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ABSTRACT

The transition to adulthood is complicated for youth with intellectual disabilities from culturally and linguistically diverse (CLD) Families. This ethnographic research explores the daily lives of six adults with intellectual disabilities who live in one urban Korean American community. In particular, the ethnographic observational, interview and textual data have been analyzed in terms of which activities associated with adulthood the participants could or could not engage in, in comparison to the practices of their non-disabled peers in this community. Besides the six focus participants with intellectual disabilities, I also interviewed six other youth and adults with disabilities, six parents of youth or adult children with disabilities and six staff and volunteers who participated in a Christian community organization. The practice of service emerged as a main theme for understanding experiences of transition to adulthood. While the Korean community actively reproduces the culture of serving as an adult, especially in age hierarchy, food serving culture, and volunteerism, the participants with intellectual disabilities in this research were excluded from opportunities to serve as contributing adult members in these areas. Instead, my participants were fixed in the role of being served, despite demonstrating a variety of examples of how they provided service to others, in purely voluntary actions in their daily lives. In conclusion, the Korean American adults with intellectual disabilities in the study struggled to claim their adult status. I argue that being an adult entails having more chances to serve others, and that therefore a Korean community such as the one I observed would need to create more spaces for people with intellectual disabilities to serve others as adults. The practice of service can be implemented in a way that would not reestablish a colonial, ableist, pity-based or charity model of disability, but rather would highlight different kinds of service to others as an element of interdependence. Recommendations for transition and further research are included.

STRUGGLES OF KOREAN AMERICANS LABELED WITH INTELLECTUAL
DISABILITIES TO CLAIM ADULT STATUS

By

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DISSERTATION

Submitted in partial fulfillment of requirements
for the Degree of Doctor of Philosophy in Special Education

Syracuse University
May 2018

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To my father, Taeok Jung, who loved to read every day
even after his hard labor as a machinist on a fishing vessel.
You taught me how to read and write by sending letters from the ocean
and motivating me to write back to you every month for twenty years.
Dad, thank you for planting the seed of joyful reading and writing in my childhood.
And, I miss you very much...

ACKNOWLEDGMENTS

The past ten years in graduate school as a PhD student and working mother have taught me a great deal about how my progress and accomplishments are not my own but the outcome of others' help. Even though this work is under my name and brings me the title of PhD, there are many people's invisible work behind this dissertation that has made it all possible.

I am very thankful that I had such a supportive chair and committee members who always encouraged me – with my high anxiety of not being good enough – that I can do this. I am very much thankful to Dr. Beth Ferri who is my ten-year advisor and the chair for this dissertation. I remember many critical learning moments in her classes, that enabled me to develop my perspective on disabilities. At every milestone of my graduate school, including my last minute completion of the dissertation process, it was Dr. Beth Ferri who helped me to move forward with her immediate help. I also cannot express how thankful I am to my dissertation committee members, Dr. Christy Ashby and Dr. Wendy Harbour. With my messy life as a mother of three children, I could not have made it through this process without their time, hard work, and strong support for this dissertation. Outside of my committee, I also greatly appreciate Dr. Marj DeVault who taught me how to do qualitative study through several classes during my coursework. I still remember my *a-ha* moment when I noticed non-immediate and invisible elements behind or between data while I read through Dr. DeVault's comments on my qualitative study term paper.

I probably could not have survived in graduate school without my friends at Syracuse University. They are the ones who were willing to listen to my struggle and understand it immediately without much explanation. It was such a comfort to know others who could relate to the pain of writing and the difficulty of getting stuff done! They were also the ones who

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CHAPTER 1: INTRODUCTION

Try to remember the first time that you felt you had gained adult status – or when others perceived you as an adult. It might have been your first date; when you left your parents' house; when you went off to college; or, as the classic Korean example, when you bought your parents winter underwear as a gift after getting your first paycheck. The list goes on and on. Becoming an adult seems to be something biological that everyone without exception experiences.

However, the transition to adulthood is not a “natural” process, but rather a socially constituted process involving what youth are expected to do, socially and culturally, to mark their entrance into adulthood, as well as the decisions and actions they take themselves (Holdsworth & Morgan, 2005). For example, the various moments that I described above already implied certain values attached to the concept of adulthood, such as physical and financial independence, which both can be categorized as a form of “ability.” Moreover, these examples assume a “normal” pathway that youth must follow regardless of the diverse ways they live their lives.

In this vein, Korean American youth and adults with intellectual disabilities are likely to have complex experiences in negotiating either their transition to adulthood or their current adult status. Moreover, the discourse of “normal” adulthood ignores cultural diversity differences in racial and ethnic background and disability. In addition, the label of intellectual disabilities creates conflicting adulthood discourses around entitlement to self-determination vs. vulnerability to exploitation (Murphy, Clegg, & Almack, 2011). This research addressed questions both of being a “grown-up” and of having “a disability” as Korean American youth and adults, in whose daily lives all three cultural identities of adulthood, disability, and Korean American-ness intersect.

Because of their different cultural expectations, some common transitional goals are not necessarily desirable from the perspective of Korean American families. For example, there is no expectation in the culture of most Korean American families that their adult children must leave their parents' house upon graduating high school or college. Many prefer to provide close support to family members with disabilities, either in the same house or nearby in the community, which may not be promoted by the school system. Moreover, even after marriage, those children may wish to stay at home and fulfill their responsibility to take care of their parents. As a result, these Korean American young people can find themselves situated awkwardly between dominant U.S. social expectations on one hand and their families' cultural norms on the other. The situation becomes even more complicated when disability identities are added to this process. Individuals with disabilities, depending on the kinds of assistance and support they need, may not fit within the dominant concept of independence. Moreover, unlike most adults without disabilities, individuals with disabilities generally need to negotiate with government agencies about who will determine, plan, and manage the services and money necessary to accommodate their daily needs, which complicates their efforts to express self-determination.

Along with an increased understanding of the importance of cultural roles in students' general learning process, special educators have recently been required to provide transition planning and implementation. Transition in general refers to the process of movement from secondary education to the post-secondary stage, such as going to college, leaving home, getting a job, etc. It also indicates the path from adolescence to adulthood. There are also transition services in special education, which are "a coordinated set of activities for a child with a disability ... that is focused on improving the academic and functional achievement of the child

with a disability to facilitate the child's movement from school to post-school activities” (IDEA, 2004). These transition services are currently required to be more culturally sensitive to individual students’ cultural backgrounds (deFur & Trainor, 2012; Geenen, Powers, Lopez-Vasquez, & Bersani, 2003; Greene, 1996). Because disability, adulthood, lifestyles, career development, and family relationships are not universal across cultures, but highly socially constructed concepts, it is essential for educators to consider the culture of students’ families in meeting students’ transition planning needs. However, despite an increased emphasis on the cultural consideration in transition, schools have not been very successful in providing culturally responsive transition supports (Trainor, 2005). One of the reasons behind this is that there are not many cultural resources tailored for specific ethnic, racial and disability groups (Kim & Morningstar, 2005).

Asian Americans have been an essentialized group in the United States (Lee, 1996). In particular, the “model minority” stereotype of Asian Americans overpowers educational research without careful examination of differences among students according to their ethnicity, class, gender, disability, and generation. This tendency has resulted in the absence of support for some Asian American students, and inevitably resulted in their silent “failure” (Doan, 2006). Recently, however, scholars have started paying closer attention to the achievement gaps among different groups of Asian Americans students, such as class (Lew, 2006, 2007) as well as other differences (Lee, 1996, 2006). Scholars have interrogated social structure factors such as class (working class vs. middle/upper class), different strategies used by different groups of Korean Americans (Lew, 2007), and the damage caused by the “model minority” stereotype to students with low academic achievement (Doan, 2006; Lee, 1996).

In a similar vein, scholars of transition studies in special education have explored the cultural experiences of the families of Korean American children with disabilities (Cho & Blair, 2010; Cho & Gannotti, 2005; Cho, Singer, & Brenner, 2000, 2003; Kim, 2004; Kim, Lee, & Morningstar, 2007; Kim & Morningstar, 2005; Park, 2012; Park & Turnbull, 2001; Park, Turnbull, & Park, 2001). These families experienced language barriers, cultural differences in communication style, and lack of consensus on educational goals in American education programs. While transition studies in the field of special education reveal that youth with disabilities from diverse backgrounds have lower rates of school completion, diminished access to post-secondary education and lower rates of employment (deFur & Trainor, 2012), the way these transition outcomes differ among and within racial groups still needs to be explored.

More importantly, the current literature does not consider how disabilities, understood as socially constructed rather than purely personal or medical, affect the experiences of Korean American youth and adults in terms of “transition” to adulthood which is typically described as a process of moving from adolescence to adulthood. Since “entering” into adult status is often connected to an individual’s accomplishments (e.g., starting a career or going to college) or skill building (e.g., managing finances) at a personal level, oppressive systems that may make it difficult for an adult with disabilities to claim their adulthood are not often discussed. While it is still challenging for people without disabilities to go through the period of emerging adulthood, and there are rigid frames of “successful” adulthood, the adult identity of able-body is rarely denied. But why do adults with intellectual disabilities need to claim their adult status? And indeed, some adults with intellectual disabilities are perpetually treated like children. More provocatively, what cultural mechanisms does society conduct that keep adults with intellectual disabilities separated from adult roles? Considering this issue as one of power and role relations

(Wolfensberger, 1991) like many other disability issues, what if society does not give a positive role – adulthood-relevant roles in this research – to these people with intellectual disabilities? As much as transition education emphasizes cultural sensitivity, culture becomes a critical element in the social model of disability in order to answer these questions as well. From which cultural practices were adults with intellectual disabilities excluded? Or, which negative or positive roles are given to adults with intellectual disabilities in a Korean American cultural context? The role that Korean American cultural mechanisms play in these experiences of disability and youth/adulthood has yet to be fully explored.

Purpose of the Study

In this vein, my purpose in undertaking this study was to explore stories of Korean American adults with intellectual disabilities and their adulthood status in their Korean American cultural context. My overarching question was: How is the adult status of Korean American adults with intellectual disabilities characterized or denied in a Korean American cultural context, as a daily practice? From this initial question, four additional questions follow, which I investigated:

1. Which cultural practices in the Korean American community are relevant to the question of adult status?
2. Which daily actions of Korean American adults with intellectual disabilities represented their adult characteristics for the community?
3. How did this Korean American community perceive Korean American adults with intellectual disabilities in terms of their adult identity?
4. How did Korean American culture play out or interact in the reproduction of ableism in the process of transition from youth to adulthood?

I hope my participants' stories challenge ableist cultural practices relating to adulthood, and inform how Korean American communities and educators should approach and support the transition of Korean American youth with disabilities toward meaningful participation in adult life.

Key Term

Youth and Adult. Youth is a more fluid category than a fixed age-group. The age range of youth can vary depending on one's regional, cultural and economic context. For example, the UN defines youth for their consistent statistics as between the ages of 15 and 24 years, while the African Youth Charter defines it as between ages 15 and 35. In Korean culture, youth can be either adolescent (7th grade -12th grade) (Cheong-so-nyun) or young people (from high school graduation until marriage) (Cheong-nyun). The determination of youth or adulthood gets more complicated when applied to people with intellectual disabilities.

While I interviewed and observed youth with disabilities in my research site, my six focus participants – whose individual stories are shared in this dissertation - were adults with intellectual disabilities. Their ages ranged from 22 to 50 at the beginning of data collection in 2015. From the very beginning of this research until the writing of this dissertation, the boundary between youth and adulthood for my participants in their daily lives has been blurry. I might well say that the subject matter of this dissertation is that blurriness itself, and the way it depends on daily actions, including how adulthood-characterizing actions were facilitated or limited in a given cultural context. It was not even a matter of which skills or qualities my participants possessed that might meet certain cultural expectations of adulthood. Rather, it was about how they were perceived, and whether they were given an opportunity to take that action. Under my

observation, my participants were perceived as children, youth, or adults at the same time in the Korean American community.

In this vein, contrary to the impression we may have about “arriving” at adulthood, the reality of the transition to adulthood is approached not as any one specific moment. Rather, it is an extensive journey of dealing with one’s own desires, social expectations progressing towards a significantly changed physical, economical and psychological status, and importantly a daily power struggle about opportunities and roles, especially in the case of youth and adults with intellectual disabilities.

Positionality

This research is shaped by my positionality, which influenced every process of data collection, findings, analysis and interpretation in some positive and some limiting ways. I identify myself as Korean female Christian without disabilities, having the resulting dual position of insider and outsider in relation to my research site, Grace, which is a Christian organization located in an urban Korean American community.

As a youth in South Korea, I had volunteer experience in a branch of the same organization, which made me aware of its potential as a research site. Being a Korean, and in particular speaking Korean as my first language, enabled me to access the research site and participants. My natural understanding of Korean culture and ability to conform to Korean cultural practices (e.g., age hierarchy) helped me to gain the trust of my participants. While I began as a stranger at the research site, I was able quickly to settle into the role of a “younger” person in relation to my “older” participants in Korean American culture. In addition, I entered this research site as a doctorate candidate in special education, as well as a former special education teacher. My language competency in English as a doctorate student and my knowledge

and experience in special education and disabilities also helped me to contribute, and to be trusted to contribute, to the research site. During the process of analysis, I automatically recalled my own similar history, cultural knowledge and practices as a Korean, and used them to help me understand data. While this insider position helped me to access the research site, it was also limiting in my collection and interpretation of the data. My interaction with participants as a Korean was constrained by Korean culture as well. My Korean identity limited me to acting towards others in the expected roles of the “younger” or “older” person, within the Korean age hierarchy culture.

In some important ways, I am also an outsider to this research site. I live in a mid-size city in the eastern U.S., with a very small Korean American community centered around three Korean churches. I attend a non-Korean church and my interaction with other Koreans is limited to a few students on campus. I did not begin this project as a member of any Korean American community, and while I gained some acceptance among members in my research site over the course of the project, my remaining outsider status presented limitations to my collection and interpretation of data. There was always uncertainty regarding data interpretation, because I had observed this community within a very narrow time and space. I also recognized the fact that I, as a person without disabilities, have limitations in understanding and interpreting the experiences of people with disabilities. Meanwhile, as a stranger I noticed some cultural practices that members in the community may have engaged in without noticing their significance. Additionally, as a person who was not already familiar with my participants, I was able to approach them with a less fixed, preconceived image, and interact with them differently than others within their community. Not only did I have dual positions as an insider/outsider, but

also each position played dual roles in facilitating or restraining my access and understanding of Korean American cultural elements and people's experience in this community.

Organization of This Dissertation

This dissertation includes seven chapters - introduction, literature review, method, three data chapters, and discussion/conclusion. To begin with, in the literature review, the social model of disability is reviewed as the disability framework that was used for this research. In particular, the current AAIDD definition of intellectual disabilities was critically examined from the disability studies perspective, in terms of its construction of intellectual impairment. The second part of the literature review presents current statistics on Asian Americans and Korean Americans with disabilities as well as the most current longitudinal studies on their transition outcomes, including residential status, employment rate, income, and educational setting (Wagner, Newman, Cameto, & Levine, 2005). Finally, the most current transition studies in special education are reviewed in terms of their traditional frameworks and limitations, the current literature on culturally and linguistically diverse (CLD) youth with disabilities and their families, and attention to transitional issues for Korean American families of youth with disabilities. The absence of youth voices is also discussed as a research gap.

In chapter three, Methods, critical ethnography is introduced as the primary research method for this study. In particular, I explore how a critical ethnographic approach can explicate cultural themes and analysis of social systems. Next, I describe the research stages, the research participants and settings, the processes of data collection and analysis, and ethical issues of this research.

The three data chapters describe how Korean American adults with disabilities struggled to be perceived as adults in the culture of serving within their Korean American community. All

three chapters have one structure in common. Each chapter shows how the Korean American community failed to recognize adult characteristics of my participants with disabilities, and instead reinforced the perception of them as children by assigning them a fixed, *served* role in its cultural practices of age hierarchy, food, and volunteerism. However, all three chapters also provided counter examples of Korean American adults with intellectual disabilities who exhibited and practiced their own adult roles in their daily lives.

The fourth chapter explains the strict cultural and linguistic practices of age hierarchy both in general and around Korean American adults with intellectual disabilities in the Korean American community. This chapter also describes ironic moments in which adults with disabilities were not treated as adults, despite the emphasis on respectful language usage toward this group. A story about an art exhibition shows the bare face of this Korean community, in the way they used images to infantilize adults with intellectual disabilities. In contrast, my participants were introduced as a discerning adult, a big sister, and a conversation partner.

Chapter five depicts food culture as a medium to represent adulthood. It provides examples of these disabled Korean American adults' food-related behaviors, including drinking coffee, food choice, social relationships over the table, etc. It also contrasts these habits with the way adults with disabilities were always served food in Korean American community events, unlike other youth and adults without disabilities. I argue that this given role in food serving culture limits Korean American adults with intellectual disabilities to being perceived as objects of loving, instead of active adult members of the community.

In chapter six, I show how Korean American elitism and ableism are promoted together during the transition to adulthood in the community. In particular, through volunteerism, ableism was constructed through the dichotomy between served (i.e., youth and adults with disabilities)

and serving (youth and adults without disabilities). Again, my participants' serving stories - as a fund-raiser and a museum guide - were presented as counter-examples to the dominant narrative.

In chapter seven, I discuss, first, how ableism as an oppressive system was found in the daily lives of Korean American adults with intellectual disabilities. This was also connected to the cultural reproduction theories. Second, I reflect on what kinds of implications these stories can have for current adult services as well as the Korean community. Last, I explain the limitation of this research, and suggest future research.

CHAPTER 2: LITERATURE REVIEW

Disability as a Social Construct

Disability framework. In order to understand the experience of Korean American youth and adults labeled with intellectual disabilities, it is essential to examine a researcher's theoretical framework of disabilities. In various academic traditions, the framework itself can be considered a paradigm, a lens through which the researcher sees the phenomena, or a cultural tool that s/he chooses, adopts, uses, and changes, in order to understand the world around him/her. From the criticalist's point of view, this framework also includes power dynamics, as a dominant group makes use of their preferred framework to naturalize the existence of hierarchical power relationships as well as their oppressive process (i.e. ideology). In this vein, many social "facts" cannot be fully understood in isolation, apart from their production or manufacturing process. For example, the question, "what is disability?" cannot be answered or explored without considering how one comes to recognize disability, the assumptions behind a given definition of disability, and the historical and cultural contexts in which one is located as a meaning-maker.

When considering disability or the experiences of people with disabilities, this kind of frame is always at work. There is always an invisible, immediate but still complex, social/historical, and interpretive process behind any situation in which "disability" is involved. These might include: when an individual identifies herself or others as disabled; when certain bodily (physical or mental) conditions or characteristics are recognized as a disability; when people use the word *disability*; when people interact with persons with disabilities in a certain manner; when social policy for people with disabilities is enacted, written, and implemented, etc. As discussed above, disability models also can be very powerful in making policy, educational

and otherwise, because they directly or indirectly influence how policy-makers approach disability and where they look for solutions for disability-related issues (Brandt, Houtenville, Huynh, Chan, & Rasch, 2011; Turnbull & Stowe, 2001).

Of course, a researcher cannot escape this process. The researcher will always bring in, utilize, change, and (re)produce a particular framework of disability in all stages of their research. Also, importantly, whatever framework the researcher employs will be welcomed, contradicted, or negotiated by the frameworks of participants in the research process. At the risk of oversimplifying, disability research – particularly qualitative research – can be understood as the interaction between the researcher’s framework and that of the participants. At this point, it is necessary to note that I do not mean that the disability framework at the abstract level determines an individual's experience. I would not position such a framework above material experience. Rather, it is fair to say that the disability framework has been confirmed in a social / historical context by material experience. Therefore, it cannot reveal itself without concrete examples. This framework is intelligible to me only when it is acted upon in reality.

Disability has been approached in a variety of ways. While further analysis is still necessary, as to how an individual or group understands disability within a social and cultural context, most approaches in the United States tend to fall into one of the disability models, namely the medical, social, cultural, and political/ legal models (Devlieger, Rusch, & Pfeiffer, 2003), as well as the religious model. When disability is discussed in the United States, it is most likely to be defined within one of these models. In the next section, I summarize how disability is defined in the medical and social models, as well as discuss the AAIDD (the American Association on Intellectual and Developmental Disability) definition of intellectual disabilities and its critiques from the perspective of the social model. I also consider how engagement with

participants will provide a window into how disability is constructed and defined in the Korean American community.

Medical model of disability. In spite of its short history in contrast to the religious model, the medical model has been very widely used for understanding disabilities, especially in societies that have developed a modernized, Western medical system, including the appearance of related professionals. This model describes disability as a defect, deficiency, dysfunction, abnormality, or medical problem residing within an individual (Bickenbach, 1993). In this model, disability is defined as a medically “abnormal” condition, which needs to be fixed, cured, or rehabilitated, even though having a disability is not like “being sick” or “having a disease.” The medical model also invites a personal narrative of ‘tragedy,’ on the grounds that disability reduces the individual's quality of life and puts them at a disadvantage. Because of the model’s individualized construction, disability and its attendant issues are very often approached as an inherent problem, rather than a social issue. This model is adopted not only in medical settings, but also in the surrounding social culture in general. In the context of the overarching Western project of modernization (e.g., desire for the perfect body; social conformity, etc.), our human variations are socially constructed as aberrancy (Snyder & Mitchell, 2005).

Social model of disability. Arguing against the medical model, disability studies provide an alternative perspective for understanding disability not as an internal condition but as a social phenomenon (Taylor, 2006). Although disability studies include very diverse scholarship from multiple disciplines (e.g., education, sociology, feminism, cultural studies, law, etc.), disability studies scholars share the crucial idea that “disability is a social construction, or if one prefers, [a] creation” (Taylor, 2006, p. xiii).

Before it was established as an academic field, a disability activist group in the United Kingdom, The Union of the Physically Impaired Against Segregation (UPIAS), started distinguishing disability from impairment. Thus, although impairment refers to “lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body,” disability is “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1976, p.14). In other words, it is society that disables and excludes people, by its discriminatory attitudes, barriers, and environment, rather than people’s physical, psychological, and mental characteristics, or impairments according to the UPIAS’ discussion. They claimed that society disables people with physical disability by “unnecessarily isolat[ing] and exclud[ing] them from full participation in society” (p.3). This distinction between impairment and disability and a critical approach to society as the root of disablement provided, in their words, the “Fundamental Principles” for the social model of disability, even though this binary definition would later become a site for critique among scholars¹.

Intellectual disabilities. The label of intellectual disabilities is a good example of how individuals’ different abilities are defined as having an “abnormal” condition without any concrete physical evidence. Instead, intellectual disabilities are defined by the lack of

¹ The question of how to understand the concept of impairment can lead to another lengthy discussion. While UPIAS (1976) originally understood impairment as very obvious biological traits (p.3), it is also read as a social artifact that cannot escape discursive practice, ideology, epistemology, etc. (Corker & Shakespeare, 2002; Goodley, 2001; Hughes & Paterson, 1997). In particular, it is interesting to examine how the engagement of disability studies with the current body theories critically interrogate the distinction between body and disability (Corker, 2001; McRuer, 2010; Samuel, 2002; Siebers, 2001). Borrowing Judith Butler’s argument in *Bodies that Matter* and applying it to the impairment/disability dichotomy, from the beginning when we recognize or acknowledge someone’s impairment, our concept of impairment may already be working as a norm to materialize our body in a certain way.

presentation of supposedly intellectual behaviors in response to test items and observed daily living skills. Deficiency in intellectual functioning is determined through the statistical concept of a normal curve and standard deviation. The definition of the American Association on Intellectual and Developmental Disability (AAIDD) is a good example of this labeling practice.

The AAIDD definition of intellectual disabilities. Beginning with the publication of their first manual in 1910 (Committee on Classification of the Feeble-minded, 1910), the AAIDD has made a great effort to establish a definition and classification system of intellectual disabilities. The definition has been changed many times, along with the identifying term for disability itself (i.e., moron, feeble-minded, mental retardation, and intellectual disabilities). The main concern of this scholarly work is how properly to distinguish people with intellectual disabilities from those without it, with the “good” intention of providing appropriate services and education. In 2010, the eleventh and most recent edition of *Intellectual Disability: Definition, Classification, and Systems of Supports* was published (Schalock et al., 2010). The 2010 AAIDD definition of intellectual disabilities, which is very similar to the previous definition (Luckasson et al., 2002), reads as follows:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior, as expressed in conceptual, social, and practical adaptive skills. This behavior originates before the age of 18. (p. 1)

For this definition, the AAIDD used a multidimensional model of human functioning, where human functioning is determined by two major components of five dimensions (intellectual abilities, adaptive behavior, health, participation, and context) and the role of support (Buntinx & Schalock, 2010). According to the multidimensional model on which the AAIDD definition was based, intellectual disabilities are the significant limitation of human functioning because of both

impaired intellectual functioning and limited adaptive behavior, even with the benefit of individual support. While we should recognize the progress made in terms of recognizing the importance of support and context, as well as the effort to reduce stigma, the definition still promotes a deficit model of disability and reflects an ableist presumption of normalcy.

Intellectual disabilities from the disability studies perspective. The first problem of the AAIDD definition, including all different versions, is the presentation of the “impaired intellectual functioning” of people labeled with intellectual disabilities as an unquestioned fact. The AAIDD committee was very careful not to define intellectual disabilities as a fixed and internal condition, but rather as manifestation of interaction of multiple bodily and environmental factors (Schalock et al., 2010). In other words, if there were sufficient supports for people who have limited intellectual abilities as well as limited adaptive behaviors, they would not necessarily have to be defined as having intellectual disabilities. Even though this sounds similar to the social model of disability, especially in viewing disability as the outcome of interaction between individuals and social factors (Barnes, 1991; Oliver, 1990, 1996; UPIAS, 1976), it fosters the medical model of disability by confirming the existence of “intellectual impairment.” The definition itself does not include the term impairment, which is instead described by AAIDD as “significant limitation” that “originates before age 18” (p.1). However, the concept can be traced not only in related articles (Buntix & Schalock, 2010) but also in an actual diagnosis process (Schalock et al., 2012). Buntix and Schalock (2010), members of the AAIDD committee, draw a parallel between the AAIDD model (Schalock et al., 2010) and the International Classification of Functioning, Disability, and Health (ICF) model (WHO, 2002). In the ICF model, impairments are defined as “problems in body function or structure such as a significant deviation or loss” (WHO, 2002, p. 11). Thus, Buntix and Schalock (2010) explain,

The ICF domains of “body functions” (impaired intellectual functioning) and of “activities” (limitations in adaptive behavior) refer to the diagnostic criteria specified in the AAIDD operational definition of ID (Schalock, Luckasson, & Shorgen, 2007b, p.118; Schalock et al., 2010, p.1), which note that an intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior ... and that these impairments originate before age 18. (p. 285)

In short, Buntix and Schalock (2010) refer to intellectual functioning and limitation in adaptive behavior as impairments of bodily functions in the same sense as the ICF model.

The AAIDD model seems to be echoing the UPIAS model in this way, and it may seem reasonable to lay out intellectual disabilities as manifested by the interaction of multiple elements, one of which is intellectual impairment, as UPIAS states regarding impairment and disability. However, the AAIDD model does clearly differ from the UPIAS model, and where it does, there are significant problems. As the concept of mental retardation was criticized (Bogdan & Taylor, 1982; Braginsky & Braginsky, 1971; Mercer, 1973), the current AAIDD model of intellectual disabilities (Schalock et al., 2010) is likewise “seriously misleading” (Bogday & Taylor, 1982, p.6). “The term’s scientific aura is deceptive in that it conceals subjective moral and cultural value judgments” (Bogday & Taylor, 1982, p. 6). While in the UPIAS conception, impairment is at least referring to something visible, such as “lacking part of or all of a limb, or having a defective limb,” (p. 20) the intellectual impairment that the AAIDD model assumes is not actually observable, but rather assumed based on other behavioral manifestations.

In spite of its multidimensional approach to intellectual disabilities, AAIDD’s operational definition of intellectual disabilities clearly shows that one critically important condition (although not the only condition) for determining intellectual disabilities is the

presence of intellectual impairment. But what are the symptoms of intellectual impairment? Where is the biological proof that an individual has this impairment? Or, how can we know that an individual has intellectual impairment? If there is such a thing, it must be related to brain function. However, one difficulty in answering these questions is that we cannot easily see the physiological activities of brain. Moreover, even with the physiological data, there is no way to access an individual's intellectual process without some interpretation of the data. As Bogdan and Taylor (1982) state about mental retardation, "We cannot see mental retardation. Nor can hear, smell, or touch it. We infer it. In this sense mental retardation is not 'real'. Mental retardation does not exist" (p.8). In other words, intellectual disabilities are "not objective conditions but concepts that exist in the minds of people who attach those labels to others" (Taylor, 2000, p. 60).

How then does the dominant model of intellectual disabilities justify its claim of its existence as an objective condition? This model presents constructed concepts of intelligence, determining which elements constitute these concepts, making lists of behaviors and tasks that may present various aspects of intellectual function, and observing and measuring these behaviors and behavioral responses. At this point, intellectual "disability" is not all that has been constructed or created by social contexts; so too are intellectual functioning, ability, impairment, and intelligence similarly constructed. Therefore, there is no pathological or physiological proof of impairment that is observed to take place before the age of 18; there is only the interpretation of statistics of behavioral manifestations as a pathological symptom (Bogdan & Taylor, 1982; Mercer, 1973). I do not claim that some people labeled with intellectual disabilities have no difficulties in doing certain tasks that others in their age groups may be able to do. The proper supports and accommodations should be provided for them. Likewise, the social system should

be critically examined for its exclusionary posture towards people with intellectual disabilities and changed to be a more inclusive system. However, these issues can be discussed without labeling and exclusionary processes. Labeling requires fundamental reconsideration: what are we constructing or enforcing through this practice?

Dexter's (1994) analogical scenario provides an intriguing basis for rethinking our fixed notion of intellectual disabilities. He imagines a society in which the clumsy people, whom he calls "gawkies," experience social discrimination because their society emphasizes grace and style in movement, analogous to the way our society stresses intellectual skills (Dexter, 1994). Although they only lack "graceful" physical movement, the "gawkies" would find themselves socially isolated, rejected, and the objects of mockery, because all processes in this society are developed to be done with a high degree grace and skill. More fundamentally, who defines which physical movements are graceful and skilled in the first place? In such a social system, education would be directed towards physical movement, attempting to maximize "grace quotient (G.Q.)." The assumption therefore emerges that gawkies cannot speak well, walk competently, or even play games successfully. Above all, it may lead to the conclusion that they have "physical movement impairment[s]," although this cannot be directly proved. The correlation of "grace" in this hypothetical society to our concept and priority of "intelligence" is quite clear. By the means of labels not very different than "gawkies," certain categories of people, in our current educational system, are excluded from full participation in schools and in society, because they do not meet arbitrary criteria of social expectations, such as "grace." As Braiginsky and Braginsky (1971) point out,

The term mental retardation is simply a metaphor chosen to connote certain assumed qualities of putative, invisible mental processes. More specifically, it is inferred that it

appears as if retarded mental processes underline particular behaviors. Or, we infer that behavior appears as if it were retarded. (p. 15)

In this vein, what are the criteria of the AAIDD model of intellectual disabilities? What does it define as intelligence? In spite of contesting perspectives on the nature of intelligence (unitary vs. multi-dimensional), the AAIDD upholds the idea that intellectual functioning can be “best conceptualized and captured by a general factor of intelligence (*g*)” (p. 34), which means that intellectual functioning can be measured as a single trait that fairly represents an individual’s intellectual ability or deficit in intellectual functioning. This idea is clearly at work in the AAIDD’s diagnostic criterion (Schalock et al., 2010):

The ‘significant limitations in intellectual functioning’ criterion for the diagnosis of ID is an IQ score that is approximately two standard deviations below the mean, considering the standard error of measurement for the specific instruments used and the instruments’ strengths and limitations. (p. 1)

Remembering Dexter’s G.Q. (Grace Quotient) analogy, what are the elements that contribute to intellectual ability? The Wechsler Intelligence Scales and Stanford-Binet Intelligence Scales are the most widely used for obtaining I.Q. scores. The WAIS-IV produces verbal comprehension Index, perceptual reasoning index, working memory index, and processing speed index as representatives of major components of intelligence. The SB-5 tests fluid reasoning, knowledge, quantitative reasoning, visual-spatial processing, and working verbal and non-verbal memory. The degree of “intelligence” is determined through the statistical concept of standard deviation. This is problematic not only because these tests measure narrow areas of intellectual activity – and more importantly measure only areas that can be in some way measurable – but also because of its dual standard of “normal,” incorporating both

an impairment model (in Mercer's word, pathological model) and a statistical model (Mercer, 1973). In other words, in order to justify the existence of "intellectual limitation or deficit," they use a statistical model of standard deviation, which does not include any medical judgment but is, medically speaking, neutral. In other words, even though some of my own measurable traits belong to the lower 20~25% of the entire population, this is not an indication that those traits are abnormal or that they are indication of a deficit. Rather, it is statistically "normal" to include sample population with characteristics showing proper dispersion. It is not uncommon to find a variance of intelligences in multiple areas (Gardner, 2011). People have different strengths and weaknesses in terms of their intellectual abilities. Yet it is not deemed necessary to classify some of these variances as "abnormal" or "deficit," or "significant limitation," but often variances are labeled as such.

Another important critique of the diagnostic process for intellectual disabilities is that the tools for I.Q. and adaptive behaviors are "codifications of the middle-class behavioral norms of the American core culture" (Mercer, 1973, p. 37). Mercer's argument about the specificity of time and space, in terms of defining or labeling intellectual disabilities, is supported by other disability studies scholars. Bogdan and Taylor (1982) state that the presumptive label of intellectual disabilities is "not a real entity, but rather a social construction." It is a social fiction, a response to persons who are perceived as different, and a combination of value, words, and ideas (Bogdan, 1986).

If intellectual disabilities is a social artifact created in a particular society, what does the process look like? What is it that promotes the labeling process of intellectual disabilities? Throughout the course of Western history, societal perception of intellectual disabilities has been shaped by various events and ideological developments. The eugenics movement, which first

appeared in the late 19th and early 20th century, may be one example. Gelb (1995) explains that 19th century degeneration theories including the creationist, the medical/psychiatric, and the evolutionary promoted “the notorious myth of the ‘menace of the feeble-minded’ but also cast a long shadow into this century” (p. 1). In the context of evolutionary thought, individuals labeled with intellectual disabilities were seen as the “missing link” between human beings and lower species (Gelb, 1995). As another example of the historical context for constructing intellectual disabilities, Nibert (1995) describes intellectual disabilities as an outcome of capitalism:

20th century capitalism in the United States, despite its ability to create surplus wealth, has failed to bring about a substantial improvement of the lives of people with developmental disabilities because their devalued social position has been used to legitimate social inequality (p. 60).

The historical shift of productivity in society, from agrarian to capitalist/industrial, created a distinct change in the lives of people labeled with intellectual disabilities. As societies began to stress interpersonal competition in an industrial context, thereby developing the requirement of certain skills and intellectual abilities, these individuals came to be viewed as essentially a burden on society, whereas they had previously been able to participate in the society. As people began to be evaluated in terms of their economic productivity, “people excluded from the work force were viewed as economic burdens on family, ‘waste humanity’” (Nibert, 1995, p. 75).

In summary, even though the current AAIDD definition of intellectual disabilities (Schalock et al., 2010) pays attention to the social context as the location in which an individual’s limited functioning is expressed, it still focuses on disability as individuals’ issue rather than as a problem of social structure. Therefore, it seeks a solution in terms of improving an individual’s functioning relative to the social norm, instead of critically examining our rigid

system that cannot acknowledge diversity in intellectual activity. While significant scholarly work has been accomplished in disability studies in Western history, there are still many areas that need to be explored further. I believe that one of these underexplored areas is the social process of disability in various settings relating to various cultural groups. Even though the social nature of disability is prerequisite among most scholars in disability studies, the process itself depends on specific contexts, as the social model of disability claims. Without these specificities, I believe that the social model of disability does not have space to stand. Looking at Korean American community and culture in terms of their construction of disability and adulthood may provide one example of how the social values and norms of a given community construct disability, as well as how people with disabilities react to this.

Asian Americans and Korean Americans with Disabilities

General statistics. According to the 2010 census, “‘Asian’ refers to a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam” (U.S. Census Bureau, 2012a, p. 2). For the purposes of the census, the Asian population was calculated as the sum of all “people who indicated their race(s) as ‘Asian’ or reported entries such as ‘Asian Indian,’ ‘Chinese,’ ‘Filipino,’ ‘Korean,’ ‘Japanese,’ and ‘Vietnamese’ or provided other detailed Asian responses” (U.S. Census Bureau, 2012a, p. 2). In the same Census, the Asian population, including those who reported Asian alone (which increased 43%) and those who reported Asian alone or in combination with another race (which increased 46%) grew faster than any other race group in the United States between 2000 and 2010 (U.S. Census Bureau, 2012a).

In the year 2011, an estimated 6.3 percent (plus or minus 0.18 percentage points) of non-institutionalized Asians in the United States – regardless of ethnicity, male and female, of all ages and all education levels –reported a disability (Erickson, Lee, & von Schrader, 2013). In other words, out of all 14,979,500 non-institutionalized Asians in the United States, 947,500 reported a disability (Erickson et al., 2013). The estimates above are based on a sample of 138,901 persons who participated in the 2011 American Community Survey (ACS) (Erickson et al., 2013). In contrast to other races or ethnicities, Asians reported disabilities at a much lower rate than any other group (Table 1).

Table 1

Disability Population According to Race

Race/Ethnicity	Estimate (%)	<u>90% MOE</u>	<u>Base Population</u>	<u>Sample Size</u>
All races	12.1	± 0.05	307,593,600	3,028,981
White	12.5	± 0.06	228,435,400	2,337,542
Black/African American	13.9	± 0.16	38,083,100	325,231
Asian	6.3	± 0.18	14,979,500	138,901
Native American or Alaska Native	16.5	± 0.66	2,466,400	34,762
Some other race(s)	8.6	± 0.16	23,629,200	192,545

Note. Disability Population According to Race. Retrieved from Disability Statistics from the 2011 American Community Survey (ACS) by Erickson et al, 2013, Ithaca, NY: Cornell University Employment and Disability Institute (EDI).

The Congressional report on the implementation of the Individuals with Disabilities Education Act provides basic information on the disability status of school-aged children, classified by race. The report states that in 2006, “9.1 percent of the general population ages 6

through 21” in the United States, or 6,081,890 students in total, were served under IDEA, Part B (U.S. Department of Education, 2011). Considering race/ethnicity, the percentage (i.e. risk index) served under IDEA, Part B was smallest for Asian/Pacific Islander students (4.66%), while American Indian/Alaska Native students (13.86%) and black (non-Hispanic) students (12.22%) showed the largest risk indexes (U.S. Department of Education, 2011). Among Asian/Pacific Islander students ages 6 through 21 under IDEA, the largest category of disability is specific learning disabilities (35.5%), followed by speech or language impairments (26.9%), and Autism (8.9%). According to this report, “[a]utism appeared in the five most prevalent disability categories only for the Asian/Pacific Islander racial/ethnic group” (U.S. Department of Education, 2011, p. 75), while “Emotional disturbance was among the five most prevalent disability categories for all racial/ethnic groups except Asian/Pacific Islander” (U.S. Department of Education, 2011, p. 75).

The Korean population in the United States increased to 1.7 million (1,706,822) in 2010. It grew 38.9% from 1,228,427 (in 2000) to 1,706,822 (in 2010), and is the fifth largest Asian group in the U.S. – considering both those of exclusively Korean ethnicity (9.7%) and those whose background is Korean in combination with other ethnicities (8.2%) – after Chinese, Asian Indian, Filipino, and Vietnamese (Erickson et al., 2013). According to the 2012 American Community Survey 1-Year Estimates (Table 2), 5.6% (± 0.3) of the total Korean non-institutionalized population (1,745,249 \pm 36,033) – that is, over 97,000 Korean Americans – reported that they had disabilities. Approximately 8,850 Korean American children (2.0% of Korean Americans under age 18) reported disabilities (U.S. Census Bureau, 2012b).

Table 2

Disability Status of Non-institutionalized Korean American Population

	Korean alone or in any combination	
	Estimate	Margin of Error
TOTAL NUMBER OF RACES REPORTED		
Total population	1,760,428	+/-35,944
DISABILITY STATUS		
Total civilian non-institutionalized population	1,745,249	+/-36,033
With a disability	5.6%	+/-0.3
Civilian non-institutionalized population under 18 years	442,851	+/-14,618
With a disability	2.0%	+/-0.4
Civilian non-institutionalized population 18 to 64 years	1,139,115	+/-23,619
With a disability	4.2%	+/-0.4
Civilian non-institutionalized population 65 years and older	163,283	+/-6,288
With a disability	25.0%	+/-1.9

Note. Retrieved from 2012 American Community Survey 1-Year Estimates by U. S. Census Bureau, 2012b, Allegany County, NY.

Both the American Community Survey, which includes people of all ages reported as having disabilities, and the Congressional Report, which includes students of ages 6 through 21 being served under IDEA, Part B, show significant disproportionality across race/ethnicity. While there are many important discussions surrounding this topic (e.g., the over-representation of African American students in special education), here I would like to focus on specifically Asian American and Korean American issues. The percentage of Koreans with disabilities in the United States seems consistent with the percentage of Koreans with disabilities in South Korea. In South Korea in 2012 (The Statistics Korea, 2013), 5% of the total population, or 2.5 million out of 50.2 million, reported having disabilities, while only 1.15% of students from preschool to

high school (85,012 out of a total of 7,384,788) are served under Korean Special Education Law for Persons with Disabilities and Others (IIPTI, 2013).

In light of these statistics, we are led to wonder why fewer Asian/Pacific Islander individuals report disabilities, and why fewer Asian students are identified as having special needs than other racial/ethnic groups. Examining disability sub-categories will be helpful in clarifying this issue. Asian/Pacific Islander students were less likely to be served under IDEA, Part B, than students in all other racial/ethnic groups combined. Asian/Pacific Islander students ages 6 through 21 were 1.29 times *more* likely to be served under IDEA, Part B, for autism, and 1.2 times more likely to be served under IDEA, Part B, for hearing impairments, than students ages 6 through 21 in all other racial/ethnic groups combined (U.S. Department of Education, 2011). At the same time, though, Asian/Pacific Islander students were 0.26 times less likely to be served for emotional disturbance than students in all other racial/ethnic groups combined (U.S. Department of Education, 2011). This risk rate contrasts sharply with that of African American students. African American students were 2.75 times more likely to be served IDEA, Part B, for intellectual disabilities and 2.28 times more likely to be served under IDEA, Part B, for emotional disturbance) (U.S. Department of Education, 2011). While the over-representation of African American students is problematic in terms of racial profiling and segregation (Ferri & Connor, 2006), the under-representation of Asian/Pacific Islander students results in the silent failure of Asian/Pacific Islander students at risk (Cowart, Wilhelm, & Cowart, 1998; Doan, 2006). While this under-representation issue needs to be explored further in order to discover its root causes, it may be the result of Asian American students' relative tendency to be unobserved (e.g., EBD); their families' reluctance to have their children's disabilities diagnosed and/or

reported; teachers' perception of Asian students (Doan, 2006); families' high expectations of academic achievement, etc.

Since I adhere to the social model of disability and have an aversion to the process of labeling, I would not assert that more Asian students need to be "identified" as having disabilities in response to the current under-representation issue. At the same time, I do not ignore the possibility that some Asian students' needs are not easily detected by teachers, which is one of the reasons for under-representation. It is true that average academic achievement among Asian American students is higher than among any other racial/ethnic group (ACT Research and Policy, 2012), and that even among students with disabilities, they show a higher rate of graduation with regular diplomas and lower dropout rates, particularly in K-12 (NLTS2, 2003). Should we conclude, because of these "positive" facts, that the educational outcomes of Asian American students with disabilities are acceptable, even good? Perhaps, instead, they have different issues that need to be examined and discussed. The statistical data relating to the outcomes of transition to adulthood, especially for Asian American students with disabilities, warrants further analysis.

Transition outcomes for Asian American students with disabilities. The most frequently used national data for transition of youth is the National Longitudinal Transition Study-2 (NLTS2), which surveyed youth with disabilities (ages 13 through 25), their families and teachers. Using NLTS2 data to explore transition issues for Asian populations is tricky, as several data sets in the NLTS2 project exclude the reports of Asian/Pacific Islanders' responses due to insufficient numbers for each sub-category. In other words, for certain questions, there were not enough Asian/Pacific Islander respondents to generate reliable statistical data. Another issue is that the ethnicity-specific micro-data cannot be seen. It would be very helpful to analyze

differences among subcategories of the Asian/Pacific Islander group. For example, the types of paid work may be dramatically different between Korean, Japanese, Vietnamese, Chinese, and other respondents. Understanding the limits of NLTS2 data for this population, I would like to examine their residential status first.

Residential status. According to the NLTS2 Wave 3 (2005), 87.80% of Asian/Pacific Islander youth with disabilities live with their parents, which is higher than in any other racial/ethnic group in the United States. While other residential options are not very often pursued among this group, more than 10 percent of Asian Pacific Islander youth live in group homes or assisted living arrangements. Considering the percentage (0.50%) of all people with disabilities living in a group home or an assisted living arrangement, the residential status of Asian/Pacific Islander youth is atypical, whether they live with parents or in an arranged living environment. For other racial groups, the rate of living with parents decreases through ages 20 and 21, and the rate of other options, especially living on one's own, increases (1.30% at age 17 to 16.90% age 20-21). For Asian American youth, the residential status typically changes during the transition period from the parents' house to a group home or assisted living arrangement. Moreover, rather than a variety of residential options being provided and explored, the high rate of group home residence suggests that this arrangement has become a default option for many Asian American youth with disabilities. Regarding the residential issues surrounding culturally and linguistically diverse (CLD) youth with disabilities, the current research shows how living with family, instead of physically "being independent," is natural and culturally acceptable for Asian or Latino families (Black, Mrasek, & Ballinger, 2003; Kalyanpur & Harry, 1997; Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005; Zhang, Landmark, Grenwelge, & Montoya, 2010). However, a discussion about the dominant cultural norm of "being independent" (leaving

parents' house and living by oneself) on the one hand, and on the other hand respecting a "family centered culture," can in some ways mask other residential issues, such as the comparatively more segregated institutional residency of Asian Americans with disabilities, and the difficulties in enabling them to prepare to deal with residential options that do not fit in this frame.

According to the residential statistics, one tenth of all Asians with disabilities are in a group home or an assisted living arrangement, which can be interpreted as a more segregated or isolated setting than other residential options such as semi-independent living, independent living on the residential continuum, or other alternative residential arrangements (e.g., living with a roommate). Research on Korean American parents suggests that these parents have a preference for group homes for their adult children with disabilities (Kim et al., 2007). It may be important to know how many Korean youth with disabilities live in group homes or arranged living, and why it has become the preferred residential decision for Korean American youth with disabilities, as opposed to other racial groups. However, I was unable to find data around this issue, nor any general descriptive statistics about Korean Americans with disabilities. I requested related data in several institutes on Korean American communities, but there were none reported. In addition, it is noteworthy that the United States Census data and Community Survey² excludes the institutionalized population, which can include Korean adults with disabilities in either a group home or in a residential institution. In summary, basic information on where Korean American people with disabilities live is missing from current studies.

² Non-Institutional Group Quarters (GQs) (ACS) includes facilities that are not classified as institutional group quarters; such as college/university housing, group homes intended for adults, residential treatment facilities for adults, workers' group living quarters and job corps centers and religious group quarters.

Employment rate. Since the average income of Asian Americans is higher than that of any other group (U. S. Census Bureau, 2012b), there is less policy attention directed at Korean Americans in poverty. However, the poverty rate for Korean American seniors is the highest among all racial/ethnic groups (Asian American Federation, 2013). According to the year 2005 NLTS2 statistics, Asian/Pacific islander youth with disabilities are more likely to have jobs (employment rate 36.00%) than other racial/ethnic groups except White youth with disabilities (54.50%). However, in the data about secondary-school age youth, Asian/Pacific youth with disabilities have the lowest percentage of any group (77.30%) to have ever reported working for pay other than work around the house. It can be interpreted that a higher number of Asian/Pacific Islander youth with disabilities, compared to other racial/ethnic groups, have never had an opportunity to work for pay. Similarly, Asian/Pacific Islanders show the lowest rate of working paid experience in the past two years (46.50%) (NLTS2, Wave3, 2005).

Considering types of jobs across race/ethnicity, Asian youth with disabilities have a much narrower range of jobs than other racial/ethnic groups. Asian/Pacific Islander youth with disabilities rarely work in certain jobs such as cashier, food service, and skilled/unskilled labor (NLTS2, Wave3, 2005). Asian youth with disabilities may work in such a limited number of jobs because of English language difficulties, availability of community businesses, issues relating to living arrangements, or cultural expectations, etc. It may also be that these youth are provided limited career options, are subject to different parental expectations and pressures, or have limited community options for employment. There is an interesting fact about the career decisions of Korean American youth: the majority of first generation of Korean immigrants are self-employed. However, in contrast to Jewish or Latino parents, Korean parents are less likely

to encourage their children to start their own business. Certain cultural expectations may play a role in the career decisions of youth with and without disabilities.

Educational setting. Asian/Pacific Islander students with disabilities have the highest graduation rate with a regular high school diploma (68.4%), and have the lowest dropout rate (15.5%) (NLTS2 Wave 3, 2005). It seems that Asian/Pacific Islander students with disabilities have better educational outcomes than other groups. However, statistics about the LRE (Least Restrictive Environment) educational setting provide a different perspective. Considering the percentage of students by race/ethnicity and educational environment setting in the fall of 2006, “compared to other racial/ethnic groups, black (non-Hispanic) students had a larger percentage associated with “other environments,” at 6.4% and the smallest percentage “inside the regular class 80% or more of the day” (U.S. Department of Education, 2011). This is followed by Asian/Pacific Islanders, with 50% of students inside the regular class 80% or more of the day, and 5.0% of students in “other environments.” Other Environments (5.1%) include separate schools, residential facilities, homebound/hospital environments, correctional facilities and parental placement in private schools (U.S. Department of Education, 2011). The Asian/Pacific Islander students are under-represented compared to other race/ethnicity. However, in terms of the Least Restrictive Environment, Asian/Pacific Islander students with disabilities are more likely to be in restrictive environments than White, Hispanic and American Indian/Alaska Native. It is also important to note that Black and Asian/Pacific Islander groups have the largest percentages of students “inside the regular class less than 40% of the day” (U.S. Department of Education, 2011).

In summary, there is a much lower rate of identification of disabilities among Asian-Americans, particularly in learning and emotional/behavior disabilities. However, while the

over-representation of disabilities in the United States has been discussed, analyzed and reflected on the level of policy, the under-representation of Asian American youth with disabilities has not been explored much as to its causes, which can result in their invisible failure in education and transition, and which can be connected to cultural perceptions and practices surrounding disability, education, and family roles. Considering transition data, the high rate of group home residency among Asian-American youth with disabilities suggests a limitation of options for different or more independent ways of living, while the group home has become the default option among families. Discussion among policy makers and academic scholars, focusing only on either “being independent” within the dominant culture or respecting the cultural practice of living with family, makes it very difficult for Asian American youth to prepare for situations in which the family is not available as a support system, or when youth and their families lack the resources to build up support circles for independent living. This problem seems to create social segregation (e.g., group home or institute, lack of opportunity to work in the community, more segregated classes, etc.) for significant numbers of Asian American youth with disabilities, despite reports that the majority in this group have a degree of success in their adult lives (e.g., graduation, income, job, etc.).

Transition for CLD Students with Disabilities and Their Families

Traditional framework of transition in special education. Transition usually refers to the process of movement from secondary education to the post-secondary stage, such as going to college, leaving home, getting a job, etc. It also indicates the path from adolescence to adulthood. The following definition, which was adopted by the Division of Career Development and Transition (DCDT) in the Council for Exceptional Children, shows the broad framework that special education has used for the transition planning process:

Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult agency services, and natural supports within the community. The foundations for transition should be laid during the elementary and middle school years, guided by the broad concept of career development. Transition planning should begin no later than age 14, and students should be encouraged, to the full extent of their capabilities, to assume a maximum amount of responsibility for such planning. (Halpern, 1994, p. 117)

By focusing on physical movement, in special education, transition has been approached in a linear way. It is defined as a process of moving from place A to place B, or from stage A to stage B. For example, in the Encyclopedia of Special Education, Transition is defined as “the process of changing from one condition or place to another. ... *from* preschool *to* school environment, transition *from* school *to* post school environment” (Transition, 2007). Similarly, Wehman defines it as “life changes, adjustments, and cumulative experiences that occur in the lives of young adults as they move *from* school environment *to* independent living and work environments” (Wehman, 2006, p. 4).

In addition to the general definition of transition, its legal definition plays an important role in practice. In the legal framework, the Individuals with Disabilities Education Act (IDEA) requires a public agency to provide “all children with disabilities a free appropriate public education that emphasizes special education and related services designed to meet their unique

needs and prepare them for further education, employment, and independent living” (IDEA, 2004). For this purpose, IDEA (2004) defines transition services as:

a coordinated set of activities for a child with a disability that -- (A) is designed to be a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (B) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests.

The federal mandate for transition planning and services plays an important role in initiating and maintaining transition practices in the school setting (Hasazi, Furney, & DeStefano, 1999; McMahan & Baer, 2001). As a specific example, Madaus and Shaw (2006) show that the requirement of transition planning to no later than age 16 with the combination of test accommodation is helpful for students with learning disabilities to prepare for going to college.

In addition to this linear orientation, another characteristic of the general and legal definitions of transition is that they focus heavily on functionality. In other words, the definitions exist in order to *do* something, rather than to *understand* something, in transition. The position statement of DCDT says that “[t]he best way to address the various dimensions of transition encompassed in this definition is to focus on transition *planning*” (p. 117). In special education, transition is naturally connected to school transition planning, and involves transition services that are evaluated by specific outcomes. Under this framework, students' transition outcome has been measured either in a binary (e.g., success or failure) or in a numeric way (e.g., employment

rate, school completion rate, college entrance rate, incarceration rate, etc.). The IDEA explicitly defines the transition service as “a results-oriented process” (IDEA, 2004), which means that it is intended to increase positive outcomes of students’ transitions, such as academic achievement or successful movement to post-school settings. Major transition studies in special education show this emphasis very well. It has been said that there is a “positive” change in the transition of students with disabilities in the United States because the postsecondary education enrollment and employment rates have significantly increased in the comparison of the National Longitudinal Transition Study of Special Education Students (NLTS) and the Second Study (NLTS2) (Wagner, Newman, Cameto, & Levine, 2005). In studies on evidence-based transition predictors (Test, Mazzotti, Mustian, Fowler, Kortering, & Kohler, 2009; Test, Fowler, Richter, White, Mazzotti, Walker, Khohler, & Kortering, 2009), numeric post-school outcomes in 23 articles are also used in order to determine the predictors for successful transition.

This is very similar to the outcome framework in relation to issues of transition for diverse student populations. deFur & Trainor (2012) also lay out school completion (e.g., high school dropout rate of Black and Latino students); engagement and post-secondary education (e.g., 4-year and 2-year college enrollment; far lower enrollment of black young adults); and employment (e.g., higher employment rate of white students with disabilities than their black peers) as a set of transition outcomes, although they emphasize the significance of students’ culture in the transition process in their article, unlike other major transition studies. As seen above, the traditional framework for transition in special education can be characterized as a linear and functional model, which focuses on movement and outcome. How does this influence our understanding of the transition of students with disabilities? In the next section, I will discuss

this framework's limitations, especially for reflecting the complexity of the transition experiences of CLD students with disabilities.

Limitations. While these traditional frameworks of transition in special education have been useful in practice, they also have some limitations. First of all, the linear approach to transition fits very well with the school system in which different institutional levels are lined up in sequence, for instance, college after high school. However, in focusing only on “arriving” at a certain stage, it is difficult to capture the complexities of transition. For example, many Korean American parents prefer a group home as a future residence for their children with disabilities. In the linear framework, the transition studies may seek a way to guarantee a successful move to a group home with appropriate services. However, it may be difficult to investigate what kind of space is produced in this process and how young people with disabilities negotiate the new space (Holdsworth & Morgan, 2005). In many cases, the stages of people's lives are not neatly divided, clear, and absolute, but vague, uncertain, and blended. Stated simply, we are expected to be adults after high school or college, but in reality it is difficult to understand how we actually become adults. It is necessary, therefore, to understand the complexity of when and how transition occurs.

In a similar vein, the functional definition of transition or transition services in special education and IDEA states which kinds of goals and services should be provided in the transitional planning process for students, families, professionals and education agencies. And the importance of transition outcomes cannot be ignored, particularly in situations where there are many marginalized groups of students with significantly less “success” in these areas. However, this does not give a comprehensive idea of what transition to adulthood means to individuals with disabilities and how they experience their transition as a negotiating process,

because many dimensions of transition cannot be fully described with numbers, “success/failure,” and service lists. In addition, this emphasis runs the risk of re-marginalizing youth after “re-failure” to achieve the transition goals (Holdsworth & Morgan, 2005).

Last, the traditional framework of transition rarely captures the cultural aspects of transition. None of the definitions by IDEA (2004), DCDT (Halpern, 1994), and Wehman (2006) mention the significance of cultural factors in transition. The IDEA lists students' strengths, preferences, and interests as the special needs that should be considered in transition planning, but not an individual student's social and family culture. It may be argued that cultural aspects have been discussed under the transition for CLD students. However, “culture” is not something important only to minority groups. For example, the DCDT counts self-determination as one of the major components for the transition planning process, along with self-evaluation, identification of post-school transition goals, and selection of appropriate educational experience. The current transition studies for CLD students with disabilities re-illuminate the main ideas of self-determination as well as independence as a cultural concept, which can be understood and practiced in a variety of ways depending on different cultures (Frankland, Turnbull, & Wehmeyer, 2004; Zhang, Landmark, Grenwelge, & Montoya, 2010). Even for students from European American backgrounds, their social culture has an impact on their transition. What about the transition experience of a female youth in an urban area, for example? In what ways is it different than that of a male youth of the same age in a suburban area, in terms of their residence plan, career, or social relationships? The traditional framework is insufficient to answer these questions. Considering the multiple / intersected identities of students with disabilities in various social contexts, the traditional framework of transition has very clear limitations in explaining their interactions in the process of transition to adulthood.

Although the traditional approach to study of transition in youth has been criticized for its excessive focus on achievement and for ignoring youth' transition experiences (Bynner, 2001; Cohen & Ainley, 2000; Holdsworth & Morgan, 2005; Te Riele, 2004; Valentine, 2003), special education seems to hold the traditional framework very firmly. Fortunately, the current transition research on CLD students with disabilities shows an imperative need to take account of "culture" in transition planning and practice. In this vein, the following summary of the current research in this area will be helpful to frame the future direction of transition studies in general.

Cultural issues. Along with an increased understanding of the importance of cultural roles in students' general learning process, special educators have recently been required to provide transition planning and implementation, which is more sensitively tailored to individual students with respect to their cultural background (deFur & Trainor, 2012; Geenen, Powers, Lopez-Vasquez, & Bersani, 2003; Greene, 1996). Since the main concepts around transition, such as disability, adulthood, lifestyle, career development, family relationships, etc. are not universal across cultures but highly socially constructed concepts, it seems impossible for educators to meet students' needs in their transition period without considering their cultures. deFur and Trainor (2012) said, "Existing transition models, however, rarely depict or explicate what roles one's cultural identities or the systemic cultures play during postsecondary transition" (p.280). Despite an increased emphasis on the importance of culturally relevant transition planning and practices, many transition plans in schools do not incorporate culturally responsive transition practices (Trainor, 2005). And, "[this] lack of attention may mean that transition professionals apply a single standard for transition without considering how this might affect CLD youth and their families" (Kim & Morningstar, 2005, p.92). One of the reasons for this failure is lower cultural exploration within specific ethnic / racial / disability groups. In other

words, although many educators realize their responsibility to consider their students' cultural background for transition planning and practice, they may not know the significance of their students' own culture in transition and how it can be utilized for the transition process (e.g., how would the transition be different or similar for a Korean American student in comparison to a Latino student?).

Here, I would like to summarize what we have learned from the current transition studies for CLD students with disabilities and what kind of future research can be helpful for educators to have a better understanding of the transition of CLD students. Along with the service-oriented approach for transition, it has been important to ask how a school can provide culturally relevant transition planning and practice. In this vein, the most popular research topics in this area are devoted to defining the challenges and issues surrounding the delivery of transition services, and seeking strategies for incorporating cultural consideration into the transition planning and practice for CLD students with disabilities. Most studies on Korean American students with disabilities, which will be discussed separately later in this chapter, are also centered around this topic.

In their transition, CLD students with disabilities face several challenges, including low enrollment for postsecondary education and employment, teachers' low expectations, low achievement in standardized test performance, and limited access to adult services (Trainor, 2005). The quantitative analysis of Geenen et al. (2003) shows that the families of CLD students with disabilities, in contrast to their European American counterparts, report significantly more difficulties in terms of insensitivity and discrimination by professionals, lack of accommodations, and contextual barriers including poverty and substance abuse. Additionally, in the same study, Native American, African American and Hispanic families also report

unresponsive services, typical adolescent issues (e.g., friendships), desire for optimum capability (e.g., self-sufficiency), and the importance of family and family values, as transition issues, during their focus group interviews (Geenen et al., 2003).

Among several issues in transition for CLD students, Landmark, Zhang, & Montoya (2007) paid close attention to the lack of CLD parents' involvement in transition planning. They found that African American and Hispanic American parents have less knowledge regarding transition planning and IEPs, compared to European American parents; Hispanic American and Asian American parents participated in the IEP and transition meetings less frequently or more passively than African and European American parents; the unstable employment position of African American and Hispanic American parents makes it more difficult for them to be involved in the transition planning process; and teaching cultural and family values is considered more important by minority parents than European American parents. Parents' involvement issues also appear in other studies of Latino parents.

Povernmire-Kirk, Lindstrom, & Bullis (2010) interviewed Latino parents of children with disabilities. In this research, parents report language issues (e.g., lack of school information in Spanish, lack of Spanish translators in the school, and teachers' lack of Spanish language skills); "a restricted range of services to undocumented Latino students" (p. 45); culturally biased services (e.g., problems with the transition goal of "independence"), difficulties for family participation in transition planning (e.g. parents' feeling unwelcome, and lack of knowledge); and lack of resources, as challenges they face in their children's transition planning.

Regarding the same ethnic group, Rueda, Monzo, Shapiro, Gomez, & Blacher (2005) show how Latino mothers have different attitudes, beliefs, and definitions of transition in contrast to the dominant culture, and how common assumptions about students' transition to

adulthood can be inappropriate for CLD students. In their study, Latino mothers set “a high priority on the development of life skills such as bathing, fixing light meals, and so forth” for their children with developmental disabilities. And they do not consider leaving home after high school as a transition goal. At the same time, they consider community involvement as a potential danger because of insufficient supervision for their children with disabilities. They also have a stronger “belief in their offspring’s competence” (Rueda et al., 2005, p. 407) than professionals, and have the desire to access more information. As seen in this research, parents of CLD students with disabilities may have different cultural beliefs, practices, and values regarding their children’s adult life than teachers and schools. Therefore, scholars in transition studies have begun examining transition with relation to cultural concepts.

CLD families may hold different values in connection to adulthood such as interdependence and family orientation. (Kalyanpur & Harry 1997; Kim & Morningstar, 2005). According to deFur & Williams (2002), factoring the complexities of youth’ diverse cultural background into transition planning means accepting that “concepts of successes and dreams that families hold for their children are interwoven with cultural perspectives” (p.107). As a first step in examining these cultural perspectives, Avoke and Simon-Burroughs (2007) suggest that “educators should take a look at the disconnection between mainstream values and the discrete values that affect families and students from CLD backgrounds” (p. 69). For instance, many CLD families uphold collectivism, in contrast to individualism, which European Americans are more likely to support as a mainstream value. These two different approaches can shape students’ transition and its planning process, including family involvement, occupational choices, and independent living, in different ways (Black, Mrasek, & Ballinger, 2003). The researchers state that “[f]or many students from collectivist groups, the school experience is

characterized by conflict, misunderstanding, and cultural mismatch” (p.21). This is because school demands, communication styles, and behavioral and educational expectations from an individualistic approach are very different than their own culture’s collectivist approach (Black, Mrasek, & Ballinger, 2003).

Regarding educational goals, self-determination, one of the most important concepts and skills in transition to adulthood, has been critically examined in terms of cultural variance. As a critical reflection on the universal usage of self-determination as a transition goal, scholars have given attention to CLD parents’ perspectives on this concept. Zhang, Landmark, Grenwelge, & Montoya (2010) found that CLD parents have different perspectives than European American parents in understanding the concept of self-determination, talking to the child about strengths and weaknesses, promoting self-efficacy, teaching independent living, goal setting, problem solving, and decision making skills. This study also found that most CLD parents are not familiar with the term *self-determination*. African American and Hispanic American parents did not talk about their children’s strengths and weaknesses with their children. Most parents (90% of participants) believed that their children demonstrated self-efficacy. European American parents more actively supported teaching independent living. Many CLD parents did not talk about having and setting goals. Regarding decision-making, parents may recognize their children’s own decisions, yet still see them as difficult because of their children’s disabilities.

Focusing on a more specific cultural understanding of self-determination, Frankland, Turnbull and Wehmeyer (2004) explored the construct of self-determination and disability in the Diné Navajo culture. The educational goal in Navajo culture is to raise a child as “a person who is equipped with both mental strength and an understanding of where they fit in the universe” (Frankland, Trubull, & Wehmeyer, 2004, p. 197) as well as “serving as a contributing member

for the well-being of the family and community” (p. 197). Navajo culture uses the concept of self-determination and self-sufficiency, which sounds very similar to the dominant concept. However, when looking at its construction, it plays out in a different way. As a conclusion, “[w]hile the Diné people values self-regulation and autonomy, they are operationalized more in an emphasis on the importance of interdependence and group cohesion above independence and autonomy” (Frankland, Turnbull, & Wehmeyer, 2004, p. 191). With this understanding, educators should promote or approach their Navajo students’ self-determination skills in a different way than their customary individualistic approach.

As seen above, the transition for CLD students with disabilities includes a wide range of issues. In addition to revealing the current issues and cultural components in transition, the current research also makes a great deal of effort to provide suggestions for culturally responsive transition planning and practices. First of all, in order to assess and support CLD students’ transition needs systematically, an ecological framework has been suggested as an alternative model to the existing approach (deFur, & Trainor, 2012; Trainor, Lindstrom, Simon-Burroughs, Martin, & Sorrells, 2008). This allows one to examine the interaction between four levels of a system (micro-, meso-, exo-, macro-) and an individual. For example, teachers’ negative attitudes and low expectations towards CLD students with disabilities during transition can be assessed as part of micro- and meso-systems (the interaction between microsystems). Cultural values such as interdependence, independence or self-determination – which are closely connected to transition – can be considered a microsystem which educators need to address in order to establish more culturally appropriate transitional goals and practices.

Second, the importance of educators’ cultural competence (Kim & Morningstar, 2005; Trainor, 2002; Lichtenstein, Lindstrom, & Povenmire-Kirk, 2008) and of increasing educators’

awareness of CLD students' transition issues (Trainor, 2005) are also highlighted in the literature. Considering the cultural discrepancy between CLD families and mainstream practices in schools, Avoke and Simon-Burroughs (2007) ask educators to engage in self-evaluation regarding "the disconnect between the mainstream values and the discrete values" (p.69) and specifically to develop "self-determination skills in different cultural settings" (p.70).

Considering the factor of collectivism vs. individualism in transition, Black, Mrasek, & Ballinger (2003) advise teachers to consider students' family and cultural values (e.g. individual vs. group achievement, cooperation vs. competition, etc.); family job traditions; exposure to various types of occupation; acceptable occupations; communication and personal interaction style; family view of disability; responsibility to the family; educational aspirations and financial realities; and willingness to relocate. In order to provide a culturally closer support, Wilder, Ashbaker, Obiakor and Rotz (2006) also suggest using a paraprofessional who shares the student's cultural background as a mentor.

Third, in regard to more specific practices, Oesterreich & Knight (2008) offer some tips for teachers to consider and increase CLD students' social and cultural capital for making a decision toward college attendance (e.g., "Create checklists of admission requirements and follow through with the students to make sure they are taking the right steps to meet those requirements", p.303). Trainor (2005) also recommends increasing the connection between schools and postsecondary outcomes as well as the connection to outside agencies. Obi (2006) emphasizes effective and efficient culturally sensitive leadership in order to deal with transition issues for ethnically diverse college students. Highlighting the cultural elements in transition, then, what aspects of Korean culture influence the transition of Korean American students and their families, and how does this appear in transition planning and practice? Considering these

questions, I would like to discuss the challenges Korean American families face in their children's transition planning process in the school.

Korean American youth with disabilities. In this section, I examine more closely the Korean American subgroup. Among the diversity of the population, there is much less research on Asian American students with disabilities than Hispanic or African American students with disabilities. The identities of Asian Americans are not monolithic; there are many different ethnicities in this category. Even though some ethnic groups share certain cultural characteristics, such as Chinese character writing, Confucianism, or Buddhism, even these common elements are represented quite differently from one Asian cultural group to another. For this reason, direct exploration of the experience of Korean American students and their families in the transition period cannot be replaced by research focusing on other Asian American groups.

The current literature (Cho & Blair, 2010; Cho & Gannotti, 2005; Cho et al., 2000, 2003; Kim, 2004; Kim, Lee, & Morningstar, 2007; Park, 2012; Park & Turnbull, 2001; Park, Turnbull, & Park, 2001) shows how linguistic and cultural differences negatively impact the ability of Korean American parents to utilize or access the current education system. However, they are not necessarily engaged in analyzing how Korean American youth perceive their school experiences, including transition planning and practice, and how they are shaped by the social cultural systems. Rather, available research points to the kinds of issues Korean American *parents* face in getting appropriate education and related services for their children with disabilities in the United States. In spite of their relative satisfaction with available services for their children, in contrast to mothers in Korea (Cho et al., 2000, 2003; Park & Turnbull, 2001), “cultural and linguistic differences between the mothers and professionals made it difficult for the mothers to receive information and services, and to interact with professionals” (Cho &

Gannotti, 2005, p.6). Understanding these differences and struggles is important for professionals to provide proper support for children and their families. For example, while writing a journal can be beneficial for European American mothers to relieve stress in dealing with difficulties in rearing their children with disabilities, it may not benefit Korean American mothers in the same way, due to a cultural background in which they have not been encouraged to write about their emotions (Cho & Blair, 2010). Considering the importance of the matter, I would like to summarize three challenges that Korean American families commonly reported in the literature: language barriers, different communicative styles, and lack of mutual consent on educational goals.

Language barrier. Getting rid of the language barrier is the most pervasive and obvious need for parents to become connected and informed, participate in IEP meetings, and communicate and negotiate with professionals for their children's education (Cho & Gannotti, 2005; Cho et al, 2000, 2003; Kim, 2004; Park, 2012; Park & Turnbull, 2001; Park, Turnbull & Park, 2001). First of all, Korean American mothers reported limited access to information and advocacy because most information / materials and meetings / trainings are provided in English (Cho & Gannotti, 2005; Park et al., 2001). Similar to Latino parents (Povernmire-Kirk, Lindstrom, & Bullis, 2010; Rueda et al., 2005), Korean American parents also refer to their English proficiency as a barrier for participation in the transition planning process. Many parents report wanting to have separate orientations provided for parents whose first language is not English (Cho & Gannotti, 2005; Park et al., 2001; Povernmire-Kirk et al., 2010; Rueda et al., 2005).

Language barriers make it difficult for parents not only to access materials and information but also to be informed about their children's school lives. According to Park and Turnbull (2001), Korean parents prefer not to speak with teachers by phone, because

communication is much more difficult on the phone than in writing or face-to-face. However, they also tend not to visit the classroom in order to find out about their children's school lives, because they are "afraid that the teacher might feel uncomfortable" (p. 139) with their visit or their observing the classes. This is also closely related to Korean culture regarding the relationship between teachers and parents. In other words, simply making a call or a visit and asking teachers how their children are doing would not be easy at all for them, because of both language and cultural issues. Moreover, because the majority of these participants' children are non-verbal, and thus unable to tell their parents directly about their school life, these parents are desperate for other ways to find out about their children's school lives (Park & Turnbull, 2001). In the absence of information written in their first language, and facing obstacles to learning about their children's school lives, they have a paradoxical "feeling of 'getting too much' [English written materials] and simultaneously 'wanting more' [teachers' written memos]" (Park & Turnbull, 2001, p. 139).

Next, the language barrier also affects their ability to discuss, negotiate, and advocate on behalf of their children's education. In particular, in IEP meetings, parents become passive because it is hard for them simply to process all of the specialized terms they hear at the meeting. (Park & Turnbull, 2001). In addition, many parents feel that they are "not proficient enough to discuss" (p. 564) important educational decisions about their children (Park, 2012). Because of their frustration in being unable to present all their opinions at the meeting, some parents want to prepare and organize their agendas before the meeting (Park, 2012). Korean parents also report that their passive attitude toward arguing their case with professionals, resulting from the language barrier, becomes another obstacle for their partnership with professionals (Kim et al., 2007).

In spite of their struggles to communicate at school meetings, the majority of these parents do not prefer formal translators (Cho & Gannotti, 2005; Cho et al., 2000; Park & Turnbull, 2001; Park et al., 2001) because of their cultural preference not to depend on others in making important decisions for their children's education (Cho & Gannotti, 2005). Since many translators are from the Korean community, parents feel that they risk "losing face" if others know about their struggles with the school system (Park & Turnbull, 2001). Instead, they would like parents of other children with disabilities to act as informal mediators between them and the school system, to support them in advocating for their children's education (Park & Turnbull, 2001). Besides the cultural issues, efficiency in delivering messages is another reason parents would not want to work with a translator (Cho & Gannotti, 2005; Park & Turnbull, 2001; Park et al., 2001). In terms of time efficiency, they worry that they cannot complete their agenda if they spend extra time on translation (Cho & Gannotti, 2005). Even in terms of the quality of translated messages, the parents are dissatisfied with formal translators provided by the school district because of their limited knowledge of the vocabulary being used at the IEP meetings (Cho & Gannotti, 2005). Moreover, they feel that formal translators are more likely on the school's side (e.g., focusing on convincing parents instead of "deliver[ing] their assertiveness to [professionals]" (Park & Turnbull, 2001, p. 137). This language barrier issue becomes even more complex when it is combined with different communication styles between families and teachers.

Different communication style. One major element that has been studied for the impact of cultural differences is communication style and its impact on the interaction between parents and professionals (Harry, 1992; Kalyanpur, 1998; Kalyanpur & Harry, 1997). The Korean culture of compliance with teachers and non-assertive communication style become an

impediment for equal partnerships between Korean American Parents and professionals (Kim et al., 2007). This cultural situation makes it difficult for parents to advocate for their children in interactions with teachers or service providers. Korean parents have a tendency to use the “most modest expression rather than directly criticizing professionals” (Park, Turnbull, & Park, 2001, p.163). As a result, they may be unable to discuss their disagreement with professionals (Park, 2012; Park, Turnbull, & Park, 2001) or to be assertive when facing teachers’ reluctance to accept their requests (Cho & Gannotti, 2005). Parents realize that “silence and obedience is not virtue anymore in the United States, where assertiveness is important in communication” (Park & Turnbull, 2001, p. 138). In addition, because situational cues are very important for Koreans to develop a conversation, difficulties in catching the situational cues in English spoken conversation also create problems for their attempts to communicate (Park & Turnbull, 2001).

The inability to have good communication because of the language barriers and different communicative styles can result in negative interactions or unsuccessful relationships between parents and professionals. In a similar vein, Povernmire-Kirk et al. (2010) stated, with respect to Latino parents’ experience, that “the existing language challenges and lack of adequate translation services, coupled with cultural differences in expectations, increased opportunities for miscommunication or lack of communication at every phase of the individualized Education Program and transition process” (pp. 46-47). However, it should be noted that parents’ less fluent English or different communicative styles do not necessarily create these communication problems, as parents report that they can still have good, productive relationships and obtain proper support from professionals if “professionals view them as partner and respect parental input (Cho & Gannotti, 2005, p. 7) instead of “overtly display[ing] discomfort in communicating with the parent” (Park, 2012, p. 563). The fundamental key for a successful relationship would

be knowing, understanding, and accepting families' different cultures and respecting them as equal partners in the conversation.

Lack of mutual consent on educational goals. In addition to the communication issues, the cultural differences between professionals and Korean American parents makes it hard for them to set mutually consented educational goals. In Cho and Gannotti's (2005) research, Korean American parents demonstrate "a high value on academic achievement and decorous social behavior" (p. 6) which is not necessarily targeted by school professionals. When the goal is part of a transitional plan, the cultural effects of the placement of value becomes more explicit. For youth with disabilities, some transitional goals may not be relevant or preferable within their families' cultures. Here is one example of how the seemingly "obvious" educational goal of independence is not universal, especially for Korean American families:

For example, in planning the transition to adulthood, professionals may provide a range of options from which students and families can choose (e.g., if the planning is about living arrangement, options may range from independent living to residential facilities) with detailed descriptions of each option. Independent living may be a strange option to Korean American parents because Koreans do not take it for granted that young adults will leave their parents to live by themselves. (Park & Turnbull, 2001, p. 168)

Since it is common for adults to live with their parents before or even after marriage, physically independent living may not be a priority for Korean American families. Some research on families of children with disabilities from other racial and ethnic backgrounds report similar tendencies (Povenmire-Kirk et al., 2010; Rueda et al., 2005). According to Holdsworth and Morgan (2005)'s comparisons of the median age for leaving home, South Koreans leave their parents' homes much later than youth from 32 other countries in Europe, North America,

Latin America, and Australia. The median age at which Korean men leave home is 26.6, in contrast to Australia (age 18.6), US (age 21.5), or even Japan (age 22.4). In addition, it is worth noting that in Korean culture, simply living with parents does not necessarily mean that youth or adults are dependent on their parents. Although it is not possible to pinpoint the moment – as most transitional periods overlap and their boundaries are more blurry than clear cut – at a certain point, it is commonly understood that adult children will take care of their parents in their parents' houses. For this reason, staying with parents, especially in the case of an eldest son, would in fact be understood as adult children's expression of their responsibility for their parents. Therefore, in some cases, Korean Americans find it more appropriate to remain in their parents' homes than to live independently.

In spite of Koreans' preference, it should not be assumed that all Korean American families consider living with their children their most preferred option for future planning. According to the research on parents' expectations about their adolescent children's future (Kim et al., 2007), the majority of Korean American parents view a "group home" as their children's best future residential option. This may be the result of their children's need of constant care, difficult family situations including younger siblings or family stress, or lack of social support (Kim et al., 2007). Ironically, many families in the existing research said that they chose to live in the United States because of their children's disabilities (Park & Turnbull, 2001) and report benefits from having a child with disabilities here (Cho et al., 2000; Park & Turnbull, 2001). Nevertheless, they are led to consider living separately from their children (e.g., having their children live in a group home) because of difficulties in "starting the new life or surviving" (Kim et al., 2007, p. 257) in a new country.

In spite of Korean American parents' high demand for group homes, there are limited options for Korean American youth with disabilities because of issues having to do with communication and food. Korean American parents prefer Korean-managed group homes because the parents can have more comfortable interactions with Korean staff, and because those homes would provide Korean rather than typical American food (Kim et al., 2007). One Korean pastor, who has been providing services for Korean Americans with disabilities and their families, also reported to me about dietary issues. "The parents believe that their children get foodsick like people get homesick" (Kim et al., 2007, p.257). Since it seems that Korean Americans are more likely to maintain their native dietary habits, one important question that families would like to ask of service providers is whether they provide Korean food for their residents.

In terms of their relationship with staff or professionals, while parents generally report dissatisfaction with professionals working with their children, they simultaneously try to "pleas[e] future staff in residential facilities and prevent possible poor treatment by getting their children's functional skill improved in the school" (Kim et al., 2007, p. 256). Ironically, whereas educators may seek to teach students functional skills as an important part of their future independent living, parents value the same skills in their children to facilitate their relationship with caretakers in a group-home context. In this vein, youth' expected roles in the future as adults and their meanings can vary greatly, depending on the context as well as family expectations and values. As Geenen, Powers and Lopez-Vasquez (2001) point out, "[h]ow one defines 'successful adulthood,' the end goal of transition planning, is determined by culture-specific values and expectations about many important issues, such as work, community integration, role expectations, and social functioning" (p. 266).

In summary of existing literature in special education or related services for Korean American students, the language barrier and cultural differences make it hard for families to access information, advocate for their children, bring up family or cultural values as educational goals, and establish successful relationships with professionals. It also demonstrates how important it is for educators to consider the cultural differences of a specific ethnic group in order to understand students' and families' needs, plan and implement culturally sensitive instruction, and establish a good partnership with students and families. For a researcher, the existing literature gives an idea of how the experience of Korean American students and their families can be explored around their cultural identities. Since education is not often represented as a cultural practice, but rather as a neutral or universal institutional practice, it is very helpful to examine their experiences, which are often located within the conflict between dominant school culture and minority family culture. It gives not only an opportunity to provide culturally responsive education and services for Korean American students and families but also a chance to critically review the educational system. More specifically, acculturation, tension and negotiation between cultural norms and minority groups' or individuals' values relating to the educational practices in a society can be an important focus for transition research. Considering the research values, there are still a number of topics that should be discussed under the heading of transition of Korean American youth with disabilities. Next, I would like to discuss what perspectives are missing in the current research on transition of Korean American students with disabilities from the disability studies perspective and what direction the future research might take.

Transition study from the disability studies perspective. As discussed in the beginning of this paper, most research in transition studies in special education has a limited approach to

understanding transition. Even current research on transition for CLD students with disabilities, in which cultural elements play an important role in understanding their transition experiences, suffers some limitations in reflecting the complexity of transition. Here, I would like to explore the disability studies perspective as a tool for this purpose, for the current research on transition for Korean American students with disabilities.

I would like to use the disability studies perspective as an alternative perspective to the traditional model of transition for youth with disabilities that I discussed above. Disability studies, centered on the social model of disability, has been developed in various disciplines. In particular, since the formal establishment of the American Educational Research Association (AERA) as a Special Interest Group in 1999, disability studies has played a great role in challenging dominant educational and research practices involving students with disabilities, such as the “distinction between research about disabled students and research about all other students”; “the objectification of disabled and labeled students;” and “the scientized reification of deficit constructs and identities” (Danforth & Gabel, 2006, p. 3). This emerging analytical framework provides a basis for exploring hidden power relationships such as gender hierarchy, ableism, and multiple oppressions. The social model of disability, which is a core part of disability studies and a theoretical background for disability activism, has been very useful for uncovering how people are “disabled” and oppressed less by their bodily impairment than by ableist ideology and social structure. However, focusing only on social constructions of disability has failed to explain some aspects of the subject, particularly by dismissing bodily experience. In the embodiment theory of disability studies, we can look at the lived experience of people with disabilities in connection to both patriarchal and ableist social systems. In addition to the social model of disability, disability studies has influenced this research in two ways. First, the

experiences of participants with disabilities themselves form the center of this research, in particular for understanding the meaning of their disabilities, adulthood and culture, as well as our social system relating to disability. Second, disability is understood as a result or part of an interlocking system that simultaneously affects other minority group issues; disability identity does not stand by itself but intersects with other identities such as race, gender and class.

Danforth & Gabel (2006) said, “Disability studies often privileges the voices of those closest to the disability experience, primarily the disabled and their families and loved ones” (p. 10), which sometimes can create tension with educational institutions or related professionals. They are the ones “who know the most about their difficulties” (p. 19) and who can teach us with their words (Bogdan & Taylor, 1982). Thus, transition and related programs should be defined not by the formally advanced purpose of the process and expected participant roles, but by the people who actually participate in it. As Bogdan and Taylor (1982) state about the importance of autobiography, “people participating in a program [should] define their own involvement” (p. 19).

Voice of students with disabilities. All participants for the current studies on Korean American students with disabilities (Cho, & Blair, 2010; Cho, & Gannotti, 2005; Cho et al., 2000; Cho et al., 2003; Kim, 2004; Kim et al., 2007; Park, 2012; Park, & Turnbull, 2001; Park et al., 2001) are Korean American or Korean parents, the majority being mothers, of students with disabilities. Rueda et al. (2005) point out that it was striking to find “the lack of a shared perspective between these mothers and the system designed to help them and their children” (p. 411). Considering the power hierarchy between families and professionals, capturing parents’ voices is certainly welcome. However, it is also striking that the transition experiences of students with disabilities from CLD backgrounds are rarely shared and discussed, even in

contrast to their parents' perspective. While the attention paid to students' involvement in the transition planning process has increased (Powers, Turner, Westwood, Matuszewski, Wilson, & Phillips, 2001; Thoma, Rogan, & Baker, 2001; Wehmeyer, 1995; Williams-Diehm & Lynch, 2007), even in this area, studies do not directly investigate students' experiences in their daily lives during the transition period. Rather, they focus more on experimental practices incorporating students' involvement in specific, limited circumstances such as the transition planning time. As a result, ironically, there is no examination of how Korean American youth experience the process of "becoming" adults with disabilities in Korean culture culture. It seems that educators and families work very hard to facilitate a positive experience for students in transition, without knowing what that "transition" actually means to youth and adults with disabilities.

In disability studies, the embodied experience of people with disabilities is considered the most essential resource for knowledge. In order to have a better understanding of their process of transition to adulthood, it is imperative to bring in the experience of youth and adults with disabilities. For example, acculturation, tension, and negotiation between cultural norms and minority group values or individuals' values in society are important topics of focus in this field. Use of the family perspective may be successful for capturing the relationship or tension between the dominant American culture and minority cultures. However, this cannot be a substitute for the students' own perspective.

In spite of the limited amount of research on Korean American students' experience in transition, the existing research, and especially the narratives of participants, shows the necessity of learning students' own ideas and experiences, not only of those with disabilities from CLD background, but of any population, with and without disabilities, in transition. Students' future

residential plans are a good example. Most literature puts significant emphasis on the cultural differences in family expectations for their children's future independence, particularly their residential situation after high school especially among Asian American and Latino families (Kim et al., 2007; Povenmire-Kirk et al., 2010; Rueda et al., 2005; Trainor, 2002, 2005). The connected concept of independence is explained in a similar way, as well. While it is common among Caucasian parents to perceive independence as a goal of transition, interdependence in the family is a more welcome concept in Latino and Asian families. There is no doubt that these findings raise an important question about independence, or independent living, as a "universalized" transition goal, and suggest different approaches for CLD families. However, the existing research seems to miss the simple point that students from CLD families themselves may have different ideas about their own future residence and independence / interdependence than their parents as well as mainstream society.

The time when people leave their parents' home varies a great deal not only among different cultural groups but also within any given racial / ethnic group (Holdsworth & Morgan, 2005). The difference between generations is one important element in transition studies, not just in the special education field, but in youth development in general (Apter, 2001; Rossi & Rossi, 1990). According to the current discourse in transition, Latino youth are "likely" to leave their parents' house after marriage, which is generally much later than their Caucasian counterparts. However, the upcoming generation may have experienced a change of ideas about being independent. They may struggle to persuade their parents to "allow" them to leave, because of the culture of their parents' generation. Similar situations may be found in Korean families. Many Korean American parents report that they prefer a group home as the future residential option for their children with disabilities. However, the reasons behind this preference do not

include their children's interests or opinions. Moreover, the preference for group homes is connected to the parents' perception of their children's disabilities. This is discussed in the following section, about handling the multiple identities of Korean American youth and adults with disabilities.

Capturing intersected multiple identities in transition. Second, disability is understood in this research as a result or part of an interlocking system that simultaneously affects other minority group issues. Disability identity does not stand by itself but intersects with other identities such as race, gender and class. For example, Ferri and Connor (2005) provide an insight into how, historically, ableism and racism have intersected in order to foster resistance against the school desegregation and inclusion movement. They conclude that, "disability and race should be understood primarily as interactive social constructs and not distinctive biological markers" (p. 453). Another disability studies scholar, Erevelles (2010) also shows, through narratives, "how individuals located perilously at the intersections of race, class, gender, *and* disability are constituted as non-citizens and (no)bodies by the very social institutes (legal, educational, and rehabilitational) that are designed to protect, nurture, and empower them" (p.127). In this vein, my participants' disability identities and their experiences are to be read and analyzed in connection to their other identities such as gender, class, race and ethnicity, as interconnected parts of an oppressive system instead of as a stand-alone axis. In particular, it is useful to examine how ableism in the transition to adulthood interplays with their Korean American identity.

The existing literature in transition fails to address the multiple / intersected identities of Korean American youth with disabilities. It is uncommon, therefore to see analyses of "postschool outcome data across groups of youth, focusing on a combination of racial/ethnic,

socioeconomic, gender, and disability backgrounds, and thus more accurately representing a person's lived experience" (Trainor & Kim, 2013, p. 125). In spite of the lack of scholarly attention given to the intersectionality of students' multiple identities in transition studies, minority parents in Geenen and his colleagues' study (2003) describe these identities' combined impact on their children's lives, typically as "larger obstacles than either barrier by itself" (p. 36). One parent in their study said, "[I]f you have to deal with the racism and you have to deal with the stigma that goes with some kind of difference of having a disability, it really is difficult." (Geenen, et al., 2003, p.36). Intersecting identities also impact transition outcomes. For instance, Oesterreich & Knight (2008) discuss how working-class CLD youth are underrepresented in college attendance. They recommend specialized services that consider the complexity of SES, gender, and race. Multiple social systems, including family, community, and society, interact with youth' multiple identities.

Going back to the example of Korean American research, parents' preference for group homes as their adult children's residence (Kim, Lee, &, Morningstar, 2007), as opposed to more inclusive options (e.g., semi- or independent living), was not viewed critically as a possible example of multiple oppression due to both immigrant and disabled status. Similarly, while the current research questions the universal goal of "independence" or "self-determination" as a Western value in contrast to Korean family values, it does not examine the fact that disability is constructed as a family burden without recognizing the interdependence and solidarity within the family, especially during the transition to adulthood. Most transition studies fail to show existing oppressive practices resulting from the able-bodied standard, which many Korean American parents maintain in their perception of disabilities. In other words, the current research cannot challenge ablest assumptions about "adulthood," because it focuses mainly on Korean American

families' culture instead of looking at the interaction between various social systems and youth's identities.

Besides ethnicity and disability, there are other intersecting experiences that have not been explored in the existing literature (e.g., how gender, class, race, age and other identities are entangled, resulting in greater or lesser oppression). Feminist disability studies provide a method to untangle and visualize disabled people's identities not as essentialized but as complex identities built on the intersection of powers around them. Most current research constructs ethnic diversity as a challenge rather than something that can be celebrated. The following statement by Wilder, Ashbaker, Obiakor & Rotz (2006) shows their perspective on diversity:

Ethnically diverse learners have added challenges, such as worldviews, values, language, family involvement, level of acculturation, expectations, decision-making style, meaning of work, importance of money and social status, and role models that may be dissimilar to the dominant school and work cultures. (p. 22)

It cannot be denied that students from minority backgrounds face added challenges because of the discrepancy between their cultures and dominant culture. In the article (Wilder, Ashbaker, Obiakor & Rotz, 2006), the authors try to offer practical suggestions for supporting Latino students with disabilities. However, while they focus on solving issues that "ethnically diverse learners have added" (p. 22), they do not reveal the social structures that actually oppress and marginalize CLD students with disabilities and do not present the multiple diversities and these students' resistance that can be celebrated as a tool to examine the dominant culture.

In the literature review, I have critically reviewed the statistics, the traditional framework of transition in special education and current studies on transition for CLD students with disabilities, as well as for Korean American families in special education. Considering the

contributions and limitations of the current research, I explored various methodological and theoretical frameworks that can help me to explain the adulthood of Korean Americans with disabilities in a more nuanced way. In my opinion, bringing experiences of youth and adults with disabilities must be the first priority for transition study. Next, the interaction between their multiple identities and social structures can be examined. In this research, these two research focuses are used to understand “adulthood” or “becoming an adult” in a more complex way, as a process of an individual’s cultural negotiation.

CHAPTER 3: METHODS

Critical Ethnography

Because the field of special education focuses primarily on the functional ability of youth and adults with disabilities – a discourse that assumes a lack of adult competence - the perception and practices of adulthood of individuals with disabilities are not very well known. This research explores the way youth and adults with intellectual disabilities participated in Korean American cultural practices that surround transition to adulthood. In this vein, my research focused on three dimensions: the daily experience of Korean American adults with disabilities; Korean American cultural practices relating to disability and adulthood; and the relationship of both of these elements to the less visible broader social system (i.e., elitism and ableism). To address these multi-dimensional questions, I incorporated a critical ethnographic method (Carspecken, 1996) in this research. Critical ethnography is described as “ethnography as critical theory in action” (Carspecken, 1996, p. 13). In other words, not only is it generally a useful tool for exploring cultural themes, but it also shares a certain value orientation with other critical researchers, and provides strategies and examples for analyzing social systems in connection to research findings.

Critical theory of power. The term *critical* is defined as “using or involving careful judgment about the good and bad parts of something” (*Merriam-Webster's online dictionary*, n.d.). However, within critical theory, critical has a more specific meaning. First, it refers both to introspection on the condition of mankind’s capability to perceive, speak, and behave, and to reflection on the oppressive systems that human beings produce (Park, 2001). Horkheimer (1972) defined critical theory in contrast to traditional theory. While traditional theory attempts to “integrate facts into conceptual frameworks” (p. 199), not problematizing reality itself but maintaining the status quo, critical theory does not consider facts as a separate entity from

theory, but as a product of social action (Horkheimer, 1972). In addition, the reasoning subject of critical theory is also distinctly historical, as a “definite individual in his real relation to other individuals and groups, in his conflict with a particular class, and finally in the resultant web of relationships with the social totality and with nature” (Horkheimer, 1972, p. 211).

In critical theory, the objects for critique are varied: fascism, instrumental and technical reasoning, positivism, scientific ideology, cultural industry, and crisis in post-capitalism. For Marx, critique also plays a role in unveiling ideology as a profit-making process, wherein oppressive class stratification is reproduced (Marx, 1844/1978). In a broader sense, knowledge, which is taken for granted, becomes a target for dissection in critical social research because it is “understood to be always a social product formed within social relations involving power” (Georgiou & Carspecken, 2002, p. 689). In this vein, critical ethnographers have a particular interest in “social structure, power, culture, and human agency” (Carspecken, 1996, p. 3) in addition to describing and interpreting cultures. Social inequalities are a major concept of critical researchers, which they aim to change in a positive direction (Carspecken, 1996; Kincheloe & McLaren, 2003; Thomas, 1993). In this value orientation, a critical researcher has an extra role. As Thomas (1993) described:

Conventional ethnographers generally speak for their subjects, usually to an audience of other researchers. Critical ethnographers, by contrast, accept an added research task of raising their voice to speak to an audience on behalf of their subjects as a means of empowering them by giving more authority to the subjects’ voice. (p. 4)

In this way, a critical ethnography approach was well-suited for this project, being concerned with understanding how oppressive practices towards Korean American youth and adults with

disabilities exist, work, and (re)produce unequal power relationships through cultural beliefs and practices surrounding the issues of their adulthood and disabilities.

There is no doubt that people with disabilities comprise one of the most marginalized groups not only in the United States, but also in the world. If they are also women members of racial or ethnic minority groups, or living in poverty, the experience of oppression is compounded. Even though the existence of oppression, especially for people with disabilities, seems obvious, the mechanism of oppression is not simple to explain. What specific conditions or oppressive practices obscured, excused, or mixed with various ideologies in mundane routines? What aspects of the (re)production of class status cannot be described simply as the product of an oppressive social system such as schooling? As Carspecken (1996) wrote:

The precise nature of oppression, however, is an empirical question and not a given belief. Much of our research attempts to clarify how and where oppression works. This is not a straightforward matter since the identities, the forms of thinking, and the beliefs of people are all ensnared within oppressive relations (p. 8).

In a similar vein, Kincheloe and McLaren (2003) assert, “[p]ower, critical theorists have learned, is an extremely ambiguous topic that demands detailed study and analysis” (p. 283).

The invisibility of oppression (the difficulty to trace it) and the importance of empirical observation illustrate the value of analyzing the oppression of people with disabilities. It is very common to consider the struggles of people with disabilities as the outcome of their inner condition rather than as the result of social oppression. Bogdan and Biklen (1977) introduced the concept of *handicapism* as a social paradigm that we can utilize to understand the experiences of people with disabilities. It is “a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral

differences” (p. 14). Using the more current term, Hehir (2002) describes *ableism* as an educational practice that fortifies prejudice against children with disabilities and contributes to lowering their academic and vocational achievement, which extends to adults with disabilities as well, as follows:

The devaluation of disability that results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with non-disabled kids as opposed to other disabled kids. (p. 1)

Campbell (2001) also defines ableism in the legal context:

A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human. (p. 44)

The concept of ableism helps us to read experiences of people with disabilities as oppression derived from the power hierarchy between able-bodies and disabled bodies. However, in spite of scholarly efforts to show ableism in various areas (Campbell, 2009; Goodley, 2014) including youth experience (McMahon, Parnes, Keys, & Viola, 2008; Slater, 2013; van Amsterdam, Knoppers, & Jongmans, 2012), many questions remain unexplored, such as how ableist assumptions vary across different cultural groups, and how they impact everybody, including people with disabilities. In addition, when we consider a set of ableist assumptions as a cultural ideology that upholds the privileged status of able-bodies, we may ask what kinds of cultural forms, meanings, rituals, and representations are used in order to maintain that status (Kincheloe & McLaren, 2003).

Considering culture as a dynamic setting in which to resist, negotiate, or acquiesce to dominant power, exploring certain cultural groups can be a valuable means of clarifying the actual mechanism of power and the role of cultural agents in the material world. In this vein, I collected empirical data showing unequal power relationships, which are stabilized, resisted, negotiated, and (re)produced through the daily cultural practices that surround Korean American youth and adults with disabilities. Within a critical framework, it was also interesting to learn how “legitimated discourses of power insidiously tell ... what belief systems and views of success may be taught” (Kincheloe & McLaren, 2003, p. 284) in the life course of youth and adults with and without disabilities in a Korean community.

Ethnography for cultural themes. The word *culture* has been a buzzword that people need to pay attention to, especially in school settings (deFur & Trainor, 2012; Geenen, Powers, Lopez-Vasquez, & Bersani, 2003; Greene, 1996). For example, culturally relevant teaching for students with special needs has been an important consideration for teachers, even though this practice in the real classroom setting is still questioned. However, culture can have very different meanings in both practice and research. In special education, cultural diversity is usually accompanied by the words *race* and *ethnicity*. Culture is structured as a fairly stable and fixed system, which includes group-consistent values and behaviors across members of certain ethnic or racial groups. Most existing literature in special education for CLD students frames culture as the social heritage or tradition of a certain group, or as explicit or implicit rules for group members. In this vein, there is an emphasis on educators knowing and accepting other groups’ cultural differences and adopting them for the transition process (deFur & Williams, 2002). On the other hand, in disability studies, disability culture is defined on the basis of shared social/political experiences, especially experiences of discrimination, oppression, and struggling.

Sharing these lived experiences with others becomes not only the basis for unity as a cultural group, despite their differences, but also the way to create new knowledge that runs counter to ableist assumptions in society. As seen in just these two areas, there are very different approaches to the term *culture*.

Since my research is positioned within special education and disability studies, in connection to my academic affiliation, it may be natural to assume a similar use of the term *culture* to what these disciplines typically use. However, in my research, the concept of culture is instead framed in the ethnographic research tradition. Ethnography as one tradition of qualitative research has developed distinct characteristics, especially regarding cultural themes, which are present but less explicit in other qualitative research methods. Ethnography is “a description and interpretation of a cultural or social group or system” (Creswell, 1998, p. 58). In this tradition, researchers explore “the meanings of behavior, language, and interactions of the culture-sharing group” (Creswell, 1998, p. 58). In other words, ethnographic research aims at “reveal[ing] what people think and show[ing] us the cultural meanings they use daily” (Spradley, 1980, p. vii). From the critical ethnographers’ perspective (Carspecken, 1996; Willis, 2000), people always incorporate the process of meaning-making in their daily living, regardless of whether or not they recognize it. Using Willis’ words (2000):

Human beings are driven not only to struggle to survive by making and remaking their material conditions of existence, but also to survive by making sense of the world and their place in it. This is a cultural production, as making sense of themselves as actors in their own cultural worlds. Cultural practices of meaning-making are intrinsically self-motivated as aspects of identity-making and self-construction: in making our cultural worlds we make ourselves. (p. xiv)

In other words, the ethnographic method is interested in spotting the cultural meanings that people produce and reproduce daily in order to understand both their worlds and themselves within these cultural worlds (Carspecken, 1996; Spradley, 1980; Willis, 2000).

In my research, culture refers to a daily practice in which an individual participates in a specific setting. In other words, culture is not abstracted or generalized cultural knowledge or beliefs outside of time and space. The analysis process explores how cultural practices across different sites are connected or disconnected to each other, and how this can be reflected on a theoretical level. Nevertheless, they are not discussed without context where cultural meaning is observed. Considering the meaning-making process, in the course of this research, Korean American youth and adults with disabilities were cultural actors who continued to interpret their worlds, position themselves within them, respond to them, and (re)produce culture. In this vein, the meaning-making process of youth and adults with disabilities, in particular surrounding their adulthood, is highlighted in this research as a cultural product of the Korean American community.

Analyzing the social systems. Critical ethnography emphasizes the linkage between daily routines observed in the field and economic, political and cultural structures (Carspecken, 1996). Traditionally, social reproduction theory claims that the social structure determines social inequalities of individuals. However, Carspecken (1996) explains, incorporating Giddens' social and system integration theory, that "actors are not forced to act by conditions: instead, they are rather strongly influenced (in the case of cultural conditions) or resourced/constrained (in the case of laws and economic conditions) to act in broadly predictable ways" (p. 37), still maintaining the possibility of "acting otherwise: acting against conditions rather than in conformity with them" (p. 37). In summary, critical ethnography "seeks to understand the

relationship of culture to social structures that largely escape the awareness of actors while influencing how they act” (Georgiou & Carspecken, 2002, p. 680).

Because of my strong interest in social systems as well as individual agents, the way that I conceptualized the social structure, especially in relation to individual experience, and the way that I actually found and identified such structures are two important questions, both in terms of the theoretical and methodological frameworks, and in terms of the individual and community levels of analyses. In the mechanical and functional understanding of social structure in education research, the determination of the social system – primarily in terms of economic class – is highly emphasized, rather than individual students’ actions. There are sufficient empirical findings to show that social systems of schools oppress minority students in order to maintain the status quo. But there are still few studies showing the process by which this happens. If we recognize that ableism and racism exist and operate, we already imply that certain social structures are present and active. But in what ways? Which forms? How can we capture these structures in a specific context? The cultural reproduction model can be helpful in exploring these questions.

Willis (1981) demonstrates the cultural reproduction model. In his research on working class male students, he reconstructs what is seen as anti-school culture, which was created by these “lads” own activities, rather than a hidden curriculum at the superstructure level, which is quite different from the explanation of the mechanical-functional model. These students’ working class status was reproduced not through the superstructure (e.g., educational institutions) but “through human agency, including the agency of those who have most to lose from these relations of production” (Carspecken, 1996, p. 183). In this process, similar kinds of working-class culture across different sites, including home, school, and work settings, play an

important role in maintaining their positive identities and their dignity amid the alienating conditions of work, while simultaneously resulting in the reproduction of their oppressive social relations (Carspecken, 1996). In his work, cultural structures are not something fixed or existing beyond individuals' actions. Rather, they are "iterated through human volition; they are never referenced in exactly identical ways from social act to social act" (Carspecken, 1996, p. 184).

The framework of cultural reproduction offers a useful way of studying the transition from youth to adulthood for youth and adults with disabilities. Existing literature tells us that youth and adults with disabilities are less likely to go to college, get stable paying jobs, or have a variety of options for living independently. Why do these things happen? We may already know the answer, namely, pervasive ableism throughout our society, which makes it hard for people with disabilities to access equal opportunities to education, employment, and residence. However, what we do not know in much detail is how ableism actually functions, how it is produced and reproduced in various contexts in which individuals both with and without disabilities continue to act and to adopt, create, and change certain cultures. This progression is something that we may be able to recognize more abstractly as a broader social system, including oppressive elements such as ableism. However, these systems do not exist completely separately from human agency. Social reproduction happens through the actions of individuals, including oppressed individuals, not necessarily by direct coercion, but more likely by daily cultural practices.

My research participants dealt with various oppressive systems including ableism, sexism, racism, ageism, etc. These issues could not be discussed apart from their daily experiences because, from a cultural reproduction perspective, these systems only work through individual agency, and they are never identical across time, space, and individuals. This is why I

needed to reach their perspective as insiders, through participant observation and interviews. In summary, considering the methodological characteristics of critical ethnography, this research aimed to find cultural patterns around and within the daily lives of Korean American youth and adults with disabilities; reconstruct cultural meanings embraced by people's language and behavior; discover particular systems which work in their context; and reflect on ways the findings connect to the theoretical level.

Research Procedures

Timeline. My data collection began in September of 2015, and ended in March of 2017. While I continued to visit my research site throughout these eighteen months, I did my most intensive fieldwork in the ten months from October of 2015 to July of 2016. During this period, I regularly traveled to this community 2 to 4 times per month, and most often stayed there for two days at a time. After the intensive fieldwork period, I visited my participants for special events such as Christmas and New Year's parties, my participants' birthdays, etc. While the key informants for this research were Korean American youth and adults with disabilities, their families and the larger Korean community were important points of research as well, in order to explore thoroughly their cultural practices. The entire research procedure timeline is summarized in Table 3.

Research site. Most observations and interviews took place in an urban county. In particular, this area has a large and growing Asian community, and it is the site of one of the largest growing Koreatowns. All participants were heavily involved in the community, meaning the greater part of their daily lives took place within that community. Most recruitment was conducted through Grace, a Christian organization for Korean Americans with disabilities. Grace was also located in the middle of the Korean community.

Table 3

Research Procedure Timeline

Dissertation Phase	Procedures	Timeframe
Data Collection	1. Recruiting participants	September, 2015 ~ July, 2016
	2. Intensive Participant Observation & Interviews	October, 2015 ~ July, 2016
	3. Follow-up Interview & Observation	August, 2016 ~ March, 2017
Data Analysis and Interpretation	1. Preliminary analysis & initial coding process	August, 2016 ~ December, 2016
	2. Analysis (stage three, four and five in Carspecken, 1996)	January, 2017 ~ August, 2017
Write-up		July, 2017 ~ March, 2018

Geographic description³. My research site was located in a major urban city in the U.S. It has one of the largest Korean populations outside of the Korean peninsula, and is also located in a very diverse county in the U.S. The neighborhood where most participants in this research either lived or worked was also one of the largest neighborhoods with a growing Asian community. The majority of residents in this area are Asians, followed by Hispanic, White, and Black, respectively, and the Korean community is the second largest ethnic community in this area after Chinese communities.

³ All geographic markers in this research are pseudonyms.

Korean American church community. Grace — the main observation setting — is a Christian group, but not the only one; many observations also took place around Korean American churches. One of the distinctive characteristics of Korean American communities is that their daily lives are heavily centered around immigrant churches. Often the daily schedules of participants with disabilities in this research, besides school or day programs, revolved around local church events (e.g., church bazaar, early morning prayer meeting, etc.). While the population of evangelical Protestants in the U.S. is 25.4% (Pew Research Center, 2014) and Christians in South Korea is 29% (Pew Research Center, 2012), 70-80% of Korean Americans in the U.S. are identified as Christian (“Korean Americans,” n.d.).

The immigrant churches play a greater role than simply that of a religious institute. While people usually visit churches for religious practices such as worship, many immigrant Koreans need to go to a church in order to acquire resources, information, and networking. Attendance in a local church has become vital for settling successfully in the U.S. It is at the local Korean church where one finds Korean food, help for language assistance and transportation (e.g., a church van or getting a ride); information on the immigration process, legal issues, and education; networking for business; leisure activities; Korean language and Taekwondo classes for children, etc. Simply, if you are on the street in this neighborhood, you would be surrounded by a variety of Korean American churches. If I were to identify the three main visible signs of a Korean community in this area, they would be Korean church buildings, Korean restaurants, and Korean cram schools, all of which happen to connect to my research findings.

Grace⁴. Korean American youth and adults with intellectual and developmental disabilities were regularly observed in Grace. This non-profit Christian organization was

⁴ pseudonym

established particularly for people with disabilities. This organization aims at not only evangelizing to people with disabilities, but also raising the Korean community's awareness of disabilities. Grace has various programs including Saturday program, after-school program, Tuesday worship, as well as a group home (i.e., Grace Home). In addition, there are often special events or activities in Grace (e.g., community picnics).

Local churches connected with Grace on behalf of people with disabilities. They were observed providing financial assistance (e.g., monthly donations to Grace; helping individuals with disabilities); space for after-school and Saturday programs; food (local churches paid for or cooked food when individuals with disabilities had events or meetings.); social relationships (participating in social/religious events as a part of youth or adult group); and volunteer work (program organizers, helpers, etc.). They offered some job opportunities as well. Six individuals with disabilities in this community regularly worked at four different churches either weekly or bi-weekly, cleaning their church buildings, including the bathrooms.

While local churches and Grace are virtually the only place in this Korean American community where assistance for people with disabilities can be found, they are also a place where discrimination and exclusion occur. Churches where youth and adults with disabilities are included as members — i.e., participating in activities together with other youth and adults without disabilities — are still very few. On the other hand, some youth and adult participants with disabilities express their strong commitment to their religious practices such as prayer, praise and worship. Simply, church and Grace form a very important place in their daily lives. But, as Ault, Collins and Carter (2013) said, support for people with intellectual and developmental disability for full participation in religious communities may be inconsistent or ignored altogether, despite the importance of spiritual and religious life.

Participants⁵.

Recruitment process. Since I did not live in a major Korean American community, it was challenging for me to find out where Korean American youth and adults with disabilities received services, which specific agencies Korean American families used for transition services, and which people might serve as “gatekeepers” for my fieldwork. In addition, almost none of the educational agencies—even districts that had the majority of Korean American students—reported the number of Korean American students with disabilities in their districts; if they keep such records at all they are not published and difficult to access. While the Chinese community in the same area had their own disability service agencies, the Korean community in the research location did not have their own agency that could provide services in both Korean and English. Without being able to locate a potential research site where I might be able to observe youth and adults with disabilities in a Korean cultural context, I considered Christian organizations in the Korean American community.

Figure 1 shows my recruitment and data collection process. For my pilot study in 2014, I visited Grace, a non-profit Korean American Christian organization which provided after-school and Saturday programs for children, youth, and adults with disabilities in the Korean American community. During the visit, I was able to observe their Saturday program, and I met approximately twenty Korean American youth and adults with disabilities there. It was the largest group of Korean American youth and adults with disabilities that one could meet in this area⁶. I decided to recruit my participants through Grace. The general recruitment and data collection process is shown in Figure 1. While I continued to observe a group of youth and adults

⁵ All names of participants and organizations including churches are pseudonyms.

⁶ While there were more community programs for younger children with disabilities, there were only two other groups that served youth or/and adults with disabilities besides Grace. Both groups were established by mothers of youth with disabilities. The first group focused on job preparation which may be an interesting research site, but it

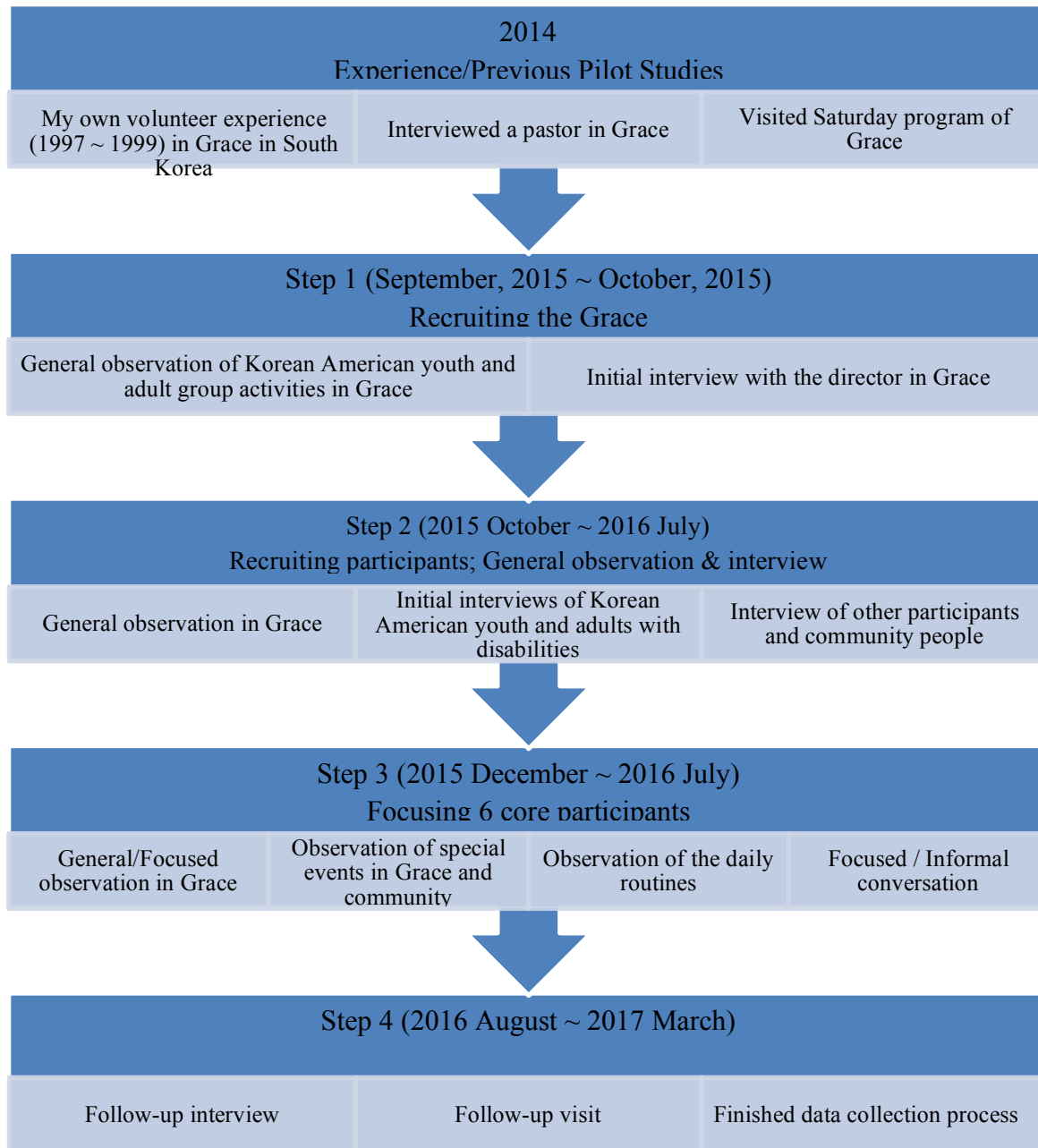


Figure 1. Recruitment and data collection process.

with disabilities in Grace throughout Saturday program and other events, I interviewed parents, staff, and community people as well. After general observation of Saturday program for youth

was just established after I began my fieldwork. The other group also had its programs running in a local church building but served younger teenage youth.

and adult with intellectual and developmental disabilities, and initial interviews with the director of Grace and twelve youth and adults with disabilities, I selected six focus participants with disabilities. I selected only six adults with disabilities from among this group, to have the opportunity to observe more of their daily lives, and to have more natural conversations. More importantly, the stories of the six focus participants were also selected since they well represented characteristics of adulthood.

Besides the twelve youth and adults with disabilities whom I interviewed – including the six focus participants – there were twelve more people with whom I had formal interviews, including parents and workers in Grace. I interviewed four mothers and two fathers of youth and adults with disabilities in the Korean American community. Grace staff included Ms. Lo, the director, Mr. Yun, the main preacher, and other long-term volunteers and staff. Most interviews were implemented as an initial conversation for gathering contextual information. The interview data in these cases were not included in this dissertation, both because their function was preliminary and because this research aimed to emphasize the voice of participants labeled with disability.

In particular, three female focus participants played a great role in this research because of their relationships with me, which were influenced by our language, gender, ages, and the nature of these participants' daily routines. I am a Korean woman who speaks Korean as the first language, and I am also younger than the three female participants. This identity had an impact on myself as a qualitative research tool.

As a researcher, I experienced how my position would differ depending on whether I spoke English or Korean with other Korean Americans. I could practically feel the immediate switch in power dynamic between the hierarchy and interacting on an equal level. In Korean, I

was automatically assigned the “upper” or “lower” level compared to my participants, depending on my relative age to theirs. When I was younger than my participants, I played the role of a servant and listener. To those who were younger than me, on the other hand, I played the role of a teacher, speaker, and advisor. But interestingly, when I spoke in English with my participants, our conversation was led instead by our shared interests and the actual content of the discussion. In contrast, when I spoke Korean with my participants, my roles as a young adult (i.e., advisee & listener) and a teacher (i.e. advisor & speaker) drove the mode of conversation. In another aspect, my conformity to the relative age rule in relation to my participants with disabilities, which is described in chapter 4, was critical to attain their trust. In particular, I happened to use this unintentional strategy to develop my relationship with three female focus participants. Our relationship as older sisters (the female focus participants) and a younger sister (the researcher) was initiated and facilitated by our language interaction. I not only called them eonni (an older sister) as well as using the proper conjugation for speaking with one’s elders, but also performed the role of dongsaeng (a younger sibling).

This example is contrary to another interaction of mine with younger participants. As soon as we spoke in Korean, they called me “Seon-saeng-nim⁷” - meaning teacher - and used respective conjugate forms, and our interaction could not go beyond the teacher-student relationship. As soon as I was called “teacher,” either by my youth participants or by other adults, I played the role of a teacher: advising, protecting, not getting into their stuff, etc. It was not my intention, but an outcome from cultural and linguistic practices. During lunchtime in the Saturday program, it was common for me to be called (or expected) to eat at the “non-disabled” adult/non-volunteer/teacher table. This is the opposite practice to other qualitative research in

⁷ This title also may be used by my participants because of my professional identity (e.g., a former special education teacher and a doctorate student), besides the age hierarchy culture.

youth and child studies. The opportunity to become their “friend,” rather than taking the role of an “adult” or “teacher,” was limited from the beginning by our Korean language and cultural practices.

In addition, it would have been particularly difficult to observe youth and young adults with disabilities who either were under age 21 or were older but attending day-habilitation programs, since their daily routines were mapped out in a formal special education / transition or adult day service program. This was one of the reasons why observation of male participants proved quite challenging as well, as most of them were youth confined to these highly structured schedules. Additionally, owing mainly to our differences in age and gender, I found it difficult to relate to the interests of these male youth participants. It is also worthy of note that the three female focus participants, whose daily lives are described as examples of adult characteristics, have the least structured daily lives and the most freedom, which allowed me to interact with them more than with any other participants with disabilities. For future research, it would be important to observe transition programs for Korean American youth and young adults with intellectual disabilities under the light of the outcomes of this research, which is about the cultural expectations of adulthood in the Korean American community (e.g., how adult serving roles are taught in a transition program).

Ranges of participants. Because my project was grounded in the understanding of culture as the product of daily practices by a given group of people, it was important for me to observe and record not only participants’ daily lives in their community settings, but also interaction between participants with disabilities and people from community. In addition, the community itself was a target for observation as well. While the key informants for this research (i.e., focus participants) were six Korean American adults with disabilities, I observed other

youth and adults with disabilities in the context of Grace, Korean Americans without disabilities around participants with disabilities (e.g., volunteers, staff, etc.), as well as people from the Korea-American community in general. Figure 2 describes the range of participants and people whom I either observed or interviewed.

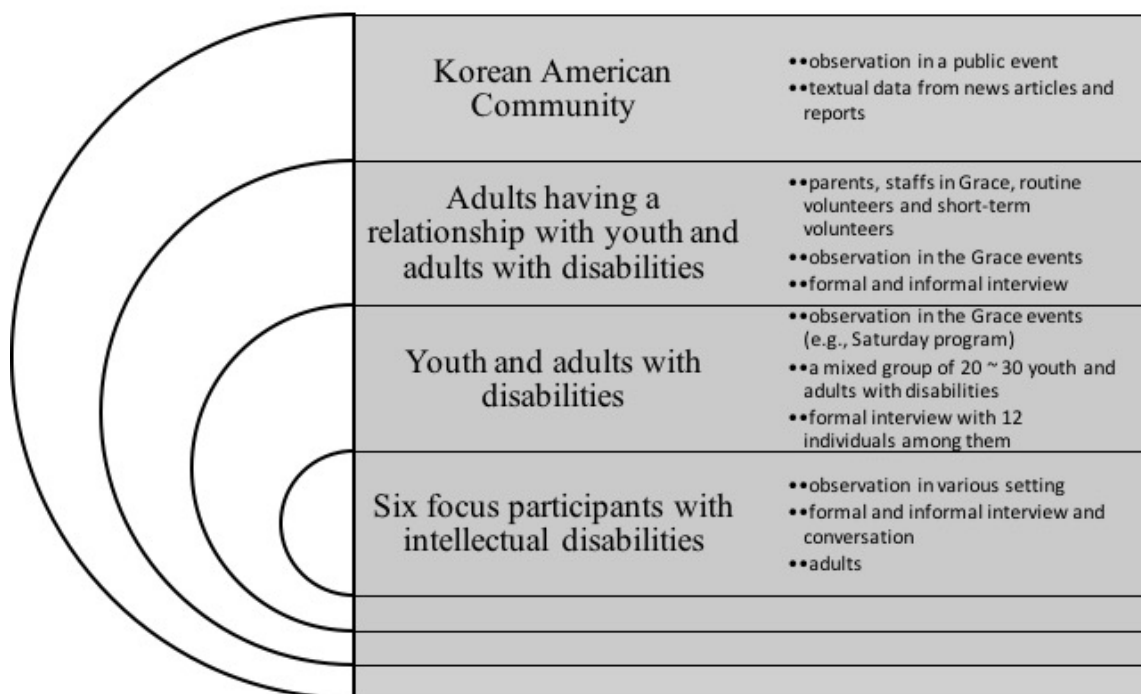


Figure 2. Ranges of participants.

Focus participants. All six focus participants (Table 4) are Korean adults with intellectual disabilities who had lived in this urban Korean American community for more than ten years. All of them attended a local church every Sunday. Jongeun and Eunju lived in the Grace Home, which is a group home run by Grace, while the other participants lived with their parents. Only Miyoung, Taejun and Junho had part-time paying⁸ jobs (i.e., church cleaning team), as described in chapter six. During my observation, Junho was temporarily fired due to

⁸ Total working hours did not exceed six or eight hours per week.

issues with his conduct (e.g., swearing, not showing up, etc.). Junho and Peter were the only ones among the six participants who received adult services; they participated in an adult rehabilitation program, which was called “Daycare” by their parents, through disability service agencies. Peter was waiting for approval of eligibility for adult services through OPWDD (Office for People with Developmental Disabilities) when I first recruited him in 2015. My observation of his museum travel, which is described in chapter six, occurred during this waiting period. During this period, he had a flexible schedule and a wide range of daily activity settings (e.g., riding the subway; visiting different museums, etc.). However, his schedule and activities were significantly constrained after he was approved for adult service eligibility and accepted in a local day rehabilitation program.

Table 4

Six Focus Participants

Name	Gender	Age*	1 st Language	Adult Service	Live in a group home	Live with Parents	Church Cleaning Team	Saturday program
Jongeun Park	Female	47	Korean		X			
Eunju Choi	Female	50	Korean		X			X
Miyoung Lee	Female	36	Korean			X	X	X
Taejun Moon	Male	25	Korean			X	X**	X
Junho Baek	Male	26	English	X		X	X**	X
Peter Jo	Male	22	English	X		X		X

*Age when research first began

**Taejun and Junho were temporary out of the cleaning team due to misconduct behaviors.

While other participants regularly attended the Saturday program that I observed, Jongeun stopped coming to Saturday program after losing interest — in her words, “it is boring.” However, she attended other special events and Summer Camp along with the five other

participants. In particular, the three female focus participants were categorized as Eonni — meaning “big sister” — participants in this research, since they share many adult experiences as big sisters in relationship to me. Their many adult characteristics cannot be explained in this research without the description of this big sister role.

While all three female participants had come to the U.S. in their late teens, all three male participants were born in the U.S. In Grace, I often observed a dichotomy as to whether an individual is Korean or American, depending on their first language. Junho and Peter were often considered American since they were comfortable speaking English. Interestingly, I rarely saw Taejun speak English, although he was born in the U.S., and his brother (younger by two years) clearly used English as his first language. The three female participants’ first language was definitely Korean, even though they might speak simple English sentences in a store or restaurant.

The Korean American ethnic identity was explored by Park (1999), and particularly the concept of 1.5 generation, *ilchŏm ose*, which is often mentioned in the Korean American community. Many young adults identify themselves as 1.5 generation. While it may indicate simple demographic characteristics, such as arriving in the U.S. at a young age between eleven and sixteen years old, it also has complex cultural and political meanings. For example, people of the 1.5 generation play a linguistic and cultural broker role between the Korean community and “dominant” American culture (Park, 1999). However, they are also ones who feel a certain conflict between Korean and American cultures, which Park (1999) described as “a milder form of Du Boisian double consciousness as a reference to and a confirmation of the existence of ambiguities and vacillations between assimilationist and nationalist tendencies in Korean American life” (p.156-157). It is interesting to note how Park (1999) highlighted the purposes

and context of usage of the term 1.5 generation in the Korean American community. It is a highly valued concept in the community because it includes “the political expectation within the Korean American community for 1.5ers to be ‘bridge builder.’”

In this sense, regardless of the age at which an individual arrived in the U.S., do my participants belong in the category of 1.5 generation Korean Americans? How do they feel about their identities between the Korean and mainstream American cultures? In my observation, the three male focus participants consumed American commodities (e.g., mainstream American pop music), while the female focus participants consumed mostly Korean cultural products (e.g., TV shows from South Korea). How do they experience this generational complexity? As Park (1999) points out, some groups of young Korean Americans, including both 1.5 and 2nd generation, share concerns about creating inclusive communities, “work[ing] towards building relations with other people of color, the oppressed, disadvantaged and despised” (p.160) with “struggle toward political empowerment of the Korean and minority communities” (p.160). Ironically, my ultimate findings in this research show how strategies of individual and community empowerment through academic excellence and charity work created exclusive practices toward the participants with disabilities in this research. It would be an interesting future project to explore the meaning of different generational categories for Korean Americans with disabilities.

Data Collection.

Participant observation. Table 5 summarizes all the different places where I engaged in observation. I observed youth and adults with disabilities, Grace volunteers and staff, and community people at local programs and events (Table 5). Many interactions with my core participants also took place in private settings. I met and observed them primarily within the local Korean American Community, but outside of formal event settings (e.g., in a commuting

van). Even when I was not with my participants, I also observed the local Korean American community itself (e.g., a Korean grocery store) and paid attention to my actions in those spaces (e.g., my eating behavior at a local restaurant). It is not an exaggeration to say that I was learning about the Korean American community as well as about my participants.

Table 5

Descriptions of Observation Events

	Events	Organized by	Participants	Places
Public	Saturday program	Grace	Youth and adults with disabilities; volunteers; staff	at two local churches (children; youth and adult)
	Tuesday Prayer Worship	Grace	Youth and adults with disabilities; volunteers; staff	The Grace Home
	Volunteer Training	Grace	Volunteers and staff	The office of Grace
	Special Events: Christmas Party, the Day for People with Disabilities	Grace	Youth and adults with disabilities; volunteers; staff; community people	at a local church
	The Summer Camp	Grace East Coast	Youth and adults with disabilities; volunteers; staff	At a hotel
	The Bazar	Korean American community fundraising organization	Youth and adults with disabilities; volunteers; community people	At a local church parking lot
	Disability Art Exhibition	the Gospel Church; Korean representative in UN	Youth and adults with disabilities; community people	At a local church
Private	Personal meetings with participants	Researcher and participants	Focus participants	Local coffee shops; participants' homes; the Grace Home; local restaurants

	Museum tour	Research and participants	Focus participants	Museum; subway stations; bus
	Cleaning job	Mr. Park (a father of a youth child with disabilities)	Focus participants	Three local churches; in a commuting van

To understand how my participants experienced and responded to cultural practices relating to disability, adolescence/adulthood, and Korean-ness, as well as the outcomes of these cultural practices, it was critical to observe their daily lives in their community. There were several techniques that I found helpful for engaging in multiple dimensions of observation. First, I used Spradley (1980)'s three different stages of observation: descriptive observation, focused observation, and selective observation. Using Spradley's observation stages (1980), I started with a wider focus (e.g., the Grace Saturday program) and then shifted to a more narrow focus (e.g., lunch time in the Saturday program) or selected observation (e.g., observing core participants at their cleaning job sites) to explore a broad range of activities of Korean American youth and adults with disabilities and to identify more significant sites or settings to observe these participants in addition to the Saturday program.

The informal analysis process was already taking place during data collection. While I observed participants and compiled my field notes, I simultaneously categorized participants' actions. And that simultaneous analysis influenced my observation process, such as looking for specific additional or relevant evidences in the research site. For example, because I had already observed the significance of volunteer activities in a Korean American community event involving my participants, it was natural to look for volunteer activities in the American Museum of Natural History when I visited there with my participants, Peter and his mother.

During observation, I kept two different types of records: a thick primary record and a journalistic record (Carspecken, 1996). The thick record was compiled at the designated sites and periods (e.g., workshop at the summer camp, art exhibition, volunteer training, etc.). I tried to keep records of verbatim speech acts, facial expressions, times, contextual details, diagrams, as well as my own comments (Carspecken, 1996). I also kept a journalistic record for observations arising from situations that were not major research sites and settings (e.g., informal conversation, general hanging out with participants, daily reflections). These events were recorded based on my memory of them after they occurred. I used a voice recorder to make a journalistic record, in particular on the road while traveling between my home and the research site. Photos, videos, google maps, and my cell phone's automatic location tag function helped me to organize and reconstruct trips.

During data collection, I was entering a new area which was very overwhelming to navigate as an outsider. Contrary to my original plan, I could not identify a theoretical saturation (Glaser & Strauss, 2012, 1967) point, at which the same instances have been observed several times, when nothing new is observed, and when enough data is collected to explain themes and concepts. There was always something new happening around my participants, even in the same program and the same setting I'd observed before, and I was often skeptical as to whether I had "enough" data to draw certain themes or connections to theory. I determined to continue participant observation until I found myself recording the same basic routines of major events (e.g., Saturday program; having coffee with participants at a coffee shop) several times (Carspecken, 1996). Even at the time of this writing, I cannot say that I finally came to know enough about my research site and participants. I can only say that I had enough data to be able to write about some parts of daily routines that my core participants happened to share with me.

Every time I reported to other participants without disabilities (i.e., parents, staff, etc.) what I had observed about my core participants with disabilities (e.g., museum guide), I witnessed their surprise in statements like, “I did not know he could do that.” It was not that they did not see them – they have known my participants much longer than I have, as they’ve seen them for more than half a day at a time, at least once per week, for several years – it was more about the invisibility of their work and, in this research, the work that could be recognized as exhibiting adult characteristics. For example, in my previous pilot study on one high school transition program in a university, it was interesting to observe which specific skills or routines (e.g., getting out a scheduler from a bag) were constituted and developed as parts of the larger picture of adult “work.” From that experience, I started this research with the perspective that adult characteristics may be traced to something that is not directly connected to a visible outcome or status (i.e., post-secondary outcomes – college, employment, housing, etc.). And more importantly, their trivial and unpaid work or skills may not be recognized or praised by others as adult characteristics, as it may be explained as an extended version of the generous concept of work (Smith, 1987; DeVault, 2014). I hadn’t noticed during data collection and analysis that what I was doing was “mapping the invisible work” (DeVault, 2014, p. 775) of my participants as adults, even though that work did not fit within the definition of labor as a job or career.

Qualitative interviewing. In addition to the participant observation, I interviewed Korean American youth and adults with disabilities, parents, staff members, and people in their community. While the formal interviews with youth and adults with disabilities was limited to the role of an introduction to each other, many informal conversations brought out more meaningful information (e.g., concerns, thoughts, experiences, etc.). Many stories that were told

in this research were collected spontaneously without my intention or plan. They were delivered over coffee, around lunch tables, or during transportation. As Kusenbach (2003) used the Go-Along method – combining interviews with participant observation – I used a concrete question about an event in which I had observed the participants taking part (e.g., “What did you hear at the worship this morning?”). I took a walk or a ride near where the participants lived or worked, while we talked about our routines, certain places – mostly Korean restaurants – that we saw during the walk or ride. Sometimes I needed to give rides to my participants, and that was a natural opportunity to hear more about them. For example, while one of my participants did not mention anything about her schooling experience in Korea during an interview, she naturally spoke about it while we talked about her current trip to Korea. Since my participants and I, like most Korean Americans, enjoyed eating out for Korean food, “eating along” was a good strategy to promote more natural interaction between me and my participants than a formal, “sit-down” interview. While the initial formal interviews were recorded and transcribed, informal conversations were reconstructed later, after I jotted down notes either during the conversations or afterward.

Textual data. The final resource was textual data, including Korean American news articles, Grace monthly newsletters, flyers and annual reports from community organizations, yellow books, etc. In particular, it was useful to understand which events happened, how they happened, how Korean American media discourse described them, how Korean Americans perceived certain topics (e.g., going to a college or food service), etc., since my observation was limited to events taking place around my participants.

Analysis and interpretation. I used several conceptual tools and stages from Carspecken’s critical ethnography method (Carspecken, 1996) in order to analyze my data. In

particular, Carspecken’s five stages helped me to articulate and reconstruct possible meanings of action and shared beliefs, knowledge, and underlying values. While I did not go through his stages, either in order or as a completed process, I used his stages selectively as a helpful tool. I summarized my process of analysis in Table 6 in comparison to Carspecken’s original five stages. It should be noted that this analytic process was not implemented in a specific order, according to thorough plans, or as a complete process. Rather, this summary represents what happened when I reflected on my process of analysis.

Table 6

Analysis Stages.

Five stages (Carspecken, 1996)	Characteristics	Stages in this research	Examples
1. Compiling a primary record	<ul style="list-style-type: none"> • Writing a thick record and a journalistic record 	<ul style="list-style-type: none"> • Data collection 	<ul style="list-style-type: none"> • Writing observation notes (“thick”) and journals
2. Conducting a preliminary reconstructive analysis	<ul style="list-style-type: none"> • Low-level coding for recurring patterns and unusual events • Initial meaning construction • Analysis of interactive power and roles 	<ul style="list-style-type: none"> • Initial coding process 	<ul style="list-style-type: none"> • Favoring Korean food • Language usage by volunteers • Coffee shop routine
		<ul style="list-style-type: none"> • Initial meaning construction 	<ul style="list-style-type: none"> • Food serving behaviors as a matter of “love”
		<ul style="list-style-type: none"> • Interpreting data by analytic frames 	<ul style="list-style-type: none"> • Contrasting roles (served vs. serving)
		<ul style="list-style-type: none"> • Looking for sharing themes across some codes 	<ul style="list-style-type: none"> • "Serving" (in age hierarchy, food, and volunteer activities)

3. Generating dialogical data	<ul style="list-style-type: none"> • Qualitative interviews • More participant observation 	<ul style="list-style-type: none"> • Informal conversation with focus participants and community people 	<ul style="list-style-type: none"> • Asking about returning of drafted youth volunteers
4. Describing system relations	<ul style="list-style-type: none"> • The relationship between the focused site and other social sites 	<ul style="list-style-type: none"> • Looking for similar practices outside of observation settings 	<ul style="list-style-type: none"> • Volunteer activity in Grace vs. Volunteer activity in a larger Korean American community setting
5. Using system relations to explain findings	<ul style="list-style-type: none"> • Analyzing and discussing findings in connection to existing social theories 	<ul style="list-style-type: none"> • Connecting findings to other literatures 	<ul style="list-style-type: none"> • Reflecting findings on theories of ableism, oppression and power, transition studies

Stage 1 and 2. After compiling records (stage 1) – a thick record and a journalistic record – I implemented the coding process (stage 2). I read my observation records several times and tried to find recurring visible patterns of interaction (e.g., the coffee time routine at Dunkin Donuts) and unusual incidents (e.g., being interested in visiting a different coffee shop, Starbucks). The initial coding helped me to select segments for which I needed further analysis. For example, after initial coding there were six major categories of themes, with twenty sub-themes. However, only the three categories that could present the best of adulthood topics were selected, analyzed further, and developed as parts of this dissertation. During the coding stage, I not only depended on “self-recurring” themes, but also looked for certain cultural topics as well. The age hierarchy system was an obvious topic that I had to explore since, as a Korean, I already knew that it was very relevant to the topic of adulthood (i.e., how were adults with disabilities perceived and treated within the rigid Korean age hierarchy system?). Even though I had learned

and observed the infantilization of people with intellectual disabilities before this project, it was still new information to witness the way it happened (e.g., the art exhibition scene) on a daily basis around my participants with disabilities, and how Koreans maintained ableist practices beyond the age hierarchy system.

Before, during, and after initial coding, I tried to “mentally [note] possible underlying meaning” (Carspecken, p.96) behind selected segments, which could be called initial meaning construction. While the natural process of meaning-making in daily life is usually tacit, researchers need to convert this process into an explicit discourse (Carspecken, 1996). This is why it is called “reconstructive” analysis, in which the meaning of interaction is “reconstructed explicitly” by a researcher. In this process, I “[went] through the selected segments line by line and add[ed] discursive articulations of tacit modes of meaning I believe[d] may underlie the interactions recorded” (p.94). For example, I observed Koreans’ repeated behaviors of food serving for youth and adults with disabilities. The meaning that Koreans attached to these recurring food serving behaviors was a matter of “love” in the public discourse of the Korean American community (i.e., the way food serving in these events was described in Korean media). But the meaning that I attributed to the public interactions across the table at meals was different than what the public discourse described, which can be explained through subsequent analytic strategies.

Because “[t]he implications involved in every act of meaning are inexhaustible in nature” (Carspecken, 1996, p.119), it is impossible to reconstruct every possible meaning. In my opinion, one feasible way to interpret data was to use analytic frames. Besides the coding and meaning construction processes, I analyzed data through certain frames which is summarized in Table 7.

The most significant analytic frames that I used during stage 2 were interactive power and roles.

The roles of serving and being served were analyzed as a power dynamic.

Table 7

Analytic Frames

Frame*	Description*	Examples
Semantic structure	Finding semantic domains, contrast sets and semantic taxonomies (e.g., work vs. non-work, kinds of work, hierarchy of work, etc.)	loving vs. loved; adults vs. children; contributing vs. receiving
Pragmatic meaning units	Searching non-discursively expressed meaning unit (e.g., role, identity, etc.)	Role of serving vs. Role of receiving
Validity reconstruction	Articulating three validity claims – objective, subjective, and normative-evaluative claims - that constitute selected meaningful acts (e.g., values, norms, beliefs, etc.)	Valued transition experience (e.g., high academic track); not-valued/not-recognized serving behaviors by participants with disabilities)
Setting negotiations and setting shifts	Paying attention to “when one actor makes a bid to alter the normative infrastructure” and when she was successful to change the infrastructure (Carsepecken, 1996, p.116)	Eunju’s subverting explanation on Korean church system (not physical space but discursive space)
Embodied meaning	Analyzing bodily posture and gestures as “enfleshed” meanings, power, culture; and their interaction.	Interpreting portrait images; Jongeun’s embodied knowledge on “good” and “bad” people; Eunju’s embodied sisterhood
Power/Oppression	Examining power relationships by using typology of power; observing the distribution of cultural milieu; and analyzing their interaction	

*Note: Frames and descriptions adapted from *Critical Ethnography in Educational Research: A Theoretical and Practical Guide*. by P. F. Carspecken, 1996, New York, NY: Routledge. Examples are added from this research.

Stage 3. In stage three, I analyzed data and used the data as supporting or opposing the possible meaning of an interaction or action that I’d hypothesized during stage two. High-level

coding was used. While the low-level codes refer to those that are “primarily objective in nature” (Carspecken, 1996, p.147) (e.g., kinds of volunteer work), high-level codes have a significant amount of abstraction (e.g., displays of contributing community membership in a young adult). Once I noticed more abstract codes (e.g., serving, fixed roles, invisibility of work, etc.), I read through the primary record slowly, repeatedly, and thoroughly, with certain codes in mind. I reviewed the data carefully to discern which behaviors and conditions could or could not be categorized under these codes. After going through stage three, I was able to see some large themes emerging, which became my thesis for this project (e.g., struggling to be recognized as an adult within the fixed role of being served).

Stage 4. In stage four, I examined the relationship among different sites of observation: the focus sites where my participants with intellectual disabilities directly and physically participated (e.g., Saturday Program, Summer Camp, etc.) and other social sites (e.g., cram schools, Korean American Community Foundation). Since my observations were limited to my participants and their surroundings, observing other private sites was beyond the scope of this research. However, it was still important to compare or contrast how the same kinds of rituals (e.g., the meaning of participating in tables) were perceived in a different or similar way. For this purpose, I used textual data such as newspaper articles or organization reports, as well as second-hand interview data.

Stage 5. In the final stage, I analyzed the connection between theories and my research outcomes. During this stage I tried to “experiment by bringing [the observational data] into forcible contact with outside concepts ... by trying to frame the whole with necessary complexity and to deliver analytic illuminating points not wholly delivered from the field but vital to conceptualizing its relationship” (Willis, 2000, p. xi). In this stage, I discussed the findings “in

light of existing macro-level social theories” (Carspecken, 1996, p.202), which included: the (re)production of ableism and culture and current models of transition education in special education.

Risks and Ethics

In conducting research, participants with intellectual disabilities are often considered “vulnerable” to coercion or harm. However, this purported “vulnerability,” which as a concept is intended to protect them from the risks of participating (voluntarily or not) in research, has its own risk of ignoring their ability and self-determination. For example, Marshall et al (2012) discussed “ethical tensions” (p. 26) between the participants’ desire to publicize their work and the research teams’ desire to maintain confidentiality in order to protect them. This tension is not unique to the research process. Considering discussions surrounding the adult lives of people with intellectual disabilities, the issue of guardianship in particular - the tension between self-determination and legal protection - has been a difficult question to resolve (e.g., how can participants be legally protected, while retaining the power to direct their own lives, instead of having their rights relegated to others?). In this vein, this ethical tension in research can be read as a micro-presentation of the conflict that adults with intellectual disabilities face. Keeping this tension in mind, I would like to summarize how I structured the consent process to minimize the risk of coercion, as well as respect the ideas of adults with disabilities, particularly in the consent process.

In particular, I made sure that the consent processes were accessible for participants, as well as for their parents or legal guardians when participants were younger than 22 years old. The forms were available in both Korean and English, and they were written in plain terms with appropriate repetition of information (Cameron & Murphy, 2007). I made sure to explain that

participation in the study was voluntary and could be withdrawn at any point, and reminded the participants of the voluntary nature of the process and of their right to withdraw at different stages throughout the course of the research. In addition, I also reminded participants that observations and interviews remain confidential and anonymous, with no exception for their families and staff who work with them.

The research process and the several stages, including the data collection, analysis, and writing process were presented to the focus participants. Often I also tried to explain the nature of dissertation work: how their stories were going to be written on papers and sometimes presented at conferences as well. It seems a critical fact how difficult it is for people with and without disabilities outside of academia to imagine the paths of circulation of their stories through the research practice. It is evident that their signing a consent form does not mean that participants understood completely what they consented to. In other words, my participants understood that they agreed to be observed and interviewed by me, but not necessarily the process after that. I also had a conversation about major research findings with some of my focus participants. While I did not get much in the way of confirmation or dispute from them, they expressed great excitement to recognize that their stories were worthy to be retold, and further willingness to talk about “more fun stuff” to me. The goal of this research is to contribute to the provision of better support for youth and adults with intellectual disabilities from diverse cultural backgrounds. I provide some suggestions that I drew from this ethnographic research on my participants’ daily lives around adulthood. Beyond suggestions, I look for opportunities and ways that I personally can assist my participants in their community as well as maintain and grow our personal relationships even after this project.

CHAPTER 4: KOREAN AGE HIERARCHY AND ADULTHOOD

In this chapter four, first, I explain how age hierarchy works in Korean culture, in particular through language practices (e.g., honorific titles). Second, while Korean American youth and adults with disabilities were also a part of these age hierarchy language practices, they often became exceptional cases even within the rigid Korean age hierarchy culture. As examples, I shared two episodes from the Grace Summer Camp and its volunteer training about exceptional language practices around the participants with disabilities. These exceptions did not reside only in language issues. Rather, they were connected to a more fundamental perception and image held by the Korean American community regarding youth and adults with disabilities. Simply, members of the Korean American community perceive youth and adults with disabilities as reflections of childhood, which I observed in two different settings — the Grace Summer Camp and the disability art exhibition. In the third section of this chapter, the Grace Summer Camp episode depicts how youth and adults with disabilities were categorized as children, and shows how this child category for youth and adults with disabilities relates to religious expectations in the Korean American community. In the second example, I describe how the image of childhood for youth and adults with disabilities was circulated and reproduced by the disability art exhibition in the Korean American community. Lastly, I provide stories of three adult participants — Jongeun as a discerning person, Junho as a mature conversation partner, and Eunju in a big sister role — as counterexamples to the childhood image of adults with disabilities in the Korean American community.

Korean Age Hierarchy

One of the most obvious cultural elements that distinguishes Korean American communities from other racial and ethnic groups, even among Asians, is the maintenance of an

age-based hierarchy. This is certainly something that Korean Americans brought with them from Korea and have continued to promote in the U.S. Similar concepts, namely age stratification and ageism, are discussed by scholars (Nelson, 2017; Palmore, 1999) writing from a U.S. context. Age stratification refers to “[a] system of inequalities linked to age” (“age stratification,” n.d.). For example, “In Western societies, both the old and the young are perceived and treated as relatively incompetent and excluded from much social life” (“age stratification,” n.d.). Ageism can therefore be a result of age stratification. However, the manifestation of age hierarchy in Korean culture occurs in ways that are more intensive, pervasive, and subtle.

In Western contexts, there is an understanding of a power hierarchy between adult and child. The Korean counterpart, however, is more complicated, sophisticated, and "exquisite," in my opinion. Within the Korean culture, specific ages are very important, in addition to the broader age ranges such as adults, teens, children, seniors, etc. The most important aspect of this process of age hierarchy is to determine the age order between two parties. Even as a researcher, my relationship to each participant varied significantly depending on whether I was older or younger than him or her. The very first thing Koreans do when meeting for the first time is to find out each other's age. It is an obvious and practical process that determines how people may and ought to interact with one another in terms of both language and manner. In other words, continuing interaction is only possible after establishing the hierarchical age relationship between two parties. Usually, this process happens privately and implicitly at first (e.g., observing how another person – whose age was already known – talks to them). You do not need to know exactly how old that person is, rather, it is important to know whether she is younger or older than you. If you still cannot figure out the order clearly after this process, or if two parties appear very close in terms of age, you need to ask. In Korean men's culture, it is often said,

“Let’s open each other’s IDs” since ID has birthday information. The age hierarchy practice was not exceptional for Korean American youth and adults with disabilities in their community. Here is the very first interaction between me and Miyong Eonni⁹ as an example.

Age hierarchy practices between the researcher and participants. In the living room of the group home that was run by Grace, five people were waiting for my interview. Most of them appeared to younger than me (late 30s), probably in their early or middle 20s. I was seated at the end of the table and started introducing myself to the young woman seated closest to me.

EJ: Hello! I’m Jung, Eunyong. What’s your name¹⁰?

(“An-nyeng-ha-**sey-yo**. Jen Jung-Eunyong-i-la-ko hap-mi-da. I-lum-i-e-ttet-khey toi-**sey-yo**?”)

Interviewee: *Jung, Miyong*

Since I did not know her age, and because it was my preference to do so with younger people anyway, I used honorific terms. This is why my sentence ended with “**sey-yo**” which is a semi-honorific ending of verbs. Miyong Eonni’s answer was brief, with no sentence ending, while she hardly showed any emotion on her face. There was a short silence between me and her. She seemed to wait for my questions. But, I felt awkward to say anything to her in Korean without knowing each other’s ages. While it was obvious whether an interviewee was younger or older than me, I could not tell about her case by judging her appearance. I need to know her age in order to decide the tone and nuance of a sentence, and proceed our conversation.

⁹ Eonni is a Korean title for addressing an older sister. It is also common to use this title among non-family members. If you are younger than a female who has a casual and close relationship with you, you would call her Eonni. I kept this title in this dissertation since three female participants who were older than me were always called Eonni, not by their names.

¹⁰ Translated sentences from Korean to English are my translations, and typed in italics. Directly quoted English sentences are not typed in italics. Romanized sentences are marked with quotation marks.

Following Korean ritual, our conversation began with finding out each other's age. Because the Korean age system is more complex (i.e., when a baby is born they are considered one year old; everyone's ages, including newborns, increase by one year together on the first day of the Lunar New Year; sometimes treating a schoolmate one year younger as a peer), it was easier for me to tell her the year I was born.

EJ: *I was born in 1980. Which year were you born?*

Miyong: 1978.

EJ: *Oh, you are two years older than me. I'm calling you Eonni from now on. Miyong Eonni!*

My participant, Miyong Eonni, was the closest to my age of the group that I met. I decided to call her Eonni, and she accepted this order very well by using "Ban-mal," meaning "talking down" when she talked to me. "Ban-mal" is not necessarily rude or impolite. It is a proper way of talking in Korean if the age order is agreed upon by both sides. While I talked to her with honorifics, she talked down to me in a legitimate way. In contrast to Miyong Eonni who immediately accepted our agreed age order, Jongeun Eonni was questioning my language usage toward her even a couple months after we first met.

Jongeun: *Why are you using "Jon-dat-mal" [meaning honorifics] to me?*

EJ: *Because you are older than me. You're Eonni to me.*

Jongeun: *You seem to be a nice person.*

As mentioned, using honorifics toward one's elders is not optional but an absolute social requirement; one is expected to follow it unless they intend to disrespect an older person. She was surprised that I, a younger person than her, kept using honorifics toward her, which implies that she was not always treated this way. Even though I used honorifics from the time we first

met, she still did not use a “legitimate ban-mal,” but rather a medium-level honorific toward me even after two months. Using honorifics was a sign of distance in relationship as well. It was not that she failed to understand that I was younger than her, but it likely meant that I was still a stranger to her.

Honorific titles. As shown in the previous conversation, the hierarchy determines each person’s title (e.g., Eonni) with respect to one another. It is rare and practically impossible to call people by their names in Korean culture unless they are same-age peers or younger. Among family members such as cousins and siblings, the difference of a few weeks or months—or even minutes in the case of twins—determines the hierarchy and respective titles in the relationship. Titles for one’s elders are: “Oppa” (an older man, spoken to by a younger woman), “Hyeong” (an older man, spoken to by a younger man), “Eonni” (an older woman, spoken to by a younger woman), or “Nuna” (an older woman, spoken to by a younger man). Anyone younger, male or female, is called “Dongsaeng” with gender identifications (e.g., “Yeo” for female or “Nam” for male). All of these titles could be translated into English as “brother” or “sister.” If the relationships are formed through school or work, there is a system of further hierarchical titles in addition to or in place of the age hierarchy. This hierarchy is determined by one’s first year at the school or one’s job title. You would refer to someone who started school before you as “Seonbae,” literally meaning the group before you. Likewise Hu-bae, the group after you, would be the title for those who began studying later than you. At work, most titles have a hierarchical relationship with each other. Coworkers who share the same job title can address each other using “Seonbae” and “Hubae,” based on their respective employment dates.

Jiyong: “Minsu!”

A Korean Babysitter: [strict voice without smile] “Jiyong, you gotta call me Minsu Hyeong.”

During data collection, I called three older female participants “Eonni.” For those who were younger than me, but not in the school system anymore, I called them by their first names with the ending “ssi.” “Ssi” can be interpreted literally as Mr. or Ms. However, if it is attached to a last name, it has the nuance of talking down to a person by implying that they have a much lower social and financial status. But when attached with a first name, it becomes quite neutral and appropriate for a person who does not have a specific title connected to any career or social status. I habitually used “ssi” with people’s first names to avoid talking down to those younger than me. This has been my subtle resistance to the Korean age hierarchy that has often been a disadvantage for young people, and particularly those individuals who are treated as children because of intellectual disabilities even after their early 20s.

The impact of age hierarchy on language determines not only titles, but also word choice and verb conjugations (e.g., “-sey-yo” in the above conversation with Miyong Eonni). There are certain words that must be used, and others that must not be used, for people who are older than oneself. For example, the normal word for birthday is Seng-il, but for the birthday of someone older than you, you would use the word Seng-shin instead. There are six different *categories* of sentence final-endings, which are ordinarily verb modifiers or conjugations, that depend on the relationships between the speaker, subject, and listener. In other words, all sentence final-endings, in questions, commands, or declarative sentences, have to be modified according to the rules of the hierarchical relationship. This is why it is critical, when meeting people for the first time, to learn whether they are older or younger than you. It has a significant impact on the way you will speak to and about that person. The role of these language variations is not merely pragmatic. It is the most fundamental element of propriety. It is an essential element of respect and admiration given to those who have lived longer and have greater experience and wisdom. It

is common to hear in South Korea that using honorifics is a way to nurture your children's upright personality which is called "inseong" in Korean (Im, 2016).

In contrast to the emphasis on respecting older people including using honorifics, Korean youth advocates criticize how youth and young adults are discriminated and oppressed by the age hierarchy system in South Korea ("Root of Oppression on Youth," 2016). Most people trace this age hierarchy back to the Confucian culture of the Chosun Dynasty (1392 A.D. ~ 1910 A.D.). The Chosun Dynasty actively used Confucianism as its standard political principle. It also established the principles for the daily behavior of the king's people – ("baekseong"). The Confucian principles of five relationships are often referred to as the source of the age hierarchy. One of these is the order between an adult and a child ("jang-yu-yu-seo"), which may be similar to the western idea of "respecting" one's elders. Ironically, observation of the age hierarchy is stricter now than it was during the period when Confucianism was declared the national "religion." During the Chosun Dynasty it was common to consider people within five years of one's own age as peers (and speak of them accordingly). The intensified or extreme version of *relative* age culture may be the result of the modern history and politics of Korea. It was after Japanese colonization that the strict hierarchy ordered by age was fortified, as a strong military and authoritarian culture arose in Korea from dictatorships and military tensions between South Korea and North Korea over four decades.

Exceptional Case of Age Hierarchy

Considering the importance of this protocol of age relationships in Korean culture, I wondered what impact the age hierarchy might have on youth and adults with disabilities. From my observations, participants with disabilities in the study often moved between various positions—at times rejecting, conforming, or reproducing these age hierarchies. Moreover,

people without disabilities in the Korean American community tried to place youth and adults with disabilities in the age hierarchies according to their age, while they also positioned these youth and adults with disabilities as exceptions to rigid cultural rules. When combined with ableism, this nearly unconditional cultural rule, the relative age hierarchy, had a notable exception. Because of pervasive ableism, adults with intellectual and developmental disabilities could not be perceived in Korean communities as adults or elders, even though the Grace staff emphasized the importance of respecting the ages of people with intellectual and developmental disabilities in a variety of ways, including Grace volunteer training especially for their annual Summer Camp. Considering the primary focus of this research (i.e., transition to adulthood and adult roles), the simplest question that it needed to address would be how young adults with disabilities are perceived by community members. In three different contexts that I observed (Volunteer training, Agape Camp, and Disability Art Exhibition), I was able to ascertain how young people with disabilities in this community were regarded in terms of their age.

Emphasis on respectful language in volunteer training. Respect for the ages of people with disabilities was considered important enough to be included in the training of volunteers for the Grace Summer Camp – the summer Christian camp for Koreans with intellectual and developmental disabilities. The head-teacher, Anna, firmly emphasized how volunteers needed to respect older people with disabilities during the Camp, in particular with their manners and language usage.

Anna: Treat our friends with respect and use age appropriate language. A lot of the friends are like us but they're in their 20s and 30s. We have some friends who are in their teens and younger, but for the most part... So, while they might not be cognitively mature, they're still 36—if they're 36—they're still 36. You need to treat them like they're

36. You're not going to baby talk [to] them, you're not going to treat them like a kid. There will be times when you might need to, like, reprimand[ing] them if they've said something, or maybe if they wandered off on their own and didn't tell you, or they bump into someone really hard and they didn't apologize or something. In that case you can say, "Op-pa or Hyeong or Eonni or Nuna, why did you do this?" or, "Why didn't you do that?" And, "You can apologize." Don't scold them like they're kids because, again, there have been instances in the past where people have yelled at them like they were kids, and that's really not appropriate, okay? And again, be sure to explain to them what they did wrong when you reprimand them, and use the right words, because they're going to forget. And let's say there was an incident during the service, and after service you reprimand them, and you say you shouldn't have done that, you know, that was wrong. They're not going to know what you're talking about, okay? It needs to be on the spot: you explain to them why what they did was inappropriate, what might be an alternate action that they could have taken instead. And, try to use positive language....So, if you frame it in a positive way, it's also more respectful. It also makes the person listening feel a little better, right, more confident. So, I want to encourage you guys to do that, so. Take time to ask your partner questions and learn more about him or her... Our friends really, really love meeting new people and they have a lot of love, so the more you give to them the more they'll give back to you. And they really enjoy having conversations with you.

Most volunteers were in their teens and early 20s. The head teacher presented slides with information about individuals with disabilities in the Grace group, with one slide allocated for each of them. There was a headshot photo on the left of the slide. The first fact shown after each name was the age, so the new volunteers could know exactly who was older than themselves.

The slides also included specific disability labels and characteristics – both positive and challenging. Reporting age at the first meeting was the routine for the Saturday program, too. The first thing each of the two groups—volunteers and individuals with disabilities— did was an introduction, being sure to include each person’s age. To make sure that new volunteers used appropriate language in terms of relative age, they needed to know who was older/younger than they were. The head teacher, Anna, acted as a role model by always calling people with disabilities by their title, such as Eonni or Oppa. Even though these main volunteer teachers, as 1.5 generation Korean Americans, seemed more comfortable speaking English, they made sure to use these Korean titles in the middle of English sentences—just as I have done with the title of Eonni in this dissertation - since the words sister and brother cannot fully represent these relationships.

This strong emphasis on the rules of respecting age in volunteer training and in Saturday program somewhat ironically demonstrates that these rules have often been ignored by young volunteers working with individuals with disabilities; the relative age rules, especially in terms of language, are part of a social code that Koreans naturally implement without needing to be reminded explicitly. It is similar to the English speaker’s intuitive use of articles like *a*, *an* and *the* without knowing exactly how they are discerned, chosen, or used. Even Korean babies just beginning to learn to speak are taught different words for ‘no’ (e.g., A-ni-yo when speaking to an elder, and A-ni to those younger than oneself). It is strange to hear someone announce that you should use honorifics for people who are older than you in a Korean community, since everyone has been obeying that rule since they first started talking as toddlers. In addition, people do not explicitly ask other’s age or introduce their age in public. Rather, the attempt to determine one’s relative relationship to a new person in terms of age is customarily done much more subtly. As

explained at the beginning of this chapter, you may ask a person privately or in a group setting after failing to figure out, but not displaying others' ages like this training. This is part of the culture that Koreans inhabit and implement naturally, albeit not publicly. In other words, the training which instructed volunteers to promote the usage of respectful language for members with disabilities already shows how they have been treated as exceptions to the age hierarchy culture in this community.

Language practices in the Summer Camp. In my observations, I noticed that middle-school-age male volunteers without disabilities did not seem to care about the age of their partners with disabilities in the camp. Most teenage volunteers that I observed seemed to avoid directly addressing their partners at all, whether by honorific titles or by their names, especially when their paired partners with disabilities were older than them. Even one volunteer in her early 40s – she did not tell me her exact age, but appeared to be late 30s or early 40s and mentioned her young children – was surprised to hear me calling Miyong Eonni as “Eonni”.

A Volunteer: Do you call her Eonni?

EJ: Yes, she is older than me.

Again, this is a strange question in a Korean community. When someone calls another Eonni, it means Eonni is known to be the older of the two. People figure this out silently, even in relationships among multiple parties. The same volunteer did not call Enjoo Eonni, who is 43 years old, by her age-appropriate title (Eonni), nor did she ask Enjoo to use that title for her. When I asked Enjoo Eonni if they were same age, she did not know exactly how old she was. Age relationships among more than two parties, including people with and without disabilities, were more complicated, especially when I was involved.

There was another volunteer, Ms. Choi. Among the three of us, Ms. Choi and Miyoung Eonni are the same age, and I am the youngest. While I call Miyoung Eonni (an older sister), Ms. Choi called Miyoung Eonni by her name (Miyoung). Sometimes Ms. Choi and I needed to talk about Miyoung Eonni. This became rather awkward because Ms. Choi always used honorifics for me, someone younger than her, with the professional title “Seon-saeng-nim” while she mentioned Miyoung Eonni without any title. While Seon-Saeng-nim literally means a teacher, it often is used to express respect to a person. In other words, Ms. Choi treated me with respect as an adult, regardless of our age order, while Miyoung Eonni was not treated as a same-age peer, but as a “younger” student.

Interestingly, I also observed some individuals with disabilities avoiding intentionally respectful language with each other, using “Ban-mal” (*talking-down*) instead. Miyoung Eonni, who is younger than Jongen Eonni and Enju Eonni, most often called them by their names, and did not use any honorific verb-endings at all when she talked about them. Also, Enju Eonni on one occasion was very upset with Seojin – who was participating in several programs for people with intellectual and developmental disabilities in Grace - because he neither called her Nuna (*an older sister*) nor treated her as his Nuna (older sister) (e.g., tapping her head). In Saturday program, it was very common to hear participants with disabilities call each other by their names regardless of their ages. It was also very rare for people with disabilities in this organization to be instructed to use respectful language with each other. These exceptions – not following the relative age hierarchy in relationships – happened not only on the individual level, but also on a larger scale.

The following example from the Grace Summer Camp reveals that these exceptional language practices – not using honorific terms – were based on more a fundamental perception

of people with disabilities as not having adult status. Moreover, despite the use of honorifics and the emphasized importance of respectful language during the volunteer training, there was still prejudice toward people with intellectual and developmental disabilities in this community that could not be hidden.

Korean American Youth and Adults with intellectual disabilities in the Image of a Child

The section will describe how Korean American community members categorize and perceive youth and adults with intellectual disabilities as children through two community event episodes: the Grace Summer Camp and the Art Exhibition titled Like Wild Flowers, Like Stars.

The Grace Summer Camp.

Hidden age categorization: Belonging to adult camp or child camp? Jiyong, my son, Joe, my father-in-law and I arrived at a four-star hotel located in an ivy league college town two and a half hours away from where my participants lived in order to participate in the Grace Summer Camp. It was a sizzling hot summer day, so we were relieved as soon as we entered the air-conditioned hotel building. We had heard from one parent that the camp she and her son had previously visited was overcrowded and uncomfortable. She also worried that it might create a stigma for people with disabilities who stayed there, so it was an extra relief to find a modernly decorated space where the Grace Summer Camp was going to take place for three days. After making eye contact with two Caucasian hotel staff members at the front desk who looked somewhat nervous and did not smile, I easily found several groups of Koreans in the lounge who had already arrived. There were ten long rectangular tables spread around the lounge area. Each table was for a different branch of Grace. The Grace Summer Camp was a place where the interaction between people with and without disabilities across various ages could be observed, both in Korean American and church community contexts. This is probably one of the biggest

events for Korean Americans with disabilities from the east coast of the U.S. and Canada. Four hundred seventy Koreans including children, youth, and young adults with disabilities as well as their families and volunteers, participated in the Grace Summer Camp, 2016, and among them one hundred twenty people were from Grace where I recruited my participants.

I happily found a familiar face at the first desk that had its branch name printed on a paper sign. It was Mr. Choi, a chief secretary in Grace. He was by himself, still waiting for other people coming from my research site, who were stuck in the weekend traffic. He and I shared the responsibility of making sure to have enough hotel room keys for “our” people. As we’d heard from that mother, sometimes there were not enough rooms for everybody, and four, five, or six people would need to share one room if we were not quick in securing enough keys.

EJ: Hello, chief!

Mr. Choi: You came.

EJ: I heard from the director that we need to get the room keys from the front desk before everybody arrives.

Mr. Choi: Don’t worry. I already took care of them.

In the middle of our conversation, I noticed that he had a camp booklet. After getting the booklet, I was in a hurry to figure out how the camp program was organized not only because of my personal interest in my son’s program, but because of confusing conversations that I had before coming to the camp with my participants.

EJ: Eonni, which group will you go to in the camp?

Miyoung: I’ll go to “Seng-in-ban” (the adult group) in the morning. After having worship there, I’ll go to “A-dong-ban” (the children’s group) because it’s usually much more fun there.

During and after this conversation, I thought that it might be a bit weird if she was going to the children's group like my son or other elementary age children, since she is a mid-30s adult woman. I also acknowledged that it might be understandable if there were some fun programs across various ages. There was another conversation with the director of Grace that puzzled me as well:

Ms. Song: Please volunteer for Seong-in-ban (the adult group). Enju, Jongeun, and Miyoung will be in Seong-in-ban (the adult group). By the way, your son will be in the child group. Technically, the child group doesn't exist, but there will be volunteer teachers for that group.

I couldn't understand why there were going to be only three people from Grace - only my Eonni participants - going to the adult program, when there were other people older than 18 or even 21 years old. I was also confused as to why she said that actually there was no children's group even though people kept mentioning it.

In order to find out about this mysterious grouping, I opened the glossy color-printed booklet. It began with greetings from the pastors. There were camp schedules which were basically constructed around five worship services, with some activities including outdoor/indoor games and some free services (e.g., acupuncture, haircut, manicure, massage, etc.) between worship times. I found that there were two different schedules, both in Korean and English, in the middle of the booklet. Immediately, I noticed that the way the programs were organized and presented in the booklet was confusing in terms who belonged in which program. Since I brought a six-year old boy in Korean age [four and a half in American age], I needed to figure out which schedule was for children. But, none of them were marked as children's programs. There were only two schedules: one is for "Mitum (sengin) camp" (*Faith adult camp*) and the other "2016

Camp AGAPE schedule.” Faith camp was written in Korean and Agape camp was written in English. At first I thought that the English schedule was just a translated version of the adult schedule. However, I soon realized this was not the case.

There were at least three different groups in this camp that I heard of: child (K-6), youth (adolescents), and adult group. I looked around the hotel lounge and found two signs, for two different programs, indicating their corresponding hall locations: “Sengin Camp” (*Adult Camp*) on the ground level and “Adong Camp” (*Child Camp*) on the lounge level. “A-dong” usually refers to younger children from Kindergarten to 6th grade, or before puberty. While there was no indication for age groups on the program booklet except the designation “2016 Camp Agape Schedule,” the sign on the lounge said *young children’s camp*.

I was onsite at the camp and, yet, found no mention about a children’s group on the booklet, while signs at the camp directed campers to the child group. Was that sign for younger children like my 4-year-old son, or for all youth and adults other than my three Eonni participants? Where should elementary age children with disabilities go? I finally decided to ask the chief secretary which schedule was for children, youth, and adults.

EJ: Chief, I saw the sign saying “A-dong” over there. That is confusing me. Is this for younger children like Jiyong?

Mr. Park: No, that’s for youth group. I don’t know why, but they have called the youth group as “A-dong.”

His answer still did not explain why adults with disabilities would go to the youth group rather than an adult group. I wondered who would actually be going to that adult camp besides my Eonni participants?

While I was exploring the hotel lounge and ground levels where the camp programs would take place, still confused about the age groupings, several rental buses arrived, including my participants. Suddenly, the lounge became crowded and loud, full of Koreans. It was an unusual experience to be surrounded not only by Koreans in the U.S., but also by so many Koreans with disabilities together in one place. As soon as director Kim arrived with my participants with disabilities, she started assigning hotel rooms for us. Usually two or three persons shared one room. I was assigned to share a room with Miyoung Eonni, while En-ju Eonni and Jong-un Eonni would share a room with another adult volunteer. The afternoon schedule started soon after we brought our luggage to the room.

It was only after going to both programs that afternoon that I finally understood which people were expected to go to which group, and how they were categorized not only by “age” but also by “something else.” The majority of these Korean American children, youth and young adults with intellectual and developmental disabilities – regardless of their ages – went to the Agape camp (“Adong-ban”; child group), while all the adult volunteers, families, and adults with disabilities other than intellectual and developmental disabilities were grouped in “the Faith Camp” (“seong-in-ban”; adult group). In addition, there were five children without disabilities who were organized into an unofficial children’s group with two volunteer teachers, even though there were children with disabilities in Agape Camp. This non-disabled child group was in and out of Agape camp. While people in the camp were consistently referred to as “children’s camp” and “adults’ camp,” they were not grouped by age but according to the existence of disabilities. Although the Agape camp was unofficially called the children’s camp, the booklet could not describe it using that term because the main participants for that camp were not children but youth and adults with intellectual and developmental disabilities.

Treating people with intellectual disabilities like children is not a new theme throughout disability history. However, in this case it is especially ironic since the Korean community ordinarily follows the age hierarchy rule very strictly. As I have established, Koreans use honorific titles and verb endings as a mark of each other's age order, and as I will show, the rule is also applied superficially to my participants. However, the Korean community still implicitly ignored the age of youth and adults with intellectual disabilities. The form of bias and discrimination by the Korean community toward people with intellectual disabilities is not explicitly stated, but rather exposed unintentionally in various contexts. One of these contexts, in which my participants spent hours every day, was a religious setting. And the way the Summer Camp was organized may be an example of religious practice in connection to Koreans' concept of the adulthood of people with intellectual disabilities.

Intersection between age categories and religious expectations. The core of Faith ("adult") Camp was four sermons preached by keynote speaker Pastor Choi, while the most important part of Agape ("children") Camp, in my observation, was praise. Before Pastor Kim, the keynote speaker for "children" Camp, spoke, this group spent quite a long time singing gospel songs and doing "body worship," which is dancing along with the gospel songs. Most songs were familiar to my participants, being the same songs the Grace group sings during every Saturday class. Many teenage youth participated in the singing and dancing, while several attendees with disabilities in their 20s were just watching the staff do this "performance." The group names (Faith vs. Agape) had noteworthy connotations as well. The "adult" camp that excluded the majority of youth and adults with intellectual and developmental disabilities was named "Mideum" (meaning *belief or faith*), and the "children's" camp was "Sarang" (meaning *love* or the Greek word *Agape*, which Grace often used).

Why were adults without disabilities, or with physical or sensory disabilities, assigned to the “Faith” Camp, while the group with intellectual and developmental disabilities were in the camp named “love?” To whom did this “love” refer? It might refer to God’s love, or it might mean to instruct people with intellectual disabilities that they, too, are to love their neighbors, as the Bible teaches all believers. However, during the Grace Summer Camp, the predominant theme throughout was the love that volunteers show and provide, which people with intellectual disabilities were supposed to receive. What a strange group name! Their group identity was determined “passively,” by others’ action towards them. Agape Camp was the group that is called “child group,” and the people who are assumed to need love from others without disabilities regardless of their age are those with disabilities. In contrast, the adults – most of them without disabilities – were supposed to develop and strengthen their “faith” during this summer camp. Do these names reflect how people with intellectual and developmental disabilities are considered to be like children, unable to have or develop their “faith” but rather be the object of other’s care and love?

Another example further highlighted non-disabled people’s perception of people with intellectual disabilities as childlike, particularly regarding their religious development. The training and the keynote speech emphasized to volunteers their responsibility to help “friends” with disabilities to meet and get to know about God during the camp. The word, “Chingu” (meaning *a friend*), is favored in this community and spoken frequently, because people without disabilities can use it to avoid the situation in which they would have to mark the age order between them and people with disabilities. It is an able-body’s “user-friendly” word that can be used to refer to individuals with disabilities of various ages, even though in the Korean community among people without disabilities, it is still very rare for younger people to refer to

their elders as friends. While taking for granted that the Bible is the means of access to knowledge of God for “most” people, as the pastor preached in Faith Camp, Agape Camp did not assume that people with intellectual disabilities would learn about God through the Bible, but rather, through the action of volunteers without disabilities. It was rare to see an individual with disability carrying a Bible in this camp, and there was no expectation that youth or adults with disabilities would have a Bible in the times of worship. In contrast, many adults without disabilities in this camp always carried their Bibles. One particular episode illustrated this “abnormal” expectation.

On the first day of camp, a teenage boy with a disability came to The Grace table looking for something. A staff person asked him what he needed. He answered that he needed a Bible, since the schedule included Scripture reading. She told him that he didn’t need to have a Bible because they would read it for him and show it on slides as well. Although I did not observe any children or adults with disabilities at the Agape camp with Bibles, I saw that Jongeun Eonni brought her Bible every day for worship in the camp. The volunteer who was paired with Joneun Eonni, sharing a hotel room with her, and being responsible to go through the camp programs with Jongeun Eonni also carried her Bible as well, even though all the Bible verses were projected on slides in the Faith (Adult) Camp as well. Why were there different expectations even in this very simple matter of whether to bring a Bible or not? Why were Agape camp attendees advised that they did not need Bibles while many people in Faith camp naturally brought their own to the service? The preacher in Faith Camp had just explained that the Bible, as a book of revelation, teaches people about who God is, and who I am as a sinner, creature, God’s child, king, priest, and holy temple. Were participants in Agape camp considered incapable of learning this through the Bible? Were they expected not to carry Bibles because of

an assumption that they could not read? Most my participants from Grace texted me often, either in Korean or English. A favorite leisure activity – especially among male participants - was to go and buy a newspaper and sports magazine and read them every day. I observed how these same youth and adults with disabilities easily used the Internet to find their favorite music or blogs that they shared with me. They also frequently engaged in Internet shopping. I have often seen their posts on Facebook. They are not merely literate, but entertain themselves daily with reading and writing. Why, then, weren't they expected to have Bibles in the worship? Why were singing and dancing the only ways they were expected to know about God or the gospel, just like what one finds in children's Sunday School classes? Why was the focus of this camp not their "faith," but the "love" of others toward them? It seemed to me that in many ways the participants with disabilities were associated with the image of children, as pure, innocent, ignorant, dependent, etc.

Some of these attitudes and practices are also reflected in many churches in the U.S. and Korea, where children are not seriously expected to learn through the Bible directly, but always as mediated by others (i.e. non-disabled adults). Children are often considered incapable of learning the depths of faith or the Bible. It seems that Korean young people with disabilities are treated like children even after they've grown up. There are several different ways to identify a person as a child or an adult. In this highly religious Korean community, the treatment of people with disabilities as children - which is a pervasive stereotypical image - appeared specifically as a religious theme: they're not perceived as grown up enough to strengthen their own beliefs, but as depending on other youth or adults without disabilities in that process. In contrast, some early teens without disabilities were, without hesitation, given the role of "helping" people with disabilities, who were often older than these volunteers, to "know God." Even though many

young people with disabilities in that group attended their local churches regularly, and loved to talk about their religious practices with me, I observed that in worship services, they were always treated as children. It was as if they were treated metaphorically as children who could not process hard food, but needed to be fed only milk. This practice of treating adults with disabilities as children was not only evident in church or religious contexts, but in other community contexts.

The disability art exhibition. I was able to observe a similar bias in the Korean American community toward people with intellectual disabilities, including the prevalent concept of their age, at a Disability Art Exhibition, entitled *Like Wild Flowers, Like Stars*. The exhibition was originally hosted by the United Nations to celebrate the International Day of Persons with Disabilities. All of the art pieces were painted by a Korean painter, and they had been shipped from South Korea to the U.S. The painter, Mr. Kim, had painted people with disabilities for over twenty years. Interviewed about this exhibition, he explained the meaning of the exhibition title as follows:

The paintings include the themes of nature, war, and the division [of Korea between North and South]. I'm looking forward to delivering the message of peace and empathy to the world, and heal discrimination and wounds through the innocence of people with intellectual disabilities.

After being exhibited for two weeks in the UN building, the paintings were transported to this Korean community where a local church would present them in another exhibition. While they received quite a lot of media attention both from South Korea and the U.S., the appropriateness and problematic assumptions that are being promoted by their portrayal of people with

intellectual disabilities remain questionable. To illustrate this point, I would like to introduce how Koreans in this community reacted to these paintings at the exhibition.

After Saturday's Christmas Party, Enju Eonni, Miyoung Eonni and I arrived at the Gospel Church building to attend the reception for the art exhibition, *Like Wild Flowers, Like Stars*. The Gospel Church is a charismatic church with forty years' history, as well as one of the biggest churches in this urban area. Among my participants, Miyoung Eonni attended this church and actively participated in worship services, workshops, and youth meetings there. One time I asked her how she chose her church after emigrating ten years ago:

EJ: *Eonni, are you going to Gospel Church with your family?*

Miyoung: *No. My mom goes to a different church. I heard that it is an American Church.*

EJ: *Then, how did you go there by yourself?*

Miyoung: *In Korea, I went to "sunbogeum" church (an Evangelical church in South Korea). I was looking for another "sunbogeum" church, and found it.*

Miyoung Eonni often texted me very late at night and told me that she had just finished her Wednesday prayer meeting or that she was going to early prayer meeting during one of the upcoming week days. When I asked her how she would get there, especially for early prayer meeting, she told me that a fellow "Cheongnyeon" (young adult) group member would meet her at her apartment at 5 a.m. to give her a ride. Since the year 2015, at least once a year, I heard from Miyoung Eonni that she'd earned a prize at the choir competition at her church. Her cellphone was full of photos about her church life including trips, dinners, and special events with young members without disabilities in this church. Here is one example,

EJ: [pointing to one photo of a group of people. The background overlooks the city in the early evening. Around the decorated table with formal dinner table settings, probably on

top of the building, fifteen young people smiled at the camera, with Miyoung Eonni in the middle of them.] *Eonni, where is this? This is a beautiful place.*

Miyoung: *My church deacon's restaurant. We were all invited there.*

Although this church has a special group of children with disabilities, organized into an after-school program by one mother of a child with disabilities, Miyong Eonni was not involved in that group at all, but rather always participated in “general” young adult (Cheongnyun) group. She was the only participant who was included with “full-membership” – not in and out - in a church group. Under my limited observation, even Covenant Church, where the leadership has a firm idea of providing support for people with disabilities in the church, had a special group only for youth with disabilities rather than including them in a general youth group. Despite her full-membership in her youth group, other members in the same church maintained their bias and stereotypes of people with intellectual disabilities, as I observed in this visit to the art exhibition.

Miyoung's work place. When I got out of my car with my Eonni participants, I found that the appearance of the building was not that of a traditional American church, but a large office complex often seen in urban centers. I could feel the atmosphere more directly when I entered the church building: inside it was rather like a modernized concert hall. The floor was marble or granite. It was decorated with a Christmas theme, including Christmas trees, flowers, wreaths, etc. Their colors were consistent and refined; all decorations were either gold or silver color. As soon as we were inside the building, Miyoung Eonni brought my attention to a bathroom near the main entrance, in a voice somewhat louder than usual: “Eunyoung, this is the bathroom that I clean.” She was working as a janitor, especially cleaning bathrooms, in three different local churches including this Gospel Church building. Miyoung Eonni, who does not ordinarily display much facial expression, also displayed her pride with a smile. And following

this statement, she naturally took a step into her workplace. It was very clean, crisp, and well-decorated, nearly resembling a bathroom in a four-star hotel. This is also the church that she attends every Sunday. Minutes earlier we were just talking about her church, but now she clearly verbally expressed her excitement.

Sadly, not long after our visit, Miyoung was notified that she could not maintain her bathroom cleaning job in this church anymore. I asked her if she knew why the church fired her. She said no: they simply told her that they were unable to hire her anymore. As this is a mega-church that has financed many mission trips - including one in which about a hundred members visited several European and South American countries to show Christian-themed dance and performance - I cannot imagine that they fired her because of the \$50 weekly cost of having her clean their bathroom. Maybe they were not satisfied with the quality of her work? I observed her worksites several times. Even in cold winter time at non-heated church buildings, she put on a pair of rubber gloves without hesitation, got sponge and rag, and cleaned toilet bowls and bathroom sinks by hand. She always made sure the toilet bowls were clean inside and out. When I met her after her cleaning job, she always brought the smell of chlorine bleach into my car as a sign of her hard work.

EJ: *Eonni, wasn't it hard to clean the bathroom today?*

Miyoung: [no hesitation] *No, it was okay.*

Since I knew how seriously she took her work, and how carefully she used her income, I was left to wonder why they decided to take away her job without explanation. I asked Miyong Eonni several times if she had found out the reason, but she still did not know why she had been fired.

After our bathroom tour on the way to see the disability art exhibition, we walked to the lounge area of this church building. Many different countries' flags were displayed, indicating

their vision of world missions. On the main floor, there was a bookstore and a café, as well as an information desk. The main hall looked like a concert hall or auditorium with several thick, soundproof doors surrounding it, which implied their charismatic worship and their famous Christian performances. The art exhibition was installed on the ground level of the church. As I descended the round staircase, several brightly-colored paintings came into view.

The hallway and main exhibition hall were full of mural-size paintings. This was the exhibition, *Like Wild Flowers, Like Stars*. Mr. Kim's exhibition included seventy-seven canvases of size 100 (about 64-inch by 51-inch for each), all joined together. The total length was 336 feet. From the first impression, the primary subjects appeared to be children, smiling over vivid and colorful backgrounds of flower beds, pasture, blue skies, and water. White butterflies flew on every canvas, uniting all the paintings into one piece. With the blue background, there were also fish swimming around the subjects. Some of the subjects were portrayed eating food, being fed, lying on the floor, running, sitting, or jumping on the green grass. Some subjects had crooked bodies or frowning faces. Some of the subjects were unclear as to whether they were clothed or not, whether they were women or men, and whether they were children or adults. There were some evidently adult subjects, who seemed to be caregivers. Of the faces that were portrayed the largest, the majority smiled, while there were also some people who cried, screamed, held their heads between their knees, and were either sad or expressionless.

Portraits of people with intellectual disabilities as a child. The young people in the Grace were the only group invited to the first day exhibition reception, because it was the only Korean organization in this city for youth and adults with Intellectual Disabilities. There are some other parent-initiated programs for younger children with developmental disabilities, mostly autism, but I did not see any children or families from these organizations. Mr. Kim's

paintings may show us fragmentary images of people with intellectual disabilities as Koreans may want to construct them. However, in the seventy-seven mural size canvases, which are supposedly connected to the “same” disability with which my participants were labeled, none of the paintings’ subjects were really connected to my participants’ lives. None of the subjects portrayed worked; drank coffee; walked on the street; went shopping; cleaned the house; watched TV; surfed the Internet; posted on Facebook; texted; read or wrote.

Probably only one common thing that I felt from these painting in connection to my participants was loneliness that I often heard from Jongeun Eonni. Some of those portrayed appear to be adolescents or adults, and the subjects Mr. Kim painted lived in a residential institution for people with disabilities, not exclusively children with disabilities. However, all media without exception, as well as the painter himself, often described his subjects as “disabled children.” Interestingly, in his paintings, not all subjects were portrayed as examples of “purity.” While simple or naked looking images were meant by the painter to exemplify purity, to me they looked like institutionalized bodies, without personalized items and in a lethargic state.

Perhaps because it was the exhibition’s opening night in this church building, there were not many people in attendance except Mr. Kim (the painter), his wife, and three mid-aged women who prepared a snack table in the middle of the exhibition area from this church. Before the formal ceremony opening the exhibition, I quickly looked around. Soon I found one Korean middle-aged woman and one young man of color – not being able to identify his ethnicity but noticing his dark skin – who were on their knees cleaning the granite floor. It seemed that we – eight young people with disabilities, the Grace director, and myself – were the principal guests invited for the opening ceremony. Two Korean men came to the main exhibition hall, and hung a

new, smaller painting on the wall. It was easy to recognize as a painting with a much different subject than the other paintings: it was a portrait of this church's pastor.

During his welcome speech, the pastor in Miyoung Eonni's church where this art exhibition was held, gave the rationale for why his newly-painted portrait done by the same painter was hanging there: "We all have disabilities. I am not different than them." But his portrait certainly was different from theirs; it featured his personal characteristics including his suit and tie, and his smiling face with eyes looking forward instead of vaguely into the air. Even his age – 60's – was clearly reflected in this portrait, unlike all the other paintings, in which the ages of people with intellectual disabilities were impossible to guess.

While we looked around, Eunju Eonni suddenly commented of the paintings, "*They are all babies, aren't they? Some of them don't have clothes on.*" I could not answer her question: why they were all portrayed as babies – naked babies. While we were looking over the paintings, a few more people came to see the exhibition. Eunju Eonni, Miyoung Eonni and I, together with two other Koreans from this church, were looking at a painting that portrayed one face, whose age and gender were left ambiguous. I could not tell whether it was a boy or girl, an adult, young adult, adolescent, child, or toddler. One of the Koreans from this church viewing the painting with us suddenly posed a question to Eunju Eonni and Miyoung Eonni: *Do you think that it is like you?* The subject of that picture we viewed at that moment had a big smile, with a half-opened mouth facing upward at the blue summer sky. It has a short hair-cut just like other subjects. It had a childlike look but it was hard to say its gender or age. My two Eonni participants did not have any answer for this kind of question. As Miyoung Eonni's friend, who was also a preacher for Saturday program, said, "*They [Koreans] don't know what to do. Not only they are strangers to Korean churches. They think that they are different kinds of people.*"

From the time we entered the building for this exhibition, there was already some awkwardness or tension. These people were invited to the exhibition because it was in some way seen as being about them. However, the simple fact is that it was not about them. We did not know about the individuals portrayed there. These were people who lived in an institution on one small island at the southwestern corner of South Korea, who had disabilities and were separated from their families and sent to this place. They became anonymous figures in Mr. Kim's paintings, with naïve looking smiles, half-opened mouths, loneliness, crooked bodies, asexuality, and childlike "innocence" - supposedly a part of nature, with no sense that they are talking, thinking, arguing, insisting, etc. Are they – the subjects represented on these canvases – anything like my Eonni participants? Not at all. The very question, "*Do you think it is like you?*" struck them as nonsense, so they had no reply.

But these two Koreans did not want to stop drawing a comparison of my two participants with the painting's subject. They did not look at these canvases as mere paintings, but intentionally sought to see my participants in them. They said moreover: *How about you stand here, and open your mouth like that child, and smile?*" That was all they wanted to see from these neighbors of theirs: a naïve smile with a half-opened mouth. Instead, my Eonni participants' mouths were tightly closed. They didn't speak a word, nor did they express any anger. They hid their eyes. While these other visitors may have assumed that my Eonni participants did not understand what they said, the sisters simply did not know how to respond to such nonsense. I felt the urge to hurry them to another place: "*Eonni, let's go over there.*" Although it might have been enlightening to hear more of what these Koreans had to say, I could not stand to hear them harass my participants this way, trying to force a connection between them and the paintings.

Their supposed relationship to his subjects was actually the result of an unfounded generalization and stereotyping. Mr. Kim's paintings have contributed to the construction of stereotypes of disabilities in other ways as well. The media made a great fuss about how he expressed "the pure essence of humanity in disabilities." To construct people with disabilities as angels, or as "a portrait of a god who came to the world as play," is not much different than thinking that people with disabilities are not worthy to be portrayed. It is an explicit statement that they are not worthy to be portrayed realistically, but only as childlike and androgynous. Moreover, these paintings contribute to reproduce stereotypical childlike, asexual, or non-communicative images of people with ID. This observation of these Korean Americans' reaction to the paintings and my participants enabled me to understand what Jongeun Eonni said about church people, which is described in the next section. In particular, I would like to use the following stories of Jongeun Eonni, Miyoung Eonni, and Junho as a counterexample to the prejudice of this Korean American community—specifically the image of child—against adults with intellectual disabilities. Their stories present their discerning, conversing and advising characteristics as *adults*, contrary to the innocent, silent and ignorant child-like image that members of the Korean American community project upon youth and adults with intellectual disabilities.

Counterexamples: Jongeun, Junho, and Eunju

Jongeun as a discerning adult: "The person is bad if ...". The incident at the exhibition was more than just awkward – it was humiliating – but at the same time I felt amazed by the foresight of another Eonni participant of mine, who had anticipated exactly this kind of scenario and chose to stay away altogether to avoid it. At the art exhibition, I immediately thought, *'Jongeun Eonni was right! This is why she did not want to come here. She knew what*

kind of Koreans we would have to deal with here.' Jongeun Eonni and I had just had a conversation along these lines at lunch earlier that day. At the Neighbor church building that day, there was Christmas party instead of Saturday program. During the party, members of the Korean community, including adults and teens, came to give inspirational speeches and performances, and to provide lunch for children and young people with disabilities. After the Christmas worship and guest talks, I went to the dining hall where Korean consulate officers' wives served lunch for people. After filling my plate with Korean food, I was searching for a seat when Jongeun Eonni came into sight. I sat down across the table from her, and we naturally talked about our lunch menu. While I was very excited to have a Korean lunch that was practically a buffet, she seemed indifferent toward the meal. As I cleaned my plate, expressing my appreciation of the food, Jongeun Eonni pointed out that they serve the same food every year, and left a lot on her plate. I suddenly remembered that I would be going to the art exhibition with people from Grace later that day.

EJ: *Eonni, you're going to Gospel church tonight, aren't you?*

Jongeun: *Why?*

EJ: *I heard that there is going to be an art exhibition. The director and other Grace people will be there.*

Jongeun: *No, I'm not going.*

EJ: *[disappointed] Oh, why not?*

Jongeun Eonni did not answer my question. Instead she asked me a question:

Jongeun: *Eunyoung, do you think that there are more good people or more bad people in a church?*

I was embarrassed with this unexpected question, and one that was hard to answer. I may have been imagining my participants as people who needed to answer my questions, not as people who would ask me questions. In other words, I was sitting there expecting easy small talk, in which I could lead the conversation with the participants with disabilities just like a research interview—where I’m the one who asks and she’s the one who answers.

EJ: I do not know. I know that there are both bad and good people in a church. Probably there are still a lot of good people.

She did not accept my naïve, vague, compromising, “safe” answer. She immediately challenged that my non-committal response reflected my unwillingness to say anything negative.

Jongeeun: I think that there are many more bad people in a church than good ones.

I did not know how to reply. And, to be honest, I had not seen this kind of direct question coming.

EJ: Uh...yeah... Eonni, why did you think in that way?

Jongeeun: You can only tell whether a person is good or bad when you are a widow, orphan, or disabled. [She continued] The person is bad if he or she looks down on you, treating you like a dog, a fool, or a young child.

I now sat silently as a sign that I agreed with her.

Jongeeun: There are too many bad people in that church. I do not go there.”

As if to relieve my embarrassment, she added, “*And you seem to be a good person.*” She stood up and left her seat to throw away the leftovers on her plate, as if nothing very serious had transpired in our conversation.

The portrayals in Mr. Kim’s exhibition cannot capture any of my participants’ characteristics, including Jongeeun Eonni’s intuition. Rather, they stand far from each other. More

importantly, my participants understand more acutely than other Koreans how this Korean community has *badly* treated people with disabilities as “a dog, a fool, or a young child.” This artwork does not stand in opposition to the dominant public image of people with disabilities. Rather, it is like a final stamp on that image. While it is far from the real identity of my participants with disabilities, it is very near to the perception of people with disabilities in this community. Simply put, and as illustrated in other episodes shared in this chapter, they are not treated as adults. The difference between the two – Mr. Kim’s paintings vs. the image of people with disabilities in the Korean community – seems primarily one that differs only in its aesthetic. One beautifies the notion of being simple-minded and childlike – the image of childhood itself is not a true portrayal of children either – the other does not have the tools to decorate this perception, and so exposes it in other ways.

In contrast to these two images, who are my participants? Through my own lens – recognizing that I am a non-disabled, educated Korean woman with a critical perspective toward ableist society – my participants are far from what is shown in these paintings. And while my description cannot capture correctly who they are either, it at least uses their words. I introduce Eunju Eonni and Miyoung Eonni in other chapters as they demonstrate their membership and participation in performing adult roles. Jongeun Eonni’s knowledge and judgment are a perfect antithesis to the “innocent,” naïve characters portrayed in Mr. Kim’s paintings, and stand in contrast to the low expectations afforded to her and communicated in the Korean community’s prejudice and ignorance towards individuals with disabilities at the camp.

In another conversation I had with Jongeun Eonni, she described herself as “having discernment.” When I asked her what it meant to have discernment, she defined it as “knowing by feeling,” elaborating that she could tell, because of her discernment, “whether that person is a

good man or not.” She added, “there are many people who do not have that kind of feeling.” In combination with our conversation at the lunch table, (“You can tell whether people are good or bad only when you are disabled ...”), I understood her as expressing how her disability identity has led to the development of a set of critical tools, to be able to judge whether people in a church will react either well or badly toward her. In other words, her status and experiences as a disabled person have helped her to create a kind of litmus test to determine whether someone is good or bad, based on how they regard her in relation to themselves. So, what she described is not in reality a “sixth sense” or bare intuition, nor is it a result of her disability per se, even though those were the kinds of terms she used to explain it. She has experienced enough mistreatment, condescension, and dismissal from others, because of her disability, to be confident in telling me there are many more bad than good people in a church. Her insight, especially catching hidden or obscured institutional and social inequities, was demonstrated again in the Grace Summer Camp. Most Korean pastors and speakers that I heard in Korean community events did not mention anything about institutional issues. The trouble that an individual endures was spoken of as a personal issue. The Korean church itself was not addressed as an object for change. Rather, individuals are problems that need to be fixed or accommodated. In fact, it was Jongeun Eonni who highlighted an institutional issue in current Korean churches.

Spotting a problem of a church: “People must fall hard into difficulty at their church.”

It was the second day of Grace Camp, just after the morning program. Since I hadn’t seen her the previous night or that morning, I was happy to find Jongeun Eonni in the lobby. The major events of the Grace camp were worship services. I was interested not only in what the preacher said to people in the Camp, but also how my participants understood and interpreted it.

EJ: *Jongeun Eonni! Where have you been? I haven't seen you since yesterday afternoon. Were you at the worship?*

Jongeun: *Yes, I was in the grown-up service.*

EJ: *Oh, that's why. I went to youth group. Was the sermon good yesterday?*

Jongeun: *Yes.*

EJ: *What was it about? Can you tell me about it?*

Jongeun: *He said that teens run away from home because of puberty. Moms don't know what to do about their teen-age children. Despite parents shaving their kids' hair, they still run away after getting a wig from their friends. They climb over the fence and run away.*

I expected the pastor to say some solutions for the audience, most of whom are middle-aged parents who may have teen-aged children.

EJ: *So... what should mom do?*

Jongeun: *I don't know.*

EJ: *It sounds like there is no conclusion in that sermon.*

Jongeun: *He said that they will come back like the prodigal son.*

EJ: *Aha, ... like the prodigal son. Then, should a mom just wait?*

Jongeun: *I don't know.*

....

EJ: *What else did that pastor say?*

Jongeun: *There was one sister who had good faith. But she went out [of a church] to the world because of the temptation. Then she came back [to the church] later.*

Jongeun sister continued with her interpretation without being asked by me.

Jongeun: *People must fall hard into difficulty at their church. That's because they are led into temptation, and they come back later.*

EJ: *Yeah, maybe.*

Jongeun: *He said that the second generations work [downtown] without resting [on the Lord's day]. They don't go to the church. He said they were the prodigal son, the prodigal son.*

EJ: *Hmm, interesting.*

Jongeun: *They don't go to the church. They were called as the prodigal son. The second generation kids [downtown]. The prodigal son.*

Jongeun: *By the way, what is the second generation?*

There was a sharp contrast between Jongeun Eonni's interpretation of phenomena and the intention of the sermon. The sermon, according to Eonni's description, criticized the non-Christian lifestyle of the second generation of Korean immigrants, in particular, being workaholics who do not rest on Sunday, drawing an analogy to the Prodigal son. However, Jongeun immediately interpreted the phenomenon of leaving a church as a sign of problems residing in the church. In other words, many people leave their churches not because they are prodigal sons, but because the churches make people suffer. As seen through these examples, she had insight to see the problem as an institutional (i.e., church) issue instead of blaming an individual, which was hard for even many adults. In addition to Jongeun Eonni as an example of a grown-up with critical analysis or opinion on current problems, I also would like to introduce Junho as a conversation partner and Eunju Eonni as my big sister, who had age appropriate adult characteristics.

Junho as a conversation partner: Talking about politics and sports. In the training, Anna, the volunteer teacher for Grace youth and adult group, emphasized that the main role of volunteers is to give the friends a chance for socializing. One of her examples for this role was to have good conversations about their interests. On the second day of the Summer Camp, at the dinner table, I went to my father-in-law's table to have dinner together. At the table were Jongeun Eonni, Eunju Eonni, Joe (my father-in-law-who participated in this camp as a babysitter for my son Jiyong, who I brought on this data collection trip), and Junho with his two young teen volunteers. Joe, who is in his early 60s, started talking about a Republican presidential candidate's acceptance speech that he had watched, and immediately Junho, who is in his early 20s joined in that conversation. The conversation smoothly followed into talk about sports like golf and baseball. Junho was clearly a good conversation partner, sharing his ideas about these topics as well as quite actively reacting to Joe's comments, by using American vocalic (e.g., "uh huh"), opinionating to what Joe said, making a smooth transition from one topic to another. On the other hand, his volunteer partners – who looked much younger, probably around 9th grade - just listened to their conversation without a single word. It was odd to observe during the Summer Camp how these two teens had been following around Junho as "helping" and "socializing" persons, but not really talking to him. Even at the dinner table, while this older white man and a Korean American young man had a pleasant conversation about politics and sports together, the young volunteers kept their silence. Here is the conversation that Junho and Joe had at the Grace Summer Camp dinner table.

Joe: We were up talking - we were talking, we were actually watching Donald Trump, and his acceptance speech. At the same time, we were actually talking--it was like, his speech went on for so long; he just kept talking and talking.

Junho: So, who are you talking about, Trump?

Joe: Yeah, Donald Trump.

Junho: I know, he's really bad.

Joe: He'd just keep talking and talking, I mean, and it wasn't just talking, you know?

He's like, yelling the whole time.

Junho: Yeah, like, I don't even understand what he's saying, like, because when he'd talk, right? He does not calm down. He keeps talking like that. Bla bla bla bla

...

Joe: But, see, I don't - I don't have as much interest in baseball as I used to. Now I like to watch golf.

Junho: I like Tiger Woods though.

Joe: Not anymore. He's gone, he has, he's been out, you know, out of it for like 7 years now. 5 years.

Junho: He's slow.

Joe: Yeah, he's not, he's not ever coming back.

Junho: Yeah.

Joe: No. He's getting old and.

Junho: How old is he, Tiger Woods?

Joe: He's forty-something. Maybe he's just forty. But he's got some - he's an old - somebody described it yesterday, he's an old forty. Cuz his body is...

Junho: He's getting weaker, right?

Joe: It's not just that, but he's had so many injuries. His arm and his back.

Junho: But some people, they're forty but they're still playing.

Joe: Yeah but it's not just the age, it's the condition, you know he's not...

Junho: 100%, yeah.

Joe: A lot of injuries, a lot of back injuries, cause a lot of problems.

Junho: I think so, and some people got, they got lucky, too, lucky that they're...

Joe: Yeah, but Tiger Woods was the best. He was the best ever when he was, when he was at the top of his game he was the best there ever was.

Junho: You think he was the best of any man.

Joe: Ever. Ever. I mean he, nobody could match him. Even the best ones from the old days would say the same thing. You know.

It was quite amazing how the interaction between Junho and Joe was so natural and unforced. They were clearly entertaining themselves and one another, while Junho's volunteers stayed silent and disengaged. They didn't seem to be the right persons for Junho to be "socializing" with—they didn't seem to be able to connect to any shared interests. I didn't hear much about politics or Donald Trump from other non-disabled/adult participants during my fieldwork. In contrast, Junho played a perfect role as an American "citizen" talking about one of the presidential candidates. Why did this young man in his early 20s need these teen boys as his socialization helpers? Junho might be a good "Hyeong" (a Korean title for an older brother) who could help *them* to be social with topics like politics and sports. Following is another example of my participant's adult characteristics that were not usually recognized in Korean community.

Eunju Eonni in a big sister role. Eunju Eonni would be a perfect example of living in a big sister role. In the Grace house (a group home for Koreans with disabilities), Eunju Eonni was responsible for daily house chores such as cleaning, getting mail, taking phone calls, "watching" other younger people with disabilities, etc., along with Jongeun Eonni. Eunju Eonni was the

oldest among the three Eonni participants—Eunju, Miyoung, and Jongeun. Eunju was not a very talkative person in comparison to Miyoung and Jongeun Eonni. However, it was her nature to listen to what others had to say, understand their situation, and then take some action if she could or offer her thoughts. It was sometimes a small thing, such as advising me not to put my hands in my coat pockets even in cold weather, because it could hurt badly if I fell or giving some advice on a major life decision, such as getting a job or raising a child. From the beginning of my fieldwork, as I was disorganized in front of all these new people I met at this organization, I could already get a sense of her helpful nature:

EJ: [with embarrassment looking for a key] *I cannot find my car key!*

Eunju: [calming voice] *Look for it carefully in your bag.*

EJ: [after taking everything out of my bag] *I found it!*

Eunju: *There it was. You'd better have a key holder like mine. [showing her key holder which keeps her cell phone and several keys altogether] You can attach it on your bag, too. This way you don't lose it, and can find it easily.*

Her advice was not bossy or insulting, but just right, and offered in a soft, calm voice. She also did not hesitate to ask and advise me about my motherhood, even though she had not experienced motherhood herself.

Eunju: *When will your children grow up? It takes quite a while for kids to grow up.*

EJ: *The twins just became one-year-old.*

Eunju: *How about walking?*

EJ: *They do walking now.*

Or, another time:

Eunju: *How are your kids?*

EJ: *They got sick. I think they got a cold.*

Eunju: *[showing how she got dressed] Keep them warm with multiple layers of clothes.*

I also shared my own current life events, such as experiences with my new position, with my participants, including Eunju Eonni.

EJ: *Sisters, I'll work on the contracts from September.*

Eunju: *Where do you work?*

EJ: *In a college.*

Eunju: *How far from the house?* [What a relevant question, as I had a long commute!]

EJ: *Two hours driving.*

Eunju: *Who will watch the kids?* [Again, that's a question my husband and I asked one another hundreds of times.]

Eunju: *You need to pack your own lunch and bring it to work. You seem to better live near the work, or [get a job] near your house. My niece works while paying \$100 [for daycare] for two kids, a baby and a walking child.*

Eunju Eonni was a calm woman who was willing to listen and give advice based on her own life experiences. How humiliating it must be for her that Koreans at the disability art exhibition asked her to open her mouth and smile like an “innocent” child!

In summary, often Korean American youth and adults with disabilities were not perceived or treated as grown-ups in this community as shown in language practices in age hierarchy (e.g., except, Jongeun, Jungho and Eunju nonetheless exhibited their own mature characteristics). Jongeun Eonni was a discerning person to critically find problems within the Korean American church community, including Korean Americans' prejudice and discrimination toward people with disabilities. Eunju Eonni offered sage and thoughtful advice, and Junho

participated in a mature and engaging conversation about sports and politics. These adult participants did not exhibit any behaviors or interactions that would lead people to compare them to the cherubic and stylized images of innocent children displayed at the art exhibition. The next chapter will describe more adult roles and characteristics within a Korean cultural context where the politics and meanings of serving food were observed.

CHAPTER 5: POLITICS OF FOOD SERVING

Because participants often were not afforded adult status, an important aspect of this research project involved exploring what it is like to be an adult in the Korean cultural context. This chapter will explore how adulthood is connected to food culture in a Korean American urban context. Food is the most significant hallmark of the Korean community. Korean restaurants are often considered the face of a Korean community and there is always food anytime Koreans gather either privately or publicly. From an ethnographic perspective, our lives are a process of meaning-making in our particular cultural context. One aspect of my data set that I repeatedly coded with an “adult tag” during data analysis was food. The meaning of eating, buying, and cooking food goes far beyond the repetitive behavior of providing nutrition for living. Through *certain* behaviors and *certain* foods, people can be satisfied physically and emotionally. People represent themselves as adults by choosing a restaurant, selecting food items, organizing meetings with others around meals, and using their own income to pay for food. Food also signals a relationship among adults and food is often a medium for developing relationships. Adults are generally those who play the role of serving food and food also represents care and love that is demonstrated in “serving” behavior.

In the chapter five, I share observational data about cultural practices around food both from the Korean American community and from the adult participants with disabilities. First of all, I provide a short description of the geographic significance of this Korean American community in terms of the meaning of Korean food and food business. Second, I explain how food is related to adult behaviors (e.g., outspoken about food) through the examples of the adult participants with disabilities, including their coffee culture. Third, I describe how the Korean American community serves food to youth and adults with disabilities. In particular, the structure

of these served dinners are summarized through the examples of the Saturday program and the Grace Summer Camp. Then, I present how the discourse of food serving and the actual meal practices produce the fixed receiving roles of youth and adult with disabilities instead of serving in this community. As a counterexample to these discourse and practices, I share the story of Eunju Eonni as a cooking and serving person as well as the story for the annual special serving dinner at the Covenant church.

Food in Korean American Community

A new visitor to a Korean community may see Korean churches and cram schools, — private tutoring places - but they will most certainly see a number of Korean restaurants. The part of the neighborhood where my participants live was known as Korean restaurant street. When you drive on Erie Blvd—the backbone of this area—you see endless signs for Korean restaurants: Korean coffee shops, Korean bakeries, Korean fried chicken places, *Kimbob* (Korean seaweed rice roll) places, Korean raw seafood places, Korean BBQ places, Korean rice cake shops, Korean sausage stew places, Korean-Chinese restaurants, etc. While smaller American cities may have only one or two non-specialized Korean restaurants, here there are all different kinds of Korean restaurants, featuring specific foods they cook and serve just like the restaurants in South Korea. The community looks exactly like a city in South Korea except for the English signs for transportation, some franchise stores, and several buildings with Chinese language signs. Although several Korean community members expressed a fear that “Chinese have been taking over this area,” it still has the distinctive look of a Korean street.

“Everything is right there.” My conversation with Mr. and Ms. Park shows the significance of availability of Korean food in this community. They were in their 20s, and a young couple living in the same area where most participants with disabilities in this research

lived as well. They used to live in a small sized city with a much smaller Korean population around.

EJ: *Why do you live here?*

Mr. Kim: *When we first moved down here, we didn't like it. . . Here rent for a small size apartment is so expensive. We wished we could move back. But then we realized that, here, everything is right there!*

Ms. Park—Mr. Kim's wife—further elaborated on what he meant by “everything” being available: *If you want kimchi, you can just go right there and buy it. If you would like to eat something, you just go out and eat it.* Their apartment was less than five minutes walking distance from a Korean grocery store (H-mart). It is not a small corner store, but a supermarket chain just like an American one. In this neighborhood, there are two more Korean supermarkets just like it. All three of these are within five miles. Moreover, between these stores, the streets were filled with Korean restaurants.

Of course, being able to eat a variety of Korean foods may not be the only, or even main, reason for Koreans to live in this neighborhood. Rather, some Koreans may not be able to leave this area because of language barriers, employment situations, or undocumented status. Many Koreans without working visas work in Korean small businesses, including restaurants in this area. However, Korean food is something that temporarily relieves the tension and worry from these and other stressors. In a country where you are surrounded with unfamiliar people, concerns, and problems, all of which you may not have needed to deal with in your mother country, food is the item that you can purely enjoy. With its familiar smell, look and taste, food is something that can bring comfort in a foreign country. In this sense, food becomes much more than it would be in the country where you are from. Having this geographic location as a context

of my data collection, many observations took place around tables, in restaurants, homes, and around catered food at local events. In these contexts, I rarely saw my participants eat non-Korean dishes.

With this same logic, that “food is everything,” if you cannot have Korean food, your life would be considered too difficult to endure. For example, Jongeun Eonni’s voice was always full of pity when she noticed that I live in a city where some Korean dishes are not available to go and eat (e.g., Bo-ssam; Korean Pork Roast). It was evident from her empathetic responses to me that she both understood and was a part of her Korean cultural context. In other words, she was someone who had an adult relationship to the importance of food in her culture.

After six hours of early morning driving, a nervous first meeting with my data-collection gate-keeper, navigating complex urban roads, and enduring the physical discomfort of ignoring my body’s feeding function from being away from my babies, it was food that comforted me—body and soul—deeply. It was such a simple food, Seol-leong-tang, which is mild, white beef broth soup eaten with rice and Kimchi. But it was like magic! After finishing one bowl completely, I had a wonderful gut feeling, ‘Yes, this dissertation fieldtrip will be good just like this food! At least I will be able to enjoy Korean food as much as I want in this city!’ It is not surprising that the first photo that I took during data-collection was of Korean food.

The Significance of Food in Adult Lives

Outspoken about food. In addition to the function of food as an ethnic mark (i.e., Koreans), food was also closely connected to adults’ behaviors, such as cooking or choosing a meal to eat, searching for a gourmet restaurant, making the effort to go to one’s favorite restaurant, spending money for food, and drinking coffee. The three Eonni sisters always clearly communicated not only what they thought we should eat, but also which specific franchise or restaurant they wanted to visit.

Jongeun: “*You know where Kangnam Chicken [a local fried chicken place] is, do you???*”

EJ: *I don't know where it is. Never been there.*

Jongeun: *Next to Kim's Dinner [another Korean restaurant]. Do you know San-su-gab-san?*

EJ: *Yes*

Jongeun: *It is on Erie Blvd.*

Jongeun: *Kangnam Chicken is attached to it. It should be spicy flavor chicken.*

Here you can see the participants guiding me as someone who was new to the area and unfamiliar to the community. They understood that this placed me in a position of needing help in finding not just appropriate food, but a restaurant that would be special for what they offered. On a hot summer day, Eunju Eonni also mentioned the food she had been craving.

Eunju: *Lately I'm not really craving chicken. I'd rather have something cold ...*

You can make Kong-guk-su (cold yellow bean soup with noodles) at home. But, you need to have a food processor. You know, one you can puree. You only need to boil beans. It's just a problem to add the right amount of salt. Well, but we don't cook it because Jongeun doesn't eat it."

Expressing what you want to eat is not exclusive to adults. Children often tell their parents what they want to eat for dinner (such as pizza, spaghetti, or PB&J sandwiches, especially for American children). However, they often do not have the prerogative to make the final decision, like their adult family members do (i.e, parents, grandparents, guardians). Children do not necessarily *need* to think about what they will eat for tonight's dinner, like adults who are entrusted with preparing food do. Children are often expected to try to eat whatever is placed on their dinner table. By contrast, most adults need to figure out all their meals – not necessarily what they want to eat but what they *can* eat. Are you going to eat a simple sandwich? Will you

cook or eat out? Skip lunch and only have a cup of coffee? If you are going to meet your friends this weekend you might first think about what and where you will eat together?

Considering the importance of the daily routine of determining meals, my three Eonni participants gave insight as to how female adults would behave in terms of the food issue. They were active in offering opinions and advice, and ultimately decided where we should go to eat. They not only knew what they wanted, but also had thought about where they thought I should go. However, eating is also closely connected to one's financial status. You can only eat what you can afford. Often, the participants had a tactic for organizing their meetings with friends and family at a place where they wanted to go, but might not be able to afford, because they knew others would pay for them.

While my three adult Eonni participants' lifestyles demonstrate how closely adult life is connected to food culture, most Korean American young people with disabilities do not get many opportunities to play an adult role in food culture (i.e. at the table or in the kitchen) or in the relationship to others through the medium of food. Simply put, with respect to food, being an adult means choosing what you eat for each meal, or at least having the choice available, even though you may let others choose for you. Also, it means you don't need to eat what you do not like at the table. From the interaction with my three Eonni participants, it also means actively looking for "Mat-jib," meaning a gourmet—although not an expensive—restaurant that serves delicious food, and making a real effort to go to the restaurant to try that food. Drinking coffee is also considered an "adult" thing, in that is much more meaningful to my participants than merely something they enjoy every day.

Coffee as a symbol of adulthood. The food that my participants—as well as I—consume every day besides "bob" (cooked rice) would be coffee. Certainly, from my observations, it was

my participants' most favorite drink. But, it had more meaning to my participants than just a specific kind of drink. Coffee was also a microcosm of the adult lifestyle. For my Korean adult participants, coffee was an easy medium to express their personal taste, choice, independence, work habits and relationships that they had control over. My very first encounter with my participants was mediated through coffee. Moreover, many of our conversations also happened about or around coffee.

Coffee shop as a favorite place. Before finalizing the recruiting process for the dissertation, I asked the director what I might give as expression of my thankfulness to potential participants. It did not take one second for her to give me a gift idea. She told me how the individuals I was hoping to connect with loved Dunkin Donuts. She was absolutely right! My first engagement with these Korean youth and young adults happened through the medium of a coffee gift card.

Around fifteen youth and adults with disabilities were hanging out before a Tuesday praise meeting in Grace House. The director Kim introduced me and explained the purpose of my visit. I tried to have some individual informal conversations with people in the Grace organization before recruiting formal participants.

Director Kim: *This teacher would like to talk with you guys. The only thing you need to do is answer some questions that she asks. She will give you a Dunkin Donuts card after her interview.*

Quite suddenly, a long line formed in front of me! They looked very excited about this interview. But I soon noticed that it was not the interview they were so thrilled about, but rather the Dunkin Donuts card that I was giving out for potential participants.

Seojin: *[with a small, shy voice] I did not get a Dunkin Donuts card.*

Me: *Seojin, I'm sorry, but it is a reward for doing an interview.*

Seojin: *[looks disappointed] ...*

Me: *Do you want to talk with me? Then I can give you one.*

Seojin: *[suddenly smiling] I want to do it!*

Although I had been told that they liked to go to Dunkin Donuts, I didn't realize they loved it quite so much. So, I prepared the Dunkin Donuts gift cards as my gift to interviewees. It became a big deal. Everybody wanted to have an interview because of the 20-dollar Dunkin Donuts gift card I had prepared to give out as a thank you for participating in an interview. The first three interviews were not expected, so I had to give them their cards the next day. I heard several times from my interviewees, "*Please don't forget the Dunkin Donuts cards.*" An interviewee also said I should wrap up the interview soon because she had to go to Dunkin Donuts and buy her coffee. She couldn't wait. On that day I had twelve interviews with youth and adults with disabilities.

Coffee is something that you choose to drink. In other words, if you do not like it, you do not need to drink it. As one might guess based on the previous episode, most of my participants simply loved to drink coffee. Therefore, the local Dunkin Donuts shops - three of them around Grace House - are most interviewees' favorite spots to go by themselves. They were the places where many conversations between my participants and me happened as well. Drinking coffee also includes many options to choose from, options that are freely based on one's own preference, including: which café to visit; what kind of coffee to buy (e.g., iced or hot); the preparation (e.g., amount of sugar and cream); the people who will join the gathering (e.g., who you will invite for your coffee time). Most of my adult participants with disabilities had strong opinions about all of these options. This may sound too obvious for most people without disabilities. However, having several options in food consumption may not be available for many

adults with intellectual disabilities, particularly those in certain residential options, which will be discussed later.

In terms of choosing a coffee shop, this particular Korean part of town is full of different coffee shops, including several franchised coffee shops from South Korea (e.g., Tous Les Jours), two Starbucks, three Dunkin' Donuts, two McDonald's, and several individually-owned (or local) coffee shops. I had not seen or heard my participants choosing to drink coffee at Starbucks or Tous Les Jours. They mostly chose Dunkin Donuts, or if it was not available, the second option was McDonald's. With curiosity, I asked Miyoung Eonni if she has been in Tous Les Jours. Since it is a Korean franchised coffee shop with employees who often can speak Korean, I would not have been surprised to hear that she got coffee there. There are four Tous Les Jours coffee shops in this community, and at least two places are on Miyoung Eonni's daily path between her home, work places, and Grace House.

EJ: Miyoung Eonni, have you been to Tous Les Jours for coffee?

Miyoung: No

EJ: Why not? Many Koreans like that place.

Miyoung: One time I looked at their menu. It is too expensive, there.

EJ: That's true. It is quite expensive.

Miyoung: Is their coffee good?

Miyoung Eonni looked quite curious about this Korean franchised coffee shop even though it is too expensive to afford to buy coffee there. However, she still seemed curious about trying other more expensive coffee.

Miyoung: Eunyoung, can you give me a Starbucks coffee card for my Christmas gift?

EJ: Yes, I can. But, why?

Miyoung: *I'm just curious.*

However, after this conversation, I got a call from Miyoung later that she changed her mind, and still wanted to get a Dunkin' Donuts card instead of one from Starbucks. Miyoung Eonni is a person who remembered the prices of lunch menus and coffee, down to the penny. She preferred to have more cups of coffee with the gift card's twenty-dollar limit. Interestingly, the year after this occasion, she seriously asked for a Starbucks card gift again and explained that she went to a local Starbucks coffee shop with the Cheong-nyun (meaning *young adult*) group in her church.

Among the three Eonni participants, there was even a distinct preference among the three Dunkin Donuts shops. After I had lunch with Jongeun Eonni and Eunju Eonni, and asked them where they want to go for coffee, Jongeun replied:

Jongeun: *There are three different Dunkin Donuts shops, and the one on Erie Blvd tastes best.*

Even among the remaining two shops, I often heard that the one near Parson Blvd was better than the one near Grace House. Also, they often considered the parking situation of each Dunkin Donuts, remembering that I had a car with me. All three Eonni participants have different ideas on what they want in their coffee.

Coffee as an expression of personal preference. One time I went to Dunkin Donuts together with my three Eonni participants after a Saturday event in a local church. We were all desperate to have a cup of coffee since there was no coffee available during the "special" lunch served by the general consulate on that day. They did not serve what was the most important food item for these adults. On the way to Grace House, we found a Dunkin Donuts and were excited to check out a new location, different from the ones we usually visit in the Grace House neighborhood. They all knew exactly what they wanted and ordered their coffee in English

without hesitation, even though these sisters cannot go to the Day program because it is only provided in English. All four of us were standing to order in the new Dunkin Donuts shop, and saying:

Eunju: [directly to a staff] Only milk [in English], *only milk* [in Korean]. [emphasizing]

It's no sugar [in English], no sugar [in English]

Miyoung: [asking me in English] *Please tell them I want* [in English] only skim milk [in Korean] *for my coffee*.

Jongeun: [directly to a staff in English] Iced coffee with Regular milk and one sugar.

EJ: [to a staff in English] Small hot coffee with cream and sugar please.

Beyond the fact that they like to drink coffee, and they have their preference for where and how to have coffee, decisions about coffee also influenced the way their daily routines were mapped out: dropping by a local café at least once a day. Simply put, they did not want to skip their coffee time and made a point to walk to their favorite café every day. If Jongeun Eonni was not seen in Grace House and someone asked where she went, the answer would be, “*probably to Dunkin Donuts.*” If I asked what Miyoung Eonni did during the day, she would say, “*I went to clean [a bathroom in a local church, which was her job], then went to Dunkin Donuts.*” When they go to a local coffee shop, they do not need to get permission or tell somebody where they go. They walked to their favorite coffee shop, spent their own money that they made or got from their families, ordered coffee in whatever way they liked, spent time at the shop, and walked back home.

Stating their own preferences extended beyond ordering their favorite coffee. Eonni participants always communicated what they wanted to eat for lunch or dinner. However, one important difference is that although they drank coffee in a way that fits perfectly within

American culture, they nonetheless insisted on having Korean dishes for their daily meals. A visit to South Korea during my data collection phase reminded me of my participants' coffee culture. At a fancy coffee shop near the ocean in South Korea, I ordered a cup of Americano coffee. There were sugar sticks but no cream with my coffee when I got it. I went to the counter.

EJ: *[at the counter] May I have some cream or milk?*

Staff: *What?*

The staff was visibly puzzled as to what I was talking about. I tried to explain:

EJ: *I would like to put some cream in my coffee. Can you give me a tiny cup of cream?*

The clerk turned around and asked another staff member, who looked like either the owner or a manager, and he told her she could give me a small cup of milk.

It took me one week to realize that Koreans do not put cream or milk in their Americano coffee. If you'd like to have coffee with cream, you would instead order Café Latte or Café Au lait. Because of my ignorance of Korean coffee culture, I seemed like a demanding and unreasonable customer. That embarrassing episode made me realize how my participants, who live in a Korean town (which is actually quite large, with more than 64,000 Koreans living there), surrounded by Koreans, Korean signs, Korean food, Korean churches, etc. nonetheless fit perfectly into American coffee culture. Although they learned to live simultaneously in these two worlds, I clearly had not.

Coffee is somehow also described explicitly as a drink for adults. Elizabeth's (one of the younger female participants) mother mentioned to me that she had told her daughter that she can drink coffee because she is old enough.

Elizabeth's mother: *I found out that Elizabeth drinks coffee recently, in the afternoon, after she came back from her daycare. She told me it's okay for her to drink coffee because she's over twenty now.*

While the term "daycare," frequently used among Korean families of adults with intellectual disabilities, sounds contradictory to adulthood, Elizabeth countered this infantilized terminology and identified herself as old enough to drink coffee.

Coffee as a drink for work. Coffee itself is a "grown-up" drink, instinctively associated with work and other responsibilities as well. Its connection to work was no exception for my participants either. As it is for countless adults in the U.S. and Korea, coffee was essential for my participants on their way to or back from the work place, particularly those who worked cleaning a local church. On Saturdays, my participants' commuting van for their cleaning job often dropped by the McDonald's or Dunkin Donuts' drive-through and left loaded with cups of iced or hot coffee, with different preferences of sugar and cream for everybody. Mike's father's offer of coffee to the six youth and adults with disabilities riding along was always met with enthusiastic approval. He was the one who organized church cleaning jobs for these youth and adults with disabilities and gave them rides. Sometimes he bought coffee for them; other times they paid with their own money. Local coffee shops, particularly, Dunkin Donuts and McDonald's, were where they usually spent the money that they made by cleaning the local church buildings. Coffee was not only a reward from their work, but a motivation for work as well. One of these participants' friends said, "*They want to make money to buy a cup of coffee.*" Miyoung Eonni also often mentioned she would like to work more because the current income was not even enough for buying coffee every day.

Coffee was also a sort of a ritual that individuals, including my participants, enjoyed doing in conjunction with particular circumstances, like going to work or out with friends. One participant's mother was surprised to hear from me that her son drinks coffee, because she never saw him with coffee at home. From my observation, this young man loved to drink coffee when he had the chance with other young people around. It was a moment for this group of young adults to participate in both a social and an adult ritual.

Buy a cup of Dunkin' Donuts

Cheap and close

My sacred ritual to start working

Every letter in this dissertation

Contains a drop of caffeine

Brewing my labor, their labor

Condensed their/our stories

Coffee as a work opportunity. Coffee also represented a possible job opportunity for the participants in Grace—making and selling coffee. As drinking coffee is connected to an adult lifestyle in both Korean and American culture, and is preferred by youth and adult participants, selling coffee has a similar cultural meaning for them. If given the opportunity, they can earn income doing something that they like. Also, by serving others, doing a job that is considered an “adult” (mature) activity, and in a way that is perfectly adapted to American culture, they could also claim adult status. Miyoung Eonni was the one who most looked forward to having a coffee shop open in the community where she could “sell coffee.” It was at the bazzare market where I first heard her express her strong wish to achieve this dream.

This market is a big bazaar event in both South Korea and in several Korean American communities in the U.S. In this flea market, individuals and companies sell new and used items. All profits are donated through two non-profit organizations for children in low-income families. The name of bazzare indicates volunteer movement.

In 2015, a one-day the bazzare market opened in the middle of the community in the parking lot of Korean Neighbor church. The purpose of the event changed from helping children in low-income families in the Korean context to helping *Bu-ru-i-ut*, meaning neighbor in an unfortunate situation in the U.S. context. Various clothes, shoes, hats, hair ties, books, jewelry, nail items, toys, and food items, including Kimchi, were for sale at the bazaar. There was also cooked food for people to buy and eat at the market, including *gimbap*, *tteokbogi*, *japchae*, Korean noodles, fish-cakes, etc. One Korean officer from the city government was there to advertise the city ID, in particular for undocumented people.

Grace also participated in the bazaar as a seller. It was Mr. Yoon, a long-time volunteer and Jongeun's friend, who organized items to sell. Mr. Yoon was the person who always tried to organize ways for "*Grace friends*" to mingle with other Koreans in the community, particularly through some kind of work. The reason he organized a bazaar table as a volunteer reflected this same motivation. He wanted the organization members to come out of their own circle and meet other Koreans in their communities. On the Grace table that he organized, there were Bibles, book marks, some religious items, a Grace pamphlet, information sheets about donation information, and coffee! Coffee was another item that he wanted to consider as a potential opportunity for youth and adults with intellectual disabilities to interact with people in their community. He brought a single-serve coffee maker, coffee capsules, paper cups, creamer, and sugar, with the idea of selling coffee at the bazaar. Even though the table represented Grace, all

coffee equipment and materials were purchased and brought by Mr. Yoon. As soon as Miyoung Eonni saw that Mr. Yoon had made a coffee table for selling, she enthusiastically asked him when they were going to open a one-day coffee shop and sell coffee.

Miyoung: *Jinseop teacher, when are we going to do one-day coffee shop? I'm ready to do [that].*

Mr. Yoon: *I'm trying ...*

Miyoung: *Eunyoung, we did [a] one-day coffee shop before. We served cup-noodle, too.*

Her face lit up with pride and she continued to tell me about their community service story from last year. The previous year, youth and adults with disabilities in Grace opened a one-day coffee shop and served coffee and noodle cups to homeless people. Later, I often heard other young people mentioning the one-day volunteer experience as something that they looked forward to having again, either as a proper job or as a “serving” opportunity. At the bazaar, only a few people were interested in the Grace organization and their coffee business. However, it was these adults with disabilities and Mr. Yoon who were very interested in making and drinking coffee.

Mr. Yoon: *Let's start by making coffee for ourselves! Let me show you how to use this coffee machine.*

Mr. Yoon demonstrated how to make coffee using the new machine, with detailed step-by-step directions. He also explained the cost for coffee ingredients and described the different flavors of coffee that he had brought. After he made a cup of coffee, Miyoung Eonni, Seojin and Junho made their own coffee with Mr. Yoon's guidance. And, Mr. Yoon made extra cups of coffee for me and others – I was still a guest, which meant I was to be served. While making and drinking a cup of coffee for themselves, they were not able to sell to others. Yet, there was still humorous, cheerful, sometimes teasing conversation among the six adults with disabilities and Mr. Yoon.

Noting how Texas Grace had been successful in opening a coffee roasting business with young people with intellectual and developmental disabilities, in addition to selling coffee, Grace also considered roasting and selling coffee beans as another option for hiring people with disabilities in this community. However, regardless of enthusiasm for opening a coffee business, according to the Grace Director, it would not be easy to get started because of the high cost for insurance and rental space. As many people in this community mentioned, the most viable option for such a business would be to set it up as a job site inside a local church building. During my data collection, for instance, one mother was about to launch a coffee shop located in her church building as a job site for her daughter with Down syndrome.

Coffee as treat for others. Coffee also played a role in fostering relationships, especially when given as a gift for others. As mentioned before, Dunkin' Donuts coffee was cheap enough for my participants to enjoy themselves, but also to give as a treat to others. Miyoung Eonni often told me, "*Eunyoung, I got paid. I will buy you a cup of coffee on Saturday.*" When participants asked me to buy something or pay for meals for them for a special occasion, such as their birthdays, Christmas, or New Year's Day, I often asked them what they would do for me in return. Most often they replied, "*I will buy delicious coffee for you.*" Sometimes they suggested, "*Eunyoung, let's eat Jjam-Bong [a spicy seafood noodles]. You buy it, then I'll buy coffee after.*" Our interaction became less awkward because both my participants and I, as adults, contributed to the cost of our socializing. And coffee was a perfect item because they could afford to serve others by paying for coffee.

Why is coffee their favorite drink as adults? What is the significance of coffee? More specifically, what does it mean to go to a local café, buy a cup of coffee, and drink coffee as an adult? Because buying coffee is an easy way to express your personal taste, choice,

independence, and relationships, I would argue that coffee serves as a kind of microcosm of the adult lifestyle for Korean American youth and adults with disabilities. I am not suggesting that my participants went to a local coffee shop in order to identify or represent as an adult in some sort of intentional way. Rather, their coffee routine was a good example, as situated within their daily actions, to illustrate what is like being an adult in relation to Korean food culture. Their coffee routine is the most significant time to show how they are independent decision-makers. As described above, they decided where, when, how to drink coffee in a natural setting where everybody participates in a reciprocal way.

The coffee culture I observed is quite different than many self-determination programs designed for people with disabilities. Often, people with intellectual disabilities can make choices, but only within limited options that are given. For example, people in group homes may not have full choice to determine tonight's dinner, but only can choose from a menu that has been planned by others. The features that I identified related to participants' coffee consumption are not exclusive to Korean American adults with disabilities, but rather universal for many people all over the world. However, the social context that my participants inhabit – identified as disabled, with limited financial status, and restricted daily opportunities – may make the meaning of coffee much more significant to them.

Adult friendship over the table. In addition to the functions of food as a representation of adult status in the Korean community--affording a person with autonomy, authority, and knowledge over specific local food and coffee, some relationships are also expressed through food items.

Talking about food. To begin with, food was a very popular topic for members of this community to talk about when meeting a new person. I was very frequently asked, "What do you

cook for dinner?” or “You probably cannot eat much Korean food, can you?” They assumed this because they knew that I was married to an “American.” The topic of food as a discussion ice-breaker was often observed at Saturday program as well. During introduction time at the Saturday program, young people with disabilities and volunteers shared their favorite food in addition to their age and hobby. Seojin made his group members laugh by saying that “My hobby is eating food,” which sounded like a joke, but can be true for many Koreans in the U.S. There was not much difference between volunteers and people with disabilities in terms of their favorite foods: many stated that their favorite food is Korean food. If they got more explicit, the list included Kim-bob, sushi, Kimchi and, the uniquely American, Dunkin Donuts food. That was probably one of the moments when the two groups were most identified as one homogeneous group: Koreans. Obsession with Korean food is much stronger in this community because they are away from Korea. However, asking others about their meals is a common practice in South Korea as well: when you meet a person around noon, you ask whether or not they’ve had lunch yet. This does not mean you are inviting them to lunch or want to know what they eat. Rather, it is a way of expressing your care for that person. You show that you care about others by asking about their meals.

EJ: [to my husband] Don’t you want to know if I had lunch today? I know this is silly but please ask me about my lunch when you give me a call during your break. I feel you don’t care about me unless you ask that question.

Talking about food as a routine in a relationship can be seen in the following conversation with my participants. One time, she showed a website. She often shared 80s or 90s Korean songs, touching stories, words of wisdom, some outrageous news, or celebrities gossip with me. This time it was about food. The headline for the linked website was “*Here are stamina healthy food for Cho-Bok day.*” Under the title, there were twenty-five photos of food including a

whole-chicken soup – the most popular dish for Chobok – abalone, loach soup, duck Shabu-shabu (Japanese meat broth fondue) that Koreans may consider good to eat for Cho-bok day. I realized that the next day was Chobok day. Although my calendar is totally American, her calendar is definitely Korean. Chobok is one of three summer special days [i.e. Korean Dog Days] in the hottest season from July to August in Korea. On these days, Koreans eat special foods that provide them some stamina to overcome hot summer days. As listed on the link that Jongeun sent, there are many different kinds of food with high protein and fat for those days. But, a whole-chicken soup and eel are the most popular foods among Koreans for that occasion. I immediately talked to Jongeun about it.

EJ: “Oh!!! I’m hungry. But, to me they are rice cakes on a painting [an old Korean saying meaning it is not real]. I’m craving a pig’s-feet dish.

Jongeun: It’s Cho-bok day.

EJ: What yummy stuff did you eat?”

She shared her photo: she was sitting at a table in a Korean restaurant. There are at least seven main dishes on the table with some more side dishes. I commented to her: “*Eonni, I’m very jealous. They look really good.*” She replied with her question: “*You didn’t get a chance to Dakgalbi [Korean chicken rib] recently?*” The next day, she showed me a meme with a joke about Bok-days and Korean’s old-fashioned favorite Bok-day food, Bo-sin-tang [Dog soup]. The picture showed four puppies seated around the tea table with cups of tea or coffee just like people. In the upper left corner, it read, “*We need to have a family meeting about how to survive until Mal-bok [the last of three Bok days].*” Many of our conversations were just like this, about Korean food that we either actually ate or found on websites.

Scheduling what to eat together. Similarly, our meetings were always planned around food as well. My participants often remembered what I said about certain food that I did not get a chance to eat for a long time, and tried to decide a restaurant that met my “needs.” During my data collection, in particular with three Eonni participants, it might be called the ‘eat-along’ method. We couldn’t imagine or schedule our meetings without planning ahead what to eat together on that day.

Miyoung: *Eunyoung, have a good Christmas.*

EJ: *Eonni, did you have a good Christmas? [It was the end of Christmas day.]*

EJ: *I cleaned my house all day.*

Miyoung: *When are you coming?*

EJ: *I should go there before school starts. But, I don’t know when I can.”*

Miyoung: *I miss you. Let’s eat chicken when you come to the city.*

And, another time:

Miyoung: *Are you seriously coming this Saturday? Let’s go to Pelicana [a local Korean-franchised chicken place] to eat fried chicken.*

The Korean word, “Sikgu” represents the importance of eating together in relationship. “Sikgu” means a family, but literally means people who have meals together. Another phrase is translated as *the relationship in which people eat rice from the same pot*—meaning a close relationship.

When I was first invited to the small table right next to the kitchen of Grace House, the director mentioned, “*This means you’ve become our Grace Sikgu.*” The importance of food in terms of relationships could also be seen in a group context (i.e. relationship between people with disabilities and others in the community). Mothers’ Group and Tuesday Praise Night may be

good examples by which to shift our focus from personal relationships to group dynamics around food.

Serving Food to the Group of Youth and Adults with Disabilities

This is a common theme that I was able to observe in this setting: people without disabilities are the ones who “serve” food and people with disabilities are those who are “served.” Often these two categories parallel those of “children” and “adults,” although this should not be overgeneralized. For instance, many children fix meals by themselves and in some cultures, they start to cook for other family members at an early age. In Korean culture, senior people often recall from their childhood how early they started cooking rice, perhaps around eight years of age. While there is some danger in generalizing this dichotomy, there remains a strong public discourse or cultural image of children being fed by adults. It was interesting to observe how Koreans feed their youth and adult children as a group.

The mothers’ group: Feeding kids together. One Saturday evening after all programs and events had concluded, some youth and adults came back to Grace House¹¹ from Hope church where they had Saturday program. They were hanging out, waiting for a ride back home. Some of the young people were playing a game of UNO, and others just sat there and watched them playing. The UNO cards were fairly worn from use and Seojin kept scores for every participant on a piece of paper in an organized way. From my perspective, it looked like a familiar routine for these young people. Nobody seemed concerned about their rides or in any great hurry to get back home. Some mothers were already there to pick up their youth or adult children, but they did not leave right away. Instead, they gathered with other mothers in the kitchen or in the small dining room. Everybody seemed relaxed and they were casually chatting.

¹¹ A group-home that is run by the Grace organization. This place is also used for Tuesday worship, parents’ meetings, etc. Youth and adults with disabilities were often also picked up at Grace House by their parents.

At one point, the mothers brought food to the middle room between the computer room where people played UNO and the hallway connecting to the kitchen and dining room and invited everyone to have dinner. It was gimbop, made with leftovers from the lunch at Agape Class. One mother said to the young people, “I made this. It is pretty good to eat, isn’t it?” The food was not individually served, but instead brought out on one dish. The young people and I got wooden disposable chopsticks, picked out our slices of gimbop and ate them. The mothers laughed and said it was nice to feed “kids”—including her own and other youth and adults who were in her son’s age—here.

I had a personal experience—being served by another mother because I am like her daughter—with a Chinese woman who had married a Korean man; she has a daughter around my age. They owned a Korean restaurant near the campus I attend. I often went there as a student, eating out for lunch. Once I ordered my lunch as usual, but the food served was not what I had ordered. It was beef seaweed soup, which wasn’t even on the menu. She explained to me: “You are very pregnant! I feel bad because you are far away from your mother during your pregnancy. I made this soup for my daughter. I cook her dinner, soup and side dishes every day. Today I feel like you are my daughter. Eat a lot and ask for more if you need it.”

As described, the dinner was very informal, reminiscent of what some Koreans, including myself, might have experienced during childhood. Many Koreans might be able to recall that some mothers and children in their own neighborhood would hang out in another neighbor’s house. The house owner did not mind other mothers using her kitchen and they all cooked food together and fed their children. It was not even unusual for children to end up eating dinner at a friends’ house. Korean children would often hear from their friends’ mothers, “*eat dinner and go home!*” Just like these mothers who fed young people with disabilities as a group of their

children, many Asian mothers have the mindset of feed others' children as if they were their own.

Meeting with the community through served hot meals. Every Tuesday Night young people with disabilities gathered at Grace House to praise God, usually with a youth music band. This is the description of Tuesday Praise Night from the Grace News Letter reads:

Hosanna Church¹² and New Heaven Church have participated in Grace's Tuesday Praise Night. This is changing society's perception of the limitations of the disabled. With hot meals provided, friends and families socialized with the disabled, asking about their day, worries, and prayer requests. In the future, Grace hopes to continue to work with local churches to further Grace's work with the disabled in God's love. Please pray for Grace.

The Tuesday Praise meeting does not only have a religious purpose, but also has an aim of creating a bridge between a group of young people with disabilities and local church members. As described in the Newsletter, the organization especially wants to change Koreans' perceptions of people with disabilities in this particular church setting. Specifically, the Grace organization hopes to give their congregation an opportunity to witness how youth and adults with disabilities seriously approach religious matters (e.g., faith, praise, prayer, worship, sermon listening, etc.), by participating in this weekly event. The key to encouraging or facilitating a positive encounter between community people and people with disabilities is the provision of "hot meals." The Praise meeting started only after the group finished having dinner together, which was also prepared or donated by local church members. These new guests from a local church were also the ones who served the food to people with disabilities, even though it is otherwise unusual for people outside of the Grace organization to serve insiders with disabilities in Grace House. Their

¹² I directly quoted from the Grace Newsletter, while the church names have been changed.

first introduction to each other takes place around five different dishes, as local people serve “hot meals” to these young people with disabilities.

Structure of dinner in community events. There was always Korean food when people gathered: Saturday program, Grace Summer Camp, celebration of the day for disabled people, a Tuesday praise service, a Korean bazaar, a community picnic, a Christmas party, during the waiting time for parents to pick up, etc. Regardless of the different purposes for gathering, the structure of lunch or dinner was very similar if the event was about youth and adults with disabilities. The lunch at the Saturday Program is a good example to show the basic elements of these meals.

Lunch at the Saturday program. The lunch was always provided by “lunch volunteers” for youth and adults with disabilities who attended the Saturday program. Lunch volunteers were mostly adult women, with a few adult men who attended Hope Church where Grace held their Saturday program. Every month, the lunch volunteers, including people who paid for catering and those who brought or served food, were listed in the Grace Newsletter. Grace used the dining-hall of Hope Church, located on the second floor of the church building. On Saturdays, in this same dining-room, lunch was also provided to Korean seniors as well as to children who attended Saturday Hangul School. Although the kitchen and dining room were shared, the lunches were organized and served separately. The lunch times, menus, and servers all differed depending on the group. When the Saturday class participants went up with their partner volunteers, they lined up in front of the long tables where rice, soup, side dishes, and dessert were placed. Lunch volunteers stood behind the table. When someone brought up an empty disposable plate, the lunch volunteers served food. Usually, one volunteer served a couple of food items (e.g., two side dishes). While the menu changed every week, and sometimes included

western food such as spaghetti or sausages, the table was always set in the Korean way, which includes rice, soup, kimchi and three to five side dishes. The western food was considered a side dish and was always served with rice. For example, spaghetti was not a main dish but one of the side dishes. Examples of side dishes were spicy pork stir fry, japchae (sweet potato noodles with vegetables and meat), teokbokki (Spicy rice cake), Korean curry, etc. Sometimes volunteers cooked one or two food items and brought them on Saturday. The food was also catered by Korean businesses and paid for by Korean churches in the community. Each event that I observed had different volunteers and financial supporters who were responsible for providing and serving food for youth and young adults with disabilities on site. Although certain events had other kinds of food, the lunch format was always very similar. To signal the importance of these meals to the organization and the community, I often heard people saying “we eat first before doing anything else” in the Grace organization.

Dinner at the Grace Summer Camp. The extended version of the Saturday meal as well as the highlight of food serving that I observed took place during the Grace Summer Camp, at which all the East Coast branches of Grace gathered for three days each year. As one senior female volunteer - the main volunteer in charge of “Sik-sa” (meals) at Grace Summer Camp - stated, *“This is one of the most important parts for the Grace Camp. It cannot be called ‘successful’ without a satisfying meal.”* At the Grace Summer Camp, I observed the unusual scene of a wide variety of Korean foods offered in the middle of a major hotel franchise, and not provided by the hotel catering service. There was a buffet in the hotel lounge, but every item had been cooked and delivered from a Korean catering business outside of the hotel. The host Grace branch was very careful to order enough Korean food and to distribute it evenly, so that none of the attendants would complain about being unable to get a certain dish that they wanted. This

requirement that food be prepared by Korean vendors and brought to the hotel must have been a requirement that was essential to awarding a contract to the hotel for this event. It also shows the importance of food to the culture and community.

Roles of Being Served vs. Serving

In all these episodes we catch a glimpse of the food sharing and serving culture in this Korean community, even while the practice is generally declining in South Korea. It sometimes happens within personal relationships, as in my own example. It also can become a group practice, such as church lunch, the mothers' group, volunteering, etc. In all of these practices, it is interesting to observe who is served and who is serving. In Korean culture, it is the role of adults to cook and serve. More specifically, the cooking is done mostly by adult women - not seniors, but old enough to be mothers of young or teen children, and the serving and cleaning by both adult women and men. It is something people would do as adults in this community, to cook and serve food for others. In this vein, we need to ask whether these young people with disabilities have been prepared for this role, or given opportunities to participate in it. There are four groups of people who are provided a meal regularly in Korean churches: children, seniors, homeless people, and people with disabilities. For people with disabilities, it does not matter whether they are young or old. It was not hard to find an occasion that older people with disabilities were served by adolescents in an event. Why is this happening? How is it always the case that even my Eonni participants never have the role of serving in this community? These questions may be answered by exploring the meaning of serving food in a Korean community. In keeping with the serving role of adults, food is also used as a vehicle to "show love" toward neighbors on the community level. The Korean community, as a group, has a consistent idea of "loving" their neighbors by "serving food".

The discourse of serving food: Loving neighbors. There are many ways of helping others: donating money to a charity organization, paying for others for some specific purpose (e.g., scholarship), providing new or used goods, or doing physical volunteer work. In connection to food, the charity pantry would be the most typical community assistance in the United States, particularly by religious groups. A variety of food items, usually non-perishable, are distributed on regular basis in a community. Some organizations also provide daily meals for specific demographics (e.g., homeless, refugees, etc.). In the Korean community, it seems that serving hot Korean food is the most favorite form of charity, even for people who have their own places to live. To do this, someone has to pay for food catering, cook the food, physically serve food, set up tables, and do serving preparation and clean-up. The Charity Flea Market, which was described in the context of the coffee business as a job for young people with disabilities, shows this Korean practice of charity through food service. Here is one news article (Seo, 2013) about how to use the proceeds from this charity flea market:

We [Korean American community people] will continue angelic love toward other ethnic neighbors in difficult situations. Koreans diligently continue to love neighbors, even from other ethnic groups. ... [We] served warm Korean food to neighbors in need. This is the second time, after one in January this year. It was covered with proceeds from the bazaars ... with the purpose of helping neighbors in a shady place. The committees of [the] Charity Flea Market and staffs ... participated as volunteers, and rolled up their sleeves to practice loving their neighbors, heartily serving food to other ethnic neighbors, etc. On that day, the other ethnic neighbors who were exposed to various Korean foods including Bulgogi, Jabchae, etc, kept saying, "welcome and thank you." There were people who asked how to make them, because they are very delicious. The director, Mr.

Wi, who participated as a volunteer, said, “our giving heart is very happy since other ethnic neighbors were very thankful,” and, “we hope that more Koreans become of one mind for the practice of loving neighbors.” Ms. Im, a board member in Beautiful Foundation USA also smiled and said, “I am very pleased to join in the chance to practice sharing.” ... The standing committee chair in the foundation said, “Sharing and volunteering will continue in the [city],” and asked for the Korean society’s interest and participation.

Rather than other options, including donating proceeds to other organizations or giving financial support toward individuals or groups, the committees decided to use proceeds from the WeAJa Charity Flea Market to pay for Korean food and physically participate in serving the food for an organization that serves people dealing with substance abuse.

Several important Korean phrases are used and circulated in this community while they serve food. These include a phrase that indicates love and neighbors and is reminiscent of the usage of the word “agape” in Grace. In a news article about, “serving food to other ethnic neighbors heartily” this practice was made equivalent to the “practice of loving neighbors.” The same equation applied to young people with disabilities. There are several events where food was served to people with disabilities in the name of “loving neighbors.” The Christmas party in Grace is one example.

Food serving in the Christmas party. On Saturday, two weeks before Christmas, there was a Christmas party in the Grace mission. The Education Center at the Neighbor Korean Church, where the Saturday program for K-6 children was usually held, was decorated with a Christmas theme, including lights, a Christmas tree, and balloons. Youth and adults with disabilities wore red Santa hats with matching white shirts. After the service and gift exchange,

all the children, youth and people with disabilities, along with the volunteers and people from the community, moved into the church dining hall. There were around twice as many kinds of food as usual set up on the long table. It was similar to a buffet setup, but with servers standing behind the food. The wives of consular officials were behind the table in order to serve food for the people. The Consul General's wife had a conversation with some other women about where she should stand. She was standing in the middle of the line and was handed a utensil and a pair of disposable gloves. She was listening to the other women as to how she should serve. Once the women found their places and got ready, the food started to be served to the people, including young people with disabilities and volunteers. They passed through the line and readily chose and received their rice, soup, kimchi, and several main and side dishes. Most youth and young people with disabilities knew what they wanted or and what they did not want. They passed on the side dishes they did not like and asked for more of what they did like. The young children's group had a separate table set up for them. They did not come to the line and receive the food; rather, the teachers selected food that the children might like or could eat, then brought it over to their table. After most people had their food and sat at their tables, the General Consulates' wives went to one table and had lunch by themselves, separated from any young people with disabilities.

This has been an annual event for General Consulates' wives for several years. They pay for the special lunch for children and young people with disabilities every Christmas and every The Day of People with Disabilities. Here is the Grace Newsletter explaining the meaning of their food volunteering:

Grace had a Christmas party with the Wives' Society of the Korean Consulate General in ... This annual event has become a new opportunity to introduce the meaning of sharing

and volunteering. They [wives of consular officials] had a service with people with disabilities and presented a gift to them. They [the wives of consular officials] got to know that anybody can be dear neighbors by having dinner together.

The newsletter described the wives of consular officials as having had dinner with young people with disabilities, explaining that this had brought them together as neighbors. Ironically, the flip side of this statement is that this group of people with disabilities would not be considered their “dear” neighbors under ordinary circumstances. Moreover, unlike the article’s portrayal, serving dinner does not necessarily join these young people with disabilities to the Korean community, either. From my observation, the consulates’ wives did not attempt to have a conversation with any young people with disabilities while there, and the two groups did not have dinner “together” at the same table. It was just a pretense or a very shallow social action to include people with disabilities as neighbors in this community. And, serving food was used as only an act of charity.

Eating and drinking whatever we want, especially as adults, can be taken for granted as something obvious and insignificant. However, when these young people with disabilities were “served,” they often did not have many choices. Just as the WeAJa committees had not asked the people whom they served, likewise youth and adults with disabilities were not asked what they wanted to eat for special day lunches like a Christmas party or The Day for People with Disabilities. There was no choice, even though one of my participants complained about how tired she was of having the same food every year.

Serving and sharing food is a beautiful thing for the community to do for one another. It is a good practice that at annual, monthly, or weekly events organized by a non-profit organization, lunch is served by community members for event participants. Food usually helps make an event run smoothly and motivates more people to participate. Food also has a very

significant cultural meaning in relationships among Koreans. As such, it seems to be something that should not be criticized. However, there are layers of hidden cultural meanings at the table and around the food. This becomes obvious if we juxtapose two different cases, the Gala dinner and the Grace Special event lunch.

What does it mean for Koreans, usually without disabilities, to sit at the annual Korean night gala dinner, which is hosted by the biggest Korean non-profit charity foundation in the city? Is this merely for philanthropy? The gala dinner table is the place where the successful stories of Koreans in the United States are shared; where Korean identity as well as charity work is glorified; where Korean leaders are recognized and strengthened through their charity work; where young leadership begins to be formed; and where the old leadership meets upcoming young leaders. In contrast, what happens around the table in which young people with disabilities receive a free special lunch from the Korean community? Where they are often identified as “unfortunate neighbors” in the community and seen as people to pity or only as objects of charity? In particular, how are these adults with disabilities robbed of their adult identity, as well as their adult serving role? In next section, I show how the participants with disabilities in this research served food for others in counter to the discourse that they are “unfortunate” neighbors that others need to serve food. The first example is Eunju Eonni who was learning how to cook and serve these food for others including myself, and the second example is the group of adults with intellectual and developmental disabilities who served food for their church members as appreciation for their support for this group.

Counterexamples: Eunju and Youth and Adults in Covenant Church

Eunju cooking for others. In one instance of the sharing of food signifying membership, I was invited to join the dinner table at Grace House. There were several different dinner times

for the people living in Grace House, but this was not one of those. It was Director Kim and Eunju Eonni's consideration for me personally.

Ms. Kim: Are you leaving now?

EJ: Yes, I have to go back home soon, so I can see my kid and the babies.

Ms. Kim: Eat something before leaving. Have a seat here.

This was my first time entering that kitchen area. There was a full-size kitchen and a small dining area right next to it. Ms. Kim was already at the table and watched me walk into the dining room. Soon, Eunju Eonni brought a bowl of Korean dried cabbage soybean soup, a bowl of rice, and a dish of Korean spicy pork barbecue. Eunju Eonni shyly explained,

Eunju: Help yourself. I made this today.

EJ: Really? It looks really good. Did you make it by yourself?

Eunju: [looking at Ms. Kim who sat on one side of the table] Ms. Kim taught me how to make marinating sauce and I followed the directions.

EJ: [after having one bite of pork] It is delicious!

Eunju: [smiling with pride, but still shyly] Is that good enough to eat?

Ms. Kim: It is easy. You just need to learn step by step. Everybody started [cooking] just like that.

It was the first time for Eunju Eonni to cook a main dish by herself. There was another mid-age woman volunteer who usually came to Grace House three days a week to prepare meals for Eunju, Jongeun, and Minsu. Even though Eunju Eonni always helped people set the table and clean, she did not usually cook for herself or others until that day. But then when she made a main dish with Ms. Kim's help, she happily served that food to Ms. Kim, the director, and me. Before driving five hours through the night to get back home, I filled my belly with the food my

participant had made and served for me. In my car's trunk, as usual, were some Korean food items including gimchi, ramyeon noodles, and kid's snacks that I'd received from Koreans in that community.

Youth and adults with disabilities at their annual "serving" day. I observed another example of my participants serving others during Saturday program. It involved five young people with disabilities who were dressed up with white shirts and black pants.

EJ: Wow! What's up? Do you guys have special things to do today?

Minjae: [showing his nice clothes and smiling] We have a dinner party at Covenant Church today. Do you want to come?

Dongsan Church is one of the few Korean churches where congregation members have made an effort to meaningfully include their members with disabilities in their church practices. The session had allocated some of the church budget for the group of young people with disabilities in the congregation. They also made their van accessible for people with physical disabilities, included individuals with disabilities in their regular Sunday service instead of having separated worship, and provided bathroom and car cleaning jobs for the group. The church donated money and food for Grace mission, and its pastor has sometimes visited Grace and delivered sermons there. Behind this church support system was the leadership of the pastor and one father of a young man with developmental disabilities. This particular dinner party is held at the end of every year. The father, who was in charge of the group of young people with disabilities as well as organizing the cleaning job for young people with disabilities, explained how important this annual dinner was:

At this annual event, these young people take the role of serving others who have supported them. We invite all people who supported us and the Class of Love during the

year, including our church members and their families [different than the Class of Agape; a group of young people with disabilities in this church]. We [him and young people with disabilities] get dressed up and serve a nice dinner, such as steaks. It is important to show ourselves to our supporters in this way, not as one who gets help, but as one who serves.

This is a consistent idea that I observed: the positive image of “serving” others in food culture. However, except this annual dinner event at Covenant Church and my participants’ one-time cup-noodle service for homeless people, it was rare for them to be given a “serving” role in this community. It was also ironic that a few of the young adults with disabilities who participated in non-Korean programs, led by American agencies, had an opportunity to volunteer for Meals on Wheels, while most my participants in Korean community were not given a similar opportunity. In other words, although the community emphasized a more serious or significant meaning for performing a serving role, it did not give that job to people with disabilities. Rather, their role was almost always fixed as an object of service—someone to be served, while other Koreans without disabilities claimed their “love” toward “neighbors” by serving food to people with disabilities.

In this chapter I showed how, in a Korean American community, beyond an individual’s taste or choice, food is also a means to determine or at least represent social relationships. On the community level, serving or providing meals is a major way of representing community “love.” On a more individual level, inviting someone into the kitchen, cooking for that guest, and sharing homemade food indicates some level of intimacy. All Koreans that I know, regardless of age, love Korean food and eat it every day if they can. However, it is the role of a mother, or other adult, to cook and serve food for their children, or young people whom they may treat like their

children. Because they were not offered the opportunity to learn and perform what is considered a beautiful and important serving role—food hospitality—in the Korean community, my participants were still seen as children, not adults. In other words, Korean American youth and adults with disabilities do not have enough opportunity to play an adult role in a food-serving culture, but get trapped in the role of being served. This dichotomy of being served and having a serving role was also observed through volunteer work in this community, which is described in the next chapter.

CHAPTER 6: VOLUNTEERISM, ELITISM AND ABLEISM

The previous two chapters explored experiences of adults with disabilities in the Korean age hierarchy culture and in food serving culture. While daily activities often reinforced the age hierarchy, there were also moments when the age rules did not seem to apply for Korean youth and young adults with disabilities. Similarly, even though serving food is one of Korean adults' roles, my participants with disabilities rarely had the chance to play that role. It is due to ableism that these people with disabilities are treated neither in accordance with their age, nor in a serving role. One of the questions this study aimed to explore is how ableism is constructed and reproduced in the transition experience of youth with disabilities in their Korean American culture. This chapter describes how Korean American elitism and ableism are interconnected during the transition to adulthood.

In order to understand the context of elitism, in this chapter I first explain the phenomenon of Education Zeal in Korea and the Korean American community, as well as the cram school business in the Korean American community. Second, I share episodes from the Grace Summer Camp and the Day for People with Disabilities, to show the figure / ground relationship between youth and adults with disabilities and youth and adults without disabilities in Korean American community. In this relationship, youth and adults with disabilities become an object that able-bodied youth and adults act upon. In other words, able-bodied individuals are encouraged to engage in volunteer work for young people with disabilities as part of the process of acquiring an elite status and ensuring “successful” career paths. In this process, ableism is often constructed through the hierarchical relationship between subject and object—between being “served” (young people with disabilities) and “serving” (volunteers without disabilities). Third, this process is reflected in a bigger picture of how the association of social status with

charity functions within a wider Korean American community. While youth and adults with disabilities become capital for other achievements (e.g., going to a prestigious college), their contribution was under-compensated. In this vein, most importantly, at the end of the chapter, I present six “serving” stories of my participants with intellectual disabilities as counter-examples.

Education Zeal in Korean American Community

Saturday morning scene. I was waiting for a bus headed downtown at 8:59am on a Saturday morning, at the intersection of Jefferson Blvd¹³ & Fayette St. The busiest area in this community, where most buses arrive and the subway stops, is not fully awake yet. At this hour it is a quiet street with light traffic and few people. Most stores had not opened yet. Suddenly, one boy and a woman who looked like his mother caught my eye, as I noticed a scuffle between them in front of a building. The boy did not want to go inside and his mother was trying to push him into the stairway leading to the second floor of the building. I looked up to the building to figure out what they were fighting about. It was written in Chinese with a short English name: U.S. Academy. Finally, the mother managed to get her son into the building, probably making it to his 9am class.

It was not hard to understand what was going on, since I remembered similar experiences from my childhood in Korea. It was a private “cram school,” where most Asian students go for tutoring every day, including weekends and vacation. There was no sleeping in on Saturday mornings and no family dinner in the evenings because many Korean and other Asian children need to keep up their academic progress at private tutoring places. Korean families’ effort to get their children on the academic top track starts early and systematically. In particular, the Korean

¹³ pseudonym

private cram school system has been planted in the U.S. by Korean immigrants and has become a main part of the daily lives of Korean American students.

This was the Saturday morning scene for many Asian students, in contrast to my participants with disabilities, who were heading to the local church for their Saturday class. It would become apparent much later that this spontaneous observation on a Saturday morning, highlighting the contrast between the routines of youth with and without disabilities in this area – one going to a cram school and the other going to Saturday program – was connected to different life paths that continued into their adulthood. Interestingly, these two separate tracks sometimes crossed in this Korean American community through volunteer events.

Visiting the Grace office. As the school year approaches summer break, Korean parents are busy arranging their teenage children's private tutoring and enrollment in cram schools to prepare either for specialized high school admission test or SAT. During one of my field trips, The Grace office was moved from the center of the neighborhood to the middle-class neighborhood. While the majority of residents in the area are White, Koreans have shown a significance increase in this area since 90s (2000 Census). It has become the largest Asian ethnicity group in this area followed by Chinese (2000 Census). The new office was located in a two-story building, next door to a Korean cram school ("Hagwon"), with a Korean senior organization on the first floor as well as a Church. When I first visited the new office to interview the director of Grace and learn about their summer camp, posters on the glass door of the building greeted me:

"Ivy League Academy congratulates our student, Jackie Lee for her acceptance to Princeton University!"

This announcement is written both in English and Korean, while there are also Chinese marks for congratulations, the name of university, and acceptance, implying that this cram school also serves (or at least recruits) Chinese students. Underneath this advertisement were twenty-three students' names listed under the names of four specialized schools in this area and the statement, “[the name of this cram school] congratulates all of the students who received an offer from specialized High Schools, and those who took on the challenge of applying.” Right next to that message, the poster highlighted that in the current year (2016) this school was number one among Korean cram schools (i.e. where the most students had received an acceptance to a university or specialized high school). Other related signs and posters were pasted on the outside of the building. One poster said, “Specialized High Schools Admission” in very large font.

Another reads:

“There is a way to a specialized high school in [the name of this cram school];”

“The choice is an admission right away;” and,

“Producing 25 - 30% of Korean students in specialized schools”

There was also a billboard highlighting a 2016 summer program, which included preparation classes for ACT/SAT, as well as specialized high school test.

Cram school business in Korean American community. Korean families' strong interest in Ivy League universities and specialized high schools can be observed in Korean American media, including advertisements in newspapers and online news websites. These media often advertise annual education fairs in Korean communities where parents obtain detailed information about specialized high school admission and Ivy League college admission process (Korea Daily New York; The Korea Times). Because of parents' strong interest in high achievement, hagwon is a unique landmark for the Korean community. In one Korean yellow-

page book issued in this community, the hagwon (cram school) category lists more than eight hundred hagwon businesses. One hundred seven of them are either cram schools or after-school academic private tutoring places in this city. Interestingly, Grace is categorized under after-school programs as well. On one Korean portal website, two hundred seventy general academic hagwon business are listed in and around this city. The names of these hagwon businesses are designed to communicate to parents exactly what they are designed to produce: Yale Academy, Brown Academy, IVY Center, Elite Academy, Mega SAT, etc. These cram schools have similar intensive test (e.g., SAT, ACT, etc) preparation programs during the summer months. According to one Korean American newspaper article, a seven-week summer preparation program in one cram school costs \$2,800. One Korean American Christian organization provides a scholarship for its summer SAT preparation program and its specialized high school preparation program. In the Internet-based *Korean Times*, the Education section is often filled with articles about college admission, offering guides for choosing colleges for application, college admission guides, the student image that colleges want, etc. The headline was 2017 UC (University of California) Application Data (Park, 2017). It explains details of UC freshman data and implications for Korean American students as follows:

... rate for in-state residents has decreased while out-of-state students have increased. The candidates' SPEC has improved. In particular, for UC Berkley and UCLA, almost Ivy-league level students are applying, so the competition has been heating up. It used to be that a GPA 4.0 student could expect to get admission. But now it's hard to guarantee UC middle level entrance. ... Therefore, many college admission professionals advise that students need strategic applications, because each UC campus has different points that they would like to see from students. (Park, 2017)

It is not very uncommon for Korean children to go to two or three – sometimes more – different private tutors, in order to excel in school. The students' daily schedules, including weekends and breaks, are filled with test preparation and private tutors. One reason for the success of this private tutoring and cram school industry is Korean parents' attitude toward their children's education. They are generally willing to invest all their resources and money in any private tutor or educational service that may help their children to get better test grades. There is a term for this phenomenon in South Korea as well as in Korean American communities, education fever ("kyo-yuk-yeol"). It could be translated as "Korean zeal for education" (Sorensen, 1994). This phenomenon is not only for middle- or upper-class families, but is a nearly universal attitude for families in Korea.

According to a 2015 report from the South Korean government (Statistics Korea, 2016), the total expenses for private tutoring and cram schools was 17.8 trillion Won (about 18 billion dollars). The report states that 68.8 percent of students from grades one to 12 used some form of private education services, and the average monthly private education cost per student was 355,000 Won (about \$360). One of the most common stories that is shared regarding Korean cram schools in the United States is typically about how much of the parents' income was spent for private tutoring. The *Korea Times* (Kim, 2011) introduced cases of Korean American families who live in a very similar environment (i.e. urban; one of the major Korean communities on the east coast).

One interviewee, a parent, said, "We chose to educate our child in the U.S., because we didn't want to be swept up in a storm of Korean private education. However, this country is not very different." All of the parents in this news article spent more than \$1,000 per month for private tutoring and lessons for their children, particularly focusing on their college entrance.

There are some middle-class families in which the parents make good income as professionals. But many Korean parents of low financial status also fund their children's private education with a significant portion of the income they've earned by working in nail shops, driving taxis, cleaning offices, and operating small Korean businesses.

Historical and social context of Korean parents' education zeal. It was not hard to find the pride of Korean parents that I interviewed about their non-disabled children who went to top colleges in this area and were pursuing professional careers. This is not to say that they did not value the lives of their children with disabilities. While being careful not to generalize, I noted that at least my interviewees described their children with disabilities providing them with different perspectives and meanings in their lives. Here are some of my interviewees' statements about their children without disabilities who did well in their academic work, some of whom began careers that were admired by their parents:

"Her brother is thirty years old. He is a Korean medicine doctor. [Her laugh and smile became more visible.] Her sister went to [one of prestigious college names]. ... She has been doing well in liberal arts subjects. She also won first place with her portrait painting, which was exhibited at the [city museum]." (a Korean Mother A)

"He is now working on Wall Street. He just bought his apartment." (a Korean Mother B)

"The other two children did really well academically. If we could afford private schools, they would go these IVY schools. They were so mature to choose all [state university] and [city university] with full scholarship for us." (A Korean Mother C)

Another mother had a daughter who graduated from a local specialized School, and is now a student at one of Ivy League Universities. In my conversation with her, I was able to see very similar happiness and pride on her face when she described her child.

I definitely learned a lot about these specialized high schools and Ivy League colleges. Sometimes both I and Korean American community people were embarrassed that I did not know these schools. After hearing from Korean parents about all of these schools, I found myself giving some excuse to my participants, such as “I’m from Syracuse University. It’s not like these Ivy League Schools.” Sometimes I also received a question about my husband: “What does he do for a living?” Since I knew they expected responses such as a doctor or a lawyer, I often said, “He is an [emphasizing] ordinary office worker.” It was not that I was ashamed of my school or my husband’s job. But it was an embarrassing moment to recognize my inability to meet their expectation, which is a familiar experience through my childhood as well. They are like my mother wishing she could push me enough to go to Seoul University.

How do we understand these Korean parents’ “education fever or zeal?” This is the manifestation of their desire for success, or the strategy for success that has been learned through Korean history. And this idea has traveled to the U.S. through Korean immigrants and delivered to other cultural groups through Korean cram schools. Korea’s academic achievement orientation, which has fueled parents’ education fever, can be traced back to the Neo-Confucianism of the Chosun Dynasty (1392-1897). In this Neo-Confucianism, social classes were categorized by occupations: “Sa” (scholars), “Nong” (farmers), “Gong” (artisans), and “Sang” (tradesmen), which was a hierarchy with scholars on top. During this era, scholars who achieved government positions after passing a public test became the major ruling class. Inevitably, education in the Chosun Dynasty, in particular for youth and young adults, mainly focused on test preparation (“조선의 과거 제도 [the national civil service examinations]”, n.d.)

Just like the gap between the education intro textbook and school reality in 2017, the reality in Neo-Confucianism was far from the original purpose of “Kong-bu” (studying), which

philosophically aimed to fulfil the nature given to the human being by “Haneul” (literally sky or heaven, meaning a creator). The image of the young scholar who studied hard and accomplished his goal to become a government officer was often presented as a successful role model for young men in old Korean folk tales. What would a youth or a young adult do in search of a “successful” life in Korea six hundred years ago? The answer is to study, especially in preparation for testing, which is just what Korean American youth do to this day!

Mother: You must make sure that Jiyong does “Kong-bu” (study) during summer break.

EJ: Mom! He probably doesn’t even know what “Kong-bu” means. He has never “studied” like other Korean kids.

Mother: You’re ruining your kid.

This “studying” culture of the Chosun dynasty toward the “successful” adult life has been inherited by modern-day Korea, despite radical social changes brought about by the Korean War. The Korean peninsula is a land of very few natural resources or as Koreans say, “a country without a drop of oil.” The majority of these few resources are located in the Jefferson Blvd area. The only resource available for South Korea to develop was their human resource. Producing a high quality of labor was the national agenda in order to generate economic growth in the process of industrialization and modernization in the absence of natural resources. Parents’ education fever is considered one of the driving factors in the Han River miracle: the dramatic growth of South Korea’s per capita income from \$158.24 in 1960 to \$27,538.31 in 2016 (Indexmundi, n.d.). On a personal level, Koreans learned from history that education is the most effective, and likely the only, ladder they can use to rise to middle-class status.

This was not just propaganda, but an important tool for class mobility that used to work effectively. After the Korean War, more than half of the Korean population lived in absolute

poverty. Often, the only way parents could hope to escape that poverty was to educate their children, get them on track for a college education, and help them to develop a professional career (e.g., teacher, doctor, office worker in a large corporation, government officer, lawyer, etc.). As an old Korean saying goes, “a dragon is born in a small stream,” and it was not hard to find examples in Korean towns where a child from a poor family studied hard, went to a top school, and became successful as a professional. Because this upward mobility through education was something that Koreans were able to observe, there was no doubt about the value of investment in their children’s education, especially aiming at getting them into the top colleges as a way to ensure their children’s lives would be better off than their own generation. Thus, educational capital was the most powerful mechanism for individuals to move up in Korean society.

I sometimes reflect on the class mobility that my family has achieved through my parents’ educational passion. I represent the first generation of college educated adults in my family. In fact, my parents weren’t even able to attend middle school; the highest level of education they received was elementary school. Both my parents’ families were very poor, living in a rural area, which was not uncommon for their generation. As teenagers they simply had to make money for their living. Despite, or because of, the brevity of their education background, they dreamed of a much better life for their children. And, they strongly believed that the only way to make their dream come true was through education and high academic achievement. I remember how they spent their money – sometimes more than they had actually made – for their three children’s private tutoring and cram schools. Their goal was very clear: sending their children to top colleges. I disappointed my mother by not making it to the top school, but still went to a decent college, got a master’s degree and am now working towards a PhD. Both my brother and sister

have four-year college degrees and are pursuing their professional careers. The money our parents spent for their children's education was something they would never regret.

Problems with academic elitism in Korean culture. Despite its positive results on both the individual and national levels, the academic-oriented hierarchy has created social issues, particularly academic cliques and academic elitism. Korean scholars count them among the social ills that need to be eradicated in South Korea, in order to reform not only education in general but also the whole society (Kim, 2002; Kim, 2004; Lee, 2003). All universities and colleges in South Korea are ranked in order, with Seoul University at the top of the academic hierarchy. The problems arising from this academic hierarchy are not limited to any particular academic field. The university from which one graduates determines their career, salary, marriage, and social group. Hong (2007) describes it as a kind of caste system, in which people's class is determined at age 18 or 19 based on which college they attend. And those few people who entered the top schools have become the leadership in most areas of Korean society. Since parents also observe how critical it is for their children to get into that academic clique to achieve better positions, more resources, and access to closed networks, this education "fever" has heated up with no remedy in sight.

Reflecting upon this social phenomenon, Korean education, from very early childhood education through high school, focuses solely on students' academic achievement with an eye toward admission to Seoul University and a few other top schools. This trend is found in the Korean American community as well, where American ivy-league schools replace Seoul National University as the academic goal. Koreans believe that attending prestigious high schools makes it easier for them to gain entrance to ivy-league colleges. In an urban setting, finding a quality high school education is challenging, especially for those with insufficient

financial resources in the city. As an alternative tactic, many Korean American parents try to get their children into special high schools. There are nine specialized public high schools in this city for academically and artistically “gifted” students. As a matter of common sense for the Korean American community, the most logical first step to achieving the goal of gaining admission to ivy-league schools is to get into one of the specialized high schools. The problem with this belief and practice is that the majority of youth do not have the opportunity to develop their abilities and careers. Rather, most Korean American youth are sacrificed as stepping stones for a few elite students without an opportunity to explore different ways of living as an adult, and their parents bear a great financial burden for private services for test preparation. In this system, not only youth with intellectual disabilities, but also any students who cannot achieve that goal become a failure. Most parents and youth are never free from the competitive race toward the extremely narrow slot of top colleges for their chance at a “successful” life. That extreme academic elitism competition impacts the relationship among peers.

The Wall Street Journal interviewed Asian students who went to a cram school on Saturday, like the scenario I observed. The article explains, “Many [Asian] parents hope to give their children an edge in getting into gifted classes in elementary years so they can get into selective middle schools and then elite [city high schools], such as [a high school name], where admission depends on a single exam score” (Brody, 2015). It also depicted how children from Chinese immigrant families consider their extra work for test preparation a “ticket to a better future” and a way to “improve [themselves]” for adulthood without “suffering” (Brody, 2015). Much like these Chinese students, it is not uncommon for Korean families to believe that preparation for a top school is preparation for life. In other words, the most important step for a successful adult life is to proceed on the highest academic track. This cultural belief has been

circulated not only through families but also through private tutoring businesses, and has been delivered to students from non-Asian cultural backgrounds who attended a Korean cram school. The New York Times (Hernándezjan, 2009) interviewed students who attended a winter break test prep boot camp in a Korean cram school in this area, and one of them was “the brown-haired, blue-eyed president of his sixth-grade class at Public School 58” and she expressed a similar belief: “It just prepares us for life. Any obstacle we face we’ll be able to conquer.” The article also described their classroom scene which, unintentionally, shows how these Special High Schools – in this article, Hunter – may impact their lives and peer relationships. After quizzing her students about the definition of the word “resentment,” which many missed on the practice test, the teacher in the article (Hernándezjan, 2009) gave an example of the usage of this word.

“Pretend your friends are applying to Hunter. There’s a chance that the person who didn’t get in might feel a little resentment they didn’t get in. They are upset the other people got in, with a little jealousy.”

Is the feeling of resentment something that you should naturally have toward your friends? No. It would be disappointing to not gain an admission to a school that you wanted to attend. Yet, despite this disappointment, resentment should not be something that should be a normal response to a peer’s success. However, it is an actual outcome that Korean academic elitism produces.

As a teenager, I had a feeling in my gut that it was not right.

I was ashamed to go to a different study room, where there were only about twenty selected students, being separated from my close friends. I was ashamed to tell my friends that I was in a specialized group for Seoul University.

Track. Separation.

Every month, there is a competition for who is going to be in those top twenty students.

I wanted to run away from that competition.

I would not sacrifice my friendship because of that study hall with resolute determination to go to the top class.

The story of Anna, a volunteer head-teacher in the Saturday program, was a good example of the limited imagination of successful adult life often seen within a Korean community. She also understood first-hand how Korean parents are often dissatisfied with their children who are not on the elite academic track. She is an ELA teacher in an urban high school. She supports students who are from families that recently moved into the U.S. She was an excellent example of how people's talent can be applied through volunteer work. She uses her planning and teaching skills for Saturday class and had been responsible with coming up with Saturday program. She also ran the program and taught the religious content as well. We had a conversation about her teaching career and she shared her parents' wish for her future.

“My parents still couldn't give up. They want me to go to a graduate school of one of ivy leagues and become a professor. They are not satisfied that I became a high school teacher. I found that my Korean colleagues in my school had an exactly same story.”

It is problematic to frame young people's lives as success or failure based on certain criteria including getting into a four-year college, a high-status job, marriage, etc. Korean community's rigid individual elitism through youth and transition period, makes it almost impossible to open up any idea of life paths except few elitist pathways.

This culture of elitism also makes it quite difficult to discuss important issues such as advocating political leadership of youth and young adults with intellectual disabilities; expanding the concept of “ability” beyond ableism; assisting youth with disabilities to write their own “successful” life story; highlighting inter-dependence; etc. In short, it is extremely hard for a

community to find various potentials of youth because there is only one norm (i.e., being able to go to an Ivy League school).

Elitism and Ableism

While the academic elitism and parents' education fever help us to understand the larger cultural environment that youth and young adults without intellectual disabilities inhabit – a high-pressured community surrounded with cram schools – these experiences also impact students with intellectual disabilities in dysfunctional ways. In the volunteer activity that I observed, both Korean elitism and ableism grew together. Below continues my story about visiting the new organization office site:

Continued episode of visiting the Grace office. After standing at the building entrance, amazed by the number of advertisements of the Korean American cram schools announcing special high school offers, I headed up to the second floor. Passing by that particular cram school, painted white with its name on a silver sign, I entered a mid-size office. There were a few long tables with chairs as well as an office area separated by a glass wall. Unexpectedly, I saw one family visiting the Grace director: two girls and one boy with their mother. At first, I thought one of the three children might have disabilities and need to register for Grace Summer camp, which was to happen a week later. My guess turned out to be both right and wrong. The mother and the director were talking about registering the boy as a volunteer for the Saturday program. The children were quiet while most of the conversation happened between the director and the mother. The boy did not ask any questions; he did not show any excitement about this volunteer experience.

Mother: *What does my son need to do there [at the Saturday program]?*

Director: *There are a teacher and teacher assistants. He just needs to follow their directions.*

...

Mother: [to her son] *Are you starting Saturday?*

Boy: *I have a pretest [for special high school admission test] at “hagwon.”*

Mother: *How long will that take?*

Boy: *Three hours.*

Mother: *How about taking the pretest today or tomorrow and starting the volunteering this Saturday?*

Boy: [no answer]

Director: *Just start from July 9 [the next week] since there will be VBS [Vacation Bible School].*

It took a quite a while for me to put the pieces together about another important function of the Grace organization especially for Korean youth without disabilities. Besides providing programs for children, youth, and adults with disabilities, they also provided volunteer work experience to Korean American students with high academic achievement. The boy was there to enroll for volunteer work in the Grace organization with the specific goal of adding that experience to his resume. And, summer is the perfect time for volunteering since many students in this community aimed to be able to present “a total package” of academic achievement and extracurricular involvement—including community service—and leadership in their applications for either a specialized high school or a prestigious college.

A total admission package including volunteer work. A similar theme of building up one’s resume as part of college application preparation emerges in various Korean cram schools

and private Korean tutoring institutions in the U.S. Advisors at cram schools not only give parents detailed, well-researched, and tested resources for the entire process of college admission, but they also offer career consultation. For example, one cram school specialized in getting students to enter professions in medicine and science. They advertised that their “packages are comprehensive” including academic advising, “extracurricular activities advising, college applications, personality development and miscellaneous support in addition” to test preparation. Interestingly, under extracurricular activities category, there is a long list of services they would provide as a private tutoring/counseling group:

- Activities Selection
- **Volunteering Opportunities** [emphasis added]
- Winter & Summer Activity Planning
- Internships & Research
- Special Programs
- Advising Levels of Participation, Achievement and Leadership in Extracurricular/Co-curricular Activities
- Identifying & Developing Student's "Hook"
- **Congressional Award/President’s Volunteer Service Award Support** [emphasis added]
- Customized 4-Year Activity Planning
- Global Leadership Programs
- Independent Projects
- Personalized List of Best-Fit Activities
- Discovery of Student’s Uniqueness Factor (Color)

- Travel & Study Abroad
- Work Experience

As seen in this advertisement, students' volunteering activities were considered a necessity for receiving good college admission. As such, these service opportunities were selected, organized, and provided by cram schools and through private consultations.

After I observed the boy and mother signing up for volunteer experience as part of the college preparation process, I was able to recognize some common practices in the Korean community that reflect the idea that students need to have not only academic excellence, but also proof of extracurricular activities, including volunteer work and self-initiated projects. The Christian organization for Korean Americans with disabilities that I observed played a role in providing an opportunity for these academically-accomplished students to further build their resumes by engaging in community service. Since there are no paid staff in this organization, the Saturday program and Camp heavily depended on volunteers for planning and implementing their programming. It seemed a good tactic to attract Korean youth into volunteer work by pursuing parents who would be motivated by the value of volunteer work in the college admission process. Involvement in service during this period of youth is also critical in establishing a continuing pattern of volunteerism for their adult lives (Bowman, Brandenberger, Lapsley, Hill, & Quaranto, 2010). As an example, there was an adult volunteer group in Grace, who started their volunteer work as teenagers, got "competitive" professional jobs, and continued to support this organization throughout their adulthood.

Is this youth volunteer practice in Korean community problematic? It could certainly be considered positive if youth without disabilities enter into peer relationships with youth with disabilities through volunteer activity, but then become allies. In other words, even though youth

may not start out with an intention to become friends or allies, but rather are motivated by a specific career goal, there is a potential for this shift in consciousness to happen. However, the framework that was outlined for these two groups through volunteering events was problematic. The event site produced fixed roles for each group: an active serving role for youth and young adults without disabilities and a passive served role for youth and young adults with disabilities. This contrast was most visible at the Grace Summer Camp (introduced in chapter four), but also in one-time special events, in which new volunteers or community members, who did not appear there regularly, came to participate in these events for various reasons of their own. The goal was not to actively diminish the potential of youth and young people with disabilities, but it nonetheless operated in this way by highlighting and more significantly recognizing the work of volunteers without disabilities. I present another example from the Grace Summer Camp in the next section.

Visible volunteer work in Grace Summer Camp. Who, or whose work, is valued at the Grace Camp? As described in the chapter four, most people with intellectual and developmental disabilities participated in Agape Camp (“Adong-ban”; meaning children’s group) in Summer Camp. Every morning and evening, Ms. Shin, a preacher, gave a brief sermon to children, youth, and adults with disabilities attending the camp. In the evening of the second day of Agape camp, Ms. Shin preached about “How do I live for God’s glory?” She listed four ways of giving God glory: show love to everybody; use your ability to serve others; share the good news with everyone; and join God’s family. She further emphasized that the second way of glorifying God was by using your ability to serve others, by highlighting that everybody has at least one thing that you are good at:

Ms. Shin: *Earlier, I saw some of you dancing; I saw someone sing very well; I saw someone who served very well as God's child.* God gives you at least one special talent ... He gave everyone [some special talent] because you use [these talents] to serve others with. So, look to somebody and [say] what your gift is. Can you tell? [People saying something in a group]

Jiyong: Mama, every day I make something, right?

Mr. Shin: [What does] God say about serving others. Can you read?

[Texts on the PowerPoint slide]: "Warmly welcome each other into the church just as Christ has warmly welcomed you then God will be glorified" Romans 15:7 (LB)]

Ms. Shin: Everybody freezes. Excellent listener....*Raise your hands if you go to church.*

Every time when you go to church, I want you to serve with smile and say hi to people.

Although the preacher mentioned that everybody has a "special talent" that they can and should use for serving others, she could not point out specific examples that would suit camp participants with disabilities, except their dancing and singing which she just watched right before her sermon. Even this dancing was referred to as a talent people have, but not one by which they might serve others. In contrast, in the next episode, the dancing of youth without disabilities was recognized as a tool to serve these youth and young adults with disabilities. Instead of specific examples of serving others, she suggested a general rule such as smiling and greeting others at the church, which was reminiscent of the portraits of people with intellectual disabilities described in Chapter 4. Is smiling the only thing that Koreans including Ms. Shin can think of as the ability of these young people with disabilities as a tool to serve others? In contrast, there were two actual examples praised by this preacher, of serving others with your special ability in this context: abilities of non-disabled volunteers and her non-disabled son.

Ms. Shin: [praising volunteers] All day long I was watching you guys. Some of you have a heart like an angel. You guys know how to serve. ... By serving the way you did, just so beautiful. I love seeing people like you guys serving. Give yourselves applause!

At the beginning of her “sermon,” she admired (acknowledged) the volunteers’ work that she observed. She described it as the action of serving with a heart like that of an angel. After expressing that they are very “beautiful,” she showed her appreciation by asking all the volunteers to stand up and give themselves applause. Later she again clearly expressed her thankfulness for volunteers’ work – not only to them but also to God in her prayer. In her demonstrations of gratitude, one phrase was intriguing because it was the same phrase this same speaker used to describe God’s love. She summarized her recognition by saying, “Thank you, to you volunteers and staff, for your unconditional love.” The same phrase, “unconditional love” was used again in her prayer indicating God’s love: “Father, what a joy and privilege it is to see, witness such a love such a serving [people]. I’m so grateful. you’re amazing God who is so unconditional love us the way you do.

In her talk, non-disabled volunteer work was defined as a model of “serving others;” recognized as the product of hearts like an angel’s; appreciated in public; and considered a human equivalent to God’s “unconditional” love. Similarly, volunteers and staff were given credit for the successful Agape Camp at the end of camp day by another pastor. It is a common and necessary practice to recognize the work of volunteers and staff in a given event, because their work is sometimes hidden behind the scenes. However, in this camp, the situation is the opposite: the work and ability of youth and young adults with disabilities were hidden, while the work of non-disabled youth and adults were highlighted in direct references by camp leaders. Another example of glorifying God that the pastor gave her audience was that of her son.

Ms. Shin: “God is doing miracles - I see God’s glory through my son. I have one son. ... He was accepted in medical school so he moves to San Francisco. You know what he wants to do. He wants to be God’s glory to be a doctor. He works in hospital for eight months as a residence. He wants to go to the third world.”

She testified that she saw God’s glory through her son because he was accepted in medical school and wanted to work in the third world as a doctor. Volunteer work is something that should be appreciated, as well as working in the so called “third world.” In this context, these are reasonable examples as “working for” [definition of serving] others. However, the question is why a specific example of “serving others” is only imagined of non-disabled people? Why does the work of non-disabled people get highlighted in an event *for* people with disabilities, like Grace Summer Camp? Is it a coincidence that these examples somehow connect to career paths that Koreans admire (i.e., volunteering for people with disabilities as a form of community service for college application; going to medical schools; or becoming a doctor)? And do Korean youth with disabilities find themselves trapped in the framework of being an object of service--being “served” instead of “serving?” Finally, was it a co-incidence that the son she is so proud of will be a doctor, a career most Korean parents hope for in terms of their children’s success?

Celebrating talents of youth without disabilities. The event of Korean Day for people with disabilities took on a similar pattern: the place for these young people with disabilities became a space for recognition of the work of young people without disabilities. The Grace organization celebrates the Day for People with Disabilities (April 20th) every year, which is a national holiday in South Korea. It was also celebrated at the Korean Neighbor Church, when and where the Saturday program for Children usually would typically happen. The ceremony was held from morning to early afternoon. The morning ceremony had a more religious and

formal ceremonial format, such as opening, praise (e.g., “Body Worship” and “Sign Language Praise), prayers, congratulatory speech, special Speaker’s speech, watching the videos of Grace activities, and closing. The president of the Korean association in the community delivered the congratulatory speech during the ceremony. And Mr. Shin, who was a Korean student with hearing impairment who attended a graduate school in a local University gave a speech in Korean Sign Language about his experience as an international student with disabilities as well as a Christian. Besides his speech, the children, youth, and adults with disabilities who regularly attended the Agape Classes were involved in the morning ceremony by performing singing and “Body Worship” which is simple dancing with gospel music. After the morning ceremony, there was a luncheon prepared and provided by Korean consulates’ wives as a form of volunteerism, which is analyzed in chapter five.

While the morning ceremony and luncheon were similar to what was done in previous years, this year the organization tried something new for the afternoon ceremony. They organized a “collaboration” with one of the youth groups in their neighborhood to celebrate this special day for people with disabilities. The youth group was called Horizon, and was composed of volunteers who attended one of the cram schools in this Korean community. There were probably about twenty high school students, not only from Korean or inter-racial Korean families, but representing other racial and ethnic groups as well. There was one Caucasian family who came to see their daughter’s performance as a part of this Vision Team, and she and her younger sister appeared to have both Asian and Caucasian racial background. Other Students had non-Korean last names. At least two students seemed to have family from India or Southeast Asia. They not only performed K-pop [i.e., Korean pop] songs, dances, and instrumental playing (e.g., violin), but also presented research projects. Unlike the morning, this part of the ceremony

involved no participation of children, youth, and young adults with disabilities, other than being part of the audience, and some of the performance was not relevant to them. In other words, if you only saw this part of the day, it would be hard to tell what special day they were celebrating. Consistent with the feeling I had during observation, I overheard one of the staff who worked for this organization say sarcastically, “What were they [youth group without disabilities] doing here on our friends’ day?” It may be possible that some music and dance performances may “comfort the people with disabilities and encourage them to have hope” (from Poster). However, it is hard to imagine how a Science Project about Diet Supplements, an App development Project, and other research projects that this Team presented could be connected to the Day for People with Disabilities. Of the six photos displayed on the event poster that advertised this special day, five were of the Horizon Team, showing four individual face portraits of young female students who played violin, sang, and danced, and this team group dancing. Only the sixth photo on the bottom of the poster was a group picture taken at the same event from the previous year, of children, youth, and adults with disabilities, along with staff, volunteers, and guests who had attended. After their performance, I found couple news crews interviewed and videotaped non-disabled youth team members as well as taking several pictures of volunteers, especially making a point to show them with people with disabilities, which was not seen last year. Here is the purpose of this event written on the event poster:

To celebrate our ... anniversary, we are trying to play the role of a bridge between the handicapped community and general population to break down the barriers that create disintegration. Essentially, we are hoping to understand each other better. Appreciation for Handicapped People Day is the only time for ruminating and reflecting on the

difficulties associated with the handicapped community. Through this day, we would like to comfort the people with disabilities and encourage them to have hope.

It may be meaningful that these youth had an opportunity to meet youth and adults with disabilities and potentially open up the possibility of developing friendships and connections between themselves and a group of individuals they may have not otherwise gotten to know. It may be true that they began attempting to understand “each other” through this event. However, none of the afternoon events that were planned, initiated, and performed by the non-disabled youth highlighted anything that would connect or engage with the interests the youth and adults with disabilities. Rather, it was a place where the non-disabled youth’ abilities and skills were emphasized and celebrated, probably as part of their resume building as well. These youth were students who had been working hard to get into prestigious colleges through the Korean private educational system while building up their portfolio of volunteering. The website of the cram school that the youth attended showed a very similar mentality, declaring, “Serve and Learn.” The website not only shared the students 10-week summer schedules filled with classes from 9AM to 4PM, all week (including Saturday, which also included evening classes from 5 PM to 8 PM), but also shared the students’ volunteer stories in South America.

“Only smart students need to volunteer.” Volunteering for others, which can be described as “serving” others, is not something that should be criticized. I likewise do not wish to criticize students who studied hard and completely gave up their “10 weeks” of summer break for the sake of a “better life” (Brody, 2015) in the long term. In other words, the problem is not that these students wish to gain admission to prestigious colleges and universities, or who volunteer to work for “others.” Yet, I would like to bring some attention to the gap between the official written or spoken purpose of these “serving” behaviors and their outcomes that were not

often mentioned in public discourse. I heard from a parent and a teacher who closely worked with Korean youth about the necessity for students to have volunteer experience for their career including college admission. This was not just about enriching, fulfilling or finding the meaning of one's life. If it were, they would not need to specify which students need this extra-curricular activity. But more than one teacher that I interviewed in this community said, "*Only* smart students need to volunteer. Students who don't excel in their academic work don't need it." Volunteer experience has become useful only for youth with potential to develop ambitious career paths, as a pathway to getting into an Ivy League school or even earlier, into a special high school. And, many times, this motivation behind their volunteerism was not spoken, instead their "serving" was portrayed as the result of their "unconditional" love.

I must also acknowledge that I, too, am another example of benefitting from my work "for" these Korean youth and adults with disabilities. I received a scholarship from the association of Korean American Medicine Doctors. At their reception event, which was one of the requirements for recipients, I found that most scholarship recipients were young Korean American undergraduate students who attended prestigious schools. In their speeches, they listed not their academic excellence, but their volunteer work or projects that they'd done in third world countries, poor neighborhoods, etc. My story was about Korean American youth with disabilities in whose midst I was about to do research. During fieldwork, I heard often how great I was to work with my participants with disabilities. I was appreciated because I was hanging out and having coffee time with my participants. But, of course, I was the one who got the most out of this relationship. I finished my data collection, wrote about them (as data), and finally am going to get my PhD. My career will continue afterward with that degree in hand, earning my salary as a university professor, and building up my academic reputation with subsequent publications. I do not contend that all non-disabled people who work for and with people with disabilities are taking advantage of people with

disabilities. Rather, I argue that it is not fair to highlight the work of able-bodied people while the benefits they receive from their relationships with people with disabilities remain hidden.

Routine volunteers vs. drafted volunteers. It is also important to mention that all the volunteer work I observed cannot be generalized within one category with a singular career/college admission purpose or motivation. Certainly, some volunteers, who had been working with these youth and adults with disabilities for many years, have more complex relationships and interactions with Saturday program participants. As seen in the previous chapter about age hierarchy, they showed more respect toward adults with disabilities and understood their character and interests, even though they are still very much framed as the “serving” people. These volunteers are also usually not youth or college students, but adults who were employed or who were raising families, or both. It is not clear what kind of purpose they intended to serve, or what potential benefits they might have expected to gain from their volunteer experience. From my interactions with this group, their motivation seemed more connected to their religious beliefs and sense of Christian responsibility. Taking on volunteer work as a part of their daily life made a salient difference between these “routine volunteers” vs. “drafted volunteers” (Allahyari, 2000) as well.

One married couple helped the Agape Class every week as well as the Agape Summer Camp every year. They usually brought their elementary aged son and daughter with them, working with/for them all day on Saturdays. They just volunteered every week because it has become a “part of their life” and they “would feel weird skipping it.” The teacher, Anna, seemed to be a very similar case. She was a high school teacher in the city and came to Agape Class every week in order to organize and lead all day activities. She was introduced into Grace Organization by her father, who was the director’s friend, and she had been helping the Saturday

program since then. It did not seem that there was any immediate or tangible benefit for her to gain from this volunteer work, despite being a major time commitment for her to spend all day every Saturday, after full-time teaching during weekdays. In fact, she attended all year, except during the weeks she had to finish paperwork near the end of her school semesters.

These two examples are very different from that of most drafted youth volunteers. Including these two examples, most routine adult volunteers that I observed were affiliated with one of the local Korean American churches in this community. Their Christianity is certainly a factor that needs to be explored in terms of its role in their practice of volunteerism in the Korean American community. However, this research does not cover that topic¹⁴, but rather focuses on its connection to academic elitism and Korean Americans' political strategy at the community level. The motivation of drafted youth volunteers in my observation was to gain distinction in seeking admission to a prestigious college. Further, the volunteerism that I observed around youth and adults with disabilities was connected to a volunteer movement in which the Korean American community leadership initiated, which the next section explains.

Volunteerism in Korean American Community

Interestingly, for Korean youth, especially for those on the elite education track, there is a need to prove not only competence, but also social responsibility, which in many ways is a microcosm of the struggle of the Korean American upper class. One community member explained that they had found that their career and financial success were not enough to compete against white colleagues. She explained that the leadership in the Korean American community reached the conclusion that in order to be empowered in the U.S., they needed to highlight their Korean identity to show the cultural and political power of Korean Americans as a group. One

¹⁴ I explained reasons in the limitations of research section in Chapter Seven.

strategy to this end involved raising funds within the community, especially from the middle-upper class, and using them for Korean minority groups including people with disabilities, seniors, homeless, etc. This was how Korean American community-wide donation and volunteerism started in particular in this urban area. This kind of volunteer activity was used to highlight their charity work for this community and to form their own leadership within and outside of their community.

One of community foundations in this area is a representative example of the function of volunteerism and charity work among Korean adults, especially those who were “the 1.5 and 2nd generation working in American mainstream” (Kim, 2017). Grace has been funded not only by Korean American individual donors and Korean churches but also by this foundation. This funding is important for this organization since this fixed amount of financial support allowed them to make their yearly plan for programs, including the Saturday program. Recently, this foundation funded \$30,000 for Saturday program. During a meeting in preparation for this grant application, the Grace organization director explained how this community foundation started.

“[the foundation name] started while Ms. Kim [one of Grace board members] worked as a secretary of the General Consulate. At that time, Koreans were successful to enter to the American mainstream, for example, becoming a president of City Bank. But that was not enough; they did not have their own identities. So, they [the Korean general Consulate] started [donation] campaign, especially in order to attract 1.5 and 2nd generation Korean Americans into the Korean community.”

Her description of this foundation is very similar to its official introduction. According to its annual report (2013), the goal of this organization is to “[transform] and [empower] communities through philanthropy, volunteerism and inter-community bridge building”. [the foundation

name] not only “has awarded ...non-profit organizations” but “has also proved to be a powerful force in promoting and spreading a culture of giving across diverse communities”

The successful establishment of this foundation has been effective in drawing the attention of 1.5 and 2nd generations of Koreans who work in American mainstream as well as next Korean leadership. Besides the written purpose, which is to establish and foster “a strategic and collective culture of giving among Korean Americans,” there was an unspoken motivation behind the participation in this community foundation, which was to foster networking in the community. For instance, “[the] most exclusive event” (according to its website) that it hosted was the Annual Gala, where people had the opportunity to get connected to the most “successful” Koreans in U.S. The keynote speakers for this event have included the president of the World Bank Group, the Secretary-General of the United Nations, the President of one of Ivy League schools, a U.S. Senator, etc. The Gala was limited to 1,000 seats and a single ticket cost \$750. People could also choose benefactor seats (\$1,250) or sponsorships (from \$10,000 to \$100,000), which were listed on the gala and annual report of this organization, with donors’ names and brief bios as well as donor group or corporation names and advertisements.

There was also an auction held by the same organization every year, with prizes such as the chance to have a round of golf with a professional golfer in the PGA, or a dinner with a famous actress in South Korea. Inviting these guest speakers and having these auction events are made possible because of the network of celebrities within this organization. Moreover, as the director in Grace said, “*because of these networks, young people...like to participate in [the name of this community foundation]*”. In particular, (according to their website) some young Korean Americans were involved in the organization, which gives them “exposure to [the name

of this organization] leadership and community partners, as well as exclusive first-access to Associate Board events”

Again, I do not intend to criticize the Korean community’s use of volunteer and charity work as a tool to satisfy their personal goals, such as upgrading their resume by gaining some experience, building up social authority and reputation by being involved in philanthropy work for a community, or accessing the network of resourceful and successful members in the Korean community by working in a large non-profit organization. The positive outcomes that volunteer experiences may bring to those served cannot be ignored, even though it should also be acknowledged that the volunteer may also receive personal gains, such as upgrading their resume. Moreover, as Musick & Willson (2008) observed,

"The actual experience of volunteering often leads to such radical changes in attitudes toward the activity that the original goals are forgotten or the volunteer becomes unable to separate his/her initial reasons for volunteering from the reasons that make sense to him/her now" (p. 71)

In addition, as stated earlier, volunteer experience in the transition to adulthood may lead to more long-lasting volunteer work into and throughout adulthood, even though a Grace staff member noted that it was rare for the adolescent volunteers, who had come in mainly to satisfy a need for community service on their resumes, to return to volunteer for people with disabilities. This is the same reason the Grace organization seeks to build a strong connection between the Korean youth to young adult volunteer groups. For a non-profit organization like Grace without paid staff, creating a broad base of volunteers is critical to plan and implement their activities and programs.

Despite not wanting to overly critique volunteerism, this phenomenon must also be interrogated in the context of Korean elitism. During fieldwork, I met many volunteers who did not express any personal goals that they may have wanted to accomplish through volunteer work in Saturday program and Summer Camp. I also could not observe any possible direct rewards that the majority of volunteers who worked for a long time in Grace may have acquired. It seemed that their volunteer activities were simply a part of their daily or yearly routines and they either enjoyed or felt obligated to spend at least some of their time this way for many different personal reasons (e.g., having a family member with disabilities; having personal experience in connection to disabilities; or a desire as a Christian to do “good works,” etc.). Many food volunteers both at the Saturday program and Agape camp were lay Korean mothers and fathers who may have early teens or young adult children. The majority of adult volunteers at the camp are not necessarily from middle-class backgrounds or professional jobs. Most of them are far from the picture of the “successful” Korean in terms of finance and career, but they work hard for their own children and families, still made time to “serve” others, and seemed to enjoy getting along with these youth and adults with disabilities as well as with other volunteers.

The issue, rather, arises when volunteer activity is connected to the Korean culture of elitism or when it positions those on the receiving end of volunteering simply as an object. Is it appropriate for youth volunteer work to be perceived within the Korean community as just a tool to improve one’s resume for college admission? How do youth and young adults with and without disabilities encounter each other when this is the way their service is framed? Why, during this transition period to adulthood, is the opportunity to volunteer in this community only offered to youth and young adults who are entering or who are already on the elite track? Why does a whole community work to provide this kind of experience only for this group? How does

volunteering in this context position youth and young adults with disabilities as simply objects to be “used” in order to achieve one’s aspirations?

A similar question can be asked regarding this community foundation. What kind of leadership does the Korean community picture through this volunteer and charity work? Why are only youth and young adults in Ivy League schools, big corporations, or world-famous non-profits considered the future leadership? Why not youth and young adults with disabilities, or others who do not have prestigious college or work resumes? Even though there are a host of Koreans who “serve” others, why are there only a few who get the spotlight for their service? Whose volunteer work is more valued than others? Whose work has been recognized above others’? Who gets more opportunity than others? Who is considered “able” to serve while others are not? Why are my participants framed as the “served” ones, at the same time being positioned as objects in this service relationship, without a chance to “serve” in Korean community?

I am arguing that elitism and ableism have become stabilized through the volunteerism and charity work of the Korean community, by highlighting the serving role of youth and adults without disabilities who are beginning or continuing along the elite track, while objectifying youth and young adults with disabilities as the “served” class in the community service context, without a chance to serve to community or others.

Counterexamples: Korean American Youth and Adults with Disabilities as a Serving Person

In order to avoid the trap of ableism, however, the concept of “serving” must be expanded to include actions outside of what is typically thought of as “serving.” One way to understand and identify “serving” outside of ableist assumptions is to hear how people described being served by people with disabilities. In other words, we must pay attention to behaviors that

are not recognized or praised as “serving,” but actually result in benefit to others. The verb *to serve* is described as “to perform duties or services for (another person or an organization)” (“serve”, n.d.) It is not the case that these youth and adults with disabilities do not serve others. Rather, it is that their service is not recognized in this community, while the service of youth and adults on an elite track is often highlighted in their volunteerism and charity work.

In many narratives from the Korean community, the most celebrated volunteer stories are of travelling for a few weeks to do volunteer work in countries in South America or Africa. Interestingly, in the ceremony for the Day of People with disabilities, performance was also considered a form of “serving” others. The most frequent forms that I observed through Grace Summer Camp and Saturday program was one-to-one assistance to youth and adults with disabilities. This was not as much about physical assistance, as only one young man with physical disabilities in this organization actually needed physical assistance for eating and moving and one youth with autism “needed a monitor” because of her wandering behavior. Rather, the main job of these volunteers consisted of just “being social” with the group. In fact, this is one participant’s favorite element of the Saturday program – getting a chance to talk to a volunteer without disabilities.

Take for instance a regular camp for children or youth during their summer. At the camp, they meet new friends, get to know each other, share their stories or interests, and simply do stuff together. That is not called “volunteering” or “serving” others. Because of social barriers and a segregated community (e.g., a separated group of children and adults with disabilities within a church), it became a special event to have youth and adults with/without disabilities partner up. And, as I have discussed, in that relationship, the non-disabled youth receive praise and extra rewards on their resume by doing this socializing “volunteer” work, while the youth and adults

with disabilities are considered the ones who were helped by volunteers. However, there are a few members who spoke about turning this stereotype upside down, which they learned through their experience with their family and friends with disabilities, which I highlight below. In addition, I will present what I observed and heard from my research participants with disabilities, in terms of their potential and practice of serving others.

Kelly's father: Being served by serving. An example that might seem very subtle to some observers, but very serious and obvious to the individual who was served, was a relationship between one young woman in this community and her father. He explained that his relationship to his daughter, a non-verbal woman with autism, was a “serving” relationship. Specifically, he discussed how she had been “serving” – and saving – him. He said that most people think that she can only live because of his assistance. But, he explained that she is really the one who “serves” him and makes him able to live. It is also noteworthy how he described his first job for his daughter, that he had never done before his wife passed away.

Kelly's Father: I would have killed myself without Kelly because I had not known how to live without my wife. But, I had to make rice and Doen-jang-jji-gae [Korean bean paste stew] for her, which I had not even done while my wife was very sick. ... I remember how I was lethargic when Kelly had a trial period for a residential facility. I came back home after dropping her off there, I was just sitting on the couch, not knowing what to do.

He confessed that the necessity to serve food to his daughter required him to stay alive instead of killing himself. He recounted that it was *she* who saved him, not that he saved her. In addition, he explained how helping others with disabilities (i.e., driving a church van especially for young people with disabilities) in this community gave meaning to his days. One acquires the purpose of living by serving others. When you serve someone else, you are actually being served in the

process. Many parts of our daily lives are just like this: you find meaning in your own life by serving others. The question comes down to whether you recognize, accept, and admire that reciprocity between serving and served, or only highlight one side of the story. And, in addition to the question of is this reciprocity recognized, are serving opportunities given to people with disabilities, as well?

Praying for others and selves. An example of the importance of the duty of serving for young people with disabilities was presented in a sermon given by Mr. Yun, the preacher who is in charge of this youth group at Saturday program in Grace. He had been working with this group for several years when my Participant, Jongeun, introduced him as her friend. They called each other friend not as a euphemism¹⁵ but with real meaning (“Dong-gab”; same age). This sermon was different than other sermons, which were given to the same group by guest preachers who didn’t necessarily have long-term and regular relationships with people with disabilities, either here or in their own churches. The pastor (Mr. Yun) did not talk about “overcoming” disabilities or needing others’ “help.” Most of all, he did not focus on the work of people without disabilities. Rather, he always gave the youth and young adult group in this organization a task that they need to work on in their daily Christian life, just like other people without disabilities may hear from their pastors. He gave a lot of examples from outside of the Bible, but it was always grounded in the Scripture. He focused on what these youth and adults with disabilities need to do in order to serve God and others. For example, one Saturday, he preached about how they should pray not for themselves, but for others. During worship time at the Saturday program, Mr. Yun, the preacher gave a sermon to the group of young people with disabilities. The preacher was standing at the front of the room, and [twenty] youth and adults with

¹⁵People in this Korean American community often used the word, “friend” as a title instead of using proper respectful titles for youth and adult with disabilities. This is also discussed in chapter four.

disabilities as well as twenty volunteers were sitting in front of him. He explained that in the bible verse he was teaching (John 15:4), Jesus was teaching his disciples. The preacher explained that there were more than twelve disciples who were all listening to Jesus give this lesson.

Preacher: How many disciples Jesus had?

[Several hands raised up in the air and some of them shouted their answers.]

A: Hundred!

B: Two hundred!

C: [A female church member was standing and talking into the microphone. She was offering an answer, but it was not understandable. The last part of her utterance included a number] fifteen.

[The Preacher started explaining about the number of disciples who stayed with Jesus. Suddenly, the group became quiet.]

Preacher: Since there were one hundred twenty disciples after most people left Jesus, there would be much more disciples originally....[He continued,] When you do pray, what do you pray for? You may pray for getting a new bicycle, or eating some delicious food. Or, you may pray for your friends or families. You also pray for others. However, in a real prayer, you do not pray for what you want, but rather pray for what God wants....Before knowing God's words, I always gave a prayer for myself. I was a selfish Tom-I-Am. I was a selfish Korean. I was not interested in others....We do not pray to God to help us, rather, we pray for what God wants us to do, for what God wants to do using us....We are not the only ones who have difficult situations. There are more people with disabilities who even cannot come here.

He then mentioned how they can serve other people with disabilities who may have much less opportunity to come out into the community. He emphasized how they can help people by their prayers. It was significant how the young people responded to his sermon with active answering, listening, laughing, and sometimes teasing the pastor. The quiet moments also showed that they were paying attention to the sermon and were genuinely responding to it. Why is it seemingly such a hard task for Korean churches to see individuals with intellectual disabilities as capable of learning Christian teaching, as people who are willing and able to take on biblical duties, and share the message they've received with others without disabilities? Why does this community not consider them agents with their own subjectivity who are can "serve" others, instead of only as "unfortunate neighbors" who need to be helped? How do these ideas that we see perpetuated in a church setting impact these individuals other life contexts?

Following the sermon about prayer, I was able to hear some of the young people's concerns and prayer requests, as sharing them was a routine during Bible study in the afternoon on Saturday. Here is the conversation from one of the groups attending the Saturday program.

Teacher Anna: Junho, I have your prayer request from last week. That was for your job search. You said you would like to learn gym training. Is it the same for this week?

Junho: Yes, same.

Anna: Minjun, you had a prayer request for your family and volunteers. Is this same?

Minjun: Yes, that's the same.

Anna: Seojin, how about you?

Seojin: For our Saturday volunteers and for the ladies.

[Everybody laughed]

Anna: Miyoung Eonni and Eunju Eonni were asking for prayer for their health.

....

Anna: There is a new friend, here. Youngjae, is there any prayer request?

[Youngjae hesitated to speak English]

Anna: It is okay to say in Korean.

Youngjae: *I would like to meet other Koreans.*

People: Oh!!

Anna: How about Kang-kuk brother?

Cheol-hui: Pray for Mary [his sister] and mom.

Their prayer requests every week showed me what their current interests and concerns were. They were not much different than any other youth and adults, including their own or their families' health issues, getting work, having more social relationships, and concerns about people who worked for them, such as volunteers. This illustrated to me that they could and often did meet adult expectations when given the opportunity to do so. In other words, they did not "act" like children, but were often more mature than people gave them credit for.

Continuing to focus the stories of my participants with disabilities, I would like to share two more stories in which participants demonstrated that they were socially active youth and adults, in contrast to the image of recipients and passive listeners. I see these counter-narrative examples as similar to the ones that I have already described in the previous two chapters (i.e., Sister Lee serving her own cooked dish and Sister Park buying a cup of coffee for me). Here, I would like to introduce Peter as an excellent museum guide who led me through every floor in the American Museum of Natural History as well as Miyoung Eonni as an active fundraiser for the special fundraising night in Grace.

Peter: Playing a volunteer role for museum tour. The fall when I started my data-collection field trip was Peter's first season without a school day. He had reached the age of twenty-two and was no longer eligible for special education services in K-12. Unfortunately, his adult services were not ready for him when he graduated. His family was waiting for OPWDD (Office of People with Developmental Disabilities) to approve Peter's eligibility and to have his adult service applications accepted, which meant that Peter had entirely "free" weekdays. He and his mother had to figure out how Peter would spend his days. Peter's mother decided to help Peter navigate the city by using discounted and free Metro cards. He started learning with his mother how to use the city bus and subway in order to go to museums in this city. When I followed them to a natural history museum, they had already finished their first round of city museum trips, except for those in Staten Island.

Peter: We didn't go to Staten Island yet (in English).

Peter's Mother: (in Korean) *We went to all the other boroughs except Staten Island. You need to take a ferry. There is a zoo that we want to go and see.*

As soon as I heard that Peter and his mother travel the city every week, making a point to visit museums where they had free admission with their city ID cards, I asked them if it was okay for me to go with them the following Saturday. The mother was quite surprised by my request. She did not expect it, and replied, "*This is the first time someone was willing to go with us.*" Later she expressed her thankfulness several times for accompanying them, even though I was the one who received genuine service from them and was grateful for their service in welcoming me. The mother asked me not to prepare anything and said that she would bring all we would need for the museum trip. I didn't know exactly what she meant.

The next Friday, I met them at the local bus stop near Park Street & Jefferson Blvd. While it was my sixth trip to the city for data collection, I was still unfamiliar with the layout of the city. I did not yet know how to use public transportation from one part of the city to the other. I completely depended on them to go to the urban museum, not only for direction, but also financially. She had already brought two Metro cards: one was reduced fare and the other was free, she explained; they are issued for people with disabilities for their transportation and accessibility. She somehow paid my fare with these Transportation Cards. I just followed them: we took a bus to a main subway station in the community. There is one main subway line in this neighborhood. In order to go to the downtown of the city, taking the subway is the most convenient and quickest way. We took the subway and switched to the line on the way. On the subway and during our walk to get there, the mother asked Peter where we should go, which lane to take and which direction to go. Peter successfully remembered the path and led us both. Arriving at the museum, she explained that they are in the process of applying for a “membership” card to allow them free admission to the major museums. In addition, she explained that certain museums have certain days for general free admission. Rather than the general suggested admission fee shown on the pamphlet, she paid only a few dollars, based on the museum’s policy that people are admitted after paying whatever amount they wish.

After admission, Peter guided us to each hall without hesitation. He looked confident about directing us to all of the museum floors, knowing the locations and contents of each exhibit. He might not have professional knowledge about the exhibits, but he tried to explain and describe every single item that we saw, such as the section of African and Asian People (2nd floor) and Hall of Native American (3rd floor). His favorite part of this museum was the 4th floor,

which focused on mammals and dinosaurs. Here is an example of how he informed¹⁶ me about display items:

Peter: And that's a stegosaurus. Here. Uh, spines.

EJ: Spine? Yeah?

Peter: That's the plate, but...

EJ: Oh, yeah, yeah. It has plates. You're right.

Peter: And the spikes that you see here.

EJ: I think... This is familiar to me, because my son has the, like, dinosaur book, and every dinosaur book has this dinosaur, I think. Stegosaurus.

Peter: Yeah. Here's the bones.

EJ: They are?

Peter: See the bones here?

EJ: Uh huh... Oh.

Peter: This right here, it has like the...

EJ: What are they?

Peter: That's the list – the triceratops, t-rex, every...

EJ: Oh, that's t-rex?

Peter: But some are like a group of carnivores here.

EJ: Uh huh.

Peter: I don't see stegosaurus but those carnivores here, herbivores here, and (inaudible).

Some eat meat, some eat plant stuff, see? See right there, t-rex eat meat all, it's the tall one.

¹⁶ He spoke English (his first language) in this conversation.

EJ: Pardon?

Peter: They're meat eaters. Some eat meat!

EJ: Oh, some eat meat! Ah, I see.

Peter: And some, triceratops, stegosaurus, eat plants.

This guided museum tour from Peter took almost two and half hours and was only stopped by his mother's suggestion to have a snack outside the museum building. We all sat down on the outside stairs of the museum enjoying the snacks and coffee that his mother had brought from home and carried in her backpack to save money for meals outside. Considering his family's non-affluent economic status, it was the best way to organize a city trip. With their strategy, information, and resources (i.e., free and reduced Metro cards, food from home, free or reduced admission fee, and Peter as museum guide), they perfectly served a guest – myself – who was new to all aspects of the trip, from the transportation, to the museum, and the city itself. In particular, what Peter did was a perfect example of volunteer work that he might be able to try to provide to others.

Volunteers who work with the public in the museum perform a variety of tasks, according to a museum pamphlet ("Volunteer", n.d.). Volunteers may conduct tours of the permanent halls and special exhibitions, operate information desks, engage students as teaching volunteers, provide hands-on learning and immersive experiences, and act as explainers in the fossil halls and in the earth and space halls, according to this pamphlet. Many of these tasks exactly aligned with what Peter did for me, with the exception of hands-on learning activities. Surprisingly, when I mentioned Peter's skills as a guide, the director of the organization was surprised that he could talk that much. Another example of volunteer work that I observed is

Miyoung Eonni whose cleaning work was described in the chapter four. Besides her cleaning job, she was enthusiastic to see tickets for the Grace fundraising.

Miyoung as a volunteer fundraiser. As another example of serving behavior, Miyoung Eonni's fundraising skills that were observed every year. Grace has an annual fundraising concert in the Fall. Starting one month from this concert, Eunji Eonni would start working to sell tickets. Even though she did not get any reward from collecting these donations, she was always ready and enthusiastic to complete this annual mission.

Miyoung: I'm going to get one hundred Grace Night tickets from the office tomorrow. I sold more than five thousand dollars last year.

EJ: Wow! You're great! How did you do that?

Miyoung: Just drop by a Korean store or ask people I meet.

After this conversation, Miyoung reported to me several times as to how much she had sold on a given day.

Miyoung: Only thirty-three tickets left from one hundred. How many did I sell?

EJ: Wow! You have sold sixty-seven tickets so far!

Miyoung: It is twenty dollars per each. So how much is the total? I sold more than five thousand dollars last year.

EJ: That is \$1,340: one thousand three hundred forty dollars.

EJ: The tickets were not enough. So, I got forty more tickets from the office.

Since Grace is a non-profit without any government funding, a special fundraising event like Grace Night is very important to make up any deficit in their budget. Miyoung Eonni plays an active role to help raise funds for this organization. And her unpaid labor—walking through the city, street by street, boldly talking to strangers, explaining the fundraising event, and selling

tickets is a perfect example of volunteer work. In this way, Miyoung is serving others in this community.

I will close this chapter by describing two other occasions that represent not only their serving characters but also their mature relationships as an adult. The first is a Saturday cleaning job scene at Covenant Church building, which is not a special event but mundane work routine for six young people with intellectual disabilities, including Miyoung Eonni. I share this example as it illustrated how these individuals provided service as reliable and responsible workers in their role as janitors in a Korean church, as well as how they took care of each other as friends. The second example was about the exchanging of gifts between myself and three Eonni participants, which I also saw as a symbol of “giving” to others.

Church cleaning job. Like everybody else in the world, all of my participants have their own weaknesses and sometimes serious problems. Two young men who were supposed to be a part of the cleaning team couldn't work on that day. One was not there because he had hit his girlfriend and the other had used profanity the previous week during his cleaning and did not give a proper notice before taking a day off. They found out that he went to some “fun” event at another church instead of coming to work. Both of them got “fired”—in their words—for the remaining six weeks of that year. Miyoung, Minjun, and Taejun also caused some “trouble” at the site because of their constant calling and texting other volunteers. Taejun was also warned about his tantrum behavior (e.g., screaming and throwing his cell phone) at work. In general, people in this community often said that all these young people with ID had gotten too accustomed to receiving something from others and knew too well how to get what they wanted from others. They were rarely described as figures who served others, contrary to my observation including this Saturday cleaning scene.

As soon as the Saturday program ended in the afternoon around three o'clock, six young people with intellectual disabilities and one old man with cerebral palsy hopped into their commuting van, which had a lift for wheelchair users and was specially purchased by Covenant Church to give rides to people with disabilities. While the Saturday program happened in a church building in the neighbor, but not far from the middle of city, their workplace was a forty-minute drive north from there, in other county. On this day, I tagged along. With Saturday's late-afternoon traffic jam in the city, and driving on the highways between counties, it took much longer than usual. However, I noted that they were not frustrated with traffic jam. Rather, they enjoyed the van ride by exchanging jokes, singing, and asking me all sorts of questions, as I was still new to them (e.g., How many children I have? What my husband is doing?). Since it was going to be late, Mr. Park dropped by a Kimbob (Korean style seaweed rolled sushi) restaurant in order to pick up pre-ordered food. While he went to pick up the food, he also asked Seojin to throw away garbage from the van.

Mr. Park: Seojin, gather all the garbage [they'd eaten cake just before leaving the Saturday program in the van], and throw it away in the garbage can outside.

Seojin: Yes [He immediately stood up and started collecting the garbage].

Jaejun: Seojin, can I help you? [Without waiting for an answer, Jaejun stood up from his seat and brought out the garbage with Seojin].

Mike: [While waiting for Kimbob,] I lost my key. There is no key.

[Mike repeated his sentence again and again].

Mike: No key. I cannot find it.

EJ: Did you have it when you got in the van?

[While I did not take any action, not taking his statement seriously, Jaejun immediately got up to help him].

Jaejun: Let me look for it for you.

Jaejun got down under the seats with his knees on the van floor to look for Mike's keys. His search continued until he found the keys under a seat, just as Mr. Park came back to the van with our food. We were all eating and talking until we finally arrived at Covenant Church, the job site.

Immediately upon arriving at Covenant Church, Miyong Eonni and five other young men (Miyoung, Seojin, Minsu, Minjun, Jaejun, and Mike) went to a room next to the church dinner hall and put their coats and bags on a couch. The size of the room and its appearance were just like a resource room in nearly any school. A large photo on the wall indicated the room's name, Class Agape, which is by far the most common name given to groups for people with disabilities in Korean churches. In the photo, there were seven young people with disabilities as well as eight adults, evidently the pastor and Sunday school teachers who were in charge of this group. An attendance sheet was displayed on the wall as well, showing eight names in Korean—seven male and one female. All the names and faces were familiar, since all of them came to the Saturday program in Grace. They had regular meetings in this room after worship on Sundays. There was a rectangular classroom stage in the front, with a drum set on the left, an electronic keyboard on the right, and a couple of microphones. Mike appeared to be very familiar with these musical instruments; he sat at the drum set and played it for a while. There were three round tables with flowers, and several chairs that were stacked up off to one side. As I looked around this room, Taejun called me:

Taejun: Sen-sang-nin [meaning a teacher; used as a title for me], charge your phone here [showing a plug with an extended cord].

I realized that they had all plugged in their smartphones before starting the cleaning job that day. Except me, Miyong Eonni, and Taejun, all the others had already gone to the areas they were responsible to clean. I followed Miyoung Eonni and Taejun. They were the team scheduled to clean the four bathrooms – all of which were on the first and second levels of this church building. They looked competent, knowing what they were supposed to do. They took garbage cans and cleaning tools, including rubber gloves and detergent, and headed to the men's bathroom on the first floor.

Taejun: Jib-sa-nim [a title meaning deacon, referring to Mr. Park who was in charge of this cleaning team] told us that we can skip Mul-cheong-so [literally meaning water cleaning; mopping floor with wet rag] because it is too cold today. Miyoung [not using the title Nu-na, even though she is older than he], because you are sick, I'll take care of the toilet bowls. You just clean the bathroom sink.

EJ: Eonni, are you sick?

Eun-ji: Yes, I have had diarrhea all day yesterday and today.

Then, I realized that her face looked very pale. However, she did not stop working, and did not turn her work over to Taejun. This was characteristic of Miyoung Eonni, who was a reliable and responsible worker. Since I started my data collection in 2015, I did not observe any occasion when Miyoung Eonni failed to show up at work or took time off without advanced notification. When I suggested meeting in the future, she always asked for the dates and checked whether they would conflict with her work schedules, usually every Wednesday and Friday, and some Saturdays. Even when she did not feel very well, she was willing to complete her work duties.

Miyoung Eonni put on her pink color rubber gloves, skillfully dissolved cleaner in water, soaked her sponge in that cold soapy water, put her hand in the toilet bowl, and rubbed it with

the sponge. It was the end of November, and so cold that day that even Mr. Park thought it was too cold to clean the floor with water. Despite being indoors, the church building usually was not heated during weekdays and Saturday. After Miyoung's cleaning, Taejun rinsed toilet bowls with a clean rag. Tae-jun explained to me that the toilet bowls needed to be rinsed twice, first with a clean rag, and then with paper towel. Each bathroom has three or four toilets, and they had to clean four bathrooms just like that. On a cold Saturday afternoon, they repeated that cleaning process thoroughly and speedily. After cleaning all the toilets, they also cleaned the bathroom sinks, using a similar process. Miyoung rubbed them with her sponge and Taejun wiped up with a clean rag. At the end, he also made sure that they had not skipped any areas. Even in the middle of cleaning, Miyoung Eonni needed to use a bathroom because of her stomach issue. However, she kept up with her cleaning work with Taejun. After finishing the job, Taejun collected all the garbage and brought it down to the first floor to put in a dumpster.

When we came down to the dinner hall from the second-floor bathrooms, other people were still finishing up their jobs. Minjun and Mike were cleaning coffee machine filters. The machine was not like those used in homes or offices, but was a commercial unit like one finds at Dunkin Donuts or a franchised café. After cleaning the machine, they refilled ground coffee in a small drawer next to the machine so that the next day church members could make coffee without having to search for it. Mike, who was always very social, found me and asked me whether I wanted some coffee. After cleaning and setting up the coffee station, Taejun gathered all the garbage in one big plastic garbage can.

All seven people and I came back to the Agape Classroom, put our jackets on, and waited until Mr. Park came to pick us up. As soon as he arrived, he paid them all in order from oldest to youngest. Each of them was paid \$25 for their two-hour cleaning job. Just as we had done on the

way to Covenant Church, the seven people and I got in the van that Mike's father was going to drive. These young people again rode cheerfully in the van, enjoying conversation without being tired.

Taejun: [his face showing concern] Miyoung, does your stomach still hurt?

Miyoung: Yes, but it's okay.

[Somebody in the van said that he wanted to have some coffee].

Mr. Park: Do you guys want to have some coffee?

[Everybody was excited to hear Mr. Park's question, and exclaimed]:

All: Yes, yes, yes!

Taejun: Let me buy coffee for all of you today! I have money. [He showed the money he had been paid that day].

Miyoung: [whispering] Eunyoung, I can buy coffee for you.

EJ: Eonni, thank you.

Mr. Park: Don't worry. I'll buy today.

[While we had coffee, I continued to ask her:]

EJ: Eonni, what are you going to do with your money?

Miyoung: It is going to be my mother's birthday. I already pre-ordered a birthday cake [at one of Korean Bakeries in the community]. They give you a discount if you order in advance.

EJ: Do you give her a gift as well?

Miyoung: I'm going to give her \$50. Do you think that it is enough?

It may be strange in American culture to give cash as a birthday gift. But it is common in Korea for a grown child to give some spending money to her parents. She often told me that she had

bought some toys or Korean snacks for her niece when she was supposed to visit her aunt and her grandparents. Interestingly, while I often observed her buying something for her family, others criticized her, saying she was demanding toward volunteers about food (e.g., asking a volunteer to buy lunch for her).

Similarly, as described in the previous example, Taejun and Seonjin who took out the garbage, were good helpers in this organization, moving heavy items, helping transport people on wheelchairs, cleaning up after events, etc. They would not only work when they were asked, but also offered whenever they could, or when they thought somebody needed their help. However, Taejun had a similar issue to Miyoung. He sometimes went into one of the Korean stores and asked for money. I occasionally had similar interactions with Miyoung and Jongeun Eonni, as well, in which they would ask for certain items (e.g., a pair of rain boots) or eating out. However, the difference was that I also made demands of them and, in so doing, I found that they were willing to give something to me in return. Here is an episode of our gift exchange.

Gift exchanges. During my observation, these three Eonni participants were not often asked to engage in a reciprocal way with volunteers without disabilities. However, I found that they were quite open to doing so.

Miyoung: I heard that you bought Jongeun [without Eonni title] rain boots for

Christmas.

EJ: I can give you, as a New Year's gift, something less than \$20. Let me know what you need.

Miyoung: Dunkin [gift card]

Miyoung: How much was Jongun's one? When are you coming?

EJ: They were \$16. Eonni, but, what are you going to give me? Jongeun Eonni said she will buy coffee.

Miyoung: I'm going to give hand cream to you.

EJ: That sounds good!!! I need one. In that case, I'll buy Dunkin Card for you.

Three weeks after our previous conversation and in the same week that I would be visiting them, Miyoung Eonni told me that she bought my hand cream already. For her and my birthday, we exchanged our gifts as well. I gave her Starbucks gift card upon her request while she gave me socks. When I visited my participants that week, Miyoung handed me a bag of gifts, including one Korean hand cream and three pairs of women's socks, wrapped with wrapping paper and ribbons. That same week, Jongeun and Eunju also gave me two bags of gifts, full of chocolates, candies, a small purse, and two lipsticks, all in return for a lunch that I had bought. It turned out that all these items were paid for by Jongeun, since Eunju did not have any money to buy a gift. After lunch, Jongeun also bought three cups of iced coffee at Dunkin Donuts for me and Eunju Eonni. It is also important to mention that Miyoung's mother gave me two jars of kimchi that she made for her family on the same day.

After receiving all gifts from my Eonni participants, they wanted to know whether I liked their gifts; whether my sons liked the candies; and how Miyoung Eonni's mother's kimchi tasted. It might be argued that they only engaged in this gift exchange with me because I had asked them to. However, it is important that they took it seriously, were thoughtful about what I (and my children) might like as a gift, and enjoyed our gift exchange. They were looking forward to that day by asking several times about my arrival schedule, hurried to give their gifts as soon as they saw me, and were eager to know how I liked their gifts. There was a mutual feeling of the joy of giving between us.

Going back to the church on cleaning day, the young men also served others by performing their paid work with diligence and pride. Most societies, including the U.S., emphasize “work”—usually paid work—and ignore other equally-valuable non-paid labor—in terms of its contribution to society. In this dominant framework, these young people have diligently offered their contribution to this community by cleaning church buildings, including the bathrooms. Even during this work, participants took care of each other, and were willing to offer anything they could. This work might be dismissed by the church community, since it was not “prestigious” work, but just an hourly cleaning job that Korean churches offered as a favor for this group. However, it was still not fair to say that these young people with disabilities always received. Rather, their adult characteristics—giving and serving to others—were simply not recognized by this community as service. More importantly, they were not usually given the opportunity to serve others, and were instead often positioned in the role of “being served.”

In this chapter, I have described how the daily discourse and practice in the Korean community confined youth and young adults with disabilities to the role of an object whom non-disabled Koreans needed to serve, thereby failing to offer these people the possibility of serving others. In addition, in the current form of volunteerism, the community “uses” youth and adults with disabilities to further feed a competitive academic system, in which very few students are seen as capable of making a “successful” transition to their adult lives. Further, this practice — using volunteer activity for acquiring admission to prestigious colleges — is a microcosm of a larger agenda in the Korean American community (i.e. “successful” middle and upper class lives in the U.S.). In this vein, I asked: What kinds of work, and by whom, receive recognition as “service” or “volunteer” work? This Korean American community must consider how to recognize different ways that all youth and adults, particularly including Korean American youth

and adults with intellectual disabilities, can learn and be recognized for their meaningful “serving” roles and afford them adult status, instead of giving privileges of recognition exclusively to youth and adults on an “elite” track. A recognition of the need for reciprocity in the server/served relationship also brings us to a different or wider definition of “serving,” which I showed through many counterexamples in this chapter. In the next chapter, I discuss how the dichotomy of service roles interact with elitism and ableism under the light of literatures of disability studies and transition studies.

CHAPTER 7: DISCUSSION AND CONCLUSION

In this dissertation I aimed to explore experiences of Korean American adults with intellectual disabilities in an urban U.S. context. In particular, I investigated: 1) how a Korean American community perceives Korean American adults with intellectual disabilities in terms of their adulthood (Research Question 1); 2) which cultural practices of the Korean American community and which of participants' daily actions were particularly related to adulthood (Research Questions 2 & 3); and, how these cultural practices interact with ableism (Research Question 4). From ethnographic observations and interviews data that I collected from the Korean American community, I identified three cultural contexts in relation to adult identity for people with and without disabilities: age hierarchy, food culture, and volunteerism. In my conclusion, I argue that adults with intellectual disabilities struggle to claim their adulthood because of the lack of opportunity to serve others within the Korean American culture of food service and volunteerism. Furthermore, Korean American youth and adults with disabilities become objects of service for the volunteer work of Korean American youth who need to "serve" in order to be "successful" in their academic elite path. Finally, I claim that, in this cultural process of reproducing serving and served roles, both elitism and ableism are fortified through a discourse of adulthood (*Figure 3*).

In this chapter, first, I lay out my argument with a summary of my findings and other related literature. Second, I provide implications for transition planning and education in special/inclusive education and Korean American community. Finally, I summarize limitations of this research and suggestions for future studies.

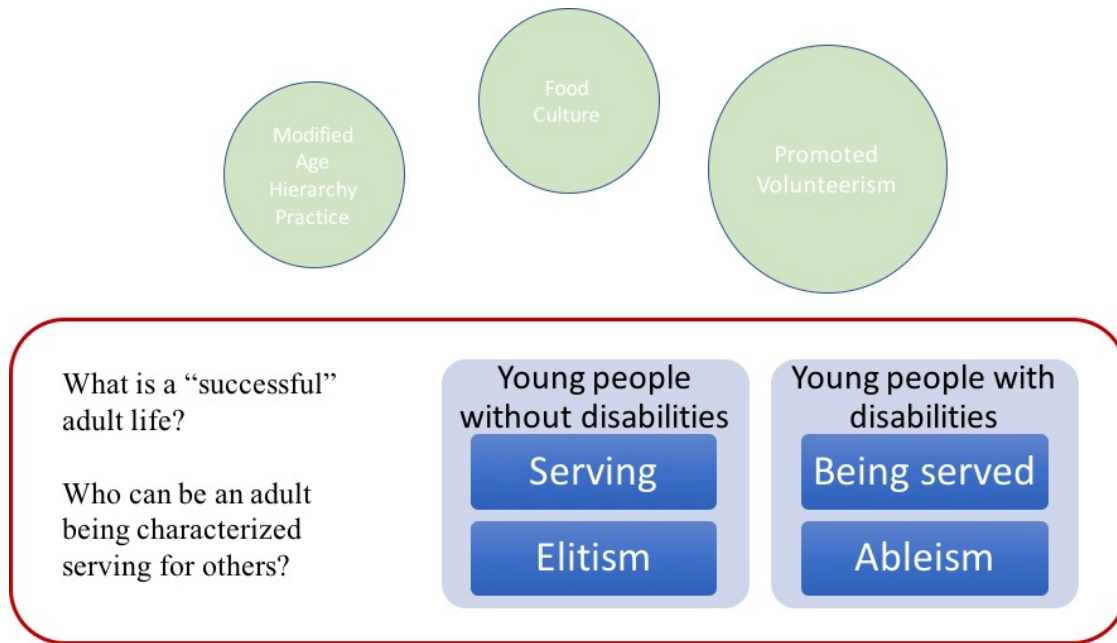


Figure 3. Summary of the research findings.

Disability and Adulthood in Korean American Cultural Context

Roles. All people take up and enact various roles throughout their lifetimes. Not only do we alter our roles according to context (e.g., lecturer at work, mother at home), but we also play multiple roles at the same time (e.g., being a mother to my children and daughter to my mother). Some roles change in response to our physical and psychological development (e.g., dominant idea of child receiving care vs. adult giving care), and some are based on the relationship between two or more parties. A paired set of roles that often appeared throughout my data analysis were the roles of serving and being served, in particular food serving and volunteerism culture. Interestingly, these roles were very much fixed depending on group membership instead of being exchangeable. In other words, there was a fixed dichotomy between these serving and served roles between youth and adults with and without disabilities.

As chapter five describes, people with disabilities, regardless of their age, are served food by youth and adults without disabilities in Saturday program, Summer Camp or other special

events. As chapter six describes, people with disabilities, regardless of their ages or disability labels, are “helped” by youth and adults without disabilities through volunteerism. It might be argued that these individuals with disabilities were served because these events were designed for them. It is true that an event’s invited guests are usually served by others. However, there is a big difference between the events planned for people with disabilities that I observed in Korean American community and general events where food is catered or volunteers provided service. Even though the work of the people serving is appreciated in both types of events, volunteer service does not become the main story of the event. Yet, that is exactly what happened in my observation sites.

For further understanding of these fixed roles, I would like to summarize public and hidden discourses behind the serving and served roles as well as potential results from this reproduction of roles (*Figure 4*). As seen in chapters 4, 5, and 6, youth and young adults without disabilities played a serving role for youth and adults with disabilities. Every time they participated in volunteer work (e.g., Summer Camp, Food serving on the Day of People with Disabilities, etc.), their work or characteristics were recognized, emphasized, and celebrated. For example, volunteers were described as having a great heart, loving their neighbors, and eventually serving the Korean American community. On the other hand, youth and adults with disabilities were described by others in the Korean American community as demanding individuals, expecting to receive everything for free, and ultimately, as people who are still children.

Behind this contrast of the public descriptions of these two groups, there are also hidden stories that were not often told. Often youth volunteers — in particular those with short-term

assignments — used their volunteer work as proof of their community service, as part of their strategy to enter the top academic or career track. In addition, similarly, the Korean American

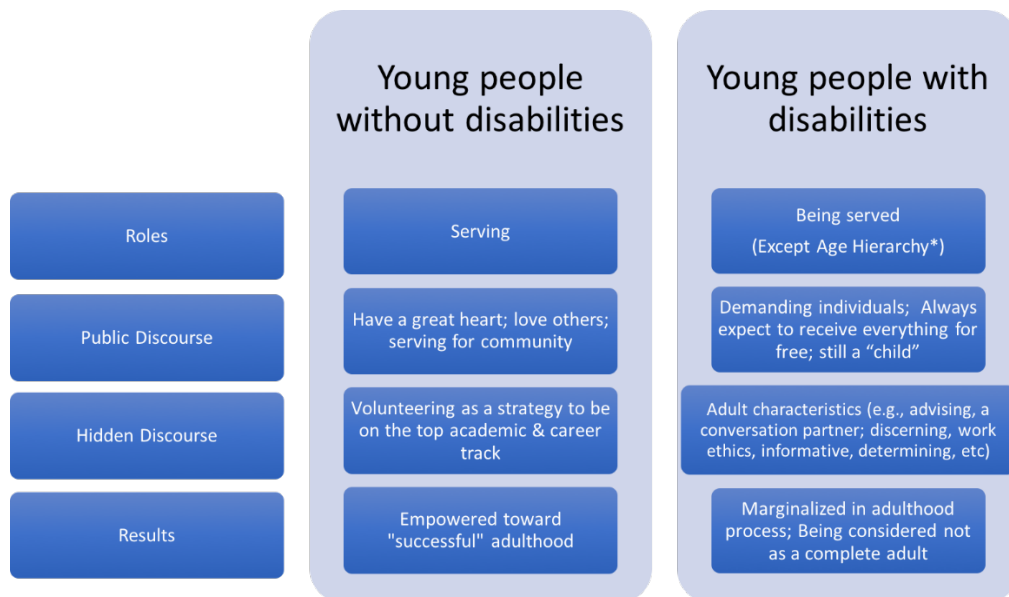


Figure 4. Public and hidden discourses behind roles of people with and without disabilities

community leadership tried to use this volunteerism as a tool to be successful as a minority group in the American “mainstream.” While the hidden motivation of youth volunteerism (e.g., gaining admission to a specialized high school or prestigious college) was only expressed in private, the immigrant community’s use of volunteerism as a strategy for success in the U.S. was explicitly promoted through media. While the positive image of volunteers without disabilities was circulated often as a public discourse, the counterpart with disabilities was rarely described with such a positive image. More specifically, positive adult characteristics of the focus participants with intellectual disabilities were rarely recognized in the Korean American community. As shown in the counterexamples in chapters 4, 5, and 6, there were several behaviors of the participants that can be recognized as positive attribution to their adulthood, such as listening to and advising younger people, having conversations with other adults about age-appropriate topics, discerning or being critical, showing a strong work ethic, providing information,

determining, voluntarily helping others, etc. Most of all, there were many instances of the six participants caring about others and doing what they could to help, which demonstrates the ethos of serving. However, these behaviors were often overlooked in the Korean American community. Because their positive adult characteristics were not recognized, while apparently childlike behaviors were highlighted, youth and adults with disabilities in Korean American community could not escape their publicly assigned role of receiving service from others without disabilities. Chapter 4 also described how youth and adults with disabilities became an exceptional case with respect to the honorific language practices of the Korean American community. Considering the pervasive usage of honorific language among 1.5 or second generation of Korean Americans (Park, 1999), the omission (e.g., not using honorific), or modification (e.g., speaking of an older adult as a “friend”), or over-emphasis on honorific language toward people with disabilities refute the claim that Korean American adults with disabilities were properly considered adults.

Roles and adulthood. As a result of the reproduction of these two opposite and codependent roles, those youth and young adults without disabilities specifically who have potential to achieve elite status, are empowered toward successful adulthood. Thus, one of the characteristics of adulthood that I found within the Korean American community was service. You may start serving for others as a transition from receiving care to providing care to others. In this vein, youth volunteer work can be a perfect example of one’s successful process of developing adulthood *and* an elite academic/career path. It also cannot be ignored that successful adult life in the Korean American community most often entails going to one of the top colleges and having a high-paying, white-collar, “mainstream” professional career. Like other youth from Asian or Latino immigrant families (Povenmire-Kirk et al, 2010; Rueda et al., 2005; Trainor,

2002, 2005), Korean American youth have strong commitment to their families (Lee, 1994; Park, 1999). This is also one of the motivations that Korean American youth have in their desire of academic and career success (Fuligni, 2007) (e.g., I have to be successful in my study and work in order to compensate for my parents' sacrifice for my education and eventually, as their adult child, provide them with comfortable care). This is not only a matter of material provision, but it is also a psychological process. The successful —again, speaking in a very narrow sense—adult child becomes the success and source of pride for her parents; and to some extent the “unsuccessful” child becomes their “failure.”

This connection between academic/career success and successful adulthood is also found at the community level as a shared belief and practice. Interestingly, the Korean American community highly values the role of 1.5 generation Korean Americans as a bridge between the American mainstream and Korean American communities (Park, 1999). In order to meet community expectations, the 1.5 generation Korean Americans should be not only competent to use both the English and Korean languages, but also “better” than their white peers (Park, 1999)- - in particular, in regard to their educational attainment and career trajectory. It is not enough to work actively only for own community, but to also to be successful professionals who win in the “mainstream” competition. These “winners” are the ones considered by the Korean American community as contributing members and the future leadership, presumably to build a strong community¹⁷.

¹⁷ Interestingly, Fuligni (2007) research also shows how Asian young adults become more distanced from their family and community culture in contrast to Latin American young adults after becoming successful in the American mainstream. The reason Fuligni attributes to this difference is that Asians more readily develop a more Western perspective of individualism, based on a successful professional career in the dominant culture, rather than group membership. This was similar to what I heard from Korean Community members as well (i.e., how many young people of 1.5 generation leave church because they are “workaholics” downtown, from a sermon at the summer camp).

In other words, the youth and adults with disabilities involved in my research live in a community where successful adulthood is extremely narrowly defined. In this elitist context, the adults with disabilities are not only actively constructed as children, but also through volunteerism they are considered as objects of care/service. This makes them even more marginalized in the transition to adulthood. Ironically, by always being in the “served” role, they were used as a “stepping stone” for the success of others and were denied their own chance to develop an adult role in the Korean American community.

Ableism and adulthood. How do these cultural practices around the service roles associated with adulthood connect to ableism? According to Bogdan and Biklen (1977), handicapism is “a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences” (p.14). The adult participants in this study, because of their disability label (i.e., intellectual disabilities), were not treated as adults. Denied a serving role and positioned by a modified or exceptional case in Korean honorific language practices, unlike other youth and adults without disabilities, these adults were perceived as unable to perform adult roles. Campbell’s definition of ableism (2001) can be also restated in light of the findings in this research:

“[a] network of [cultural] beliefs, processes and practices” in the Korean American community, especially in the community service context, “produces a particular kind of self ... as the perfect, species-typical and therefore essential and fully [adult]. In other words, disability then is cast as a diminished state of being [an adult].” (p. 44).

While the findings from this study illustrate the ways that ableism informed how the adults with disabilities were perceived — as occupying a diminished state of (adulthood), the complexity of the ableism in this Korean American culture could best be described as a spectrum of ableism. In

Figure 5, I show how there are three ability groups on the spectrum including youth and young adults on the elite track, youth and young adults without high academic achievement, and youth and young adults with intellectual disabilities. While the first two groups' adulthood is assumed, the adult status of the third group with intellectual disabilities is denied in this community because of their "disability." Within the first two non-disabled groups there is still a distinction because of the pervasive elitism. Even though the group who are not on the academic track are not treated like the disabled group, their adulthood is not presumed as a potential success, and they are not given leadership or volunteer opportunities.

The Korean American community's ableist attitudes toward people labeled with intellectual disabilities contributed to a devaluing or ignoring of their adult status. In other words, Korean American adults with intellectual disabilities were struggling to assert that they were indeed adults, but these assertions were ignored or discounted. Others' acknowledgement of their adult status did not develop despite their adult characteristics or behaviors (i.e. working, socializing, participating in food or religious practices). In the literature review, I summarized how intellectual dis/ability is socially constructed (Bogdan & Taylor, 1982; Bogdan, 1986; Gelb, 1995) by an arbitrary selection of certain behaviors (Dexter, 1994) or an arbitrary score on a cognitive measure (Mercer, 1973).

According to the findings, it is also constructed by differing interpretations of the same or similar behaviors, depending on whether someone has been given a disability label. Similarly, although definitions of ableism (Bogdan & Biklen, 1977; Campbell, 2001; Hehir, 2002) typically focus on how different ways of being and doing are devalued and treated as inferior, I would argue that ableism also prevents similar behaviors from being recognized as similar, as portrayed through many of the counter examples of participants presented in this dissertation. In other

words, because my adult participants were labeled with intellectual disabilities, their positive skills, behaviors, and attitudes, which would be attributed to adult identity in the case people without disabilities, were not interpreted in the same way for the participants. Therefore, the presumed childlike status of adults with disabilities is not changed but maintained despite activities such as.

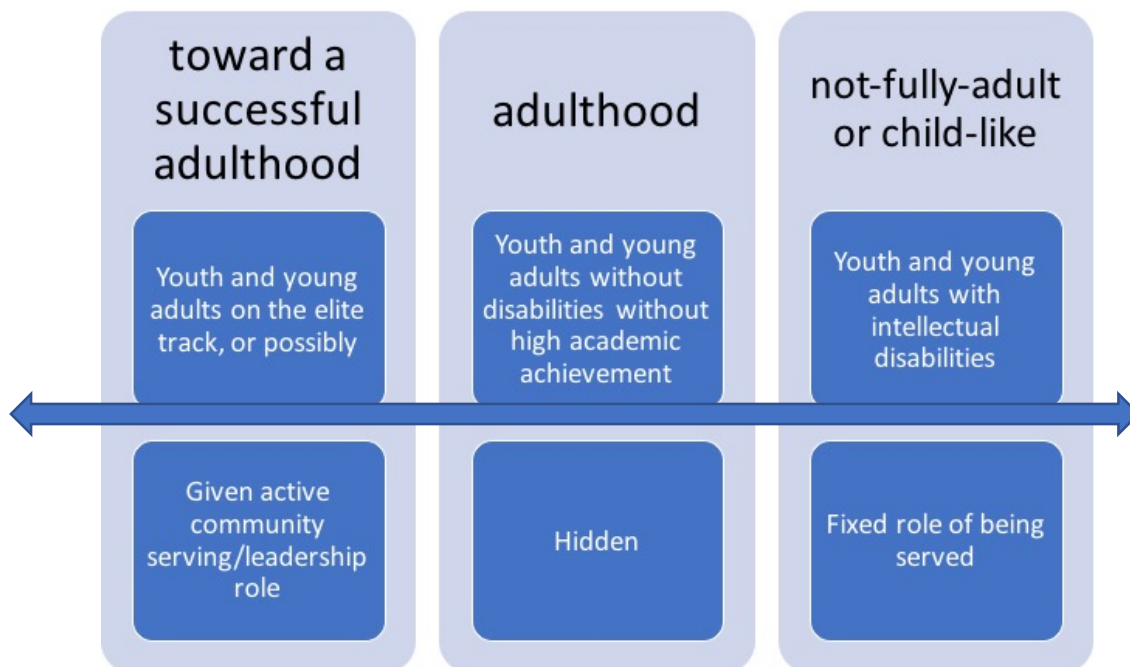


Figure 5. Spectrum of ableism.

In contrast, Korean American adults without disabilities, regardless of their achievement, do not need to *claim* their adult status even though there are still cultural expectations and norms that they need to meet as fully-adult (e.g., financial independence). In other words, people may say that someone without disabilities has not achieved adult goals sufficiently or completely, yet, they do not treat him/her as if they literally were a child. Moreover, the rigid age hierarchy system that dominant Korean culture embraces and reproduces does not give much room for people to ignore other person's age in relation to your own age. Therefore, there is a clear presence of "unequal treatment" (Bogdan & Biklen, 1977) in terms of granting adult status for

youth and adults with intellectual disabilities, in contrast to youth and adults without disabilities. This is the result of ableism.

Ableism, space, and roles. Although not being treated as an adult can be understood as a result of ableism, the actual mechanism of reproducing ableism requires further explanation. Kitchin (1998) understands the reproduction of ableism as a socio-spatial process. He argues that “spaces are currently organized to keep disabled people ‘in their place’” (p.345). He further states, “spaces are social texts that convey to disabled people that they are ‘out of place.’” Connecting his argument to the power relations, Kitchin notes that “Space is instrumental in the reproductive, sustenance and resistance of disablist practices. The organization and writing of space are expressions of disablist power relations within society” (p.354). Space was central to the ways that ableism is sustained and reproduced.

Space and culture are distinct, but related constructs. Space creates a setting for daily cultural practices; space is also structured, designed, and decorated with cultural connotations. In this vein, it seems reasonable to use the socio-spatial theoretical framework as a tool to flesh out the practices of Korean American culture, especially as a power relation between abled and disabled bodies. Most of all, I noticed from my data that there is great significance to the question of which persons or roles are assigned to stand or stay in which physical place. For example, there was a clear physical division across long tables between people with disabilities who were served food, and those who served food as volunteers. Even at Grace House — a group home in the Grace organization — residents with disabilities were not standing behind the food. They were standing in line and receiving food which was served by new community visitors, who had come to volunteer and stood on the other side of tables. In addition, we can conceptualize a role (e.g., serving and being served) as a designated space as well. Some people

may be able to choose which role they would like to “take” part or enter into. However, some are excluded from the space of a particular role; they cannot access that space, but are forced to stay in the space associated with another role. The cultural practices of service in the Korean American community are “organized to keep disabled people ‘in their place,’” (p.345) which in a variety of ways was the role of an object to be served. The same cultural practices “convey to disabled people [and non-disabled people] that they are ‘out of place,’” (p.345) not belonging to the group of adults who are identified by their acts of community service. Yet, the participants with intellectual disabilities in this study demonstrated how they naturally occupied adult roles in their daily lives, within the same cultural contexts, regardless of the community’s perception and their exclusion from adult serving roles. In this sense, the current cultural practices of modified age hierarchy, food serving, and volunteerism in the Korean American community are “instrumental in the reproductive sustenance *and* [emphasis added] resistance of disablist practices” (p.354).

Based on my findings, I argue that one of the cultural tools for reproducing ableism in the Korean American community involves the politics of community service. As explained already, the serving role in Korean American volunteer practices for youth and adults without disabilities is connected to the image of successful adulthood. Because this image is also tied to Korean American elitism, volunteer experiences are not considered a necessity for youth and young adults without high academic achievement. In other words, because youth volunteer activity is constructed as a part of the “package” for prestigious college admission, volunteer opportunities are not considered essential to other youth who are not on the high academic track. In addition, even though many adults without so-called “successful” adult careers participated in volunteer activity in the Korean American community, their work was not visible; only a group of elite

leadership was highlighted through media and community events. Thus, ableism and elitism were reproduced together through the mechanism of community service. In this process, successful adulthood, adulthood, and denied adulthood are delineated as three distinct groups. The findings of this dissertation have important implications, particularly in relation to adults with intellectual disabilities, which I will highlight next.

Implications for Emerging Adulthood of Youth and Adult with Intellectual Disabilities.

Transition. The findings of this research have important implications in terms of transition planning and services related to transition education in special education. In the literature review, I critically reviewed how the dominant model of transition to adulthood in special education is linear, outcome-oriented, and focused on a set of skills and services that does not reflect the complexity of adulthood as the process of negotiating a new space (Holdsworth & Morgan, 2005). While the transition in special education is usually understood as a short period between the stages of youth and adulthood (Halpern, 1994; Transition, 2007; Wehman, 2006), this period is “long enough that it [constitutes] not merely a transition but a separate period of the life course” (Arnett, 2004, p.69). The youth and adults with intellectual and developmental disabilities including six focus participants that I observed in the research site ranged widely in age, from 7th grade to late 40s. There were also widely different levels of physical, social and psychological development within this group. Despite these differences, they also shared similar struggles toward or in their adulthood, such as difficulty finding a job, building relationships, dealing with emotional issues, etc. Although the transition planning and services in special education ends at age 22, these challenges continued in participants’ lives. This is, of course, true in the case of many youth and adults with and without disabilities. Most people continue to face challenges, work to figure them out, negotiate with them throughout their adulthood, especially

early in adulthood. Therefore, Arnett (2004) terms this period as emerging adulthood and describes it as “the age of identity explorations, the age of instability, the self-focused age, the age of feeling in-between, and the age of possibilities” (Arnett, 2004, p.69). Because of many social barriers to even exploring possibilities or trying out options, adults with intellectual disabilities seem to have an even longer “instability” in their adulthood, which makes it more reasonable to understand transition as an extended, separate period of their life course.

Another issue with the current transition planning and practice is that it not only obscures what happens during adulthood, but also limits what can happen during adulthood. The Saturday program group that I observed could be categorized into two subgroups: those who still attend a school and those who are out of the K-12 school system. The age of 22 is the cut-off point in most states for services under IDEA. The difference between the two groups was a matter of which building they stayed in during the daytime (either a school if they were under 22 or a day rehabilitation center if they had aged out of school). This division also determined who paid for services (either the school district or the Office for People with Developmental Disabilities or OPWDD). The concept of transition or emerging adulthood is not familiar to most families, unless you are directly involved in special education. I had the opportunity to observe a OPWDD orientation exclusively targeting Korean American families for adult services. It provided useful information about when, what, and how parents should prepare (e.g., paperwork) to get adult services. This is an important point in the process of transition to adulthood because many families experience an unintentional service gap after age 22 and before they can establish OPWDD service eligibility, which was exactly the case for Peter, one of my participants. Ironically, Peter seemed to navigate his urban environment much more during this “transition” period than he was able to do after becoming eligible for adult services, when his schedule and

movement was much more highly structured by service providers. This lack of freedom of movement and individual choice is exactly the opposite of how we might characterize emerging adulthood. Where is the adult “freedom” and “choice” that we associate with emerging adulthood? Most Korean American parents of youth and adults with intellectual disabilities do not have the resources to enable them to imagine and prepare options for their children’s adult lives in any way other than to drop them off and pick them up at the day habilitation center, which they referred to as “Day Care”¹⁸. Transition planning and services may not be able to give families and youth and adults with disabilities who live in the urban Korean American community the tools to prepare for life as an adult. Instead, transition planning and services may work as a temporal “placeholder” in order to extend their stay in the educational system until they are eligible for adult services.

Complexity of daily life. Although my participants regularly exerted self-determination in terms of food consumption (e.g., choosing where and what to eat), they still experienced obstacles in their ability to represent their adulthood in Korean food culture. As I have stated, they were not given a chance to play a food serving role in the context of their community. This food serving role includes a wide range of actions, such as simply giving out food at an event, cooking for others, sharing their food, buying a meal or coffee for others, paying for others’ food, etc. While food-related skills are often mentioned as a part of transition planning, they are often framed as simple isolated skills such as “can order in a cafeteria or fast food restaurant,” “can fix a lunch for one,” “can plan weekly menu of nutritious meals,” “has ‘good’ table manners,” etc. (Washington State Department of Social and Health Services, 2000). These

¹⁸ There are other options besides using a service agency, in which daily activities are mapped out by one institution without much input from parents and not reflective of adults’ choices. For example, a Self-Direction plan allows parents and adults to choose activities or specific services, manage their own funding, hire staff, etc. However, I observed only one family in my research site who actually used a Self-Directed option for their 10th grade child.

isolated skills do not capture a complete picture of food rituals that adults in a given cultural community may implement. For example, the Division on Career Development and Transition in CEC (Halpern, 1994) identifies some transition goals including maintaining one's own home, community involvement, personal and social relationships, employment, and post-secondary education. According to my observation in the Korean American community, a serving role in food culture can be expressed from all of these goal areas. It is a food prep skill, a social skill, a form of community involvement, a job-related skill, etc. These isolated skill sets cannot capture the *meaning* of the combination of these skills, not only in a particular ethnic culture, but also within an ableist culture, in which these individuals live.

Another example of food as evidence of complexity of daily life relates to group-homes. Considering the Korean community's daily routine of eating only Korean food with few exceptions, it is understandable that many parents are concerned about their children's future residential options. Most parents I met considered a group home as their children's most likely residential option for the near future. And many of them ask the Grace if they are accepting more residents for their group home because it is only Korean group home in that community and it serves Korean food cooked by Korean women for every meal. The biggest concern that parents have when they send their adult children to a regular American group home is the inaccessibility to Korean food. In other words, even though these youth and adults with disabilities habitually eat Korean food every day, they cannot continue their Korean food consumption once they enter any of the other group homes. Collins' explanation (2008) of the meaning of trans-national culinary consumption gives some insight to its importance:

It is argued that culinary consumption in transnational worlds can also more subtly represent an effort to recreate familiarity through reference to characteristics of everyday

life before migration that may include what appear to be both global and local products. Such familiarity is then not necessarily about group loyalties or identities but rather an example of the importance of practical know how and familiar sensations in feelings of belonging and attachment. (p. 151)

What food is served in a group home is not only a dietary and nutritional issue, but may also include a deeper meaning than simply choosing the menu. As soon as you move to an “American” group home, parents might worry that you will also lose your Korean food and your “feelings of belonging and attachment” (Collins, 2008) associated with it.

As deFur and Trainor (2012) said, “[e]xisting transition models ... rarely depict or explicate what roles one’s cultural identities or the systemic culture play during postsecondary transition” (p. 280). It is also not easy to capture the complexity of culture and adulthood into a structured and formal process such as transition planning and services.. In fact, I believe that the list of skills and services are still useful to be provided to youth and adults with certain needs. However, as families and educators aim to support and improve the quality of life for youth and adults with intellectual disabilities, culturally relevant transition planning that would be tied to the communities and culture of students should be developed. As the first step of this process, I would like to carefully warn of how educators and service providers may oversimplify the process of emerging adulthood. Educators need to understand how complicated each person’s life is within the context of their culture and in relation to power/privilege. Does a transition program or checklist implicitly deliver the message that if a youth with intellectual disabilities cannot “attain” these basic skills, he cannot be an adult? Most focus participants do not or cannot cook their own meals. However, as described in my findings, they manage and practice adult food culture in their own ways as adults. Do these lists become another prerequisite or readiness

skills for adulthood (i.e., treating adults with intellectual disabilities as children because they cannot cook or do not have certain skills)? Or do these skill sets imply that attaining them will secure an individual's good adult life. These hidden assumptions and values behind transition planning and practices boil down to an exclusive focus on individuals' competence as a condition for a successful adulthood. And, as this research illustrates, adulthood is not only a question of individuals' "abilities," but also a matter of structures (e.g., cultural norms and beliefs, perceptions on disabilities, etc.).

In a similar way, Cowley (2013) criticizes the way the current concept and practice of self-determination for youth with disabilities is narrowed down to an individual's a set of skills without considering the social structure (i.e., barriers and opportunities to exert their agency). The term self-determination becomes an empty word if there is no context in which they can act it out. Ironically, special education or adult disability services often attribute "failure" of transition to adulthood to the individual. In Stewart, Law, Rosenbaum, and Willms (2001)'s qualitative study, youth with physical disabilities "identified a poor fit between [them] and the adult world they were entering" (p.3). Echoing the fact that "[social systems] both support and constrain individual actions and outcomes" (Raffo & Reeves, 2000, p. 147), the youth with disabilities highlight the importance of "environmental support to enable them to 'build their own bridges' to the adult world. In other words, the achievement of a successful adulthood experience requires not only individuals' competence but also social support for youth and adults with disabilities. According to the findings of this research, individual competences cannot be recognized without social support.

How, then, can a community support youth and adults with intellectual disabilities? To provide some suggestions toward answering this question, I would like to discuss the social role

valorization theory (SRV) (Wolfensberger, 1991) and cultural reproduction theory. Since SRV theory focuses on valued roles as a critical component for a “good” life (Osburn, 2006), it can be connected to service roles in this research. This theory describes how people with disabilities are “subjected to a systematic — and possibly life-long — pattern of such negative experiences” (Osburn, 2006, p.5) including “[b]eing cast into negative social role” (p.5). In order to increase the positive experiences of people with disabilities, SRV theory suggests making an action plan to arrange physical and social conditions on four different levels: the individual, the primary social system (e.g., family), the intermediate secondary social system (e.g., community), and the larger society of the individual (e.g., the service system). In this research, I explore the “serving” role in the Korean American community as a particular social role. In the SRV framework, arranging a space and an activity that provides this serving role (e.g., volunteering) to a person with disabilities can be one way to increase “good things in [their adult] life” (Wolfensberger, Thomas & Caruso, 1996).

Bowman, et al (2010) provided qualitative data as to how community engagement activities, including college volunteering and service-learning have a positive impact on adulthood well-being, “includ[ing] personal growth, purpose in life, environmental mastery, and life satisfaction” (p.14). Similarly, Hill, Lapsley and Brandenberger (2010) compared four different life purpose orientations (creative, prosocial, financial, and personal recognition), and showed that only prosocial orientation, which means being willing to help others or participate in social change, predicted middle-age adulthood well-being (i.e., greater generativity, personal growth, and integrity). Interestingly, Bowman, et al (2010) also show how their college grades are negatively correlated with the level of their prosocial activities. It is perhaps ironic of me to suggest volunteering activities for youth and adults with disabilities as a way of serving others

after having criticized the practice in the Korean American community. It is important to arrange an environment that can provide valued roles to youth and adults with intellectual disabilities for their quality of life (Osburn, 2006; Wofensberger, Thomas & Caruso, 1996). And, one valued role in the Korean American community is service in their food culture and volunteer culture. Bowman et al (2010) and Hill et al. (2010) also show how these prosocial actions are related to well-being. In this sense, providing volunteer experience for others to youth and adults with intellectual disabilities can be a positive experience both for themselves and for the Korean American community to recognize the value of community members with disabilities and to establish their adult status as individuals who can serve others.

However, this serving role needs to be more carefully examined in terms of the relationship between people who serve and people who are served, and the outcomes of serving actions. Reflecting on cultural reproduction theory (Carspecken, 1996; Willis, 1981), social reproduction happens through the actions of individuals, including oppressed individuals, not necessarily by direct coercion, but more likely by daily cultural practices. And, the social structures behind the cultural practices “largely escape the awareness of actors while influencing how they act” (Georgiou & Carspecken, 2002, p. 680). This research describes how the serving action may be used as a reproduction mechanism of the unequal power structure (i.e., elitism and ableism in Korean American culture). While community service or the serving role is or should be valued, we also need to recognize that it is also influenced by an unequal social structure which is not often visible, and may result in reproducing the same structure. In this vein, SRV may conceptualize positive/negative social roles in an overly simplistic way. For example, positive roles that my focus participants played were not very visible in the community discourse. Why were their adult characteristics not recognized? It may be because of pervasive

ableism in the community as a structure to restrain people's recognition. Giving a positive role may not suffice to change an oppressive system. In addition, even practicing one's positively perceived role may still reproduce oppression. For example, I described how my participants positively evaluated their one-time serving role for Hispanic homeless people. I cannot be certain how that serving role worked out, since it took place before my data collection. However, what if it had the potential to result in fortifying existing racism or prejudice toward homeless people among this Korean American community? Might it establish an unequal relationship between my participants who served and the homeless people who got served? The practice of cultural roles needs to be approached in relation to the larger social system in a way that resists unequal social relations rather than reproducing them. On the other hand, we also need to recognize the possibility of "acting otherwise: acting against conditions rather than in conformity with them" (Carspecken, 1996, p. 37). My research participants dealt with ableism, causing them to struggle to claim their adulthood. However, they also showed that ableist notions are not correct by taking cultural actions. I think that this is one possible way to break open a crack in an unequal social structure like ableism.

An environment where *we* provide service for *each other* should not operate on a charity — typically religious — model that predominantly empowers those who provide "help." Instead, it should be a format of not only "helping" people, but also changing an unequal power structure *by* those who receive "help," with allies' support. In this way, I imagine Korean American youth and adults with intellectual disabilities driving Saturday program with volunteers' support as an adult learning process centered around what they want and what they believe they need to learn as adults. What do they want to know about their Christianity, Bible, or church? What kinds of roles do they want to try to take in their church community or Korean American community?

Which other minority groups can they be allied with? How do they support other minority groups? How can they support each other in Saturday program? There are many questions that we can ask in order to make our service for others more the way it is supposed to be, for *others* instead of for ourselves, while still accepting that our serving behaviors become meaningful to our own lives as well. In this sense, Tracy Thresher, who is a self-advocate with autism, gives us a good insight about the purpose of life.

The self-advocacy movement for people with disabilities has its roots in the broader civil rights movements of the 1960s and 1970s. *By teaching others to self-advocate and make their voices heard, I feel like my life has purpose* [emphasis added]. For educators, I recommend teaching students the power of self-advocacy and speaking up to meet their goals in life. Green Mountain Self-Advocates brings together self-advocacy groups in Vermont. GMSA has empowered many people through education and conferences. (Thresher, n.d.)

I envision the Korean American community providing a support system to enable the participants in this research to take on the role of a teacher and advocate, like Tracy. Thus, they can serve the Korean American community and help transform it into a space that welcomes more diverse forms of meaningful lives for all.

Korean American community. As we consider transforming Korean American communities into a more inclusive space, it is necessary to discuss Korean elitism and cram school practices. We can expect Korean parents to take a “down-to-earth” approach and ask a simple question regarding this issue: “Should I send my child to a cram school, to help her get into a good college, so she can have a successful and better life in the future?” I heard similar questions everywhere in the Korean community that I observed. People also say, “I would like to

do something different than sending him to a cram school. But I fear that my child would be left behind at school.” Many of the concepts underlying these statements are culturally informed, including the definition of success, a better life, competition, the purpose of education, the role of college, sufficiency of schools in education, etc. In chapter six, I described Korean elitism practices as the result of a very limited imagination as to the meaning of a successful or good life, a concept that does not ultimately benefit the majority of youth and adults. While utilizing educational resources from business sectors in a community (e.g., a cram school) is an effective strategy to increase academic achievement within a school system, it is not the only way to facilitate a good future life as an adult. The Korean American community needs to ask different questions, such as the following:

How do you as a parent envision your child’s good life? How does your child want to shape his adult life? What is an individual’s purpose in life? Do academic and career success guarantee one’s well-being? Considering adult life in a community, what do Korean Americans need to do in order to create a “community¹⁹” that fosters more symbiotic rather than oppressive relationships? Can Korean Americans ever say that their community is empowered while some members, including people with disabilities, are marginalized within the community itself? Simply, is the Korean American community a good place to live, where people can find support for each other? Korean American churches also need to ask themselves some questions. What is the biblical of service to others? Are current Korean American church practices for people with disabilities aligned with such biblical commandments as “love your neighbor *as yourself*” [emphasis added]? Do Korean American churches exclude people with disabilities from

¹⁹ The definition of community in ecology seems perfect to describe an ideal image of human community in non-academic terms. Community is defined as “a group of interdependent organisms of different [people] growing or living together in a [particular area].”

membership, instead of accepting each other as members of *one* body? Making space in the community for Korean Americans to have a conversation about these questions may be the first step toward building an inclusive community.

After data collection, one site I strongly wished to observe was Peter's day habilitation program, which is funded by OPWDD (Office of People with Developmental Disabilities) for adults with intellectual disabilities, of age 21 and older. Families refer to it as "daycare," and the same term²⁰ was found in service for seniors as well (i.e., Adult Day Care Services). Most adults with intellectual disabilities in my observation site received the same or very similar services. While the purpose of day habilitation is participation in the community, Peter's daily routine after receiving this service was more constrained than before. Interestingly, the day habilitation program provides volunteer experience as a way to develop skills (e.g., communication, transportation, etc.). However – while further research is needed, including observation of Peter's day services – based on our conversations, these services do not seem to have the nature of the museum tour that Peter volunteered to give me. Peter can and needs to work in the community directly, not in this day habilitation system that supposedly acts as a bridge between Peter and his community. One lesson that my research has confirmed is that the supposition that youth and adults with disabilities cannot participate in the community is simply untrue. Rather, they are in general not allowed to work, worship, learn, and hang out together with their age peers, under the rationales of ableism and the deficit model of disability. In this sense, support and services for youth and adults with intellectual disabilities should allow for individuals' interests, passion, autonomy, decision-making, freedom, choice, relationships, etc., such as Peter

²⁰ While daycare infantilizes adults with intellectual disabilities, day-habilitation is also a troubling word which can medicalize adults with intellectual disabilities as having a deficit of "something" that they never had in the first place, in contrast to "rehabilitation" meaning re-gaining something that has been lost.

and other adult participants in this research demonstrated throughout their *daily lives*. In order to do so, it is necessary to recognize the value and importance of a “normal” environment with support. Social skill programs cannot replace peer relationships, and a day-habilitation program, including structured volunteer experience, cannot replace adult life in one’s community. On the contrary, it tends to block “real” opportunities to explore adulthood.

Limitations and Future Studies

I would like to lay out four research limitations and related future research topics. First, the data collection for this research took place over a limited period of time (i.e., nine months of intensive data collection), within a certain setting and events (i.e., Korean American Christian community), and with specific participants. While these cultural practices seem to exist in many places, the findings cannot be generalized in application to other Korean American communities and other cultural communities without examining their own practices specifically. In addition, there are other cultural elements within this research site, and the participants’ other identities (e.g., gender, class, etc.) need to be further explored in relation to their daily lives and adult status.

Second, this research focuses on the experience of adults with intellectual disabilities in their community, especially around Christian community settings. While emphasizing the various roles of a church, and the importance of the church space in the Korean American community, it still cannot capture all dimensions of the participants’ daily lives. The community service roles may be salient in the data because of the research setting where I collected data. Korean American family settings in particular still need to be explored, since they may be more influential to their children’s adulthood by means of their cultural expectations and beliefs, which may or may not resemble the findings of this research. Local schools and service agencies

in the Korean American community also need to be examined in order to see how cultural ideas of adulthood in public education and service settings interact with Korean American culture.

Third, this research does not focus on the voice of youth, even though there were Korean American youth with intellectual disabilities in most observation settings. In other words, what they experience in the community setting is similar to what the focus adult participants with intellectual disabilities experience. However, their actions and reactions to Korean American cultural practices are not explored in this research. Related to the second limitation, since they are still in the “American” educational system, they probably have more “travel” between the dominant American culture and Korean culture than do the focus participants in this research, who stay in their Korean American community for the majority of their time. Also, youth with intellectual disabilities may show different characteristics of their emerging adulthood.

Last, while the main research site was a Christian organization, I could not further interpret data in terms of the religious system, even though the community roles of Korean American churches and their inclusive / exclusive practices toward people with disabilities were one of the initial themes of this project. In order to analyze the charity model of disabilities in the Korean American religious context, Korean American churches themselves, including their theologies and practices, need to be analyzed. Historically, in a Judeo-Christian religious context, people with disabilities have been positioned as “proof” either of God’s displeasure — a sign of past sins or lack of true faith – or of the power of God to heal (as in healing rituals, healing the lame, blind, etc.). In the modern context, there is a similar relationship whereby non-disabled individuals “prove” their faith through “good works” towards less fortunate others, by performing service to others. However, further cultural studies are needed to find out whether Korean churches practice their religion in a similar way to that of western Judeo-Christian

churches. Korean protestant churches in South Korea and the U.S. have transplanted older Korean religious cultural elements (e.g., Shamanism, Buddhism, Confucianism, etc.) into their Christian practices and belief systems (Park). For example, most community food serving practices that I describe in chapter five were implemented in the Korean American Church context. However, I wondered whether the rationale or motivations behind this practice may be connected to the concept of Bosi, which is a common Buddhist practice of offerings, including food items, in South Korea. It seems that the current food serving practice has more in common with Bosi than with American church food pantry practices. In order to see under what kinds of religious model of disability the Korean American church community operates; how their religious model is connected to the charity model; and how these two models are practiced around people with disabilities in Korean American local churches, I need to collect more data directly from Korean American churches (e.g., interviewing pastors and members, observing their teaching and religious routines, collecting their theological statements, etc.), which I hope to get an opportunity to do.

Final Thoughts

My intention for this dissertation is to understand better the experiences of youth and adults with intellectual disabilities in Korean American cultural contexts, particularly during their emerging adulthood. In other words, this is about a Korean American cultural construction of dis/ability and child/adulthood, which is mediated through two different roles (i.e., serving vs. being served) in community service activities that I observed. I argue that, as a result, ableism and elitism promote each other and are reproduced by Korean Americans as cultural agents in this process. However, the most important part of this dissertation is its relating the stories of adult participants labeled with intellectual disabilities. Like other Korean Americans, they

conform to Korean American culture. They also internalize ableism in a certain context. However, they also take cultural actions that contradict ableism by implementing adult roles in their cultural practices. In other words, regardless of their intentions, Korean American adults with intellectual disabilities put cracks in the unequal structure, which is built with cultural beliefs and actions, and they do so by practicing Korean American culture. How fascinating it has been to observe culture not only as an oppressive mechanism but also as a tool of resistance! And I hope that this dissertation is one footprint, a visible trace of invisible cultural processes of oppression and resistance. Thus, it can inform people in determining their cultural actions, and help in creating a more inclusive community for youth and adults labeled with intellectual disabilities.

Appendix A: Interview Guide (Parents - English)

Hello, my name is Eunyoung Jung and I'm a PhD student in special education. I'm interested in how you think about your child's future adult life after his/her graduation. I'd like to talk about your child's transition plan, current programs he/she participates in, your hopes and dreams for him/her, and your ideas about adult life.

1. Would you please tell me your child's daily routines?
 - a. at school
 - b. after school
2. Please tell me any specific activities relating to his/her transition to post-secondary stage. (e.g., job, college, residential options, etc.)
3. Would you please explain your child's transitional plan, if she/he has one?
4. How do you envision your child's adult life?
5. Would you please describe your hopes or dreams for her/him? What worries do you have about her/his graduation?
6. What was like for you to become an adult?
7. Where do you usually find resources for your child's education and transition?
8. What would be the most helpful support for his/her transition to adulthood? Are there any services that you wish to have?
9. Do you have something that you and your child have prepared for the future?

Appendix B: Interview Guide (Youth / Adult- English)

Hello, my name is Eunyoung Jung and I'm a PhD student in special education. I would like to hear about how you think about your daily activities including at the transition program, at the church, or with your family. I also would like to know what you would like to do in the future.

1. Would you please introduce yourself? How do you describe yourself?
2. Would you please tell me your favorite food, activity, place, or persons in your life?
3. What do you usually do during the weekend?
4. Please tell me what you did today.
5. Would you please tell me about any special event that you had in the past one month?
6. Would you please tell me about this place?
7. What was the most surprising or unforgettable event for you recently?
8. (Sharing his/her picture that the participant brings) You brought this photo to share with me. Why did you choose this photo? Can you tell me about this picture?
9. What do you want to do after graduation from high school?
10. (Showing a picture from observation) I saw you doing this activity. Can you explain what you were doing, and how was it?
11. What are the most current concerns to you?
12. Can you picture yourself in ten years?

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 file://hd.ad.syr.edu/02/ab7ae4/Documents/Downloads/2015%EB%85%84+%EC%B4%88%C2%B7%EC%A4%91%C2%B7%EA%B3%A0+%EC%82%AC%EA%B5%90%EC%9C%A1%EB%B9%84%EC%A1%B0%EC%82%AC+%EA%B2%B0%EA%B3%BC.pdf

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- Williams-Diehm, K. L. & Lynch, P. S. (2007). Student knowledge and perceptions of individual transition planning and its process. *The Journal of Vocational Special Needs Education*, 29(3), 13-21.
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- Wolfensberger, W. (1991). *A brief introduction to Social Role Valorization as a high-order concept for structuring human services*. Syracuse, NY: Training institute for Human Service Planning, Leadership and Change Agency.
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EUDCATION AND LICENSURE

Ph.D. in Special Education (Anticipated May 2018)

Syracuse University

Dissertation – *Struggles of Korean Americans Labeled with Intellectual Disabilities to Claim Adult Status*

Advisor: Beth A. Ferri, Ph.D.

Certificate of Advanced Studies in Disability Studies, 2014

Syracuse University

Certificate of Advanced Studies in Women and Gender Studies, 2013

Syracuse University

Masters of Art in Special Education, 2005

Pusan National University, Republic of Korea

Thesis - *The Curriculum Implementation of Special Education Teachers in Science Classes for Students with Intellectual Disability*

Bachelors of Art in Special Education, 2002

Pusan National University, Republic of Korea

Minor: Biology Education

Teaching Certification:

Special Education, 7-12, Permanent Certificate, Ministry of Education & Human Resources Development, Republic of Korea

TEACHING EXPERIENCE

Higher Education Teaching

Elmira College, Department of Teacher Education, Childhood Special Education (2016-Present)

Full-time Instructor (2016-Present)

Courses Taught:

- Teaching Students with Disabilities in the Inclusive Classroom - Undergraduate
- Curriculum Design and Instruction in Childhood Special Education - Undergraduate
- Managing Behaviors of Students with Disabilities - Undergraduate
- Assessing Students with Disabilities - Undergraduate
- Instructional Design for the Inclusive Classroom – Graduate / Hybrid Course

Student Teaching Supervisor (2016-Present)

Syracuse University, Department of Teaching and Leadership (2008-2011)

Instructor - Spring 2011

Courses Taught:

- Introduction to Inclusive Schooling - Undergraduate

Teaching Assistant – Fall 2008-Fall 2010

Courses Assisted:

- Introduction to Inclusive Schooling - Undergraduate
- Practicum in Pre-K Inclusive Education - Undergraduate
- Differentiation for Inclusive Education - Undergraduate
- Psycho-Educational Assessment Seminar - Graduate
- Adapting Instruction for Diverse Student Needs – Graduate

Pusan National University, Department of Special Education

Instructor - Spring 2007

Courses Taught:

- Classroom Management for Special Education Teacher - Undergraduate

Inje University, Department of Special Education

Instructor - Fall 2006; Fall 2007

Courses Taught:

- Development and Application of Instructional Materials in Special Education - Undergraduate
- Materials and methods for teaching in special school - Graduate

Catholic University of Pusan, Department of Speech and Hearing Therapy

Instructor - Spring 2007; Fall 2007

Courses Taught:

- Education for Students with Intellectual Disability
- Education for Students with Learning Disability

Busan Presbyterian University, Department of Special Education

Instructor - Fall 2006

Courses Taught:

- Education for students with Intellectual Disability

Secondary School Teaching in Korea

Busan Hyewon Special School, Busan (2008)

After-school Science Program Teacher

- Create & implement Science Program which was designed for different cognitive process styles (consecutive/simultaneous)
- Teach students with intellectual and developmental disabilities in grades 7 through 9

Pusan Solvit Special School, Busan (2007)

Special Education Teacher

- Support students with intellectual and developmental disabilities in grades 7 through 12 in a special school
- Taught Science and Social Studies

Busan Hyewon Special School, Busan (2003-2004)

Special Education Teacher

- Supported deaf students & students with intellectual and developmental disabilities in grades 7 through 12 in a special school
- Taught Science and Math.

Dongrae Horticulture High School, Busan (2002)

Special Education Teacher

- Supported students with special needs in an inclusive / resource room setting
- Taught Korean Language Art
- Collaboratively planned and implemented transition programs

PUBLICATIONS

Peer Reviewed Journal Publications:

- Ashby, C., **Jung, E.**, Woodfield, C., Vroman, K., & Orsati, F. (2015). Wishing to go it alone: The complicated interplay of independence, interdependence and agency. *Disability & Society*, 30(10), 1474-1489.
- Woodfield, C., **Jung, E.**, & Ashby, C. (2014). Hoping for greatness: An analysis of experiences of novice facilitators. *Research and Practice for Persons with Severe Disabilities*, 39(4), 274-289.
- Lee, M., Kang, Y., & **Jung, E.** (2007). Exploration on the intervention strategies based on the personality for students with mental retardation in an inclusive Setting. *Korean Journal of Mental Retardation*, 9, 71~96.
- Jung, E.**, & Kang, Y. (2006). A study of the science teachers' curriculum implementation in a special school for student with mental retardation. *Korean Journal of Special Children Education*, 8, 253-281.
- Hwang, S., **Jung, E.**, & Lee, M. (2006). An attitude toward science teaching between elementary pre-service teacher and special elementary pre-service teacher. *Korean Journal of Special Education*. 13. 111~130.
- Kang, Y., Kim, J., & **Jung, E.** (2006). An explorative study on usability of practical intelligence in discriminating student with mental retardation. *Korean Journal of Mental Retardation*, 8, 79~93.
- Kang, Y., Lee, M., & **Jung, E.** (2006). Exploration of the component factors on images of good elementary teacher based on implicit theories. *Korean Journal of Fisheries and marine science education*. 18, 283~292.

Publications in Preparation:

- Jung, E. (in preparation). Critical Ethnography as a Tool to Analyze the Politics of Roles in Ableist Practices in Korean American Community.
- Jung, E., & Ashby, C. (in preparation) Lexical analysis of essays produced by individuals with autism who type to communicate.
- Jung, E., & Ferri, B. (in preparation) The social construction of vagrants: Media discourse about beggars in South Korea in 1987.
- Jung, E. & Ferri, B. (in preparation) The production and circulation of inappropriate metaphors of disability in Korean newspapers, 1907-1910.

Education Software & Workbook:

- Lee, H., Park, H., & **Jung, E.** (2005). *Context story learning and making software & workbook: My house, my town*. Seoul: Paradise Welfare Foundation.
- Lee, H., Park, H., & **Jung, E.** (2004). *Verb and opposite words learning educational software & workbook for children with developmental disabilities: Riding in the fun train*. Seoul: Paradise Welfare Foundation.

Translation:

- So, T. (2004). *Cynthia's Story: A guide dog for people with physical disabilities* (D. Go, H. Lee, H. Park, & **E. Jung**, Trans.), Seoul: PICD Go, D., Lee, H., Park, H., & Jung, E.

Education Magazine:

- Go, D., Lee, H., Park, H., & **Jung, E.** (Eds). (2004, 2005). *Technology for children with disabilities* (Vol. 3- Vol. 6), Seoul: Paradise Welfare Foundation.

NATIONAL PEER-REVIEWED PRESENTATIONS

- Jung, E.** (Paper Accepted). *The reproduction of ableism at a meeting of young Korean American people with and without disabilities*. Paper accepted for 2018 American Educational Research Association Annual Meeting, New York, NY.
- Jung E.** (2017, April). *Current absence and future potential of Korean methods and methodology in DSE*. Paper presented at the 2017 American Educational Research Association Annual Meeting, San Antonio, TX.
- Jung E.** (2017, June). *The social construction of vagrancy and disability: Newspaper discourse about vagrants in South Korea in 1987*. Paper presented at the 2017 AAS (Association for Asian Studies)-in-Asia Conference, Seoul, Republic of Korea.
- Jung, E.** (2016, June). *The urban lives of Korean American youth with disabilities*, Paper presented at the 2016 Second City Disability Studies in Education Annual Conference/Midwest Summer Institute, Des Moines, IA.
- Jung, E., & Nichiporuk, K.** (2015, April). *Communication as a skill, not a gift: Practice of movement for communication*, Panel presented at the annual meeting of American Educational Research Association, Chicago, IL.
- Jung, E.** (2014, December) *Transition of Korean-American youths with disabilities through the perspective of Disability Studies*, Paper presented at the annual conference of TASH, Washington D.C.

- Jung, E.**, Woodfield, C., & Vroman, K. (2014, December) *iPad for communication: iPad app training for the development of independent typing*, Paper presented at the annual conference of TASH, Washington D.C.
- Ashby, C., **Jung, E.**, Orsati, F., Reutemann, C., & Vroman, K. (2014, April). *The complicated interplay of independence, interdependence, and agency*, Paper presented at the annual meeting of American Educational Research Association, Philadelphia, PA.
- Jung, E.** (2014, March). *Understanding the experience of transition to adulthood through critical Youth + Disability Studies*, Paper presented at the 7th Annual Conference on Equity and Social Justice, Syracuse, NY.
- Jung, E.**, Ashby, C., Reutemann, C., & Vroman, K. (2013, December). *Comparative study on linguistic features of people with autism and their facilitators*. Poster presented at TASH, Chicago, IL.
- Ashby, C., Vroman, K., Reutemann, C., & **Jung, E.** (2013, December). *Making the dance look easy: lessons learned from facilitated communication trainers*. Paper presented at TASH, Chicago, IL.
- Ashby, C., Chadwick, M., **Jung, E.**, Orsati, F., Reutemann, C., & Vroman, K. (2013, December). *The development of independence for individuals with disabilities who type to communicate*. Poster presented at TASH, Chicago, IL.
- Orsati, F., **Jung, E.**, Reutemann, C., & Vroman, K. (2013, June). "A world of difference": *Analyzing the development of independence of individuals with disabilities in typing to communicate*. Panel presented at the Society for Disability Studies 26th Annual Conference, Orlando, FL.
- Jung, E.**, & Reutemann, C. (2012, August). *Narrative analysis on experiences of novice facilitators and FC Users*, Poster presented at the annual conference of the ISAAC, Pittsburgh, PA.
- Jung, E.**, Rosati, F., & Retemann, C. (2012, August). *Research in Facilitated Communication: Shifting from "If" to "How"*, Paper presented at the 14th Annual Autism Summer Institute, Concord, NH.
- Jung, E.** (2010, June). *The production and circulation of inappropriate metaphors using disabilities in Korea from 1905 to 1910*. Paper presented at the annual conference of Society for Disability Studies, Philadelphia, PA.
- Bacon, J., **Jung, E.**, & Miyazaki, Y. (2010, June). *Parents perspectives on their children's education: a critical view on laws and school practices*. Paper presented at the annual conference of Society for Disability Studies, Philadelphia, PA.
- Jung, E.**, Bacon, J., Orsati, F., & Miyazaki, Y. (2009, May). *Parents perspectives on their children's education: a critical view on laws and school practices*. Paper presented at the ninth annual second city conference on Disability Studies in Education, Syracuse, NY.

RESEARCH EXPERIENCE

Syracuse University, Institute on Communication and Inclusion (2011-2015)

Research Assistant

- Funded by NLM Family Foundation and the John. P Hussman Foundation.
- Collect and analyze qualitative and quantitative data involving communication strategies for individuals with low incidence disabilities, particularly autism.

- Conduct lexical analysis study. This involved collecting linguistic data from people with autism, and analyze them using lexical analysis program and statistical tool.
- Assist to provide communication training for people with autism, families, and staffs

Syracuse University, Campaign for Deaf Access, Syracuse University (2010-2011)

- Collect qualitative interview data involving Deaf patients' access to medical service, in particular healthcare providers' experiences with Deaf patients, communication in a medical setting, and awareness on ADA (American Disability Act) law.

Pusan National University, The National Project Brain Korea 21: Taskforce & Comprehensive Supporting System for Lifelong Education (2006)

- Conduct literature review of current research on lifelong supportive system for children with disabilities
- Work to support a partnership between Pusan National University and local special schools, in particular for developing an instruction method for students' preference of cognitive process
- Participate in data collection and analysis, and published articles.

Graduate Courses and Workshop related to methodology

- Courses - Statistical Thinking; Introduction to Qualitative Research, Advanced Seminar: Qualitative Research I; Advanced Seminar: Qualitative Research II
- Workshop - Advanced Statistical Analysis Workshop for Educational Research (2007, Seoul University)

Paradise Institute for Children with Disabilities, Paradise Welfare Foundation, Seoul

- Served as a committee for Paradise Research & Practice Grants
- Coordinate abroad program for college students in disability related fields (in Australia) (2005)
- Plan and coordinate Korea-Japan Able Art forums (2004, 2005)
- Served as an editor for *Technology for Children with Disabilities v.3 ~ 6* (periodical magazine for parents and professionals)
- Coordinate government certifying training programs for special education teachers
- Participate in developing and upgrading educational softwares for children with disabilities (Math software; Listening with Momo; Computerized Language Analysis; & Computerized Reading Inventory for the classroom)

SCHOLARSHIPS, AWARDS, AND GRANTS

- American Educational Research Association DSE SIG Graduate Student Travel Grant, 2017
- School of Education Travel Grant, Syracuse University, 2017, 2014, 2013
- Korean American Medical Practitioners Association of New York Scholarship, 2013
- Center on Human Policy Travel Grant, Syracuse University, 2014
- Graduate Student Organization Travel Grant, Syracuse University, 2013
- Future Professoriate Project, Syracuse University, School of Education, 2010-2012
- Research & Creative Grant Competition, Syracuse University, 2010

- Korean Honor Scholarship, Korean Consulate General in the U.S., 2010
- Brain Korea 21 Scholarship, Institute for Research & Industry Cooperation, Pusan National University, 2006 – 2007
- University Scholarship, Pusan National University, 1999, 2000, 2001

SERVICE TO CAMPUS COMMUNITY

Institute on Communication and Inclusion Staff (2010-2015)

- Support local families of children and adults with autism
- Provide communication training workshops as a team (local workshop twice a year and national conference once a year)
- Organize a social meeting of people with autism who type to communicate (once a month)
- Design and facilitate both on-site and web-conference meeting for communication support staffs (once a month)

Beyond Compliance Coordinating Committee (2009-2012)

- BCCC is a student advocacy organization, comprised of students with and without disabilities committed to raising awareness of disability issues on campus and pushing the university to move beyond compliance with laws.
- Work as a treasurer (2010-2011), applying for grant, implementing budget
- Plan the BCCC conference, *Disability in an Intersectional Lens: A conference of Emerging Scholars in Disability Studies* in 2010

PROFESSIONAL ORGANIZATIONS

- American Educational Research Association (Disability Studies in Education SIG)
- TASH (The Association for Persons with Severe Handicaps)
- Society for Disability Studies
- American Association of Intellectual and Developmental Disabilities (Multi-cultural Concerns SIG)