because the actor-network created productive linkages between their physical capabilities, environmental affordances, and the objects they wanted to carry upstairs. One component of each participants' life hack consisted of individualized procedures that changed the way he interacted with stairs. These participant-centric interaction patterns allowed Cecil and Leon to share the demands of climbing stairs with the steps and handrail/cane-crutch, respectively. The second component of both life hacks was the re-appropriation of a container. The laundry basket and trash bag enabled Cecil and Leon, respectively, to transport multiple items without dropping them. The basket's size and shape enabled Cecil to pull it up one step, rest it on that step, and then move himself up a step. Similarly, the size and durability of the trash bag allowed Leon to load it with items and pull it up the steps as he ascended them. Both Leon and Cecil served as human agents in actor-networks which combined their ability to climb the stairs using individualized procedures, the affordances the stairs provided that allowed them to do so, and task-specific "containers" to
overtake practice elements and carry items up several stairs. The human and non-human agents in each actor-network made physical capabilities, the will to do something independently, personal preference, functional limitation, steps and their affordances, containers and their features, situational circumstances, and knowledge about the ways non-disabled people deal with stairs productive.

**Using lower extremities (legs/feet).**

The final group of life hacks enabled participants to engage in practices that typically require the use of one’s lower extremities. Study participants leveraged both object-centered and action-oriented life hacks that made it possible for them to do these activities despite being partially or completely unable to use their legs or feet. Each underlying daily life practice demands coordinated utilization of practitioners’ lower extremities as well as very specific and precise movements. Participant life hacks made it possible for them to engage in these practices despite the required bodily movement their lower extremity impairments precluded.

Ross [Face-to-Face interviewee] described a time when he wanted to go on a hike with his boyfriend. He could not use his wheelchair on the hike because the trail had stairs. When describing his initial feeling when he saw the trail and realized it might prevent him from enjoying the hike with his companion, Ross said he felt "disempowered...frustrated, and angry." Instead of forfeiting the opportunity to go on the hike, Ross walked the trail on all fours. Non-disabled individuals can use their legs to go up the stairs. Ross, on the other hand, leveraged his upper body strength and ability to "walk" on either his hands or all fours. His procedural life hack consisted of leveraging an alternative way to walk using his upper body to supplement and sometimes replace his legs. He used this method in other everyday life contexts, but in this instance, his way of ambulating combined with the environment to bridge a situational demand-
capability gap. By utilizing his individualized ambulation method on the trail, Ross could climb the stairs and travel with the other hikers even though he could not hike in the traditional sense of this practice or use his wheelchair. Ross admitted that walking on all fours depleted most of his stamina and made finishing the hike laborious and tiring, but he did complete the entire hike. The inaccessible trail could have kept Ross from going on the hike that day, but he decided to leverage the abilities he developed over time. His way of ambulating configured the practice of hiking in a way that made it accessible. Rather than succumbing to the mismatch between the demand to walk up the stairs and his wheelchair usage Ross was enabled to hike by his developed way of getting around in different environments.

At the time of our first interview, Arnold was working on an artifact-centered life hack that would allow him to do something that typically requires the use of one's lower extremities. Arnold cannot use his legs, and this prevented him from accessing foot-controlled equipment such as sewing machines and the Tungsten Inert Gas (TIG) Welders he wanted to use. At the time of our interviews, Arnold was working on a set of foot pedal pushers that would make it possible for him to operate pedal-controlled machinery using his voice instead of his feet. He got the idea from another Makerspace member who designed something similar that could be used to weld oil and gas pipelines in the oilfields. In the following excerpt, Arnold described his plan to develop his pedal pusher life hack to operate equipment foot pedals:

I’ve also been working on...I call it an electronic foot pedal pusher. There’s a lot of machinery like sewing machines, TIG welders, and other things where your hands are busy, so they give you a foot pedal to work the machine. That’s great, except when your feet don’t work you can’t push the pedals. What I’ve been doing is an Arduino thing with a speech recognition system that controls a servo that will push on the foot pedal and let me use voice control to work the pedal. [Telephone interviewee]

Arnold’s past experiences, social interactions, and knowledge of electronics all influenced his foot pedal pusher idea and his vision to use it. Arnold's goal was to replace the physical task of
using his legs and feet to press and depress the pedals with a voice-activated system that enabled him to use speech instead. The proposed pedal pusher life hack would allow Arnold to speak instead of making the controlled leg and foot movements that using foot pedals typically requires. A Servo is a small electrical device with a coded-signal-controlled output shaft ("What a servo: A quick tutorial," n.d.). A servo can be used to supply motorized movement along a 180-degree range. The shaft moves to any angle within the range at the behest of input signals.

An Arduino board can be programmed to send the signals that control the output shaft on the servo. A power supply would provide the energy needed to convert speech into input signals that move the servo motor shaft to desired angles. The voice-controlled servo, a non-human agent, would convert Arnold's commands into precise physical movements that pressed and depressed the pedals.

*Actor-network enabled practices requiring the use of one's lower extremities.*

The two exemplars outlined in this section and several others described by participants offer evidence that mobility related impairments did not stop them from doing tasks that typically make demands on an individual's lower extremities. Participants proposed and leveraged life hacks that bridged these demand-capability gap.

Ross did not form an actor-network with objects but rather changed the way he used his body and interacted with the physical environment. He leveraged his personal capabilities as well as general environmental affordances in a way and at a time that allowed him to overtake hiking practice elements, including personal motivation, socially shared ways of hiking, and the social interactions involved in hacking that nearly disabled him. Ross' life hack enabled him to overtake practice elements such as the stairs and socially shaped hiking techniques that were at odds with his usual mobility methods. Arnold and his proposed innovation life hack, if developed and
utilized, would form an actor-network capable of pressing and depressing foot pedals despite his inability to use his feet. In the resulting actor-network, the foot pedal pusher would make measured and controlled movements at Arnold’s command which he could not perform with his feet because of his lack of lower body motor control. The actor-network would match Arnold's ability to use his voice to the proposed foot pusher's ability to convert his voice into mechanical movements that press and depress machine foot controllers. The non-human actor would change the way Arnold interacted with foot pedals and relieve him of the need to use his lower extremities. The actor-network would also change the nature of the interaction by substituting the leg and foot for a shaft that is connected to a servo and positioned to simulate the same controlled movements a person using foot pedals would make.

**Participant Life Hacking, Practice, and Dis/Ability**

Practice-related standards, rules, and social norms all factor into the equation for all individuals who engage in social practices or attempt to do so. Whether written or implicit, standards, rules, and social norms enacted across time and space bring structure to practices. They either enable or limit individual actors in specific instances of doing or attempting to do a specific practice. For example, an activity such as eating a formal meal has a specific set of tools (e.g., fine china, salad fork, dessert spoon, etc.) and social conventions (e.g., placing your napkin in your lap and using the soup spoon for soup, dessert fork for dessert, etc.). Everyone at a formal meal is expected to follow these conventions no matter when or where the meal occurs or who is in attendance. Failing to follow the rules of etiquette at a formal meal can at least draw unwanted negative attention and may even result in loss of social capital or status in extreme cases. Humans play sports, drive vehicles, and perform just about every practice there is with some awareness of the relevant social norms, laws, and rules of etiquette that bear on those practices even if they are
tacit. Although people can and do cut others off in traffic and run red lights, they do so at the risk of safety, legal, and other negative repercussions. They more than likely know what they are doing and the potential consequences of their actions. Following or failing to follow the conventions associated with these practices (particularly when other people will know about these infractions) can also have social and practical consequences individuals may want to avoid. Sometimes the risk of facing these consequences can be sufficient to motivate someone to follow social, legal, and other practice conventions. At the same time, the existence of rules and norms for social behavior implies the need to suppress activity that does not conform to expectations (de Certeau et al., 1998).

Practice artifacts are devised, developed, marketed, and sold with either specific guidance or a reasonable expectation of how people will use them. Design artifacts, professional guidance, usage agreements, and similar measures often embody and reinforce these expectations. According to de Certeau, an entity with will and power (e.g., business or scientific institution) that can isolate itself from other entities (e.g., customers) can then strategize and manipulate power dynamics between those two entities (1984). Institutions that devise, develop, market, and repair artifacts, or make and enforce the rules regarding their use impose a certain order on consumers and force them to operate within it (de Certeau, 1984 Kindle version. loc 695, section 3). The networks that produce, deliver, distribute, and sell consumer products and services tend to exclude the target audience members from many of these processes, making them non-factors in the design and development of the artifacts that configure their daily life practices (de Certeau et al., 1998). Whether intentional or not, these institutions make strategic rationalizations that may exert power and will over consumers and give these entities the means to manage consumers (de Certeau, 1984). The distance between practitioner-consumers and entities that
create the products, environments, and rules of engagement for consumer goods matters because it sometimes benefits those involved in production networks and disadvantages the consumer. It allows these entities to operate autonomously, leverage acquired knowledge, and make plans with little to no regard for the individualized and variable circumstances consumers face (de Certeau, 1984). The assumptions and expectations birthed out of their perspective get codified in the artifacts, built environments, and policies that co-constitute and configure people's daily life practices.

Although participant impairments co-created demand-capability gaps, it is important to note that practice breakdowns were often the result of disability-inducing circumstances. Demand-capability gaps were endogenous to practice, and in the preceding sections, I explained the role of participant-life hack-design artifact actor-networks played in reconciling these gaps and enabling participants. Now, I want to describe the other side of the demand-capability practice breakdown equation which also played a role in constituting participant practices. As the following examples illustrate, for many participants, life hacking was a consumer-driven resolution to the implications of the assumptions and expectations which not only conflict with physical impairment but also configure practices in ways that create demand-capability gaps and thus disable.

Participants in this study rarely took the objects and ways of using the body which co-constitute social practices as a given. Instead, they subverted social practice elements and the dynamics among them to close the demand-capability or demand-desire gap for personal gain. In general, consumption creates space for "making do," or artfully (re)-using the outputs of production beyond the purview of the owners of the systems of production (de Certeau, 1984). Making-do takes many forms, but it most commonly entails leveraging the outputs of production
as inputs in creative consumer activities. Consumption in this sense is less of a passive utilization of what powerful entities force upon consumers and more of an off-the-radar exploitation of the outputs of production for consumer-driven purposes. It includes the full gamut of life hacks from simple usage drift to changing the form and structure of artifacts and everything in between. Consumption in a truly de Certeauian sense is consumer production that uses existing artifacts and exploits facets of rules and norms to one’s advantage. In other words, the artifacts, laws, norms, shared ways of moving and utilizing the body, and other constitutive practice elements become the ingredients for life hacking projects and daily life practices. Participants in this study engaged in several forms of "making do" via life hacking. In most cases, the separation between entities that control the means of production and participant-consumers emboldened participants in their efforts to close demand-capability gaps.

The most common form of making do took the form of tactics. Tactics are deliberate actions by an individual agent who lacks the will, power, and location necessary for autonomy (de Certeau et al., 1998, Chapter Chapter Kindle version, loc 695, section 3). Although not always intentionally, tactics undermine the efforts and intentions of the entities that control consumers, whether intentionally or via unintended consequences, through networks that produce, deliver, distribute, and sell consumer products and services. Participants were often forced to work within the confines of what these networks offered to them via their products and services. Many times, the norms and assumptions codified in product design, prescribed ways of using objects, formal service agreements, and customer service models inspired participants to life hack to finds ways around them. In this sense, life hacking was a form of "making do" that consisted of creatively taking advantage of what these networked macro-level entities produced and offered in the context of their everyday lives.
Life hacking as “making-do”.

One example of a de Certeauian tactic was Stuart’s Xbox controller modification life hack. The participant, his Mom, and Uncle altered a commercially distributed product governed by the terms and conditions of the product's warranty. That agreement excludes hardware repaired or modified by a third-party from repair service typically covered by the warranty (“Xbox Services Terms & Conditions,” 2015). Microsoft reserves the right to void a customer's warranty if an attempt is made to bypass the technical limitations of the console or any accessories, including a controller (“Xbox Services Terms & Conditions,” 2015; “Xbox Warranty and Registration FAQ | Xbox Warranty,” 2016). In other words, any attempts to add features to the controller that might give the user an advantage in a game are prohibited. The tongue trigger that Stuart's Uncle wired to the controller could have been considered an instance of bypassing technical limitations.

Microsoft has the freedom to impose the design of its gaming console with its accessibility issues and reified assumptions about users onto consumers. Stuart and his family "poached" on Microsoft's territory by modifying accessories the company developed, marketed, and sold (de Certeau, 1984). While the original controller's inaccessible design limited Stuart's ability to play games as well as he wanted, it also served as one of the raw materials he and his allies used to make gaming more accessible for him. Ironically, their actions went against the legal restrictions outlined in the warranty's terms and conditions. When asked whether the terms and conditions factored into his life hacking efforts, Stuart said, "it did not stop me, and I didn't even think about it." Stuart's controller life hack suggests that tactics may not always be intentionally subversive, but they can still undermine and contradict constituent elements of professional design practices and the outcomes of those practices.
Arnold's design and use of the mill stick life hack represent another example of a de Certeauian tactic. This life hack solution allowed him to undermine the able-bodied norms embedded in the physical design of the milling machines. The designers of the milling machines available in Arnold's Makerspace decided that all potential users should be able to stand and reach a certain height with their hand and then reified it in the machines' design. As a result, the power switch, speed control knob, and brake are located above most people's head and therefore they are inaccessible to individuals who cannot stand, are short, or cannot reach very far above their heads. Making the location of these controls fixed and inflexible further reified the designers' assumptions and decision about who should and should not be able to access them. Whether intentional or not, the entities responsible for the design and development of the equipment in Arnold's Makerspace practically excluded individuals like him from using it. Arnold could have accepted this reality and resorted to asking non-disabled members for assistance whenever he needed to operate the controls. He also could have given up on participating in a daily life activity he enjoyed. Instead, Arnold developed innovation life hacks that allowed him to use the mills despite the assumptions the designers made and then reified in the design. Arnold's mill stick and other equipment “tools” allowed him to poach on able-bodied territory. He took advantage of the opportunities afforded by a Makerspace that welcomed him as an individual with a disability as well as his past experiences and capabilities as a DIYer. The unique circumstances that Arnold faced made it possible for him to use professional design outcomes that otherwise excluded him.

**Life hacking as tactical consumption of AT & durable medical equipment**

Several participant life hacks involved modifying or adding something to mobility equipment, and they were always tactical. For instance, Sheila's power chair wrist rest, the plate catcher
Scott added to his walker, and Wallace’s wheelchair drinking system, computer headset, and armrest skin protection add-ons all used mobility equipment as inputs in their artifact-centered life hacks. Rather than using mobility products as is or in ways pre-determined by professionals, these participants made well-informed modifications to equipment to make it a useful non-human agent in local actor-network enabled practices. Tactics as ways of "making do" occur on the terrain imposed on it by a business, institution, or other entity (de Certeau, 1984). When participants modified mobility equipment or added something to it that aided them in their daily life practices, they were taking accessibility products with their given features and affordances (or lack thereof) and attaching items to them. These items provided additional features and affordances exploitable by resultant practice constituting actor-networks. For instance, the wrist rest that Sheila’s husband added to her power chair provided an affordance she leveraged in her mobility practices. She also used her wheelchair and the platform to write since the latter gave her more hand control and thus enabled her to use a pen. The mesh netting Scott added to the seat of his walker made a difference in both his mobility and eating practices. Finally, the drinking system and computer headset microphone Wallace’s caregivers attached to his wheelchair made a difference in his mobility, drinking, and computer usage practices. For all three of these participants, the mobility device itself lacked something useful that could aid them in both mobility and non-mobility-related practices. Durable medical equipment (DME) designers more than likely did not intend to make participant eating, drinking, mobility, and computer usage practices challenging or inefficient. Nevertheless, they could not always account for the centrality of these objects in consumer's lives, each consumer's unique context of use, or the different daily life practices individuals with mobility impairments participate in beyond mobility-related ones. While describing the wrist rest, Sheila conceptualized the relationship
between mobility equipment, her wrist rest add-on life hack, and tactical consumption of DME as follows:

Sometimes I must depend on something that’s expensive like this damned car [Sheila and her husband were in the middle of purchasing a new accessible van at the time of our first interview]. When nothing, there’s no alternative, there’s nothing else that can be accomplished, then I’ve got to think that way [working with husband to develop a life hack]. There have been those incidences, sure. If I need a motorized wheelchair, I need a motorized wheelchair. We can’t come up with that. But when I got this chair, I had to be able to rest my hand on something to have the fine motor skill. So Jack built this thing right here. [Face-to-face interviewee]

Wallace echoed the same sentiment when describing a homemade set of hand rest covers his caregivers added to his power chair:

We buy fake lamb’s wool, fake sheepskin or lamb’s wool. I’m not sure. It goes by several names. But we take some of that and we’ve sewn coverage to go over where my hands go to better protect my skin. So even with a $30K customized [power] wheelchair, we’ve still had to make some adaptions to it as well. [Video-Chat interviewee]

The two examples above and several others offer evidence that although professionals in the DME industry have specific ideas about how consumers should use power chairs, participants saw them as both a mobility aid and a resource they could leverage in various non-mobility-related practices. They found ways of "making do" that may have been unappreciated by representatives from the DME industry. While the industry has a general knowledge of its customers (e.g., individuals with limited or no mobility) and the number of mobility devices sold, few attempts are made to understand the myriad of ways consumers modify and use products in their daily lives (de Certeau, 1984). Some participant tactics consisted of combining DME with either general consumer items or homemade artifacts to make it fit their contextualized needs and preferences or to empower themselves to do different types of practices. Sheila captured the tension that tactics assuaged between consumers and professionals who are formally responsible for the acquisition and set up of DME when she described the
Sheila did her best to work with physical therapists and a DME distributor to get her new wheelchair properly fitted but could not get the professionals to listen to what she knew she needed:

Sheila: …most people I was dealing with were professionals, and they come up with all kinds of professional ideas. I’ve been working with the Physical Therapy Department here to get a new wheelchair. And it’s a good thing I know what I need and what I can use and what I can’t use, because I can’t tell you. I’ve had the wheelchair company come twice now and I’ve been very specific about what I need, and they come with the wrong freaking chair.

I just met with them again yesterday. They came with the wrong chair. I said I’m sorry. I’m not going to get a chair that isn’t going to work for me. I said one of the things I keep telling you is the control. Do you see this thing [points to the power chair hand rest add-on] that was adapted so that I could rest my hand and have fine motor skill? Otherwise, I’d be [demonstrates disjointed and extreme joystick movements], and they go ‘oh, yeah.’ I look at the control you have and it’s not going to work...

Me: Do you feel like sometimes those experiences with professionals have more of a…
Sheila: They know what’s best for you, and don’t you forget it. And they don’t need your input; you need to listen to them. Not all of them, but a lot of them. [Face-to-face interviewee]

Sheila described a disconnect between the actions and knowledge of the professionals she dealt with and both her knowledge and experience as not only a consumer but also the human agent in her daily life practices. The physical therapist and wheelchair distributor tried to give Sheila a product with predetermined features based on their professional knowledge and did a poor job of listening to her input. The influence these individuals wielded as members of institutions that own the means of production and establish the rules regarding the adoption and use of DME made the outputs of their efforts more important than the way Sheila desired to use DME in her daily life (de Certeau, 1984). Interestingly, these entities influence consumer practices via not only their product and service offerings but also the assumptions they make about consumers while developing goods, providing services, and interacting with consumers. For instance, the unwillingness of a distributor who may not have any personal experience with impairment to make certain product updates and modifications a consumer deems necessary can make it more
difficult for those consumers to do what they want to do in their daily lives. In response, consumers can either accept what is given to them or modify it to meet their needs. In Sheila's case, she had a husband who could make and attach needed add-ons to her wheelchair. Other participants also had one or more allies who could attach needed add-ons to DME or possessed the ability to do it themselves. Regardless of whether they disagreed or were indifferent to the specific activities of consumers, the actions of professionals had less of a limiting effect on participants who possessed the capability to modify and add accessories to their mobility equipment. These individuals were free to undermine the guidelines, rules, and assumptions imposed on them by professionals whenever they decided to do so.

The LIFE of Life Hacking: Practice Theory and Phenomenology

Chapter five introduced the term life hack as two separate but interrelated words that could be used to label participant adaptation, modification, and design-like activities as well as their attempts to address accessibility-related issues. Although popular use of this term conforms to the compound noun form, separating life from hack affords emphasis on what the component terms mean separately as well as when combined. Chapter seven will focus specifically on the word hack. Here, the focus is on the word life, or both the context of life hacking activity and the whole of one's lived experiences. The practice-theory oriented analysis of life hacking presented in this chapter offered a unique and participant-centric view of design and disability within the context of the daily lives and constituent practices of individuals with physical impairments. Professional design and traditional evaluation approaches cannot lead to a full understanding of the downstream in-situ practice impact of decisions made for or on behalf of individuals with disabilities because of their tendency to decontextualize users from their poly-constituted local practice contexts. The practice theory analysis presented in this chapter kept participants, their
embodied activity, and their experientially grounded perspectives at the forefront to show the role of objects, impaired bodies and their respective agencies in co-constituting, maintaining, and reshaping the practices that comprise their everyday lives. The analysis examined the practices that constituted participants' lives, the actor-network configurations that enabled participants to demonstrate agency in those practices, and the roles participants and objects played as co-agents in networked practice-enabling entities. This approach accounts for the situational complexity of everyday life and the interactions between various practice constituting elements that make it complex.

From a phenomenological standpoint, this chapter uniquely captured how participants experienced and addressed impairment-related issues in and across practice engagements using their bodies, know-how, design artifacts, personal artifact-centered life hack outcomes, and activity-oriented life hacks. In this chapter, I unpacked contextually situated aspects of embodied lived experience that constituted practice engagements across multiple episodes and interviewees. Findings include explanations of the essentials elements of life with physical impairments as perceived and experienced by people with those impairments entangled in practice engagements along with different types of artifacts. The findings are unique to the laboratory of daily life and inclusive of in-situ aspects of practice activities that dis/enabled participants. One reason why the term life hack is appropriate for this study is the unique insights about the lived experiences and everyday lives of participants the practice theory analysis presented in this chapter affords. Although this chapter focused on life hack-enabled practices specifically, the findings highlight aspects of professional design practices, design outcomes, life hacking activities and outcomes, and individuals with impaired bodies as well as the practices these elements collectively constitute. In other words, the life hacks and related activities
participants described had implications for non-life hacking-related aspects of their lives. In fact, life hacking empowered participants to reach a specific end: capable engagement in daily life practices on their terms. The term life hack acknowledges not only the enmeshed nature of the means and ends of daily life practices but also the reality that means and ends are most likely to complement each other when embodied human practice agents play an active role in defining both.

**Conclusion**

This chapter offered an endogenous look at participants' life hack-enabled daily life practice activities through the lens of practice theory. More specifically, the analyses used sensitizing constructs from different practice theory approaches to offer an empirical explanation of what contributes to the dis/enablement of participants in their daily life practices. Co-/participant bodies, required ways of using the body to perform social practices, objects, and knowledge or "know-how" collectively constitute practices and configure them in specific ways that enable or disable. Participant life hacks usually filled a void in participant practices created by a mismatch between the ways of moving and using the body practice tasks required of them and what they could physically do with their bodies. This chapter described six different life hack-enabled practice tasks: 1. Managing personal mobility while carrying something; 2. Controlling the body, bodily movements, or both; 3. Manipulating objects; 4. Reaching or retrieving something; 5. Transporting objects up or down a flight of stairs; and 6. Completing tasks that require one’s legs, feet, or both. Each of these tasks represents demands that different practices place on the physical body of anyone who engages in them across time and space.

The analyses above offer empirically grounded insights about how bodies, objects, and know-how configured the six different practice tasks. Sometimes participants who had mobility
impairments engaged in practices that required carrying something while using their preferred mobility method. Functional limitations, preferred mobility methods, characteristics of participant bodies, or a combination of these factors made the dual task of independently moving self and another entity difficult for participants. Artifact-centered and action-centered life hacks bridged the gap between task demands and participant capabilities by allowing human and non-human actor-networks to meet carrying-related task demands collectively. Different combinations of artifact-centered life hack outcomes, re-appropriated objects, and procedural life hacks configured productive actor-networks that relied on participant-centric ways of using the body and accounted for functional limitations, mobility methods, mobility equipment, and participant bodies. Participants formed actor networks with life hack outcomes (e.g., Scott’s walker with mesh netting), everyday objects (Ross' towel), and fixtures in their environments (e.g., Leon's kitchen counters and Ross' linoleum floor) that collectively met carrying and movement-related task demands as an integrated unit.

Another set of participant practices required a measure of restraint, controlled movement, or both. Carrying-related life hacks facilitated actor-networks that shared the demands of the required task and allowed the participant to use his or her preferred mobility method. Body and bodily movement-related life hacks, on the other hand, led to actor networks that aligned the body movement participants could perform with practice task demands. Like carrying related life hack-enabled practices, actor-networks configured movement related ones by distributing task demands across the human and non-human actors. The non-human actors in movement-related life hack-enabled practice tasks often consisted of re-appropriated objects that served as prostheses that either augmented or replaced participants' functional capabilities. The resulting actor-networks negated the impact of participants' movement-related limitations on their ability
to engage in the underlying practices. The re-appropriated artifacts possessed features and affordances that either prevented unwanted body movement or facilitated required bodily movement via the use of alternative parts of the body. Re-appropriated objects offered affordances such as the strength, flexibility, and dispensability of the zip ties and features such as the Velcro straps, webbing straps, and hand grips on the leg cast handles. These features and affordances made the respective non-human agents mesh with the human agents, their capabilities, and functional limitations in productive ways that facilitated the controlled and restrained movements that practices demanded.

Practices that forced practitioners to interact with objects in precise and controlled ways proved difficult for participants who had dexterity or motor control limitations. Practices such as dressing and grooming, eating and drinking, recreational activities, and operating electronics via different input interfaces all require interactions with objects. Manipulation-related life hacks bridged the gap between task demands associated with interacting with practice artifacts and participant capabilities by either making and modifying artifacts that fit the participant’s functional capabilities or re-appropriating existing objects. The artifact-centered life hack outcomes and re-appropriated objects joined with human agents to make the actor-network able to manipulate objects in ways that practices demanded despite participants’ functional limitations. The artifact-centered life hack outcomes and re-appropriated artifacts resulted in actor-networks able to overtake all the constituent practice elements. While the underlying practices demanded capabilities that participants did not possess, actor-networks conjoined human agent capabilities with non-human agent features and affordances in ways that empowered the combined entity to interact with the required practice artifacts. The actor-networks made it possible for participants to do tasks that typically require objects such as
clothing, eating utensils, drinking cups, video game controllers, arts and crafts materials, Makerspace equipment, power chair joysticks, and computer input devices. In some cases, actor-networks consisting of modified practice artifacts afforded slightly different ways of interacting with those artifacts. In other cases, participants created new artifacts that allowed the resultant actor-network to perform practice tasks using entirely new interaction methods. In both instances, the participant was free to use the physical capabilities he or she possessed to do tasks that made additional demands of the body that participants did not possess.

Some practices required reaching, grabbing, pulling, and retrieving something and functional limitations made these tasks difficult for participants. Reach and retrieval related life hacks led to actor-networks that either extended the capabilities of the human agent or changed the dynamic between the human and non-human actors. These actor-networks made each reach and retrieval-related task productive by either leveraging the features of existing or adapted artifacts to access objects far away from a participant's body or using alternative bodily activities the human agent could perform to reach and retrieve something. Re-appropriated objects and artifact-centered innovation life hack outcomes serving as the non-human agents in actor-networks either reduced the need to reach and extend the arm or significantly reduced how much reaching a participant had to do to accomplish a practice task. Characteristics of brooms, canes, and reacher tools such as form, length, and rigidity gave non-human agents exploitable features that served as extended capabilities of the human agent in actor-network practice entanglements. Reach and retrieval artifact-centered life hacks changed the nature of the practice by exchanging the demand placed on practitioners' bodies to use a practice artifact for a feature of the artifact.

Practices that required a person to move objects up or down one or more flights of stairs were difficult for participants who had mobility impairments. Stair-related life hacks were
primarily action-oriented, and items such as trash bags, laundry baskets, and the stairs each participant climbed served as the non-human agents in actor-networks. Individual stair climbing procedural life hacks enabled the participant to climb the stairs. The non-human actors shared the physical demands of carrying multiple items on a flight of stairs with the human agents, effectively allowing the participant to offload some of the required work onto the steps and containers used. The three agents that collectively engaged in stair climbing and weight carrying practice activities changed the nature of the weight-bearing task. The actor-network allowed the human to use his preferred mobility method to go up the stairs while the non-human agents bore most of the weight the participant willed to move up the stairs. The size and shape of the laundry basket, size and durability of the trash bag, and position of the stairs made it possible to offload some of the weight-bearing demands onto them. Since the human agent did not have to devote a significant portion of his effort to bearing the weight of the items in the bag and basket, he could instead focus that attention on climbing the stairs and pulling the items along as he went. The actor-network transformed the task of simultaneously supporting the weight of several items while climbing stairs into pulling those items up the stairs one or a few steps at a time in between moving oneself up one or a few steps.

The last set of practices required the use of one's legs, feet, or both, which was difficult or impossible for some participants who had mobility impairments. Practice tasks demanded coordinated utilization of one's lower extremities as well as specific and precise lower extremity movements. Related life hacks obviated the need to use one's legs and feet to complete these tasks by allowing the human agent in resultant actor-networks to realize agency via its networked interactions with objects and developed ways of performing constituent practice tasks. Environmental affordances, physical capabilities, and innovation outcome features afforded
these alternative ways of using the body and interacting with practice artifacts. Participants could form actor-networks with the environment and innovation outcomes that collectively leveraged the physical capabilities the participant possessed instead of forcing them to conform to the demands of social practices. Participants walked on their arms and hands instead of their lower extremities or worked on voice-controlled interfaces that converted speech into simulated foot movements. One actor-network changed what a practice task demanded from the participant by transferring it from his lower extremities to his upper extremities while the second one allowed the participant to exchange foot movement with speech. The non-human agent in the first one was the ground which served as a surface which enabled multiple navigation methods with different physical demands and degrees of difficulty depending on the person. The non-human agent in the second actor-network (the voice-controlled interface) replaced human leg and footwork with hardware and voice-activated mechanical movements that mimicked the actions the human agent could not perform. In both instances, the human agents were free to use their inherent capabilities while the non-human ones either replaced ways of using the body that participants could not perform or provided environmental affordances and afforded alternative bodily activities they could perform.

In addition to examining how participant life hacks bridged demand-capability gaps, this chapter also analyzed life hacking-enabled practices within the context of daily life. This task consisted of using sensitizing constructs from de Certeauian approaches to understand participants’ in-situ production and consumption-related practices. In line with this chapter's endogenous focus on practices, this section sought to unpack how bodies, minds, objects, and knowledge/know-were implicated in participants' life hacking activities in defensive, opportunistic, or retaliatory ways. Findings suggest that life hacking represented the ways
participants managed assumptions about disability and expectations of people with disabilities embedded in the artifacts sold and marketed to them. In this sense, life hacking represented localized forms of making-do, or artfully (re)-using the outputs of production beyond the purview of the owners of the systems of production (de Certeau, 1984). Participants made-do by undermining rules, expectations, and norms related to practices and embodied in professional design outcomes. Participants undermined social practice structure and entities that make, market, and distribute design outcomes and services to them by using these outcomes as inputs in their productive life hacking projects and related practice activities. Instead of surrendering to uninformed assumptions and different forms of control embodied in products and corollary services, participants leveraged those artifacts and exploited the physical distance between entities that make them and themselves to resist norms, expectations, and assumptions that disabled them in practice contexts. For some participants, tactics allowed them to resolve tensions between DME industry professionals and themselves resulting from the provision of products and services that did not address the concerns or meet the needs of consumers. For others, tactics simply allowed them to reconcile what DME professionals provided to the realities of their daily lives.

This chapter took an endogenous look at participants' life hacking-enabled practices to derive empirically-grounded insights about the different ways participants, objects, and various agencies constituted and configured those practices. The next chapter examines ancillary human interaction related aspects of life hacking, participant practices, and daily life with a physical impairment. I will discuss participants online and offline life hacking-related social interactions as well as the potential value of those interactions to human-computer interaction and accessibility research communities interested in empowering individuals with disabilities.
Chapter 7 - The Sociality of Life Hacking and the Practices It Configures

Life hacking and life hacking-enabled practices did not happen in a vacuum. Individuals other than the study co-/participants and their allies, when applicable, also factored into participants’ practices or gained information from participants that shaped similar practices for them. Life hacking activities allowed participants and other individuals with disabilities in their social networks to engage in daily life activities productively. Participants’ ancillary interactions with other people not only coincided with everyday practices but also benefited people with similar disabilities who did not participate in this study. Additionally, life hacking not only impacted participant interactions with family members, professionals, and other members of society but also empowered participants to control their destinies when people, structures, and systems within society placed barriers in their way. The most common social characteristic of participant life hacking activity was the exchange of information and knowledge that factored into their efforts and those of other individuals with disabilities. Almost all participants shared things like know-how, expertise, personal experiences, and information about specific life hacks in online environments, offline settings, or both. In addition to sharing their knowledge and experiences with others who had similar impairments, many participants also sought guidance, feedback, and input from other individuals with impairments which informed their life hacking activities and related practices.

A second social factor that factored into participants’ life hacking efforts was assistance from other people. More specifically, participants described specific attributes of assistance from others that were amenable to personal goals such as independence and self-determination. In chapter five, I described the nature of meaningful versus undesirable help from the participants’ perspective. This chapter delves deeper into the type of assistance from other people which
participants valued most. A third major social factor of life hacking was the influence of other people on participants' self-perception, growth, and development as individuals with disabilities. Whether these outsiders shaped the participants’ world view, view of themselves in the world, or desire for independence, they played a role in helping participants realize and develop their ability, willingness, and propensity to life hack.

Finally, life hacking allowed participants to react and respond to different socio-political realities individuals who live with impairments sometimes face through their actual and mediated encounters with others. Mediated in this sense means embodied within durable medical equipment and various other design artifacts that help give practices their structure and consistency. In contrast to medical and corporate models of disability that assert people with disabilities are passive targets of other people’s actions, life hacking activities involved intentional and targeted reactions to challenges, perspectives, and assumptions that did not fit participants’ actual or desired realities. Participants actively pushed back against wrong assumptions and norms in ways that challenged their veracity. This identity work not only factored into their life hacking efforts but also shaped their perceptions of other individuals with disabilities as well as their interactions with non-disabled people.

**Information-Communication-Enabled Life Hacking-Related Interactions**

Seventy-five percent of study participants (12) described one or more instances when they used online platforms to produce or distribute content related to specific life hacks, life hacking experiences, or everyday life issues requiring a life hack. Many of these participants engaged in offline life hacking efforts as well as online knowledge and information sharing activities. Sixty-nine percent of participants (11) described at least one instance of talking about life hacks with others offline. They participated in offline life hacking activities and had related conversations
about them with people they knew or met in offline environments. Participants tended to use multiple media channels for life hacking-related purposes and 56% of them (9) communicated with people about their life hacks both online and offline. Overall, interviewees used communication channels in similar ways. One interview question asked participants whether they discussed or shared life hacks with others, and sometimes participants had mentioned these interactions before I asked the question. I always probed into the nature of each interaction participants mentioned. Table 21 provides a breakdown of the different online and offline life hacking-related activities participants described by communication channel.

Table 21 - Unique instances of participant life hacking-related social interactions

<table>
<thead>
<tr>
<th>Platform/ Channel</th>
<th>Seek/Find</th>
<th>Produce/ Share</th>
<th>Connect/ Discuss</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Online</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YouTube/ Spinalpedia</td>
<td>11</td>
<td>8</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Facebook (groups/ pages/ friends) or Twitter</td>
<td>4</td>
<td>4</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Blogs/message boards/forums</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Personal website</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>E-commerce/ software developer websites</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Photo sharing website (Pinterest)</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Reddit</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Online</strong></td>
<td>28</td>
<td>22</td>
<td>12</td>
<td>62</td>
</tr>
<tr>
<td><strong>Offline</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offline social networks</td>
<td>4</td>
<td>7</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Store employees</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>TV/print materials</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Random People</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total Offline</strong></td>
<td>14</td>
<td>11</td>
<td>4</td>
<td>29</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td>42</td>
<td>33</td>
<td>16</td>
<td>91</td>
</tr>
</tbody>
</table>

Some participants did not engage in communication activities related to their life hacks. Those who did, however, tended to use multiple channels to produce and share their life hacking
knowledge, seek and find insights from others, and connect and discuss issues related to life hacking with others. Participants who communicated online used YouTube, Facebook, online forums, blogs, Pinterest, Reddit, e-commerce websites which allow consumers to leave comments, and personal websites. Participants found, shared, or discussed something related to a life hack offline via print/TV media sources, people in their offline social networks, strangers, and store salespeople.

**User-generated content platforms and the social construction of disability.**

In chapter 5, I talked about how the life hacking activities of individuals who live with impairment contradict deficit model thinking. The deficit model assumes the proper relationship between people with disabilities and experts who provide products and services designed specifically for them is one of dependency. In this arrangement professionals proscribe solutions that will *cure* individuals with disabilities (Ellis & Kent, 2011). The deficit model confers authority to researchers and professional designers and does not give consumers with disabilities much room to influence design via their experientially-grounded perspectives on disability and everyday life. Although participants' life hacking activities contradicted deficit model thinking, one could argue their efforts are too dispersed and individualized for researchers and designers to glean any insights from them and, therefore, are unimportant. However, as the next section shows, life hacking is not only an activity that occurs in the silos of people's private lives but also a social phenomenon among a loose yet potentially growing number of individuals with disabilities who sometimes connect and communicate with each other about their life hacking activities in various online environments. Later parts of this section will describe participants' offline and Internet-mediated life hacking-related communication activities. Nevertheless, given the heralded benefits of the Internet and new media to individuals with disabilities seeking to
challenge status quo social constructions of disability (Ellis, 2010; Ellis & Kent, 2011) and the way life hacking challenges deficit model narratives, this chapter pays special attention to participants’ online life hacking-related behavior.

In many ways, it is easier than ever for anyone who wants an audience to find one online. Wikis, blogs, social networking websites like Facebook and Twitter, file-sharing, forums, and YouTube represent some of the different online channels which people can currently access to create, share, and find user-generated content. User-generated content is information voluntarily posted online by everyday citizens at their discretion for a few select people or the entire online world to see. There are no monetary costs associated with using and posting content on these platforms other than the cost of acquiring the necessary digital technologies and Internet service required to access them. Internet cafes, schools, public libraries, municipal Wi-Fi "hotspots," and other various places make accessing a computer, the Internet, or both possible for those who cannot afford the costs associated with private access. Goggin & Newell (2006) argue that individuals with disabilities who have access to the Internet can publish alternative narratives and reach diverse audiences with relative ease. Further, they assert that Internet-mediated interactions give people familiar with the experience of being disabled a way to educate both impaired and non-disabled individuals about the socially constructed nature of disability. The alternative narratives these individuals can publish online are uniquely different from deficit model disability conceptualizations in two distinct ways. First, they are grounded in the lived experiences of the publisher, who most often has direct experience with impairment, rather than the experiences of people who have earned professional degrees or titles which declare them experts on disability-related concerns. Second, individuals with disabilities play an active role in telling others about their lived experiences and thus construct experientially grounded narratives.
about who they are, what they can do, and what life with an impairment is like from their vantage point.

Although there are still accessibility issues which prevent some individuals with impairments from publishing and accessing content online, exploitable opportunities to produce and contribute user-generated content are invaluable for members of the disability community who can access them (Ellis & Kent, 2011). The basis for this assertion is the mainstream media’s propensity to represent disability in ways that reinforce the idea that non-impaired bodies represent the standard of normality (Ellis & Kent, 2011). These ideas suggest that impaired bodies are deviations from normality and often justify societal devaluation of people who have impairments. Blogs, forums, YouTube, and other mediums which allow anyone with an Internet-connected device to share social and personal commentary give individuals with disabilities who use them opportunities to be producers of media and culture (Goggin & Noonan, 2006) and to take charge of their own image (Ellis, 2010). Mainstream media tends to individualize disability or esteem the “super crip” inspirational disabled person motif (Ellis, 2010), and thus advocate that impaired bodies conform to able-bodied standards while ignoring the role society and its norms play in disabling people with impairments.

When individuals with impairments leverage online platforms to share their experiences, they are simultaneously portraying counter-narratives to mainstream media representations of disability and playing an active role in the social construction of disability (Goggin & Noonan, 2006). Platforms like YouTube which afford video and textual commentary enable individuals with disabilities to not only challenge traditional media narratives privileging the opinions of so-called experts who have no direct personal experience living with impairment (Ellis, 2010; Ellis & Kent, 2011), but also do it in living color for the world to see. Ellis and Kent (2011) refer to
YouTube as a "social and political space for people with disabilities” (p. 57). It is in spaces like YouTube where individuals with disabilities can receive the attention and respect they deserve as the experts of their lived experiences (Ellis, 2010; Goggin, 2009). Characterizing YouTube and other user-generated content platforms as social and political spaces makes sense given the way they empower people with impairments to share narratives that both challenge uninformed assumptions which impact them in their daily lives and resonate among others who have direct experience with impairment. As user-generated content platforms become more popular among members of the disability community, the political work of shaping societal constructions of disability become more accessible to those most acquainted with impairment and therefore, best able to comment on the impact of those constructions on their lived experience and related social, psychological, and emotional well-being. The knowledge about disability, design, and life hacking that individuals with disabilities share and co-construct on these platforms benefit members of the disability community in other ways as well. Specifically, online activities allow them to validate their experiences, flesh out the nuances between those experiences, collectively challenge ideas that do not align with their perspectives, and learn new ways to do things in their daily lives.

**Online life hacking-related content consumption and social interactions.**

Although participants mentioned offline life hacking-related social interactions as well, their online activities seemed to support many of the ideas about user-generated content platform use by individuals with disabilities just mentioned. Several participants accessed websites which hosted user-generated content, and many of them used or planned to use the information themselves. Some participants used online forums to ask questions and learn from the experiences of others. Their online activities often informed their offline life hacking efforts. The
following subsections explicate how participants’ Internet-mediated and offline social interactions coincided with their life hacking activities as well as how participants leveraged user-generated content platforms to perform some of the social and political identity work referenced above.

*Learning from others via user-generated content.*

Arnold and Wallace, who both live with spinal cord injuries, have a history of posting life hacking-related questions to online message boards. Wallace asked questions on a dedicated message board whenever he needed more information about the voice software he leveraged to control his computer using the voice macros he created. Neil and Arnold were both members of wheelchairjunkie.com, an online forum specifically for individuals who use wheelchairs. Arnold was also an active member on wheelchairdriver.com. Members of both forums often discuss homemade mobility equipment modifications and other types of life hacking activities. Neil both posted questions on different message boards and private messaged other members. Arnold was a member of 30+ various forums (not all disability related) and posted questions on specific ones whenever he needed life hacking-related information.

*Finding life hacks.*

Participants’ life hacking-related online learning and knowledge discovery activities went beyond intentionally reaching out to others and asking questions. Several participants performed online searches or browsed websites that host user-generated content until they found something that informed a project or task they wanted to do. Samantha’s knitting bricolage life hack was a good example. She explained that sometimes she used Google to search for things and sometimes she browsed the "pages full of ideas" on Pinterest.com. As the excerpt below reveals, this is where she found out how to make her knitting life hack:
As I mentioned, I make a lot of stuff, like crafts and stuff, and I was having issues holding onto the yarn. It was too small, and I was trying to make a hat, I think. One of the Pinterest things had a picture where someone put a hollow pen around it, and it made it so you could hold onto the pen, and then the yarn would just come out the other end, so I was able to do that, and I got that from Pinterest. [Telephone interviewee]

Other participants similarly found information and resources which other individuals with disabilities had posted on online platforms that host user-generated content which informed their life hacking efforts. For instance, Leon said he consulted blogs when researching ways to address accessibility-related issues in his daily life. Several participants referenced YouTube as a useful source for life hacking-related information. For example, whenever Scott wanted to figure out the best way to bring one of his life hack ideas to fruition, he would find a YouTube video and "watch how they make something or what they do and...pick up some ideas from that"

[Telephone Interviewee].

Finding inspiration to life hack.

Sometimes participants unwittingly discovered life hacking guidance while perusing content posted on online platforms with user-generated content. For instance, Arnold said he once performed an online search and found a YouTube video posted by someone else with a disability. Before his spinal cord injury, Stuart lived and played rugby in Australia. After his injury, he visited websites like YouTube and Reddit to find inspiration when he felt down or depressed. Occasionally, he found content that motivated him to figure out ways to adapt and life hack. For instance, Stuart found a video posted by another YouTuber who used a wheelchair and competed in bodybuilding competitions which inspired him to start working out. To do so, he had to figure out how to modify his workout equipment. He called the video "life-changing" because it motivated him to pursue an activity he enjoyed but did not realize he could do with a spinal cord injury. He said he was in better shape at the time of our interview than he was as a
rugby player partly because of content he found on YouTube which motivated him to modify his workout equipment and start lifting weights.

**Online content production and social interactions**

The flow of life hacking-related knowledge and information was not one-directional. In addition to learning from content posted by others, participants also shared life hacking-related content online. Common forms of sharing included participating in forum discussions, posting picture or video demonstrations of specific life hacks, answering questions, and making suggestions or recommendations to other individuals with disabilities.

**Disseminating life hacking content.**

Participants leveraged several content sharing websites to disseminate life hacking exemplars and related information with others. Erin posted photos of her head paintbrush and other life hacks on her Facebook page for others to see. One of the most used platforms among study participants was YouTube. Wallace, Tabitha, Stuart, Erin, and Grant all had YouTube channels at the time of our interviews. Everyone except Tabitha posted at least one video that explicitly focused on life hacking. Wallace, for example, created a "screencast" instructional video showing how he operated his computer hands-free using homemade macros and his computer headset life hack. Erin similarly made a video showing how she used her head visor with a laser mounted to it and a letter board to communicate with other people. Grant had an entire series of YouTube videos demonstrating many of the life hacks he used in his everyday practices. According to the series introduction video, the purpose of the videos was to share some of the things Grant learned since acquiring a spinal cord injury to help others with similar injuries. In several videos, Grant described and showcased both the objects and methods he used to do daily life activities such as opening doors, grooming, eating, dressing, and using electronics.
Both Tabitha and Wallace had personal websites and used them to distribute potentially valuable resources to individuals with disabilities. Both websites recommended existing products and vendors that sell items which individuals with certain disabilities and impairments might find useful. Tabitha did not post many life hacks, per se, but purposefully shared materials intended to help website visitors find ways to live independently despite having a disability. Wallace, who engaged in more life hacking-related activity than Tabitha, shared some of his homemade solutions via his website along with other content intended to help individuals with spinal cord injuries.

In addition to using personal websites to disseminate life hacks, participants leveraged other online channels to share life hacking-related insights with specific people. Both Arnold and Wallace communicated with product makers to offer feedback on products they used as life hacking materials or inputs. Wallace used three different computer programs for his hands-free computer control life hack. One of the programs, Knowbrainer, integrated with Dragon Naturally Speaking voice recognition software. He wrote several macros which allowed him to use his voice to perform otherwise manual tasks such as using a mouse to point and click. He shared some of his macros with the Knowbrainer software developers, who integrated them into later versions of the program. Wallace also made a YouTube video demonstrating his way of using the software with his voice command macros and modified headset. Many of the message board members were non-disabled, and they said it was "eye-opening" for them to see how he used the program as someone with a high-level spinal cord injury.

Arnold shared a time when he provided feedback to a product designer based on his life hacking experiences via online engagement. Arnold's leg handle life hack was made possible by a product designed by a third party. He initially received this product while he was in rehab.
immediately after his spinal cord injury. In addition to the SCI, Arnold broke his leg because of his injury and had to wear a splint. The original purpose of the cast handle leg lifter was to allow a user move his or her leg around while it was in a splint to relieve pressure. In addition to using the product for its originally intended purpose, Arnold re-appropriated it to make repositioning his foot on the footrest of his wheelchair easier. Arnold eventually asked for a second leg handle to use with the leg he did not break. After using the two leg handles for a while, he bought a new pair on Amazon.com. What Arnold did in addition to buying the product led to future improvements in the product’s design:

When the initial pair started to wear out, I got online and ordered some more. I left a nice review on Amazon and the guy contacted me saying, ‘you’re the first person who’s talked about using them as a paraplegic.’ I made some suggestions. I said they’re great the way they are, but there’s things you could do that would make them, to me, a better product. He has been working slowly on incorporating those. I’m working right now with the latest version of them. He’s changed the name from cast handles to leg handles. They were made with just one version of it that allowed the buckles to be in one position on one leg and a different place on the other leg. Because they were facing the same direction that makes sense. I said it would be better if you made a left one and a right one, so that you can get the buckles in the best place on both legs. He’s done that. I also suggested – the original webbing was this bright blue, which really stuck out like a sore thumb. I said it’s better if you make it black webbing because that’s a little less obvious when you look at it, and he’s done that. [Telephone interviewee]

Like Wallace's feedback and macro suggestions to the Knowbrainer software developers, Arnold offered input on the design of the leg handles which was grounded in his personal experiences as a consumer with a disability integrating the product into his practices. Both participants understood the context surrounding his use of the product in ways that designers could not foresee. Their life hacking-enabled practice experiences gave them insights product developers found valuable and incorporated into later versions of their products.
Responding to questions and providing input.

Several participants responded to life hacking-related questions directly posed to them via instant messenger and other online conversation platforms as well as indirectly via internet forums, Facebook groups, and message boards. Erin and Wallace belong to Facebook groups for individuals with cerebral palsy and quadriplegia, respectively. Both said they occasionally responded to questions posted by other members of the respective groups. Erin "chimed in" whenever someone brought up a problem or issue with which she had some experience. Wallace similarly said individuals with high-level quadriplegia and their parents posted questions in the Facebook groups he joined. Many of them asked for advice or input on "medical related stuff," wheelchair issues, or other concerns. Wallace responded to these and other more direct requests for help via Facebook. Wallace also has a personal website and a YouTube channel. At one time, he received many questions via his website and email. At the time of our interviews, however, he received more questions via Facebook than the other online platforms he used.

As mentioned earlier, Arnold was a member of several different online forums. In addition to posting personal questions, he also offered advice and guidance to people when they had life hacking questions or concerns. Two of the forums he mentioned by name were specifically for individuals who use wheelchairs. Members of both forums ask a broad range of questions about mobility products. Some of them are very technical. Specific life hacking-related topics include, among others, programming a power chair controller or overriding certain safety features on a power chair. When describing his activities on one of these forum websites Arnold said:

I find I’m very good at collecting little odd bits and pieces of information, so if somebody posts something with a question I can chime in with a suggestion as to things to look at and check, wherever I can contribute back. [Telephone interviewee]
Arnold possessed in-depth technical knowledge of power chairs which he knew other forum members recognized and valued. Sometimes they would reach out to him with their questions via private messages, although he usually discouraged this behavior because it prevented the whole community from reading and possibly gaining something from his responses. Samantha also used content-sharing platforms to disseminate useful life hacking information and resources. Sometimes she used the re-pin and comment features on Pinterest.com or the share feature on Facebook to share the life hacks she found online with others.

_Conserving online to discuss non-life hacking-related topics._

Interspersed in participants’ online life hacking-related interactions were opportunities to connect with other people who either had similar impairments or knew someone who did. Five participants said they were members of Facebook pages and groups for people with their disability. Members of these pages and groups sometimes talked about homemade solutions to issues they faced. According to Neil and Kimberly, a frequent topic was "personal adaptations" or "DIY things," respectively, and both admitted to finding related content that either informed a previous life hacking project or could potentially factor into a future one. However, participants said they talked about more than just life hacks in these spaces. In fact, life hacking represented one of many topics related to having a disability they discussed with others. Participants, other individuals with disabilities and allies also chatted about issues such as accessibility products, medical professionals, recreational activities, and everyday life practices contributors could not successfully adapt. Sometimes these interactions were instrumental in helping the interlocutors to make meaning out of the experience of having a disability as well as non-disability related aspects of everyday life.
The social interactions Kimberly had with other people with Cerebral Palsy in a Facebook group helped her to "combat feelings of isolation and clinical depression" [IM Interviewee]. Although she did not explain how these interactions helped her, it was interesting how the same Facebook group where she discussed life hacking with other individuals with CP also served as a community where she made social connections which helped her combat depression. Neil was a member of the same Facebook group as Kimberly, and he also found this community useful for more than just life hacking input. First, he found a lot of "solidarity" among the members of the Facebook group. At one point, he referred to it as "crip camp," or a place where he built relationships with several other individuals with cerebral palsy. The solidarity Neil praised was attributable to the fact that multiple members often related to each other's experiences and found value in each other's recommendations. A second benefit he mentioned was the willingness of online community members to support each other. In addition to the Facebook group for people with C.P., Neil was a member of an online forum for individuals who use wheelchairs. He said he joined the forum for the "camaraderie," "support," and "collective brain power to figure out what’s going on with something" [Face-to-Face Interviewee]. The owner of the forum has C.P., and he is an executive at a large mobility product company. The forum owner often answered questions Neil and other members posted about their mobility equipment. One time Neil needed a leg rest for his wheelchair and the owner sent one to him free of charge. As revealed in the examples described above, participants did more than discuss life hacks on the different platforms they utilized. They used these platforms to not only interact with people who had similar impairments to both provide but also receive support and encouragement with daily life issues they faced as individuals with disabilities.
Offline life hacking-related content consumption, production, & social interactions.

One of the more common types of offline life hacking communication and information sharing activities participants engaged in was synchronous offline discussions. Several participants communicated with other individuals with disabilities or their family members about specific life hacks in different offline contexts. For instance, both Sheila and her husband Jack remembered "talk[ing] to a few people" about their baby crib, adapted comb, and elevator button life hacks in face-to-face conversations. Sheila shared specific life hacks with others only when "they [are] things that they might [use], depending on the individual" [Face-to-Face interviewee]. Scott and Tabitha both also talked about life hacks with people in their offline social circles. For example, Scott led a support group for people with multiple sclerosis and shared some of his life hacks with his "compatriots who have MS" in the support group as well as some of his friends Telephone interviewee]. When she was younger, Kimberly had face-to-face conversations with other people who had cerebral palsy and often discussed different life hacks with them. Tabitha had many friends with disabilities whom she met online and occasionally spoke to over the phone. Tabitha was usually the person offering guidance and making suggestions about the best way to accomplish daily life tasks with an impairment during these conversations with her friends. Although many of Tabitha's suggestions were product and service recommendations, she also talked about cooking and other life hacks which enabled her to live independently.

Participants also responded to inquiries strangers made about their life hacks and related practices in face-to-face contexts. For example, Grant mentioned instances when someone saw one of his homemade wheelchair modifications or a piece of adaptive equipment he used and then asked questions about it. When Grant was out in public, people sometimes asked him about the custom-made wheelchair armrests he designed and then hired fabricators to construct for
him. Leon said people sometimes asked him about his way of accomplishing certain tasks or his personal experiences as an individual with C.P. For instance, once someone who also had cerebral palsy asked Leon why he used only one cane crutch. The conversation occurred during a job interview, and at one point the interviewer wanted to know if it was better to use one cane-crutch or two. Arnold similarly answered life hacking questions in face-to-face environments. However, many of the questions were not specific to disability or impairment issues. As a Makerspace member and volunteer, Arnold often answered and asked questions related to Maker activities. Sometimes people would ask for his opinion about the best approach to solving a problem or the right tool to use for a project. Although the other members did not have paraplegia and did not create impairment-related life hacks in the Makerspace, they still benefitted from Arnold’s expertise and knowledge as an individual with paraplegia who life hacked personal solutions to impairment and daily life issues.

**Learning from others offline.**

Sometimes participants gathered information that informed their life hacking efforts via offline dialogue with third-parties such as sales associates. Scott and Sheila’s husband Jack both mentioned seeking information from salespeople at retail establishments that informed a life hacking project. Personal research or a general awareness of what they needed enabled these individuals to acquire the information they needed from third-parties. For instance, the inspiration for Scott's window lever innovation life hack resulted from a conversation he had with a Home Depot employee. Scott had six-foot-high windows in his home, and it was difficult for him to bend down to operate the levers that opened and closed them. Before deciding to make an extension handle that would allow him to exploit the lever from a standing position, Scott asked the Home Depot employee if the window manufacturer made one. The negative response
motivated Scott to make one. Both Grant and Scott admitted to asking for guidance from hardware store associates with things such as identifying and locating materials for a future life hacking project.

Sheila reached out to a wheelchair repair company to figure out a workaround for one of its procedures which she found inconvenient. She said replacing tire inserts was a difficult task and, as a result, durable medical equipment repair companies forced consumers to get new wheelchair tires through their insurance provider when they blew out instead of getting them repaired. As an active individual who gets flat tires quite often, Sheila found it impractical to keep going to her private insurance provider for new tires and feared the provider would eventually stop paying for them. One day she reached out to the repair company and together with a company representative figured out she could buy and keep an extra set of tires on hand to avoid waiting for new tires when her old ones went flat. This way of dealing with flat tires not only suited her active lifestyle but also allowed her to ship the busted tires directly to the repair company at a much cheaper rate and thus avoid her insurance provider altogether.

Neil, Erin, and Samantha gathered information from other types of offline sources which informed their life hacking efforts. Neil admitted to getting input or feedback on his life hacks from his parents, physical therapists, and occupational therapists. Similarly, Erin indicated that her parents and personal care aides influenced or provided input on her life hack ideas. Samantha worked at an independent living center, and her supervisor had a visual impairment as well as back issues. Sometimes she asked her supervisor about his experiences or sought his input on ways to deal with her back issues. Their conversations did not revolve around making or modifying artifacts but rather buying and leveraging products in ways that would help her avoid placing extra pressure on her back.
Online and offline life hacking-related interactions.

There seemed to be a connection between the know-how that co-constituted participant practices: both resulted from and informed their life hacking efforts and factored into their social interaction. There was an inextricable link between participants’ ability and willingness to life hack in the context of their daily lives and their interactions with others. Identifying, making, and using solutions often required input from others who either shared relevant information with the participant directly or posted something online which indirectly inspired or assisted the participant in his or her life hacking efforts. Additionally, working on life hacking projects gave participants insights into how to address practice dynamics which disabled them. Several of them shared what they knew with others in either online or offline environments. Although the degree of sharing by participants varied, many of them provided advice, guidance, ideas, and other forms of support to individuals who shared their impairment, needed life hacking-related input, or both.

Each example of online and offline life hacking related interaction suggests that some individuals with disabilities empowered themselves and others to life hack through social engagement. For some study participants, engagement was direct and took the form of face-to-face or digitally mediated conversations. For others, it was indirect and involved consuming content produced by someone else or producing content which others might find useful. YouTube videos, for example, were a popular form of digital content that allowed participants to either learn from others or share their knowledge and experiences with others indirectly via trace digital content. Other user-generated content platforms such as online forums, Facebook, and Pinterest facilitated asynchronous life hacking-related content sharing, discussions, troubleshooting, feedback, and informal Q&A. Whether participants wanted to discover what
individuals with similar impairments did in certain situations, share their life hack solutions, or discuss non-life hacking related issues, they leveraged communication channels that connected them with the right people for those tasks. Participants who were less likely to interact with people and content online still found ways to connect with others and talk about things related to their life hacking efforts and other salient issues. Those who did leverage online platforms found them useful for multiple reasons like life hacking and daily life concerns advice or support and to express solidarity with other individuals who have disabilities. Life hacking-related benefits were only one of several that participants derived from their interactions in these spaces.

One takeaway from participants’ online behavior is that online platforms which allow individuals with impairments to produce and consume content contain socially constructed knowledge about technology, design, and life with a disability in general. Participants used these platforms to discover, access, produce, and co-construct knowledge about ways of addressing impairment-related concerns, practice breakdowns, life with a disability, and different psycho-social aspects of life with a disability. Participants described what life hacking-related activities they engaged in online as well as the online communities they frequented to interact and engage with others who shared their perspectives, interests, or various aspects of their experiences. While some of the forums, Facebook groups, and other platforms participants used are not open to the public, participants also mentioned online activities suggesting that life hacking-related content also exists on YouTube, blogs, e-commerce websites, personal websites, and other sharing websites for anyone who is interested to see. A close examination of this content will likely unearth ways that multiple individuals who live with impairments leverage these platforms to make meaning out of their offline experiences, share their personal impairment-related experiences, and exchange life hacking solutions, input, or advice. Participants who used
various online channels for these and other purposes validate the assertion that these platforms allow individuals with impairments to post content that challenges incorrect assumptions about disability and norms that affect their valuation and treatment by non-disables individuals who live with them in society. As the preceding section shows, user-generated platforms empowered participants and other individuals with physical impairments to use examples from their lives to name what disables and enables them, critically evaluate those forces, and tell the world how they deal with disabling aspects of practices. In doing so, participants and members of the online communities they frequent disseminate experientially grounded perspectives on disability that challenge passive, needy, aberrant, “super-crip” and other tropes undergirded by the deficit model, exploited by the medical-industrial complex, and perpetuated by mainstream media.

The meaning and social implications of receiving assistance from others

Another aspect of participants’ life hacking activities and daily life practices was receiving assistance from others. Most participants described at least one instance when they had to negotiate how other people should assist them with a practice task. When a participant received assistance from someone, he or she engaged in social interactions with people who were often non-disabled and sometimes lacked familiarity with his or her needs, desires, and capabilities. Participants needed different types assistance in their daily lives and some needed help more than others at different points in their lives. For example, Scott, Leon, Cecil, and Samantha could get through most of their day with minimal assistance, while other participants like Wallace and Kimberly needed help with most activities of daily life. Despite these differences, participants described similar examples and explanations of what they perceived to be valuable assistance from another human being. Many of them also provided similar personal insights into the relationships between receiving help and their perceived independence as individuals with
disabilities. As the examples in this section illustrate, all attempts to assist participants were not appreciated. Also, all participants expected to derive benefits from assistance and to be respected as individuals regardless of the amount or type of help they needed.

**Negotiating self-determination and meaningful help from others.**

The desire for independence was a common theme among most participants in this study but notably, not the only one as revealed in the next section. Although each person needed different amounts of help with life hacking and daily life activities, most placed a similar value on not being limited by other people because of their disability. Most study participants expressed some apprehension about receiving too much help or assistance on the wrong terms. They placed a very high value on self-determination and doing things independently. Some even avoided assistance from others whenever possible. Participants expressed these sentiments throughout our conversations, and the following quotes represent a few examples:

Dominic: i'm too stubborn to let anything or anyone keep me from doing what needs done. [IM interviewee]

Deanna: I can’t speak for all people, but some people don’t want to be independent. They want to depend on people, but me, I like to be independent as much as I can. [Face-to-face interviewee]

Leon: I want to be independent. I don’t want to always ask people because it takes away some of your independence I feel when you have to ask somebody. Because I’m such a person who always wants to do it and my pride gets in the way, because like I said, we have it hard as it is anyway. I make it a challenge to do what I can do and I feel like I’m letting myself down when I have to ask for help. [Face-to-face interviewee]

Sheila: All these [adaptations] that we’ve come up with have allowed me to be more independent and able to do things myself, rather than to purchase something that might be expensive to help me or get help from someone. I’d rather do it myself if I can. [Face-to-face interviewee]
These and other participants who verbalized the value they placed on independence had something in common. They sometimes life hacked to avoid asking for or receiving unsolicited assistance they neither requested nor valued as meaningful. Samantha [Telephone Interviewee] admitted that she sometimes "forced" herself to do physically demanding tasks despite her back and chronic pain issues because "people didn't really understand" the nature of her disability since her primarily invisible impairments. People in Samantha’s life sometimes linked her requests for help to being lazy, which made her less willing to ask people she did not personally know for assistance even when she needed it. Similarly, Dominic had a procedural life hack that enabled him to independently lift and carry 120-pound crates at work despite having hemiplegic cerebral palsy, hand numbness, pain from scoliosis, herniated disks, arthritis, and knee issues. Dominic refused to ask for help at work because he had a tough boss who "viewed disabled people as lesser th[a]n him." His supervisor's attitude made him feel like he "had something to prove" and doing his job without assistance was his way of doing so [IM Interviewee]. Other participants like Deanna, Leon, and Neil said they resented it when people attempted to help without asking whether they needed it or waiting for them to request it. They shared several instances when they preempted unsolicited assistance from others by relying on a life hack solution. Arnold, who was unfamiliar with the experience of disability until his spinal cord injury, conveyed that he felt embarrassed and frustrated whenever he had to hire a mechanic, plumber, or other professional to complete tasks that he once could do himself. Although he had to request help with certain tasks, he was not very keen on it and sometimes found ways to obviate the need to ask. For instance, Arnold had all the pool plumbing under his pool deck redone so that he could access and service it from his wheelchair independently instead of asking someone else to do it for him.
Participant efforts to avoid unsolicited help were common. Nevertheless, as with most individuals in general, participants needed and received help from time to time. Interestingly, they had similar ideas about what constituted meaningful versus undesirable help from others. Whether participants sought assistance with specific life hacks, daily life practices, or both, the individuals who helped them exhibited similar ways of thinking and doing that shaped the quality of the aid in the eyes of the participant. Meaningful support typically happened on the participant's terms, respected his or her wishes, and acknowledged his or her value as an individual. Participants who were open to asking for help avoided assistance divorced from these three things.

**Participant-informed assistance.**

Comments from several participants suggested that assistance from others was ideal when they requested it and people paid attention to their desires and input. Some participants stated this explicitly. For instance, although Leon did not like it when others assumed he needed help, he did ask for it when he needed it. He provided the following example of meaningful assistance he received from a transit driver who helped him ascend a steep hill with his cane-crutch. The example was remarkably different from others he described where people gave unsolicited assistance:

[Talking about a recent instance when he went to a friend's birthday party] Call-A-Ride let me off, there were steps. I tried to go up the steps and I thought this is not going to work. Because the older I’m getting, I’m scared of falling and I don’t want to break anything. I have never broken anything yet, thank God, and I don’t want to break anything.

I thought well, the steps aren't going to work, so they had a little ramp, but the ramp went up a hill. There was no railing. There was no kind of railing at all. I thought how am I going to get up there? The Call-A-Ride driver, he saw that I was having difficulty trying to get up it. He says, ‘do you need me to help you?’ I said yeah, would you let me catch your arm so I can walk up this? So, he let me. He got off the van and let me hold his arm till we got up to the door. [Face-to-face interviewee]
Later in the same interview, while discussing an episode where someone did not ask if or how to help him, Leon closed the story by explaining, "You can help me, but let me show you how to help me." The transit driver allowed Leon to tell him what he needed and Leon valued the driver’s willingness to seek his input first. Other participants expressed this same desire for others to help them based on their input and guidance. For instance, Deanna said she often got frustrated when family members took it upon themselves to help her without giving her a chance to try to complete a task independently and then ask for help if she needed it.

Perhaps the best exemplar of a participant receiving assistance on his or her terms came from Wallace. As an individual with a spinal cord injury who relies on caregivers for assistance with most daily life practices, help from others was an unavoidable reality for Wallace. Nevertheless, the nature of the interactions he had with his caregivers revealed a high level of respect for him as well as an acknowledgment that he should have a stake in decisions that affect him. Wallace admitted that although his caregivers followed the same basic daily routines, there were times when his needs changed or he discovered a better way to do self-care or other tasks. Sometimes he had to work to help his caregivers to help them understand when and where change was needed. Wallace attributed his ability to influence them to the fact that he knew them personally and they were willing to both listen to him and consider his input:

First off, you’ve got to communicate. You’ve got to know who you’re talking with. Some people you approach in certain ways; some people you approach other ways, but it’s just about communication and communicating that this is better for me. The people that we’re talking about [his caregivers], if they see that it’s better for me, they typically want what’s in my best interests, especially regarding my healthcare. [Video-chat interviewee]

Participants like Wallace, Deanna, and Leon all viewed assistance from others as beneficial when the people providing it listened to them first and foremost. Help on the participants' terms factored in his or her needs, opinions, and desire to exercise personal agency. It acknowledged
the participants as people who were more than their impairments and possessed an inalienable stake in what happened to them. Participants who valued help on their terms wanted others to acknowledge them as people who could make their own decisions rather than passive subjects looking for others to make decisions for them. Despite what others sometimes assumed, these participants did not equate receiving assistance with an automatic abdication of personal choice. Instead, they viewed it as a collaborative effort initiated and guided by their needs, desires, and insights.

**Assistance that contributes to participant-driven efforts.**

Meaningful help also involved contributions from others to participant-driven or inspired life hacking projects. These contributions usually took the form of guidance, technical expertise, and resourcefulness. Erin, Grant, Neil, Dominic, and Sheila all described instances when a family member, friend, or third-party possessed technical or other expertise and offered related support to the participant in his or her life hacking projects or everyday practices. For instance, although the outcome was not specifically related to accessibility or disability, Dominic sought advice from a relative who was a Ford technician when he made do-it-yourself repairs to his truck. Neil similarly reached out to specific individuals for guidance whenever he needed to do something in his daily life and was not sure how to accomplish it. To figure out the best person to ask for help with a given situation Neil explained, "I decide pretty much whomever I think would be most knowledgeable" [Face-to-Face Interviewee]. Erin's head pointer life hack which enabled her to communicate with others was the result of a collaborative effort. The life hack made communication less "labor intensive" for her by eliminating the need to use her hands to point to items on her letter-board [IM Interviewee]. One of Erin's friends who was comfortable doing
electrical work connected the laser pointer to the battery back for her. This friend possessed the
delicacy and physical capability that Erin needed to make the head pointer a reality.

The development of most of the life hacks Grant and Sheila described also required
technical knowledge and physical capabilities they did not personally possess. Grant
conceptualized and planned many of his life hacks and then relied on his wife to contribute the
physical labor needed to turn his plans into actual solutions. As the following explanation
indicates, there were times when neither he nor his wife possessed the necessary capabilities to
make something. In these instances, he paid professionals fabricators to execute his plans:

Grant: Yes. I will normally design something in my mind. Or sometimes on a computer.
Once I think I have all the bugs worked out, my wife is normally the person who makes it
happen. If it is something she cannot do like fabrication, I have a group of fabricators that
make things for me.
Me: Cool! Are these fabricators people you know personally?
Grant: No; they are professionals who make items for fishing boats. Everything they
make is light, compact, and has no sharp edges. They can make just about anything I ask.
The downside is the cost. They are over $100 per hour. [IM interviewee]

Sheila relied on her husband to make many of the artifact-centered life hacks she leveraged in
her daily life practices. While Grant and his wife paid a premium to access what they did not
possess as a team, Sheila could count on her husband Jack to figure out what to do and the best
way to do it because of his physical capabilities and previous experiences working on diverse do-it-yourself projects.

Assistance that contributed to participant-driven efforts came from individuals who
brought knowledge, technical capabilities, and artifact-centered life hacking experience to bear
on participants’ life hacking projects. Another way to label this type of assistance is practical
resourcefulness. Participants described instances when caregivers, relatives, retail sales
associates, and others offered something practical, timely, or both that contributed to their life
hacking efforts or life hack-enabled practices. Both Tabitha and Deanna described instances
when a family member purchased or acquired something they ended up using in their daily life practices. It was difficult for Deanna [Face-to-Face Interviewee] to reach certain parts of her body since she had limited use of her arms. Deanna's father purchased a "scrub brush" from a thrift store which enabled her to wash under her arms independently when bathing. Tabitha's step-father similarly acquired a tool which she nicknamed "the grabber" and used to retrieve items beyond her grasp while seated in her wheelchair [IM Interviewee]. Both Grant and Scott relied on the resourcefulness of hardware store employees when devising various life hacks. Grant sometimes described the raw materials he wanted to purchase for a life hacking project to a Home Depot sales associate who would then tell him where to find those items in the store. Scott described an episode when he asked a Home Depot employee if the manufacturer of the windows in his home made a lever extension pole that would obviate the need to bend down to open and close his windows. The sales associate's feedback prompted him to buy some PVC pipe and make one himself.

Wallace had glowing praise for his caregivers because of their ability to "think outside of the box" [Video-Chat Interviewee]. He had a pretty good relationship with his primary paid caregivers who were both mothers. Wallace described mothers in general, and these two women specifically as, "...always resourceful. If there is a problem or if there’s something that’s frustrating them, they might on their own try and think of a better way to do something." Wallace sometimes brainstormed with his caregivers to figure out life hacks and other solutions to address practice barriers. He also mentioned a former nurse who understood certain matters that individuals with spinal cord injuries faced so well that she preemptively prepared for them. Both the nurse and his caregivers helped him to devise or use solutions that addressed the issues he encountered in his daily life. People who provided useful help to individuals like Wallace,
Scott, Grant, Tabitha, and Deanna contributed something to participant efforts to make, modify, and leverage artifacts that co-configured the daily life practices in enabling ways. The extent of the contribution varied depending on the participant's general level of independence and ability to do the physical activities life hacking required. Nevertheless, meaningful contributions always empowered the participant in his or her efforts rather than taking away his or her agency. The contribution was meaningful in the sense that it empowered the participant to do the things he or she deemed necessary or worthwhile that he or she might not be able to do without the assistance.

**The role of others in participants’ personal development as life hackers**

For many participants, two driving influences in their efforts to address everyday life issues and seek independence were past experiences and the influence of non-disabled individuals. Other people’s support (or lack thereof) at different phases in participants’ lives encouraged them to not only life hack and seek independence but also view themselves as capable of doing so despite their impairment status. Several participants talked about how various people in their lives helped them to value their independence and seek ways to protect and preserve it as much as possible. For individuals who lived with disability from birth or a young age, past experiences with others generally made them less willing to ask for help from others, more prone to disregard the negative perceptions of others, and unwilling to let other people make decisions for them. Individuals who acquired a disability, on the other hand, seemed to devote time and energy to trying to beat the low expectations people placed on them because of their disability. For both groups of participants, family members, medical professionals, and others played various roles in helping them to develop the mentality they attributed to themselves as individuals who engage in life hacking related activities. It is important to note the two groupings were not mutually
exclusive. Sometimes participants who lived with a disability from birth found themselves fighting against the low expectations of others and individuals who acquired a disability later in life engaged in life hacking activities to avoid asking for help.

**Medical professionals’ incorrect guidance and low expectation bar.**

Scott, Arnold, Grant, Wallace, and Stewart knew life with and without a disability. Participants who lived life with and without a disability described instances when life hacking enabled them to overcome the low expectations others had of them as well as barriers people put in their way because of their disability. For instance, the negative prognoses and prescriptions some of these participants received from medical professionals stood in stark contrast to the life hacking-related activities they engaged in after the onset of disability. Grant provided an example of the low expectations medical professionals can have of people who acquire a disability: “The doctors told my wife to leave me while I was in the hospital since she would end up leaving anyway. I needed to learn to live on my own since she was not going to be there in the future” [IM interviewee].

It was in the face of assumptions like this one that Grant and his wife immediately started modifying his environment and the artifacts within it. While he was still in the hospital, they implemented a bricolage life hack on the nurse's call button so that it would not fall off his bed whenever he tried to use it. They attached a piece of Velcro to the button and the side of the bed. During our first interview, Grant said after 14 years of living with a spinal cord injury, he could perform most of his everyday life practices independently using various life hacks. Instead of leaving him so that he could learn to be more independent, Grant's wife played a critical role in helping him to maximize his independence by turning many of his life hack ideas into realities.
Wallace also began challenging the limitations his doctors placed on him and his caregivers soon after his injury. Wallace's doctors taught his caregivers an impractical method of taking care of an important health issue that did not fit the realities of his daily life. The high level of Wallace's spinal cord injury precluded him from independently coughing and clearing his throat when needed. The SCI rehabilitation center where Wallace resided after his injury introduced him and his family to the Cough Assist machine which clears secretions from one’s throat. The standard protocol at the time was to operate the machine in two-person caregiver teams. The rehab center taught this method to Wallace's family even though one of the respiratory therapists knew how to operate it with one person. Wallace and his family realized that two-person teams were impractical soon after he went home. They started experimenting and eventually figured out a procedure that allowed one caregiver to operate the Cough Assist machine. The respiratory therapists placed limitations on Wallace and his life that were grounded in their professionalized perspective on spinal cord injuries and the best way to care for individuals who have them. Their assumptions and guidance did not match the schedule of his caregivers. As a result, Wallace and his caregiving team had to figure out a way to manage this aspect of his health that matched the realities of his daily life.

Instead of giving in to the low expectations and uninformed guidance of medical professionals, Grant, Wallace, and their families adjusted to life with a spinal cord injury by life hacking and making things work for them. Their readiness to do so soon after the onset of disability revealed an unwillingness to give in to medical professionals’ tendency to devalue the quality and value of the life of an individual with a disability. These participants’ earliest post-impairment life hacks were reactions to the disheartening opinions and uninformed perspectives of medical professionals. The lives participants sought to make for themselves differed from the
ones medical professionals predetermined for them. Medical professional guidance served as an impetus for participants’ careers as individuals with physical impairments who life hack to live the lives they desire.

**Pushing participants toward independence through “tough love”**.

Samantha life hacked not only to make different practices more accessible and easier but also to avoid asking others for help. Her tendency to avoid asking people for help grew out of a high school experience. Samantha started engaging in life hacking activities and finding ways to be more independent ten years before our interviews while she was in high school. She had a run-in with a "very anti-accommodation" teacher who told her, "you’ll never make it in the real world if you can’t do things on your own" [Telephone Interviewee]. After this incident, Samantha started seeking more independence and doing whatever she could to avoid relying on others for help. This formative experience as a teenager made her less willing to ask others for help. At times, it motivated her to put extra stress on her body to accomplish tasks when life hacking was not an option despite the pain associated with this additional stress. Dominic similarly had formative experiences that contributed to his propensity to avoid asking for help and instead find ways to do everyday life activities independently. Although there were a few tasks that he needed help doing, other people played a negligible role in most of his daily life practices. He said his family members had a different way of helping him in life which consisted of pushing him when he wanted to give up on something difficult and not "babying" him. When asked how he felt about this aspect of his upbringing Dominic said, "I love em for it. The world is cruel. You gotta have thick skin to handle it" [IM Interviewee]. Notice that both Samantha and Dominic encountered people who expected them to deal with impairment and accessibility related challenges without complaining or seeking assistance from other people. Although their feelings about how these
individuals treated them differed, both participants responded by minimizing their dependence on others. In both cases, people's unwillingness to help them or “tough love” made them more self-reliant and less willing to seek assistance from others.

**Fostering self-determination in participants.**

Three participants talked about people and defining moments in their lives that ignited a sense of pride and self-determination in them. Cecil mentioned a teacher who had a major impact on him through her words of support and encouragement. Cecil started living in his own place when he was 20 or 21, and this teacher told him something that he still remembered 25+ years later:

> Oh yeah. Miss [teacher’s name] brought me a long way...because she even told me, people [are] going to be mean to you, be rough to you, but stand up and if you know what’s right keep pushing. [Face-to-face interviewee]

Cecil said this and other advice from his former teacher not only helped him to make the transition to independent living but also encouraged him to figure out procedural life hacks that enabled him to manage “rough” people and various other challenges associated with living alone as an individual with a disability. Ross' mother also had a major impact on him growing up, and in his opinion, her "instincts" were the reason why he was so self-determined as an adult with a disability. Ross explained how his mother always believed he would live a full life and exercise his capabilities to the greatest extent possible. She did therapy with him at home and modified some of the exercises she did with him. Ross explained how and why her efforts influenced him:

"My initial abilities were definitely derived from my mom's adaptations and her drive for me to find ways to live” [Face-to-face interviewee]. Ross also said his "intention" and "internalized belief" that he would live the full life as an individual with a disability was the result of his mother who believed these things for him since he was a baby. Ross said his mother helped him
to develop his body so that it "serve[d] him" and he told a story about the role she played in helping him to discover his ability to walk on his hands.

As a child, Ross did something with his mother called the "wheelbarrow." She would hold his legs up in the air while he walked on his arms and hands. As the following excerpt details, one day this therapy exercise led to a new way of ambulating that Ross still used as a 45+-year-old adult:

One of the stories I tell is how the phone rang, and [my mother] was doing this wheelbarrow, and she goes, 'We're going to have stop now because I'm going to let go. I have to answer the phone.' She let go of my legs, and I just kept going in a plank position because my legs were really light and at this point, I had developed my upper body. I just held my butt in the air and my legs sticking out and I kept doing the wheelbarrow without her, and it was like, 'I don't need her. This is fun. I like doing this.' That's how I started walking on my hands. [Face-to-face interviewee]

Ross' mother helped him to develop certain capabilities that he built on throughout his life. She reinforced her homemade therapy with positive affirmations that helped him to internalize the belief that he could be active and self-fulfilled individual despite his physical impairments. Her influence gave him the capabilities and confidence to explore and find ways to do activities such as gymnastics, dancing, racquetball, skating, and horseback riding without letting the physical demands of these tasks or people's uninformed assumptions stop him from trying.

Members of Sheila's family instilled a similar set of beliefs in her as a child. Her mother shattered the glass ceiling in her career by climbing the corporate ladder and eventually getting a managerial position in a male-dominated field. Sheila respected her mother for her achievements. During one of our conversations Sheila explained that she lived in a family of fighters, and people who knew her from childhood often said she had the same fighter spirit her mom and other family members possessed. Sheila explained how this shared "fighter" mentality impacted her outlook on life as an individual with a disability:
People tell me I’ve always been kind of a go-getter. I never really, I just never really thought of myself as just being a person with a disability who couldn't have a life and who couldn't live normally like everyone else. So, I guess I’m a fighter. Our family is kind of like that. We’ve all been fighters all our lives. [Face-to-face interviewee]

Although Sheila did not say her mother was the same kind of cheerleader and advocate as Ross' mom, she nevertheless shared her mother's perseverance. Her mother's positive influence on her manifested itself in an experience she shared about trying to go to college and start a career. Despite her desire to go to college as well as her aptitude to succeed academically as revealed by a series of Vocational Rehabilitation tests, the state she lived in refused to provide any financial support for college. After six weeks of testing, Sheila's case manager told her the state would not send her to college because she had a "severe disability." When Sheila asked for an explanation, the woman retorted, "Well, because you're classified as having a severe disability, and people with severe disabilities don’t get jobs, so we can’t waste that money." Sheila was heartbroken and angered by this woman's words. She referred to the experience as "the end of me participating in the system" and the beginning of her crusade to "do it on my own" and "show them all." Sheila worked hard to find a job and build a successful career. Just like her mother who had to fight against discrimination against women, Sheila fights against discrimination against people with disabilities as a disability rights advocate. Like Cecil and Ross’ interactions with their teacher and mother, respectively, Sheila's interactions with family members like her mother set the tone regarding the type of life she would live as an individual with a disability. Those interactions also gave her the confidence to fight when people or situations stood in the way of her living that life.

Life Hacking as Political Statements and Reactions to Disability Oppression

So far, this chapter has presented different ways that various people factored into or influenced participants' life hacking activities, everyday practices, and personal development as individuals
with disabilities. Participants' past and present experiences with others often shaped how they addressed accessibility and impairment issues, viewed themselves, and interacted with others. Participants needed different types and amounts of assistance from others and when they received assistance on their terms, the result was empowerment rather than dependency. Life hacking enabled participants to not only address practice-related issues but also react to the uninformed opinions and incorrect assumptions about them, explicitly, and individuals with disabilities in general held by the people and institutions that supposedly help the disability community. The following three socially constructed realities, which many individuals with disabilities encounter, factored into participants’ daily lives and related practices. One was oppression, or the subjection of individuals who belong to a social group to political, economic, cultural, or social devaluation via structures of domination and subordination grounded in ideologies of superiority and inferiority (Charlton, 1998). It is marginalization imposed on a culture or group (e.g., people with disabilities) by a more dominant culture or group (e.g., non-disabled people). The dominant and subordinate structuring is systematic and grounded in the prevailing party’s belief in and maintenance of this dichotomy. The dichotomy is maintained by systematically excluding members of the inferior group from the political, economic, and cultural life of society and its economic system, thus rendering those individuals powerless to change their standing in society (Charlton, 1998). Oppression does not simply exist in the ideologies and activities of non-disabled members of society. It is both an existential and experiential reality in the everyday lives of many individuals with disabilities that can impact them practically, socially, economically, and especially psychologically.

Oppression is linked to the second social reality which is dis/ableism. Dis/ableism can be defined as discrimination against individuals with disabilities combined with the pedestalization
of non-disabled bodies and those who possess them. Ableism undermines the psychological and emotional well-being of individuals with impairments and disabled scholars refer to this dynamic as “internalized oppression” (Mercer, 2002). Internalized oppression is the low self-esteem and sense of achievement individuals with disabilities experience combined with the reinforcement of the small value non-disabled people place on individuals with disabilities which produces the negative views individuals with impairments have about themselves (Rieser, 2006). It occurs as individuals with impairments grapple with who they, their value within an ableist society, and how to resolve the resulting cognitive dissonance.

Technological artifacts, disability-oriented services, and policies that govern their provision and use may seem like good things for individuals with impairments on the surface and may even provide some practical benefits to them. However, these same things can simultaneously reinforce ableist and oppressive ideologies that violate the true experiences of disabled individuals and fail "to improve their material circumstances and quality of life” (Oliver, 1992, p. 105). According to Goggin and Newell (2003) who wrote about the social construction of disability in new media and technology, artifacts such as the wheelchair, cochlear implant, and contemporary digital communications/media technologies are "forms of management and regulation" (pp. 10–11). Their assertion points to the difference between appearance and reality when it comes to various efforts intended to help the disability community. These disconnects are often the result of excluding the views and perspectives of individuals with impairments from decisions related to the design and development of products, services, policies, and efforts that will impact them. For instance, ableist norms and assumptions codified in design artifacts can effectively control the aspirations of individuals who live with impairments as well as their movement and access to various parts of the social world (Goggin &
Newell, 2003). Ableism does not hold decision-makers accountable when they do not critically evaluate the assumptions non-disabled individuals make about individuals with impairments during the decision-making process. Instead, they leave individuals with disabilities to cope with the downstream impacts of decisions people who have no direct experience with impairment made on their behalf without their input. Similarly, medical and other service professionals who operate under ableist ideas will focus on normalizing people with impairments rather than encouraging them to embrace their capabilities and figure out individualized ways to address impairment-related challenges.

The third manifestation of uninformed opinions and incorrect assumptions that factored into participant’s daily life practices was paternalism. *Paternalism* is the tendency to treat individuals with disabilities like children and justify this treatment by linking personal responsibility to the amount of control one has over his or her body relative to non-disabled individuals (Fulcher, 1989). The assumptions undergirding paternalism are that people with disabilities are not only inferior to non-disabled individuals but also unable to take responsibility for themselves (Charlton, 1998). Members of the Disability Rights Movement link paternalism to the oppression of people with disabilities through their relegation to the status of “subjects” who need to be controlled and cared for by others even if that care goes against their individual will, culture, traditions, and sovereignty (Charlton, 1998). Under paternalism, non-disabled people project themselves as benign, well-meaning, and all-knowing *protectors* who must care for individuals with impairments since they cannot take care of themselves. Paternalism attributes childlike qualities to all individuals with identifiable impairments regardless of their age or actual capabilities and often forces them to accept “help” that goes against their wishes or best interests. It does not allow the individual to grow into a self-determined and self-actualized
human being because opportunities to do so are taken away from him or her by the non-disabled protector. People with impairments who seek or demand self-determination in effect attack the practice and perpetuation of paternalism by non-disabled individuals as well as within various social institutions such as family, the education system, the medical industry, social agencies, and charities (Charlton, 1998).

In addition to the practical barriers participants encountered, socio-political factors such as ableism, paternalism, and oppression also shaped their practices and motivated them to life hack. In this final section, I examine how some participants’ life hacking efforts represented reactions and responses to the three social realities just outlined. Sometimes life hacking involved intentionally challenging ideologies participants perceived as oppressive often embodied in people's beliefs, attitudes, and actions, institutional policies and procedures, or design artifacts and practices. For example, Sheila’s home state refused to fund her college education even though she scored high on all the state’s college aptitude tests. A vocational rehabilitation case manager told Sheila that “people with severe disabilities don’t get jobs” and therefore her state would not “waste” money sending her to college [Face-to-Face Interviewee]. Sheila made it her life’s mission to prove this woman wrong. Life hacking enabled Sheila to excel in her career and live a self-determined life despite institutionalized ableism which prevented her from going to college. This section examines this and other instances when participants engaged in life hacking activity in response to ableism and paternalism or to resist oppression they experienced as individuals with disabilities.

**Life hacking as ways to “make-do” and resist paternalism.**

Deanna, Neil, and a few other participants had people in their lives who seemed to be against their efforts to life hack and seek independence. There were tensions between these participants’
desire for self-determination and the desire of loved ones to either coddle or normalize them. These tensions forced participants to make do. "Making do" refers to finding an equilibrium between the proximity imposed by public life and the distance needed to protect one's private life (de Certeau et al., 1998).

Deanna, for instance, often found herself in a tug-of-war with her parents over her independence. She was 24-years old and engaged at the time of our interviews. Deanna was making proactive attempts to improve her cooking skills and figure out ways to make this and other practices more accessible and easier to do. Although her parents occasionally gave her tasks to do in the kitchen, they limited her as far as what they allowed her to do independently. In response, Deanna sometimes practiced her cooking skills and kitchen-related life hacks while her parents were sleeping. Throughout our interviews, Deanna said her parents often tried to squelch her desire to be more independent. Her way of dealing with it involved exploiting moments when she could create distance between herself and her parents to prevent them from trying to "take over" whatever tasks she attempted to do independently. Neil experienced another type of paternalistic familial resistance to his procedural life hacks. When asked about any barriers to life hacking, Neil said his family “loudly” criticized him or forced unsolicited help on him whenever they saw him "doing something slightly different" from the way a person without cerebral palsy might do it [Face-to-Face Interviewee]. Although their reactions made him self-conscious about using his life hacks in their sight, they did not stop him from using them when he was beyond their purview.

Neil experienced a tug-of-war with his family that was like the one Deanna had with her parents. Both participants were more apt to re-appropriate objects and utilize procedural life hacks than to make, modify, or fix artifacts. Both also learned to leverage their life hacks beyond
the gaze of others who either challenged their efforts to do things for themselves or disapproved of their ways of doing things. "Making do" allowed them to enjoy the benefits of life hacking, trying new things, and learning to be more independent without getting criticized for doing so by people who sought to control them or limit their ability do things for themselves.

**Reacting to oppressive attempts to devalue, dominate, or exclude based on Dis/Ability.**

Sometimes participants engaged in life hacking activities and found unique ways to do things independently simply because others devalued them or made negative assumptions about their capabilities. Life hacking represented intentional efforts to not only prove others wrong but also refuse to be marginalized and controlled by others’ assumptions and beliefs about individuals with disabilities. Sheila resolved to stop "participating in the system" and prove her critics wrong after her vocational rehabilitation counselor crushed her dreams of going to college. Life hacking allowed her to follow through on her resolution and prove her capabilities to people like the counselor who doubted her.

Dominic somewhat similarly life hacked in response to his former supervisor at a retail store. He said his old boss "viewed disabled people as lesser than him" and refused to let any employee use pallet drivers or hand trucks to move heavy freight [IM Interviewee]. The situation Dominic related exemplified systematic oppression. The structures and policies that his boss enforced worked against Dominic by privileging people who had the physical ability to carry the freight by hand while inconveniencing those who did not. Additionally, Dominic did not have any power to influence or change the rules. Instead, he was subject to the same rules as his non-disabled co-workers even though those rules had vastly different implications for both groups. Dominic could have done several different things in response, such as file a complaint with
human resources, use a hand truck or other moving tool against his boss' wishes, quit his job, or ask someone for assistance. Instead, he decided to use a procedural life hack to lift and move the 120-pound crates independently to "prove" himself. While some might disagree with his choice, Dominic decided to work within the constraints forced on him for the sake of showing his supervisor that he could do the job. Erin also shared an example of a life hack-enabled way of fighting back against uninformed ideas about people with disabilities which could have prevented her from taking a class she wanted to take. Despite having limited use of her hands, Erin wanted to take a painting class as a college student. The teacher was "perplexed" when Erin showed up on the first day of class because she did not think someone who could not use her hands would be able to complete the assignments. The teacher assumed that since Erin could not use her hands, she would not be able to paint. Erin described what she did to show the teacher she could paint as follows: "I showed up with a paintbrush attached to my head, and she soon realized that I was just as capable as her other students" [IM Interviewee]
Leon described an experience from childhood where he wanted to play sports with his peers, but they would not allow him to do so because he had a physical disability. His peers linked playing baseball to being able to stand and assumed he could not play because he could not stand and ambulate without using a mobility aid. One day after many unsuccessful attempts to convince his peers to include him in the game, they gave him a bat. He kneeled in the batter's box to hit the ball, and some of the children vocalized their doubt in his ability to play. One kid purposely threw the ball at him and knocked him down. Leon said he believed the child's intention was to discourage him from trying. Nevertheless, Leon was determined to show them he could play and ended up hitting a home run on the first real pitch he received. Whereas
Dominic proved his boss wrong by finding a way to work within the constraints placed on him and his non-disabled co-workers, Erin and Leon leveraged life hacks that allowed them to ostentatiously demonstrate their capabilities to people who assumed they were incapable of doing something. Dominic, Erin, and Leon did not take other people's negative sentiments or incorrect assumptions about them as an indication to give up on their goals but rather resolved to demonstrate the abilities they knew they possessed. Life hacking enabled them to do so.

Dominic, Sheila, Erin, and Leon all decided to invalidate incorrect assumptions about their capabilities and value as individuals with disabilities through their life hacking efforts. Sheila’s rehabilitation counselor, Dominic’s boss, Erin’s painting instructor, and Leon’s childhood peers all made judgments about people with disabilities that were grounded in their biases and perspective as non-disabled people. These individuals seemed to perceive themselves as dominant, superior, and more capable than individuals with impaired bodies. Their attempts to exclude and control participants while privileging other able-bodied people were oppressive towards participants and other individuals who live with impairments. Participant reactions reveal that life hacking was more than a means to practical ends. It also served as a weapon participants used to fight back and resist ideas, perspectives, and assumptions that limited them. In these instances, life hacking represented a demonstration of capability, personal significance, and worth in the face of limitations and barriers imposed on them by non-disabled individuals.

**Life hacking as rejecting able-bodied norms and ableist assumptions.**

Behavioral norms and pre-determined ways of how the body should be used co-constructed participants’ life hacking-enabled practices in distinct ways as outlined in chapter six. Exogenous to participant life hacking-enabled practices, norms represented socially shaped standards that defined life as an individual with a disability in ways that sometimes conflicted with how
participants wanted to live their lives. Ableist norms may be embodied in the products, services, and policies made by non-disabled individuals and undermine the agency, value, and self-worth of the individuals with disabilities who consume them. If individuals with disabilities begin to see themselves through the lens of ableism, they, in effect, internalize the oppression imposed on them by non-disabled members of society who see their bodies, minds, and personhood as superior to those of disabled individuals. In contrast to people who overtly marginalized participants with their words, actions, or inaction, norms were unspoken but powerful influences that shaped what an individual or entire group thought about people with disabilities in general and study participants, specifically. Institutions, environments, artifacts, and non-disabled individuals all play a role in perpetuating ableist ideologies about disability and participants faced challenges when these norms conflicted with the way they viewed themselves and attempted to live their lives. Several participants framed their efforts to life hack and find ways to do what they wanted and needed to do as opposing social norms and ableist ideologies as well as medical professionals’ low expectations of individuals with disabilities. For example, Sheila felt that more people with disabilities should engage in life hacking activities. She said too many of them did not life hack within the context of their everyday lives because of the influence of a social norm that governs the way social service programs operate:

Me: Have you ever been in any groups, whether online or in person, groups where people have discussed or shared or mentioned their own adaptations?
Sheila: No, you know, I haven't. I think a lot of people depend on professionals to figure out something for them.
Me: Why do you think that is?
Sheila: Maybe because they’ve been conditioned to think that way. Maybe they just don’t sit there and figure out maybe I could do this, and this would be better than getting this other piece of equipment. If you’re on Medicaid, Medicaid will buy a lot of equipment for you. They’re stingy in a lot of ways with some stuff, but it’s certain medical products, which makes me angry. But they will buy some adaptations for you so you don’t have to figure them out. I had to figure them out because we’d be paying privately. And besides, I just didn't think it was necessary for a lot of it. Or a couple of
times I did get something and it didn't work, so it was waste. [Face-to-face interviewee]

Sheila identified a norm governing the interactions between individuals with disabilities and social insurance program representatives. This norm implies that individuals with disabilities are less self-determined and more willing to accept whatever entities that purportedly serve the interests of the disability community say or do on their behalf. The implications are that individuals with disabilities who have Medicaid are less likely to play an active role in finding solutions to the issues they face. Disability studies scholars confirm Sheila’s assertion that economic, social, technological, and ideological forces as well as dependency-creating social policies uninformed by the perspectives of individuals with disabilities create dependency (Oliver, 1992). Sheila juxtaposed life hacking and relying on Medicaid in a way that made Medicaid seem like a system that controlled individuals with disabilities while life hacking empowered people to avoid being controlled by that system. In her opinion, social insurance providers reinforced an assumption that people with disabilities do not have agency. She further asserted that many individuals with disabilities on Medicaid accept this as assumption rather than challenging it. These ableist assumptions are reified in normative Medicaid service provision models that make consumers more willing to passively wait for these entities to improve things for them and less willing to try to improve things for themselves. Life hacking activities, and particularly artifact-centered ones, on the other hand, enabled Sheila and her husband to avoid this passive dependence. Their efforts, which included figuring out what worked for her instead of relying on a third party to do so, contradicted ableist and oppressive service provision models that she felt governed the relations between individuals with disabilities and social insurance providers.
Neil similarly implied life hacking was somewhat synonymous with transcending ableist ideologies that dictated what individuals with disabilities do in their daily lives. He also framed his efforts as a counter measure to oppression previously internalized. In Sheila's example above, professionals and entire industries thrived because of an expectation that people with disabilities would give deference to these institutions and submit to the control they wielded over their lives. Neil, on the other hand, grappled with ableist and oppressive performance standards imposed on him by therapists and the internalized oppression he experienced when he was younger as a result. Neil described the resistance he encountered whenever his parents or other non-disabled individuals saw him perform a practice activity in an individualized or unique way. These people automatically assumed that if his method of doing something differed from the way non-disabled individuals did the same tasks, his method was "not the right way" and therefore a sign of "weakness." In other words, the people closest to Neil made able-bodies and their capabilities the standard that Neil should emulate and discouraged deviation from that standard. At one point, Neil said he was “self-conscious” about life hacking because of people’s negative reactions and responses to him whenever he did so. A similar dynamic played out with his physical and occupational therapists who labeled his procedural life hacks as "cheating" even though they were more efficient for him and sometimes offered other personal benefits. For instance, Neil had a way typing that involved rhythmically using two fingers on his right hand and one on his left instead of all ten fingers. An occupational therapist tried to get Neil to use all his fingers to type even though his method worked better for him. The following exchange reveals how Neil learned to deal with the ableist expectations his occupational therapists tried to force on him:

It’s interesting, the OTs were saying – this is recent – they were saying that changing my pattern caused cognitive overload. It’s more cognitive processes going on because I’m constantly trying to decide what’s the most efficient way to get from here to here? Me: What did you think of the OT’s opinion?
Neil: I was typing like this for the past 12-16 years; I don’t think I’m going to change. [Face-to-face interviewee]

Although Neil's occupational therapist explained what made two-handed typing better than his method, the explanation was grounded in a belief that typing the way someone who did not have a dexterity impairment did was preferable to the method Neil used for him most of his life. Part of the problem with the OT's guidance was that it did not take Neil's preferred way of typing into account. Instead, the therapist operated on the assumption there was only one “right” way to type, and aberrations were something to be corrected rather than embraced. Although Neil's developed and preferred way of typing resulted in more cognitive processing according to the therapist, it did not negate the reality that it worked better for him. Interestingly, the fact that his therapist discouraged him from using his method because it was different from the way non-disabled individuals typed did not convince him to conform to the norm.

Another experience Neil had with a physical therapist further illustrates how ableist norms have the potential to govern the behaviors of individuals with disabilities and potentially lead to oppression. It also shows how life hacking can empower someone with a disability to reject ableism and resist internalized oppression which may have controlled him or her in the past. In the exchange below, Neil said he thought able-bodiedness was something he should strive for as a young person. At that time, he connected doing what his therapists instructed him to do with changing his disability status:

Neil: So yeah, when I was younger, I used to be what physical therapists would all be seeing in their dreams.
Me: Really?
Neil: Yeah. So, I was the one who if the PT said do five I would do ten. And it was just to try to get over my CP. [Face-to-face interviewee]

Neil did not explicate the relationship between going above and beyond on his therapist-prescribed exercises and "get[t]ing over" cerebral palsy. Nevertheless, both therapist interactions
described suggests a link between therapy and an internalized desire to be normalized. Neil grappled with this link both as a child and young adult. When he was younger, he gave into the pressure towards normalization that seemed to be associated with therapy and even worked harder than his physical therapist recommended in hopes of speeding up the process. As Neil's interaction with his occupational therapist regarding his typing method suggests, the pressure towards normalization did not affect him as much as a young adult. He weighed what his physical therapists suggested against his individualized way of typing and chose this life-hack-enabled method.

Both Sheila and Neil linked their life hacking efforts to rejecting the norms that guided the efforts of institutions and professionals who provided services to individuals with disabilities. These norms were grounded in ableist assumptions about things such as who should address the issues someone with disability faces and what standard should a person with a disability strive towards in life. In Sheila's example, the ableist norms governing the provision of social insurance to individuals with disabilities motivated her to life hack so that she could avoid the different forms of control these entities exert over the lives of consumers. Neil's experiences with therapists suggest these professionals operated under the assumption that able-bodiedness and normalcy were the standards that individuals with disabilities should aspire to and aberrations were unacceptable. Although it took some time, Neil learned to embrace his capabilities as an individual with physical impairments. He stopped trying to conform to ableist standards and started choosing to do things the best way he knew how to do them even when non-disabled people in his life disagreed.
The HACK in Life Hacking: Socio-Political Implications

This chapter not only described how participants used the Internet for life hacking purposes but also explained some of the politics entangled in their life hacking efforts. Obviously, the Internet and computers play a central role in the activities of traditional hackers. Other non-computer-related forms of hacking exist as well, however, including telephone fraud or "phreaking" creating devices that can be used to “steal” the magnetic code on a credit card, changing subway passes or card readers to ride for free, and “rigging” parking meters (Leeson & Coyne, 2005). At its core, hacking is about securing unauthorized access to computers, digital networks connecting ICTs, or both (Jordan & Taylor, 1998). ICTs and networks serve as both the tools and the targets of hackers. Interestingly, both allow hackers not only to carry out well-known goals such as breaking into computer networks and demonstrating their technological prowess but also subvert the will of institutions and entities that restrict people’s access to them (Leeson & Coyne, 2005; Nissenbaum, 2004). More importantly, the Internet serves as the social gathering place for hackers as well as their information, tool, normative practice, and goal sharing network (Holt & Kilger, 2008). Although hackers say they operate in informal networks with small numbers of people both online and offline, they primarily organize themselves socially online (Holt & Kilger, 2008).

As the first major section of this chapter reveals, many participants in this dissertation research study leveraged online networks and user-generated content platforms that also facilitated social interaction and resource sharing. While traditional hackers have historically used web forums, Internet relay chat (IRC) channels, and blogs to interact and share resources (Holt & Kilger, 2008), participants primarily used social media, YouTube, blogs, and both personal and e-commerce websites for the same general purpose. Although some participants
mentioned several one-off offline life hacking-related interactions as well, Internet and user-generated content platform-facilitated interactions were more common.

Another finding from this chapter that parallels those from studies that identify common characteristics of traditional hacker communities relate to the political motivations and implications of participants’ life hacking activities. Like the terms hack and hacker, *disability* is socially constructed. Today people often equate hacking with illegal and harmful activities such as electronic vandalism, national security threats, and illegally copying and distributing software or other electronic works with intellectual property rights attached to them (Leeson & Coyne, 2005; Nissenbaum, 2004; Turgeman-Goldschmidt, 2008). However, there are hacker subgroups that do not have malicious intentions. They are motivated by a desire to solve complex problems and make society a better place (Leeson & Coyne, 2005), and see hacking as acts of scavenging, tinkering "bricolage," or making creative use of resources (Nikitina, 2012). The news media and private sector entities that malicious hackers target work hard to control the overall narrative about hackers without attempting to distinguish the benevolent ones from those with malevolent intentions. As a result, societal discourses, largely shaped by the media, cast all hackers in the same negative light. The same thing happens to the disability community because of one-sided media portrayals. Like traditional hackers with good intentions, study participants who life hack challenge dominant media and societal narratives about disability grounded in ableist, oppressive, and paternalistic ideologies and uninformed by the views and perspectives of individuals with disabilities.

The tenants of the Hacker Ethic guided many of the earliest hackers, and one could argue that some study participants internalized a comparable set of principles that shaped their life hacking efforts. Hacker ethic principles include a belief in the immense power of computers to
improve people’s lives and create art and beauty, mistrust of centralized authority, disdain for anything that intentionally restricts free access to computing, and an insistence on evaluating hackers based on technical talent/skill and individual accomplishment only (Leeson & Coyne, 2005; Levy, 1984; Nissenbaum, 2004). Participants in this dissertation research study begrudged paternalistic efforts to limit them, preferred covert life hacking activity around people who tried to suppress their efforts, defiantly resisted attempts to devalue them or their abilities because of their impaired bodies, and believed life hacking enabled individuals with disabilities to resist attempts to normalize, marginalize, or make them excessively dependent on others. Many of the principles and ideals that guided benevolent hackers and study participants did not match mainstream media constructions of these groups. Instead, the standards and principles that influenced their behavior suggested members of both groups not only operated on principle but also did not deserve to be labeled and defined in the ways the media and society tend to do so. Relatedly, the activities of benevolent hackers and participants contradict the motivations the media ascribes to hackers and capabilities it attributes to people with disabilities. These parallel contradictions point to the politics surrounding hacking and disability as well as the barriers that both benevolent hackers and individuals with disabilities encounter when parties with little or no direct experience construct each group's dominant societal narrative.

The comparable ways of using Internet platforms for social purposes by both hackers and study participants as well as each group's principled wrangling over socially constructed narratives about them offer further support for the utilization of the term life hack in this study. As this section highlights, participants engaged in projects for reasons that were dissimilar yet comparable to those of hackers. They used the same types of online communication platforms for similar purposes as hackers. They also faced adverse consequences for being excluded from
the social shaping of how society understands and values people with disabilities in the same way that benevolent hackers faced negative consequences because the media and other entities grouped them together with malignant ones.

Study participants had physical impairments, and their specific life hacking activities, goals, and motivations were all related to their impairment-related experiences. Although hackers typically do not hack for impairment-related reasons, there were still notable parallels between them and study participants. For instance, the use of the Internet for social interaction purposes among hackers and the Internet-mediated interactions participants described mirrored each other even though most hacking related activity is mediated by the Internet while most life hacking activity occurred offline. There were also comparable socio-political goals between participants and traditional hackers. For instance, one of the goals of hackers is to free the Internet from bureaucratic control (Nissenbaum, 2004). Some study participants similarly life hacked to free themselves from the control of individuals and institutions that did not fully understand their needs and capabilities, perspectives, and wishes. Arguably, the most significant parallel was the way that both study participants and traditional hackers used their respective activities to make political statements and undermine the efforts of institutions that control the means of production as well as the lives of the people they purportedly help.

The various similarities between the social interactions and socio-political realities encountered by both participants in this study and traditional hackers support certain assertions made in chapter five. First, life hacking goes well beyond adapting, a term both accessibility and HCI researchers use to capture attempts to overcome accessibility challenges or make design artifacts more usable and useful to individuals with disabilities (Anthony et al., 2013; Kane et al., 2009; Moran, 2002). This chapter examined social dimensions of participant life hacking, daily
life practices, and the activities that constitute both. There is an inextricable link between the phenomenological, or way people perceive, experience, and act in the world (Dourish, 2004) and both the physical and social world. Life hacking, just like any other phenomenon, is circumscribed by temporal, spatial, social, technological, political, economic, and other conditions that factor into people’s perceptions, lived experiences, and actions. The term life hack, which is a clever yet non-obvious way to deal with an everyday life issue (Potts, 2010) acknowledges the boundedness of related participant activities to the phenomenological as well as their insoluble connection to the social, as described in this chapter. The term life hack fits in the context of this dissertation study because of the way it captures the practical aspects of participants' lives, the issues that serve as the backdrop for their life hacking activities, and the creativity that participants exhibit in both their life hacking activities and the practices they enable.

**Conclusion**

This chapter examined various social aspects of life hacking including participant interactions with people, institutions, and social constructions of disability which both inspired them to life hack and co-constituted their practices. The first section focused on participants' life hacking-related social interactions, and most importantly, their online user-generated content platform-mediated interactions. For years, disability and media studies and disability studies scholars have praised the potential of the Internet to level the playing field for individuals with disabilities when it comes to portraying accurate representations of disability in the media. They argue that platforms like blogs and YouTube empower individuals with impairments to construct narratives about disability that are grounded in their lived experiences. Participants in this study used multiple user-generated content platforms to both consume and produce content related to life
hacking and life with a disability, in general. Consumption activities included learning from life hacking content posted by other individuals with impairments, discovering life hack solutions to model, and finding inspiration to try something new. Content production activities included creating and disseminating content about specific life hacks, responding to life hacking-related questions, providing input on someone else's life hack projects, and connecting with other individuals with similar impairments to discuss topics related to life with a disability. Online content production and consumption activities, as well as analog offline activities, empowered study participants and those who interacted with them or the content they produced to support each other's efforts to address accessibility, impairment, and everyday life concerns. Additionally, participants' online user-generated content platform-facilitated interactions captured exchanges of experiential and co-constructed knowledge about design, disability, and life hacking.

One takeaway from the first section of this chapter is that user-generated content platforms where people with disabilities talk about their life hacking activities and other related topics could potentially serve as a readily available source of data for researchers and designers interested in empowering individuals with disabilities in ways they will value and appreciate. Participants and members of the online communities they frequented disseminated experientially grounded perspectives on disability, design, and life hacking that contradicted the medical and corporate models of disability. At the same time, the different kinds of content and range of topics participants said they and other contributors discussed on these platforms illustrate some of the diversity among individuals with disabilities in general, which is not always easy to replicate in research recruitment methods or surveys, usability tests, and other research methods. A second takeaway is that online platforms enabled participants and other individuals with
impairments to disseminate experientially-grounded narratives about their personal experiences and challenge societal notions about disability, design, and life with an impairment. Life hacking as a phenomenon challenges the deficit model of disability and different approaches to addressing impairment-related issues by shining the spotlight on individuals with disabilities who do not fit into mainstream media, "expert", or other non-consumer disability narratives. Life hacking-related user-generated content posted online by individuals with disabilities makes their localized attempts to not only deal with the downstream impacts of deficit model thinking embedded in products and services but also proactively respond to these impacts accessible to the world via the Internet.

The second section of this chapter examined the meaning and implications participants ascribed to getting life hacking assistance from other people. It describes how participants valued assistance from people who contributed something useful and necessary to their life hacking projects. The operative word in the preceding sentence is their projects. Regardless of how much help participants needed or their level of independence, they valued assistance from people who either supplemented or complimented their capabilities instead of people who sought to do things for them. In other words, allies and co-participants were collaborators. The power dynamic that undergirds the “assistance” individuals with disabilities sometimes receive did not exist in these collaborative efforts. Co-participants and allies offered advice, manual labor, and technological expertise that enabled or enhanced participant-driven efforts. The help they offered participants was practical, timely, and made good use of available resources. They did not hijack participant life hacking efforts but instead empowered participants to develop useful and usable life hack solutions that based on their needs and preferences.
The next section explored the role that other people played in participants' growth and development as individuals with impairments who life hack. Some participants mentioned people in their lives who shaped their worldview, view of themselves in the world, or desire for independence. Others found the motivation to start life hacking after medical or other professionals placed low or restrictive expectations on the type of life they could live with a disability or offered guidance that would lower their quality of life and self-determination. They wanted to exceed the low expectation bar medical professionals set for them after their injury and overcome the limitations these same professionals placed on them and their caregivers. At times, it seemed like doctors tried to steer participants and their caregivers towards despair and hopelessness or to control certain aspects of participants’ lives. Their words and actions, however, ended up inspiring a sense of hope and creativity in participants as well as fueling their will to live a full and self-determined life. Other people in participants' lives pushed them to life hack and seek more independence via "tough love." Participants in this camp described one or more people from their past who refused to assist them with tasks or allowed them to struggle and figure out ways to do those tasks independently. Although participants placed different valuations on these experiences, they all said these social interactions were formative and life changing. "Tough love" sometimes appeared harsh and potentially harmful. However, participants attributed their unwillingness to ask for or accept help from others as adults to specific childhood and adolescent encounters with people who refused to help them or made them feel bad about asking for it. In contrast to people who showed "tough love," individuals in other participants' lives fostered a desire for self-determination through their advice, support, or personal example. Some participant interacted with allies and family members who encouraged and nurtured their desire for self-determination. These people helped participants develop a sense
of pride and self-confidence which made it easier for them to figure out ways to address challenges to their independence as individuals with disabilities. Other participants had someone in their life who worked closely with them to develop their physical capabilities and figure out different procedural life hacks. A third group of participants had someone in their life who set a good example for them to follow and instilled a sense of pride and self-confidence in them.

The fourth section of this chapter looked at three socio-political realities many people with impairments identify with which not only shaped participant practices but also motivated them to life hack. This part of the analysis looked at life hacking in the face of paternalism, oppression, and ableism, whether embodied in the beliefs, attitudes, and actions of non-disabled members of society, institutionalized in disability-related policies and procedures, or codified in design artifacts and practices. Participants conveyed three different types of life hack-enabled reactions. The first one was a form of making-do which consisted of leveraging life hacks beyond the gaze of paternalistic family members and other people in participants’ social circle. Participants avoided life hacking related activities when others who were critical of their efforts could see them but engaged in them when those people could not see what they were doing. The second type of reaction was a defiant resistance to oppression imposed on participants by non-disabled people. It entailed life hacking for the express purpose of invalidating incorrect assumptions about their capabilities and worth as individuals with disabilities. The third reaction was circumventing ableist norms embodied in institutional and professional practices via life hacking. Participants matched attempts to either normalize them or make them unnecessarily dependent on others with self-regulated life hacking activity. They turned down social insurance and ignored professional guidance that cast them as inferior to non-disabled individuals, led them in ways that contradicted their best interests, limited their personal agency, or caused cognitive
dissonance because of the disconnect between embedded ableist assumptions and participants’ view of themselves.

The last section of this chapter revisits the term life hack and my decision to use it to refer to the phenomenon explored in this dissertation research study. In it, I compared some of the social and political aspects of participant life hacking to those of traditional hackers. Findings include parallels between participant activities and those of traditional hackers, including similar ways of using the Internet for social interaction purposes as well as the comparable political motivations behind their life hacking and hacker activities, respectively.

**Chapter 8: Discussion**

The goal of this final chapter is to discuss a few research, design, theoretical and practical implications of my findings. First, I compare participants’ life hacking activities to those described in the literature and discuss the implications of life hacking for researchers. In the next section, I describe areas of overlap between participant life hacking activities and research and design practices as well as lessons members of these communities can learn from extant life hacking content posted online by individuals with disabilities. In section three, I offer empirically-backed suggestions on how to ensure the perspectives, insights, and motivations of individuals with disabilities who engage in life hacking activity inform DIY-AT research. Section four offers empirically-backed user empowerment guidelines. User empowerment refers to the development of tools that empower individuals with disabilities to create and configure accessibility products to solve problems themselves (Glinert & York, 1992; Ladner, 2008). Section five explicates several areas of overlap between participant life hacking activity and

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39 HCI and accessibility literature, specifically
40 Disability/accessibility design, specifically
critical design as well as some ways the life hacking activities of individuals with disabilities could inform critical design research. In the next two sections, I talk about the practice theory implications of this study and provide a final justification for my use of the term life hack throughout this document. In the two concluding sections, I briefly summarize the limitations of this study, possible future research, and my conclusions.

**Implications of Life Hacking for HCI and Accessible Design Research**

Findings from this dissertation study include the identification of six different types of life hacking activities. Participant life hacks consisted of both artifact- and activity-oriented behaviors. User-centered design practitioners make usability and usefulness top priorities in their efforts (Dourish, 2004) and participants’ artifact-centered life hacking efforts similarly resulted in outcomes they could use in the context of their everyday practices. Artifact-centered life hacks had much in common with the joint production-consumption behaviors of prosumers (Xie et al., 2008) and the value creation activities of user innovators (von Hippel, 2005a). Participant innovation, modification, bricolage, and repair & maintenance life hacks involved many of the same activities that hobbyist-hackers and DIYers enjoy and that draw the attention of a growing number of HCI researchers (Dalton et al., 2014; Rosner, 2010; Rosner & Ryokai, 2010; Tanenbaum et al., 2013; Wang & Kaye, 2011). The activity-oriented life hacks participants described offer evidence of one type of adaptive activity that HCI/accessibility scholars and research on DIYers and hackers typically ignore. These efforts had much in common with the innovative ICT consumption activities that domestication scholars examine (Silverstone & Haddon, 1996). Admittedly, some accessibility scholars acknowledge the

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41 As stated in chapter two, a growing number of human-computer interaction researchers are beginning to adopt critical design approaches

42 I say “final” because I have made arguments for the use of this term in three of my results chapters
propensity of individuals with disabilities to develop unique ICT interaction methods (Anthony et al., 2013; Kane et al., 2009). Studies like these, however, typically pay more attention to adapted, modified, and homemade artifacts rather than unique ways of interacting with artifacts or accomplishing tasks.

The reason this dissertation research study uncovered activity-oriented procedural and object re-appropriation life hack categories is attributable to an intentional focus on practices rather than technology, dis/abled bodies, or other constituent elements of practice in isolation. Findings from this dissertation study suggest that accessibility researchers interested in learning from the adaptation experiences of individuals with disabilities as well as including their perspectives and insights in published research should look beyond artifact-centered and Maker-oriented activities. Although one person did engage in Maker-enabled life hacking activities, participants’ activities also included repairing, maintaining, combining, modifying, and uniquely leveraging existing artifacts in addition to creating new ones. The diverse life hacking activities participants described suggest the scope of accessibility research is currently too narrow and researchers should explore a wider range of adaptive behaviors that coincide with the daily life practices of individuals with disabilities. A slightly broader scope may lead to the discovery of new and insightful ways to design useful and useful artifacts, involve more individuals with disabilities in efforts to make and adapt technology, address practice barriers, and productively collaborate with others on design-related projects. Exploring the diverse adaptive activities of individuals with disabilities would also lead to insights grounded in the activities, perspectives, and lived experiences of individuals who live with disabilities as well as those of non-disabled researchers and DIY-AT stakeholders.

43 The Maker movement and Making are central pillars of DIY-AT
Accessibility/Disability Research Design and Participant Life Hacking Activity Overlap

Table 22 below highlights various aspects of accessibility/disability research design approaches present in participants’ life hacking activities. User-centered design approaches make artifact usability and usefulness top priorities and seek to create room for the needs and abilities of end-users to influence design (Dourish, 2004). Researchers or professional designers adopting a user-centered approach take the needs and capabilities of diverse users into consideration and sometimes involve users in the design and development process (Iivari & Iivari, 2006), although to different extents. Participant life hacking was user-centered in two ways. First, rather than designing according to the perceived needs of others, participants’ individual needs, abilities, and interests always drove their life hacking efforts. Life hacking reconciled mismatches between user capabilities and the physical demands of practice activities in ways that were unique yet productive. Participant life hacking entailed creating productive arrangements of impaired bodies, physical capabilities, objects, practice demands, and context grounded in their first-person understanding of these and other practice-constituting factors. Second, whether they worked independently or with assistance from someone else, participants always played an active role in life hacking efforts. Each participant’s specific capabilities, interests, level of independence, and interactions with others shaped his or her life hacking projects and the role he or she played in them. Whereas user-centered approaches acknowledge the value of including end-users in design activities but often fail to do so, life hacking always allowed the participant to play an engaged and meaningful role in addressing their accessibility and daily life concerns.

Aspects of specific user-centered design approaches championed by accessibility scholars also manifested themselves in study participants' life hacking activities. Some participatory design initiatives involve end-users in design practices, but only to the extent that involvement
allows designers to model use contexts and give all users equal to access and exercise control over their design outcome-enabled activities (Dourish, 2004). Assistive technology co-design makes AT end-users, their experiences, and their values the central focus of design activities through iterative design and engagement with intended end-users (De Couvreur et al., 2011; De Couvreur & Goossens, 2011). Accessibility researchers have involved individuals with disabilities in participatory co-design efforts, but most often as passive contributors or research subjects (Azenkot et al., 2011; Gollner et al., 2012; Moffatt et al., 2004). Specific participatory design and AT-Codesign initiatives embraced representative and proxy forms of end-user involvement where the researchers substituted individuals with disabilities with domain experts (Allen, Leung, et al., 2008) and caretakers (De Couvreur et al., 2011; De Couvreur & Goossens, 2011), respectively. Researchers and other non-disabled parties develop an understanding of context, end-user experiences, and end-user values through design prototype- and caregiver-mediated interactions with individuals with disabilities. Study participants, on the other hand, directed their own life hacking efforts while addressing these and other user-centered design concerns. Participants' direct experiences, perspectives, and understandings along with their individual or collaborative involvement in design-like activities both motivated and guided their life hacking projects.

Empathic design is another user-centered design approach used by accessibility researchers, and participants' life hacking activities mirrored some of its core considerations. Accessibility researchers who employ and advocate for empathic design work towards developing a personal understanding of the motivations, emotions, mental models, priorities, and struggles of end-users with disabilities and then partner with them during the information creation and design processes (McDonagh et al., 2009). The goal is to foster a deep
understanding of individuals with disabilities through collaborative partnerships with them. Researchers and non-disabled contributors develop this understanding using ethnographic research methods (as opposed to conversational ones) and through simulated disability experiences. Instead of playing passive roles in the research and design process, individuals with disabilities are invited to co-construct knowledge and co-design accessible technology (McDonagh et al., 2009).

Findings from this dissertation research study suggest that individuals with disabilities who possess the requisite knowledge, capabilities, and access to support, if needed, are already equipped to achieve empathic design goals by themselves or with support from people they know and trust. Participants in this dissertation research study possessed intimate knowledge of themselves and brought this knowledge to bear on life hacking projects birthed out of their motivations, interests, priorities, and struggles. Whether they worked alone or with others, participants engaged in life hacking activities in natural and emergent ways that prioritized their practice interests and goals. Participants and co-participants possessed accumulated knowledge and embodied know-how, which enabled their self-driven efforts. Additionally, co/participants/allies usually had a history of working together, and these cumulative experiences gave them the skill and know-how needed to fulfill their respective roles. Life hacking experiences combined with the interpersonal relationships undergirding collaborative efforts seemed to foster aspects of empathic design naturally.

The parallels between accessible design and participant life hacking suggest designers and researchers have a lot to learn from individuals with disabilities, contrary to deficit disability model assumptions. Participants possessed sticky forms of knowledge resulting from their

\[44\] Embodied know-how will be explained in a later section
embodied and sometimes collaborative involvement in all life hacking efforts as well as the practices that necessitate them. *Stickiness* refers to the incremental costs of transferring tacit knowledge about needs and use contexts from the user to producers or “problem solvers” in a usable form. When costs are high, stickiness is high. When costs are low, so is stickiness (von Hippel, 2005a). Non-disabled empathic designers effectively try to gain a second-hand understanding of the accumulated knowledge of end-users with disability through their engagements with them over a fixed amount of time. Individuals with disabilities and allies who have a history of addressing accessibility and everyday life issues possess this knowledge in a readily accessible form they can leverage immediately to address a situation.

Empathic design’s orientation towards developing a personal understanding and connection with end-user concerns is meant to help practitioners acknowledge and overcome the assumptions of traditional design practice and deficit disability models that undergird them. Nevertheless, it is a time and resource intensive approach to accessible design that is impractical for most design professionals. Co-/participant life hacking circumvents these limitations of empathic design while allowing the participant to reap the benefits of collaborative engagement in design–like activities with people who have naturally developed an understanding of their needs as well as a connection with them. Accessibility scholars wanting to use user-centered design approaches like empathic design should consider learning from exemplary adaptations-related collaborations like those described by co-/participants in this study. Studying collaborative life hacking activities involving individuals with disabilities may lead to insights that can inform empathic design collaborations that allow individuals with disabilities to make significant contribution to joint efforts.
### Table 22 - Accessibility/Disability Research Design Aspects of Life Hacking

<table>
<thead>
<tr>
<th>Approach</th>
<th>Primary Research/Design Focus</th>
<th>Life Hacking Parallels/Building Blocks</th>
<th>Life Hacking Particularities</th>
</tr>
</thead>
</table>
| User-Centered    | End-users and their needs, abilities, & preferences                                             | *Users influence design  
*Usability and usefulness are primary considerations                                               | *Foci of all accessibility/disability research design approaches are central to participant life hacking |
| Participatory     | Use context of all end-users                                                                  | *Potential to include IwDs in design activities                                                         | *Participants played active roles in individual or collaborative design-like and personal adaptive activities |
| AT-Co-Design      | Experiences & values of end-user(s)                                                            | *Makes IwDs/AT user the central focus of design project  
*Research/design activities can take place in everyday life environments                                   | *Participants brought their own understanding and experiential knowledge to bear on practice-related issues they encountered |
| Empathic          | Motivations, emotions, mental models, priorities, & struggles of end users                     | *Emphasizes need to respect and understand IwDs  
*Attempts to overcome ableist assumptions of non-disabled researchers  
*IwDs encouraged to play a collaborative and active role in design activities                             | *Assistance from co-participants/allies was often directed by the IwD rather than directed or forced on them by a third-party  
*Participants were the primary influencers, decision-makers, and initiators of efforts                  |

**Online life hacking-related content: Methods implications for HCI & accessibility researchers.**

Several participants in this dissertation research study talked about their online life hacking related activities. HCI scholars interested in hobbyist-hacking talk about the social interaction and information sharing activities that hobbyist-hackers engage in online (Buechley et al., 2009; Kuznetsov & Paulos, 2010; Wang & Kaye, 2011). DIY-AT advocates, on the other hand, have explored the potential of online communities to either enable non-professionals to engage in DIY-AT activity or provide needed support to individuals with disabilities who want to design and adapt assistive technology themselves (Hook et al., 2013; Hurst & Kane, 2013; Hurst & Tobias, 2011; Leduc-Mills et al., 2013). Both camps mostly ignore the online life hacking
content that participants in this study described, posted, and consumed. As demonstrated by Anthony et al. (2013), online platforms like YouTube can offer readily available user-generated content that can be analyzed to understand interface issues and identify user adaptations. Findings from this dissertation study not only confirm the availability of this content on multiple online platforms but also point to the potential of using it to understand design, disability, and empowerment from the perspectives of individuals with disabilities. These platforms afford consumer-driven constructions of disability that can inform the accessible design practices of non-disabled individuals.⁴⁵

Study findings also point to the similarities between non-disabled hobbyist hackers/DIYers and individuals with disabilities who life hack, which challenges the notion that individuals with disabilities do not possess the same capacities as non-disabled people. For instance, the tools Arnold developed to access Makerspace equipment might be useful to non-disabled makers and DIYers as well. Similarly, some participants described life hacking as a hobby they enjoyed. DIY-AT researchers could learn different ways to make equipment more useful in everyday practices by engaging individuals with disabilities who found ways to do so themselves. By examining existing online life hacking content posted by individuals with disabilities, the HCI community might learn ways to make interfaces and tools that not only empower individuals with disabilities on their terms but also provide utility to non-disabled individuals. User-generated content platforms like the ones mentioned by participants host readily available data that can inform these efforts. Additionally, using the content on these

⁴⁵ “Consumer-driven constructions of disability” has two different things here. First, I am referring to the everyday end-user/citizen/consumer perspectives and constructions of one’s self and the community he or she belongs to afforded by domestication, prosumption, DIY, hacking, and life hacking activities. Second, I am referring to disability knowledge originating from individuals who have one. Social model adherents assert that individuals with impairments can and should play a role shaping societal understandings of disability and technology rather than letting people with no direct experience with impairment control the disability narrative. Consumer-driven constructions of disability are based on the experiences and perspectives of individuals with disabilities rather than the assumptions of deficit disability models.
platforms as a data source would enable many researchers to understand issues that surround the use of artifacts from the perspectives of end-users while circumventing recruitment challenges.

**Life Hacking Implications and Accessible Design/DIY-AT**

**Meanings and motivations.**

Participants linked their life hacking activities to three stimuli: 1. practical goals such as dealing with accessibility issues and engaging in daily life practices; 2. external motivations such as the desire to prove people who doubted their capabilities wrong or avoid unwanted assistance from others; and 3. internal goals such as living a self-determined life as a person with a disability. Hackers motivations somewhat similarly include a shared belief in free and open access to technology, practical goals such as undermining systems of power and authority, and intrinsic factors such as the pleasure and sense of fulfillment they derive from their escapades with technology and otherwise mundane artifacts (Leeson & Coyne, 2005; Nissenbaum, 2004). Motivations that were specific to participant life hacking activities included closing practice demand-capability gaps, managing psychological aspects of living with a disability, overcoming various forms of dis/ableism, oppression, or paternalism, and fighting back against disabling elements of their practices, including other people who tried to limit participant engagement in those practices. Like hackers, participant motivations were multi-faceted and had social, political, and identity construction implications.

Overall, altruistic goals seem to motivate HCI/accessibility research, user-centered design, and DIY-AT activities. These goals include considering end-user needs and capabilities when either designing technology interfaces (Dourish, 2004) or making universally accessible and usable technology (Mace et al., 1990), empowering individuals with disabilities (Glinert & York, 1992; Ladner, 2008), and making DIY-AT activities more accessible to individuals with
disabilities (Hook et al., 2013; Hurst & Kane, 2013). Individual need, desires, preferences, personal interests, economic factors, and politics all factored into bottoms-up approaches as well as participants' life hacking activities. At the same time, DIYers’ desire for self-reliance and self-determination (Gauntlett, 2013) as well as hackers’ self-described intellectual curiosity with technology and desire to explore and experiment (Levy, 1984) were also reflected in participant accounts of their life hacking motivations.

Unlike most accessibility research, participant life hacking motivations offer insight into why individuals with disabilities might get involved in design-like projects. Finding from this study suggest researchers tend to focus exclusively on practical technology and impairment-related concerns while ignoring crucial disabling social, cultural, and psychological aspects of life with an impairment. HCI and accessibility scholars involved in research and design activities should further explore the motivations of individuals with disabilities who life hack. By gaining a better understanding of what drives some individuals with disabilities to engage in adaptive DIY-AT-like behaviors without their support, researchers can better align their efforts with the interests of their target audience. Table 23 below compares participant life hacking motivations to core domestication, end-user innovator, prosumer, DIYer, DIY-ATer, and hacker motivations.
Table 23 - Accessible Design, Consumption, DIY, DIY-AT, and Hacking Parallels with Life

Hacking Meanings & Motivations

<table>
<thead>
<tr>
<th>Paradigm/Approach</th>
<th>Meanings &amp; Motivations</th>
<th>Participant Life Hacking Parallels</th>
</tr>
</thead>
</table>
| UCD/UD            | •Design accessible artifacts/interfaces  
                      •Usability/usefulness  
                      •Bridging demand-capability practice gaps  
                      •More independence/personal freedom  
                      •Deal with accessibility issues  
                      •Participate in diverse hobbies/personal interests  
                      •Managing psychological aspects of living /w disability  
                      •Prove others wrong, avoid unwanted assistance  
                      •Save money  
                      •Manage ableism, disability oppression, and paternalism  
                      •React to and resist disabling practice elements |
| Domestication/Prosumption/E-U-I | •Individual desires, needs, and preferences  
                                     •Interests (hobbies)  
                                     •Reduce dependence on manufacturers, producers, and other third-parties |
| DIY               | •Hedonistic benefits  
                      •Personal, professional, political, material, etc. benefits;  
                      •Save time or money  
                      •Maximize utility |
| DIY-AT            | •Empower IwDs  
                      •Entertainment/"hedonistic" benefits |
| Hacking           | •Hacking as hobby  
                      •Intrinsic/collective interests (e.g., undermine systems and structures of authority)  
                      •Politics/ideology  
                      •Both external outcomes & intrinsic goals |

Embodied knowledge.

Knowledge and know-how represent elements of both user-centered and bottoms-up problem-solving/design approaches that also manifested in participants' life hacking activity descriptions. These two constructs, however, configured participant life hacks and related daily life practices in unique ways that would be difficult for the average non-disabled designer to fully understand or emulate. Previous embodied problem-solving, design, adaptation, and related experiences along with the knowledge actors accumulated as they engaged in those experiences contributed to their ability to engage in future life hacking projects. Past personal experience with technological artifacts and familiarity with their features and affordances similarly informed
future efforts. Watson & Shove (2005) analyzed the DIY projects of several UK consumers and discovered the same connection between experience and future competence. Dissertation study participants connected life hacking know-how to things that informed their efforts such as previous life hacking experience, aspects of their practice environments, awareness of artifact/environment features and affordances, and the services available to them.

Consumption research on do-it-yourself practices and projects say that practical knowledge and skill enable everyday consumers to bring commodities into relationships with each other and transform these ‘raw materials’ into something useful (Watson & Shove, 2005). Consumption researchers distinguish between knowledge that is embodied in human subjects and embedded in objects and they view DIY activities as a negotiation between the two (Watson & Shove, 2005). Study participants demonstrated know-how that allowed them to negotiate their embodied knowledge as well as the knowledge associated with social practices, their underlying activities, and constituent objects.

The combined contemporary practice theory/Latourian actor-network theory analytical framework which guided the analysis in chapter six of this dissertation uncovered an ignored yet meaningful source of design-related knowledge within the HCI and accessibility research communities: competence resulting from daily life practice entanglements involving impaired bodies. Competence refers to the combined embodied human and embedded object knowledge of actor-networks that enables action (Watson & Shove, 2008). In the Latourian sense, actor-networks engage in practices rather than a person alone. The glue that bonded together participants’ life hacking activities and their utilization of life hacks in practice contexts was their intimate knowledge of the demands practices placed on the body, their bodies (including their actual physical capabilities), and existing or adapted artifacts. This glue consisted of embedded
knowledge and embodied know-how when it comes to closing demand-capability gaps in ways that fit the context and all involved actors. Participants’ embodied know-how is the epitome of highly sticky information with design relevance.\textsuperscript{46} This embodied know-how did not exist in a vacuum. It was a product of participants’ cumulative lived experiences with a disability, actor-network practice entanglements, and embodied interactions with objects, environments, and other individuals. No matter how sophisticated a participant’s life hacks was, he or she possessed a unique and individualized knowledge that contributed to his or her effort to devise, make, and productively utilize it. This form of knowledge allowed them to understand highly contextualized aspects of their daily lives and personal practices as well as act to productively configure practices.

Forlano (2016) talked about her embodied experiences hacking the complex socio-technical network of technologies she uses as a person with diabetes. Her research draws on the work of feminist theorists who place a high value on embodied and highly contextualized ways of knowing and making sense out of lived experience (Forlano, 2016). This dissertation research study similarly offers insight into how the embodied knowledge and experiences of participants informed both life hacking efforts and related in-situ practice activities. Although the formal and practical knowledge possessed by non-disabled design stakeholders often leads to useful and usable artifacts that positively impact the lives of many individuals with disabilities, this study suggests the embodied knowledge possessed by individuals with disabilities who engage in life hacking activity also has design value.\textsuperscript{47}

\textsuperscript{46} von Hippel (2005a) used the term information stickiness to refer to the incremental costs of transferring tacit information about needs and use contexts from the user to producers or “problem solvers” in a usable form. When costs are high, stickiness is high. When costs are low, so is stickiness.

\textsuperscript{47} Non-disabled design stakeholder knowledge refers to the research and design capabilities of professionals in the assistive technology and rehabilitation technology industries as well as HCI and accessibility researchers.
Designing, addressing an issue, or solving a problem for someone with a disability is subject to a limitation that life hacking by individuals with disabilities is not: the disconnect between design/problem-solving knowledge and embodied know-how grounded in lived experience with physical impairment. Design and problem-solving knowledge disconnected from this embodied know-how both motivated participants to life hack and enabled them to figure out individualized ways to productively configure daily life practices. Researchers and designers who want to create more usable and useful accessible technologies or tools should consider tapping into the knowledge and insights of the eventual end-users. Examining the life hacks and related enabled-practices of individuals with disabilities offers insights into how embodied knowledge co-configures practices along with design artifacts and other elements of practice.

**Guidelines for User Empowerment Grounded in Self-Empowerment Efforts**

In recent years, HCI and accessibility scholars have directed more of their attention and efforts towards user empowerment. Most DIY-AT studies pay more attention to HCI researchers designing accessible Maker tools for individuals with disabilities and getting non-disabled non-professionals involved in DIY-AT projects than enabling individuals with disabilities to address the issues they face. Additionally, three assumptions undergird the idea of user empowerment in these studies. First, researchers assume empowerment can be boiled down to either granting individuals with disabilities access to technology or giving them the opportunity to participate in a pre-determined type of design-like activity. In doing so, they ignore the link between empowerment and the freedom to act according to personal interests and priorities (Meissner et al., 2017). Second, researchers do not sufficiently acknowledge or value the difference between

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48 User empowerment refers to the development of tools that empower individuals with disabilities to create and configure accessibility products to solve problems themselves (Glinert & York, 1992; Ladner, 2008)

49 DIY-AT refers to the creation and adaptation of assistive technology by non-professionals, including people with disabilities and their families, friends, and caregivers emerging technology (Buehler, Hurst, & Hofmann, 2014; Hook, Verbaan, Wright, & Olivier, 2013; Hurst & Tobias, 2011).
developing something an individual with a disability will use in a very particular practice context and individuals with disabilities participating in activities and practices in ways that make them feel empowered. Third, user empowerment is grounded in traditional conceptualizations of empowerment where one party must create opportunities and provide the means for another party to participate in an activity (Meissner et al., 2017). In other words, HCI researchers presume classes of empowered and disempowered individuals based on impairment status and legitimize their work by claiming its goal is to empower the disempowered (Meissner et al., 2017).

The life hacking activities and related everyday practices of participants revealed two lessons HCI and accessible design communities should incorporate into their empowerment initiatives. First, empowerment is subjective and specific to the individual and his or her practice engagements. In their efforts to get individuals with disabilities actively involved in making for accessibility purposes, past researchers found that participant DIY-AT projects could be linked to three subjective experiences of empowerment: 1. Increased personal autonomy; 2. The ability to enable other individuals with disabilities; and 3. Demonstrating newly learned making skill (Meissner et al., 2017). Participants in this dissertation study also linked empowerment to their personal agendas rather than products and services. Participants leveraged life hacks to gain independence, achieve self-actualization, control personal destiny, maintain economic independence, overcome social or psychological aspects of living with a disability, enjoy recreational and entertainment activities, and undermine efforts to control the way they lived. Participants derived benefit from items they could exploit to both engage in practice activities and live life on their terms. Findings suggest HCI and accessibility researchers and designers as

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50 I will discuss specific control mechanisms and different participant responses to them in a later section.
As well as and DIY-AT advocates should design flexible and adaptable artifacts that can both serve as life hacking inputs and create room for individuals with disabilities to leverage them for subjectively-determined ends. Rather than linking empowerment to design or Maker-like activities only, researchers and designers should consider the various ways individuals with disabilities uniquely configure their practices and thus empower themselves as well as the meanings and motivations behind these efforts. They should avoid pre-determining how individuals with disabilities should use design outcomes and what contributions they can and cannot make to design-like projects. Instead, they should focus on enabling individuals with disabilities to exploit technology and other design artifacts for self-determined ends within the context of their daily lives and constituent practices.

The second finding that HCI and accessibility researchers should take heed of is that adaptation/design-like assistance does not empower by default. Study participants who received life hacking and practice assistance from spouses, caregivers, fabricators, and even strangers had similar perspectives on empowering versus disempowering assistance. They did not value assistance that was uninformed or under-informed by their perspectives and insights. They did, however, value assistance that was complementary to their capabilities, knowledge, experiences, and goals and enabled them to configure practice activities in productive ways. Interestingly, participants who valued the life hacking and practice-related assistance they received from others did not distinguish their contributions to these collaborative efforts from those of the people who helped them unless I specifically asked them to do so. This finding suggests collaborative efforts that treat individuals with disabilities as equal to non-disabled stakeholders and allow them to contribute in diverse ways are more likely to empower. Just like the participants in this study, individuals with disabilities who have opportunities to impact design-like activities and feel like...
their perspectives and interest matter may see themselves as contributors even if they cannot do the physical labor the underlying activities require.

Non-disabled researchers, designers, or others who have a genuine interest in helping, supporting, and empowering individuals with disabilities should avoid making assumptions about their desires, needs, and capabilities. Granted, this is easier said than done since these three things vary by individual and it is impractical for researchers and designers to talk to or engage every member of the disability community. Nevertheless, an initiative like DIY-AT that involves both non-disabled non-professionals and individuals with disabilities should consider the nature of interactions between these parties because it can make a difference in ensuring contributors with disabilities feel empowered. Findings from this study suggest that in addition to getting involved in the physical labor of design-like activities, individuals with disabilities may feel empowered by assistance from people who listen to them, consider their perspectives, and allow them to inform the collective effort. Participant accounts of the type of life hacking assistance they valued most suggest empathic design values are ideal for collaborative empowerment efforts. These values include respectful curiosity, deep understanding, the suspension of judgment, and giving individuals with disabilities the opportunity to co-construct knowledge with non-disabled stakeholders (McDonagh et al., 2009; McDonagh & Thomas, 2010; Strickfaden & Devlieger, 2011a).

Collectively, the results chapters in this document explicate several linkages between practice engagement and life hacking. Participants life hacked to realize self-determined practice goals and interests including engaging in sports and recreational activities, hobbies, and personal interests that people may not associate with having a disability as well as enjoying a life free from the control of others. Life hacking represented participant created matches between the
circumstances and demands associated with living with a disability and their embodied knowledge, local circumstances, personal capabilities, goals, and interests. It afforded self-determined practice selection and configuration by the same individuals who live with impairment and engage in the chosen practices. Some participants’ ways of engaging in practices challenged ableist assumptions about what individuals with disabilities can do, what “normal” practice activity looks like, and who should make consumption, health, safety, and other decisions for individuals who have physical impairments. For several participants, their life hack-enabled ability to engage in practices others considered off limits to them because of their impairments was empowering to them. For them, the accomplishment of practice-specific goals and the pursuit of personal interests led to a sense of self-determination and autonomy. Non-disabled contributors to DIY-AT, accessible design, and similar projects must be aware that for some individuals with disabilities, empowerment may mean challenging norms and figuring out a way to do the same things non-disabled people can do. Due diligence is needed to ensure the interests and goals of individuals with disabilities undergird empowerment efforts rather than ableist assumptions about what disabled bodies can do relative to non-disabled ones. Perhaps one way forward is to follow disability studies scholar Mike Oliver’s call for emancipatory research that seeks to facilitate the empowerment process for individuals with disabilities once they have decided to empower themselves (Oliver, 1992). This would involve putting the knowledge and skills that researchers possess at the disposal of individuals with disabilities and letting them decide how they should be used for self-empowerment purposes (Oliver, 1992). Interestingly, study participant and ally life hacking collaborations mirrored the emancipatory research dynamic articulated by Oliver.
Aspects of Critical HCI Design Found in Participant Life Hacking Activity

Table 24 below highlights aspects of HCI critical design research approaches reflected in participants’ life hacking activities. Several scholars in the HCI community have begun adopting critical stances and methods to examine design practices and outcomes. So far, researchers have paid little attention to the applicability of critical making, critical design, postcolonial computing, and values-oriented design research approaches to accessible design practices and outcomes. These approaches could potentially afford new and nuanced insights about the social construction of disability (Goggin & Newell, 2007) and various politics involved in the practice of design (DiSalvo, 2014; Goggin & Newell, 2007; Ratto, 2011a; Ratto & Boler, 2014).

Critical making explores the links between "scholarly research on critical social issues and design methodologies" with the purpose of "furthering critical knowledge through joint material production" (Ratto, 2011b, p. 252). It involves identifying concepts, theories, and ideas that can be materialized and explored through physical prototypes, collaborative prototype design with diverse stakeholders, and iterative prototype reconfigurations, discussion, and reflection (Ratto, 2011b). These activities lend themselves to individuals with disabilities actively participating in the co-construction of design artifacts and co-determination of their form, function, use, and underlying values. Critical design, somewhat relatedly, leverages design artifacts to spur critical reflection on daily life and the assumptions, values, ideologies, and behavioral norms embedded in design artifacts that mediate people's lives (Bardzell & Bardzell, 2013). A core tenant of critical design is that design practices and outcomes can be appropriated to challenge and critique ideologies such as capitalism and the expectations it places on people (Dunne & Raby, 2001). Critical design researchers attempt to work with potential design end-users to both interrogate existing design and point to possible alternatives undergirded by different assumptions.
Although there are few exemplars currently, critical accessibility making and design could both engage individuals with disabilities in design-related conversation and give voice to accessible design consumers whose perspectives and insights about disability and design often do not significantly factor into accessible design practices. Engagement should consider the past and present self-directed life hacking activities of individuals with disabilities. Through design, manufacturing, marketing, and similar activities taken-for-granted assumptions about what constitutes “normal” that privilege non-disables bodies and ways of doing things get reified in technology (Foley & Ferri, 2012). Participant life hacking not only challenged these taken-for-granted assumptions but also resolved many of the conflicts they created for participants. By examining the life hacking efforts of individuals with disabilities, critical design researchers will discover the alternative design futures these individuals conceptualize and implement in response to the taken-for-granted assumptions in design.

Post-colonial computing is not a specific critical design research method or practice but rather a sensitivity to the cross-cultural power dynamics involved in design practices. Post-colonial computing represents a response to the uneven balance of power, wealth, economic strength, and political influence which marked global colonial relationships in the past and continue to shape geopolitics to this day (Irani et al., 2010). The goal of post-colonial computing is context sensitivity and inclusive interpretations of cultural-technical phenomena (Philip et al., 2010). The cultural and power dynamics that post-colonial computing pays explicit attention to similarly undergirds accessible design projects where non-disabled researchers, designers or others make and adapt things for individuals with disabilities, often based on their assumptions and positionality as members of a predominantly non-disabled culture. In contrast to post-colonial computing, value-oriented perspectives acknowledge that design is not a neutral practice
but rather a value-laden one (JafariNaimi et al., 2015; Shilton, 2017). Values-oriented approaches acknowledge that values not only shape decisions made before, during, and after the design process but also influence end-use in ways that are sometimes less than ideal. Researchers adopting values-oriented approaches could potentially integrate the perspectives of individuals with disabilities into accessibility/disability design processes and help ensure that design outcomes reflect end-user values instead of ableist ideas and assumptions. Examining the self-directed life hacking activities of individuals with disabilities represent one way to identify alternative values-in-design from the perspective of individuals who live with impairments and already act according to their values rather than those of researchers, designers, manufacturers, and disability service providers.

Critical HCI design research approaches focus on societal norms, politics, assumptions, values, and critical aspects of design processes. These approaches involve researcher-led co-engagement in design-like activities and discussions with people who are not researchers or designers. The goal of these approaches is to foster critical reflection about the process and outcomes of design, the cross-cultural politics involved in design activity, and the value-laden nature of design. Interestingly, aspects of participants' local individually-focused life hacking activities and related social interactions were comparable to the goals and interests of HCI critical research design approaches. Like Forlano's (2016) work, participant life hacking activity demonstrated different aspects of what a critical accessibility design research projects might look like and uncover.\(^{51}\) Unlike most values-oriented, critical making, and critical design projects, life

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\(^{51}\) The auto-ethnographic study conducted by Forlano (2016) mentioned earlier identified alternative design futures she identified as a person living with diabetes navigating her embodied experiences managing the complex socio-technical network of technologies for people with her condition. Her research describes various ways she creatively managed medical technology designed, manufactured, and marketed by people operating under assumptions that contradicted the way she wanted to live as a person with her condition. For research purposes, she intentionally adopted sensitivities to adaptation-related concerns and activities which, interestingly, several participants in this study did unconsciously as well.
hacking took place in participants' natural environment. Their efforts were not intentionally critical or carried out to discover new knowledge. Life hacking had practical value, and yet the same issues critical HCI design researchers examine circumscribed life hacking efforts across participants. Instead of adopting a critical lens or designing artifacts that foster critical discussion yet have little practical value in their daily lives, participants actively addressed the same social, political, and material issues HCI scholars adopting critical approaches seek to understand. Participants engaged in adaptive behaviors guided by their interests, assumptions, values, insights, knowledge, and abilities rather than those of researchers or designers. Participants also determined design form, function, and values for themselves and thus ensured life hacking outcomes would lead to practice engagements they found meaningful. Several participants not only shared political aspects of disability and design but also framed their life hacks as reactions to these issues.

Findings from this study suggest HCI community interest in critical design approaches should not only look at existing top-down disability/accessibility design methods and rely on researcher-driven projects but also explore consumer-driven design-like activities that happen in the everyday lives of individuals with disabilities and do not involve researchers. Although critical methods and lenses have their place, results from this study suggest the issues HCI researchers adopting them find most interesting are manifest in the life hacking activities of individuals with disabilities. Critical analysis of the self-directed life hacking activities of individuals with disabilities and the issues circumscribing their activities may lead to new knowledge about the relationship between values, societal norms, culture, and design as well as material and conceptual aspects of design and disability.

52 Consumer-driven includes domestication, prosumption, DIY, and hacking
<table>
<thead>
<tr>
<th>Approach</th>
<th>Primary Research/Design Focus</th>
<th>Life Hacking Parallels/Building Blocks</th>
<th>Life Hacking Particularities</th>
</tr>
</thead>
</table>
| Critical Making     | Societal norms embedded in design during design process                                        | *Affords analyses of politics of design/design artifacts  
*Anyone can participate in the collaborative materially-mediated design activities involved in critical making  
*Asserts end-users should determine design form, function, use, and values  
*Participant life hack based on their interests, assumptions, values, insights, knowledge, and abilities rather than those of researchers, designers, or others  
*Participants' life hacks allowed them to play active roles in determining design, form, function, use, and values without assistance from researchers using a variety of different artifacts and techniques  
*Through life hacking and enabled practices, participants actively demonstrate ability and self-determination, resist disability oppression, and circumvent ableism and its disabling effects  
*Some participants used online platforms to discuss offline life hacking activities as well as issues and concerns that are unique to HCI design research perspectives |                                                                                                                                                                                                                                                                  |
| Critical Design     | Design-enabled engagement intended to inspire critical reflection on material and conceptual aspects of design | *Affords critical analysis and critique of material and conceptual aspects of design  
*Seeks to challenge status quo when it comes to design and constructions of end-users  
*Helps identify alternative design approaches/outcomes undergirded by session participant ideas/assumptions                                                                                                                                 |                                                                                                                                                                                                                                                                  |
| Postcolonial Computing | Cross-cultural politics of design practices                                                   | *Values contextual, cultural, and historical sensitivity  
*Seeks to neutralize power dynamics that typically structure design  
*Privileges alternative cultural understandings                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                  |
| Values-Oriented Design | Value-laden nature of design as a practice                                                   | *Assumes values are codified in design and impact/configure use  
*Seeks to incorporate end-user values and viewpoints into design process  
*Seeks to make link between values and design practices transparent  
*Seeks to align user and designer values                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                  |
**Theoretical Implications of Participant Life Hacking**

Within the disability studies research community, the medical model and social model of disability represent different approaches to addressing disability issues.\(^{53}\) \(^{54}\) The medical and social models focus on impairment and politics, respectively. HCI and accessibility research too often consists of non-disabled researchers conducting accessibility/disability design projects intended to benefit individuals with disabilities, which is problematic since the HCI and accessible design research communities tend to view disability through deficit disability model lenses and their personal perspectives as mostly non-disabled individuals. Deficit models frame individuals with disabilities as a homogenous group dependent on others to make interventions that will cure disability or manage the effects of it (Rieser, 2006). Proponents of the social model assert that individuals with disabilities have a right to influence practices and decisions affecting their lives. Unfortunately, deficit models are prevalent in accessibility research and practice because individuals with disabilities and their perspectives rarely factor into the underlying activities in meaningful ways.

Despite the apparent differences between the deficit and social models, they have two things in common. First, both confer authority to control the disability narrative, albeit to different parties. Second, both oversimplify disability and inadequately account for the perceptions and experiences of individuals who have them. Disability is not static and one-dimensional like disability models suggest but rather the product of dis/enabling networked

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\(^{53}\) The medical model equates disability to impairment and attributes qualities such as incapacity, deficiency, and dependency to individuals with disabilities (Fulcher, 1989; Goggin & Newell, 2003). The medical model not only individualizes the problem of disability by blaming it on the individual but also over-medicalizes it by ignoring non-impairment issues that create difficulties for individuals with disabilities (Rieser, 2006; Shakespeare, 2006).

\(^{54}\) According to the social model, disability is not an individualized problem but rather a socially constructed one that makes impairment its foundation (Mercer, 2002). Disability is not a state or characteristic of a person but rather an event that occurs whenever someone who has an impairment encounters physical, social, or other barriers that limit their access to the same opportunities as a non-disabled person (Goggin, 2009; Rieser, 2006).
entities. Scholars from diverse fields such as sociology and thematic studies have advocated for the use of Science and Technology Studies (STS) as an alternative theoretical lens to examine disability issues and a way to include individuals with disabilities in the conversation about social phenomena. These scholars frame disability as dynamically determined by the interactions among embodied humans as well as non-human entities (objects), places, ideas, and realities that constitute social practices (Galis, 2011; Schillmeier, 2010). They argue that the best way to bridge body versus society and materiality versus culture divides that are characteristic of modern disability models is to link the embodied disability experience to socio-material practice configurations (Galis, 2011).

The analysis presented in chapter six of this dissertation study adopts the practice theory and STS sensibilities that Galis and Schillmeier recommend. Like other research that examines disability issues through the lens of actor-network theory, findings from this dissertation study suggest that dis/ability is not a state attributable to a person, technology, socio-cultural factors, or a combination of these things. Instead, it is the result of networked associations among multiple heterogeneous entities (Galis, 2011; Moser, 2006; Moser & Law, 1999; Schillmeier, 2010). Participant life hacks configured practice actor-networks in ways that enabled engagement in the underlying social practice activities. Life hacks bridged practice-demand/human-agent-capability gaps which disabled participants in the context of everyday social practices. Specific social practice activity demands reflected in participant accounts included transporting someone or something, moving or relaxing the body, simultaneously dealing with stairs and carrying something, manipulating objects, and using body parts affected by impairment. Participants who engaged in practices that demanded these activities often did not possess the requisite physical
capabilities needed to perform them. As a result, they faced demand-capability gaps which disabled them in practice contexts.

Heterogeneous actor-networks consisting of the human body (or bodies), design artifact, life hack outcomes, and the physical environment closed demand-capability gaps in several different ways. One gap closure method allowed the human actor to offload some of the demands a given practice places on all practitioner bodies onto objects and things in the immediate environment. A second and third method consisted of allowing the features and affordances of objects to serve as prostheses that replaced or supplemented, respectively, the physical capabilities of a human actor engaging in practice activities. Both prostheses methods freed participants up to use the functional capabilities they had rather than forcing them to leverage capabilities they did not possess. A fourth strategy involved employing unique action-oriented life hacks that allowed the actor-network to productively exploit the features and affordances of the non-human actor. The fifth and final method consisted of the human agent interfacing with the environment and available affordances contained within it using his or her developed/preferred ways of moving and using his or her impaired body.

Rather than linking disability to design, knowledge-production activities, impairment, technology, and social factors in isolation, this study unpacked local engineering activities that allowed participants to realize agency as actors in heterogeneous human-non-human networks. Their activities suggest design artifacts do not possess inherent standalone value or serve one pre-defined purpose. Instead, the degree to which artifacts enabled the configuration of networked practices in ways individuals with disabilities deemed productive and meaningful determined their purpose and value. Participants’ life hack-enabled ways of closing practice demand-capability gaps, forming productive actor-networks, and making daily life practice
activities accessible were grounded in their embodied experiences rather than the perspectives, knowledge, and interests of primarily non-disabled researchers and designers. Participant and co-participant/ally first-hand awareness of demand-capability gaps, previous life hacking experience, and ways of wanting and desiring all played a role in enabling participants to devise life hacks and productively leverage them in the context of their practices. Finally, participant dis/abilities were neither one-dimensional and static nor rendered them passive and needy.

Looking at life hacking through the lens of practice theory and Latourian actor-network theory suggests that dis/ability is the product of practice configurations and actor-network-enabled ability to shift these configurations in ways that afford the overtaking of all practice element.

This dissertation illustrated the value in examining the existing design-like activities of individuals with disabilities as well as the different ways non-/impairment, non-/technological, non-/human and various other dualities simultaneously constitute and are constituted by design and daily life practices. The analytical sensitivities adopted in this study afforded an examination of the role impairment, politics, and technology/objects collectively played in creating as well as resolving the demand-capability gaps which disabled participants in their practices. The disability studies, HCI, and accessible design research communities could use a similar combined practice theory/Latourian ANT framework to overcome current accessible design and disability model limitations. Such analyses would lead to the identification of alternative disability constructions that reflect individual lived experiences with impairment and nuanced understandings of how different aspects of disability, design, and everyday life collectively dis/able people with impairments in their daily lives.
The Case for Life Hacking: Responding to Controlled Interactivity

Several participants talked about life hacking in the context of a struggle with other parties. More specifically, life hacking enabled these participants to respond to and manage attempts to control him or her, other members of the disability community, or the disability narrative. Control mechanisms resulted from assumptions about the capabilities, interests, and desires of individuals with disabilities and they often limited the participant and other individuals with physical impairments in their daily lives. One control mechanism mentioned by participants was assumptions and ableist capability expectations embedded in design artifacts, services, and some non-disabled people’s efforts to help individuals with disabilities generally, or a participant directly. Another consisted of products with features, functions, and affordances or professional guidance that configured participant everyday practice activities in unproductive or undesirable ways. Some life hacks allowed participants to manage control mechanisms so they could engage in recreational practices that demand the use of inaccessible artifacts, use durable medical equipment for alternative or multiple parallel purposes, engage in practices in individualized unique ways, and live life on their terms rather than someone else's.

The control mechanisms participants referred to in their accounts of when and why they life hacked manifested themselves in different forms. Some were embedded in design artifacts and attached to services and support participants received from non-disabled people. Control mechanisms in the form of guidance from non-disabled people participants encountered who devalued them as individuals either forced them to conform to ableist norms or discouraged them from engaging in adaptive behaviors. In some instances, control took the form of outright paternalism, disability oppression, and patronizing forms of assistance.
Design is a human activity, and humans make assumptions. As a result, research and design projects led by non-disabled people can perpetuate the underlying assumptions of deficit disability models. The chances of this happening are high when non-disabled stakeholders make decisions that are uninformed or under-informed by the lived experiences of individuals with disabilities. Even when stakeholders attempt to include individuals with disabilities in design projects, their efforts can still have adverse downstream impacts. When designers and decision-makers are non-disabled, have access to the means of production, and stand to gain from their efforts to help members of the disability community, there is always a possibility they will subordinate the interests and perspectives of individuals with disabilities to their own. As the following excerpt from the book The Disability Business: Rehabilitation in America suggests, some professionals have a vested interest in maintaining control over the disability narrative for the sake of their self-interest:

The multiple stakeholders in the disability business have their own interests. Human services agencies and industries rely on the construction and maintenance of such social problems as disability to keep them in business, for without recognized and defined social problems, human service agencies would have no reason to exist (Albrecht, 1992, p. 69). To be fair, researchers and assistive/rehabilitation technology professionals have good intentions. For example, HCI/accessibility communities direct their efforts towards considering end-user needs and capabilities throughout the design process (Dourish, 2004). Universal design initiatives seek to design products and environments that are universally accessible and usable (Mace et al., 1990). A primary goal of assistive technology research and design communities is to help increase, maintain, and improve the functional capabilities of individuals with disabilities (Alper & Raharinirina, 2006). Finally, a primary goal of the rehabilitation technology industry includes making individuals with impairments able to function to the highest degree physically, socially, and psychologically possible (Albrecht, 1992). Despite these and other noble intentions
that guide researchers and professional designers, control mechanism grounded in ableist assumptions that are either embedded in design artifacts or attached to services and support provided to individuals with disabilities sometimes exclude, isolate, and limit them in their daily lives (Foley & Ferri, 2012). It was against the backdrop of the different control mechanisms mentioned above that the term *life hack* seemed to capture participants’ design, adaption, and problem-solving efforts accurately.

Participant descriptions of their adaptation, problem-solving, and design-like activities as well as the control mechanisms that motivated them to do so were local hacker-like responses to *controlled interactivity*. According to Stromer-Galley (2014), when an entity engages in controlled interactivity it projects the image that something empowers and gives agency to consumers while concurrently structuring the use of it in ways that advance the interests of that entity. Controlled interactivity was fundamental to President Barack Obama's 2008 presidential election campaign's online communication strategy. While visibly advocating for both citizen agency in change efforts and digital communication technology-facilitated grassroots mobilization, the Obama campaign leveraged the use of these technologies by supporters to advance its messaging strategy (Stromer-Galley, 2014). Similarly, although accessibility researchers, accessible technology designers, disability service providers, and non-disabled people participants interacted with offered products, services, help, and guidance to them, their efforts often structured participant practices in ways that did not always match their goals and interests. Non-disabled HCI, AT, and RT stakeholders can structure the practices of individuals with disabilities in ways that grant them the authority to perpetually address disability issues without taking heed to many of the downstream effects of their efforts while reaping benefits.
from doing so (Albrecht, 1992; Albrecht & Bury, 2001). Life hacking allowed participants to either circumvent or overcome the impact of these imbalances in their daily lives.

One of the tenets of the hacker code is mistrust of centralized authority and bureaucracies. Many computer hackers directed their efforts towards systems of authority and control that limited people's access to technology or prevented them from using it in individually-determined ways (Jordan & Taylor, 1998; Leeson & Coyne, 2005; Nissenbaum, 2004). For them, hacking was a way to undermine bureaucracies and centralized authority by exploiting technologies or other artifacts, their features and affordances, and the rules and social norms associated with their use, which collectively served as control mechanisms. Participants in this study described several activities that enabled them to do the same thing. These activities included de Certeau's concept of "making-do" and tactical consumption as well as the outright rejection of ableism, paternalism, and uninformed assumptions coupled with self-determined and at times, clandestine engagement in practices.55 56

In the same way that hackers leverage technology to undermine systems of authority and attempts to control technology users, participants “made-do”, leveraged products for individually-determined purposes, and resisted attempts to define and patronize them in response to the control mechanisms mentioned earlier. While hacker activities circumvented and undermined attempts to limit how people use computers, networks, and various technologies, participant life hacks allowed them to circumvent and undermine mechanisms that placed limits on their embodied daily life practices. The term life hack acknowledges the parallels between hacker and participant motivations and activities while emphasizing the inextricable link

55 Making-do refers to artfully (re)-using the outputs of production beyond the purview of the owners of the systems of production (de Certeau, 1984).
56 Tactical consumption consists of using professionally-designed artifacts and consumer products as inputs into consumer-driven problem-solving and design-like projects.
between these activities and participants' embodied lived experiences as individuals with disabilities.

**Study Limitations**

As with all research, this dissertation study had several limitations. The most significant one was my inability to directly access the perspectives and insights of researchers, designers, manufacturers, service providers, and various other people who factored into participants' life hacking efforts. It is relatively safe to assume that most HCI/accessibility researchers and AT/RT designers are non-disabled based on work of scholars cited throughout this dissertation.

Participants usually offered insights into the people in their lives who influenced them or their life hacking efforts and the nature of their interactions with these people. Nevertheless, I did not talk to researchers, designers, or most of the people participants mentioned directly. I only spoke to one person who assisted a participant with her life hacking activities. In chapters five and seven, I talk about the people participants linked to their life hacking activities and their openness to participants’ perspectives and insights using generalities. I tried to avoid attributing intent directly to these individuals as much as possible. Although at times I used published research and participant comments to talk about the influence of co-participants, allies, and other people as well as the potential motivations behind them, I avoided making absolute claims about their intentions unless a participant said something to justify it.

Another limitation of this study was my inability to directly observe participant life hacking and related daily life practice activities. Although my goal was to understand how participants address accessibility and related issues in the context of their daily lives, I could not identify a non-obtrusive way to observe this behavior. Life hacking activity usually emerges as participants encounter situations necessitating them. Asking people to devise a life hack on the
spot or re-enact past life hacking experiences would have placed an undue burden on them and likely de-motivated people from participating in the study. Therefore, the primary basis for the findings in this study is participant accounts of their past life hacking activities and related daily life practices. Obviously, accounts of past experiences may be incomplete or not entirely accurate since human memory is not always complete or accurate. Additionally, verbal accounts of practices do not convey all the details about how people perform and experience them or the different ways of knowing that constitute them (Pink, 2012). I could not confirm what participants said about the nature of their life hacking activity and related daily life practices since unobtrusive direct observation was not an option. Nevertheless, participant accounts made it possible to explore certain aspects of life hack-enabled practices that would be impossible to uncover via direct observation such as demand-capability gaps as well as the life hack meanings, motivations, and social dynamics.

My recruitment methods allowed me to include people in the study who had speech impediments or just did not want to talk via video chat or phone. Nevertheless, participant accounts obtained via instant messenger-facilitated interviews often lacked the depth and richness of interviews conducted using alternative channels and therefore did not inform the results as much as non-IM interviews. Additionally, the number of participants who used YouTube, Facebook, and online forums for life hacking-related purposes was mostly attributable to my choice to recruit individuals with disabilities who posted life hacking-related content on these platforms in the past.

As described in chapter three, I ran into some issues with the recruitment questionnaire used to screen potential participants. Several people who initially expressed interest in the

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57 Feedback from a kind and thoughtful questionnaire respondent helped me to realize people did not always connect with the language I used in the recruitment questionnaire to refer to the phenomenon.
study either did not complete the questionnaire or did not respond to my follow-up email once I sent a link to the questionnaire to them. In my attempt to avoid defining the phenomenon up front, I made it difficult for respondents to understand my intentions and link their activities to the phenomenon as described. These issues likely discouraged some otherwise eligible individuals with disabilities from participating in the study. I eventually revised the questionnaire after losing contact with several people who initially expressed enthusiastic interest in the study. It is possible that my results would have been different if many of the eligible individuals who did not complete the questionnaire or respond to my follow-up message would have participated.

This dissertation research study included individuals with mobility and dexterity impairments due to cerebral palsy, quadriplegia, paraplegia, arthrogryposis, multiple sclerosis, common variable immunodeficiency, and stroke. There are several other disabilities with associated mobility and dexterity impairments that are not represented such as Parkinson’s disease, spina bifida, and muscular dystrophy. The results of this study are specific to those who participated and their representative disabilities and physical impairments. Findings are not representative of the disability community or subgroups within it. The actual population of individuals with mobility or dexterity impairments includes people who engage in life hacking activities more and less frequently than study participants as well as people who do not engage in any life hacking activities. It also includes individuals with disabilities who are more and less independent than the people who participated in this study. Participants in this study do not represent all individuals with mobility and dexterity impairments who have a history of life hacking. There may be individuals with the same disabilities and impairments as my participants who engage in similar activities without realizing it or may be less inclined to talk about their activities. The participants in my study were 16 individuals with unique experiences,
perspectives, goals, and backgrounds who happen to have disabilities. As individuals with disabilities who engage in life hacking activities, study participants belong to a sub-segment of the disability community that HCI, accessibility, AT, and RT communities mostly ignore. Nevertheless, it would be shortsighted and irresponsible to assume their experiences, perspectives, and capabilities are representative of other individuals with disabilities who engage in similar activities. Additional research is needed to confirm whether other individuals with disabilities who engage in life hacking activities share similar perspectives and experiences.

Future Research

In chapter seven, I described many of the online platforms participants used for life hacking-related purposes and how they used them. Several participants used YouTube to share and find life hacking-related content. I have reviewed their channels and several others with life hacking-related content that features someone with a physical impairment. Anthony, Kim, & Findlater (2013) content analyzed 187 YouTube depicting the mobile device interactions and in-the-wild adaptations of individuals with physical disabilities. Findings from their study suggest that YouTube video and secondary data analysis can offer unique insights into artifact interaction behaviors in non-laboratory environments. I would like to build on their work and my own by examining life hacking content on YouTube featuring a person with a disability. More specifically, I would like to analyze videos, comments, and channel content to identify how different ICTs both configure their daily life practices and factor into their life hacking efforts. Doing so would allow me to observe situational life hacking activity and related lived experiences. I plan to identify aspects of daily life practices involving ICTs and related life hacking activities captured in existing YouTube content featuring individuals with physical disabilities which could inform the efforts of HCI/accessibility researchers. In addition to
analyzing content on YouTube, I would like interview content publishers with disabilities to discuss the life hack and related daily life practices content in their videos.

**Conclusion**

The goal of this dissertation research study was to understand how individuals with mobility and dexterity impairments address accessibility and daily life issues in the context of their daily lives. The research provides empirical evidence of several diverse adaptive, innovative, and design-like activities individuals with mobility and dexterity impairments engage in independently or with informed support. Additionally, this study illustrates how professionally-design products and various practical, social, and political issues can factor into the mundane practices of individuals with physical impairments in ways that either enable or disable them. Throughout this document, I compared non-disabled people’s efforts to design accessible solutions or participate in consumer-driven accessible design-like activities to the self-empowered life hacking-enabled practices of individuals with disabilities. I hope non-disabled researchers, designers, manufacturers, disability service providers, and others who care about disability and design issues will consider the findings in this study. Finding suggests that when design outcomes and other practice elements disable individuals with physical impairments in their practice engagements or people force help/support on them which ignores their capabilities and interests, some of them empower themselves by life hacking. It only makes sense to learn from the efforts of those who do. I hope these findings will inspire members of these communities to work towards ensuring that individuals who live with impairments can live self-determined lives to the best of their ability, influence the practice of design, and shape the societal disability narrative.
### APPENDICES

**Appendix A: Phase I Recruitment Questionnaire Screening Questions**

<table>
<thead>
<tr>
<th>Item/Question</th>
<th>Intended Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you ever made or developed your own tool or tactic to do something you needed or wanted to do? [Yes/No]</td>
<td>To determine eligibility of potential participant (Screening)</td>
</tr>
<tr>
<td>Have you ever modified an existing object or tactic created by someone else? [Yes/No]</td>
<td>To determine eligibility of potential participant (Screening)</td>
</tr>
<tr>
<td>Have you ever worked with a family member, friend, ally, or anyone else you know personally to either develop a new tool/tactic or modify an existing one? [Yes/No]</td>
<td>To determine whether potential participant works with others to engage in adaptation, modification, and design-like activities</td>
</tr>
<tr>
<td>What types of activities do your tools, tactics, modifications, and adaptations allow you to do? [includes a list of activities of daily life ADLs]</td>
<td>To identify practices potential participant engages in that necessitate adaptation, modification, and design-like activity. (Answers inform initial interview protocol)</td>
</tr>
<tr>
<td>What type of impairment do you have? [Dexterity/Mobility/Both]</td>
<td>To determine type of physical impairment potential participant has</td>
</tr>
<tr>
<td>How does your impairment impact your movement and/or dexterity? (Briefly describe)</td>
<td>To determine nature of potential participant's physical impairment</td>
</tr>
<tr>
<td>In general, how often do you ask other people for assistance with everyday life activities? [Never, Not very often, Sometimes, Often, Very often]</td>
<td>To get a sense of potential participant's level of independence</td>
</tr>
<tr>
<td>Do you prefer to be interviewed face-to-face or via telephone, Skype, Google Hangouts, or another video chat service?</td>
<td>To give potential participant the opportunity to choose the interview platform</td>
</tr>
<tr>
<td>If someone who is already a participant in this study told you about it then please enter his or her referral coupon code below. Please do not enter the person's name. If the person who referred you does not have a referral code then ask him or her to contact the researcher.</td>
<td>To identify and give incentives to participants who refer other participants</td>
</tr>
</tbody>
</table>
### Appendix B: Phase II Participant Initial Interview Questions

<table>
<thead>
<tr>
<th>Item/Question</th>
<th>Platform(s)</th>
<th>Intended Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walk me through a typical day for you from the time you get out of bed until the time you go to sleep?</td>
<td>F2F</td>
<td>To break the ice and give participant opportunity to discuss aspects of adaptation, modification, and design-like activity and related practices without being prompted to do so</td>
</tr>
<tr>
<td>Are there aspects of your daily life that you find challenging?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To uncover aspects of practices that make them difficult for participant and/or necessitate adaptation, modification, and design-like projects</td>
</tr>
<tr>
<td>What makes [challenging aspects of your day] challenging?</td>
<td>F2F</td>
<td>To uncover additional details about challenging aspects of practices</td>
</tr>
<tr>
<td>How do you address these challenges?</td>
<td>F2F</td>
<td>To give participant a chance to describe specific adaptation, modification, and design-like activities that allow him or her to address challenging aspects of practices</td>
</tr>
<tr>
<td>Do you have adaptive practices or tools for dealing with these aspects of your life?</td>
<td>F2F, Phone/Video Chat</td>
<td>To explicitly ask if participant has adaptation, modification, and design-like activity outcomes that allow him or her to address challenging aspects of practices</td>
</tr>
<tr>
<td>Does your mobility/dexterity impairment affect your daily life? If so, how?</td>
<td>F2F, Phone/Video Chat</td>
<td>To uncover details about how impairment factors into daily life practices</td>
</tr>
<tr>
<td>Have you ever faced product or environmental accessibility issues? Explain.</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To identify how different aspects of practices limit/disable participants</td>
</tr>
<tr>
<td>Have you ever faced product or environmental accessibility issues? How did/do you address these issues?</td>
<td>F2F, Phone/Video Chat</td>
<td>To give participant a chance to broach and describe specific adaptation, modification, and design-like activities/outcomes that allow him or her to address limiting/disabling factors</td>
</tr>
<tr>
<td>How did/do these issues impact your ability to do the things you want or need to do in the context of your daily life?</td>
<td>F2F</td>
<td>To elicit discussion about less apparent aspects of daily life practices and adaptation, modification, and design-like activities (e.g., goals, intentionality, and agency)</td>
</tr>
<tr>
<td>Have you ever faced economic, social, employment/educational, or other issues related to having an impairment?</td>
<td>F2F</td>
<td>To identify additional factors that constitute daily life practices</td>
</tr>
<tr>
<td>What made [economic, social, employment/educational, or other issues] difficult?</td>
<td>F2F</td>
<td>To give participant a chance to describe how different entities/agencies/factors structure and shape practices</td>
</tr>
<tr>
<td>How did/do you address [economic, social, employment/educational, or other issues]?</td>
<td>F2F</td>
<td>To give participant a chance to talk about specific adaptation, modification, and design-like activity and related practices without being prompted to do so</td>
</tr>
<tr>
<td>Question</td>
<td>Method</td>
<td>Goal</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>How did/does X impact your ability to achieve goals, accomplish tasks, and address issues in the context of your daily life?</td>
<td>F2F</td>
<td>To give the participant a chance to describe how specific factors he or she mentioned structure and shape practices</td>
</tr>
<tr>
<td>On the recruitment questionnaire, you said that you ask people for assistance with daily activities [insert participant selection]. Who are the people that you go to for assistance?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To give participant a chance to expand on recruitment questionnaire response and find out who he or she goes to for assistance with daily life issues</td>
</tr>
<tr>
<td>On the recruitment questionnaire, you said that you ask people for assistance with daily activities [insert participant selection]. What types of things do you ask for assistance with?</td>
<td>F2F, Phone/Video Chat</td>
<td>To give participant a chance to expand on recruitment questionnaire response and ask why he or she seeks assistance from certain people with daily life issues</td>
</tr>
</tbody>
</table>

**Problem-Solving, DIY, and Allies**

<table>
<thead>
<tr>
<th>Question</th>
<th>Method</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your general approach to facing/addressing accessibility, impairment, and everyday life issues?</td>
<td>F2F</td>
<td>To uncover meta aspects of adaptation, modification, and design-like activity</td>
</tr>
<tr>
<td>What objects do you rely on to accomplish the routines of your daily life? By “objects” I mean electronic devices, computer equipment, assistive technologies, durable medical equipment, or anything else that you use to do your day-to-day activities.</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To determine some of the objects participant uses while engaging in practices</td>
</tr>
<tr>
<td>How did you go about discovering, choosing, and acquiring these items?</td>
<td>F2F</td>
<td>To uncover who and what informs participant's discovery/selection process</td>
</tr>
<tr>
<td>Who or what informed your decision to acquire these items?</td>
<td>F2F</td>
<td>To uncover who and what informs participant's purchase/acquisition, use decisions</td>
</tr>
<tr>
<td>Have you ever developed your own modified way of using or interacting with any of these objects?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To elicit discussion about less obvious adaptation, modification, and design-like activity</td>
</tr>
<tr>
<td>Have you ever customized computer hardware/software to your own preferences?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To elicit discussion about ICT-related adaptation, modification, and design-like activity</td>
</tr>
<tr>
<td>Have you ever customized computer hardware/software to your own preferences? If so, what did you do?</td>
<td>F2F, Phone/Video Chat</td>
<td>Probe intended to elicit discussion about ICT-related adaptation, modification, and design-like activity</td>
</tr>
<tr>
<td>Have you ever customized computer hardware/software to your own preferences? If so, how did you figure out how to do so?</td>
<td>F2F</td>
<td>To give participant a chance to describe specific adaptation, modification, and design-like activity outcomes that allow him or her to use ICTs</td>
</tr>
<tr>
<td>What does your [customized computer setup] allow you to do?</td>
<td>F2F</td>
<td>To elicit discussion about less apparent aspects of ICT-related practices and</td>
</tr>
<tr>
<td>Question</td>
<td>Method</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>On the recruitment questionnaire, you said that you have engaged in do-it-yourself activities related to [insert participant selections]. What exactly did you adapt, modify, and/or create?</td>
<td>F2F</td>
<td>To give participant a chance to expand on recruitment questionnaire response. Explicitly asks participant about the less apparent aspects of practices and adaptation, modification, and design-like activity.</td>
</tr>
<tr>
<td>On the recruitment questionnaire/ your YouTube video/blog or forum contributions, you said that you have engaged in do-it-yourself activities related to [insert practices]. What exactly did you adapt, modify, and/or create?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To give participant a chance to expand on recruitment questionnaire response. Explicitly asks participant about adaptation, modification, and design-like activities/outcomes that allow him or her to do specific practices.</td>
</tr>
<tr>
<td>On the recruitment questionnaire/your YouTube video/blog or forum contributions, you said that you have engaged in do-it-yourself activities related to [insert practices]. What exactly did you adapt, modify, and/or create?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To give participant a chance to expand on recruitment questionnaire response. Explicitly asks participant about adaptation, modification, and design-like activities/outcomes that allow him or her to do specific practices.</td>
</tr>
<tr>
<td>Do you still utilize this/(these) object(s)?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To ask participant if he or she still uses the adaptation, modification, and design-like activity outcome(s) he or she referred to on recruitment questionnaire.</td>
</tr>
<tr>
<td>How do these objects help you?</td>
<td>F2F, Phone/Video Chat</td>
<td>To give participant an opportunity to share his or her account of various agencies implicated in his/her adaptation, modification, and design-like activity-enabled practices.</td>
</tr>
<tr>
<td>If you had to devise/make/modify certain DIY solutions again what would you do differently?</td>
<td>Phone/Video Chat</td>
<td>To give participant opportunity to explain the role that knowledge/know-how plays in his or her adaptation, modification, and design-like activity-enabled practices.</td>
</tr>
<tr>
<td>Have you modified, or developed other categories of objects or adaptive practices that you did not include on the questionnaire?</td>
<td>F2F</td>
<td>To give participant a chance to expand on recruitment questionnaire response. Assumes participant may remember additional adaptation, modification, and design-like activities/outcomes he or she did not mention during the conversation.</td>
</tr>
<tr>
<td>In general, what do your DIY outcomes allow you to do?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To elicit discussion about less apparent aspects of daily life practices and adaptation, modification, and design-like activities such as goals, intentionality, and agency.</td>
</tr>
<tr>
<td>Question</td>
<td>Methodologies</td>
<td>Purpose</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
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<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>What would you do if you did not have the DIY outcomes that you use?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To uncover attributes about the participant as a person who engages in adaptation, modification, and design-like activity such as how he or she faces issues</td>
</tr>
<tr>
<td>What would/do you use if you did not have a specific DIY outcomes that you use? (I usually referred to one the participant described)</td>
<td>F2F, Phone/Video Chat</td>
<td>To give participant a chance to discuss other adaptation, modification, and design-like activities/outcomes he or she conceptualized, used in the past, or currently uses when there isn't an alternative</td>
</tr>
<tr>
<td>On the recruitment questionnaire you indicated that you ask other people for assistance [insert frequency selected] when addressing everyday life issues...Who are the people that you go to for assistance?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To give participant a chance to expand on recruitment questionnaire response. Explicitly asks participant to talk about people who assist him or her with practice activities</td>
</tr>
<tr>
<td>What did this/(these) individual(s) contribute to your efforts to adapt or create something?</td>
<td>F2F, Phone/Video Chat</td>
<td>To get participant to talk about the roles people who help them with practice activities play in his or her adaptation, modification, and design-like activity efforts</td>
</tr>
<tr>
<td>Why did you choose to collaborate with this/(these) individual(s)?</td>
<td>F2F</td>
<td>To get participant to describe how he or she chooses people to assist with life-hacking related projects</td>
</tr>
<tr>
<td>Does this individual assist you with other things besides modifying or creating things?</td>
<td>F2F</td>
<td>To give participant opportunity to explain other ways people factor into their practices and l adaptation, modification, and design-like activities</td>
</tr>
<tr>
<td>What informs your decisions to collaborate (or not collaborate) with others?</td>
<td>F2F, Phone/Video Chat</td>
<td>To elicit discussion about less apparent aspects of daily life practices and adaptation, modification, and design-like activity such intentions, goals, and how able-bodied individuals interact with individuals with disabilities</td>
</tr>
</tbody>
</table>
## Appendix C: Phase III Participant Exit Interview Questions

<table>
<thead>
<tr>
<th>Item/Question</th>
<th>Platform(s)</th>
<th>Intended Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Do-it-Yourself History</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Recall a list of the do-it-yourself projects/outcomes discussed during the initial interview] have I captured most of the adaptations we discussed? Would you like to add others?</td>
<td>F2F, Phone/Video Chat</td>
<td>To refresh participant's memory and hopefully help him or her to remember additional adaptation, modification, and design-like activities/outcomes we did not discuss during first interview.</td>
</tr>
<tr>
<td>How long have you engaged in adaptation/modification/innovation activities like the ones we discussed last time?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To understand participant's background/history as a person who engages in adaptation, modification, and design-like activity.</td>
</tr>
<tr>
<td>How often do you engage in these activities?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To understand participant's background/history as a person who engages in adaptation, modification, and design-like activity.</td>
</tr>
<tr>
<td>How many solutions have you conceptualized? (estimate)</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To understand participant's background/history as a person who engages in adaptation, modification, and design-like activity.</td>
</tr>
<tr>
<td>How many solutions have you developed?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To understand participant's background/history as a person who engages in adaptation, modification, and design-like activity.</td>
</tr>
<tr>
<td><strong>Terminology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have been using the term do-it-yourself during our meetings. How would you label the activities that we have been discussing?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To elicit discussion about the nature of participant's adaptation, modification, and design-like activities from his or her perspective.</td>
</tr>
<tr>
<td>I have been using the term do-it-yourself during our meetings. How would you define the label you just gave me?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To elicit discussion about the nature of participant's adaptation, modification, and design-like activities from his or her perspective.</td>
</tr>
<tr>
<td><strong>DIY Facilitators/Barriers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did anything or anyone make it hard or easy for you to develop your solutions?</td>
<td>F2F, Phone/Video Chat</td>
<td>To elicit discussion about less apparent aspects of daily life practices and adaptation, modification, and design-like activities such as barriers and enablers.</td>
</tr>
<tr>
<td>How did x make your efforts harder?</td>
<td>F2F, Phone/Video Chat</td>
<td>To understand how barriers/facilitators factored into adaptation, modification, and design-like activity-enabled practices.</td>
</tr>
<tr>
<td>How did y make your DIY efforts easier?</td>
<td>F2F, Phone/Video Chat</td>
<td>To understand how barriers/facilitators factored into life adaptation, modification, and design-like activity-enabled practices.</td>
</tr>
<tr>
<td>Question</td>
<td>Method</td>
<td>Note</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Are there specific materials that you like to use when you are creating a DIY solution? If so why?</td>
<td>F2F, Phone/ Video Chat, IM</td>
<td>To give participant an opportunity to identify some of the raw materials that factored into his/her adaptation, modification, and design-like projects</td>
</tr>
<tr>
<td>Are there other factors that impeded your adaptation, modification, and innovation efforts that you did not mention last time?</td>
<td>F2F</td>
<td>To give the participant a chance to describe how different factors structure and shape practices (variant of question asked during previous interview)</td>
</tr>
<tr>
<td>Have you ever faced rules, policies, or procedures that impeded your DIY efforts?</td>
<td>F2F, Phone/ Video Chat, IM</td>
<td>To identify additional barriers/facilitators that factored into adaptation, modification, and design-like activities and related practices</td>
</tr>
<tr>
<td>What role (if any) do friends, family members, or allies play in enabling you to overcome impediments (if applicable)?</td>
<td>F2F</td>
<td>To give participant a chance to describe indirect ways co-participants and allies factor into their adaptation, modification, and design-like activity efforts</td>
</tr>
<tr>
<td>DIY Communities/Resources</td>
<td>IM</td>
<td>To elicit discussion about who or what influences that factor into participant's adaptation, modification, and design-like activities</td>
</tr>
<tr>
<td>Who/what influences your efforts to develop your own solution to accessibility, impairment, or everyday life issues?</td>
<td>IM</td>
<td>To elicit discussion about who or what influences that factor into participant's adaptation, modification, and design-like activities</td>
</tr>
<tr>
<td>When you want to develop your own solution to an accessibility/impairment/everyday life issue, who do you typically talk to first?</td>
<td>F2F, Phone/ Video Chat</td>
<td>To give participants a chance to describe indirect ways people factor into their adaptation, modification, and design-like activity efforts</td>
</tr>
<tr>
<td>When you want to develop your own solution to an accessibility/impairment/everyday life issue, who else do you talk to?</td>
<td>F2F, Phone/ Video Chat</td>
<td>To give participants a chance to describe indirect ways people factor into their adaptation, modification, and design-like activity efforts</td>
</tr>
<tr>
<td>When you want to develop your own solution to an accessibility/impairment/everyday life issue, what resources do you consult?</td>
<td>F2F, Phone/ Video Chat</td>
<td>To elicit discussion about various resources that factor into participant's adaptation, modification, and design-like activities</td>
</tr>
<tr>
<td>When you want to develop your own solution to an accessibility/impairment/everyday life issue, where do you look for these resources?</td>
<td>F2F, Phone/ Video Chat</td>
<td>To elicit discussion about where participant looks for resources that factor into his or her adaptation, modification, and design-like activities</td>
</tr>
<tr>
<td>Can you give me specific references to online or offline DIY resources that you have used in the past? (You can email any other ones you remember later to me when you have time)</td>
<td>F2F, Phone/ Video Chat, IM</td>
<td>To ask participant for names and references to resources that factored into his or her adaptation, modification, and design-like activities. (I usually reviewed these resources after the interview)</td>
</tr>
<tr>
<td>Have you ever looked for DIY knowledge or solutions devised/developed by others? If so, where did you look?</td>
<td>F2F</td>
<td>To elicit discussion about where participant looks for adaptation, modification, and design-like activity-related information or</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Question</th>
<th>Method</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you ever looked for DIY knowledge or solutions devised/developed by others?</td>
<td>Phone/Video Chat</td>
<td>To elicit discussion about where participant looks for adaptation, modification, and design-like activity-related information or finds out about specific projects or outcomes</td>
</tr>
<tr>
<td>What specific online/offline/or other resources did you use to find solutions devised/developed by others?</td>
<td>F2F</td>
<td>To ask participant for names and references to resources that factored into his or her adaptation, modification, and design-like activities. (I usually reviewed these resources after the interview)</td>
</tr>
<tr>
<td>Did you adopt solutions devised or developed by others as is or did you make your own modifications?</td>
<td>F2F</td>
<td>To find out how participants leveraged knowledge from others in their adaptation, modification, and design-like projects</td>
</tr>
<tr>
<td>Do you ever describe or discuss your DIY solutions or knowledge with others? If so, with who?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To give participant an opportunity to talk about who he or she discusses adaptation, modification, and design-like activity-related topics with individuals besides co-participant</td>
</tr>
<tr>
<td>Do you ever describe or discuss your DIY solutions or knowledge with others? Why do you do this?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To give participant an opportunity to talk about motivations behind adaptation, modification, and design-like activity-related conversations with individuals besides co-participant</td>
</tr>
<tr>
<td>Do you ever describe or discuss your DIY solutions or knowledge with others? Where do these conversations take place?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To find out where participant's adaptation, modification, and design-like activity-related conversations take place</td>
</tr>
<tr>
<td>Are you involved in any online or offline associations, groups, networks, etc. composed of individuals with dexterity, mobility, or other impairments who share, discuss, or collaboratively work together to devise and develop adaptation, modification, or innovation solutions?</td>
<td>F2F, Phone/Video Chat</td>
<td>To give participant an opportunity to talk about any adaptation, modification, and design-like activity-related social networks he or she might be a member of and the types of things members discuss (Sometimes I referred to social networks the participant already mentioned or platforms I knew the participant used)</td>
</tr>
<tr>
<td>Are you involved in any online or offline networks where individuals with dexterity, mobility, or other impairments share, discuss, or collaboratively work together to devise and develop modifications, activity adaptations, etc.?</td>
<td>IM</td>
<td>To give participant an opportunity to talk about any adaptation, modification, and design-like activity-related social networks he or she might be a member of and the types of things members discuss (Sometimes I referred to social networks the participant already mentioned or platforms I knew the participant used)</td>
</tr>
<tr>
<td>Question</td>
<td>Interaction Type</td>
<td>Objective</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Can you describe your interactions with X group/association/network?</td>
<td>F2F</td>
<td>To elicit discussion about participant's actions and interactions within adaptation, modification, and design-like activity-related social networks</td>
</tr>
<tr>
<td>Would you consider yourself an active member of this group/association/network?</td>
<td>F2F</td>
<td>To elicit further discussion about participant's actions and interactions within these social networks</td>
</tr>
<tr>
<td>What does your involvement entail?</td>
<td>F2F, Phone/Video Chat, IM</td>
<td>To elicit further discussion about participant's actions and interactions within these social networks</td>
</tr>
<tr>
<td>How do you use the information that is shared within these groups?</td>
<td>F2F, Phone/Video Chat</td>
<td>To give participant an opportunity to explain how the information shared within adaptation, modification, and design-like activity-related social networks factor into his or her adaptation, modification, and design-like activity efforts and related practices</td>
</tr>
<tr>
<td>Why are you involved in these associations, groups, networks, etc.?</td>
<td>F2F, Phone/Video Chat</td>
<td>To give participant a chance to explain the benefits/rewards of being a member of adaptation, modification, and design-like activity-related social networks</td>
</tr>
<tr>
<td>Why are you involved in these networks?</td>
<td>IM</td>
<td>To give participant a chance to explain the benefits/rewards of being a member of adaptation, modification, and design-like activity-related social networks</td>
</tr>
</tbody>
</table>
### Appendix D: Phase III Co-Participant Face-to-Face Interview Questions

<table>
<thead>
<tr>
<th>Item/Question</th>
<th>Intended Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Problem-Solving, DIY, and Allies</strong></td>
<td></td>
</tr>
<tr>
<td>How do you know [participant's name]?</td>
<td>To break the ice and give co-participant an opportunity to share whatever he wants to share about the participant [I briefly explained the purpose of the interview before asking this question]</td>
</tr>
<tr>
<td>What role does [participant's name] play in his/her DIY activities?</td>
<td>To get the co-participant to talk about the role the participant plays in their collaborative adaptation, modification, and design-like activity efforts</td>
</tr>
<tr>
<td>What does [participant's name] contribute to his/her efforts?</td>
<td>To get the co-participant to talk about the participant's adaptation, modification, and design-like project contributions</td>
</tr>
<tr>
<td>What role does [participant's name] play in conceptualizing solutions?</td>
<td>To get the co-participant to talk about the role the participant plays in initiating adaptation, modification, and design-like projects</td>
</tr>
<tr>
<td>What role does [participant's name] play in creating solutions?</td>
<td>To get the co-participant to talk about the role the participant plays in creating/developing adaptation, modification, and design-like project outcomes</td>
</tr>
<tr>
<td>Has [participant's name] ever run into any challenges or difficulties while creating a DIY solution? (probe)</td>
<td>To elicit discussion about less apparent aspects of daily life practices and adaptation, modification, and design-like activity from perspective of co-participant (e.g., barriers and enablers)</td>
</tr>
<tr>
<td>What role do you play in [participant's name]’s DIY activities? (Prompt ally with specific examples mentioned by the participant)</td>
<td>To get co-participant to talk about the role he or she plays in collaborative adaptation, modification, and design-like project efforts</td>
</tr>
<tr>
<td>What do you contribute to [participant's name]'s efforts in general? (probe)</td>
<td>To get co-participant to talk about his or her contributions to collaborative adaptation, modification, and design-like projects and related practices</td>
</tr>
<tr>
<td>What role did you play in helping [participant's name] conceptualize solution Y? (probe)</td>
<td>To get co-participant to talk about the role he or she plays in initiating participant adaptation, modification, and design-like projects</td>
</tr>
<tr>
<td>What role did you play in helping [participant's name] to make solution Y? (probe)</td>
<td>To get co-participant to talk about the role he or she plays in creating/developing adaptation, modification, and design-like project outcomes</td>
</tr>
<tr>
<td>What role did/do you play in helping [participant's name] use solution Y? (probe)</td>
<td>To get co-participant to talk about the role he or she plays in helping participant use adaptation, modification, and design-like project outcomes to do practice activities</td>
</tr>
<tr>
<td>Do you talk to other people besides [participant's name] about DIY solutions for individuals with impairments/disabilities?</td>
<td>To find out if co-/participant talk to other people about adaptation, modification, and design-like activities/outcomes. [Supplements participant accounts]</td>
</tr>
<tr>
<td>Who else do you talk to about DIY solutions?</td>
<td>To give co-participant a chance to talk about different people who factor into his or her collaborative adaptation,</td>
</tr>
<tr>
<td>Question</td>
<td>Explanation</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>What types of things do you talk about with these individuals in relation to DIY?</td>
<td>To find out why co-/participant talks to other people about his or her collaborative adaptation, modification, and design-like activities with participant [Supplements participant accounts]</td>
</tr>
<tr>
<td>Have you ever shared DIY knowledge with someone else?</td>
<td>To find out if co-/participant shares or discusses things he or she knows or has learned from his/her adaptation, modification, and design-like activities with others. [Supplements participant accounts]</td>
</tr>
<tr>
<td>Have you ever asked anyone else for advice?</td>
<td>To find out if co-/participant ever seeks adaptation, modification, and design-like activity-related guidance or support [Supplements participant accounts]</td>
</tr>
<tr>
<td>Have you ever looked for DIY solutions developed by others? If so, where did you look?</td>
<td>To elicit discussion about where co-/participant looks for adaptation, modification, and design-like activity-related information or finds out about specific outcomes developed by others [Supplements participant accounts]</td>
</tr>
<tr>
<td>Have you ever looked for DIY solutions developed by others? What did you use to find these solutions?</td>
<td>To ask co-participant for names and references to resources that factored into his or her adaptation, modification, and design-like activities. (I usually reviewed these resources after the interview. Supplements participant accounts)</td>
</tr>
<tr>
<td>Did you adopt these solutions as is or did you make your own modifications?</td>
<td>To find out how co-/participants leveraged knowledge from others in their adaptation, modification, and design-like projects (Supplements participant accounts)</td>
</tr>
<tr>
<td>Are you involved in any associations, groups, networks, etc. composed of individuals with disabilities or individuals who work with individuals with disabilities who share, discuss, or collaboratively work together to devise and develop adaptation, modification, or innovation solutions? What does your involvement entail?</td>
<td>To elicit discussion about co-/participant's actions and interactions within adaptation, modification, and design-like activity-related social networks (Supplements participant accounts)</td>
</tr>
<tr>
<td>Would you consider yourself an active member of this group/association/network?</td>
<td>To elicit further discussion about co-/participant's actions and interactions within these social networks (Supplements participant accounts)</td>
</tr>
<tr>
<td>How do you use the information that is shared within these groups?</td>
<td>To ask co-participant to describe how information shared within adaptation, modification, and design-like activity-related social networks factor into collaborative adaptation, modification, and design-like activity efforts and related participant practices (Supplements participant accounts)</td>
</tr>
<tr>
<td>Why are you involved in these associations, groups, networks, etc.?</td>
<td>To give co-participant a chance to explain the benefits/rewards of being a member of adaptation, modification, and design-like activity-related social networks (Supplements participant accounts)</td>
</tr>
</tbody>
</table>
Appendix E: Member Check E-Mail

Hello [Participant’s real name],

I hope you are doing well. Thank you again for participating in my dissertation research study. I appreciate your time and willingness to share your stories with me.

I recently finished drafting my dissertation results chapters. Several participants indicated they would like to see my findings. I’ve attached drafts of the results chapters to this email for your review if you would like to read them. I welcome your comments, questions, and suggestions.

In addition to sharing my findings with you, I wrote this email to make a request. One of the goals of my work is to honor the perspectives and accurately represent the experiences of everyone who participated. To the best of my ability, I tried to accurately capture everyone’s way of seeing the world and understanding their do-it-yourself/life hacking activities. I would like to know whether you agree with the interpretations in the attached chapters. If you disagree with something I said about you or your experiences, could you tell me what I can do to fix any mischaracterizations you see? I will use your feedback to make sure the final draft of my dissertation accurately portrays the perspectives and voices of all participants.

Please note that I’ve used pseudonyms in the attached chapters to maintain your anonymity and protect your identity. Please let me know if there are details about you or your experiences that you would like me to add, change, or remove. Also, if you have any digital photos of specific adaptations/life hacks that you are willing to let me include in the final draft, please feel free to share them with me. If you decide to share any photos, I will be sure to blur all identifying details about you such as your face and any location information.

Please do not hesitate to send your comments, suggestions, and questions to me if you have any. It would be helpful if you could send your feedback to me by August 8, 2017.
### Appendix F: Participant Terms and Descriptions

<table>
<thead>
<tr>
<th>Term</th>
<th>Focus</th>
<th>Participant</th>
<th>How Participant Used/Defined Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy adaptation</td>
<td>Activity</td>
<td>Neil</td>
<td>&quot;ways to manage my energy levels throughout the day&quot;</td>
</tr>
<tr>
<td>Adaptive tools</td>
<td>Activity</td>
<td>Stuart</td>
<td>&quot;how we manage, how we do things&quot;</td>
</tr>
<tr>
<td>Independent/Way to be</td>
<td>Activity</td>
<td>Stuart</td>
<td>Enabled by strangers</td>
</tr>
<tr>
<td>independent</td>
<td></td>
<td>Grant</td>
<td>Arranging your life so that you do not have to rely on the capabilities you no longer possess</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wallace</td>
<td>Something you seek as you feel more empowered in certain areas of your life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Deanna</td>
<td>&quot;Finding your own way to live everyday life.&quot;</td>
</tr>
<tr>
<td>Responding to a Need</td>
<td>Activity</td>
<td>Sheila</td>
<td>Doing things as needed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sheila’s husband</td>
<td>&quot;you just respond to what’s in front of you&quot;</td>
</tr>
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<td></td>
<td></td>
<td>(Jack)</td>
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<tr>
<td>Strategies or Techniques</td>
<td>Activity</td>
<td>Cecil</td>
<td>Different ways two people with the same disability do the same activity</td>
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<td></td>
<td></td>
<td>Ross</td>
<td>Individualized ways to use the body to do things</td>
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<td></td>
<td></td>
<td>Arnold</td>
<td>&quot;on-the-fly kind of things&quot;</td>
</tr>
<tr>
<td>Way or Developed Way</td>
<td>Activity</td>
<td>Deanna</td>
<td>&quot;Your own ways to do stuff&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ross</td>
<td>&quot;the way that I've chosen or managed or found to go about it&quot;</td>
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<td></td>
<td></td>
<td></td>
<td>&quot;just the way I do things&quot;</td>
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<tr>
<td>Tactic</td>
<td>Both</td>
<td>Tabitha</td>
<td>&quot;Using what I have or found to adapt to continue to be able to live as independently and productively as possible&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Arnold</td>
<td>&quot;evolv[ing] stuff on the fly&quot;</td>
</tr>
<tr>
<td>Adapt or Adaptation</td>
<td>Both</td>
<td>Erin</td>
<td>Something &quot;you have to find a different way [to do] because of your disability&quot;</td>
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<tr>
<td></td>
<td></td>
<td>Dominic</td>
<td>&quot;finding the simplest way to do the task with what I've been given to work with&quot;</td>
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<td></td>
<td></td>
<td>Ross</td>
<td>Allows a person to try something new</td>
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<td>Altering the way a person learned to do things before the onset of disability</td>
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<td></td>
<td></td>
<td>Neil</td>
<td>&quot;Figuring out the best way to do something&quot;</td>
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<td>What non-disabled individuals view as the &quot;wrong way&quot; to do something</td>
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<td></td>
<td></td>
<td>&quot;Adapting to my body and my environment&quot;</td>
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<td>Something you do so quickly that you don't realize it</td>
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<td></td>
<td></td>
<td>Tabitha</td>
<td>&quot;Really small things&quot; one does to live independently</td>
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<tr>
<td></td>
<td></td>
<td>Scott</td>
<td>“I saw something on the Internet that would work, but they were made for bicycles. I said oh, okay. I could adapt this; this would work on a walker.”</td>
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<tr>
<td></td>
<td></td>
<td>Sheila</td>
<td>Using an object in a unique way to accomplish a task</td>
</tr>
<tr>
<td>Term</td>
<td>Focus</td>
<td>Participant</td>
<td>How Participant Used/Defined Term</td>
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<tr>
<td>Do-It-Yourself or DIY</td>
<td>Both</td>
<td>Erin</td>
<td>Something &quot;you have to find a different way [to do] because of your disability&quot;</td>
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<tr>
<td></td>
<td></td>
<td>Sheila</td>
<td>&quot;figure out how you can do it yourself through adaptation...and be creative about it&quot;</td>
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<tr>
<td></td>
<td></td>
<td>Tabitha</td>
<td>&quot;Creating something or taking something and making it your own to help you?&quot;</td>
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<tr>
<td></td>
<td></td>
<td>Neil</td>
<td>Alternative to buying a product</td>
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<tr>
<td></td>
<td></td>
<td>Scott</td>
<td>&quot;Building something that I find will solve a need that I have&quot;</td>
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<tr>
<td>Life hacks or Lifestyle hacks</td>
<td>Both</td>
<td>Leon</td>
<td>&quot;Capable ways of doing things in life in general&quot;</td>
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<td></td>
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<td>&quot;Adapting life to the way that you live&quot;</td>
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<td>&quot;adapting life to make it more accessible for yourself&quot;</td>
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<td></td>
<td></td>
<td>&quot;whatever you can find to help you&quot;</td>
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<tr>
<td>Homemade accessibility</td>
<td>Artifact</td>
<td>Samantha</td>
<td>&quot;Creat[ing] or alter[ing] something to make it work for you&quot;</td>
</tr>
<tr>
<td>Modify, Modified, Modification, or Little Modification</td>
<td>Artifact</td>
<td>Wallace</td>
<td>&quot;Little changes&quot; and &quot;little different ways to improve the routines that we do&quot;</td>
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<td></td>
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<td>&quot;make things safer and better and easier all the way around&quot;</td>
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<td>&quot;customized and personal to my situation&quot;</td>
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<td>&quot;Taki[ng] an existing product and...us[ing] it a little differently&quot;</td>
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<td></td>
<td></td>
<td>Grant</td>
<td>&quot;Changing my environment...to make it possible or easier for me to interact with it.&quot;</td>
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<td></td>
<td></td>
<td>Stuart</td>
<td>Using Sugru to &quot;stick&quot; an accessory back on wheelchair</td>
</tr>
<tr>
<td>Recycle, Repurpose, or Reuse</td>
<td>Artifact</td>
<td>Arnold</td>
<td>&quot;Taking something made for one purpose and mak[ing] it work for whatever task I'm trying to accomplish&quot;</td>
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<td>Using &quot;something that was originally meant for something else&quot;</td>
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<td></td>
<td>&quot;tak[ing] something that was sold for doing one thing and using it to do something else&quot;</td>
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<tr>
<td>Self-developed solutions or tools</td>
<td>Artifact</td>
<td>Arnold</td>
<td>&quot;Rather than going out to try to buy something new...I’ll look for something I can adapt and make work for what I want&quot;</td>
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<td></td>
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<td></td>
<td>Repurposing /recycling/reusing &quot;something that already exists&quot; or &quot;mak[ing] something from scratch&quot;</td>
</tr>
<tr>
<td>What You Need-Type Solution</td>
<td>Artifact</td>
<td>Stuart</td>
<td>Specialized for the individual and his/her needs &quot;a certain something [that] I have to create it to get the needs met that I’m looking for&quot;</td>
</tr>
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<td>&quot;[Things] that I’ve created that are just for me that only I use&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&quot;[Things] that I came up with or I had help coming up with&quot;</td>
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</table>
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- Member of Disabled in Action of Greater Syracuse, Inc.; Jul 2014 – 2016