"Being Grown": How Adolescent Girls with Disabilities Narrate Self-Determination and Transitions

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ABSTRACT

Across the United States young women with disabilities are experiencing economic and educational disadvantages. Although post-school outcomes have shown improvement, young women continue to experience high unemployment rates, low wages, and high rates of poverty. In this study, I explore the experiences of four teenage girls who have been labeled as having learning disabilities and intellectual disabilities. Through in-depth interviews, supported collage making, document review, and the AIR Self-Determination Scale, I examine how they experience girlhood, schooling, and transitions. I consider the ways in which adolescent girls with disabilities negotiate special education, social relationships, and the salient and permeable borders of girlhood and adulthood. I consider how the policies and practices of special education both produce and police gendered narratives of behavior and compliance.

I also examine the liminal space of post-school transitions. I contemplate issues of equity and access to opportunity, while examining the consequences of labeling, segregation, and interlocking systems of oppression such as race, class, and gender on these opportunities. Further, I consider the participants’ diverse understandings of and experiences with self-determination. In the conclusion, I present a framework for a more equitable and culturally responsive approach to transitions and describe the implications of this study for teachers, parents, students, and teacher preparation programs.
“BEING GROWN”: HOW ADOLESCENT GIRLS WITH DISABILITIES NARRATE SELF-DETERMINATION AND TRANSITIONS

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DISSERTATION

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This dissertation was written in response to the young women with disabilities across the country who have left high school to face low-skilled, low-paying jobs and little access to post-secondary education. It is a matter of social justice that educational systems continue to allow these inequities to exist. To the four young women who participated in this study, I cannot thank you enough. Thank you for sharing your experiences with me, thank you allowing me access to the fascinating and complicated world of adolescent girlhood, and thank you for trusting me with your stories of segregation, institutionalization, friendship and sexuality.

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CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

My interest in the experiences of teenage girls with disabilities began after working with a high school student in upstate New York. Hannah is a 17-year-old high school student with whom I have been working with over the past several years. She has dreams of becoming a television chef, is a self-proclaimed foodie, is passionate about civil rights, and is currently researching local colleges and universities. Hannah, who is labeled with an intellectual disability (Down syndrome), began her first foray into person-centered transition planning two years ago, took her first general education mathematics class last year, and for the first time told her parents and teachers that she did not want to take a typing course because typing is boring. She takes classes for credit, problem-solves the intricacies of the Pythagorean theorem, writes scripted drama, and studies for the GED. Hannah, and the thousands of other young women and girls who are in the midst of transitioning out of secondary education while residing somewhere in-between the socially constructed boundaries of adulthood and adolescence/childhood, is the reason I did this dissertation. I’ve been working with Hannah as an educational consultant for two years now and her journey through high school and her transition into the adult world continue to have their ups and downs. Hannah and her family continue to fight for her to be included in more general education classes and fight to receive feedback on her progress with transition-related goals.

My interest in the experiences of teenage girls with disabilities not only stemmed from my educational work with Hannah, but also from my personal “feminist click of awakened consciousness” (p. 7) after reading DeVault’s (1999) book Liberating Method. DeVault named what I had been experiencing during my time with Hannah and throughout my preparation for this dissertation, but that which I was not confident enough to claim: I was slowly becoming a

1 Names have been changed for confidentiality purposes. Participants have chosen their own pseudonyms.
feminist researcher. Like DeValut, I was getting angry at what I was experiencing and what I was learning. I was reading articles by the power-players in the field of special education and books by the writers of what I call “self-determination for those kids,” but was scoffing as I read. Eye roll, after exclamation, after crumpled paper.

During this same time, administrators at Hannah’s school had tried to intimidate me over the phone minutes before a transition-planning meeting: “Hannah can’t be included in math. She doesn’t have the prerequisite skills. And we didn’t hire you to criticize our teachers.” After Hannah did become included in high school math, I read articles by Phil Smith, Pat Rogan, Bernard Cooney, and feminist researchers such as Dorothy Smith (2005), Susan Wendell (1996; 2006), Patricia Clough (1994), and Sharlene Nagy Hesse-Biber (2007). They were all just as angry as me.

While Hannah was not a participant in this study, due to our prior relationship, the moment I walked to my car after my first interview with Britany I knew the decision to explore the narratives of teenage girls with disabilities was the correct one. Britany was a self-described “super-senior” during the time of our interviews. She spoke about her classes with an air of boredom and a hint of sarcasm – “they’re great… my teachers are wonderful.” With an appearance of disinterest, which later faded and revealed a great deal of anger and frustration, she shared a story of girlhood “drama” and teenage bullying:

Well, I went through drama like all of last year pretty much. And it was really hard because there was name calling, leaving you out, and not accepting you, and not responding back to phone calls or texting. And like not being nice. And no one likes that. So, I had to do it all of last year and it was really sad and painful at times, but I knew it was my last year there and I was happy because this year I can start all over with a new
beginning, and no drama, and basically things are going really good right now.

I had set out to do a study about teenage girls with disabilities and how they understood and experienced self-determination and the transition to post-school life. Above, Britany describes a transition of sorts: she lived the experience of bullying during her senior year of high school, graduated, and transitioned through her “last year” of high school. But this was not Britany’s last year. As a teenage girl with a disability label and an Individualized Educational Program (IEP), Britany returned to her suburban high school with less “drama,” but with an emotional pain leaving wrinkles in her teenage narrative. This was not the linear, school-to-“adult” life, transition narrative I had expected.

In the stories that follow four participants share their thoughts on college, discuss what work they want to do when school is finished, and talk about IEP planning, meetings, and goals. But, the narratives are messy. The transitions are not linear and many borders are straddled simultaneously. They experience self-determination and make choices in sometimes subtle and, other times, in radical ways. And all the narratives are wrapped up in a web of class, race, gender, sexuality, and dis/ability. The narratives the participants shared were much more interesting, exciting, heart-breaking, and important than I had initially realized.

In this study, I explore the schooling and transition experiences of four adolescent girls with disabilities in learning, specifically labels of intellectual disability and learning disability. I examine their narratives of adolescent girlhood, while considering the ways in which borders between girlhood and womanhood are both experienced and produced. I explore the ways in which students with disabilities experience schooling, transitions, and self-determination. In addition, I consider how access to opportunity, social and cultural capital, and the culture of special education create inequitable transition experiences for the participants.
In the following sections of this chapter, I review the current literature and present the theoretical framework that grounds this mixed-methods study of the experiences of adolescent girls with disabilities in learning (intellectual and learning disability labels). First, I begin with a feminist disability studies framework that guides my inquiry. Then, I examine the literature on self-determination, including recent studies that examine the effects of self-determination on transition, explore instructional models for self-determination, and investigate barriers to self-determination and successful transitions, such as attitudes and beliefs, remediation, and limited opportunities for engagement in transition planning. In the final section of this chapter, I present recent studies that have explored the experiences of adolescent girls and young women with disabilities in particular, and describe how this study adds to this body of work.

**Theoretical Frameworks**

**Feminism(s)**

Feminist scholars challenge “the right of the powerful to define realities for us all” (DeVault, 1999, p. 1) by resisting authorized knowledge production that ignores the experiences, stories, and perspectives of women. As Lundgren (1995) notes, “since women have been invisible in our history and culture and are still invisible in most areas, it remains a task of the highest priority in feminist scholarship to do research about women” (p. 2). Feminist scholars attempt to render the invisible visible by examining the complex materiality of women’s experiences, which are also discursive and ideological (Clough, 1994), and strive for multiple and variable expressions of reality (DeVault, 1999).

According to DeVault (1996), one key component of feminist methodology lies in the excavation of women’s experiences in order “to find what has been ignored, censored, and
suppressed, and to reveal both the diversity of actual women’s lives and the ideological mechanisms that have made so many of those lives invisible” (p. 32).

Feminist research is concerned with understanding the ways in which “broader social order oppresses different categories of people by race, gender, or class” (Taylor & Bogdan, 1998) and explores subjects of importance to women. Feminist methodologies seek to disrupt representations of women that have historically excluded women’s experiences and concerns from “dominant avenues of knowledge building” (Hesse-Biber, 2007, p. 3), and instead provide a critique of patriarchal knowledge production that “has constructed and sustained women’s oppression” (DeVault, 1999, p. 30).

Feminist researchers are guided by the assumption that language is not the only source of meaning, but that power operates through material practices and struggles, as well as through discourse (Giroux, 1991). Discourse, for instance, may produce the meanings attached to intellectual disability, but young women experience the effects of those ableist meanings in very material ways. In addition, feminist researchers reject the notion of the all-knowing ethnographer and the idea that others can be objectively known (Trinh, 1989). Rather, they seek a more complicated, plural, and oftentimes contradictory representation of the empirical world that is instead “a product of the interaction and negotiation between researcher and researched” (Bettie, 2003, p. 22). Feminist theorists challenge the idea of one truth, and instead embrace multiple, partial, assembled truths (Haraway, 1990).

Feminist methodology is defined by advocating for changes in women’s status, a challenge to epistemological ideologies that sideline the knowledge of women, and calls for social justice. Recognizing “the importance of women’s lived experiences with the goal of unearthing subjugated knowledge” (Hesse-Biber, 2007, p. 3), feminist perspectives challenge the
status quo of knowledge production and subvert authorial knowledge claims made by those in positions of power (i.e., researchers who make claims about the self-determined lives of students with intellectual disabilities without taking the time to actually speak with those students).

**Disability Studies.** Similar to the ways that feminist theory provides researchers with the opportunity to challenge patriarchal conceptualizations of gender, disability studies scholars challenge ableist conceptualizations of the body and provide a discursive and material space for diverse understandings and experiences of disability. Disability studies scholars conceptualize disability as a socially constructed interaction between the material body and the ideological and discursive world in which the body resides. Rather than an individual, naturally occurring experience, oftentimes represented as disease, deviance, or deficiency (Shakespeare, 2006), disability is conceptualized as the result of historically situated and contextual structures that oppress and marginalize such bodies (Davis, 2006). As Wendell (2006) notes, “much of what is disabling… is also a consequence of social arrangements” (p. 247).

Conceptualizing disability through socio-cultural rather than medicalized perspectives provides the opportunity for critiques of “authoritarian professional epistemologies that silence both the perspectives of disabled persons and the development of non-deficit orientations of disability” (Danforth & Gabel, 2006, pp. 5-6). The tenants of social constructivism, many of which serve as a basis for disability studies, highlight the ways in which meanings attached to difference do not inherently reside in bodies (Davis, 2002; Wendell, 1996), but rather are given life through social practices that surround people and the communities in which they participate (Goode, 1994). As such, meaning is in constant flux (Corker, 1998). Corker further elucidates that
culturally embedded discourses construct the dominant experience of disability within a
given culture, time or social context… [which] is reinforced by and interpreted through
social practices and social structure. (p. 221)

Authors such as Bodgan and Taylor (1976) and Danforth (1997), explore social
construction, specifically related to mental retardation or intellectual disabilities. They describe
how the meanings associated with the label mental retardation are contextual, rather than the
result of an innate, naturally deficient condition (Danforth, 1997). In other words, mental
retardation is a “concept which exists in the minds of the ‘judges’ rather than in the minds of the
‘judged’”(Bogdan & Taylor, 1976, p. 47). The consequences of this label are “made real” when
people are denied access to opportunities, are segregated in schools and communities, and
discriminated against.

Contextual understandings of disability provide room for analyzing the aforementioned
medical discourses that create a seemingly natural border (Ferri, 2006) between ability and
disability, and intelligence and mental retardation. Key to deconstructing this border is ableism—
the underlying foundation for dominant constructions of disability. Originally termed
handicapism and defined as “the widespread prejudice and discrimination against people with
disabilities based on their labels” (Taylor, 2006, p. xviii-xix), ableism involves assumptions and
practices of discrimination, exclusion, and unequal treatment toward people with disabilities
(Gabel, 2005; Hehir, 2005; Taylor, 2006). People with disabilities, and more specifically people
with intellectual disabilities, are faced with

- exclusion from competency; exclusion from central location and therefore presence;
- exclusion from opportunity; exclusion from acceptance and valued status; and exclusion
  from power and self-determination. (Kliwer & Biklen, 1995, p. 88)
Such oppressive assumptions and practices are guided by notions of normalcy where it is believed that the body can be perfected through progress and the “elimination of deviance, [in order] to create a dominating, hegemonic vision of what the human body should be” (Davis, 2006, p. 8). Hehir (2005) highlights the many ways that ableism plays out in the real world:

The devaluation of disability 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… (p. 15)

Ableism brings one’s attention to the ways in which the nondisabled experience, body, and position are centered and privileged, whereas people with disabilities become relegated to the margins (Linton, 1998). In addition, institutionalized ableism speaks to the ways in which oppression is more than “a problem of individual attitudes [and] prejudiced people” (Kimmel, 2003, p. 2), but is a social and structural phenomenon.

The social model views disability not an individual experience, but rather a social/interactionist experience. In response to the medical model of disability, where disability is conceptualized as residing in individual, diseased bodies (Shakespeare, 2006), social model conceptions of disability shift the focus to oppressive environments in which disabled bodies live and interact (Corker, 1998; Longmore, 2003). Rather than a problem located in bodies, disability is viewed as “a problem located in the interaction between bodies and the environment in which they are situated” (Garland Thomson, 1997, p. 296).

Because the inherent difficulties people with disabilities face are not relegated solely to the body, the social model does not view the need for the person with the disability to change (Shaprio, 1994). No longer, as the medical model would have it, is it most important or even necessary for the body to be repaired, remediated, cured, or supervised (Davis, 2002). Instead
the focus shifts to advancing social justice (Siebers, 2006), resisting and changing an oppressive socio-cultural environment wrought with stigmatizing labels and stereotypes (Corker, 1998; Charlton, 2006), addressing issues of inaccessibility, and transforming ableist institutions and ideologies (Longmore, 2003). Quoting disability activist Judy Heumann, Shaprio (1994) shows us that

\[
\text{[d]isability only becomes a tragedy… when society fails to provide things we need to lead our lives—job opportunities or barrier-free buildings for example. It is not a tragedy to me that I’m living in a wheelchair. (pp. 19-20)}
\]

When disability discourse provides space for diverse understandings of the experience of disability—inde
dependent, (inter)dependent, autonomous, competent—the professionalization of the medical model shifts as well. Historically, medical and rehabilitation professionals as well as teachers and administrators (Charlton, 2006; Ferguson & Ferguson, 2006) were positioned as the experts on the experience of disability. The social model “[a]ssumes that disabled people are the experts on disability” (Gabel, 2005, p. 9).

Feminist scholars and disability studies scholars have long stressed the importance of centering voices of women and people with disabilities in research, policy, and practice. As Longmore (2003) notes however, the power to determine meanings and define experiences of disability have been placed in the hands of able-bodied professionals. People with disabilities, particularly those labeled with intellectual disabilities, have been positioned as “unqualified to speak for themselves, to interpret their own experience. They have frequently been rendered voiceless” (p. 7). Professionals have laid authorial claim to what it means to be disabled, leaving out the actual voices of people with disabilities. Under the guise of strong objectivity, it is believed that the knowledge of the professional is unobstructed by the social world. But all
knowledge is situated and mediated by the social world. By re-centering these voices, “truth(s)” and authority can be relocated to the disabled, female experience.

Bogdan and Taylor (1976) stress the importance of listening to the stories and experiences of people with intellectual disabilities because, “people who are labeled [as such] have their own understandings about themselves, their situations, and their experiences… [which] are often different from those of the professionals” (p. 51). Disability studies scholars and feminist scholars continue this battle over authorial knowledge, but not without complication. Specifically in the realm of disability, epistemic hierarchies remain with people with intellectual disabilities relegated to the margins of the margins (Couser, 2005). By reimagining the epistemology of young women with intellectual disabilities steps can be made to reconceptualize them as knowers.

**Feminist Disability Studies.** According to Wendell (2006), “feminist theory… offers perspectives and categories of analysis that help to illuminate the personal and social realities of disability, and… would in turn, be enriched by a greater understanding of disability” (p. 243). Wendell stresses the importance of intersectionality when theorizing women’s oppression and the ways in which the social construction of disability embodies issues similar to gender such as the tensions between dominant ideologies of independence and cultures that value interdependence, cultural questions of beauty and the body, issues of solidarity and diversity, and the relegation of the female body and the disabled body to the private world.

By theorizing a feminist disability studies, Wendell argues that greater attention be paid in feminist theory to issues of disabled embodiment and intersections between the social constructions of gender and disability. In addition she argues for increased feminist theorizing of disability due to the large percentage of women with disabilities. Garland-Thomson (2006)
further elucidates on the potential of feminist disability studies: “feminist theory can offer profound insights, methods, and perspectives that would deepen disability studies” (p. 257) through the comparative analysis of the female subject position as well as the disabled subject position.

**DisCrit Theory.** The various frameworks of feminism, disability studies, and feminist disability studies have all been critiqued for the lack of attention these theories pay to race and class. White privilege oftentimes goes without critique in these theoretical frameworks (Anzaldua, 1987; Bell, 2011, Clare, 1999; hooks, 1994; Hong Kingston, 1989; Lorde, 1984). A recent article by Annamma, Connor, and Ferri (2012) provides an alternative and complementary framework for theorizing the intersections of race and disability: Dis/ability critical race studies or DisCrit. It was my intention to explore the ways in which various social locations shape the experiences of high school girls with disabilities. How do disability, race, class, and gender shape the schooling experiences of adolescent girls with disabilities? Do these social locations also shape their understanding of girlhood? And how do disability, race, class, gender, and sexuality intersect to influence the opportunities provided to the participants to live self-determined, post-school lives? Therefore, DisCrit provides the potential for a dual analysis of race and disability at the same time it adds complexity to my theoretical frameworks.

The disproportionality of students of color in special education continues in today’s schools (Artiles & Bal, 2008; Artiles, Harry, Reschly, & Chinn, 2002; Artiles & Trent, 1994; Blanchett, 2006; Ferri & Connor, 2005; Smith & Kozleski, 2005). African American students are at particular risk for being labeled with intellectual disabilities or emotional/behavioral disabilities when compared to their White peers. These disability labels also lead to the greatest amount of segregation in schools (Artiles et al., 2002; Ferri & Connor, 2005). According to the
OSERS (2008), 48% of students with intellectual disability labels and 27% of students with emotional disturbance labels spend more than 40% of their school day outside of the general education classroom, compared to only 12% of students with specific learning disabilities.

According to Annamma et al. (2012),

Given the racial gap in graduation, incidents of discipline, and incarceration rates, along with vast over-representation of students of color in special education and the lackluster achievement rates within many of these special education programs, we must critically examine why so many students labeled with a dis/ability, particularly students of color, are either experiencing failure or being perceived as failing and on what grounds. (p. 6)

Annamma et al. (2012), indicate that, “it would be nothing short of irresponsible to leave race out of dis/ability related research in special education” (p. 4), given these highly problematic features of schooling. DisCrit offers a theoretical framework for analyzing both race and disability as socially constructed, interdependent phenomena. The emerging theory also resists add-on approaches to understanding various social locations, but rather, embraces intersectionality. DisCrit provides a framework for understanding how racism and ableism operate through policies, discourses and structures of education. Because social and cultural capital contribute to successful transitions (i.e., linkages to adult services), opportunities for self-determination (Trainor, 2008), and experiences of schooling, it is imperative for researchers studying the transition from school to post-school life to pay attention to the various social locations experienced by students with disabilities.

Federal legislation has also been enacted in order to promote successful post-school transitions for students with disabilities. The Individuals with Disabilities Education
Improvement Act (IDEIA; 2004) federally mandates the presence and implementation of secondary to post-secondary transition services for students with disabilities.

**Transition Legislation and Outcomes**

Specific legislation regarding transition services was first recognized in the 1990 reauthorization of the IDEA (now renamed the IDEIA). According to Lehmann, Bassett, and Sands (1999) the addition of transition-related services to the IDEA stemmed from “disappointing postschool outcomes for students with disabilities” (p. 160) and was devised to ameliorate these outcomes in order to improve the quality of life for young adults with disabilities.

The vehicle for the transition from school to life after school is the Individualized Education Plan (IEP). Educational goals and services are designed to support students and families as they navigate the oftentimes uncertain transition from school to life after school. Beginning around age 14, a student’s IEP must contain a statement of transition. Between the ages of 15 and 16, the IEP must reflect a process of educational programs, goals, supports, and services (Kohler & Field, 2003; Lehmann, Bassett, & Sands, 1999) designed to support students during the transition from secondary education to the various services that provide support to young adults with disabilities (Mallory, 1995) including but not limited to: post-secondary education, independent living, and employment. It is important to note that a great of the focus of transitions planning continues to center around vocational training and independent living, rather than post-secondary education (Causton-Theoharis, Ashby, & DeClouette, 2009). In addition, many transition plans fail to even mention postsecondary education (Mallory, 1995).

In addition, transition team members are expected to identify strategies for supporting students in accessing their rights to self-determination and community participation (Savage,
Transition teams are to ensure that the student’s education is reflective of his or her post-school hopes and ambitions (Kohler & Field, 2003).

In light of the complex sociopolitical environments in which transitions occur, authors such as Kohler and Field (2003) stress the importance of viewing “transition planning not as an add-on activity… but rather as a fundamental basis of education that guides the development of all educational programs” (p. 176). In order to turn the vision of successful transition into an actualization of a student’s dreams for the future and to recognize the complicated nature of transitions, various authors (Kim & Turnbull, 2004; Richard, 2004; Savage, 2005; Shogren, et al., 2007; Smith, English, & Vasek, 2002; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000) highlight the value of student-centered transitions, student involvement (specifically required in the IDEIA), and transition planning teams that focus on student strengths, abilities, interests, preferences, wants and needs. Unfortunately, given the statistics regarding post-school outcomes, transition planning oftentimes falls short and student-driven processes are rarely realized.

Rather than focusing on individual preferences and needs as the guiding force behind decision making, students with intellectual disabilities are oftentimes placed within a limited set of available educational and adult services (Kim & Turnbull, 2004). Young adults with intellectual disabilities are often placed within educational and adult services that are not the best fit in terms of their interests and needs. They also do not experience “high levels of quality full-time employment, independent living, success in postsecondary education, or community engagement” (Kohler & Field, 2003, p. 174). This said, many authors (Morgan & Morgan, 2006; Richard, 2004; Shogren, et al., 2007; Smith, English, & Vasek, 2002; Wehmeyer et al., 2000) have examined the effects of self-determination policy and practice, student and family involvement, and student-centered transitions planning as means to improve such outcomes and
to re-center student needs and preferences throughout the transition from school to life. One component of a student-centered transition is self-determination.

**Self-Determination**

In order to research experiences and understandings of self-determination, it is useful to begin with how the concept is understood in the current literature. Wehmeyer (2005) defines self-determination as “a characteristic of a person that refers to volitional actions that enable people to be causal agents in their lives” (p. 115). A closer look at this definition, demonstrates a reliance on skill-sets in defining self-determination. To be considered a self-determined person one must be able to set goals, make choices, problem-solve, develop safety skills, self-instruction skills, and self-awareness. Oftentimes there is a heavy reliance on psychological terms and individual behaviors when describing self-determination (Cowley & Bacon, 2011). This focus on individual skill sets and behaviors leave little room for understanding how access to opportunity also shapes experiences with self-determination (Shogren & Broussard, 2011).

Authors such as Ward (2005) describe self-determination in terms of better controlling one’s life and destiny, stressing the importance of dignity in risk, and highlighting opportunities to make choices and solve problems. Other authors such as Mithaug, Mithaug, Agran, Martin, and Wehmeyer (2003) theorize the learning of self-determination, positing that it is dependent on both capacity and opportunity. Shogren, et al. (2008) explains these two components as follows:

Capacity refers to the knowledge, abilities, and perceptions that enable students to become self-determined; opportunity refers to the chances provided to students to apply their knowledge and abilities related to self-determination. (Shogren et al., 2008, p. 96)

Some researchers (Cowley & Bacon, 2011; Smith & Routel, 2010) stress the importance of diverse understandings of self-determination and argue for more political meanings of the
concept. The concept of self-determination was initially intended as a radical human right of people with intellectual disabilities to “gain an adequate voice and representation in society” (Nirje, 1972, p. 177). No matter the understanding, self-determination has become a hotly researched topic in the field of special education and guides policies such as the IDEIA (2004). As Mallory (1995) notes, “an important goal of transition to adulthood would be the ability to have full control over one’s own life to enjoy opportunities to be directly involved and have final say in such matters” (p. 219).

Outcomes. Several authors (Agran, Blanchard, & Wehmeyer, 2000; Sinclair, Christenson, & Thurlow, 2005; Wehmeyer & Palmer, 2003; Wehmeyer et al., 2000) have demonstrated the positive effects of self-determination on secondary and post-secondary outcomes. Such outcomes include the attainment of “educationally valuable” outcomes (Wehmeyer et al., 2000, p. 445) such as social and behavioral skills, increased levels of engagement, lower dropout rates, and consistent attendance (Sinclair et al., 2005). Other outcomes include academic-specific achievements such as following directions, and fluency and accuracy of responses (Agran et al., 2000; Wehmeyer et al., 2000).

Positive post-secondary outcomes of students with high levels of self-determination include increased financial independence, increased independent living skills, and improved access to employment benefits (Wehmeyer & Palmer, 2003). Citing Wehmeyer, Kohler and Field (2003) emphasize the importance of self-determination on the achievement of educational goals, employment rates, and higher wages—students who demonstrate higher self-determination in high school and who participate in their educational programming are more likely to meet these outcomes. In order to realize a successful post-school transition, students should be encouraged to develop their self-advocacy skills (Kohler & Field, 2003) and should be
provided with opportunities to apply such skills. Models for achieving such have been developed by various professionals.

**Instructional Models and Measurement.** Field, Hoffman, and Posch (1997) identify the following themes common to self-determinate transition models: choice, control, and freedom. In addition, students must have a foundation of self-esteem and self-awareness. Not only must this foundation be present, but students must also have “the ability to act on this foundation to be self-determined” (p. 286). Although little research has critically examined this ability to act—or in other words, the opportunities to demonstrate self-determination—several authors (Agran et al., 2000; Richard, 2004; Sinclair et al., 2005; Wehmeyer et al., 2000) have examined the efficacy of self-determinate models of instruction for increasing self-determination and improving such secondary and post-secondary outcomes.

Various pre-packaged, empirically validated models of instruction and methods for teaching self-determination—Self-Determined Model of Learning/Instruction (Agran et al., 2000; Wehmeyer et al., 2000), KNOW NO BOUNDS (Richard, 2004), The Self-Advocacy Strategy (Test & Neale, 2004), and the Check and Connect Model (Sinclair et al., 2005)—currently exist for use in schools. The purpose of many of these models of instruction is to promote self-determination in students with intellectual disabilities and to provide them with opportunities to develop skills such as self-awareness, self-advocacy, and goal setting (Test & Neal, 2004).

Through the Self-Determined Model of Learning/Instruction teaching methods are modified placing the student at the center of learning. Positive outcomes of this model of instruction include increased self-determination, improved goal orientation, increased goal achievement, and increased satisfaction with instruction (Agran et al., 2000; Wehmeyer et al.,
Similar transition models such as KNOW NO BOUNDS and Check and Connect, also focus on improving self-advocacy and stress the importance of student-centered learning. The Check and Connect Model has resulted in increased student engagement in school, lower dropout rates, and increased school attendance (Sinclair et al., 2005).

Using the Self-Advocacy Strategy, Test and Neale (2004) specifically examined ways to increase student participation at IEP meetings, positing active participation as a key indicator of self-determination. Using the Arc’s Self-Determination Scale, the authors measured levels of self-determination and quality of verbal contributions prior to and following the seven-stage, fourteen-week Self-Advocacy Strategy. The Self-Advocacy Strategy is specifically designed to “prepare students to participate in education or transition planning conferences” (p. 140) and centers around students developing the necessary skills in order to (a) recognize and voice their strengths, interests, needs, and goals, (b) listen and respond to the input of others, (c) ask questions, and (e) communicate transition-related goals and specific actions necessary in order to achieve those goals. All four students involved in the study significantly improved the quality of their verbal contributions, but significant gains were not made in overall self-determination as measured by the Arc Self-Determination Scale. This was mainly due in part to the small sample size (n = 4).

Although learning skills that will help you to speak up at IEP meetings and become a self-advocate are clearly valuable, they are only part of the equation. Many instructional models of self-determination tend to position teachers as scientific technicians and users of professional interventions, who are charged with remediating and correcting deficits and faults related to self-determination. The foundations of such instructional models make little to no mention of the ways in which oppressive structures and ableist assumptions fit into the aforementioned
components of self-determined behavior. In addition, advocating at IEP meetings may not be a student’s main goal. Students may want to advocate with their parents or advocate for access to social contexts or opportunities. Similar to other areas of traditional special education, research and practice in the area of self-determination has charged itself with fixing students with disabilities.

**Barriers to Self-Determination**

Instructional methods on self-determination have shown positive results for students with intellectual disabilities, such as increased participation in transition planning and increased goal achievement (Agran et al., 2000; Wehmeyer et al., 2000; Ward, 2005). However, environmental barriers continue to exist for students transitioning from school to post-school life. These barriers include such lack of parent, student, or adult agency involvement, transition plans not focused on student preference, interest, or need, lack of accommodations, lack of available options, and opportunities requiring cultural and social capital (Kinnison, Fuson, & Cates, 2005; Mellard & Lancaster, 2003; Morgan & Morgan, 2006; Shogren et al., 2007; Smith et al., 2002; Trainor, 2008). In addition, Smith and Routel (2010) cite the lack of collaboration between families and schools, transition goals incongruent with student wants and needs, professionals positioned as experts, and limited understandings of self-determination all as contributing factors to poor post-school outcomes.

**Attitudes and beliefs.** A major roadblock to the realization of a self-determined life lies with the attitudes and beliefs of those who work with students with disabilities. Ward (2005) notes that, “far too many teachers who work with students with severe disabilities believe that the skills and knowledge related to enhanced self-determination… are too complex for their students to learn” (p. 109). Ward’s assertion is supported by research (Wehmeyer, 2005).
showing that teachers working with students with severe disabilities do not believe self-determination skills to be important or achievable for such students. Such attitudes are not indicative of supporting one’s opportunity to exercise self-determination. Citing Bremer, Kachgal and Scholler (2003), Rossetti, Ashby, Arndt, Chadwick, and Kasahara (2008) note that students who have self-determination skills—even strong ones—can be thwarted in their efforts toward self-determination by people who present barriers or do not provide needed supports. (p. 366)

These ableist attitudes and beliefs can contribute to a culture of special education where professionals and adults are placed in positions of power and students with disabilities remain at the margins. Oppression and exclusion occur when students with disabilities have self-determination skills and are not invited to their transition planning meetings. The future dreams of students with disabilities become directed by adults and students are silenced.

**Colonized skill building.** Although learning the skills necessary in order to advocate for one’s education and transition services and goal is clearly important, Smith and Routel (2010) pointedly note the colonial ideologies that ground the notion of teaching self-determination to others. Self-determination is frequently described something to be acquired through a step-by-step process in which an individual exhibits certain degrees of self-determination (choice, control and freedom), or is provided with tools to become more self-determined (Agran et al., 2000; Wehmeyer et al., 2000). Oftentimes, self-determination in schools is driven by prepackaged curricula where teachers are encouraged to “concentrate their efforts on specific tasks for students, such as teaching about career interests and job-seeking skills” (Lehmann, Bassett, & Sands, 1999, p. 167) rather than changing teaching beliefs and philosophies.
When self-determination is conceptualized as a skill to be taught, rather than a right (Smith & Routel, 2010), there is often little to no mention of how dominant ideologies, unjust educational practices, and lack of societal support and response (Thoma, Rogan, & Baker, 2001) influence whether or not a person can act with volition or be a causal agent. As Trainor (2007) notes, “little research has examined what effect, if any, sociocultural interactions have on self-determination practices of young adults with disabilities” (p. 32). By framing self-determination as a skill to be taught, it is also implied that there is an agreed upon way to be self-determined, that is believed to be a-contextual, ahistorical, and a-cultural.

**A-contextual understandings.** According to Wehmeyer (2005), “self-determined people are causal agents in their lives. They act ‘with authority’ to make or cause something to happen in their lives” (p. 117). At first glance, this conceptualization of self-determination appears empowering, but throughout his 2005 piece titled “Self-Determination and Individuals with Disabilities: Re-examining Meanings and Misinterpretations,” Wehmeyer fails to contextualize self-determination and locates self-determination within the bodies of people with disabilities as a “dispositional characteristic of individuals” (Shogren et al., 2008, p. 95). Such definitions of self-determination do not lend themselves to the interdependent nature of life and situate the “self” as uninfluenced and separate from “others.”

By situating self-determination and causal agency within the self, and only discussing ways to teach self-determination, we tend to gloss over or entirely miss the contextual, socially constructed, and culturally situated world in which students with disabilities reside. Authors such as Shogren et al. (2007) have begun examining ecological predictors of self-determination and note the importance of opportunity as well as supports and accommodations when defining self-determination. This said, “capacity, as influenced by learning and development” (p. 489) remains
foremost in this definition and intelligence continues to be reified as a predictor of self-determination.

When self-determination is conceptualized without context, there is also little to no mention of how dominant ideologies, environmental barriers, unjust educational practices, and ableist assumptions influence whether or not a person can act with volition or be a causal agent. When authors fail to theorize self-determination in a socio-cultural context, deficit-driven discourses begin to emerge. The current literature appears at worst, to refer to causal agency as neutral, without context or culture, and not located within history or time and at best, inexplicitly names the environment as a factor without much analytical detail (Trainor, 2007).

The effectiveness of instructional programs for improving self-determination skills and the resultant measurement of such skills have overwhelming taken up space in the research field, leaving little room for research that begins with a presumption of self-determination and focuses the problem of self-determination on lack of opportunity or ableist assumptions and practices of others. The research field must expand beyond providing skill instruction to an examination of the sociocultural barriers that exist to providing “opportunities to practice choice and decision making” (Ward, 2005, p. 110).

Recent qualitative research by Shogren and Broussard (2011) attempts to address not only gaps left by the skill-based research agendas pervasive throughout the self-determination literature, but remains one of the few studies to date to explore the perspectives held by actual people with intellectual disabilities. Through their interviews with 17 adults with intellectual disabilities, the authors found that the participants held very diverse understandings of self-determination ranging from making simple choices such as what movie to see on the weekend, to major life decisions involving living arrangements and dreams for the future. Themes emerged
regarding self-advocacy skills and learning about self-determination, in addition to attitudinal, environmental barriers, and lack of opportunities to express self-determination.

**Student Involvement in Transition Planning**

Paramount to addressing the aforementioned barriers to self-determination and transitions for students with disabilities is the involvement of students in the transition planning process. Although the IDEIA (2006) emphasizes the importance of involving students and families in the decisions surrounding their education, “many parents have voiced concerns that they are not full participants in the IEP and transition planning process” (Salembier & Furney, 1998, p. 62). Even more striking is the lack of involvement by actual students with disabilities. Transition plans can even serve as a barrier (i.e., matching students to available programs that inhibited access to adult status) to goals of young adults when their voices and input are neither included nor valued (Cooney, 2002). Even though students and family members are required to attend transition-planning meetings, Morningstar, Turnbull and Turnbull (1995) found that few students actually attend their IEP meetings and “are not actively engaged or involved in making decisions regarding the goals and objectives, including those involving life after high school” (p. 258). When students are not asked or encouraged to participate in their transition from school to life after, the opinions more typically heard are those of parents and professionals.

More often than not, students play a peripheral role (Cooney, 2002; Trainor, 2005) in their transition planning and are greatly uninvolved in the process. When students with disabilities are left out of their transition process or are positioned as “passive recipients of transition-related information” and “engaged only peripherally in transition-related activities” (Lehmann, Bassett, & Sands, 1999), the right to self-determination cannot occur. Research has shown that students are more likely to meet their educational goals when there are involved in
the goal setting process (Kohler & Field, 2003). But, when that student’s voice is missing the process is not student-centered, is often one-sided, and leaves little to no room for an expression of self-determination.

In their qualitative study of eight students with developmental disabilities, Thoma, Rogan, and Baker (2001) explored transition planning for these students by focusing on their level of involvement in the transition process. The authors found that adults, parents and educators, were the driving force behind transition planning from start to finish, rather than students with disabilities. Although questionnaires were often used to help students describe their goals and to assess their interests related to education, community activities, and employment, oftentimes the teachers had a great deal of influence over this process and led students to desired outcomes. Only one student was involved in person centered planning as a means to assess goals and to support choice making. In addition, the “process of job exploration continued to demonstrate teacher and/or adult control” (p. 22), where students explored employment choices through adult-driven surveys rather than through experiences.

In regard to actual transition planning meetings, many students were not prepared for these meetings, which were very formal in nature and oftentimes uncomfortable for families and students. Rather than enabling “students to prepare for their desired adult lifestyles” (Thoma, Rogan, & Baker, 2001, p. 22), transition meetings were led by adult transition team members (often times professionals from the school) and many times students were not consulted regarding the structure, members, and agenda for their meetings. At times students were not even physically present at their meetings and when students were present, progress was discussed as if they were not there, with “professionals spend[ing] much of their time talking with parents and not with students” (pp. 23-24). The lack of participation by students with disabilities can be seen
as a direct consequence of the IDEA not distinguishing between parent and student participation, but rather establishing a surrogate decision-making process.

**Person-Centered Planning.** One way to re-center the student during his or her transition from school to life is through student-centered transition planning, informed by the tenants of person-centered planning. According to O’Brien and O’Brien (2002), person-centered planning can invite, align, and direct shared efforts to create positive community roles for people with disabilities. It allows people to exercise their practical wisdom to work for more inclusive more just communities. (p. x)

Student-centered planning provides students with disabilities with a circle of supports that “recognizes their individual strengths, interests, fears, and dreams and allows them to take charge of their future” (PACER Center, 2004, p. 1). Student-centered planning is more than teaching students to take control of the choices regarding their lives, but is about allowing students to take control—it is about professionals and parents stepping aside and positioning students as change agents. This said, person-centered planning is not common practice in transition planning (PACER Center, 2004) and oftentimes such planning falls short by focusing on parent and professional involvement rather than supporting student involvement (Cooney, 2002).

Thoma, Rogan, and Baker (2001) suggest that students should be in control of transition planning rather than educational professionals. Students should be positioned as having a larger role in their meetings and can be encouraged to make important decisions regarding their meeting such as who to invite, where and when to hold the meeting, and what the agenda should entail. Transition planning must be a shared responsibility where students are viewed as partners in their education.
Kim and Turnbull (2004) describe the phenomenon of shared responsibility as Person-Family Interdependent Planning by drawing off tenants of both family-centered planning (often used during early childhood education) and person-centered planning (often used during adulthood). By having student-directed meetings, students can learn how to best problem-solve, make decisions, advocate for themselves, and to “determine the supports they need by being an active participant” (Thoma, Rogan, & Baker, 2001, p. 27). Students must be encouraged to actively participate in their transition planning meetings and their circle of supports must make efforts to provide them with creative ways of expressing their dreams (PACER Center, 2004). Student-centered planning is not something that can happen overnight, but when the student’s circle of supports place greater emphasis on the student’s dreams for the future, rather than their own for that particular student (Held, Thoma & Thomas, 2004) remarkable changes can occur.

**Qualitative Research and Transitions**

Although many researchers stress the importance of student-centered approaches to transition planning (Morgan & Morgan, 2006; Richard, 2004; Shogren et al., 2007; Smith et al., 2002; Wehmeyer et al., 2000), few actually examine student perspectives and experiences during transition through qualitative methodologies (Cooney, 2002; Trainor, 2005; 2007). As Morningstar, Turnbull, and Turnbull (1995) note, centering student voice in the transition from school to life “has typically not been part of the professional literature” (p. 258).

When these stories are told, interesting discrepancies emerge. Studies by Trainor (2005; 2007) have uncovered mismatches between students’ IEP goals and self-reported plans for the future, a lack of student involvement, an overreliance on family during the transition process, and perception of the individual as a service recipient rather than a causal agent. In addition to
mismatches between IEP goals and self-reported plans for the future, Trainor (2005) found that students relied more heavily on their family than schools during the transition from school to life. Other researchers have found discrepancies between student and parent perspectives, and educator and professional perspectives (Cooney, 2002; Morningstar, Turnbull, & Turnbull, 1995). Students and parents had very positive expectations for the future (Morningstar, Turnbull, & Turnbull, 1995). Students were excited about what the future held for them and discussed the importance of finding “honest work, the freedom to spend time with friends and family, and personal living space” (Cooney, 2002, p. 432), while parents “emphasized their child’s strengths and capabilities and pointed out that his or her personality traits and accomplishments were indicative of a promising adulthood” (Cooney, 2002, p. 429). Home environments tended to facilitate self-determination in students with disabilities and family members supported students in making decisions regarding a vision for the future (Morningstar, Turnbull, & Turnbull, 1995).

In stark contrast, teachers and professionals made planning and placement decisions “within a context of the effect of the person’s disability. Once a context was established, they prescribed programs with practical interventions designed to improve the deficit” (Cooney, 2002, p. 431). Educators and professionals viewed students in terms of their disabilities and attempted to fix such deficits through interventions. Although teachers discussed students in terms of both strengths and weaknesses, oftentimes there was a greater emphasis placed on weakness.

New Conceptualizations of Self-Determination and Transitions

Current definitions of self-determination strongly reflect the cultural ideologies of independence and individualism (Harry, Rueda, & Kalyanpur, 1999; Smith & Routel, 2010; Trainor, 2005). According to Ward (2005) “it is difficult to be independent… when they [people with severe disabilities] depend on their parents and other care providers to attend to their
physical needs” (p. 111). Yet, as Harry, Rueda, and Kalyanpur (1999) pointedly note, “the principles of individualism/self-reliance” (p. 125) are imbedded in the research literature and practice of services for people with disabilities. As previously mentioned, research has shown that teachers do not always believe it important for students with severe disabilities to learn self-determination and/or that they don’t have the ability to learn such skills (Wehmeyer, 2005). Because the foundation of these beliefs may indeed lie within Western notions independence, then perhaps the construct of self-determination needs to be broadened to more accurately reflect the interdependent nature of all lives (disabled or not).

The interdependent nature of life is not only reflected in theoretical research on transition and self-determination, but in empirical studies as well. Cooney (2002) has shown that young adults with intellectual disabilities oftentimes discuss the importance of living close to their families or going to them for help and support. Their discourse was one of interdependence and “[g]enerally, young adults acknowledged the importance of needing help from parents and friends as sources of both emotional and physical support” (p. 429). Accordingly, teachers must broaden their view of what student involvement and participation entails (Lehmann, Bassett, & Sands, 1999) in order to make space for diverse frameworks and expressions of self-determination (Harry, Rueda, & Kalyanpur, 1999).

Kim and Turnbull’s (2004) Person-Family Interdependent Planning stresses the importance of balancing student-centered planning with input and supports from family members. The work of these authors highlights the collaborative possibilities of self-determination when the concept itself is expanded to reflect ideas of independence that are inclusive of interdependent supports. Kim and Turnbull note that in order to “actualize self-determination, young adults with disabilities can engage in self-determination with appropriate
on-going supports from those who know them well” (p. 55). When ideologies of individualism drive understandings and practices of self-determination, little room is left for definitions of self-determination that highlight the “importance of interdependence, reciprocity, and inclusion” (Smith & Routel, 2010).

Critiques of transitions and self-determination currently exist that outline the ways in which dominant, Western culture situates people with disabilities as individuals who need to be fixed and are in need of services in order to live meaningful lives (Smith & Routel, 2010) or forces people with disabilities to ascribe to “mainstream indicators of quality of life” (Harry, Rueda, & Kalyanpur, 1999, p. 125). Smith and Routel (2010) recommend human service and education fields begin reconceptualizing self-determination as a concept that is relative to the individual experiences of each person and his or her family, rather than definitions which may exclude certain demonstrations of agency, competency, and advocacy. By understanding the various meanings individual families make of self-determination, teachers and transitions support staff will be less likely to impose “predetermined or stereotypic beliefs about what is culturally normative or valued” (Harry, Rueda, & Kalyanpur, 1999, p. 127).

**Schooling and Adolescent Girls with Disabilities**

There continues to be a paucity of research regarding the experiences of adolescent girls with disabilities, particularly girls with learning disability or intellectual disability labels. Over the past 20 years, when researchers have addressed issues related to adolescent girls with disabilities, the focus has been deficit-driven and oftentimes centers on problematic behaviors and aggression. This body of research is not particularly useful for this study. However, by juxtaposing the intent of this study against the backdrop of (a) the low number of research studies in general and (b) deficit-driven basis of the available research, I demonstrate the
significance of this study. I also describe the few studies focusing on the experiences of 
adolescent girls with disabilities. These studies examine girlhood, self-determination, and 
transitions through the perspectives of the participants themselves.

**Problematic Behavior and Aggression**

In 1989 Ritter used the Child Behavior Checklist to estimate social competence and 
problem behavior in 51 adolescent girls with learning disabilities. When compared to a control 
group of adolescent girls without disabilities, the participants’ scores were significantly higher in 
areas of anxiety, somatic complaints, depression/withdrawal, hyperactivity/immaturity, 
delinquent, aggressive, and cruel behavior. According to Ritter, the poorer scores of social 
competence and greater behavior problems may be linked to the participants’ fears, anxieties, 
self-esteem, and self-confidence. Talbott, Celinska, Simpson, and Coe (2002) also examined 
problematic behaviors of adolescent girls, but focused their study on the experiences of 30 young 
women of color, from low-income, urban backgrounds who were identified as at risk for 
developing emotional and behavioral problems (13% of the participants had identified 
disabilities).

The participants engaged in one 30-minute interview with the first-author and data was 
also collected using the Conners’ Teacher-Rating Scale. This particular scale assessed items such 
as oppositional behavior, cognitive problems, hyperactivity, anxiousness, perfectionism, and 
social problems. Approximately one-third to one-half of the participants demonstrated scores of 
clinical significance for each of these areas except perfectionism. The authors found that three 
salient fights had been described by the majority of the participants. Episode one was a physical 
fight between girls, episode two involved gossip leading to a physical fight, and episode three
involved gossip and physical threats. All three events were ended by adults at the school and resulted in school suspensions.

As special educators experience greater interaction with general education students without identified disabilities, yet demonstrate at risk behaviors, they play a greater role in violence prevention. According to Talbott, Celinska, Simpson, and Coe (2002), attention and awareness would ideally occur as part of broadened preparation of special education teachers regarding the psychosocial, developmental, and cultural factors that contribute to students’ aggressive and violent behavior in school… This study, and other studies like it, offer clues as to what violence prevention programs must contain; namely, means of identifying precursors to violent episodes. (p. 215)

One qualitative study of the experiences of adolescent girls with emotional/behavioral disability labels provides an alternative to stories of social incompetency and problem behaviors. Jones (2007) reconfigures these “problems” as act of agency and self-determination in the face of oppressive systems and structures. Jones claims to ground her work in disability studies and critical feminist frameworks, noting the disparate gap of research and voices of people with disabilities. She emphasizes the array of knowledge one can learn regarding oppression from the framework of ableism (prejudice and discrimination based on dis/ability). Jones also notes the reliance of contemporary narrative methodologies on verbal/linguistic abilities of participants. Expressive communication differences can serve as a barrier for some students with disabilities to engage with researchers in traditional ways and has “resulted in the voice of people with disabilities remaining unheard, leaving a crevasse so deep in the literature that our understanding about how power and culture influence our lives is incomplete” (p. 33).
The young women Jones (2007) worked with had been labeled with ED/BD (Emotional Disturbance/Behavioral Disorder) and were receiving their education in a segregated school program. Adolescent girls and young women represent a minority within this disability label. Jones sought out to answer the following research questions: (a) how the young women reacted to the culture of the ED classroom, “given their gender minority status and their personal experiences with trauma” (p. 34) and, (b) how the identities of the young women were produced and shaped by their responses to their schooling. Jones notes that she did not simply approach these research questions in an interpretive manner, but also through a critical call for social justice by hoping “these students would be able to recognize how their actions of resistance and accommodation against these power forces [subjugation through segregated schooling and stigma] actually contributed to their further disempowerment” (p. 34). Jones is cognizant of the ways in which resistance is not appreciated in today’s schools and how demonstrations of self-determination must meet middle class, school values in order to be recognized as such.

Jones chose to develop a supportive autobiographical ethnography, where her role as researcher was to help the young women generate their own autobiographies. Using field notes, interviews, and student-written journals, Jones chose to share the stories that were developing, rather than checking with the young women on the accuracy of what she was observing and hearing. Jones became concerned with the accuracy of her representation of their story and if the narrative accurately reflected their perceptions. The ethnography became a co-authored, symbiotic relationship in which the reader is presented with two lenses to one story.

Jones (2007) drew on auto-ethnography as her research method. Readers are able to learn the stories of each participant, but also become aware of “a multitude of power issues in both the school culture and society in general” (p. 35). One young woman’s autobiography is riddled with
horrific experiences with abuse, rape, and self-injurious behavior set against the backdrop of school demands that are quite irrelevant to her life, given the personal atrocities she is faced with every day. A second participant’s narrative reflects a school culture that is uninterested in the concerns of young women. Curriculum demands are placed so low that it is obvious to this young woman that the school views her and other adolescents labeled similarly. One participant’s narrative also poignantly demonstrates her agency and “her need for control as she continually attempts to usurp her teacher’s power claims, adamantly refusing to do some of the work assigned” (p. 36).

Through this ethnographic method, these attempts at agency are not viewed as misbehavior or noncompliance (which has been seen in studies that address similar issues in non-emancipatory ways), but as a struggle to live a self-determined life in the face of oppression. This study stands in stark contrast to previous research regarding adolescent girls with disabilities. To purpose is not to describe the perceived deficits of the participants, or to police adolescent girls with disabilities, or to measure the emotional adjustment of students with learning disabilities. Quite the opposite was true. Jones’ (2007) study centers the voices and lived experiences of adolescent girls with disabilities, while providing an analysis of oppression, segregation, and the culture of special education.

Ferri and Connor (2010) also center the voices and experiences of adolescent girls with disabilities in their analysis of five autobiographical portraits of young women who received special education services. The authors interrogate the participants’ multiple subject positions as working-class women of color, labeled disabled, and examine how the participants resist these constraints.
The “unofficial marking” (Ferri & Connor, p. 108, 2010) of special education spaces (classroom, accessible busses, schedule and report cards, etc.) in schools led to stigma associated with disability. Participants resisted this stigma by avoiding intrusions and avoiding verbal confirmation of a disability label. In addition, the authors found that many times the participants were the only girl in a special education class, and that being a girl with a disability label left them undesirable in the eyes of boys. Ferri and Connor found that the young women experienced “a pervasive fear of being negatively perceived because of one’s social identity. Negotiating tow, maybe three, social identities that have been associated with negative stereotypes, it is no wonder many of the participants sought to manage this threat” (p. 110).

Ferri and Connor (2010) also found that the participants often defined themselves according to traditional gender roles and described strengths in areas such as writing, drawing, dealing with other people’s problems, cooking, being on time, and being a good listener. Many of the participants resisted the ableist assumption regarding women with disabilities and parenting and opening discussed their worries about being a parent with a learning disability. These, among other stories shared by the young women in this study, offered important insights into intersectionality and special education, and through their research Ferri and Connor (2010) brought forth narratives that are currently underrepresented in the area of girlhood studies and neglected in educational research.

**Self-Determination and Girlhood**

Through an extensive search of the current literature, I was able to find several articles examining post-school employment and career outcomes for women with disabilities (Boeltzig, Timmons, & Butterworth, 2009; Doren & Benz, 1998; Doren & Benz, 2001; Lindstrom, Benz, & Doren, 2004; Noonan, Gallor, Hensler-McGinnis, Fassinger, Wang, & Goodman, 2004). Studies
regarding the experiences of adolescent girls with disabilities were more difficult to find. Although there continues to be a gap in the current literature regarding the experiences of adolescent girls with disabilities, qualitative studies do exist that have attempted to center these narratives. These include Trainor’s (2007) examination of self-determination and diverse adolescent girls with learning disabilities, Peterson’s (2009) case-study of the self-determination of a young woman multiple disabilities, Hogansen, Powers, Geenen, and Gil-Kashiwabara (2008) exploration of the transition goals and experiences of young women with disabilities, and Erevelles and Mutua’s (2005) analysis of girlhood from the standpoint of a young woman with Down syndrome.

The purpose of Trainor’s (2007) qualitative study into the experiences of young women of color identified as learning disabled was to examine their “perceptions of self-determination, as well as their postsecondary transition preferences, strengths, and needs” (p. 33). Trainor conducted focus-group interviews and individual follow-up interviews with seven racially diverse young women with learning disabilities from a large urban school district, all of whom qualified for free or reduced lunch. Interview protocols for focus groups addressed knowledge, skills, and attitudes related to self-determination. In addition, open-ended questions were used to examine the participants’ postsecondary goals and dreams. In attempt to demonstrate triangulation, Trainor examined the transition goals for the young women included on their Individualized Education Plans, but found that the goals were not individualized and “appeared to be generated from a master list” (p. 35).

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2 It is unclear why Trainor chose to frame her interview questions solely around internalized conceptions and components of self-determination such as knowledge, skills, and attitudes rather than exploring the participants’ contextual lives as well.
Trainor’s (2007) results highlighted three themes related to perceptions of self-determination: (a) they believed themselves to be self-determinate women and were able to describe ways in which they demonstrated self-determination citing choices they’ve made, goals they’ve worked toward, and instances of self-advocacy, (b) the participants “belied this self-perception by revealing key self-determination components in need of development” (p. 36) and, (c) participants were provided with limited opportunities for transition planning.

Peterson (2009) also examined self-determination and young women with disabilities, but used a case-study methodology instead. Peterson presents “Shana’s Story” as a response to the conceptualization of self-determination as a set of skills to be learned. Peterson indicates this approach undermines the democratic intent of self-determination. Through qualitative inquiry, Peterson found that self-determination had many pitfalls, appeared to be a conflict of interest to the culture of special education, and operated as a mechanism of normalization.

Shana’s teachers failed to provide her with a learner-centered teaching approach, did not take her expressions of self-determination seriously (i.e., her desire to cook and to date), did not appreciate her cultural background, and failed to recognize and capitalize on her multiple strengths. Implications for Peterson’s (2009) study include the need to embrace learner-centered approaches to instruction, further explore the link between curriculum, pedagogy, and self-determination, and to examine how legislation may actually subvert autonomy, respect, and liberty of students with disabilities.

Hogansen, Powers, Geenen, Gil-Kashiwabara, and Powers (2008) also examined the transition experiences of adolescent girls with disabilities. Citing gender inequities in transition outcomes, the authors conducted interviews with 146 adolescent girls with disabilities, parents, and special education professionals. The authors attempted to address the lack of information
available regarding how young women with disabilities experience transitions. Findings indicated divergent transition goals, factors shaping those goals, sources of support, and issues related to cultural and linguistic diversity.

Hogansen, et al. (2008) found that the young women identified goals related to careers, post-secondary education, family and relationships, economics, and independence. Many of the participants had multiple goals. Parents shared similar goals to their daughters, but explained any discrepancies as being related to the “unrealistic” nature of expressed goals. Professionals expressed very vague goals for the participants. When goals were described in detail, the professionals discussed their role as keeping the goals “realistic.”

Various factors shaped these transition goals and included the presence of mentors, peers, family, teachers, and access to opportunities. Participants also identified several sources of support as well as barriers to successful post-school transitions. Participants were oftentimes not involved in transition planning, were not supported to participate in their IEP meetings, and described how special education did not help them meet their academic needs or transition goals. Participants believed that work experiences would increase their chances of success, expressed the need for social support from friends and family, and described a lack of collaboration between stakeholders. Hogansen, et al. (2008) recommend the following practices to promote successful transition:

- youth involvement in transition planning, participation in extracurricular activities and general education, career planning and work experience individualized to the student’s career interests, instruction in skills such as self-determination, self-advocacy and independent living, and mentorship. (p. 231)
Erevelles and Mutua (2005) frame transitions within the larger realm of adolescent girlhood and present the narrative of Sue Ellen, a 20-year-old young woman with Down syndrome. Through open-ended interviews, the authors followed Sue Ellen through her journey through adolescent girlhood and her future possibilities. Central to Sue Ellen’s narrative was the controversial issue of sexuality, where she reconstituted girlhood and disability in the face of dominant discourses of hegemonic femininity and ableism.

Sue Ellen existed within the liminal space of adolescent girlhood as she resisted her mother’s protection and descriptions of her as a “little girl.” She attempted to claim rank in both the realms of girlhood/womanhood and took up both normative and oppositional tropes of femininity. Sue Ellen was eager for a life of semi-independence, yet was hesitant to leave her home. It was also important for Sue Ellen’s mother to provide her with opportunities to express her “girled” sense of self through “tween” pop music, dancing and attending social events.

Erevelles and Mutua (2005) describe the complexities of the “non-girling” of adolescent girls with disabilities, while acknowledging the limited “girl” spaces in which they occupy. By articulating “girl power” as an opposition to traditional femininity and an expression of independence, assertiveness, and strength girls with disabilities are oftentimes rendered invisible. “Girl” is typically not recognized until that marker becomes “dangerous, troubling, and unwanted” (p. 254). Sue Ellen reconfigured a new spaced for herself within the discourse of girlhood.

In other words, Sue Ellen did not view herself in a passive manner, but proactively asserted sexual expression and created her own identity as a woman, not a girl. These assertions also provided Sue Ellen’s mother with an opportunity to rethink her own assumptions regarding her daughter’s sexual identity. Her mother was concerned about the lack of sex education
available to girls and young women with intellectual disabilities, but began recognizing her daughter as a woman rather than a girl. In conclusion Erevelles and Mutua (2005) describe the significance of Sue Ellen’s claims to girlhood/womanhood:

True, Sue Ellen’s initial claims to “girlhood” follow patriarchal rules. But her radicality does not lie in her opposition to those rules but in her insistence that she be recognized as a sexual/gendered subject where her difference as embodied in her disability rewrites the landscape of “normative” girlhood and “girl power.” (p. 268)

After a review of the current literature on transitions and students with disabilities, it is clear that certain voices are missing. Although many researchers (Smith et al., 2002; Shogren et al., 2007; Wehmeyer et al., 2000) stress the importance of listening to and centering the voices of students with disabilities during transition planning, few researchers actually (Cooney, 2002; Peterson, 2009; Shogren & Broussard, 2010; Trainor, 2005; 2007) examine the perspectives and lived experiences of these students. Little space is made available for individual narratives in which young women tell their stories (Ferguson & Ferguson, 1995).

**Statement of the Problem**

Across the United States young women with disabilities are faced with obstacles to living a self-determined life, not experienced by their male counterparts. According to Rousso and Wehmeyer (2001), high school girls with disabilities experience the effects of the “double jeopardy” of both disability and gender:

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3 Throughout this dissertation I struggled with how to name the participants I was working with. Transition-aged young women with intellectual disabilities can span the ages of 14 to 21; this is a large range to be considered a “girl” or a “young woman.” Girlhood studies have emerged as a salient area of research that seeks to reclaim girlhood as a site of agency, rather than the “genesis of women’s problems” (Currie, Kelly, & Pomerantz, 2009; p. 3). At the same time, the label of “girl” can be infantilizing to a young woman in her twenties: particularly a young woman with the label of intellectual disability who has historically been left out of the conversation of what it means to be a woman (Trent, 1994). Other researchers choose to use the language of both: girls and young women with disabilities or GYWDD
Males with disabilities are more likely to be employed, work full-time and remain so than are females. When employed, females with disabilities are more likely to be employed in unskilled jobs than males in spite of a lack of differences between sexes in I.Q., achievement, and basic job skills. (p. 7)

Missing from this description of disparity are questions of race and class. Collins’ (1990) matrix of domination better captures the interactive and intersectional nature of identity and systems of oppression, rather than the more simplistic and additive “double jeopardy.” Men with disabilities may be more likely to be employed than women with disabilities, but both race and class can act in different ways upon this oppression. As Collins’ notes,

Replacing additive models of oppression with interlocking ones creates possibilities for new paradigms. The significance of seeing race, class, and gender as interlocking systems of oppression is that such an approach fosters a paradigmatic shift of thinking inclusively about other oppressions, such as age, sexual orientation, religion, and ethnicity. (p. 225)

Multiple and simultaneous systems of privilege and oppression overlap and interlock, but the implications on post-school success are not always acted upon in equivalent ways.

Recent research by Trainor (2007) indicates the trend in gender inequity in schooling and postschool outcomes remains. Limited access to high quality instruction and special education services has had a negative impact on opportunities for self-determination and engagement in post-secondary education transition planning, resulting in economic and educational disadvantages, greater high school dropout and unemployment rates, lower wages, and higher

(Owen, 2010). During interviews and collage making with the participants, none of them identified as a young woman. Each identified herself as either a teenage girl or an adolescent girl. Throughout this dissertation I use both of these labels to respect their self-identification, but I also use young woman to reflect my own understanding.
poverty rates. As Clare (1999) so beautifully states, “Disability snarls into gender. Class wraps around race. Sexuality strains against abuse. This is how to reach beneath the skin (p. 137).

Post-school failure is not a phenomena relegated just to women with disabilities. Dropout rates of U.S. students are dismal: one-third of all students (with and without disabilities) are failing to graduate from high school. Smith and Routel (2010) argue that services to support students with disabilities in the transition from school to life have not been a success. Citing the Office of Special Education and Rehabilitative Services (OSERS) (2003) and the President’s Committee for People with Intellectual Disabilities (2004), Smith and Routel note that approximately 41% of students with disabilities drop out of school. Moreover, 26% of students with intellectual disabilities fail to complete their schooling.

Poor post-school outcomes follow students with disabilities who enter the world of adult services and supports. The difficulties students with intellectual disabilities in particular, and their families face in navigating the confusing adult service world and post-secondary education system have led to “prolonged financial and social dependency” (Mallory, 1995, p. 218). Cooney (2002) cites the discourse of clienthood in the world of adult services as a catalyst for limiting placement, fostering dependency, and denying adulthood. When planning for life after school, students are marginally engaged and oftentimes completely left out of the planning process, according to Cooney. Although transition planning has improved various post-school outcomes for students with disabilities, it has yet to serve as a catalyst for the realization of the future dreams and aspirations for young adults with disabilities, specifically young women.

**Purpose of the Study**

A dearth of literature exists specifically exploring the lives of adolescent girls with disabilities (Ferri & Connor, 2002; Erevelles & Mutua, 2005). Even when attempts are made to
include the voices of transition-aged youth with disabilities (Test & Neale, 2004), efforts are not always made to creatively engage with student participants, resulting in student narratives going unreported. The result is an issue of representation and knowledge production.

The authority of teenage girls with disabilities has been rendered invisible by professionals who have determined that it is their duty to determine what successful transitions look like, what constitutes an expression of choice, and what steps young adults need to take in order reside within the boundaries of self-determination—authorial claim (Clough, 1994) has been laid to the experiences of young adults with disabilities. I argue that more space must be made in the current literature for the experiences of young women with intellectual disabilities. By doing so, we may realize the potential in young women to demonstrate expressions of self-determination, interdependence, autonomy, and competence.

In order to realize diverse understandings of the experience of disability, we must strive for shifts in authorial knowledge by positioning young women with disabilities as experts on their material and social high school experiences, rather than professionals (Charlton, 2006; Ferguson & Ferguson, 2006) whose epistemologies “silence both the perspectives of disabled persons and the development of non-deficit orientations of disability” (Danforth & Gabel, 2006, pp. 5-6). To begin this shift in authorial knowledge, I drew heavily on the theory and practice of a transformative, mixed methods approach (Creswell, 2003; Creswell & Pano Clark, 2011; Mertens, 2005; Mertens, 2009). Although this study does not meet the tradition definitions of mixed methods research, Mertens’ theory of transformative research was central to my work (2005; 2009).

The transformative strategy is the strategy of choice for mixed-methods researchers whose scholarly inquiry is already guided by an emancipatory, social justice agenda (Creswell,
I drew on both qualitative (Bogdan & Biklen, 2007; Taylor & Bogdan, 1998) and quantitative (Kazdin, 2003) research methodologies, in order to explore self-determination and the experiences of young women with disabilities. In particular, qualitative methods (in-depth interviewing supported by participant-generated images, participant observation, and documentation review) were given priority in this dissertation, in order to explore the following research questions:

1. How do young women with disabilities navigate the transition from school to life after; what are their experiences with transition?
2. Do young women think about self-determination (i.e., making choices, demonstrating control, advocating) and what does it mean to them?
3. In what ways do young women with disabilities experience self-determination in school and at home; if opportunities and barriers exist, how are these experienced?
4. What are their dreams and hopes for their life after school?
5. Do race, class, gender and dis/ability shape the participants’ experiences with schooling, transitions, and self-determination? If so, how?

In addition, a short quantitative survey based on the AIR Self-Determination Scale (Wolman, Campeau, DuBois, Mithaug, & Stolarski, 1994) was given in order to generate descriptive data regarding the opportunities for self-determination provided by schools and families to the participants.

The remainder of this study is organized into five chapters. In Chapter Two, I outline the research design, the methodology that informs such a design, participants, and how the mixed-methods data was collected and analyzed. The three data chapters that follow are described below.
In Chapter 3, *Negotiating the Borders of Adolescent Girlhood*, I begin by highlighting the everyday practices of adolescent girls by drawing on their constructions of friendships and sexuality. Next I discuss the ways in which the participants reconfigure adolescent girlhood through counter-narratives to stereotypical gender roles. In conclusion I discuss how mothers and daughters navigate the borders between girlhood and womanhood, while the culture of special education produces them.

In Chapter 4, *Constructing Self-Determination*, I present each participant’s self-determination narrative as an individual narrative derived from their interviews and participant-generated collages. Following the individual narratives, I present an analysis of the self-determination narrative presented through the participants’ Individualized Education Plans (IEPs), highlighting notable discrepancies, and then mix the participants narratives with numbers (the AIR Self-Determination Scale). In conclusion, I share the contradictions that emerged from the mixed data and briefly summarize commonalities across the participant narratives.

In Chapter 5, *Narrating Transitions*, I present these visions of the future as unlimited dreams and explore post-secondary education, the world of work, friendships, and interdependent living. The realization of these dreams is situated within the larger context of opportunity. I share the participants’ struggles and successes with planning and decision-making, and accessing meaningful work.

Chapter 6 concludes with the theoretical and practical implications of this study, with regard to transitions, girlhood, and strategies for conducting qualitative research with teenagers with disabilities. In addition, I provide recommendations to students, educators, parents, and researchers for changing the ways young women with disabilities experience high school and transitions, and addressing the inequities they face.
CHAPTER 2: METHODS AND PROCEDURES

Research Design

This study drew on the theory of mixed methods research design (Creswell & Pano Clark, 2011), which is a method of collecting, analyzing, and interpreting both qualitative and quantitative data. Data can be “mixed” either concurrently (by combining or merging data) or sequentially (by building). Priority is given to either the qualitative method or the quantitative method, or both, and the procedures can be used in a single research study. Combining qualitative and quantitative data can provide a more complete and complex understanding of a particular research purpose, such as the need to understand the experiences of young women with disabilities and their access to educational opportunities.

This research provides a depth of evidence for understanding a given research problem than either quantitative or qualitative methods can provide alone, and as Creswell and Pano Clark (2011) note, mixed methods research “provides a bridge across the sometimes adversarial divide between quantitative and qualitative researchers” (p. 12) with the potential for greater collaboration across various research paradigms. Epistemologically speaking, mixing narratives with numbers may appear incongruent at first, because of the seemingly intact binary between positivism (grounded in notions of generalizability, reliability, and cause and effect) and constructivism (where reality is constructed by both researchers and participants, experience and discourse are central, and induction is key) (Stewart & Cole, 2007).

Yet, feminist researchers such as Lin (1998) and Stewart and Cole (2007) argue that the binary is not so clear and that when mixing narratives with numbers the researcher can refuse this binary. A researcher using a mixed methods approach does not have to be grounded in both
positivism and constructivism. Trainor (2011) further describes how this particular aspect of mixed methods research can be used to transform special education research:

Using mixed methods research allows us [special education researchers] to escape the false dichotomy of interpretivism-positivism while simultaneously expanding the community of scholars, and thus the knowledge we generate. (p. 219)

Special education researchers Klinger and Boardman (2011) further elaborate on the benefits of mixed methods research, because it “legitimizes the use of multiple approaches in answering research questions. It is inclusive, pluralistic, complementary, and eclectic” (p. 209).

Feminist researchers Stewart and Cole (2007) note that quantitative methods can be used with qualitative methods to reach interpretivist or constructivist aims such as revealing “the mechanisms that underlie… relationships in particular contexts or cases” (p. 328).

The key is that feminist research is driven by the discursive, social, and material experiences of women. Stewart and Cole (2007) further note that feminist scholars recognize that social science research has often “left out” or ignored aspects of phenomena that they care about, they are much less inclined to believe that a single method is the “royal road” to understanding. Thus, feminist scholars have often embraced pluralism partly as a strategy that might be less likely to produce such a narrow and selective picture of human experience. (p. 329)

In addition, mixing narratives with numbers is one way for researchers to speak to new and different audiences (i.e., conversations between traditional special education researchers and inclusive or disability studies-oriented scholars) in order to effect change. Feminist scholars who are comfortable with complexity, contradiction and “messiness” can also find a home in mixed methods research (Stewart & Cole, 2007, p. 330). I chose to use both qualitative and quantitative
methods in order to provide a comprehensive account of self-determination and transitions, to discover paradoxes and contradictions (Creswell & Pano Clark, 2011) in experiences of and opportunities for self-determination, and to explore new perspectives and frameworks regarding self-determination for young women with disabilities. Such paradoxes and contradictions may not have been uncovered through qualitative research methods alone.

When conducting a mixed methods study, the researcher must make certain methodological decisions regarding implementation (order of methods), priority of methods (which method receives more emphasis), when both sets of data (qualitative and quantitative) will be integrated, and the theoretical framework (Creswell, 2003). This study included both quantitative and qualitative data gathered concurrently. The diagram of the research phases is presented in Figure 2.1.

![Figure 2.1. Data collection methods.](image)

In addition, qualitative methods received more emphasis. Priority was given to the qualitative methods because they represented a larger component of the data collection, analysis, and interpretation, and aligned more closely with the feminist framework that guided this study. A smaller, quantitative component was also used through the student and parent versions of the
AIR Self-Determination Scale (Wolman et al., 1994), specifically an adapted version of the Opportunities Subscale.

Thematic analysis of the qualitative data occurred both simultaneously with and at the conclusion of qualitative data collection. Statistical analysis of the quantitative results was descriptive in nature (Cohen, Manion, & Morrison, 2007) and provided a snapshot of the state of opportunities for self-determination for the participants. Analysis consisted of interpreting the meaning behind the participant’s stories and experiences (qualitative), explaining descriptive statistics (quantitative), and understanding the relationship between the two.

Overall the goal of this study was to explore the following questions: (a) How do young women with disabilities navigate the transition from school to life after; what are their experiences with transition? (b) What does self-determination (i.e., making choices, demonstrating control, advocating) mean to them? (c) In what ways do young women with disabilities experience self-determination in school and at home; if opportunities and barriers exist, how are these experienced? (d) What are their dreams and hopes for their life after school? (e) Do race, class, gender and dis/ability shape the participants’ experiences with schooling, transitions, and self-determination? If so, how? Although my small sample size (N = 4) and concurrent design precluded the use of more intensive statistical analysis, the qualitative methods and questionnaire were guided by a specific transformative paradigm. A transformative paradigm grounded in feminist disability studies provided an overarching framework for the study and guided the research question, data collection, analysis, and interpretation.

**Transformative Research**

I approached this dissertation through the transformative lens of feminist disability studies and from a critical perspective regarding self-determination and post-secondary education
transitions. Transformative research is informed by a particular theory that provides a framework for, and serves as the driving force behind, all aspects of the research process (Creswell & Pano Clark, 2011). Historically, social science theories have guided much transformative research, but more recently, emancipatory theories such as feminism and disability studies serve as frameworks. Oftentimes an emancipatory theory is used in order to research the experiences of marginalized groups (such as young women with disabilities) in order to effect changes related to social justice (Creswell & Pano Clark, 2011).

More specifically, Creswell and Pano Clark (2011) outline the purpose of transformative research as follows: “to conduct research that is change oriented and seeks to advance social justice causes by identifying power imbalances and empowering individuals and/or communities—that is, the purpose for mixing methods in the transformative design is for value-based and ideological reasons more than for reasons related to methods and procedures” (p. 96). The transformative strategy is the strategy of choice for researchers whose scholarly inquiry is already guided by an emancipatory social justice agenda (Creswell, 2003). I feel that my scholarly agenda, which is currently guided by a feminist disability studies lens, is emancipatory in nature and fits well within the transformative mixed method paradigm.

This dissertation also operated under the assumption that reality is socially constructed. A constructivist approach to research is grounded in the idea that “knowledge is socially constructed by people active in the research process, and that researchers should attempt to understand the complex world of lived experience from the point of view of those who live it” (Mertens, 2005, pp. 12-13). In addition, this dissertation was guided by the basic tenants of feminist research (outlined by Mertens) which include: (a) a focus on gender inequities, (b) gender discrimination is systemic and structural, (c) research is political, (d) the research process
can lead to positive or negative effects on participants, (e) knowledge is situated and the researcher must engage in critical reflection and, (f) “there are multiple ways of knowing; some ways are privileged over others” (p. 18).

According to Creswell and Pano Clark (2011), the aspect of the transformative strategy that makes it different from other research strategies is the social change purpose and the emancipatory theoretical lens that strongly influences and guides the entire research process. Creswell and Pano Clark stress the importance of the chosen critical theory and emancipatory aim, guiding the problem statement, review of literature, research questions, data collection, analysis, and interpretation. Researchers who choose the transformative approach define their research problem in response to discrimination and oppression of marginalized groups, resist deficit-driven assumptions, epistemologies, and theories, and “develop questions that lead to transformative answers, such as questions focused on authority and relations of power in institutions and communities” (p. 98).

In addition, transformative researchers make attempts to capture the complexity of the research problem, are concerned with ethical issues of research, avoid labeling participants, and “frame the results to help understand and elucidate power relationships” in ways that “facilitate social change and action” (Creswell & Pano Clark, 2011, p. 98). According to Mertens (2005), researchers using the transformative paradigm attempt to address politics of representation inherent in research and investigate issues of social oppression.

This dissertation was defined by a call for change—changes in the status of adolescent girls with disabilities and changes to epistemological ideologies that sideline their knowledge and experiences. I recognize the importance of their lived experiences and my goal was to unearth their “subjugated knowledge” (Hesse-Biber, 2007, p. 3). My intent, as evidenced by the
desire for social change inherent in transformative research, was to not only better understand the experiences of adolescent girls with disabilities, but to generate possibilities for changing the ways they experience schooling and transitions, and to address the inequities they face as young women.

Data Collection

Building Trust

It is important to note that in order for people to share their stories, a certain level of trust must exist. By engaging in multiple interviews (four) I was able to develop a certain amount of rapport with each participant. The supported collage-making (which will be described in detail later) that accompanied each interview also seemed to put the girls at ease. The various magazines, large white paper, and brightly colored markers lent a sense of creative creation to the process. All of the participants asked to keep the collages they had made and some displayed them throughout their home or in their bedroom.

I developed a set of open-ended questions to guide each interview, but our discussions felt more like a conversation. I engaged in memo-writing throughout the data collection process and caught myself saying, “This doesn’t feel like a study about Special Education.” How do “tween” television shows on the Disney Channel, long conversations about food interests, and inner-clique fights relate to transitions and self-determination? I realized that was the wrong response. As Gerson and Horowitz (2003) note, “[t]he best interviews become a conversation between two engaged people, both of whom are searching to unravel the mysteries and meanings of a life” (p. 210). This was the narrative that was being shared and it was my job as a researcher to understand the implications of these experiences.
I also interviewed each participant in the setting of her choice (which was either their dining room table or school library). I asked each participant if they wanted their parents present during the interviews. Even though each girl said no, an adult was always around whether a librarian walking through the library, a parent making dinner in the kitchen, or staff person doing paperwork in their office. I met each participant for about 15 minutes on a day prior to the first interview to get to know each other and to explain the study.

**Collecting Data**

By examining both qualitative and quantitative representations of opportunities for self-determination and transitions, I was better able capture the complicated ways in which young women with disabilities must navigate their transition to post-school life, and how they negotiate access to opportunities. As the dissertation progressed, the study became more about schooling and transitions and less about self-determination. Less of an emphasis was placed on the quantitative data, and information derived was incorporated into a larger chapter on transitions. A greater emphasis was placed on the participants’ narratives. I drew on Riessman’s (2008) conceptualization of narrative:

… narrative can refer to an entire life story, woven from threads of interviews, observations, and documents… [P]ersonal narrative encompasses long sections of talk – extended accounts of lives in context that develop over the course of single or multiple research interviews. (pp. 5-6)

I used multiple in-depth interviews, and “stories” derived from participant-created collages and IEPs to weave together a contextual story about girlhood, schooling, and transitions.

**Qualitative Strategies.** Qualitative research questions are driven by complex, contextual topics rather than hypothesis testing (Bogdan & Biklen, 2006) and data is typically collected by
spending a substantial amount of time interacting with people. The foundation of qualitative research is to understand the perspectives and lives of participants and the qualitative researcher immerses herself in the worlds that are constructed by such perspectives and experiences (Gerson & Horowitz, 2003). Qualitative researchers are concerned with going to the people (Taylor & Bogdan, 1998) and are “committed to understanding social phenomena from the actor’s own perspective and examining how the world is experienced” (p. 3).

Qualitative research is oftentimes open-ended with researchers using questions such as “What is a typical day like for you?” in which participants lead the researcher through the narrative of her or his day, life, experience, etc. (Bogdan & Biklen, 2006). The purpose is to uncover a deep and rich understanding of a particular person’s experiences, perspectives, and life. This data is reflective of the ways in which people “construct, interpret and give meaning to… experiences” (Gerson & Horowitz, 2003, p. 200).

By beginning with experiences and examining the both/and nature of the personal and political, qualitative methods also do work to counter the “objectivity” typically found in educational and social science research (DeVault & Gross, 2007). Beginning with experience is not without its critique, but when experience is considered in a manner that makes room for multiple truths that are discursively (Scott, 1992) shaped by language, history, and political climates, the materiality of such experiences can serve as a strong call for political action (DeVault & Gross, 2007). DeVault and Gross (2007) suggest a critical approach to experience that makes space for authorial knowledge claims while recognizing that “working with accounts constructed linguistically, that experience recounted is always emergent in the moment… listening shapes the account as well as the telling… [and that] both listening and telling are shaped by discursive histories” (p. 179).
The key is that qualitative researchers are not only interested in the social lives of their participants, but seek to understand the ways in which “people are embedded in large social and cultural contexts and how, in turn, they actively participate in shaping the worlds they inhabit” (Gerson & Horowitz, 2003, p. 203). As is common in qualitative research, I approached my research questions in a mainly inductive manner. Inductive approaches to research questions involve building abstractions from data rather than seeking out data to prove or disprove a particular hypothesis (Bodgan & Biklen, 2006).

This said, I also approached this research from the feminist perspective of excavating the stories of young women to uncover potential marginalization; therefore my approach was not entirely inductive. I approached this study with the understanding that many young women with disabilities are experiencing educational inequity in schools. Gender, race, socio-economic status, and disability are all at play in shaping these experiences. I approached this dissertation from the critical position that disability, gender, race, and socio-economic status are socially constructed and traditional special education (including paradigms of self-determination) has relegated students with disabilities to the margins of schooling. These beliefs shape my research agenda. As Bogdan and Biklen (2006) note, feminist researchers approach their work as a dialogue with the participants and their interactions with the world around them.

**Multiple Qualitative Methods.** Qualitative researchers may miss important information about participants if only one research method is used (Kusenbach, 2003). In previous research (Lehmann, Bassett & Sands, 1999) attempts have been made to access the experiences and perspectives of transition-aged youth with intellectual disabilities through semi-structured interview methods alone. When researchers are not able to obtain the rich narratives they are looking for, they fail to report the students’ stories and instead turn to parents or teachers for
information silencing students with disabilities and further marginalizing their competence, perspectives and experiences.

The unfortunate assumption is made that students labeled with intellectual disabilities do not have the insight to share their stories or the capacity to reflect on their lives. Rather, we as researchers must look to the systems that have been put in place that limit the opportunities for these young adults to ever share their stories. What kind of trust do students have in a society that has consistently denied them access to the definitions of a learner (Ferri, 2006), who have positioned them as incompetent due to a socially produced ideal of intelligence (Biklen, 1992; Hayman, 2000; Kliewer, 1998), who have never previously asked them what was important to their lives and what they thought about themselves, who have segregated them in basements, hallways, and wings of schools, or who have positioned them outside a very narrow definition of self-determination and success?

Due to these social injustices, it is important to use a number of qualitative methods (in combination) and to adapt those methods to meet the needs of the participants. As researchers we must develop trust and rapport with our participants, we must look to creative ways to engage with students, and we must not simply brush aside a response that doesn’t give us what we need or a behavior that doesn’t fit our ableist, white, middle-class conceptions of agency or understanding. Qualitative research can provide us with a deeper understanding of the ways in which adolescent girls with disabilities navigate their schooling experiences and can provide insight into “the social contexts that enable or constrain action” (Gerson & Horowitz, 2003, pp. 203-204). Through a combination of interviews, participant-generated images (i.e., supported collage-making), and document review, I was better able to explore the complicated lives of adolescent girls with disabilities.
**In-depth interviewing.** In order to access the stories and experiences of adolescent girls with disabilities, I began with in-depth interviews. I conducted four interviews with each participant, each lasting approximately 1-2 hours. All interviews were digitally recorded and transcribed later. According to Bogdan and Biklen (2006), the purpose of in-depth interviewing is to gather “descriptive data in the subjects’ own words so that the researcher can develop insights on how subjects interpret some piece of the world” (p. 103). In relation to schooling, transitions, and access to opportunity in and outside of school, individual interviews can provide researchers with insight into how systemic social issues and structures shape the experiences (Gerson & Horowitz, 2003) of adolescent girls with disabilities.

My interview schedule (see Appendix B) built off Cooney’s (2002) interviews with transition-aged youth with intellectual disabilities who shared their dreams for their future, recognized the cultural and economic capital of employment, and voiced desires for adults to view them as capable, independent persons, in addition to Trainor’s (2007) qualitative exploration of self-determination and young women with learning disabilities, Thoma, Rogan, and Baker’s (2001) look into transition planning for students with disabilities, and Shogren and Broussard’s (2011) examination of self-determination and adults with intellectual disabilities. The interview guide served as a starting point, but I also followed the participants where their narrative may took me. In supporting young women with disabilities, or any adolescent for that matter (Bettie, 2003; Luttrell, 2003) in sharing their narratives, it was important for me to approach the interview in an open-ended manner to ensure that the participants were able to share their personal stories. The important point was to understand that the participants are the experts on their lived experiences and to understand educational opportunities through their perspective.
Given the lack of opportunities many young women with disabilities have had in sharing what is important about their education with professionals or in directing their educational paths (Cooney, 2002; Smith & Routel, 2010) and dominant constructions of competency, it was important for me to come to the interview prepared with various probes (“give me an example,” “take me through _____,” or “what did you say then?”) in addition to the aforementioned interview guide. As Bogdan and Biklen (2006) note, “[n]ot all people are equally articulate or perceptive, but it is important for the qualitative researcher not to give up on an interview too quickly” (p. 105). Through the course of this study I conducted seven surveys, reviewed collected 50 pages of IEP documents, collected 16 participant generated collages, and transcribed over 300 single-spaced pages of participant interviews.

**Supported collage making.** In addition to in-depth interviews, participant-generated images serve as a means to access the stories of young women with disabilities and can provide rich data about their lived experiences (Bogdan & Biklen, 2006). Images (in particular participant-generated images), in addition to words, can communicate meaning and can provide valuable insight into the everyday lives of the participants. According to Riessman (2008), “images become ‘texts’ to be read interpretively” (p. 142) and authority is blurred and participants have more “control… over the meanings of images” (p. 143).

Luttrell’s (2003) study of pregnant teenage girls used visual representation (participant-created collages) in addition to participant observations and interviews. Luttrell initially experienced difficulties with interviewing these young women in part due to emergent understandings of the self, experienced in different ways by adolescents; interviews resulted in bits and pieces of stories. In order to engage the young women in a more emancipatory way and to not give up on them, Luttrell worked with the students on journaling, improvisation, self-
portraits and collage making. Her participants either drew themselves or used materials such as magazines, construction paper, markers, etc. to create a collage about their identity as a pregnant teen.

Mehta (2010) used participant-generated images in a similar way in her dissertation examining the experiences of Indian students with disabilities and inclusion. She described the process as “life-mapping” where participants created a time-line collage highlighting important events in their life. Participants used magazines, drawings, photographs, and other artifacts over two sixty-minute sessions. The students were very engaged in the process and Mehta served as a facilitator and supporter throughout. The method led to animated discussions and helped participants elaborate on various events in their lives.

Drawing on the work of Luttrell (2003) and Mehta (2010), supported collage making occurred during each in-depth interview. The supported collage making was particularly useful for Hope, who had difficulty with verbal expression, and in getting conversations started about particular topics. The supported collage making was a way for me to adapt the in-depth interviews and support the participants in providing rich detail about their experiences at home, in school, and in the community. Images provided context cues for the participants, and I used images as prompts for further discussion.

I used details from a recent participatory-action research study by women with intellectual disabilities, The Women’s Group – Community Living Winnipeg (2010), to develop “craft boxes” (p. 275) to use during the interviews. I brought a large canvas bag containing markers, construction paper, crayons, pencils, scissors, glue sticks, tape, and magazines to each interview. I spoke with several teenage informants and searched the Internet for lists of popular magazines for both adolescent girls and boys. I also asked each participant, during our first
meeting, what magazines they read or would like to use. A few examples of the magazines I brought to each interview include *Glitter: For Girls who Rock*, *Sports Illustrated for Kids*, *Word Up*, *Discovery Girls*, *Seventeen*, *Right On*, *Hip Hop Weekly*, and *Transworld Skateboarding*. Participants were also informed that they could draw images on their collage or create them with construction paper. As I learned more about the participants’ interests, I added additional magazines such as *Rachel Ray Magazine* and *Family Circle* (several participants expressed strong interests in food) and *J-14* (a magazine containing many images of pop stars and Disney Channel actors). The interviews occurred over a four-month period and I was sure to update the selection of magazines on a weekly or monthly basis, depending on the magazine’s distribution cycle.

Although I was sure to conduct the interviews in an open-ended manner and follow the participants where their narratives took me, each interview centered on a particular topic: (a) being an adolescent girl, (b) current schooling experiences, (c) thoughts about the future, and (d) meanings of self-determination (which was framed as choices). The supported collage making corresponded with the interview topic for that day. I gave each participant the opportunity to choose which topic we would explore on a given interview day. The topics of being an adolescent girl, thoughts about the future, and meanings of self-determination were most directly related to my research questions, but after discussions with my dissertation committee I also added the topic of current schooling experiences. This provided the participants with the opportunity to discuss their thoughts about the future in relation to their present experiences with school.

When beginning each collage the participant and I brainstormed adjectives that could be used to describe that day’s topic. First, I would ask the participant what words they believed
described the topic (i.e., “What words would you use to describe high school?”). Then, using the thesaurus feature we searched for additional adjectives. I typed up any words the participant chose on my computer for her to see. Each participant had a choice to either use the words on their collage or not. Participants also added words of their choice throughout that were not searched for, but rather emerged from our conversations. At times, collages were filled with both words and pictures, while at other times a single word accompanied a collage. Still yet, some collages contained words alone. Table 2.1 provides a sample of descriptive words chosen by various participants for each collage topic.

Table 2.1

*Sample of Descriptive Words Chosen by Participants*

<table>
<thead>
<tr>
<th>Collage Topic</th>
<th>Being a Girl</th>
<th>School</th>
<th>The Future</th>
<th>Self-determination</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptive Words</td>
<td>Teenage girl</td>
<td>Fantabulous</td>
<td>College</td>
<td>Activist</td>
</tr>
<tr>
<td></td>
<td>Role model</td>
<td>Graduation day</td>
<td>Chef</td>
<td>Fighting</td>
</tr>
<tr>
<td></td>
<td>Go to parties</td>
<td>Talent show</td>
<td>Reading</td>
<td>Anti-bullying</td>
</tr>
<tr>
<td></td>
<td>Fun</td>
<td>School dances</td>
<td>Boyfriend</td>
<td>Helping</td>
</tr>
<tr>
<td></td>
<td>Swearing</td>
<td>Fun</td>
<td>After school</td>
<td>Supporter</td>
</tr>
<tr>
<td></td>
<td>Chastity</td>
<td>High school</td>
<td>Teacher</td>
<td>Pick</td>
</tr>
<tr>
<td></td>
<td>Juvenile</td>
<td>Friends</td>
<td>Friend</td>
<td>Help cook</td>
</tr>
<tr>
<td></td>
<td>Drama</td>
<td>Culture</td>
<td>Home</td>
<td>Shoes</td>
</tr>
<tr>
<td></td>
<td>Spontaneous</td>
<td>Style</td>
<td>Family</td>
<td>Make my own</td>
</tr>
<tr>
<td></td>
<td>Guys</td>
<td>Care</td>
<td>Scared</td>
<td>choices</td>
</tr>
<tr>
<td></td>
<td>Growing</td>
<td></td>
<td>Study</td>
<td></td>
</tr>
</tbody>
</table>

Probes for each collage are described in Table 2.2. The probes were autobiographical (Lutrell, 2003) and interest-based in nature. These probes merely served as a guide throughout the interviews and collage making. Open-ended probes that were relevant to all collages were also used and included, “What is important about that image?” “Why did you pick that picture?” “Tell me about what you made.” I was also open to the idea that participants may choose to go in a different direction with their collage. For example, images from collages about being an adolescent girl reflected many high school experiences. In addition, the images from collages
about the future contained important information about gender and girlhood. I asked questions from the interview guide when appropriate and also followed the direction of each participant during her collage making.

Table 2.2

Sample of Collage-Making Probes

<table>
<thead>
<tr>
<th>Collage Topic</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being a girl</td>
<td>1. What do teenage girls do?</td>
</tr>
<tr>
<td></td>
<td>2. What is good or bad about being a teenage girl?</td>
</tr>
<tr>
<td></td>
<td>3. What do girls do after they graduate?</td>
</tr>
<tr>
<td></td>
<td>4. What girls or women do you look up to?</td>
</tr>
<tr>
<td>School</td>
<td>1. What is school like?</td>
</tr>
<tr>
<td></td>
<td>2. Can you walk me through a day at school?</td>
</tr>
<tr>
<td></td>
<td>3. What do you like about school?</td>
</tr>
<tr>
<td></td>
<td>4. What don’t you like about school?</td>
</tr>
<tr>
<td></td>
<td>5. What things do you like to do at home?</td>
</tr>
<tr>
<td></td>
<td>6. What is the hardest thing about school? The best?</td>
</tr>
<tr>
<td>The future(^\text{4})</td>
<td>1. What are your dreams for the future?</td>
</tr>
<tr>
<td></td>
<td>2. What things do you like to do?</td>
</tr>
<tr>
<td></td>
<td>3. What things are you good at?</td>
</tr>
<tr>
<td></td>
<td>4. What would you like to do after graduation?</td>
</tr>
<tr>
<td></td>
<td>5. What goals do you have?</td>
</tr>
<tr>
<td></td>
<td>6. What worries do you have about after graduation?</td>
</tr>
<tr>
<td>Self-determination</td>
<td>1. What choices do you make during your day?</td>
</tr>
<tr>
<td></td>
<td>2. What is a really important choice you’ve made?</td>
</tr>
<tr>
<td></td>
<td>3. What choices do you make in your life?</td>
</tr>
<tr>
<td></td>
<td>4. What plans do you make?</td>
</tr>
</tbody>
</table>

The participants also chose when the collage making would occur during the interview. Victoria, Britany, and Hope varied how they wanted the interview sessions to go. At times they

\(^4\) Probes regarding life after school were adapted from Making Action Plans (MAPS; Falvey, Forest, Pearpoint, & Rosenberg, 2000). MAPS, and similar person-centered planning tools such as Pearpoint, O’Brien, and Forest’s (1998) Planning Alternative Tomorrow’s with Hope (PATH Planning), are typically visual in nature and grounded in transition-planning literature.
wanted to talk first. I used my interview questions and the general topic as a guide, but also followed their emerging narratives. Then they would begin their collage making and I would probe them about what they were creating and talk more about the topic. At other times the reverse order occurred: collage making started the interview and typically lasted throughout the time of the interview. Aminah chose to begin each interview with the collage making, and the collage making lasted the duration of each interview. I was able to ask the participants questions from my interview guide, probe them about their chosen images, and follow their narratives throughout. There was a lot of information for me to keep track of during sessions when collage making lasted the entirety of the interview, but I took notes throughout and this particular approach to the interview allowed the participants’ narratives to unfold in a more organic way.

Although the participant was responsible for creating the collage, I facilitated the process with the aforementioned probes and assisted with any supports in physical tasks such as cutting or gluing as needed. I often used hand-over-hand support with Hope during cutting, pasting, and writing due to her fine-motor difficulties. Photos were taken of each collage and the process was digitally recorded. Verbal information was later transcribed.

By using participant-generated collage, in addition to interviews and participant observations, I had what Riessman (2008) calls “layered meanings” (p. 166). I believe a combination of these qualitative methods is essential in capturing the complex ways in which teenage girls with disabilities experience schooling, transitions and self-determination. Everyone’s lives are representative of multiple truths and multiple methods may be the best way to capture these complexities.

**Quantitative Strategies.** As is typical with most qualitative and quantitative research, I gathered the following demographic data about the participants: ethnic/cultural background,
socio-economic status (free or reduced lunch status in addition to parents’ education level), age, special education services received, and percentage of time spent in the general education classroom. Quantitative data collection also focused on identifying opportunities for the participants to demonstrate self-determination at home and at school. The quantitative data collection was used to provide another layer of information to the following research question: In what ways do young women with disabilities experience self-determination in school and at home; what opportunities are they provided with; what barriers exist?

The primary technique for collecting this data was through the Opportunities Subscale (student and parent forms) of the AIR Self-Determination Scale (Wolman et al., 1994). I developed three surveys (see Appendices B and C) to capture this information from the perspectives of the participants and their parents. The surveys were paper-and-pencil in nature and both the student and parent surveys were completed after the final in-depth interview. I asked each participant if she would like to read and complete the survey on her own, or if she wanted my support. All four student participants preferred that I read the survey aloud to them and transcribe their responses.

Instrumentation. The AIR Self-Determination Scale (Wolman et al., 1994) was developed in order to assess a student’s level of self-determination and to use this as a guide for developing strategies for improving abilities and opportunities related to self-determination. Because the focus of this dissertation was critical in nature and explored educational equity in the lives of young women with disabilities, only the Opportunities Subscale was used. I was not interested in measuring a set of self-determination skills (I am critical of the belief that self-determination is a set of skills that can be defined and measured), but am interested in how students access opportunities. The supports, resources, and environment in place all impact a

5 Aminah’s mother chose not to complete the survey.
student’s opportunity to live a self-determined life (Wolman et al., 1994). No matter how much a student knows about herself or how skillful she is at expressing her dreams, if opportunities are not in place for her to act on those dreams self-determination cannot be realized to the fullest.

Questions on the Opportunities Subscale are presented on a 5-point Likert-scale with options as follows: Never, Almost Never, Sometimes, Almost Always, and Always. Examples of questions presented on the student version include: (a) People at school listen to me when I talk about what I want, what I need, or what I’m good at; (b) People at school let me know that I can set my own goals to get what I want or need; (c) People at home encourage me to start working on my plans right away; and (e) I have someone at home who can tell me if I am meeting my goals. The Opportunities Subscale is divided into two sections: Opportunities at School and Opportunities at Home. There are six questions related to opportunities at home and six questions related to opportunities at school, for a total of twelve questions that assessed the opportunities provided to the participants for living a self-determined life.

The Parent version presents the same questions, but is worded in a different manner to reflect the participant (student vs. parent). Each question is reflective of a specific construct related to opportunities for self-determination and are outlined in Table 2.3. According to Wolman, et al. (1994) opportunities for self-determination are related to supports for students with disabilities in (a) thinking about themselves, their needs, and their dreams; (b) providing opportunities for student to act on those needs and dreams; and (c) supporting students as they evaluate their goals and make adjustments to their post-school paths.
Table 2.3

Constructs Addressed Through the AIR Opportunities for Self-Determination Subscale

<table>
<thead>
<tr>
<th>Measured Construct</th>
<th>Details</th>
<th>Student Form Questions</th>
<th>Parent Form Questions</th>
</tr>
</thead>
</table>
| Thinking           | • Opportunities and support to identify and express interests, needs, and abilities.  
• Opportunities to set goals to achieve dreams. | 1. People listen to me when I talk about what I want, what I need, or what I’m good at.  
2. People let me know that I can set my own goals to get what I want or need. | 1. People listen to when my child talks about what s/he wants and is good at.  
2. People let me know that s/he can set his or her own goals to get what s/he wants. |
| Doing              | • Opportunities to make choices and plan in order to meet goals.  
• Opportunities and support to take action. | 1. I have learned how to make plans to meet my goals and to feel good about them.  
2. People encourage me to start working on my plans right away. | 1. My child has learned how to make plans to meet his or her own goals and to feel good about them.  
2. My child is allowed to act on his or her plans right away. |
| Adjusting          | • Support in evaluating actions.  
• Support to alter plans if necessary. | 1. I have someone who can tell me if I am meeting my goals.  
2. People understand when I have to change my plan to meet my goals. They offer advice and encourage me when I’m doing this. | 1. My child has someone to tell him or her when s/he is meeting his or her own goals.  
2. People understand my child when s/he has to change plans to meet his or her own goals. They offer advice and encouragement. |

The two large sections of the AIR Self-Determination Scale (Wolman et al., 1994) include Capacity and Opportunity. These sections can be combined for an overall score related to self-determination, but are designed to be used independent of each other as well. Once all questions are completed a score can be derived based on the choices made by the participant. While this score was not a magic number by any means, it provided me with an idea of how the participants and their parents perceived their opportunities for self-determination.
The validity and reliability of the AIR Self-Determination Scale (Wolman et al., 1994) was field tested with approximately 450 students with and without disabilities. Reliability correlations for the scale were quite strong and ranged from .91 to .98. The constructs examined through the Self-Determination scale explained approximately 74% of the variance. The authors note “a robust relationship between the underlying factors revealed in the data, the scores for each item in the instrument, and the conceptual constructs upon which the instrument was developed” (p. 46). The Opportunities subscale is a valid and reliable instrument for measuring a student’s opportunities for self-determination.

Selecting Participants

I used purposeful sampling, where participants are intentionally chosen because they can facilitate the exploration of one’s research question, and recruited four adolescent girls with disabilities enrolled in junior high schools and high schools throughout the metropolitan area. I focused on a small sample size (N = 4) because of the need for in-depth, rather than broad, understandings of experiences self-determination and transitions. Sample sizes in qualitative research are often small with data that is “rich in description of people, place, and conversations” (Bogdan & Biklen, 2006, p. 2).

I recruited participants on a voluntary basis by contacting both not-for-profit organizations and advocacy groups in the metropolitan area, and local school districts through approved email solicitation and flyers in which participants (or their parents) could contact me. Criteria for selecting participants included: (a) female, (b) label of intellectual disability or mental retardation as indicated on the IEP, (c) diverse racial and/or socio-economic backgrounds, (d) currently attending high school and (e) transition-aged (between the ages of 15 and 21). The selection criteria were later expanded to include a participant (Victoria) who attended a local
junior high school (but due to grade retention was 16 years of age) and an adolescent girl with a learning disability (Aminah). All participants, as well as their parents, provided written consent to participate in the study. How I came to meet and collect data with each participant varied. Therefore, what follows is a description of how each adolescent girl came to be a participant in the study and how data collection occurred with each girl.

Participants and their Settings

Victoria. I was initially contacted by Victoria’s mother, a social studies teacher at a local high school, who indicated that her daughter was interested in participating in the study. I met Victoria and her mother at their suburban home after school one day to share the details of the study. I was informed that Victoria was retained in two grades, so even though she was 16 years old, she currently attended a suburban junior high school. Victoria was excited to participate, was transition-aged, and currently had transition goals outlined on her IEP, so I decided to expand my criteria to include her in the study. During our first meeting she and her mother told me about a commercial Victoria had just filmed in New York City for an anti-bullying campaign to end the use of the R-word (“retarded”). Victoria and her mother consented to all aspects of data collection and we started working together that week. Each of our interviews and collage-making occurred at her home around the dining room table.

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6 I was contacted by a local special education teacher indicating Aminah fit the criteria for inclusion in this study, but later discovered that she had a label of a learning disability. Aminah self-selected for participation in this dissertation and after consulting with my dissertation advisor we decided that it would be beneficial to keep her in the study. The experience of her learning disability label, as well as the consequence of the other participants’ intellectual disability labels, is discussed throughout this study. Aminah’s label provided important insight into the culture of special education and accessing opportunities throughout transitions. I was able to explore the social construction of disability more clearly and examined the boundaries between disability categories and the reification of such categories.

7 Whenever I met with the participants, whether that be at their homes or school, I was sure to dress casually. I typically wore sneakers or moccasins with jeans and a sweatshirt or long-sleeved t-shirt (which is my usual clothing of choice outside of work). Although I am visibly older than the participants, I do pass as a younger adult. I did not want to appear to be too much of an adult figure and I wanted them to become comfortable with me when sharing their stories of high school.
Victoria was in ninth grade during the time of this study and was included in some regular education classrooms, but was also taught in segregated classrooms (which served as her primary educational setting). She is an “ungraded” student who is on track to receive an IEP diploma. Victoria has a label of intellectual disability (Down syndrome) and is actively involved in the local Special Olympics. She is White and from an upper-middle socio-economic background. Victoria loves all things related to Disney and “tween”-pop culture. She is a soft-spoken girl who has a few close friends who she hangs out with on the weekends and who participate in cheerleading with her. Victoria enjoys talking on the phone to her boyfriend after school, going out to eat at local restaurants, and speaking to her imaginary friends.

Victoria is in ninth grade at Westlake Junior High School. Westlake is a suburban school that serves approximately 1,400 students in grades 8 and 9. The school would not be considered culturally diverse: 1% of students are Native American, 5% of the student population is Black, 1% is Latino/a, 1% is Asian, while 90% of the students are White, and 2% are multiracial. 27% of the students qualify for free or reduced lunch (which is lower than the state average of 51%), 4 students at Westlake are English Language Learners, and 15% of the student population is identified as students with disabilities.

**Britany.** Britany’s mother also contacted me indicating her daughter may be interested in participating in this study. Britany and Victoria share a great deal in common. Both of their mothers are teachers, they attend suburban school districts, and both girls are White and from upper-middle socio-economic backgrounds. I met Britany at her home as well and she was also excited at the prospect of talking about being a high school girl. Britany’s mother was quick to remind her that being a girl wasn’t always fun and eluded to some troubles Britany had experienced the previous year. This said, Britany is a talkative and energetic young woman who

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8 All names of schools and adult agencies have been changed.
had a lot to say about her schooling. Britany and her mother consented to all aspects of data collection, and interviews occurred at their home.

Britany is a self-described “super-senior” who was nineteen years old at the time of the study, and had returned to high school for an additional year. She receives most of her education in a self-contained classroom, but was included for social studies and “specials.” She also has a label of intellectual disability (Down syndrome) and received an IEP diploma the year prior to this study. Britany enjoys the more “tween”-oriented television shows on channels such as Disney or ABC Family, but complains that her mom limits the kinds of shows she can watch. She frequently discusses issues she has had at school with what could be described as “frienemies” such as “drama” at school, gossiping, and getting text and Facebook privileges taken away. She works at a local restaurant and loves her job there – especially the food and being able to sing in the kitchen with the chefs (a friend of the family owns the restaurant).

Britany is a returning senior at Longview High School. Longview is a suburban school that serves approximately 626 students in grades 9-12. It is not a diverse school: 93% of the student population is White, 3% of the students are Black, 2% are Asian, and 1% are Latino/a. Longview is located in a more affluent suburb and only 9% of its students qualify for free or reduced lunch (which is significantly lower than the state average). One student is an English Language Learner and 12% of the student population is identified as students with disabilities.

**Hope.** Hope’s Medicaid Service Coordinator contacted me explaining that she had a young woman on her caseload who may be interested in the study. Through this Service Coordinator I met with Hope and her legal guardian at the group home where Hope lived. Hope began legal guardianship approximately three years prior, but maintains a relationship with her mother, grandmother, and a sister who resides with her grandmother. Hope’s legal guardian
expressed concerned over the lack of inclusion at her high school and was in the middle of trying to get Hope included in the school play. It is always difficult for me when parents and/or participants express concern over a lack of inclusion, but I explained that I would not be able to advocate for Hope or her guardian. As an inclusive educator this was a frustrating experience for me, especially as I got further into the data collection and learned that the participants with intellectual disability labels where rarely included in general education classes, and when they did the experience appeared quite marginal. All this said Hope appeared to be a very happy young woman, who always had a smile on her face, and who was very eager to participate in this study – the collage-making aspect was particularly intriguing to her. Hope and her legal guardian consented to all aspects of data collection, and interviews occurred at Hope’s group home. As I will describe later, this was both an emotional and logistical challenge for me.

Hope lives in a group home where she is the youngest of 5 housemates (most of whom are at least twenty years older than she). She receives all of her academic classes and physical education in segregated settings, is included for “specials,” and has been involved in cheerleading in the past. Hope communicates using verbal speech, but speech differences due to cerebral palsy make speaking difficult for her: she does not speak in long sentences. Hope uses a manual wheelchair and at times it is very difficult for her attend after-school functions or visit with friends, because all of her housemates use wheelchairs as well and arranging transportation is difficult. In spite of all this she has an amazing personality and is rarely seen without a smile on her face. She loves her mother, sister, and grandmother and recently had her first glass of wine while celebrating her 21st birthday with her housemates and legal guardian. Hope is a young, Black woman labeled with an intellectual disability. She is from a lower socio-economic
Hope is very close with her advocate and jokes frequently with one of her housemates. Hope is a 21-year-old attending her final year at Hoover High School. Hoover is a suburban school that serves approximately 1,170 students in grades 9-12. It is not a culturally diverse school: 90% of the student population is White, 3% of the students are Black, 3% of the students are Native American, and 1% is Latino/a. 23.5% of students at Hoover High School qualify for free or reduced lunch and 1 student is an English Language Learner. 18% of the student population is identified as students with disabilities.

**Aminah.** A Special Education teacher at a local urban high school contacted me about Aminah, indicating she was interested my dissertation. I met Aminah at her high school and shared with her information about the study. Aminah was quiet, shrugged her shoulders, and nervously giggled when we first met. Aminah wanted to share the consent forms with her mother and preferred to be interviewed at school during her study halls. I did not ask why, but we were able to find plenty of quiet space at school to chat. Aminah is a 15-year-old African American girl with a learning disability label. She is from a lower socio-economic background, receives free/reduced lunch at her school, and spent a great deal of her childhood under the care of her godmother. Aminah and her mother consented to all aspects of data collection.

Aminah lives at home with her mother and stepfather. She has two younger sisters and two older brothers. She likes playing with her sisters, but explains that they annoy her as well. Aminah listens to pop and hip-hop music, and wants to pursue nursing or medicine after graduation. She has many friends at her school and after about 15 minutes into our first interview, Aminah became a very animated speaker cracking jokes about her classmates and drama at school. Aminah will oftentimes get in trouble in class for talking out of turn and is a
very social person. She struggles with her math classes, but is currently on track to receive her Regents diploma. Aminah self-identifies as a “sporty” girl and is uncomfortable with girls who wear “sexy” clothing. Aminah is fully included in all of her classes, receives push-in resource support, and stays after school to receive tutoring support from a not-for-profit agency that collaborates with the local university.

Aminah is a ninth grader at Jefferson High School. Jefferson is an urban school that serves approximately 1,305 students in grades 9-12. It is one of the most diverse high schools in the metropolitan area and is known for its cultural diversity (20% of the students attending Jefferson are English Language Learners). 59% of the students are Black, 23% are White, 10% are Asian, and 8% of the student population is Latino/a. There is significant economic diversity as well: 68% of students at Jefferson High School qualify for free or reduced lunch. 19% of the student population is identified as students with disabilities. The student participants described in these vignettes are presented in Table 2.4.

Table 2.4

*Participants*

<table>
<thead>
<tr>
<th>Student</th>
<th>Age</th>
<th>Disability Label</th>
<th>School Setting</th>
<th>Race</th>
<th>Lunch Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Victoria</td>
<td>16</td>
<td>Intellectual Disability</td>
<td>Suburban</td>
<td>White</td>
<td>Does not receive free or reduced lunch</td>
</tr>
<tr>
<td>Britany</td>
<td>19</td>
<td>Intellectual Disability</td>
<td>Suburban</td>
<td>White</td>
<td>Does not receive free or reduced lunch</td>
</tr>
<tr>
<td>Hope</td>
<td>21</td>
<td>Intellectual Disability</td>
<td>Suburban</td>
<td>African American</td>
<td>Receives free or reduced lunch</td>
</tr>
</tbody>
</table>
Qualitative Analysis

Qualitative data collection and analysis occurred simultaneously. My analysis involved working with the various forms of data (interview transcripts, participant-generated images, and Individualized Education Plans), organizing that data, coding and synthesizing the data into themes, and looking for patterns and relationships (Bogdan & Biklen, 2006). As I collected data I engaged in methodological and analytical memo-writing. Using the memo feature of Atlas.ti (Version 6.2), I took note of emerging themes, additional interview questions, my thoughts and feelings about the data, and reflexive information about myself as a researcher.

Feminist disability studies epistemologies and understandings of the social and material world framed the meaning I made of the data. A feminist analytical framework (Madison, 2005) was used to explore gender in the data. Data was analyzed for intersections of race, class, disability, and gender (Collins, 1990) and the ways in which these intersections affected how the participants experienced schooling, transitions, and access to opportunities. Charmaz’s (2006) social-justice orientation to grounded theory (Glaser & Strauss, 1967), guided my data analysis as well. I approached the data inductively and paid attention to the themes that emerged through close analysis of data. Charmaz extends grounded theory to the social justice arena by asking, “What do these stories indicate? What might they suggest about social justice?” (p. 517).

Drawing both on Collin’s matrix of oppression and Charmaz’s extension of grounded theory, I
tried to understand what the data showed about equity, access, oppression, agency, and social justice.

Once data collection was complete, I finished transcribing any interviews and used the open-coding feature on Atlas.ti to code the data. Through Atlas.ti I was also able to upload and code each collage and IEP. The collages and IEPs were interpreted alongside the transcribed interviews. Analysis of the images focused on what the girls constructed. I analyzed each collage alongside the respective interview transcript in order to see how each participant verbally described the images. For example, with Victoria’s adolescent girl collage I coded her images of lipstick, cheerleading, and hearts as “hegemonic femininity” and “adolescent girl interests”. She positioned some of these images near a large picture of hamburger, which was coded as “food interests.” I was then able to create a memo regarding the contradiction of these images and the potential transgressive quality of lipstick (accessing womanhood) and food interests. I was interested in how the collage supported the narrative that was being told, but I was also interested in any contradictory or divergent information. The same was true for the IEP.

I then searched through my data to develop coding categories (Bogdan & Biklen, 2006) that represented my understanding of any regularities or patterns. Codes were related to the setting, situation, perspectives, ways of thinking, events, activities, and relationships. These codes reflected the understanding that social life is (a) partial, plural, and situated, (b) material as well as socially constructed and, (c) constitutive of multiple readings. I then began collapsing and combining codes, and used Atlas.ti’s networking feature to map out the codes and visualize thematic intersections. Figure 3.2 provides the beginning of one such map (due to the size of the map, not all parts of represented here). This particular map contained 378 data vignettes. The maps allowed me to use a constant comparative method of analysis (Charmaz, 2005; Mertens,
I was able to compare different levels of data such as participant-data, data within categories, and across participants and categories. Once all the data was coded and organized, I developed overarching themes that became the two data chapters of this dissertation.

**Figure 2.2. Partial data map of “being an adolescent girl.”**

**Quantitative Analysis**

Descriptive statistics were used to provide a snapshot of participants’ demographic information, as well as the opportunities for self-determination they experience at home and at school. According to Cohen, Manion, and Morrison (2007), descriptive statistics are exploratory in nature and their analysis “is responsive to the data being presented, and is most closely concerned with seeing what the data themselves suggest” (pp. 506-507). Frequencies, percentages, and cross-tabulations were generated in order to represent a picture of opportunities for self-determination. Nominal data (or data that could be transformed in a nominal manner) such as age, race, disability label, socio-economic status, and percentage of time spent in the
general education classroom was organized by the overall Opportunities score, Opportunities at Home scores, Opportunities at School scores, and answers to specific questions on the Opportunities Scale. Data was presented as counts or percentages of responses based on the aforementioned nominal variables.

By examining and comparing frequencies, percentages, and cross-tabulations I was able to show overall Opportunities scores for the participants, as well as scores specifically related to opportunities at home and at school. I determined how many of the participants felt they were being listened to at school and at home, how often they were informed of the importance of setting goals and planning for the future, if they were being supported with their post-school goals and if they received encouragement, if they received mentorship on their progress towards their post-school dreams, and if they were supported in changing these goals and offered advice on what steps to take next. All the components of the Opportunities subscale were also compared according to demographic variables.

Results related to opportunities for self-determination provided insights into the experiences of the participants, and as with qualitative methodologies, the goal was to follow the various narratives of the participants. Due to the small sample size of this study, and my epistemological framework, I did not test hypotheses or attempt to make generalizations. The quantitative data analysis was descriptive in nature, added another layer of meaning to the study, and provided me with the opportunity to examine converging data as well as contradictory information.

**Narratives and Numbers Analysis**

Using steps outlined by Creswell and Pano Clark (2011) for merged data analysis, my primary datasets (in-depth interviews, participant-generated images, and document reviews)
were analyzed first as previously described. The secondary dataset (the AIR Self-Determination Scale) was analyzed next, followed by a mixed data analysis to determine how the secondary dataset best supported or problematized the primary dataset and vice versa. The mixed data analysis involved the comparison of both datasets. The results of the two datasets (qualitative data and quantitative data) were compared across two dimensions: (a) qualitative themes and (b) scores derived from the AIR Self-Determination Scale. Specifically, I compared the views and experiences present in each theme with the participants’ perceptions of their opportunities for self-determination, and determined how the quantitative data supported or diverged from the qualitative data. Two strategies were used to merge and compare both sets of data.

**Merging Data.** I merged the data in two ways for data analysis. To begin, a side-by-side comparison of the merged data involved comparing data vignettes and the participants’ narratives with the descriptive statistics derived from the Opportunities Subscale. This strategy allowed me to support, problematize, and add complexity to both the qualitative narrative as well as the descriptive statistics. For example, many of the participants who shared narratives reflecting many opportunities for self-determination, rated dissatisfaction with opportunities for self-determination. This is the most popular strategy for comparing narrative and numerical data (Creswell & Pano Clark, 2011). My primary question during this analysis was the following: How does information generated from the Opportunities Subscale relate to the participants’ narratives and experiences?

In addition, a joint display (described in further detail in Chapters 4 and 5) was developed so that qualitative and quantitative data could be visually compared, resulting in the merging of data. Qualitative themes were arrayed across the top of the display, while a quantitative scale of Opportunities for Self-Determination scores was arrayed along the left. Through the joint-display
was able to make sense of any relationships between a standard “opportunities score” and the actual experiences of those participants.

Ethical Concerns

Misrepresentation is always a concern when conducting research with students with disabilities. Due to historical atrocities experienced by people with disabilities and women in the name of science, constant reflection on research practice is of utmost importance. I felt it was important to remain “mindful of hierarchies of power and authority in the research process… including power differentials that lie within research practices that can reinforce the status quo, creating divisions between colonizer and colonized” (Hesse-Biber, 2007, p. 3). I took several steps in an attempt to conduct my research in an ethical manner. These steps included: following Syracuse University’s Institutional Review Board (IRB) guidelines for responsible research, conducting member checks, and reflexively analyzing my position as a researcher.

Responsible Research

According to Syracuse University’s IRB, people with intellectual disabilities fall under a specific class of participants: vulnerable. While I do not agree with the terminology used to describe people with intellectual disabilities and believe that people labeled as such have been advocating strongly for their rights over the past several years, people with intellectual disabilities have been subject to atrocities in the name of research and science. I am sensitive to this history and made every effort to limit the risks to the participants.

Participants were able withdraw from the study at any time without repercussion and did not have to answer any questions they were not comfortable with. Privacy of participants was ensured by having in-depth interviews either at the participant’s home (with parents present) or a quiet location at their school. Pseudonyms (chosen by the participants) were used for all
participants as well as locations. All audio recordings, transcripts, participant-generated images, documents, and surveys remained in a locked drawer. Some participants were under 18 years of age. I obtained written consent from a parent or guardian in addition to assent from all participants for all aspects of data collection. Assent was obtained by reading aloud an assent script with participants.

Some information was uncomfortable for the participants to discuss. For example, Britany experienced a great deal of trouble with cliques and fights with friends at her school. I became cognizant of her discomfort and reminded her that she could choose to not answer any questions that she was uncomfortable with. This said, I believe the benefits of sharing one’s story and talking out one’s experiences at school outweigh the risks. Some participants, such as Aminah, benefited from talking about their future plans.

At the beginning of our interviews, Aminah shared that she wanted to attend a local private university for medicine. By the end of our time together Aminah talked more and more about nursing, several colleges and universities in the area, the grades she wanted to get in her high school classes, and the studying she would do in college. Aminah and the other participants also appeared to enjoy creating their stories through collage. Hope, in particular, frequently shared how fun the collage-making was, displayed the collages on her dining room walls, and appeared to really enjoy the creative process of searching for images, choosing where to place the images, and sharing what they meant to her.

**Member Checks**

I could not eliminate my researcher gaze or eliminate my research self from the interpretation of the participant’s experiences, but I engaged in a limited number of member checks in an attempt to address issues of misrepresentation and to provide more power to the
participants in this study. I read sections of transcribed interviews aloud and some of my emerging ideas about their narratives to each participant at the end of data collection, and asked them for their thoughts. I also discussed aspects of the data and my emerging codes with several graduate students in my field. In addition, I was fortunate to have the opportunity to share my emerging themes with several professionals in the field of inclusive education throughout the country. Through professional conferences and job talks I had invaluable conversations, particularly about access, race, and class, which added depth and complexity to this study.

**Researcher Position**

Even though I approached my research from a critical perspective by beginning from the belief that all people with disabilities are competent individuals capable of reflecting on their lives, I am able-bodied and I must try to understand and navigate the power dynamics inherent in my research. Feminists often make attempts to decolonize (Smith, 2005; Trinh, 1989) the research process, engaging in reflexive exercises that highlight the both/and nature of a female researcher interviewing women, and do work to limit eroticizing others (Bogdan & Biklen, 2006). An important feminist strategy to consider when exploring these narratives is that of reflexivity or “turning back on oneself… [and] the ways in which the products of research are affected by the personnel and processes of doing research” (Davies, 2008, p. 4).

One goal of reflexivity is to address issues of representation where the researcher may be positioned as an outsider, who may be making superficial analyses of an observed setting or experience, which is more reflective of the researcher’s standpoint, than what she may be observing (Kusenbach, 2003). I must be concerned with issues of misrepresentation, especially when conducting fieldwork with disenfranchised groups such as students with disabilities. As Sanchez-Jankowski (2003) notes, analyzing and representing the lives of participants occurs
through the “knowledge-bank” (p. 145) of the researcher. This knowledge-bank is influenced by my positionality and social location as a researcher, and

is used to identify, catalogue and categorize. [It] is of course the information and the apriority conceptualized schema that individuals have accumulated and developed to make sense of the constant stream of everyday information. (p. 145)

Because of this knowledge-bank and my various social locations (white, able-bodied, female, etc.), I cannot and should not attempt to erase myself from my writing or representations (Trinh, 1989). Objectivity was not my goal.

Reflexivity provides feminist scholars with the opportunity to reflect on how to navigate working in/between their research (i.e., female researchers interviewing and observing female adolescents (Cowley, 2010)), consider their own social locations (DeVault & Gross, 2007), and potentially blur the colonized boundaries between researcher and participant (Trinh, 1989).

I engaged in reflexive memo-writing throughout the course of this study in order to better understanding my connection to this research as well as my outsider (Villaverde, 2008) status as a White, able-bodied researcher. While it was neither easy, nor comfortable I scrutinized myself throughout and tried to better understand my own biases and knowledge-bank. Memo-writing helped me think about how my own experiences and social locations shaped the schema I used to understand participants’ narratives. I became comfortable with my discomfort in trying to interpret the interlocking systems of race, special education, and opportunity. I became comfortable with my discomfort as an able-bodied ally sharing the stories of teenage girls with disabilities. And I disrupted my comfort, as a woman whose personal history is greatly shaped by class, in interpreting relationships between socio-economic status and opportunity.
Several memos centered on particular challenges with data collection. As previously mentioned, Hope was a 21-year-old woman who lives in a group home for people with developmental disabilities. During data collection and analysis I found myself becoming distracted by and angry with Hope’s living situation. She shares a room with an elderly woman and has four additional housemates. One housemate appeared to be in his early thirties, while all other housemates appeared at least twenty years older than Hope. Hope has little privacy at her home. She chose to be interviewed and create her collages around her dining room table. Hope’s legal guardian also agreed this would be a good place to interview Hope and create collages. I was never entirely comfortable with this situation, but for the majority of Hope’s interviews her housemates were either hanging out in their rooms or watching television in the living room. My anger and distraction did not deal with the act of data collection, but rather with the institutionalized life of a high school student.

My background is in adult human services and for several years I have been highly critical of institutionalized settings such as large group homes or sheltered workshops. I initially struggled with how this knowledge-bank colored my interpretations of Hope’s narrative, particularly her path to employment in sheltered work and her living arrangement. Later I became comfortable with my critical interpretation of Hope’s future employment and living arrangements, but I have not become any less angry. I cried when I transcribed her interviews and again when I analyzed them. Hope’s narrative was initially not easy for me to share. I have since harnessed this emotionality and realize the implications of Hope’s experience on effecting change for other young women like her.

In this chapter I outlined the research design of my dissertation, shared background information about each participant, and discussed the methodological and analytical framework.
I also shared any ethical concerns I had and the steps I took to make this study more emancipatory and reflexive. In the following data chapters I present my findings and subsequent analysis. Through data vignettes, survey information, and participant-generated collages I share the participants’ experiences with girlhood and schooling, their understandings of self-determination (i.e., making choices, advocating, and demonstrating control, and their thoughts about transitions and the future. I also critically analyze how various, interlocking systems of oppression shape their narratives.
CHAPTER 3: NEGOTIATING THE BORDERS OF ADOLESCENT GIRLHOOD

Victoria, a ninth grader at Westlake Junior High School, and I were talking about what it means to be a teenage girl. I asked her about the kinds of things teenage girls do at school. At first her response didn’t strike me as particularly unique or out of the ordinary for a teenage girl, “We like hang out. Hang out, just talk together. Talking together and... play together on the playground.” Victoria’s understanding of teenage girlhood includes the practices of hanging out and talking. Her understanding also includes the practice of play, specifically playing on a playground. Victoria constructs adolescent girlhood through both the child-like practice of play, and the more adult practice of “hanging out.” Victoria, and the other participants in this study, actively negotiated the permeable boundaries between girlhood and womanhood when describing their understandings and experiences of being a teenage girl. In this chapter I begin by highlighting the everyday practices of adolescent girls by drawing on their constructions of friendships and sexuality. Next, I discuss the ways in which the participants reconfigure adolescent girlhood through counter-narratives to stereotypical gender roles. In conclusion I discuss how mothers and daughters navigate the borders between girlhood and womanhood, while the culture of special education produces them.

The Practices of Adolescent Girls

In Bettie’s (2003) ethnography of high school girls, she describes the practice of girl talk as, “the discourse of emotional injuries and insecurities, [which] is often the basis for friendship and is what bonds girls” (p. 29). Girl talk involves hanging out and making connections. As the young women in this study and I discussed fashion, movies, relationships, and sports, I found myself dialectically taking up the practice of girl talk. I naturally have a tendency to overuse the word “like” and find myself using up-speak (phrasing a statement as a question) at times, but
when transcribing our interviews I noticed the more comfortable the participants and I became, the more I found myself inadvertently code-switching to these aspects of adolescent girl talk. I was initially weary of my code switching, but soon realized the genuine mode of talk I engaged in with the participants. Bettie argues that by paying attention to girl talk, qualitative researchers open up possibilities for privileging the private spheres of life. By paying attention to girl talk and the private sphere of the participants, I discovered that friendships and sexuality were common themes that spanned the narratives of all four participants.

**Friendships and Diverse Social Scenes**

Female friendships can be vital relationships for adolescent girls to develop. Young women can serve as social support for each other, facilitate adjustment during adolescent years, and help to create a sense of well being, but acceptance in female friendship circles is not readily available to all young women (Crothers, Field, & Kolbert, 2005). Each of the participants experienced friendships in diverse ways. Hope’s friendship narrative appeared sparse when compared to the other participants. Separate classrooms, inaccessible transportation, and segregated housing produced fewer opportunities for her to establish meaningful friendships. Britany shared her difficulties with negotiating what she described as “drama” with various high school girls, while Aminah and Victoria discussed their everyday experiences with friends such as talking, hanging out, attending parties, and participating in structured social events.

**Negotiating dramatic relationships.** As seen in Figure 3.1, Britany chose to represent adolescent girlhood with various words including, “go to parties, drama, swearing, cursing, juvenile, travel, etc.” Her chosen images included favorite television characters, pop culture icons, and young women singing and shopping. Throughout other collages, Britany chose magazine article headings such as, “I was bullied for my beliefs” and “Are cliques always bad?”
in addition to images portraying adolescent girls arguing. During the year prior to this study, Britany had a rather significant falling out with several friends. The “drama” of this falling out was something Britany and I often discussed.

![Image](image.jpg)

**Figure 3.1.** Britany’s collage representing her construction of adolescent girlhood. Images reflect her musical and television interests. Text reflects “things teenage girls do” such as, travel, swear, and go to parties.

Britany: I texted Kimberly and Samantha a lot and they really did not like it. So, I lost my texting.

Danielle: Oh, are those your friends? That you text?

Britany: Um, just Kimberly. Me and Samantha, we’re not really friends anymore. I went through drama like all of last year pretty much. And it was really hard because there was name calling, leaving you out, and not responding to phone calls or texting. And like not being nice. And no one likes that so, I had to do it all of last year and it was really sad and painful at times, but I knew it was my last year there and I was happy because this year I
can start all over with a new beginning, and no drama, and basically things are going really good right now. Anyways, basically drama is about like not accepting someone in the group, and being mean to them, and bugging them or something.

Britany felt a great deal of loneliness the previous year and was very upset during her fights with these former friends. She described instances of bullying, meanness, and emotional pain. The bullying Britany described began when she was left out during a school choir trip.

Britany: Like in the beginning of the year, Madison said to me, “For the chorus trip it’s gonna be me, Natalie, and Arianna.” And that really made me upset ‘cause I wanted to be with them in a group and I wasn’t really a part of it. So, that’s when after that I said, “Madison is stupid” and I called her the b-word. I won’t say it out loud ‘cause I don’t wanna get into trouble. I called her the b-word and she got back at me. Like, she went to one of my really closest friends Kaylee and said, “I don’t like you” to her because she was good friends with me and that really made me upset and stuff. I couldn’t sit at their table anymore.

While it can be confusing delineating between all of these young women, the problem occurred when Britany was excluded during a choir trip. Britany became upset and called the young woman, Madison, who was excluding her, a name. Madison then ostracized other friends of Britany’s and Britany began feeling excluded at school as well. During the time of this study, Madison had graduated, so Britany had experienced less “drama” that school year. However, this incident remains clear in Britany’s mind and she continues to carry the negative effects of feeling socially excluded.

According to Crothers, Field, and Kolbert (2005), aggression in friendships occurs just as often during female friendships as compared to friendship between men. The aggression is categorically different though, in that adolescent boys are more likely to display physical aggression, whereas adolescent girls use their social intelligence to gossip, socially exclude, steal friends, and isolate each other. The authors defined this type of aggression as relational. They examined whether or not gender identity status related to the use of aggression in female
friendships of adolescent girls, and then used focus groups to better understand the participants’ experiences with this relational aggression.

Results indicated that adolescent girls who identified with more traditional gender roles and femininity engaged in more relational aggression toward their female friends. Femininity appeared to restrict the participants’ options in regard to conflict management. As a result, they chose to either repress their emotions or indirectly manage conflict through rumor spreading or alliance building. Operating within sexually oppressive structures, the participants were forced to practice their aggression in covert manners, while remaining overtly nice.

Britany experienced similar difficulties in negotiating the female power dynamics in her friendships. Madison had built alliances that excluded Britany and Britany responded through name-calling and persistent texting. While I cannot speak to the gender identity status of the infamous Madison, many of the images throughout Britany’s personal collages represented more traditional gender roles and hegemonic representations of femininity. Such images included flowers, young women shopping, dresses, handbags, perfume, and makeup. Perhaps this identification contributed to her aggressive relationships with female friends.

According to her IEP, Britany engaged in “fantasy relationships with peers… [which] make it difficult for Britany to interact successfully with her peers.” Her IEP also indicated that she began having friendships with her younger peers, who often left her out. In order to support Britany at school, she is provided with social models, social stories, positive reinforcement, and redirection away from socially inappropriate behaviors. There is no mention of diversity awareness to the larger school population, anti-bullying initiatives, or the availability of social support for all students at Britany’s school. The focus remains on fixing Britany’s “socially inappropriate” behaviors, rather than addressing the culture of schooling or other students.
**Ninth-graders experiencing un/structured friendships.** Aminah and Victoria are both ninth-graders who discussed friendships and social activities as practices of adolescent girlhood. When creating her collages, Victoria would not only choose images that resonated with her, but also chose images of movie stars who she indicated her best friends liked (even though she did not like those movie stars as much). She played basketball with her friends and was also involved in organized cheerleading with them. Victoria interacted with her friends throughout the school day and would talk to them frequently on the phone after school.

Danielle: So what kind of things do you talk about with your friends?

Victoria: We talk about... I know we talk about boys I think, um boys, and good stuff, and we talk about being, um... We talk about being nice, and we talk what we’re doing over the weekend, and what we’re doing over Christmas break or vacations, and all that. And yeah, try to plan something. And yeah, like sleepovers.

Victoria’s mother would also arrange for outings with Victoria and her friends. Victoria didn’t seem to have a great deal of involvement in planning these activities. She appeared to more readily discuss talking and hanging out with her friends, rather than the structured activities organized by her mother.

Danielle: What do you do on the weekend with your friends or family?

Victoria: Um, well I like to do with my friends is we go out and play we just, um sometimes we, um...

Mother: You had that barbeque with your friends a couple of weeks ago.

Victoria: Oh yeah, a barbeque and a campfire outside.

Danielle: Oh where did you do that?

Victoria: At my boyfriend’s house.

Danielle: Oh, cool. What else did you do for that?

Victoria: And we um...
Mother: Next weekend a bunch of you and your friends are going to the movies, Victoria.

Victoria: Oh yeah, so movies next weekend. Hmm, I’m going to the movies next weekend [laughs]? I didn’t know that.

Danielle: Do you know what movie you’re going to go to?

Victoria: I have no idea [laughs]. I hope my mom knows.

Victoria required more processing time to describe the activities she does with her friends, but her mother interjected with two activities: a barbeque and going to the movie theater. Victoria was excited when describing both the barbeque and the movie, but did not seem to be aware that the movie outing had even been planned. Like Victoria, Aminah also described the practices of hanging out and talking with friends. However, Aminah’s experiences with social activities appeared to be less structured and were not initiated by adults.

Aminah began by describing the positive qualities of her friends. She greatly valued their honesty and described her commitment to them over several years.

Danielle: What do you like about your friends?

Aminah: They’re honest. They’re cool to hang out with. Yep. I think I only have hmm… two best friends in here, at Jefferson.

Danielle: So what kind of things do they do that are honest?

Aminah: My friend Chantell tells the truth. Like, if I ask her for her opinion and stuff. But, then we like to play around and all that other stuff ‘cause we know what we… if we say something we don’t really mean it. Me and my friend Latina have known each other forever, since we were little.

According to Aminah’s IEP she gets along well with her peers and is liked by many students. Aminah’s friends describe her as “funny, crazy, and athletic,” and she also enjoys using the computer for social networking. Aminah appears to experience little social stigma attached to her disability label. She has a reading disability and receives push-in supports from a special education teacher. Aminah, along with many other peers, attends tutoring sessions after school to
help her with math skills. She has no want for friends and oftentimes was interrupted by various classmates during our interviews to share the latest gossip, discuss clothing choices of other females, or engage in playful banter. For Aminah, her experience of “the social scene” was quite different than Victoria’s. Aminah and I were discussing girls who skip school and the things they choose to do instead, one of these being attending parties.

Danielle: And so you said that high school girls go to parties too. What kind of stuff goes on at parties?

Aminah: Uh huh [gives me a look as if to say, “ Seriously. You want to know?”]. Hmm… fights and stuff. Like, some people they will have fun. Like, the last time it was a girl party, and we’d have fun, and then they started fighting. I saw blood and stuff on the floor, and they kicked us out, and then I just went home. My brother was still there. It’s crazy. See what young-ins do? What young people do these things? They ruin everything.

Although Victoria and Aminah both described enacting in some sort of social scene, how they accessed that scene, the experiences they had, and the ways they made meaning of social events differed. Aminah’s social practices may have appeared more risky, but more readily reflected a typical high school social scene compared to Victoria’s sleepovers that could be constructed as more child-like. Aminah receives her special education services in her general education classrooms and has access to friends and students in her school throughout her day. She is has access to friends who have IEPs and friends who do not. Victoria is escorted to her self-contained classroom the minute she steps off the bus, spends most of her day in this segregated space, and eats lunch in the cafeteria with her teachers or paraprofessional (Victoria’s experience with policing and special education will be described in more detail in the following chapter). Many of Victoria’s friends also receive special education services. The differences in how Aminah and Victoria accessed and made meaning of friendships and social scenes led to me to question if the consequences of labeling, such as segregated special education, produce
barriers to the creation of meaningful friendships? Segregation is closely tied to issues of sexuality as well.

**Sexuality.** People with disabilities are oftentimes faced with ableist assumptions regarding sexuality, typically being constructed as asexual or not interested in sex (Asch & Fine, 1988; Gordon, Tschopp, & Feldman, 2004). When sexuality is discussed, particularly in regard to women with intellectual disabilities, the discourse is one of protection against violence or is saturated with assumed heterosexuality (Abbott & Howarth, 2007; Anuos & Feldman, 2002; Leicester & Cooke, 2002; McClimens, 2004; Parkes, 2006; Wilkerson, 2002). Coupled with the potentially tumultuous years of adolescence, the sexuality of young women with intellectual or learning disabilities is shrouded in a dangerous silence. Adolescents with disabilities may experience negative self-image or experience difficulties developing intimate relationships, due in part to the stigma of their perceived differences (Gordon, Tschopp, & Feldman, 2004). All of the participants discussed various aspects of heterosexual relationships, whether a boyfriend, participation in school dances, intimate acts such as kissing, or frustration with being denied the opportunity for a sexual relationship.

Throughout our interviews, Aminah described the various friendships she had with the boys at her high school and what sort of boys she likes to hang out with. Aminah is a social person in her school and has many friends, both male and female. During our conversations she shared that she pitied her friends who obsessed over boys and demonstrated a sense of pride at ignoring texts and phone calls by boys. Her narrative made room for relationships with boys at her high school, while also maintaining some power and control over which ones she let into her circle of friends. Socially, Aminah is a self-confident young woman who has clear definitions of the qualities of not only a good friend, but a good boyfriend as well. In the interaction below,
Aminah had just written the word “guys” on her collage (see Figure 3.2) about being a teenage girl.

Danielle: Why did you put guys on there?

Aminah: ‘Cause [laughs].

Danielle: [laughs]

Aminah: ‘Cause my godmother says that’s all I think about. It’s true [laughs]. She’s right. ‘Cause I got a lot of people in my phone, but I don’t have any girls on my phone.

Danielle: You have a lot of guys on your phone?

Aminah: Yes. Um… I only talk to some of them, ‘cause I don’t like calling people.

Danielle: Do they call you?

Aminah: Yeah, I just don’t answer [laughs].

Danielle: You like screen your calls?

Aminah: Uh huh. I look at them, and I see a call, and then I just put it back into my pocket.
Aminah’s collage representing her construction of adolescent girlhood. Text reflects the practices of teenage girls, such as friendship and drama, in addition to likes and interests including adolescent boys and fashion style.

Aminah would oftentimes use the phrase “bein’ grown” to denote some image, action, or idea as being related to sexuality. She would shake her head at images of women wearing revealing clothing while saying, “ugh, bein’ grown.” She also indicated that drama at school involved peers gossiping about others “bein’ grown” (i.e., engaging in sexual activity). She would usually shake her head, smirk, or laugh when making this statement. When girlhood involved intimate relationships, Aminah became shy and uncomfortable in her discussions. Aminah experienced more friendships, social relationships with boys, and access to parties with non-disabled peers than the other participants, but was the only participant not to describe a
specific intimate relationship. She had created space for boys within her circle of friends and appeared to enjoy their attention, but had not developed comfort with intimacy, particularly physical intimacy.

Throughout Hope and Britany’s experiences with adolescent girlhood, both described boys who accompanied them to school events such as dances. As Hope was creating her collage about adolescent girlhood, which was one of the most image-laden collages any of the participants created, we began talking about the things teenage girls do.

Danielle: So what do high school girls do?

Hope: Um… talk on the phone.

Danielle: What kind of things do they talk about?

Hope: Um… Boyfriends and friends.

Hope shared that she had a boyfriend who used to live near her prior to her move to the group home. Hope had just selected an image of two female friends and began describing the image to me. Prior to Hope choosing this image, we had been discussing her upcoming birthday dinner.

Hope: That’s me and my friends [indicating the chosen image].

Danielle: So, are your friends going to your birthday?

Hope: Um… yeah. My boyfriend.

Danielle: Who’s your boyfriend?

Hope: Tom.

Danielle: What do you and Tom do?

Hope: Talk. He used to go to school with me. He graduated.

Danielle: What’s he do now?
Hope: Um… at home. He lived by me.

Danielle: What do you and your boyfriend like to do?

Hope: Talk about school.

Danielle: Was he in that picture from the dance?

Hope: Yeah.

This was the one time Hope mentioned her boyfriend, David, and it was unclear if Hope had retained this relationship after moving into the group home. Hope indicated that she talked on the telephone with David about topics such as school. They had attended a school dance in the past and Hope showed me a picture of the two of them from this dance prior to our interview. She did not add the picture to her collage, but it was important for her to share the image with me. David had since graduated from high school and I did not believe Hope would be taking him to her school dance during the year of this study. Rather, Hope shared that she would dance with her teacher this year.

Hope: I’m going to my prom, with no John Riley [one of Hope’s housemates].

Danielle: What do you do at prom?

Hope: Dance with the teacher.

Hope’s collage about adolescent girlhood (see Figure 3.3) contained many images of adolescent girls and adult women. There was one image of a boy. The image portrayed a young male and female couple walking past a set of lockers while holding hands. The couple is walking away from a young woman who had a sad look on her face. The image of the upset-looking young woman is larger than the teenage couple and she appears to be the focus on the image. Could this young woman represent Hope?
One participant, Victoria, spoke a great deal about her boyfriend throughout our interviews. Victoria has had a boyfriend, Geoff, for a while now. They are both engaged in activism around disability awareness (ending the R-word campaigns). Each night Geoff calls Victoria and they chat about their day. In the exchange below, Victoria’s mother and little brother walk in while we are starting to discuss teenage girl interests.

Mother: Who’s the hot boy?

Little brother: Geoff.
Mother: Is Geoff your hot man?

Victoria: Yeah.

Danielle: So, who’s Geoff? [Victoria’s mother and little brother have left]

Victoria: My boyfriend.

Danielle: Does he go to school with you?

Victoria: No he’s at KD.

Danielle: Where do you get to see Geoff since he doesn’t go to your school?

Victoria: Um… I see him like sometimes, Special Olympics. Sometimes we go, I go to his house, sometimes he goes to mine.

Danielle: What kind of stuff do you guys do?

Victoria: Um… like [we] do our love stuff and just do our thing.

Danielle: What’s that mean?

Victoria: It’s our love thing where we have to kiss and all that stuff. And do something on our bodies.

Danielle: I see. And what do you like about Geoff?

Victoria: Um… I like about Geoff is um… wrestling matches, wrestling.

Danielle: Oh, so he wrestles?

Here I must be a self-reflective researcher and admit that I wasn’t ready to discuss things teenage girls and boys do with their bodies. Was “wrestling” code for physical intimacy? Or did Victoria like that her boyfriend was an athlete? Unfortunately I will never know. My personal anxiety around discussing sex with the participants prevented me from questioning her further. I do not believe it was Victoria’s intellectual disability label that made me uncomfortable. In fact, I was happy that Victoria was involved in a healthy relationship and was supported by her family members. But, if I’m going to continue research in the area of girlhood and disability, I must be
able to ask those tough questions about sex. I may never be completely comfortable, but the participants’ deserve the opportunity to share their stories. Stories such as these demonstrate that young women with intellectual or learning disabilities have a sexual identity, should be supported in their relationships, and deserve access to sex education just like other teens. These sexuality narratives were just one way in which the participants reconfigured girlhood. In the following section I describe other ways in which the participants’ produced counter-narratives to ableist, hegemonic femininity.

Reconfiguring Girlhood: Resistance and Counter-Narratives

Giroux, Lankshear, McLaren, and Peters (1996) describe a counternarrative as an oppositional response to an official or hegemonic narrative. Hegemonic narratives are “those legitimizing stories propagated for specific political purposes to manipulate public consciousness by heralding a national set of common cultural ideals” (p. 2). For example, the collages regarding adolescent girlhood created by both Hope and Britany reflected the cultural ideals of cheerleaders, skirts and dresses, long hair, makeup, and perfume. The collage (see Figure 3.4) Britany created to represent the high school experience reflected these ideals as well.
The concept of counternarratives provides a useful way of thinking about how the young women talk about themselves. These narratives can also be referred to as a local counter-practices. One type of counternarrative is the little stories addressing oppression to hegemonic narratives. The participants in this study shared various stories and practices in oppositional response to hegemonic narratives of femininity. These stories and practices included: sports and food interests, and physical altercations.

**Divergent Interests**
Many of the participants shared particular interests that occupied spaces outside the realms of hegemonic femininity. Victoria and Britany frequently described the foods they liked to eat. Britany shared that the best parts of her employment at Rob’s BBQ were when she was able to taste the food cooked by the chefs and when she carried out food to guests; she enjoyed seeing all the delicious appetizers, entrees, and desserts. Victoria also shared all the foods she enjoyed eating at school, while Aminah pasted images of her two favorite school lunches to a collage on experiencing high school (quesadillas and macaroni and cheese).

Aminah and Victoria also shared many stories related to sports and athletics. Victoria’s collage on adolescent girlhood (see Figure 3.5) reflected both hegemonic femininity as well as counter-interests such as sports and food. Her collage included Edward Cullen, baseball, burgers and makeup. Victoria placed a large photograph of a hamburger above a photograph of teen heartthrob, Robert Pattison. Adjacent to the words that Victoria wrote, “Cheerleading is fun make sure you enjoy it too,” she placed the cutout of a St. Louis Cardinals’ baseball player sliding into a base. This is not to say that the image of a hamburger alone is counterhegemonic, but that the placement of the image near a “teen heartthrob” indicates that Victoria has reconfigured typical girlhood to make room for her varied interests.
Figure 3.5. Victoria’s collage representing adolescent girlhood. A variety of diverse images are represented including male athletes, male and female rappers, clothing, makeup, and food.

Victoria’s collage reflects a complicated and contradictory representation of teenage-girlhood. She also actively rejected certain aspects of childhood and reconstitute new meanings of girlhood that create space for non-traditional practices of femininity.

Victoria: I don’t like princesses, but I know my sister likes princesses. She likes Tinkerbell. I’m gonna cut out Summer, this little girl.

Danielle: Sounds good. What do you like about Summer? About that girl?

Victoria: Summer is one of my favorite seasons, and it’s after the rain, and you go to summer school. Relax a little bit.

Danielle: What’s Summer holding in that picture?

Victoria: Oh, she’s holding a softball.

Victoria’s sister is much younger than her, and Victoria chooses not to include Disney princesses as part of her identity as a teenage girl. Victoria not only challenges traditional modes of femininity (i.e., princesses), but also has actively constructed a new identity for herself that
includes sports. She participates in organized cheerleading, floor hockey, and other sports through the Special Olympics, in addition to playing basketball with her friends and watching sports on television with her family. Aminah reconstituted girlhood to create a space for participation in sports as well.

Aminah views college athletics as one avenue of support for post-secondary education. She plays Amateur Athletic Union (AAU) basketball and helps out with tournaments put on by the league for younger children. She also expressed interest in college volleyball, softball, and track and field. Aminah chose various pictures and words reflecting athletics throughout several of her collages. These included images of football players and volleyball players, and the word “basketball.” Sports were not only an area of interest to Aminah, but shaped various aspects of her identity as well.

One word Aminah chose to describe adolescent girlhood was “perseverance.” She explained that she chose that particular word because, “When I wanna do something I like to stick to it until I like finish it.” Aminah then used participating in high school sports as one example. Even if Aminah disliked the sport and wanted to quit, she stuck to it through the end of the season. Aminah also actively resisted images portraying hegemonic femininity by identifying herself as “sporty” and resisting “girly” fashion styles.

When flipping through the pages of a magazine, Aminah began concentrating on one page in particular. I asked her about this magazine page.

Danielle: What’s it say? The sporty girl?

Aminah: Uh huh.

Danielle: So, what’s it mean to be a sporty girl?

Aminah: A girl that likes to play sports a lot. Too many sports at that.
She then chose an image of the former female rap group, TLC, to represent her own personal style. Aminah particularly identified with Lisa “Left-Eye” Lopez, who’s style entailed baggy pants, floppy hats, and eye black under her left eye (eye black is grease worn by football players and baseball players under their eyes to reduce glare from the sun). Aminah made it clear that she was not interested in “girly style” such as skirts and dresses. She identified “in the middle.”

Danielle: What’s her [Lisa “Left-eye” Lopez] style?

Aminah: They all dead, but I think they all had style then. Her style was like, she wasn’t like girly, she wasn’t. I don’t think she was.

Danielle: Would you describe your style as girly?

Aminah: [shakes head]

Danielle: No?

Aminah: I’d be in the middle.

The abundance of counter-practices and images oppositional to hegemonic femininity led me to wonder if this sense of self contributed to Aminah’s social skills at school, easy-going attitude, and her wealth of friends. Unlike Britany, Aminah did not experience problems with relational aggression (i.e., covert aggression done to damage a particular person’s social status), This may be due, in part, to her dis-identification with traditional femininity. Crothers, Field, and Kolbert (2005) suggest “African American adolescent girls may encounter familial socialization practices that proactively prepare them for dealing with oppression, prejudice, and overt and covert discrimination” (p. 349).

As previously described, Crothers, Field, and Kolbert (2005) examined the correlation between gender status identification and relational aggression. Although this research cannot be generalized to African American adolescent girls due to the small sample size, they did find that
girls of color were less likely to identify with traditional feminine characteristics, and engage in significantly less relational aggression than White participants. Aminah did not engage in overt or covert aggression, but described the physically aggressive actions of other adolescent girls at her high school. She also described these young women as having “snotty attitudes” and “cool” or trendy clothing styles.

**Physical Altercations**

Not all counter-practices are productive. Aminah described violence and the threat of Tasers by security guards at her high school. She and I were discussing adolescent girls who had what she described as “snotty attitudes.” Aminah explained that some of these young women had more friends due their “cool” fashion style, but they also argued with people and were disliked by others. Aminah indicated that these “snotty attitudes” also contributed to school fights.

Danielle: So people get into fights here at school?

Aminah: Uh huh, a lot of them.

Danielle: What kind of things happen?

Aminah: Oh, it always starts and then people get madder. And then they start to fight and then the principal and everybody comes. They break it up and send the people home or the person who started it. But the last time there was a fight, um, it was downstairs in the hallway next to the office and the bathroom, and they decided they wanted to bring out their Tasers and everybody ran.

Danielle: Who brought out the Tasers?

Aminah: The security guards. It was like a bunch of people and so they all just scattered and ran. But they caught the, it was like six girls fighting.

Danielle: Six girls.

Aminah: Uh huh, it was crazy.

Whether Aminah believed the use of Tasers to be “crazy” or the fact that six young women were involved in a physical altercation is not clear. Either way, this narrative of violence
among young women diverged from many of the participants’ descriptions of adolescent
girlhood. Neither Victoria or Hope shared instances of verbal or physical aggression between
young women, but gossiping, popularity and covert acts of aggression were a salient feature of
Britany’s experience with adolescent girlhood. I cannot say with certainty whether Aminah’s
narrative is reflective of her experiences with inclusion and less supervision during unstructured
times at school, or her status as a student of color in an urban school. However, the particular
counter-practice described by Aminah is reminiscent of Trainor’s (2007) study into adolescent
girls with learning disability labels and their perceptions of self-determination.

Participants in Trainor’s (2007) study described their goals for the future, including post-
secondary education, employment, marriage, and starting a family. They demonstrated
competence in how to achieve these goals, but at times engaged in behaviors that may have set
them off course. Trainor found that the “decisions and choices that negatively affected the
educational trajectories of these adolescent girls ranged from decisions to engage in physical
altercations at school to knowingly breaking rules of conduct that carried stiff penalties for
suspension” (p. 40).

Aminah did not identify with the young women she described as physically fighting and
often stressed the importance of not caving in to peer pressure. Aminah had established a sense
of self where physical altercations were not needed and she had developed a sense of awareness
of the potentially negative impacts of certain behaviors on the post-secondary trajectory she was
beginning to establish. Like the other participants, Aminah inhabited spheres of adult behaviors
and understandings, while also retaining features of girlhood.
Occupying the Borderlands

Erevelles and Mutua (2005) describe adolescent girlhood as a liminal time, or an inbetween and transitional period that, “marks that confusing and complex space of liminality where one is not quite a child and not quite an adult either” (p. 253). Adolescent girls with disabilities struggle when claiming girlhood or womanhood due, in part, to oppressive societal attitudes that position them outside the boundaries of sex and gender; perpetually childlike, asexual beings. In response to emancipatory claims of girl power (Bettis & Adams, 2005), where discursive shifts away from traditional conceptions of femininity (i.e., quiet, passive, acquiescence) to spaces of individualism and self-determination occur, the authors discuss intersections of gender and disability. Girl power, Erevelles and Matua argue, remains steeped in ideals of traditional beauty, heteronormativity, and Whiteness. Ableism is at play as well in the constructions of independence and assertiveness that can marginalize the experiences of teenage girls with disabilities.

For many of the participants the enactment of adolescent girlhood reflected permeable boundaries and unstable entry points into adulthood. Aminah’s first response to what it meant to be an adolescent girl reflected the transition from childhood to adulthood. She described this process as “growing up” and through her construction of teenage girlhood she created a process. Growing up was a liminal action that occurred over time and at different times for different people.

Danielle: So, what does it mean to be a teenage girl?

Aminah: [laughs] Um… I don’t know. It’s just like growin’ up. That’s what my mom keeps saying. She says that we have to like, take on more challenges and stuff than we had to do when we were little. When we were younger.

Danielle: Like what kind of challenges?
Aminah: Like, um, maybe like our grades or something. Like, we gotta keep our grades up and ‘cause my mom actually just yelled at me for that [laughs]. And then like you can’t be… how do I put this? You can’t be dirty. You at least have to have style or something.

Danielle: So if someone has style, what might they look like?

Aminah: They’ve got the new name-brand clothing, like Aero or Hollister.

Aminah’s mother has contributed to her conceptualization of adolescent girlhood by signifying that time period as one where children grow up, take on more responsibility, and leave aspects of childhood behind. Growing up entailed taking on greater challenges such as putting forth more effort in school in order to receive high marks. It also entailed greater hygienic responsibilities and a greater focus on outward appearances such as “having style.” Aminah also described key differences between experiencing middle school versus high school, and described a close friend’s path toward growing up.

Danielle: So, why did you put growing up on here?

Aminah: ‘Cause people change from when they were in middle school and high school. A lot of people changed in my school.

Danielle: How do people change? Like, what’s the difference?

Aminah: Like, they’ll be like my friend Shel. She actually, she used to be a little childish some, but when we came to Jefferson she actually like, she grew up you know? She’s different from what she used to be. She’s like a little more mature.

Danielle: So, what kind of things do childish people do?

Aminah: Like, they play around and like get mad. They be really loud and stuff. Then we grow up and we’re quiet. You don’t have, you learn how to control your temper and stuff. Not me [laughs].

Danielle: Not you? What’s it like when you don't control your temper?

Aminah: Bad, ‘cause then I end up getting mad at somebody, and doing something bad, and I get in trouble. I tell my mom or stepdad.
Aminah’s description of the transition from childhood to adulthood demonstrates the liminality of this time period. Not all students end their “childish” behaviors and even Aminah herself recognizes behaviors that she engages in that are not quite “mature.” However, she also recognizes the consequences of “childish” behaviors such as loosing her temper. Aminah occupies both spaces of childhood and adulthood at various times and through different behaviors. She resides a time of childhood when loosing her temper, but resides in a time of adulthood when putting forth effort in her schoolwork.

Victoria occupied both spaces of girlhood and spaces of womanhood as well. She is involved in a relationship with her boyfriend Geoff, where the two of them travel together, demonstrate physical, intimate contact, and converse nightly over the telephone. Victoria would like to live with and marry Geoff in the future. The relationship appears to be mature in nature and is based on shared interests and values. Victoria’s relationship with Geoff positions her within the boundaries of womanhood. At the same time, the following dialogue demonstrates the ways in which Victoria is simultaneously positioned in the boundaries of girlhood.

Victoria: I love acting.

Danielle: Where do you get to do acting?

Victoria: Some in my room maybe and sometimes I do it in school a lot, but sometimes I get in trouble doing that [laughs].

Danielle: Why do you get in trouble doing that in school?

Victoria: I got no idea [laughs]. I have no idea why.

Danielle: Oh, do you like do that in the classroom?

Victoria: Yeah, in the classroom.

Victoria explained that in the classroom she would act out scenes from various movies and television shows, such as Twilight, to herself. According to Victoria’s IEP her interests are
immature compared to other students and she “need reminders not to talk to her invisible friends
during the school day.” Victoria’s behavior of acting out scenes from movies in her classrooms
and her relationships with invisible friends signify her occupation of space more reminiscent of
childhood. Her invisible friends, or “imaginaries” are very significant to her as she indicated
their importance in her construction of the future.

Danielle: So, is there anything else that you wanna share with me that’s important for you
about your future?

Victoria: About my future? Um… what’s important about my future is me being a
wonderful student, and a wonderful girl, and hard worker and um… hard worker and I’m
a fabulous and same with fantabulous. In my future I like to play games in my future, I
like to in my future I like to talk to my friends a lot, talk to my imaginaries, imaginaries. I
talk to my grandma, Cheri; I talk to Sammy. They’re like not there so I’ll talk to them in
my future. Where I wanna go in the future, I wanna go to California, to California, New
York City, Myrtle Beach, Dairen Lake, and Sea Breeze. And I’d like to do my pictures,
read, and sports in my future. Being in sports and hobbies in my future. And all that
[laughs].

In addition to these stories, the words that some participants chose to describe adolescent
girlhood (which some chose to add to their collages) reflected the act of straddling borders as
well. As seen previously in Figure 3.1, Britany chose a variety of words to describe being a
teenage girl. One of these included the phrase, “young lady.”

Britany: How about young lady?

Danielle: When you hear the word young lady, what is that?

Britany: Like sitting properly, like this [demonstrates legs crossed and a straight back],
not showing anything at the bottom, and acting like your age. Being mature, responsible,
and doing chores and stuff. Which I should be doing now, but I can do later. And
basically having fun no matter what.

Britany engaged in code-switching here. First, she began by describing a young lady
using phrases reflective of traditional femininity (i.e., sitting properly, not showing anything at
the bottom). She then began to describe a young lady in a way that reflected Aminah’s
conceptualization of growing up (i.e., maturity and responsibility). Finally, Britany discretely
subverted this construct of teenage girlhood, by indicating the importance of “having fun no
matter what.” Britany has taken up a particular discourse for being a young woman that reflects
hegemonic ideals of femininity and mature behavior. At the same time she occupies a space of
childhood “fun.”

I believe that the concept of borders most accurately depicts the participants’ experiences
with adolescent girlhood. Although the borders between girlhood and adulthood they
experienced are permeable and non-linear, the word border signifies literal or theoretical
structures. Merriam-Webster defines a border as, “an outer part or edge; boundary.” Some
borders can be crossed and returned back through again. This in-between nature of experience is
captured by cultural studies authors such as Anzaldua (1987) in addition to authors in the field of
disability studies and special education (Erevelles & Matua, 2005).

In her semi-autobiographical work, Borderlands/La Frontera: The New Mestiza,
Anzaldua (1987) rejected an either/or mentality in relation to her Chicana identity and embraced
a new Mestiza consciousness or a “consciousness of the Borderlands” (p. 76). Anzaldua further
describes the borderlands as follows:

Cradled in one culture, sandwiched between two cultures, straddling all three cultures and
their value systems, la mestizo undergoes a struggle of flesh, a struggle of borders, an
inner war. Like all people, we perceive the version of reality that our culture
communicates. Like others having or living in more than one culture, we get multiple,
often opposing messages. The coming together of two self-consistent but habitually
incompatible frames of reference causes un choque, a cultural collision. (p. 78)
The borderlands are constructed as rejections of rigid boundaries, a tolerance for ambiguity, sustained contradictions, and assemblages. The borderlands is not a comfortable space to occupy, but Anzaldúa understands them as necessary.

I do not wish to co-opt Anzaldúa’s (1987) theory of the borderlands. Her creation of the Mestiza was in response to racial strife, cultural marginalization, and the violence of oppression. Yet, her work resonated with me throughout this study. Her conceptualization of semi-permeable, yet incompatible borders between race, class, culture, and gender struck me as central to the experiences of adolescent girls with disabilities. Through segregation, overprotection, and a discourse of safety borders have been created around the boundaries of womanhood for adolescent girls with disabilities. The participants in this study, Aminah, Britany, Hope, and Victoria, all occupied this uncomfortable space of “habitually incompatible frames of reference” (p. 78). In the following section I describe in more detail the ways in which these borders are produced through both families and the culture of special education.

**Mothers and Borders**

For many years research on families of children with intellectual disabilities focused on the perceived stress and burdens of raising a child with this disability label (Helff & Glidden, 1998). Over the past several years, research has begun to focus on the positive aspects of families of children with disabilities. Some families report that having a son or daughter with an intellectual disability has had a positive impact on their family life (Blacher & Baker, 2007). Parents also tend to have more positive attitudes regarding transitioning to adulthood when compared to professionals and educators (Morningstar, Turnbull, Turnbull, 1995). This said adolescence can be a time of anxiety, trepidation, and discomfort for parents of children with and without disabilities (Fong, Wilgosh, & Sobsey, 1993; Kidwell, 1982; Montemayor, 1983; Taylor
& Selzter, 2011). Research by Taylor and Selzter (2011) suggests that the stress that occurs from exiting from high school and uncertainty regarding disability services can cause family relationships to become less positive over time.

Britany’s relationship with her mother appeared to reflect both the positive aspects of raising an adolescent along with the more anxiety-causing aspects. Britany’s mother provided her with a great deal of support when navigating tumultuous friendships and Britany often sought out her mother for advice. One of Britany’s worries about eventually living on her own, was that she would not be able to talk with her mother as much or rely on her for “good advice.” Rossi and Rossi (1990) report that mothers tend to have closer relationships with their daughters than with sons of a similar age. During my time spent at Britany’s home it became clear to me that she had a close relationship with her mother. However, their relationship was not without struggle.

Britany would frequently describe instances of her mother not allowing her to engage in typical teenage activities such as watching particular television shows of the “tween” variety that were deemed of too adult in nature for 19-year-old Britany. Britany was also not allowed texting or social networking opportunities such as Facebook, due to previous misuse. It was unclear how long Britany had been denied this privilege, but it did not appear she would be joining Facebook in the near future. By denying her access to these social networking opportunities, Britany’s mother may have inadvertently denied her access to friends and peers. In regard to interests related to the borders of girlhood/ womanhood, the excerpt below demonstrates the ways in which both Britany and her mother negotiate these borders.

Britany: Like, one time when it was during my surgery. Like after my surgery that I had she really wanted to see this movie called Puss in Boots. I really didn’t want to see that and she basically wants us too, but…
Mother: Well I’m gonna rent it.

Britany: What? [exasperated]

Mother: Oh yeah, we’re getting it from Netflix as soon as it comes out.

Danielle: Why didn’t you want to see that one?

Britany: I can’t be seen in school watching that movie. It would ruin my popularity.

Danielle: How come it would do that?

Britany: ‘Cause that popular kids don’t watch cartoons.

Mother: Popular kids watch Disney Channel?

Britany: Some do.

Mother: Oh…

Britany: But still it doesn’t mean anything.

For Britany, watching a cartoon such as “Puss and Boots” was relegated to girlhood. She was uncomfortable with her mother’s interest in this cartoon because of the perceived effect on her “popularity.” Popularity was relegated to womanhood. By indicating that watching television shows on the Disney Channel “didn’t mean anything,” Britany effectively gave that practice space in neither the boundaries of girlhood or womanhood. She was able to maintain liminality for some of her interests that may have appeared more childlike. Her mother made choices regarding the boundaries of girlhood and womanhood as well. For her, the practice of watching cartoons resided within both spheres, but certain “tween” television shows remained in the borders of womanhood and were not accessible to Britany. Both Britany and her mother made choices about these boundaries to best serve their particular needs and interests.

Another practice that required a consideration of border crossing was the act of wearing makeup. Britany, Hope, and Victoria all indicated that makeup was an entry point into
adolescent girlhood. Yet none of them appeared to wear makeup. During an interview with Victoria, her mother subtly created a boundary around the practice of wearing makeup. Britany had stated that teenage girls were interested in popularity. For her, popularity meant wearing makeup, talking to boys, and having “fashion.” But she did not actively claim this particular identity. During a later interview the following unfolded:

Danielle: Alright, so we’re doing Victoria’s collage about the future.
Danielle: Alright, whatever you want to do.

At the end of this interview, Victoria’s mother came into the dining room to see her collage.

Mother: Makeup?
Victoria: Yeah, makeup Mom. I like makeup.
Mother: Oh no. Oh no [feigning a dramatic tone].
Victoria: [laughs]

Victoria liked makeup and identified it as an adolescent girl practice, but did not currently engage in that practice.Victoria chose to represent makeup on her collage regarding the future, and stated that in her future she’ll like makeup. Victoria had not currently accessed this particular sphere of hegemonic adolescent girlhood. Through her mother’s joking tone and Victoria’s choice not to engage in this practice, both women relegated the practice of wearing makeup to the sphere of womanhood.

**Special Education Produces Borders**

The culture of special education also contributed to border creation and limited some of the participants’ access to adult status. The most significant way in which this occurred was
through school-based “super-senior” policies. Hope and Britany, who were ages 21 and 19 respectively during this study, experienced the enactment of policies related to students with disabilities attending public school until the age of 21, if they choose.

Britany spent approximately four hours of her day at school, while the other time was spent at her Rob’s BBQ or retail store jobsites. At times, Britany struggled with the age difference between her and her peers when at school. According to her IEP, Britany’s senior year had been challenging:

since she’s had to be understanding of social changes within her small circle of friends.

Many of her older, more mature peers have graduated from high school and had always kept an eye out for Victoria and redirect her if necessary. She has yet to find a niche of mature and empathetic girls to replace them. Since Victoria is a senior this year, Victoria’s friendships have been with younger girls who don’t know or understand Victoria. She is often feeling left out. (p. 3)

During our interviews, Britany indicated that her “super senior” year was going better, but she continued to experience isolation from her peers and instances of covert aggression as previously described. Where was Britany’s place in school now that she had participated in high school graduation, but had returned? She appeared to occupy an uncomfortable, and sometimes painful, borderland between girlhood and womanhood. Britany also shared that she was glad to be returning for just one more year of schooling. For students with intellectual disability labels, options other than attending school until age 21 are limited. More services are becoming available to support students with intellectual disabilities in higher education, and with statewide self-determination planning more young adults are afforded creative options for community integration and supported employment. But these options remain available to few students.
For participants such as Hope, post-secondary education and supported employment were not presented to her as opportunities. Remaining in school provided an alternative to sheltered work. Although public schooling is likely a welcome alternative, Hope’s three extra years produced various barriers to the enactment of adulthood. Hope had shared with me that she saw her friends at school and they played games together.

Danielle: So you said you and your friends play Apples to Apples. What other kinds of things do you and your friends do?

Hope: On the computer.

Danielle: Oh you go on the computer? What kind of things do you do on the computer?

Hope: Play games.

Danielle: Do you get to do these things at school?

Hope: Yeah. Not tomorrow.

Danielle: Not tomorrow? What stuff are you doing at school tomorrow?

Hope: Birthday.

Danielle: Oh your birthday, cool. What are you doing for that?

Hope: Go out for a drink. On Thursday.

Danielle: Very cool. Who are you doing that with?

Hope: The house.

Danielle: That sounds like fun. Do you know where you get to go?

Hope: Spaghetti Warehouse.

Danielle: What are you gonna get to drink?

Hope: White wine.

In the span of approximately 30 seconds, Hope discursively shifted from childhood practices of playing games at school to adult practices of drinking wine. Hope turned 21-years-
old during this study and shared numerous times that she was going to have her first drink on her birthday. She was very excited about this rite of passage. I was struck by Hope’s statement that she played the board game *Apples to Apples* while at school, as she described classroom activities. Hope participated in a community-based vocational program, but the majority of her time was spent at school in her life skills classroom. She frequently mentioned playing games in that classroom. The juxtaposition of this child-like practice in relation to the adult practice of drinking wine made Hope’s occupation of the borderland apparent.

For some students with disabilities, staying in public school until the age of 21 has several advantages including more time preparing for independence, more opportunities to access the community, and additional time and resources for transition planning. Certo and Luecking (2011) recommend that at age 16, students with significant intellectual disabilities be provided the option of community-based full inclusion, rather school-based full inclusion in order to establish better post-school outcomes. The authors also recommend that students “develop a history of employment prior to school exit where they have been directly hired by employers and have resumes that document their ability to work” (p. 160). It is hoped that this service delivery model will create a presumption of community integration and employability. I believe policies such as this would also position returning students with disabilities within the borders of adulthood. Perhaps Hope’s narrative would then reflect visiting the library with friends, working at a local daycare, and having her first class of wine. Not playing games in a life skills classroom.

In this chapter I shared the participants’ narratives related to their constructions of and experiences with adolescent girlhood. Friendships and sexuality were two practices that occurred throughout all the participants’ narratives. Participants like Aminah, who did not experience
segregation at school due to her disability label, enjoyed many friends and acquaintances. She was an active member of her school’s social scene and spoke with boys often on her phone. Participants like Victoria and Britany experienced a great amount of policing and structure when it came to friendships and intimate relationships. At times the culture of special education policed these two participants through segregation and behavior management, while at other times the participants’ mother constrained their daughters access to peer groups through structured and monitored leisure time. This protection demonstrates a tension between the supports these participants’ mothers provided in regard to their daughter’s heterosexual relationships. Hope’s institutionalized life caused her social experiences to diverge greatly from the other participants and prevented her from accessing typical experiences with friends and peers.

The participants also reconfigured girlhood through counter-practices such as heterosexual intimacy and claims of sexual agency, in addition to enacting divergent and contradictory interests related to food and sports. They recreated meanings of girlhood that fit their complex needs and interests. In conclusion, the participants occupied the borderlands between girlhood and womanhood. Sometimes participants appeared to actively choose to reside within the borders through their diverse interests, while at other times the young women were denied access to womanhood through poor special education practices (i.e., playing childhood board games at school) or limits places on them by other adults (i.e., being denied access to social media or certain television programs). In the next chapter, I will explore the participants’ conceptualization of self-determination and their access to opportunities for making choices and controlling the direction of their lives.
CHAPTER 4: CONSTRUCTING SELF-DETERMINATION

As Smith and Routel (2010) note, self-determination has many meanings – these meanings are as diverse as the people who experience self-determination. In order to respect the diverse understandings people hold regarding their own self-determination (i.e., making choices, advocating, demonstrating control, etc.), I present each participant’s construction of self-determination as an individual narrative derived from their interviews and participant-generated collages. Following the individual narratives, I present an analysis of the self-determination narrative presented through the participants’ IEPs, highlighting notable discrepancies, and then mix these qualitative accounts with numbers (the AIR Self-Determination Scale). In conclusion, I share the contradictions that emerged and briefly summarize commonalities across the participant narratives.

It is important to note that throughout this study I did not approach self-determination as a skill, which is the traditional and pervasive approach to self-determination in the current literature. Rather I approached self-determination as a concept constructed by the participants’ experiences. When relying on the participants’ expertise regarding their own self-determination, more epistemological space is created for political and contextual understandings, and issues related to social justice can be analyzed more readily. This approach is more reflective of a disability studies understanding of self-determination, where the concept can be understood through the lens of opportunity and access, and in a more nuanced fashion less reliant on remediating or building skills.

The participants shared a variety of ways in which they experience self-determination. Victoria and Aminah characterized self-determination as “making good choices” or “good behavior. Victoria also framed advocacy as her activist work for the end the R word campaigns,
while Aminah demonstrated control over where she attended high school, her career path, and negotiating family tensions. For Hope, her opportunities for self-determination, control, and advocacy operated through the constraints of segregated schooling and living environments. Britany demonstrated moments of resistance by attempting to engage in the behaviors of a typical 19-year-old, and also demonstrated a great deal of control over her future through her involvement in statewide self-determination planning.

Following these diverse narratives, I describe the ways in which the participants’ IEPs failed to reflect their understandings and experiences with self-determination (with the exception of Britany’s). Then, while undergoing the complex task of mixing qualitative and quantitative data, I found that the participants whose narratives reflected a more self-determined life, generally reported greater dissatisfaction with their opportunities for self-determination. In the concluding section of this chapter I bring forward possible explanations for this and other contradictions that appeared through the mixed-method analysis.

**Victoria: An Anti-Bully Activist with Good Behavior**

I first met with Victoria in her parents’ house in a suburban development. She wanted her first interview to focus on self-determination and advocacy. Her mother shared with Victoria that this meant, “Doing what you need to do to get the things you need.” Victoria began talking about her recent trip to New York City where she starred in an anti-bullying public service announcement about ending the use of the “R-word.” A few days later, Victoria and I began her interview.

We used an online thesaurus so that Victoria could choose a few words that she liked to describe self-determination or advocacy. The first words Victoria chose were advocate, activist, and fight. She later included two of her favorite “tween” stars from popular culture, Miley Cyrus
and Hannah Montana (who is a Disney character played by Miley Cyrus), Team USA, and the phrases “anti-bullying” and “helping with my friend with all of their other stuff” (see Figure 4.1). These words alone reflected two major aspects of Victoria’s understandings of self-determination: advocating for what one believes in and being a good person. For Victoria, these aspects of self-determination were closely related, but also diverged in important ways that will be described in the following sections.

![Victoria's collage](image)

*Figure 4.1.* Victoria’s collage representing her understandings of and experiences with self-determination. She constructed self-determination through her activist, anti-bullying work as well as everyday choices.

**Anti-Bullying Activism**

As demonstrated in Figure 4.1, the word “activism” is presented center-stage in large letters on Victoria’s collage signifying the importance of her activist work. Victoria’s first choice
of people who represented activists was a group of adolescent girls who appeared to be friends.
When I asked Victoria what they girls were doing, she described them as follows, “they’re lifting up that girl and they’re like carrying her by her feet. Carrying her.” For Victoria, an activist (or a self-determined person) is someone who helps others – literally carrying the weight of another person. I found this interesting and wanted to know more about Victoria’s connection to activism.

Danielle: Is there anything that you do that you might think is something an activist does?
Victoria: I might help out with my friends and with their stuff.

Danielle: Can you tell me what things you do to help?
Victoria: Helped picking up their stuff. Lockers and stuff like that. Helping them get their binders when I drop something on the floor I helped them pick that up.

One way that Victoria experienced activism was through a rather everyday experience: helping (and being helped) to pick up things such as binders if they are dropped as school.

Victoria’s experiences with activism (which she connects to advocacy and self-determination) span both the everyday occurrence of helping a friend with a dropped object and the rather unique opportunity of participating in a nationwide anti-bullying campaign.

Choosing a female, “tween” celebrity holding a sign triggered Victoria’s anti-bullying narrative.9 I knew Victoria had travelled to New York City to participate in an anti-bullying event and wanted to know if there was a connection here.

Danielle: Did you do that [hold a sign] when you went to New York City?
Victoria: Actually, I was acting.

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9Victoria chose many “tween” female actresses and singers to represent activists as well. When asked why she chose these young people as activists, she indicated that they were hugging and smiling. I believe at this point during her collage making, Victoria was interested in representing things she was interested in such as music and Disney television shows, as she also began choosing famous celebrities of whom she was a “huge fan.”
Danielle: Oh, you were acting? Okay.

Victoria: Yeah. It was about when these girls tried to be mean to me and bully me. That’s what it’s supposed to be all about, about being mean. They said the r-word [retard], bullying me and all that, and where Justin comes in a falls. I look at him and he falls, my boyfriend.

Danielle: Do you remember what kind of things you said in your video?

Victoria: Mean girls were trying to steal away my bag and I had to say, “Please stop” and they still keep on stealing my bag trying to say, “Uh, you’re stupid” or “A retard.” And I gotta say, “Please give me my bag back.” And the mean girls say, “Your parents must hate themselves.” And I say, “Please stop. I’m not a retard, I just want my bag back.”

Danielle: How did you feel when they said that stuff to you?

Victoria: Hurtful.

Victoria participated in a second scene as well, where her boyfriend Justin trips and falls and is laughed at by the same mean girls. These anti-bullying public service announcements were part of a campaign to end the use of the r-word.

Socioeconomic status and cultural capital shaped Victoria’s experiences with activism. Bourdieu’s (1986) concept of cultural capital indicates that certain social or cultural assets promote social mobility. Societies place social value on certain habits, dispositions, and skills, leading to issues of inequity. The self-determination Victoria demonstrated by participating in such a campaign was not simply the result of her interest in the issue or her acting skills. Victoria had access to this opportunity, due in part to her upper-middle class socio-economic status (travelling to New York City and obtaining hotel accommodations requires economic capital) and her family’s familiarity with the campaign (a mother who was a graduate-educated, high school Social Studies teacher with the cultural capital to advocate with her daughter). This is not to diminish Victoria’s commitment to anti-bullying or to make light of the importance of her involvement with the cause to end the use of the r-word. Instead, my desire is to situate this
experience within the context of Victoria’s privileged position of a White, upper-middle class adolescent with cultural capital.

Anti-bullying resonated personally with Victoria as well, as she was the victim of bullying at her school. After choosing the word “fighting” and double-underlining it on her collage, Victoria described a disturbing incident where she was the victim of bullying and sexual aggression.

Danielle: So are there things that you fight for or that you’ve had to fight for?

Victoria: Well somebody was bullying me that one time last year. He pushed, well I was down the stairs going to class, I was up the stairs and he was at the bottom. He pulled me down the stairs and pulled me into the bathroom and started to kiss me. He was also mean to me last year.

Danielle: What did you do?

Victoria: I was [laughs nervously] starting to fight and I, when I had to yell for help I had to fight him. That’s why I had to fight him.

This traumatic event continued to resonate with Victoria and her mother who indicated that the school failed to provide support, stating that without videotape they could not prove the assault occurred. Victoria now has a game plan in the event another incident occurs: yell for help, try to fight back, and tell an adult. This event may have led, in part, to Victoria being more closely monitored at her school and escorted to all of her classes by a paraprofessional as evidenced by our discussion of choosing classes for the following school year.

Danielle: How do you figure out what classes to take?

Victoria: It’s on your schedule, like an agenda… Next year I think the teacher’s gonna give me a schedule of what classes I have to go to and I have to stay with the teacher at all times, but I don’t know what she’s gonna do next year. I got no idea [laughs].

Danielle: You said that you’re teacher is with you all the time. How do you get from class to class?

Victoria: The teacher had to walk you up to class and say with them. But like if you’re in
Special Ed. you stick with the teacher at all times that they can watch you and all that stuff.

Danielle: What do you think about that?

Victoria: I like that really.

Danielle: And why do you like that?

Victoria: Because it’s easier for me when I walk with the teacher and not just straggle around like the other kids in my school… So we just stay with the teacher all times and the teacher walks up to class with us and walks us to lunch and we just brush our teeth after that.

Chenoweth (1996) examines violence toward women with disabilities in Australia, citing extreme marginalization and exclusion as factors leading to greater vulnerability and abuse when compared to women without disabilities. Chenoweth notes how “many of our social practices involving women with disabilities… such as overprotection, segregation, the training of women with disabilities to comply with requests from staff… all increase the incidence of abuse and violence rather than prevent it” (p. 391). Whether her monitoring was the result of the violence she experienced or not, Victoria’s schooling experiences spanned the scope of all of these practices: overprotection, segregation, and compliance. Her Special Education teacher meets her as she steps off the bus, throughout her day she is escorted from class-to-class by a paraprofessional, and she eats her lunch with teachers in the school cafeteria. Victoria’s IEP indicates that she “needs adult monitoring and supervision throughout the school day, especially in unstructured settings and transitions such as the hallway.” There did not appear to be any thought given to how a peer may have supported Victoria throughout the hallways instead of an adult.

Victoria’s disability label and her association with special education, has marked her as a student who requires policing. Victoria noted how the special education students had to stick
with their teachers at all times and, unlike “the other kids” at her school, shouldn’t “straggle.” Victoria has even taken up this discourse and believes it to be easier to walk with her teacher. Although Victoria takes comfort in walking the busy halls of her school with an adult, what typical high school experiences is she missing through this monitoring? What opportunities for social interaction in the information spaces of school are diminished? There is a certain amount of dignity of risk that is not afforded to Victoria, and as Chenoweth (1996) notes, this overprotection can actually lead to more violence rather than prevent it. Victoria has taken a stand against bullying and violence through her public service announcements (both of which experiences are absent from her IEP), yet her self-determination narrative is also shaped by a discourse of policing and compliance.

**Choosing to be Good**

Making choices in one’s life remains a large component of current conceptualizations of self-determination (Ward, 2005; Wehmeyer, 2005). Choice is a concept that operates through opportunity and is shaped by social location and capital. In Ratner’s (2000) analysis of agency and culture, he noted how “agency always operates within and through a social structure” (p. 421). Intention and action are socially constrained. For students with disabilities, choices in school are oftentimes limited and students may not be given the opportunity to act upon the choices they would like to make (Cowley & Bacon, 2011). For Victoria, choice operated within a discourse of compliance and good behavior.

Danielle: At home, what kind of choices do you make?

Victoria: Good manners and behave.

Danielle: Are there other things you choose to do at home?

Victoria: Sing and dance upstairs in my room and I like to write a lot in my room on paper.
Victoria enjoyed singing and dancing to her favorite “tween” musicians, Miley Cyrus, the Jonas Brothers, and Candice. She also enjoyed watching her favorite Disney channel television shows. However, the first choice Victoria mentioned was related to having good manners and behaving well. Needless to say, I found this surprising. Victoria shared both everyday choices as well as the theme of good behavior when discussing the choices she made with her friends at school as well.

Danielle: How about when you’re with your friends? What things do you choose to do?

Victoria: Well, we get good manners and behave and be sweet and nice to each other and we just give out candy and hang out.

Danielle: What do you do when you hang out?

Victoria: Sometimes we listen to music and sometimes we get our homework done together.

Danielle: How about at school? Are there choices that you make at school?

Victoria: You can’t talk when the teacher is talking and whenever you say something you gotta raise your hand. There’s the golden rule.

Danielle: What’s the golden rule?

Victoria: Golden rule is, um, it’s hard to explain.

Danielle: Is that like “do onto others?”

Victoria: Yeah I think that’s it. Be respectful to one another, be nice, try not to get into trouble.

As with the choices she makes at home, choices with her friends and at school reflect everyday experiences and the things Victoria enjoys in life: hanging out with her friends, listening to music together, and eating school lunch. Victoria loved choosing what to eat for lunch and shared at length her favorite foods: pizza, meatball submarine sandwiches, and cheesy mashed potatoes. But again, the discourses of compliance and good behavior constrained
Victoria’s ability to act with agency. Victoria has constructed an aspect the self-determined person as a young woman who is polite, behaves, follows classroom rules, is respectful toward others, and doesn’t get into trouble. Ashby (2008) reported similar findings regarding the ways in which middle-school students with disabilities constructed smartness.

For an eighth grade student with the label of autism in Ashby’s (2008) study, being smart meant that you were nice and that when teachers looked for smartness, they were looking for good behavior. The parents of a female middle school student in Ashby’s study relayed similar responses when constructing their daughter’s competence:

- Christy: Where are some situations where Hillary really does well?
- Don: I think she is extremely well behaved. She always seems to be doing the right thing in class. I think she has a maturity about her. She works hard, she takes her work seriously. (p. 178)

Hillary constructed smartness in a similar manner when “she responded that being smart meant being ‘good’” (p. 178). As Ashby notes, as was similar to my experience, we failed to recognize the cultural contexts of schooling for our participants in these situations. The cultural of schooling, particularly the culture of special education has provided students with way of thinking about both self-determination and competency: working hard and having good behavior.

The narrative constructed through Victoria’s IEP rearticulated the gendered culture of compliance and politeness. Victoria’s present levels of performance are littered with adjectives describing her as sweet, likeable, polite, kind, hard-working, and is described as a “happy young lady that [sic] is motivated to do well and to please those around her.” This culture is particularly problematic for young women. Victoria’s constructions of choice as politeness, following rules, and being nice and sweet, in addition to the value placed on compliance and pleasing others
reflects antiquated gender stereotypes that, according to Chenoweth (1996), can contribute to violence against women with disabilities.

I also believe the phrase, “Make good choices,” that is used by many adults and teachers today, has been taken up by adolescents and is used to understand their sense of self. Scholars such as Desjardin (2012) demonstrate how the “make good choices” discourse has significant consequences on the bodies of young women with intellectual disabilities. Desjardin discusses the “voluntary” sterilization of young women with intellectual disabilities and how these young women are taught to make “the right choice” (i.e., sterilization), otherwise they are not allowed to have sex. Parents are no longer forcibly sterilizing their young daughters, but instead ask them to make the “good choice.” Aminah, also a ninth grader during this study, constructed self-determination with “good choices” in mind while leaving room for agency by directing several major life experiences thus far.

**Aminah: Making “Good Choices” as a Means to an End**

Aminah volunteered for this study after speaking with her special education teacher. Aminah and I met for an hour at a time in her high school library, and our final interview focused a great deal on self-determination. When I asked Aminah about the choices she makes in her life, she was initially confused. But as Aminah walked me through the choices she made at home and school, it became clear that her life experiences (both the everyday and major events in her young life) led her to construct self-determination in a very particular way: things she wants to do, things she has to do, and the impact that “making good choices” has had and will have on her life.

**Things I Want to do and Things I “Hafta” do**
From the start of our interview, Aminah differentiated between the choices she wants to make and the choices she has to make. The following excerpt demonstrates this clear discursive shift between choosing to do things and needing to do things.

Danielle: Walk me through your day. When you get up in the morning what’s it like?

Aminah: What’s it like?

Danielle: What stuff do you choose? Like, what things are you able to pick?

Aminah: Oh, what type of clothes I wear, or what else? I don’t know, that’s it. I mean, ‘cause everything else I know I need to do.

Danielle: Like what kind of stuff?

Aminah: I gotta brush my teeth, take a shower [laughs].

Danielle: So, what about at school? Are there things that you get to choose at school?

Aminah: Um, I choose a lot of things. Like if I wanna do my work or not. Or like some days, I’ll have them days where I just don’t wanna do anything. I don’t, but I hafta.

Danielle: Who says you have to?

Aminah: My mom [laughs].

Even though Aminah discursively differentiates between the everyday things she has to do and the everyday things she wants to do, she still actively makes the choice to do the those things she constructs as necessities, not choices: chores, self-care, school work, etc. Aminah also differentiates between choice and things she “has to do” at home. Chores are something she has to do, even though she actually chooses whether or not to do those chores, but taking her sisters to the park is something she identifies as a choice.

Danielle: What about stuff on the weekends? Do you get to choose things to do on the weekends?

Aminah: Oh, I leave, but I haven’t left for a while. If it was the weekend I’d like choose to take my sisters to the park or something.
Danielle: What kind of stuff do you do with them at the park?

Aminah: We play um, my sister was mad. She was standing there, and I called her, and she looked at me, and I was like, “Tag you’re it.” And then my little sister asked if she could play, so we just started playing. I like playing with them for some reason. It’s fun, I don’t know. So, it’s fun. It be fun sometimes, but then like if I’m home I usually lay down and watch TV or talk on the phone the whole night. That’s it [laughs]. Or if I leave, I’ll go to my godmother’s house.

These choices may seem rather mundane at first glance, but given Peterson’s (2009) case study of one young woman’s self-determination, these mundane choices are quite important and, in a relative sense, demonstrate the amount of control Aminah has over her life. According to Peterson, “efforts at creating and fostering environments that support students in their freedom to exert authority, autonomy, and responsibility over their lives have gone unrealized” (Good Intentions Gone Bad: The Quandaries Surrounding Self-Determination section, ¶ 2). In Peterson’s research, Shana’s (a high school student with a disability) meals and snacks were predetermined. She completed an application for a predetermined job and had no input or control over her physical therapy sessions (i.e., scope and type of exercise or whether to receive the service at all). Peterson discovered that Shana was quite self-determined, but was rarely presented with opportunities for authentic choice. For Aminah, even the opportunity to authentically make seemingly mundane choices, is an opportunity.

The choices Aminah makes throughout her day, particularly the behaviors that she feels she must engage in during school are constrained by the similar cultural of schooling experienced by Victoria: following rules and staying out of trouble. Aminah described such school rules as staying in the classroom, not missing classes, not “acting up,” staying out of the hallways, not fighting with each other, and not putting others down. The consequences of not following the school rules results in “ISS” or In-School Suspension, a place where Aminah states you must sit, be quiet, and are not allowed to do any work. Aminah herself has experienced this
consequence due to talking out of turn in class and subsequently arguing with her teacher. Again, Aminah’s mother ties into this situation – she was glad her mother was not telephoned, as she would be very angry with her. While Aminah understands rules and behavior in a way that is similar to Victoria, her narrative diverges in how she experiences the culture of special education.

**Major Life Choices**

Aminah’s agency appears to be shaped by several major life experiences including adjusting to family fights, changing her enrollment to a cross-city school, and navigating college entry, as well as the way she experiences the culture of special education.

Danielle: So can you think of any really important choices you’ve had to make?

Aminah: Well, I had to ‘cause my mom and my aunt [Aminah’s former guardian] was fighting, arguing so, ‘cause I like to hang out with my aunt a lot. So, I had to make a choice to stay home instead of go see her and so, that’s what I did. I stayed home for like two or three weeks, or a month [laughs]. It was a long time, but I seen her on Monday? Tuesday? Yeah it was Tuesday. I just couldn’t handle it, so I seen her on Tuesday and she said come over on Friday.

Danielle: How did you figure out to choose to stay home instead of going to your aunt’s?

Aminah: ‘Cause I know how my mom would get. She’d get mad ‘cause I didn’t tell her. Then she’d be like, “Um yeah you can call her, but just tell her I’m not home” [laughs]. So I decided not to say anything.

Aminah frequently described making choices that would not make her mother mad. While we did not get into the details of what occurred when her mother would get angry, Aminah sometimes shared her mother’s drinking habits and behavior when under the influence of alcohol. It appeared that Aminah’s mother and her aunt had a tumultuous relationship and Aminah attempted to navigate that relationship as best she could. It saddened me that the situation described would be the first experience Aminah shared with making an important choice. Aminah demonstrated skill in navigating this family tension, but I wondered how this
skill would be understood from a traditional self-determination framework. Goals, planning, and self-regulating take up a great deal of epistemological space. Trainor’s (2005; 2007) and Peterson’s (2009) work provided the closest narrative to what Aminah had shared – narratives of grandmother’s discouraging sexual relationships and young women fighting with peers over family honor. The language of goal-setting and self-regulation are irrelevant to the self-determined narrative of an adolescent girl navigating family troubles shaped by race and socio-economic status.

Aminah initially indicated that the choice of not visiting her aunt in order to appease her mother was the “one thing” involving an important choice in her life. In previous interviews, Aminah shared that she had chosen to attend her current school, which was located over six miles from her home, rather than her neighborhood school.

Danielle: You mentioned earlier that you chose to go to this school.

Aminah: Oh yeah!

Danielle: So how did you do that? How does that work that you chose this school?

Aminah: I don’t know. I just... ‘cause we moved from Maple over here on the East side, and then my mom told me I had to go to Hillsborough, and then I just, over the summer I was waiting and waiting for a while, and then when the month came up I started begging her [laughs]. Me and my brother did it and she said that we could both go to Jefferson ‘cause my brother was coming from Jefferson. We moved and he was at Jefferson at the time, but she said we can’t, and I was not happy ‘cause I actually thought I was going to Hillsborough, and I don’t know nobody there, and I don’t like nobody there.

Danielle: How did you have to convince her?

Aminah: [laughs] Oh, she was sitting down and then, like I’d go do something or I’d go into the living room and I’d be like, “I’m going to Jefferson. And she’d be like, “No you’re not” [laughs]. And I was like, “Why not?” I told her that everybody went to Jefferson, but she said she went to another. And I told her I don’t like people at Hillsborough. And I told her, “Why should I go to Hillsborough when my brother’s going to Jefferson?” And I think she called Jefferson and registered. Yeah, so that’s what she did. And she told me I’m going to Jefferson, but I’m gonna have to take a couple of busses to get there. Doesn’t matter to me [laughs].
This was such an important choice for Aminah, to continue her schooling with the friends she had prior to her family move, that she was willing to take two busses across town and get up at 5:20am in order to board that bus at 6:30am. Again, I believe that this story may have been overlooked if self-determination was approached through a traditional or purely quantitative orientation. How can a researcher “score” the skill involved in making decisions like Aminah has had to make or pass judgment on the kind of self-determined person she is or is not? Smith and Routel (2010) note that

almost a decade of qualitative research on self-determination as understood and created by people with disabilities and their families (avoiding, pointedly, constructions by professionals and service industries) has found that the idea literally means something different to each person, whether they have a disability or not. (Self-Determination and Transition: Individually Relative Definitions section, ¶ 5)

The authors posit that constructing self-determination as a set of skills to be taught and measured reflects colonialist tendencies where an in-group (people without disabilities) teaches an out-group (people with disabilities) to gain something the out-group does not have, but should. Therefore, the in-group controls the definition of self-determination and who counts as a self-determined person going so far as to determine how much self-determination a member of the out-group possesses.

A final important choice that Aminah shared related to her desire to attend the local private university to pursue pediatric medicine or nursing. Aminah actively made choices that will allow her to gain entry to college and (as will be described in Chapter five) has developed an identity as a first-generation college student. Her IEP also reflects Aminah’s post-secondary education goals to attend college, her chosen career path in medicine, and her desire to live
independently. I asked Aminah about something important in her day that she wants to make
sure she gets to do.

Aminah: Stay after school. ‘Cause my grades, they were going through high and then in
the middle and then it gets a little lower. But then some of the classes are a little higher,
so I have to stay after school.

Danielle: What kind of stuff do you do when you stay after?

Aminah: I go to my classes. It just, if we stay here they go to [local university] tutors and
they help me with my math. I only ask them to help me with my math ‘cause I don’t get it
like that. Then, if it’s another day I’ll stay after with the teacher.

Aminah also described the college applications she would need to fill out and the
personal essay she would have to write. Aminah feels that will be easy to write, “‘Cause I love
myself.” Aminah then added two phrases (see Figure 4.2) to her collage – up until this point
Aminah’s collage was a blank sheet of white paper and these were the only phrases to be
portrayed on her college, no images.

Aminah: Making my own choices every day. Hmm… what choices do I make? I make
good choices. I do.

Danielle: What’s that mean to make good choices?

Aminah: Like if somebody asks me to do something, anything. Anything I don’t like that
I don’t wanna do I tell them “no” ‘cause I know the consequences. And I just know I’ll
get in trouble if I do stupid things. I mean things like, not if it’s just if I wanna laugh. I’ll
do something stupid so I’ll laugh. But if it’s something else that I really don’t wanna do,
don’t wanna do at all.
Aminah’s understanding of choice is guided by self-policing. She wants to attend college for pediatrics or nursing and is aware of the consequences of peer pressure. Aminah’s conceptualization reflects agency, rather than the social constraints that shape Victoria’s understanding of choice. Of course, all choice is socially constrained. The key is trying to understand why some young women construct “good choices” in a way that leaves room for agency, while others are not afforded this opportunity.

One reason may be related to Aminah’s disability label: learning disability. For Aminah, this provides her with less segregation and monitoring than Victoria, who is labeled with an intellectual disability. All of Aminah’s classes are in general education classrooms and she
receives push-in resource support from special education. Aminah is independent as she travels the hallways of her school and does not eat lunch with her teachers. Aminah experiences the culture of special education in a much different manner than Victoria. The monitoring Aminah experiences is similar for all the students at her high school, while Victoria experiences an additional layer of policing through the culture of segregated special education. This may explain, in part, why Aminah retains her sense of agency when conceptualizing the meaning of choice.

**Hope: An Institutionalized Life**

Hope and I met after speaking on the phone with her legal guardian, Joyce. Joyce thought Hope might be interested in sharing her story with me. Indeed, Hope was very excited to talk about school and the future, and was quite proud of the collages she created as they hung the walls of her group home. Hope struggled at times with verbal communication and articulating her thoughts, but created her collages with ease and excitement. When we began discussing advocacy and choices this changed. As evidenced in Figure 4.3, her collage contained the fewest images of her four collages, and her responses to my questions on this topic required the most prompting. Although I can only speculate, the vibrancy missing from Hope’s collage and responses may reflect the authentic choices and self-direction missing from her life. Central to Hope’s self-determination narrative is her advocate Wendy, but their relationship, and much of Hope’s life, operates within the institutionalized structures of the human services industry.
Figure 4.3. Hope’s collage representing her understandings of and experiences with self-determination. Her collage reflects activities she engages in with her advocate and her interest in cooking.

An Advocate and Friend

Hope shared with me her friendship with Wendy, a woman who worked at Hope’s group home and who served as her advocate. Throughout my time with Hope she would oftentimes discuss things to do with friends at school and she described many of the females on her collages as images of her friends. This said, Wendy was the only friend who was provided with a name. In the human services industry advocates oftentimes provide guidance to people with disabilities, attend service-planning meetings as support people, and serve as allies. Hope’s conceptualization of Wendy as an advocate, reflected a relationship that straddled work and friendship.

Danielle: What are some things that your advocate does?
Hope: Um, do my hair.

Danielle: What are some other things that Wendy does?

Hope: She spends time with me.

Danielle: What kind of things do you do when you spend time together?

Hope: Cook together, do laundry together.

Danielle: So how does that work when you guys… how about when you cook together. How does that work?

Hope: I read off the menu.

Danielle: And what does Wendy do?

Hope: She cooks.

Danielle: Do you do anything else with the cooking?

Hope: Make juice.

Adolescent girls do each other’s hair and spend time with each other, but Hope’s relationship with Wendy is more complicated. At what first appears to be a working relationship between a young adult with a disability and her care worker, Hope and Wendy shared genuine affection for each other and often joked together during my visits. Wendy was proud of the collages Hope created and would many times ask her to share what the images meant to Hope. The two smiled and laughed together in the mist of “time spent together” involving laundry and cooking meals for Hope’s housemates.

Hope did not experience many opportunities for making friends with people her own age. She had previously been involved in cheerleading at her high school, but was not involved in extra-curricular activities during the school year of this study. Hope’s guardian encouraged her to choose between cheerleading or the school play for this academic year. Hope chose the school play, but during this study she had not attended any rehearsals, did not have a role, and her
teachers struggled finding a place for her in this event. She would be attending the school’s annual Homecoming dance and Prom, but other outside activities appeared to always be within the scope of the group home activities and with her housemates. Hope’s opportunities for interactions with youth her own age was further complicated by inaccessible transportation – all of Hope’s six housemates, including herself, used wheelchairs and two accessible vans were available to the house. Hope’s IEP indicated that she “would like to be able to access the community more often, by being able to utilize transportation in a personal vehicle.” This “service” outlined in Hope’s coordinated set of transition activities addressed a clear need of increased community access, but plans for implementing this service or supporting Hope to achieve this goal were absent from the IEP.

Marquis and Jackson (2000) explored the relationships between people with disabilities and service workers in 14 agencies across Australia, including both young and older adults with disabilities. For people with disabilities requiring home-based services, quality relationships with service workers are of great import. The authors note how many times, “it is more difficult for people living in services to expand their social world and relationships with service workers may be the only validating relationships in their lives” (p. 411). With the instances of abuse occurring throughout residential services in the United States, it is important for Hope to have her supportive and validated relationship with her service worker. But for a high school student, is this enough?

**Institutionalized Choice**

Throughout my interviews with Hope she expressed a strong interest in food and cooking. Her collages would oftentimes contain images of food (her only image on the self-determination-related collage was that of a hamburger) and she would show great interest when
perusing the pages of Rachel Ray’s magazine. With pre-planned meals and grocery lists, Hope’s involvement with cooking was limited to reading aloud a menu and stirring juice. Although at school, Hope was more engaged with the actual art of cooking her involvement with cooking at her home reflected just one of the many instances of choices operating within institutionalized structures.

Hope makes many choices throughout her day and in her life – what clothes to wear in the morning, what to eat for lunch, and the kinds of extracurricular activities she participates in. Hope is an early riser who does not choose her own breakfast. She does not choose where to sit on the bus and does not choose the courses she takes in school. Hope has the opportunity to choose what to eat at her school cafeteria and shared with pride that she chose her current jobsite through her high school’s transition program. Hope also chose to participate in cheerleading during the school year prior to this study. After returning to her group home at the end of the school day Hope watches television programs and then eats dinner at approximately 5:00pm. After dinner she gets ready for bed and is asleep by 7:00pm.

During the course of our interviews, Hope would frequently mention her upcoming summer job at a place called Alliance. Hope believed she would be engaging in computer work at this job and we talked about her involvement in choosing this course of employment.

Danielle: So how did you get this summer job?

Hope: There’s a waiting list.

Danielle: And did you pick that place to go?

Hope: Greg did [the residential manager].

Hope was not certain what the computer worked involved or what other job tasks she could have done at Alliance. Later I found out that Alliance is a sheltered work center where
people with disabilities (oftentimes with intellectual disabilities) engaged in piece-rated “work” such as packing toothbrushes into boxes. Individuals are typically not paid an hourly wage, but rather are paid based on the amount of work produced or a subminimum wage.

I was struck by the lack of opportunity provided to Hope to choose what her post-school employment would entail. As previously mentioned, Hope proudly shared that she had chosen her current jobsite in senior living. Hope also informed me that she would like to take nursing classes at the local community college and would like to continue employment in the area of care work. So, I was initially caught off guard that Hope would begin work in sheltered employment at the age of 21 – another institutional structure added to her already institutionalized life – and that she did not choose this path. There did not appear to be any attempts to match Hope’s employment with her career aspirations. My reaction was also colored by my previous experiences with sheltered work. I was employed for three years with an agency where people with disabilities were warehoused under the guise of “pre-vocational work opportunities” and received weekly paychecks of $3.10 for unwinding metal wire from spools. So when Hope shared that she would be doing “computer work” I tried to be hopeful. This did not last long.

All of Hope’s housemates were “employed” at one of two local work centers, and a Medicaid Service Coordinator was the individual who brought it to my attention that employment at Alliance typically involved “piecemeal” work. As Hope and I were discussing her work at Alliance a housemate, John, arrived and began arguing with Hope that she would not be doing “computer work.” He was quite adamant and skeptical, and informed Hope that a woman was already in charge of the computer work. John scoffed at the idea that Hope would be working in the offices. The Medicaid Service Coordinator attempted to appease both John and
Hope, indicating that perhaps they would find a way for Hope to help in the offices. I remained skeptical.

When analyzing Hope’s narrative I was often drawn to Peterson’s (2009) analysis of “Shana’s Story.” Shana attended a residential school and often shared with Peterson that the choices she made really came down to choosing between two bad choices. Shana, like Hope, enjoyed cooking and was quite skilled at it, but complained of the systematic nature of her cooking instruction and the fact that her teachers always chose what she would be cooking. Also like Hope, Shana was restricted to the employment assigned to her and was given little opportunity to advocate for advancement or additional job duties. Shana was not given the opportunity to pursue her own interests and was tracked into a pre-determined place of employment. The way in which Hope’s life unfolds in such a pre-determined way can be explained, in part, by the institutionalized culture of her residential services (Goffman, 1963; Sinecka, 2009).

Sinecka (2009) conducted qualitative case-study research regarding the community-based living experiences of two men with development disabilities. Sinecka argues that although the participant’s living arrangements may not be total institutions (Goffman, 1963), they retain institutionalized characteristics. These characteristics included a governing system of coordinated activities formerly administered by managers and staff members, inflexible schedules, restrictive organization of one’s day, and isolation. Hope’s narrative reflects these characteristics as well. The remnants of total institutions found in today’s human services industry shape the opportunities Hope has for making choices and directing her life in a self-determined way. Indeed, Wehmeyer & Bolding (2001) found when adults with intellectual disabilities moved to community-based living and work environments from more restrictive
settings, significant changes in self-determination, autonomy, and opportunities for choice and decision-making occurred. The authors posit that congregate living or work settings negatively impact opportunities for self-determination.

I question the ease in which Hope has moved from one institutionalized setting to the next (a medium-sized group home, to segregated classrooms, to a sheltered workshop). Given Hope’s young age, economic and cultural capital may play a part as well. I was able to find little research on possible reasons for adolescents with disabilities living in group homes. Shapiro and Chandler (2012) provided anecdotal evidence of families in similar situations and indicated that 6,000 children under the age of 21 were currently living in nursing homes across the United States. The authors cited medical costs and Medicaid denials as potential reasons for this exorbitant number. Hope began receiving legal guardianship three years prior to this study. Her guardian obtained a post-baccalaureate degree, but worked multiple part-time jobs. While I hesitate to generalize, I cannot help but ask myself, “Would Hope reside in a group home (at her young age) if her social location reflected an middle- or upper-class background? How can her situation not raise concerns of social justice?” Hope’s self-determination narrative could not diverge more from that of Britany – a young woman with an intellectual disability in the beginnings of consumer-directed services.

**Britany: Control through Cultural Capital**

When I first met Britany I was greeted by the sounds of guitar music emanating from her two-story colonial located in a manicured, suburban development. Britany’s mother believed she might be interested in participating in this study, and had even participated in a different research study as a middle-school student. Britany was on board, but made a concerted effort to not appear too over-eager. She made it clear that the interviews could not conflict with her many
extracurricular activities, but did show a spark of interest at the idea of sharing her stories of schooling and transitions. She was particularly enthused about discussing the “drama” and trials of being a high school girl.

In the end, Britany’s collage on self-determination (see Figure 4.4) was unique as it contained only titles of magazine articles (“I was bullied for my beliefs,” “How do you deal with cliques?” and “Are tween girls too young for boyfriends?”) compared to her other collages that were smattered with images. This said those titles reflected many of the themes Britany shared across the span of our two months of interviews. Similar to the other three participants, Britany’s self-determination narrative was shaped by both her everyday experiences as well as her social location. Britany often fought for control in her life, but did so from a cultural position of privilege and opportunity.
Figure 4.4. Britany’s collage representing her understandings of and experiences with self-determination. Britany chose key phrases representing her experiences in navigating difficult friendships as well has her desire for more control (i.e., intimate relationships and access to social media).

Fighting for Control

Given my knowledge of Britany’s involvement with the statewide self-determination project, I wasn’t surprised with her response to my initial interview question.

Danielle: So, this is Britany’s interview on self-determination and choices. You picked the word determination. What does that word mean to you?

Britany: It means success in your life, and it means that we are determined to make change in our planet and also our environment. And I just think that determination comes from willpower ‘cause we all have willpower. And sometimes it’s just hard for us to deal with determination in our life.
Britany cited the planet and caring for the environment was one example of a cause that some people are determined to change. In addition, her construction of willpower and determination framed her desire for control over many things in her life from navigating peer pressure and expressing her sexuality, to choosing what clothing to wear and what television programs to watch.

Britany elaborated on her construction of determination and success as doing good deeds, making positive choices (“not smoking and not drinking and getting too drunk and stuff”), and not being mean to each other. In the context of schooling, choice meant avoiding peer pressure.

Danielle: What things do you choose to do at school?

Britany: I choose not to get involved with the peer pressure of trying to be cool, like smoking. People think that smoking is all cool, but it really isn’t.

Danielle: What other choices do you make in school?

Britany: Oh, the drinking of course, going out and clubbing, of course.

Danielle: So are there people at your school that do that stuff?

Britany: Sometimes. Sometimes people go out to parties and get high or something. Or swear and curse. That’s going around a lot in my school now.

As examined in Chapter three, much of Britany’s narrative regarding the experience of girlhood centered on the influence of cliques, fights with friends, and struggles with popularity. Social outlets and friendships are important to Britany and she must navigate the social choices she makes. Britany chooses to avoid the peer pressure of “trying to be cool” by drinking, clubbing, smoking, and partying.

But when Britany and I discussed what it meant to make plans and the plans she has for herself, these topics came up in a very different way.

Danielle: What other plans do you have?
Britany: I also want to go out clubbing, like go out to parties. And someday when I turn 21, in two more years, Kelly and I are going to one place she said, Jasper’s or something like it on St. Patrick’s Day. And we want to go to Jasper’s or to someplace and I will have a green beer. I just gotta wait two more years.

Britany has constructed a boundary regarding appropriate choices – this boundary appears to be based on time and age. 19-year-old Britany chooses not to participate in parties, clubbing, or drinking, but the plans for 21-year-old Britany involve choosing to go to clubs and parties. This appears to be a personal boundary that provides her with comfort. Other boundaries are not so comfortable for Britany.

Many of the ways Britany described her fights for control reflected the liminal space of adolescence. As a 19-year-old high school student with an intellectual disability, Britany’s identity straddles the borders of childhood and adulthood. Her experience is complicated by her mother’s apparent desire to shelter Britany from the transition from girlhood to womanhood. Two seemingly simple, yet quite complex examples of this include the monitoring of Britany’s television watching and clothing choices.

Danielle: How about at home? What things do you get to choose at home?

Britany: I get to choose when I go to bed and I also get to choose what I watch, but that doesn’t usually work because my mom, she is so controlling of what I watch.

Danielle: How does she do that?

Britany: Like, I can’t watch certain stuff on TV, like The Suite Life and stuff on Disney Channel, like Pretty Little Liars, or like mean girls movies, or like the Halloween movies in October of course. And it’s hard because I like to watch those types of stuff on TV, but I can’t. That’s why I have to watch stuff on YouTube.

Pretty Little Liars is a popular television program on ABC Family involving cliques, the disappearance and death of a friend, and threatening text messages. Britany was 19-years-old, yet her mother did not allow her to watch this show because of the seemingly intense content, in effect placing limited on the choices Britany is able to make. Britany subverted her mother’s
monitoring by accessing the program in secret on the Internet. She also recognized the ways in which this monitoring positions her outside the realms of a typical teenager.

Danielle: What do you think of that? [Her mother monitoring her television programs].

Britany: I think it’s wrong, because I want to be like everyone else. I don’t want to be treated as an individual like at home.

Britany also subverted her mother’s wishes regarding clothing choices. Britany mentioned that she also chose what to wear and as her mother walked in the conversation shifted slightly.

Britany: Well, I also get to choose what I wear. I mean if I get to choose what I wear then I would wear like belly shirts.

Danielle: What was that?

Britany: Belly shirts [laughs]. Yeah belly shirts [laughs].

Danielle: Why are you laughing?

Britany: I think it’s funny [laughs].

Mother: You are funny.

Britany: That’s right [laughs].

It appears that Britany does not have complete freedom with her clothing choices as she stated, “If I get to choose.” During my time with Britany her clothing reflected a simple, “preppy” style, but the simple act of teasing her mother about her desire to wear belly shirts signified a shift of control and a decided boundary crossing of girlhood to adulthood. The shift between girlhood and womanhood is seen in future clothing conversations as well, where Britany’s narrative reflects the interdiscursivity (Lewis & Ketter, 2004) of rearticulating both an adult discourse as well as a more child-like discourse.

Danielle: What else is the high school image?
Britany: Like, if you’re like me and I like to dress down and I like to dress preppy. Like, today I’m dressing preppy, because I have this nice fake fur vest plus white pants as you can tell right here. I stained my pants ‘cause last night I was frosting cupcakes that my mom made and apparently I had to eat it fast and somehow got stains on my pants.

Britany’s narrative rearticulated a sexualized discourse regarding the choice to wear revealing clothing, while at the same time she rearticulated a less mature discourse of choosing to wear cupcake stained clothing – at points her narrative resides within certain permeable boundaries. Erevelles and Mutua (2005) describe these boundaries as the liminal space of adolescence where young women navigate the spaces of childhood and adulthood. The authors highlight a case study of a young woman who, like Britany “struggles to claim girlhood/womanhood” (p. 256) in the face of oppressive structures, including the protective discourse of parents. The participant, Sue Ellen loudly claimed, “I am a woman now!” Britany’s claims may appear more subtle, but she clearly understands her differential treatment. This is also articulated when Britany shared that she was interested in dating, but that is wasn’t fair that she was not able to have sex. She did not want to talk about this topic further, but understood the differential treatment between herself and other young women.

**Privileged Opportunities**

Britany’s self-determination narrative demonstrated an actualization of many dreams with the potential for additional dreams to be realized in her future. All the participants shared a diversity of ways in which they viewed themselves as self-determinate. What was striking to me were the multitude of opportunities presented to Britany that contributed to her ability to demonstrate autonomy, make critical life choices, and direct her future. Opportunities to choose her jobsites, opportunities to attend her transition planning meeting, opportunities to begin self-directed services, and opportunities to attend a college program of her choice.
Britany truly enjoys her current job placement at Rob’s BBQ. The restaurant is owned by a family friend and Britany engaged in a variety of job tasks including food preparation, assisting servers, bagging carry-out items, and bringing food items to customers. The atmosphere is relaxed and Britany enjoyed singing and dancing with the cooks and trying various menu items. She would like to continue working at Rob’s BBQ after she finishes high school. Britany’s positive experiences at the restaurant have contributed to her interest in the culinary arts program at a local community college. These post-school dreams are reflected throughout Britany’s IEP and she has begun the process of self-directed services by transition planning with her family and adult services agency.

Danielle: And so do you get to go to meetings that’ll help you plan for the future?

Britany: Yes.

Danielle: What stuff happens at those? Can you walk me though one of those meetings?

Britany: Well, we basically talk about my future and what it’s going to be like. Like, what I get to do in my free time. If I have free time I could always cook something, or make something for a snack, or go work out, or work at Rob’s or something. So, a little bit of something every day.

Danielle: Did you talk about other things?

Britany: We talked about the program, and how many hours I’d be working at Rob’s, and how much money I’ll get at Rob’s if I do work there, and how this is gonna fit into our summer schedule ‘cause we travel sometimes, so…

Britany was the only participant to attend multiple IEP meetings, the only participant who was listed on her IEP as a participating member at the meeting, and her IEP constructed Britany was an agent:

Britany’s day will consist of a half day in classes at the high school and a half day on a job site. She continues to have choices in where she’s placed. In the beginning of the school year she worked at a nursing home, but decided it was not a good fit. She has
enjoyed working in the public as a server/prep cook at the Rob’s BBQ and Fajita’s restaurants.

Her experience with self-determination, specifically related to IEP meetings, was more positive than the experiences of the other participants. Britany not only has a say in where her jobsites will take place, but has been given the opportunity to change jobsites if she believes they are not right for her. Britany’s agency was reflected throughout her IEP. In addition, the document was littered with information about her dreams for the future, her transition goals, the supports she needs to see those goals through, and the choices she makes and wishes to continue making. Kohler and Field (2003) stress the importance of viewing “transition planning not as an add-on activity… but rather as a fundamental basis of education that guides the development of all educational programs” (p. 176). In Britany’s case, transition planning was not an add-on activity but rather, provided a framework for many of her educational supports and services.

It was remarkable to hear the stories of a young woman who has so many opportunities to live a self-determined life, but in the end I was left with a sense of unease. Britany has the right to choose a place of employment she enjoys, to hire a support staff person who best matches her interests and needs, and attend the college of her choice. The ways in which Britany’s experiences diverged from Hope’s experiences were striking. Britany’s access to opportunities for self-determination is shaped by the ways in which her label of intellectual disability intersects with her cultural and socio-economic locations. Her Whiteness and upper-middle socio-economic status grant her a certain amount of privilege that may not be experienced by other young women with intellectual disability labels. This is not to say that Britany does not experience oppression. She will not receive a high school diploma, spends a great deal of her high school day segregated from her non-disabled peers, and is restricted in the choices she
makes regarding clothing, television, and relationships. But I could not ignore the privilege she experiences as well. What would self-determination look like for Britany if her family friend did not own the restaurant where she completes her job placement? What would self-determination look like if Britany did not have the financial capital to travel with her family? What would self-determination look like if her mother were not a highly educated special education teacher with knowledge of adult services?

Even though people in the United States are keenly aware of issues of class, Manstios (2003) posits, “we don’t speak about class privileges, or class oppression, or the class nature of society” (p. 33). But the impact of class is real. Manstios further states that “class standing has a significant impact on chances for educational attainment [and] all Americans do not have an equal opportunity to succeed” (p. 45). Class domination is one of the forces, or spheres of oppression that holds people back. Whiteness also provides Britany with privilege (Jensen, 2003; McIntosh, 2004). This is not to say that Britany does not deserve her opportunities and does not deserve access to the consumer-directed services she is beginning. It means simply that she has experienced advantages as a White student including statistics such as 83.5% of U.S. teachers are White (U.S. Department of Education, National Center for Educational Statistics, 2012) while 86% of special education teachers are also White. White students are over-privileged in the school curriculum, their cultural experiences are more readily reflected in K-12 textbooks, and they will be more likely to have a supervisor who is also White (Jenson, 2003; McIntosh, 2004).

As a young African American woman with an intellectual disability from a low socio-economic background, Hope does not experience these race or class privileges. She doesn’t necessarily choose to be employed at a sheltered work center or live in a group home with six individuals 20 years her senior, but is limited and confined by the opportunities presented to her
– she lives at the precipice of racism, classism, and ableism. Britany’s life is enhanced by the social and economic opportunities presented to her. Britany’s White privilege intersects with her class privilege to create a context of choice, autonomy, and self-direction. In the conclusion of this study, I will outline recommendations for more culturally responsive transition planning that takes into account the diversity of student experience and attempts to provide students with greater access to opportunities. Students should not have to rely on their race and socio-economic status in order to be provided with the opportunity to live a self-determined life.

**Self-Determination and the IEP Narrative**

The IEP is the cornerstone of a student’s educational programing, that describes a student’s special education supports and services, in addition to her present levels of performance, annual goals, individual needs, accommodations, post-school outcomes, and transition-related activities. It is created through a team effort, but research shows that students with disabilities don’t often attend IEP meetings or participate in its development (Morningstar, Turnbull, & Turnbull, 1995). Once a student reaches age 16, her IEP must reflect transition-related goals related to post-secondary education, employment, and independent living as well as strategies for supporting self-determination and community participation (Savage, 2005; Thoma, Rogan & Baker, 2001). I conceptualized the IEP as a document that reflected a certain narrative. In some cases the IEP rearticulated the participant’s narratives (gender stereotypes, a culture of segregation and monitoring, opportunities for self-determination), but oftentimes those personal narratives of self-determination were missing. For three of the participants I analyzed, information related to self-determination, advocacy, or choice is mentioned only 2-3 times per IEP. But for Britany, self-determination was central to the narrative presented by her IEP.
Missing Narratives

A self-determination narrative is reflected twice throughout Victoria’s 15-page IEP. According to her IEP, one of Victoria’s transition needs is to “develop self-advocacy skills.” I combed through her IEP trying to find out how exactly she will develop these skills and asked myself the following questions, “Who will support her?” “How will these skills be taught?” “Will Victoria be given opportunities to demonstrate self-advocacy skills?” “What would a self-advocacy skill look like?” While I was unable to find any information in the IEP regarding a detailed plan for supporting Victoria in becoming a self-advocate, the IEP did articulate one activity related to this goal: “Victoria will advocate for her learning needs in an educational setting.” It is still unclear what is meant by learning needs, how Victoria will be supported to do this, and what it will look like when Victoria accomplishes this goal. Victoria’s self-determined actions of national anti-bullying advocacy are not reflected in her IEP. Victoria has never attended an IEP meeting (due to meetings being scheduled during academic class periods) and I wondered if she had would her self-determination have been more reflected in her IEP? Discrepancies such as this and limited, vague information regarding self-advocacy were common through the other participant’s IEPs.

Aminah’s IEP rearticulated her personal narrative of being a strong advocate for herself. This trait is described as a strength Aminah demonstrates. The only need reflected in the transition-related sections of her IEP was to “develop appropriate work skills,” by researching career choices and completing a Strength-Based Assessment related to vocational training. Again, the self-determination narrative was minimal. Trainor’s (2007) exploration of self-determination and the experiences of diverse young women with learning disabilities also uncovered a paucity of opportunities for transition planning. Will Aminah’s strength in advocacy
and skill at navigating the high school culture actually be a detriment? According to her IEP, Aminah’s current levels of performance indicated that certain supports and services were not needed. I was left wondering whether Aminah’s dreams of attending college would be realized, or if she, like many young women with learning disabilities, would slip through the cracks?

According to Hope’s IEP, “She has done a better job of speaking up for herself. She will order food at a restaurant and request the different items she needs from the variety of stores at the mall.” Although these instances of speaking up for herself may seem mundane, it is particularly important that Hope is given the opportunity to choose food at restaurants and items at stores given her living and future employment environments reflect characteristics of institutions. As with all four participants, Hope’s IEP indicated that she needs to be given access to self-advocacy skill development, but no where in the IEP did it mention what this development would entail. The IEP’s coordinated set of transition activities indicated that Hope would “be provided with the opportunity to participate in activities that explore different career choices” within her desired field of working with children. The minimal emphasis on choice described in Hope’s transition activities raised two questions for me: (a) Where did the disconnect occur between Hope’s desire and school support to work with children and her actual post-school employment in sheltered work? And, (b) What opportunities for choice-making may Hope have missed out on given the single example of career choices?

**An Anomaly of Self-Determination**

For each of the previous participants, self-determination (i.e., self-advocacy, choice, independence, planning, etc.) was reflected approximately two to three times in the narrative of their IEPs. Britany’s IEP was quite different – I coded 17 instances of self-determination in her IEP. Britany is also the only participant who is listed as attending her IEP meeting.
Independence, advocacy, and choices appeared to drive the development of her IEP. Evidence of Britany’s self-determination, participation, and involvement in transition planning was seen in the document’s meeting information, present levels of performance, management needs, measurable post-secondary goals, annual goals, and coordinated set of transition activities.

In regard to Britany’s academic skills, her IEP states that she works well independently and “prefers to work alone with little guidance or prompting.” Britany is constructed as an independent person in aspects of her academic life, but socially her IEP reflects a need for “positive reinforcement to choose to behavior appropriately.” As Britany shared her schooling experiences in Chapter four, she had difficulty maintaining friendships and did not always know how to navigate the social intricacies of group dynamics. Britany’s IEP also indicates a level of independence with attaining her annual goals. One of Britany’s coordinated transition activities stated that she “will meet with her school counselor to develop self-determination skills and work towards completing her annual guidance review.” Although it is disappointing that, yet again, a participant’s IEP stresses the development of self-determination skills with no indication of how to achieve that goal, it was refreshing to see this level of personal ownership of goal attainment.

Britany’s IEP also reflected the importance of control she had shared throughout her interviews. According to her IEP, it is important for Britany to know that others have high expectations of her and providing her with choices motivates her. The importance of control, choice, and independence is reflected throughout the description of Britany’s post-secondary goals as well. She chooses her jobsites and in the past has requested different a different jobsite due a poor match. The IEP reflects her desire to attend an institute of higher education and her interests in courses and career paths. Her choice to live independently, with support, in the future
is reflected as well. It is clear that Britany was an active participant during the development of her IEP and the topics she shared with me during our many interviews were reflected throughout the document. It is important to note that Victoria, Britany, and Hope attended different suburban schools, but with similar demographics, so I am unable to say how much Britany’s particular school contributed to her unique experience with student-centered transition planning.

**Narrative and Numbers: The Opportunities for Self-Determination Scale**

Looking at quantitative data from the Opportunities for Self-Determination Subscale (Wolman et al., 1994) adds an interesting layer to the qualitative narratives presented in the previous sections. Due to my qualitative research background and epistemological stance, I gave priority to the qualitative methods and data in this study, but including the quantitative data highlights both congruencies and contradictions between both sources of knowledge (Creswell & Pano Clark, 2011). In this section I provide the descriptive data generated from the student and parent forms of the Opportunities for Self-Determination Subscale, as well as individual student responses. I merged quantitative data with qualitative narratives in two ways: (a) side-by-side comparison and, (b) a joint display.

**Comparing Data Across Participants.**

Descriptive data in Table 4.1 shows that on average, the student participants self-reported greater opportunities for self-determination at home (mean = 26) than at school (mean = 24), with moderate-high satisfaction with overall opportunities for self-determination (mean = 50). Parents reported fewer opportunities for self-determination both at home (mean = 23) and at school (mean = 17), with moderate satisfaction with overall opportunities for self-determination (mean = 40).
Table 4.1

*Mean ratings for the occurrence of opportunities for self-determination at home and school*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Opportunities at home</th>
<th>Opportunities at School</th>
<th>Total (possible 60)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Students</td>
<td>26</td>
<td>24</td>
<td>50</td>
</tr>
<tr>
<td>Parents</td>
<td>23</td>
<td>17</td>
<td>40</td>
</tr>
</tbody>
</table>

When examining the descriptive data for how the participants rated their opportunities for self-determination at home and school, I looked at any ways race, socio-economic status, disability label, and inclusion in the general education classroom might shape the participants’ responses. Hope and Aminah were African American students who received free and/or reduced lunch at school (see Table 4.2). Their self-reported ratings of opportunities for self-determination were quite different. Hope reported high ratings for both opportunities for self-determination at home and school. Her overall rating of opportunities was 60 out of 60. Aminah was moderately satisfied with her opportunities for self-determination at home, but was not satisfied with her opportunities for self-determination at school. Victoria and Britany (White students who did not receive free and/or reduced lunch) were less satisfied with their opportunities for self-determination at home, opportunities for self-determination at school, and overall opportunities for self-determination.

Given the small sample size, I cannot make generalizations as to why this phenomena occurred: that the participant (Hope) living the most institutionalized and restrictive life, with the fewest opportunities for authentic choice-making and self-direction reported the most opportunities for self-determination, while the participant (Britany) with the most student-directed IEP, who was taking the steps necessary to direct her future adult service provisions reported the least opportunities for self-determination. The ways in which adolescents from
various cultural and economic background interact with adults provides some insight into this phenomenon.

In an ethnography of class and childhood, Lareau (2003) shares the stories of 12 families from low, working, and middle class backgrounds. Lareau indicates that children from low and working class families typically do what adults ask, protest little to adult requests, and perform requests without comment. In fact, in over a span of 20 observations Lareau observed a child in the McAllister family (low socio-economic status) argue with an adult on only one occasion. Through her observations with the Williams family (middle socio-economic status), Lareau concluded that the development of reasoning and negotiating skills was highly valued. Sometimes a democratic form of parenting was viewed within the family, where parents were “out-voted” with children frequently determining what the family would eat for dinner. Middle class children often shared their personal opinions on various matters and their parents offered choices rather than directives. The children would bargain to secure small advantages, refuted their parents, and employed resistance tactics when challenging parental authority. Therefore, a class culture may have shaped they ways in which Victoria, Aminah, Hope, and Britany constructed and responded to their opportunities for self-determination.

Table 4.2

Comparisons of opportunities for self-determination ratings by race and socio-economic status

<table>
<thead>
<tr>
<th>Participant</th>
<th>Race</th>
<th>Free Lunch Status</th>
<th>Opportunities at Home</th>
<th>Mean</th>
<th>Opportunities at School</th>
<th>Mean</th>
<th>Total</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope</td>
<td>AA</td>
<td>Y</td>
<td>30</td>
<td>30</td>
<td></td>
<td></td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>Aminah</td>
<td>AA</td>
<td>Y</td>
<td>25</td>
<td></td>
<td>19</td>
<td>27.5</td>
<td>44</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Victoria</td>
<td>W</td>
<td>N</td>
<td>25</td>
<td></td>
<td>27</td>
<td></td>
<td>52</td>
<td></td>
</tr>
</tbody>
</table>
A paradox appears to be at play, when examining inclusion and disability label, rather than race and socio-economic status. Using percentage of time spent in the general education classroom, I examined the ratings of opportunities for self-determination based on educational setting (see Table 4.3). The less time the participants spent in general education, the higher their ratings for opportunities for self-determination. This data contradicts the narratives of many of the participants, who actually experienced fewer opportunities for choice at school, and greater monitoring when in more restrictive settings. I believe the culture of special education where compliance, good behavior, and appeasement of adults may contribute to these less critical perceptions. A similar phenomenon may be reflective through the comparisons of opportunities for self-determination by disability label portrayed in Table 4.4

Table 4.3

Comparisons of opportunities for self-determination ratings by educational setting

<table>
<thead>
<tr>
<th>Participant</th>
<th>% of time in general education</th>
<th>Opportunities at Home</th>
<th>Mean Opportunities at School</th>
<th>Total</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aminah</td>
<td>≥ 80%</td>
<td>25</td>
<td>19</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Britany</td>
<td>40%</td>
<td>24</td>
<td>20</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Victoria</td>
<td>40%</td>
<td>25</td>
<td>24.5</td>
<td>27</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>23.5</td>
<td>48</td>
</tr>
<tr>
<td>Hope</td>
<td>&lt; 20%</td>
<td>30</td>
<td>30</td>
<td></td>
<td>60</td>
</tr>
</tbody>
</table>
I compared Aminah’s (who was labeled with a learning disability) ratings of opportunities for self-determination to the ratings of the other participants, all of who were labeled with intellectual disability. Aminah was more critical of her opportunities for self-determination, particularly opportunities at school (she was slightly less critical than the other participants in regard to opportunities at home) with a rating of 19, compared to the other participants with a rating of 25.7 Aminah’s rating of her overall opportunities for self-determination was much less (44), than the other participants (52). These results both support and contradict the participants’ self-determination narratives.

Students with disability labels such as intellectual disability are more likely to receive their education in restrictive settings, such as a special education classroom (Cosier & Causton-Theoharis, 2011; Ferri & Connor, 2005; Fierros & Conroy, 2002; Oswald, Coutinho, & Best, 2002; Taylor, 1988) and this culture may contribute to the participants with intellectual disabilities more readily indicating their satisfaction with opportunities for self-determination (which is contradicted by their narratives). The culture of special education is comprised of a “teachers as technicians” mentality where students with disabilities are “fixed” through the process of remediation. The culture emphasizes conformity and compliance. Hope had little to no say in her future employment options, much of the way Victoria constructed the concept of choice centered on politeness, good behavior, and pleasing others, and Britany continually fought to be viewed as a young adult. When faced with a quantitative rating system of their opportunities for self-determination, the three participants were less likely to critique their situations. In particular, Hope’s intersecting social locations and experiences (lower socio-economic status, African American, and restrictive residential, school, and work situations)
appear to contribute to her construction of self-determination and her satisfaction with her opportunities.

Table 4.4

Comparisons of opportunities for self-determination ratings by disability label

<table>
<thead>
<tr>
<th>Participant</th>
<th>Disability Label</th>
<th>Opportunities at Home</th>
<th>Mean</th>
<th>Opportunities at School</th>
<th>Mean</th>
<th>Total</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aminah</td>
<td>Learning Disability</td>
<td>25</td>
<td>19</td>
<td></td>
<td></td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Britany</td>
<td>Intellectual Disability</td>
<td>24</td>
<td>20</td>
<td></td>
<td></td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Victoria</td>
<td>Intellectual Disability</td>
<td>25</td>
<td>27</td>
<td></td>
<td></td>
<td>52</td>
<td></td>
</tr>
<tr>
<td>Hope</td>
<td>Intellectual Disability</td>
<td>30</td>
<td>30</td>
<td></td>
<td></td>
<td>60</td>
<td></td>
</tr>
</tbody>
</table>

**Individual participant data.** As provided in Table 4.5, Victoria rated her opportunities for self-determination at home as 25 out of 30 possible points and rated her opportunities for self-determination at school higher with a 27 out of 30 possible points. Overall, Victoria appeared to be highly satisfied with her opportunities for self-determination giving those opportunities a total score of 52 out of 60. On a scale of 1-5, Victoria reported that at school, people always listen to her when she talks about what she wants, needs or things she is good at, let her know she can set her own goals, encourage her to start working on her plans right away, and understand when she has to change her plans to meet her goals. Victoria reported that sometimes she has someone at school who can tell her if she is meeting her goals. She reported nearly identical opportunities at home, but indicated that she never has someone who can tell her if she is meeting her goals.
Table 4.5

*Victoria’s ratings for the occurrence of opportunities for self-determination at home and school*

<table>
<thead>
<tr>
<th>Item</th>
<th>Opportunities at Home</th>
<th>Opportunities at School</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People listen to when me when I talk about what I want, what I need, or what I’m good at.</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>2. People let me know that I can set my own goals to get what I want or need.</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>3. I have learned how to make plans to meet my goals and to feel good about them.</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>4. People encourage me to start working on my plans right away.</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I have someone who can tell me if I am meeting my goals.</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>6. People understand when I have to change my plans to meet my goals. They offer advice and encourage me when I’m doing this.</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Aminah rated her opportunities for self-determination at home as 25 out of 30 possible points and rated her opportunities for self-determination at school lower with a 19 out of 30 possible points. Overall, Aminah appeared to be moderately satisfied with her opportunities for self-determination giving those opportunities a total score of 44 out of 60. On a scale of 1-5, Aminah was most satisfied with people at school letting her know that she can set her own goals to get what she wants or needs, and that she has someone at school who can tell her if she is meeting her goals (see Table 4.6). Aminah reported that at school she has almost never learned how to make plans to meet her goals and to feel good about them. Aminah rated many of her opportunities for self-determination at home higher when compared to school, reporting that at
home people always listen to her when she talks about what she wants, what she needs, or what she is good at, encourage her to start working on her plans right away, and she has someone at home who can tell her if she is meeting her goals.

Table 4.6

Aminah’s ratings for the occurrence of opportunities for self-determination at home and school

<table>
<thead>
<tr>
<th>Item</th>
<th>Opportunities at Home</th>
<th>Opportunities at School</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People listen to when me when I talk about what I want, what I need, or what I’m good at.</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>2. People let me know that I can set my own goals to get what I want or need.</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>3. I have learned how to make plans to meet my goals and to feel good about them.</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>4. People encourage me to start working on my plans right away.</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>5. I have someone who can tell me if I am meeting me goals.</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>6. People understand when I have to change my plans to meet my goals. They offer advice and encourage me when I’m doing this.</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

Hope rated complete satisfaction with her opportunities for self-determination both at home and at school with as 30 out of 30 possible points for each. Overall, Hope appeared to be highly satisfied with her opportunities for self-determination giving those opportunities a total score of 60 out of 60. Among other items (see Table 4.7), Hope reported that both at home and at school, people always let her know she could set her own goals to get what she wanted or
needed, was always encouraged by people to start working on her goals right away, and always had someone who could tell her if she was meeting her goals.

Table 4.7

*Hope’s ratings for the occurrence of opportunities for self-determination at home and school*

<table>
<thead>
<tr>
<th>Item</th>
<th>Opportunities at Home</th>
<th>Opportunities at School</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People listen to when me when I talk about what I want, what I need, or what I’m good at.</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>2. People let me know that I can set my own goals to get what I want or need.</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>3. I have learned how to make plans to meet my goals and to feel good about them.</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>4. People encourage me to start working on my plans right away.</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>5. I have someone who can tell me if I am meeting my goals.</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>6. People understand when I have to change my plans to meet my goals. They offer advice and encourage me when I’m doing this.</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

As shown in Table 4.8, Britany rated her opportunities for self-determination at home as 24 out of 30 possible points and rated her opportunities for self-determination at school higher with a 20 out of 30 possible points. Overall, Victoria appeared to be moderately satisfied with her opportunities for self-determination giving those opportunities a total score of 44 out of 60.

On a scale of 1-5, Britany reported that at school, people always let her know that she can set her own goals to get what she wants or needs, and understand when she has to change her plans to meet her goals. Britany reported that she never has someone at school who can tell her if she is
meeting her goals, and people at school almost never encourage her to start working on her plans right away. Britany reported her opportunities for self-determination at home more positively and rated greater opportunities on all items except for people at home listening to her talk about her wants, needs, and strengths, and people at home letting her know she can set her own goals.

Table 4.8

*Britany’s ratings for the occurrence of opportunities for self-determination at home and school*

<table>
<thead>
<tr>
<th>Item</th>
<th>Opportunities at Home</th>
<th>Opportunities at School</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People listen to when me when I talk about what I want, what I need, or what I’m good at.</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. People let me know that I can set my own goals to get what I want or need.</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I have learned how to make plans to meet my goals and to feel good about them.</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>4. People encourage me to start working on my plans right away.</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>5. I have someone who can tell me if I am meeting me goals.</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>6. People understand when I have to change my plans to meet my goals. They offer advice and encourage me when I’m doing this.</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Merging these quantitative responses regarding frequencies of opportunities for self-determination with individual participant narratives provides yet another layer of analysis and contradiction. A joint display merging the participants’ total scores on the Opportunities for Self-Determination subscale with individual participant narratives regarding choice, planning, and goals is presented in Figure 4.5. These three constructs most readily reflect the content presented.
throughout the scale. I have examined the construct of choice extensively throughout the chapter, so I will focus specifically on the ways in which the joint display points to contradictions in planning and goals between the Opportunities for Self-Determination Subscale score and the data gathered through interviews.
<table>
<thead>
<tr>
<th>Subscale Score</th>
<th>Choice</th>
<th>Planning</th>
<th>Goals</th>
</tr>
</thead>
</table>
| 60             | **Hope** | **Danielle**: How did you get this summer job? **Hope**: There's a waiting list. **Danielle**: And did you pick that place to go? **Hope**: Roger did [Residential Manager]  
*Additional choices:* clothing, make-up, cooking, school jobsite, food, cheerleading, school lunch. | **Danielle**: Have you talked to people about the job you want after graduation? **Hope**: Nope, not yet. **Danielle**: Do you ever go to meetings at school? **Hope**: Yes. With Mrs. Mullen. And Donna. **Danielle**: What things are talked about? **Hope**: I walk. That I stand. Math. | **Danielle**: So have you ever seen your IEP? It’s a bunch of pages about school stuff. **Hope**: Um… no. **Danielle**: Do you have any transition goals? **Hope**: No.  
*Additional goals:* community college, nursing classes, sheltered work. |
| 52             | **Victoria** | **Danielle**: At home, what kind of choices do you make? **Victoria**: Good manners and behave. **Danielle**: How about when you’re with your friends? **Victoria**: Well, we get good manners and behave and be sweet and nice to each other. **Danielle**: Are there choices that you make at school? **Victoria**: You can’t talk when the teacher is talking and whenever you say something you gotta raise your hand.  
*Additional choices:* sing, write, dance, television, hang out with friends, school lunch. | **Danielle**: Do you ever go to meetings about school? **Victoria**: Meetings? No. **Danielle**: Like have you seen your IEP? **Victoria**: Oh my IEPs yeah. I mean I don’t think yes, no maybe. **Danielle**: And so you have an IEP and at the end of the year or the beginning of the year have you ever gone to any meetings with your teachers about your IEP? **Victoria**: My mom does. **Danielle**: So what kind of things do you talk about with your friends? **Victoria**: We talk about boys and good stuff. We talk about being nice and we talk what we’re doing over the weekend and what we’re doing over Christmas break or vacations and all that. And yeah try to plan something. **Danielle**: Cool. **Victoria**: Like sleepovers. | **Danielle**: And so do you know on your IEP, do you have anything called transition goals? **Victoria**: Yes. I have two. Of course mom wants me to read a lot and read a lot and do some DOL and reading comprehensions and I think math stuff. Like money maybe and money and money, adding, subtracting, or adding, subtracting, multiplying, division, fractions.  
*Additional goals:* Attend college, become a chef, be healthy, work in a restaurant, live with her boyfriend, get married. |
**Aminah and Britany**

| Danielle: What stuff do you choose? Like what things are you able to pick? |
| Aminah: Oh, what type of clothes I wear, or what else? I don’t know. That’s it. I mean, ‘cause everything else I know I need to do… Or like some days I’ll have them days where I just don’t wanna do anything. I don’t, but I hafta. |
| **Additional choices:** Clothing, friends, “if I wanna do my work or not… to take my sisters to the park.” |
| Danielle: Do you ever make plans? |
| Aminah: Sometimes, but then sometimes something happens or something comes up then I change it. ‘Cause I was supposed to go to the mall with my Valleyside teacher and my friend, but the day before we went they got into a car accident so I couldn’t go. |
| Danielle: Are there other examples of plans that you’re able to make? |
| Aminah: If a weekend comes up I ask my mom, ‘cause if me and my friends wanna go do something she says yeah and okay, I go do it. But if I get her approval I end up doing something. I do something bad and I get in trouble and I can’t go. |
| Danielle: Have you seen your IEP? |
| Britany: Sometimes. |
| Danielle: Do you have any transition goals on that? |
| Britany: A few. I can’t remember what they are now. |
| **Additional goals:** to travel, play college sports, get her driver’s license, live close to her family |

| Danielle: What things do you choose to do at school? |
| Britany: I choose not to get involved with the peer pressure of trying to be cool like smoking. People think that smoking is all cool, but it really isn’t. |
| **Additional choices:** clothing, bedtime, television programs, extracurricular activities. |
| Brittany: Well we basically talk about my future [at transition planning meetings] and what it’s going to be like. Like what I get to do in my free time. If I have free time I could always cook something, or make something for a snack, or go work out, or go to work. So a little bit of something every day. Like in the summer, I will get to do a bunch of activities in the summer with my program that I’m a part of now and I will also get to have some time to hang out with my friends from high school too. |

*Figure 4.5.* Joint display comparing individual Opportunities for Self-Determination Subscale scores to individual narratives.
When asked about transition goals, the participants were unclear as to whether they had transition goals or not. Participants either stated they did not have goals, were not sure if they had goals, or described goals their parents and/or guardians had developed for them such as walking or reading comprehension. Although the participants did not seem to have a construction for the word “goal,” they all shared their dreams for the future, plans with friends, or things that they wanted to accomplish. I was left wondering if goals were not a common discourse in their home and school lives, or if they simply framed their wants for the future in a different manner.

Bits of each participant’s narrative of dreams for the future were reflected in various aspects of her IEP, such as Hope wanting to work with children or Britany’s goal to live independently. Phrases such as “Aminah would like to attend college for health or science related coursework,” “Victoria will receive on the job training,” or “Hope is interested in attending an adult education program.” As previously mentioned, Britany was the only participant who’s IEP was clearly guided by her dreams for the future. Her transition goals provided a framework for the majority of the IEP document. The participants rarely attended IEP meetings, but information regarding the participants’ goals was somehow relayed at those meetings in their absence either by teachers or parents/guardians. These experiences are not atypical with current research indicating that students often play a periphery role in the transition planning process (Cooney, 2002; Morningstar, Turnbull, & Turnbull, 1995; Salembier & Furney, 1998; Trainor, 2005) and are either left out entirely or positioned as passive recipients (Lehmann, Bassett, & Sands, 1999).

I was left wondering how rich, student-centered, and powerful the IEP would be if the construct of “goals” was discussed in a matter that reflected the participants’ conceptualization of future plans, and if the participants were supported to attend and meaningfully engage in their
IEP meetings. Britany was the only participant who attended multiple IEP meetings and was beginning to engage with self-determination planning (i.e., consumer-directed services). Her IEP very closely reflected her self-determination narrative and it was clear that she had much say in the document’s development. It is ironic that the participant with the most student-directed IEP, participatory transition planning, and establishment of consumer-directed services, rated her opportunities for self-determination on the low end of the range for participant ratings (44/60). However, Britany’s narratives did reflect a great deal of parental control and restriction over certain aspects of her life such as social opportunities and leisure time.

Britany was also the only participant to conceptualize planning in terms of preparing for her future. Hope briefly mentioned attending an IEP meeting where topics of discussion included walking, standing, and math. There appeared to be a disconnect between Hope’s narrative where she shared her wishes to attend the local community college, take nursing classes, and care for children. Victoria and Aminah had not attended an IEP meeting (perhaps due to their younger age) and constructed planning in terms of social activities with friends. Aminah discusses making weekend plans with her friends, while Victoria would share her plans for the holidays, after school activities such as choir performances, and sleepovers with her friends. Based on the Opportunities for Self-Determination subscale, Aminah did not feel supported to make and carry out her plans through school, while Victoria was reported satisfaction with the support to make and carry out plans both at home and at school.

For these four participants, it appeared that either the constructs examined through the AIR Opportunities for Self-Determination subscale (identify needs and interests, set goals, make plans, and evaluate actions) did not reflect the ways in which the participants conceptualized self-determination and choice, or perhaps different questions are needed. For example, the
question used to examine the following construct (opportunities to set goals to achieve dreams), was “People let me know that I can set my own goals to get what I want or need.” Why was “dreams” left out of the question wording? Is the opportunity to set a goal the most salient feature of achieving a dream? What else is needed in order for a student to achieve her dreams?

Self-determination is such as complex construct and agency is so greatly shaped by context, that I have become skeptical about using a scale such as to appropriately measure the opportunities provided to students with disabilities to live self-determined lives. This is not to say that I do not believe it may be useful to have a reliable measure of opportunity, but the measure must take into account the relevant features of a student’s life – the “everyday,” the potential adult constraints, the school environment, and the culture of special education. Six questions regarding the support to make plans and goals was not enough – at least within the parameters of this study.

In this chapter I shared the participants’ narratives related to their constructions of and experiences with self-determination. Self-determination is a very personal and diverse construct, but I also presented some common themes including experiences with creating change, everyday choices as self-determination, constraints and structures impacting expression of self-determination, choice articulated as good behavior, and access to opportunities. Similar to the enactment of girlhood, self-determination operated through constraints produced by both families and the culture of special education. In addition, the participants’ diverse and intersecting subject locations complicated both their experiences with and perceptions of self-determination. In the next chapter, I will explore the participants’ experiences with transitions and their thoughts about life after school.
CHAPTER 5: NARRATING TRANSITIONS

In an interview with Aminah, a freshman at Jefferson High School, I asked her what she wanted to do after she finished her schooling.

Aminah: Be a doctor, some kind of doctor. I forgot what it’s called already. It’s a doctor that works with kids or a baby.

Danielle: Like a pediatrician?

Aminah: Yeah. I forgot, ‘cause it’s a long word [laughs].

Aminah is an African American student with a learning disability, who is from a lower socio-economic status and attends an urban high school. She lives with her mother and stepfather across the city from Jefferson High School. Although Aminah has not attended a transition-planning meeting with her school or family (her most recent planning meeting was scheduled on a half-day of school and Aminah was absent) she knows the career she wants, has spoken to her family about it, and would like to attend the local private university to pursue this career.

Transitioning from high school to the post-school world can be an uncertain time for many students. For students with intellectual or learning disabilities, the uncertainty may be intensified by the need to navigate post-secondary education, employment, and independent living supports through adult service agencies. The participants in this study shared fears about their lives after graduation, but shared exciting dreams as well. In this chapter, I begin by presenting these visions of the future as unlimited dreams and explore their diverse experiences with post-secondary education, the world of work, friendships, and interdependent living. Yet, I also situation the realization of these dreams within the larger context of opportunity. I then share the participants’ struggles and successes with two areas of post-school transitions that reflected inequitable opportunities: (a) planning and decision-making and, (b) accessing meaningful work.
Unlimited Dreams for the Future

Researchers in the field of transition find that students have very positive expectations for the future and see bright things for themselves (Morningstar, Turnbull, & Turnbull, 1995). Students are excited about what the future holds for them and discuss the importance of finding work, spending time with family and friends, and making housing arrangements. When discussing the future, parents of children with disabilities emphasize their child’s strengths and capabilities, and point out accomplishments that indicate a promising adulthood (Cooney, 2002). Although the participants in this dissertation expressed anxiety and uncertainty about the future, a great deal of their narratives centered on their wants for the future, things that were important to them, and their excitement around teenage rights-of-passage such as driving, graduating, and moving out of their childhood homes.

In an interview with Brittany, a returning senior at Longview High School, I asked her about the things she wants to do after she graduates.

Brittany: Well, I still want to work at Rob’s BBQ, which I love. I was there this afternoon working and I love it there. I also want to audit some classes at JCC. Maybe take classes like English, music, and U.S. History… I also want to go and work out at the Y, and I also want to do chores around my house, and prepare dinner and stuff.

Danielle: How about where you want to live?

Brittany: That's kind of easy. I really want to live in an apartment with a roommate.

Brittany is a White student from a middle-upper socio-economic background who attends a suburban high school. She has an intellectual disability label. Brittany lives with her mother and father, and is very involved in transition planning with her school and local adult services provider. Brittany knows where she wants to work after high school, where she wants to go to college, and where she wants to live. All the participants shared dreams of experiencing college in some manner or another. This said, “attending college” meant something different to each girl
and more often than not, reflected access to opportunities, planning practices, and negative consequences of labeling.

**Diverse Paths to Post-Secondary Education**

Over the past several years, post-secondary education has become a more and more viable option for students with disabilities. This said, transition planning continues to center around vocational training and independent living, rather than post-secondary education (Causton-Theoharis, Ashby, & DeClouette, 2009) and many transition plans fail to even mention higher education as a possibility (Mallory, 1995). Opportunities for post-secondary education and the planning involved with this option varied from participant to participant.

**Hybrid models.** Both Hope and Brittany shared their desires to attend their local community college. Hope was interested in taking nursing classes, while Brittany was interested in the culinary arts as well as courses about Shakespeare and history. Neither Hope nor Brittany constructs “college” as anything other than a typical college experience, yet both will access college through the more non-traditional route of services and programs for young adults with developmental disabilities. For Hope and Brittany this means the Foundations Program at JCC.

Information about the Foundations Program at this community college is outlined in both students’ IEPs. Hope’s IEP indicated that she “has interest in attending an adult education program upon graduation, perhaps JCC Foundations Program,” while Brittany’s IEP reflects her interest in attending a “post-secondary training program” at either JCC or the local private university. Opportunities for experiencing post-secondary education have become a more viable option for students with intellectual disabilities as a result of the inclusive schooling movement (Causton-Theoharis, Ashby, & DeClouette, 2009). Such programs provide students with intellectual disabilities with many opportunities. As Causton-Theoharis et al., note,
intellectual stimulation, emotional growth, academic gains, an expanded social network, increased self-confidence, and independence are just some of the aspects that many college students enjoy. (p. 88)

Hart, Grigal, Sax, Martinez, and Will (2006) describe these programs as occurring on a continuum of inclusiveness: the substantially separate model, the mixed/hybrid model, and inclusive or individual support model. The program described in Hope and Britany’s IEPs is most accurately described by the mixed/hybrid model due to its location on the campus of a local community college, some degree of interaction with nondisabled students, and the option of taking or auditing college courses, some of which focus on developing life skills (Causton-Theoharis et al., 2009).

Both participants shared interests in living at home with their families, or in Hope’s case continuing residence at her group home, participating in courses related to job-development or hobbies such as cooking, and developing independent living responsibilities such as laundry and house-cleaning. Options such as the Foundations Program provide students with intellectual disabilities the opportunity to be a part of campus life, participate in college courses, and learn “to navigate a world of high expectations [developing] the skills needed for successful adult life” (Hart et al., 2006). Aminah and Victoria described dreams of post-secondary education by accessing the local private university.

**Traditional models.** During one interview Victoria’s immediate response when asked about what girls did after they graduated high school was, “I guess we go to college and get a job.” In addition, when asked about what kinds of things people did at college Victoria indicated that students take classes to try to figure out what kind of employment they would like. For
Victoria, this meant the culinary arts. She has dreams of becoming a chef and also shared that at college, she would like to exercise and stay healthy.

Danielle: So, I know it’s ninth grade and it’s kind of far away, but what are your dreams for after you graduate?

Victoria: I wanna go to college and I wanna learn how to be a chef.

Danielle: So, how do you do that? What do chefs learn?

Victoria: So, we always have to read in order to be a chef. We gotta read. You have to do fractions. You have to do math work, and all that… Then you cook and all that.

Similar to Britany and Hope, Victoria’s constructed college as a means to an employment goal: being a chef. I also asked Victoria where she would like to attend college and she mentioned the local private university:

Victoria: Um… [laughs] I’m gonna be in the same college where I went to [local university], I forgot what the name was. But my boyfriend, Geoff, he wants to come down to where I live. He wants to be in the same college as me. Of course, he wants to come to college with me and be in the same place together. We can be in the same college at where I go to [local university].

Victoria, who has not yet attended a transition-planning meeting, is also able to clearly articulate her dreams for the kind of job she wants when school is finished and where she wants to attend college. Victoria’s college narrative also reflects her desire to remain close with her boyfriend Geoff. Rather than seeing college as a barrier to her continued relationship, Victoria has constructed college as an experience that will naturally involve her current boyfriend. Her understanding of post-secondary education reflects the social aspect of higher education as well as the academic.

Victoria’s IEP does not mention anything about post-secondary education.

With post-secondary education becoming more of a viable option for students with intellectual disabilities, and Victoria’s understanding of the valuable connection between a college
experience and future employment it is unfortunate her dream is not reflected in her transition planning. It is also likely that Victoria will need academic and social supports if she attends college, but such supports are not a part of her narrative and are not discussed in her IEP. Kohler & Field (2003) refer to the importance of a transition-focused education, where transition-related goals and choices shape a student’s educational programs and services. This conceptualization of transition “represents a shift from disability-focused, deficit-driven programs to an education and service-delivery approach based on abilities, options, and self-determination” (p. 176). Victoria may miss out on important services, classes, and community connections if her desire for a college experience does not become part of her transition plan and if her transition planning continues to occur in a non-student-centered manner.

Aminah expressed in detail her plans for post-secondary education. Similar to the other participants in this study, her very first response about what to do after graduation was to attend college, although her perspective reflects the possibility of a not-so-bright future for some teenage girls.

Danielle: So, when girls graduate from high school what might they do?

Aminah: Some will probably go to college, some might not. Some might not [laughs]. Some might not even graduate from here.

Aminah’s narrative reflects the possibility of school failure for some high school students, but she does not identify herself as one of those students who may not graduate. Aminah’s dream is to attend the local private university to play sports and to study to become a pediatrician. Through her collage (see Figure 5.1) on the topic of the future, Aminah chose images of the local private university, college sports, and wrote the words, “study, study, study.” She understands that becoming a physician can take many years and admits that she may not have the grades to pursue this career. In later interviews, she discusses nursing as an additional
option, and describes other public and private universities in the area that she may attend.

Aminah is currently on track to graduate from Jefferson High School with a diploma that will provide her access to the traditional college route.

Figure 5.1. Aminah’s college on the topic of the future. The images present represent her dreams to attend post-secondary education where she hopes to play college athletics. Text also represented things that are important to her such as studying, her home, and family.

Aminah’s goal for post-secondary education is clearly articulated in her IEP: “to attend college for health or science related coursework.” Yet there is no indication of the coordinated set of transition activities that must be in place to support Aminah toward the realization of this goal. It is not uncommon for mismatches to occur between the expressed post-secondary goals of students with disabilities and goals and services outlined on student IEPs. In her 2005 study into
transition planning and diverse students with learning disabilities, Trainor found missing connections between the goals expressed by students and goals, supports, and services outlined on student IEPs. Many students expressed intentions for attending a university or community college, but were not enrolled in college-preparatory courses and were exempt from exit exams.

Transition planning remains an add-on (Kohler & Field, 2003) activity for Aminah and is not the driving force behind her education. Aminah was aware that she would need to take an exit exam from her high school in order to attend college, but was unaware of the courses she needed to take to prepare her for this exit and was unaware of the college courses she would need to take to pursue a health-related career. Even though Aminah has a clear idea regarding which college she wants to attend and what career path she would like to pursue, is fully included in her classes, and is on-track for a Regents Diploma, there are no specific activities outline to support her toward this career path. It is as if all Aminah needs to do is graduate with her Regents diploma in order to attend college. No Special Education transition services are indicated and there is nothing to reflect the financial burdens of post-secondary education.

The World of Work

Employment was closely related to the participants’ understandings of the college experience as all of them framed post-secondary education as a means to their ideal career path. Britany’s desire to continue her work in the food industry, at a local barbeque restaurant, reflects her choice to take cooking classes at the local community college and to study culinary arts. While the food industry may be viewed as stereotypical employment for a person with an intellectual disability, Britany frequently discussed food interests throughout her interviews and shared how learning about and working with food is fun to her.

Danielle: So, you wanna keep working at Rob’s BBQ. Is there other stuff that you thought about that you wanna do when you’re done?
Britany: And I really wanna go to JCC and take some classes up there. Like music, and English, and William Shakespeare, and a cooking class up there.

Danielle: Nice. Is there a certain kind of cooking that you’d like to take?

Britany: I really wanna do culinary. Not pastries, ‘cause I just eat the food. Me and sweets are not that good, ’cause I like sweets.

Later in our interviews Britany shared the specific aspects that she likes about the food industry. Britany is a young woman who enjoys trying new foods, working with food, and appreciates the visual and culinary aspects of food. While the term “foodie” is not part of her vernacular, I believe she would identify as one.

Danielle: And when you take care of the food, what kind of things you do with the food?

Britany: Well, I helped Chrissy out with the food. I bring people's food to their table and that's really fun. I like doing that, because I can see the food, which is a really good part of it [laughter].

In addition, Britany’s IEP reflects her jobsite choices as ones related to food and also reflects her culinary interests in post-secondary education. As discussed in Chapter 5, Britany is very much involved in the development of her IEP and has demonstrated agency when deciding which jobsites are a good fit for her and which are not.

Hope attends a suburban high school with similar demographics as Britany’s high school. Hope is the youngest of her six housemates who currently live in a support group home for persons with developmental disabilities. She is a very energetic young woman who demonstrated a great deal of compassion and friendship toward her housemates, many of whom were 20 years older than she. During our interviews she would often joke with her housemates, ask them about their day, and showed interest in their lives. Below Hope describes the type of employment (care-giving) she is interested in.

Danielle: And so what happens after graduation?
Hope: Get a job.
Danielle: Do you want to get a job?
Hope: Yeah.
Danielle: And what kinds of stuff do you want to do?
Hope: Take care of people.
Danielle: What do you do when you take care of people?
Hope: Change people.
Danielle: Any other stuff?
Hope: No.

One way Hope looks to achieve this goal of care-work is through post-secondary education. Hope shared with me that she would like to take nursing courses at the local community college.

Danielle: Have you talked to people about the job you want to do after graduation?
Hope: Not yet.
Danielle: Do you want to do any more school?
Hope: Yeah.
Danielle: Have you thought about where?
Hope: Umm… JCC.
Danielle: Have you thought about any classes?
Hope: Nursing.
Danielle: What do you want to do with nursing?
Hope: With babies.
Danielle: And what kind of stuff would you do?
Hope: Take care of them.

Even though Hope’s narrative required more prompting and direct questioning than Brittany’s, she also is also able to clearly articulate her dreams for the kind of job she wants when school is finished and where she wants to attend college. During later interviews with Hope, I began to understand how the institutionalized nature of Hope’s life and a lack of opportunities to direct her post-school choices appeared to diminish the enactment of her post-secondary pathway to employment, as well as her choice of care-work.

Later in this chapter I share the surrogate decision-making Hope has experienced and the unfortunate reality of her future employment in sheltered work. A 2004 study by Chambers, Hughes, and Carter revealed that parents and siblings of students with cognitive disabilities were most likely to identify traditional work environments for people with disabilities such as sheltered work, day programs, or enclaves. It was refreshing to learn of both Victoria’s and Brittany’s desire to pursue work related to the culinary arts and the family connections present for both to enact this desire. This said, Hope’s employment route appears to be moving toward traditional work for persons with disabilities.

In addition to discussing dreams of employment and post-secondary education, friendships and opportunities for socialization were salient features of many of the participants’ narratives. Britany shared her fears of losing her high school friendships, while for Victoria her boyfriend Geoff was an important part of her conceptualizations of the future.

**Accessing Friendships and Relationships**

Research on friendships and students with disabilities demonstrates a great variety in the features of friendships, the characteristics of friendships, and the impact of inclusion on forming friendships (Fish, Rabidouz, Ober, & Graff, 2006; Rossetti, 2011; Webster & Carter, 2007).
Oftentimes social relationships between students with disabilities and their non-disabled peers take the form of helping based on benevolence (Kunc, 1992), while at other times friendships are “reciprocal and meaningful relationships that are chosen individually, occur outside of friendship programs, and are based on shared interest” (Rossetti, 2011, p. 23). Research by Harry, Park, & Day (1998) found that similar features (reciprocity, liking, affection, and having fun) existed in the friendships between students with developmental disabilities. No matter the form of friendship or social relationship, the participants in this study placed a certain amount of value on ensuring accesses to friends after their schooling was completed.

Below, Britany and I discuss her post-graduation worries. One of the biggest worries she had about transitioning out of high school was being apart from her friends and family.

Danielle: Are there any other worries that you might have about after school’s done?

Britany: Not going to Longview anymore, ‘cause I’ve been going to Longview basically ever since I was like Kindergarten pretty much. And I made so many friends there and it’d be hard to leave them, but I know that I get to go back to visit every now and then.

Danielle: And so what kind of things could you do? So, if you did miss your family when you lived on your own what kinds of things could you do to help that?

Britany: I could call them every once in a while and to talk to them over the phone or over email.

Danielle: What about with your friends from high school?

Britany: My friends? I can just call them or go hang out with them sometimes if I’m not working. Or if I’m not doing something then I can always hang out with them, or call them, or talk to them over Facebook, or text them with something.

Britany had a tumultuous relationship with some of her female classmates during her high school years and oftentimes sought out the advice of her mother when navigating what Britany described as, “drama.” This said, friendship has become a prominent feature of schooling for Britany and she has devised strategies for ensuring her continued access to friends. In
addition to Britany’s ideas about calling and hanging out with her friends in order to remain in contact, she also has service supports that are currently being arranged that will allow her to continue socializing and “hanging out” with her friends.

Britany: Like in the summer, I will get to do a bunch of activities with my program that I’m a part of now. And I will also get to have some time to hang out with my friends from high school too.

Danielle: So, you have a program that does stuff in the summer?

Britany: Yes.

Danielle: What kind of things do you do?

Britany: Well, we will go to the Y one day, and another day we’ll go to the zoo, and bowling one day or something. It’s like a bunch of activities that I like to do now.

Unfortunately, and given the importance of community inclusion for people with intellectual disabilities, these structured activities that create social opportunities for Britany are oftentimes programs only for persons with disabilities. Britany clearly delineates between the people she socializes with in her “program that she is a part of now” and her friends from high school. The reciprocal friendships based on shared interests will not necessarily occur through her adult service provider.

Loneliness, isolation, and a lack of friendships are commonly reported themes in the literature regarding adults with intellectual disabilities (Fish, Rabidoux, Ober, & Graff, 2006). The lack of opportunities for making friends is compounded when one’s isolation is physical in nature as well (i.e., high school students living in group homes and receiving services in sheltered work). Like Britany, the construct of a friend was something important to Hope and continued friendship was a key feature of successful post-school transitions. However, Hope may also experience difficulties accessing authentic friendships. The first thing Hope described as happening during graduation reflected the emotion behind leaving her high school friends.
Danielle: So what do you do at graduation?
Hope: Cry.
Danielle: You cry? Why do you cry?
Hope: I’ll miss my friends.
Danielle: Are you graduating with any of your friends?
Hope: No.
Danielle: Did some of your friends graduate last year?
Hope: Yeah.
Danielle: Ok. Do you get to see them?
Hope: Yeah.
Danielle: What kind of things do you do with them?
Hope: Play games with them.
Danielle: You play games. What games do you like to play?
Hope: Board games.

It was unclear if Hope does in fact see her old friends now, because she began talking about the things she does at school with her friends such as playing board games. Complicating this conversation are definitions of “graduation” which occur throughout the state in which Hope resides. A student with a disability may “graduate” with a certificate of completion at age 18, but may return to that high school for services until age 21. Hope and her guardian had elected not to participate in “graduation” until Hope’s final year of eligible schooling, the year this research study took place. Either way, the frequency of Hope’s references to friends in during our interview regarding the future, and the sheer number of images on her collage that she indicated were friends, demonstrates friendship to be of importance to her now and in the future.
Throughout our discussion of her future-themed collage, Hope frequently referred to images of young women her ages as her “friend” or “friends” (see Figure 5.2). Never did she refer to a name of a particular friend. She did indicate and ask for support in writing the names of her teachers and residential staff next to certain pictures. Unfortunately, Hope had little interaction with students outside of her segregated classroom, and due to inadequate access to transportation her involvement in social activities outside of school is limited as well. I question the actualization of Hope’s dreams for friendship given the institutionalized life that has been created for her, and in the conclusion of this study I will describe ways in which educators can take a more culturally-responsive approach to transitions, where the discrepancy between Hope’s desire for continued friendships and her limited access to actual interaction can be addressed.

Figure 5.2. Hope’s collage of her future reflecting images of her self, friends, and teachers. All the images represent people who Hope would like to have in her post-school life as well as her cooking interests.
At the end of one my interviews with Victoria, I asked her if there was anything else she wanted to share that was important to her future. Victoria began to list many things such as being a “wonderful student,” a hard worker, playing games, and travelling. Talking to friends “a lot” was also an activity she wanted to continue in her post-school life. Continuing a romantic relationship was also of importance to Victoria’s future. When discussing her living options for when she completed high school, Victoria hesitantly described living with her current boyfriend Geoff, who would then be her husband.

Danielle: Where would you wanna live?

Victoria: Um, good question [laughs]. I would, maybe I wanna go down to my boyfriend’s, where my boyfriend lives. I’ll be Mrs. Oak and he’ll be Mr. Oak.

Danielle: Who are they?

Victoria: Um, like, um, Mr. and Mrs. Oak is like well my boyfriend’s last name.

Danielle: Oh ok.

Victoria: My boyfriend’s last name is Oak so that’s why my boyfriend wants me to be Mrs. Oak. Mr. and Mrs. Oak together. So that’s like one last name, my boyfriend’s last name. I’ll be Mrs. Oak and he’ll be Mr. Oak.

Victoria’s collage (see Figure 5.3) on the topic of the future, reflects many things that are important to her including attending college, becoming a chef, travelling, and exercising. The collage also reflects her desire to have a boyfriend in the future. Several images throughout this collage represent heterosexual relationships: an image of a young celebrity couple carrying an infant, an image of a movie couple from one of Victoria’s favorite films, and two young adults embracing and surrounded by a heart and the text, “Break the ice by midnight. Make him yours by the time the ball drops (really!).”

Of the four participants, Victoria was the only one currently involved in an intimate relationship, but all the participants described previous heterosexual relationships and interests in
young men. With the advent of disability rights, advocacy, and the Independent Living Movement, individuals with disabilities have experienced empowerment and self-determination in their lives. Unfortunately, attitudes and policy regarding reproductive rights and sexuality remain negative and the current discourse regarding sexuality includes terminology such as capacity, asexuality, the inability to care for children, and the need for protection from sex (Berson & Cruz, 2001; Crawford & Ostrove, 2003; Dotson, Stinson, & Christian, 2003; Murphy & O’Callaghan, 2004; NYSACRA, 2007).

Current policy regarding sexual relationships between persons labeled with intellectual disabilities is steeped in the medicalized language of protection, capacity, IQ, and professional expertise. The state in which Victoria resides defines the following: “Any sexual contact between persons receiving services and others, or among persons receiving services, is considered to be sexual abuse unless the involved person(s) is a consenting adult” (NYSARCA, 2007).

Professional “expertise” is used to determine whether or not an individual has the capacity to engage in sexual activity. If through this “expert” assessment an individual is deemed without capacity to consent, she cannot engage in sexual contact. If she does, an investigation must ensue and local authorities must be notified.

Although the intent of these regulations may be to protect individuals with developmental disabilities from sexual abuse, the “expert” determination of capacity is reminiscent of the eugenics era. Jefferies and Nichols (1928) as cited in Shapiro (2001) define eugenics as, “simply preventing the unfit [including the feeble minded] from bringing children into the world… By one means or another the unfit must be prevented from propagating their kind if we every hope to improve humanity to any great extent” (p. 208). Throughout the eugenics era people with disabilities were devalued and seen as burdens to society. It was also believed that disabilities
were hereditary and could be passed down from one generation to the next. By preventing individuals with disabilities from reproducing, it was believed such “negative” traits would eventually be removed from the gene pool. A developmental disability was constructed as abnormal, intelligence was valued, and such intelligence was believed to be biological in nature.

The reliance on IQ for determining capacity to consent to sexual activity remains in use today. Murphy and O’Callaghan (2004) outline the following areas as important to determining capacity to consent to sexual activity:

- Basic sexual knowledge; knowledge of the consequences of sexual relations, including sexually transmitted diseases and pregnancy; an understanding of appropriate sexual behavior and the context for this; an understanding that sexual contact should always be a matter of choice; the ability to recognize potentially abusive situations; and the ability to show skills of assertion. (p. 1349)

Authors such as Berson and Cruz (2001) argue against the “wrongful intrusion upon reproductive liberty” (p. 427) and point out that oftentimes courts overly rely on protecting the best interests of persons with developmental disabilities. In addition, Leicester and Cooke (2002) posit the following questions, “Why should two [people with intellectual disabilities] who want to have sex together need anyone else’s consent?” and “Why should the question of whether such relationships are morally permissible arise in connection with this group and not for the rest of us [not labeled intellectually disabled]?” (p. 181).

Unfortunately it is able-bodied individuals making the determination of “best interest” and persons with developmental disabilities are put in a position to prove their capacity through assessment. Although the knowledge areas described by Murphy and O’Callaghan (2004) are important for anyone wanting to engage in a sexual relationship, the problem occurs when
individuals with disabilities are assessed for capacity. A person without a disability label may want to have a discussion with parents or a school counselor about issues such as sexual knowledge, choice, and assertion prior to engaging in sexual activity, but individuals with certain disability labels such as intellectual disability are expected to be assessed for this knowledge. Murphy and O’Callaghan rightly suggest that more opportunities for sex education should be provided to people with disabilities and argue for a redefinition of capacity to consent. This said, the authors fail to disrupt the ableist notion that people with developmental disabilities must earn the right to a sexual relationship.

Figure 5.3. Victoria’s collage on the topic of the future. She lists 14 things that are important for her future including college, reading, and travelling. Images present her favorite musicians and television actors, as well as her interests in sports and food.
Families and Community Living

The participants wove a family narrative throughout their dreams of post-secondary education, employment, housing opportunities, and friendship. Mothers and sisters in particular, were central pieces of the ways in which the young women both constructed and planned for the future. During most of the interviews, the participants discussed their relationships with female family members. At times Aminah shared stories of her brother who attended high school with her, and Britany’s father would occasionally stop by during an interview. More often, the participants shared stories of their mothers, sisters, and other female family members. In addition, Victoria’s mother and Britany’s mother would check in from time to time during our interviews.

Various researchers have stressed the importance of family involvement in transition planning (Salembier & Furney, 1998; Kim & Turnbull, 2004) and find that although transition may be a stressful time for both students and family members, family member perceptions of student ability positively shape goals and choices (Cooney, 2002). While each participant shared worries for the future, stress and fear were not central tenants of how they understood transition.

In addition, physical proximity to their family was a major consideration when it came to housing arrangements and post-secondary education. These findings are consistent with previous research by Trainor (2005) demonstrating that students with disabilities rely more heavily on their families than educational professions for support of post-school transitions. The IEP and formal transition-related goals did not appear to be salient features of the participants’ understandings of post-school transitions. Rather, more informal family conversations and support shaped the post-school narrative.
All the participants throughout many interviews discussed family involvement, but the ways in which families shaped these narratives varied from participant to participant. For Britany, her mother served as an important advisee in her struggle to navigate friendships, while Victoria’s mother facilitated her involvement in extracurricular activities. Aminah relies on many women in her immediate and extended family for guidance and support, while Hope enjoyed visiting with her family and speaking to her sister over the telephone. Proximity to family was also a salient feature of how many of the participants constructed interdependent living.

**Families providing support and guidance.** It became clear during my time with Aminah that her family members were very important to her and played a central role in many aspects of her life. During our interviews, Aminah had been practicing to take her driver’s permit exam with the support of her grandmother. For Aminah, driving was a marker of transitioning to adulthood or which she referred to as, “bein’ grown.” Aminah’s grandmother would frequently take her on driving lessons, except of course when Aminah would drive the wrong way down a one-way street. After this incident her grandmother thought it would be best to give herself a bit of a break. Aminah laughed as she described having to wait until her grandmother would practice with her again. Aminah’s aunt, or godmother, has played a central role in Aminah’s life as well.

Aminah lived with her godmother until she turned eight years old, at which time disagreements arose with Aminah’s mother regarding custody. She then began living with her biological mother, but continues to rely on her godmother for advice, guidance, and support. Aminah is very close with her godmother and she serves as an adult role model. Aminah looks up to the adult women in her life as evidenced by the exchange below:

**Danielle:** So, are there any girls or women that you look up to?

**Aminah:** My godmother. But my godmother, we always, I tell her everything.
Everything. Well not every, everything, but I tell her most things and then some things I
don’t tell her, I tell my grandmother. And then my grandmother tell her and they be
talking about it.

Completing high school was a value instilled in Aminah by these adult women and their
opinions shaped how she understood the negative implications of failing. During a conversation
regarding the reasons for students being expelled from school and later dropping out it is clear
that the females in Aminah’s life are important to her and she does not want to disappoint them.

Danielle: What kind of things do people get kicked out of high school?

Aminah: Like, bringing certain stuff to school, or fighting, or getting into trouble with the
teachers and stuff. Even though that happens all the time. Like people do like things that
they don’t like or something like that, I guess. I never got kicked out. I wanted to, but…
Then I’d get in trouble by my mom and that’d be mean.

Danielle: What happens when you get in trouble?

Aminah: She grounds me. She’d yell at me first, and then she’d realize that I’d just make
that face to the point where I just don’t care, and then she’ll ground me. It’s funny though
[laughs]. But I do get in trouble. She gets mad at me, and then she’ll tell my dad, and then
he’ll tell my godmother, and then she’ll tell my aunt, and then they’d all be mad at me.
Especially my grandmother. I don’t like talking to my grandmother.

Danielle: How come?

Aminah: She’s mean. So… hmmm… Ooooo…. Dream. I don’t know how you spell that
word I was just about to write down ‘perseverance.’ Wait what does that word mean
again?

At first glance it appears that avoiding punishment is Aminah’s major concern. But
perhaps there is more to her story. This conversation occurred while Aminah was creating a
collage about what it meant to be a high school girl. For Aminah, “perseverance” was a word of
great import; persevering through high school completion. Britany’s family also served as a
salient feature of her narrative and she would often share stories about her mother and the
support she provided to Britany during difficulty times.
Britany often shared activities she would do with her mother such as travelling, attending plays, shopping, volunteering with their church, planting flowers, and going out for ice cream. Britany indicated that she loved spending time with her mother and would often joke with her if her mother happened to be nearby during our interviews. Throughout high school, Britany has experienced difficulties with navigating friendships. Her mother has served as a support person throughout these difficulties, and it became clear that Britany valued her mother’s input and advice. Britany also expressed a significant worry about finishing high school related to the importance of her relationship with her mother and other members of her family.

Danielle: Do you have any worries about what happens after school’s done?

Britany: Well, I worry about not living in my house that I live in right now, ‘cause I’d be missing my mom too much, ‘cause I love her and she gives me tons of good advice about friendships and keeping friendships. And also my dad, ‘cause he’s funny and he’s wonderful to be around with sometimes, and my brother.

Britany’s mother frequently encourages her to be positive about her school peers, sometimes to Britany’s annoyance. During an interview, Britany and I were discussing things that adolescent girls do. Britany had listed the words “drama, go to parties, travel, swearing, and cursing” among others. Britany’s mother entered the room as we were discussing her choice of words.

Mother: Now wait a minute Britany.

Britany: What?

Mother: You’re talking about a lot of negative things.

Britany: [sighs] They’re not all negative stuff.

Mother: Flip it to the positive.

Britany: What are you talking about?

Mother: ‘Cause that’s what you like to do sometimes, say the negative things.
Britany: No! Mom! Mom! No I don’t.

Mother: Yeah.

Britany: No I don’t. Not always.

Mother: Yeah. So you say “no” and that’s negative.

Britany: I’m stating my opinion. Can you just be quiet and let me do what I want to do?

It is clear that her mother’s advice is not always welcome as Britany subverts her mother’s opinion that young women must be positive. Britany asserts, quite accurately, that she is stating her opinion. Adolescent girls engage in positive activities such as travel and fun, but also engage in activities perceived to be negative such as swearing. During this exchange, Britany’s father also walked in and supported Britany by suggesting that Britany’s mother not get involved and that this was Britany’s project. Through her narrative, Britany made several attempts to distance herself from her mother as well. The two appeared to have a close relationship, but Britany also expressed the importance of her independence.

During a conversation about the good side to being a teenage girl, Britany discussed having fun, going out to eat with her friends, using Facebook and Twitter, and the importance of not always wanting to be with your parents, but rather being with friends. Britany was no longer able to use a Facebook or Twitter account, and also had her texting privileges taken away. Britany did not believe this was fair and indicated that her mother, “completely destroyed” her fun. I came to realize that Britany’s narrative reflected the ups and downs of many family relationships. She clearly cared about her mother and enjoyed spending time with her, but was sure to discuss her frustrations with her mother as well. During one minute of an interview Britany would appear exasperated with her mother and would then jokingly pick on her the next.
For Victoria and Hope, discussions of family members did not occur as frequently, but both participants shared examples of why their families were important to them.

Victoria’s family narrative centered on the doings and activities of family life, where her mother often served an initiator of extracurricular activities. She shared experiences such as viewing a campus radio station with her family and friends, her mother transporting her to school choir concerts, cheerleading, and Special Olympics activities such as floor hockey practice, and helping her arrange sleepovers with her friends. When completing her collage based on the topic of the future (see Figure 5.3), Victoria made a list of 14 words signifying things of importance to her. Only at the end of our interview did she add the word “family” to her collage, and then only after her mother jokingly complained about its absence.

Mother: This is it girlfriend. Oh looking toward the future are we?
Victoria: Uh huh.
Mother: College, work in restaurant, exercise, boyfriend. Really?
Victoria: [laughs]
Mother: Friends, where’d mom fit into that picture?
Victoria: [laughs] You?
Mother: I know, I know. I’m insignificant in your life now [walks away laughing].
Victoria: Well, we also gotta put family in there.

Perhaps family is such a common element to Victoria’s life that she did not construct her family members as people that would not be a part of her future, or something that she needed to be sure was present during her post-school life. Victoria’s younger brothers and sisters would often stop by during our interviews and asked questions about the collages she was creating. Her younger brother was particularly interested in the idea of college and sat down to share with us
where he wanted to attend college and want sort of career he’d like to pursue, and when arranging for future interviews Victoria was sure to approach her mother for help in picking a date on their family events calendar. Perhaps family life was such a stable component of Victoria’s present that is wasn’t necessary for her to list them when constructing a collage about important considerations for her future.

Like Victoria, Hope’s narrative for the future did not center a great deal on her family, but for a categorically different reason. Hope did not live with her family during the time of this study and did not have a great deal of contact with her sister, mother, or grandmother. She shared that she enjoyed spending time with them and talking to her sister on the telephone, but the concept of family did not appear to contribute to Hope’s conceptualization of post-school life. Quite the opposite from Victoria, family life was not a stable component of Hope’s present, therefore family life was not a salient feature of her future.

Hope’s guardian served as an advocate for her in regard to post-school transition planning and would attend her IEP meetings. It was unclear how involved Hope’s mother was in her life, but during one of our interviews, she shared that she had seen her mom that weekend. Hope chose not to elaborate on what she and her mom did together that day. This said, Hope often indicated that certain images on her collages represented her mother or sister, and she became excited during the holidays, discussing spending Christmas with her grandmother.

Hope: I can’t wait for Christmas.

Danielle: It’s coming up soon isn’t it?

Hope: I’m going to my grandma’s place.

Danielle: Oh nice. Does your grandma live around here?

Hope: No.
Danielle: No? Is that kind of a drive too?

Hope: Yeah.

Danielle: What do you do at your grandma’s for Christmas?

Hope: Spend time with my grandma.

Hope’s younger sister lives with her grandmother. Hope was able to visit her sister at times, where they would watch television together, and she was sure to telephone her sister on her birthday. During each of our interviews, Hope shared that she would be visiting her grandmother and sister during the weekend, but the frequency of these visits was not clear. It did not appear that Hope had actually visited after each of our interviews, but rather was discussing a future weekend where she would be seeing her family. The separation Hope experienced from her family may have also contributed to the absence of family from her narrative regarding community living.

**Constructing interdependent living.** In their study of 16 Latina mothers of young adults with developmental disabilities, Rudea, Monzo, Shapiro, Gomez, and Blacher (2005) found transition to be a home-centered phenomena, and value was placed on family and home instead of individuality and independence. Cooney (2002) has also shown that young adults with intellectual disabilities oftentimes discuss the importance of living close to their families or going to them for help and support. Their discourse was one of interdependence and “[g]enerally, young adults acknowledged the importance of needing help from parents and friends as sources of both emotional and physical support” (p. 429). Aminah, Britany, Hope, and Victoria all shared visions of their future that were shaped by aspects of interdependent living. Both Aminah and Britany expressed the desire to live within close proximity to their families, Hope voiced the
preference to remain with the six housemates of her supported group home, and Victoria shared the importance of living with her future husband.

Family has been a critical feature throughout Aminah’s narrative and remains so in the area of interdependent living. Aminah constructed her post-school living arrangement by creating space for independence, but also family support. Although Aminah does not wish to live in the same house as her mother and sisters, she does want to live near her family, her grandmother in particular.

Danielle: Where do you wanna live when high school’s done?

Aminah: When high school’s done?

Danielle: Like after you graduate?

Aminah: Oh, I don’t know. I never thought of that. Home. Home. Hmmmm… Maybe that. [cutting out the word “home”].

Danielle: And so why did you pick the word Home?

Aminah: ‘Cause you asked where I would live and I’d live close to my house and my grandmother. I wanna live in that house, yeah.

Danielle: So, it’s close to your home, but you wouldn’t have to live in your house?

Aminah: Yeah.

As with other aspects of schooling and transitions, Aminah straddled the borders of independent living. She expressed the desire to leave her mother’s home, but to remain in close proximity to her family. She even expressed the desire to live in her grandmother’s actual house. While it is not clear whether Aminah meant that she would want to live with her grandmother, or simply that house, she is able to construct independence in living as a concept encompassing both independence and closeness with her family.
Several times throughout our interview Aminah referenced her grandmother and she appeared to be a woman who greatly shaped Aminah’s understanding of growing up. As previously mentioned, transition-planning meetings had not occurred for Aminah and her family. After noticing the central role Aminah’s grandmother and godmother both have played throughout her life, I was left with the following question. What potentially invaluable information would Aminah’s grandmother or godmother provide during such a meeting and what might Aminah’s educational team miss by not actively connecting with such a valuable source?

Constructing post-school living arrangements in an interdependent way was seen in Britany’s narrative as well. Britany also expressed the desire to live near her family and described in detail the type of living arrangement she would like, qualities of a good roommate, and what things she would need to do when living away from her family.

Danielle: How about like where you want to live? In the future?

Britany: That's kind of easy. I really want to live in an apartment with a roommate.

Danielle: Do you want to stay in [this city] or do you want to go someplace else?

Britany: I want to stay in [this city].

Danielle: So, living in apartment with a roommate. What's that like, what do you imagine it to be like that if you have an apartment?

Britany: Like, take care of the house, and clean, and prepare dinner, and do the laundry, and fold the laundry, and all the basics.

Danielle: And have you though about who you might want to have as a roommate?

Britany: I have not yet thought about it, but I want to be with someone who's nice, who is outgoing, and always tells the truth for everything no matter what.

Through Britany’s conceptualization of independence in living, she is able to create space for maintaining closeness with her family. Although Britany’s post-school residence means independently living in an apartment with a roommate, she did share some trepidation about
living on her own and worried about missing her mother. I asked Britany what she could do if she found herself missing her family and she indicated that she could call them on the phone or talk to them via email. Britany did not indicate that she would need to visit or physically see her family, but was able to construct a balance between her desire for independence and her desire for family comfort.

Victoria did not create a narrative of interdependent living as supported by her family, but rather her narrative reflected interdependent living as supported by an intimate partner. After graduating high school, Victoria would like to get married to her current boyfriend and live together. Victoria’s family is very supportive of her current relationship with Geoff and they are close friends with his parents. Given the previously discussed policies oppressing the sexual lives of people with intellectual disabilities and current research on caregivers’ negative attitudes toward sexual expression, I was immediately cynical toward the potential reality of Victoria living with and marrying her current boyfriend.

Much of the research regarding sexuality, sexual relationships, and parenting by individuals with intellectual disabilities occurs outside of the United States (Aunos & Feldman, 2002; Liecester & Cooke, 2002; Parkes, 2006). This current body of research indicates that able-bodied teachers, professionals, and parents continue to have negative and conservative attitudes towards sexual relationships and people with intellectual disabilities. For example, Aunos and Feldman (2002) found that “75% of parents surveyed were against their children marrying and raising children,” while “a majority of parents were against marriage even if their child would use contraception” (p. 289). Teachers and professionals also held negative beliefs toward marriage, with Griffiths and Lunsky (2000) indicating that attitudes may be more negative now toward sexual relationships and marriage of people with intellectual disabilities than compared to
20 years ago. This is reflected in Desjardin’s (2012) work as well concerning coerced sterilization of young women with intellectual disabilities in the name of “good choices.” However, the majority of people with mild intellectual disabilities want to marry and raise a child (Aunos & Feldman, 2002).

Later I read an article in the Washington Post (McCarthy, 2013) about two adults with intellectual disabilities and the success of their five-year relationship and subsequent commitment ceremony. Bill Ott and Shelley Belgard met when they were 12-years-old at a local dance. They stayed close friends and attended several dances and proms together. After losing touch, the two met again on a cruise ship in 2007. The following January they were engaged. The couples’ parents were initially skeptical, but were eventually convinced of the depth of Bill and Shelley’s commitment to each other. On September 2nd, 2011 the two walked down the aisle in a commitment ceremony rather than an official marriage, in order for Shelley’s health insurance to remain secure. This said, in everyone’s eyes the couple live a married life.

Un/Limited Opportunities

All four participants conceptualized post school transitions around the areas of post-secondary education, employment, friendships and relationships, and family support for interdependent living. Although each participant experienced these areas in diverse ways, the theme of unlimited dreams pervaded each area. However, not all the participants experienced access to these dreams in the same way. I uncovered two primary areas of unequal opportunity evident throughout the participants’ narratives of post-school transitions: experiences with planning and decision-making, and accessing meaningful work.

Planning for the Future
Beginning at age 14, a student’s IEP must contain a statement of transition needs. The focus of this statement is on the student’s course of study, is based on her current levels of educational performance, and is directly tied to her post-school goals and IEP goals and objectives. Starting between the ages of 15 and 16, the IEP must reflect a process of educational programs, goals, supports, and services (Kohler & Field, 2003; Lehmann, Bassett, & Sands, 1999) that are designed to support students during the transition from secondary education to the various services that provide support to young adults with disabilities (Mallory, 1995) including but not limited to: post-secondary education, independent living, and employment. These coordinated sets of transition activities are designed to support schools in identifying community agencies, coordinating a plan for needed services, connect agency staff to families, and infuse interagency collaboration as a critical element of planning.

In addition, transition team members are expected to identify strategies for supporting students to access their rights to self-determination and community participation (Savage, 2005; Thoma, Rogan & Baker, 2001), and are to ensure that the students education is reflective of his or her post-school hopes and ambitions (Kohler & Field, 2003). Transitioning from K-12 schooling to higher education and the world of adult services can be a difficult thing to navigate and can involve a great deal of planning.

**Planning and cultural capital.** Some students, such as Britany, were well on their way to experiencing the reality of their post-school dreams. Britany is a part of a statewide initiative focused on self-determined support services. Through a Home and Community Based Waiver program, young adults like Britany are provided with the opportunity to design and individually tailor her support services to her needs and desires. Below Britany describes a recent meeting she had with her self-determination broker and family.
Britany: Well, we basically talk about my future and what it’s going to be like. Like, what I get to do in my free time. If I have free time I could always cook something, or make something for a snack, or go work out, or go to work. So, a little bit of something every day. Like in the summer, I will get to do a bunch of activities in the summer with my program that I’m a part of now and I will also get to have some time to hang out with my friends from high school too. We talked about the program, and how many hours I’d be working at Rob’s, and how much money I’ll get. And how this is gonna fit into our summer schedule ‘cause we travel sometimes, so…

Danielle: Will stuff with your money be any different after you’re done with school?

Britany: Sort of. I can’t go over my budget. Like over the amount that I will get at Rob’s if I do work there. I have to make a certain amount of money if I work there.

Danielle: Ok. Who did you meet with to help you with this?

Britany: Well, my parents were there of course, my service coordinator, and the startup broker came too.

Danielle: So, you have a broker. Are you doing Self-Determination?

Britany: Yes.

Danielle: Ok. So, what does that mean that you’re doing this Self-Determination?

Britany: That it means that I set up my future after high school like, do a bunch of activities and stuff with this new program, and just pretty much have fun.

Britany was the only participant who was involved in the State’s Self-Determination Project. The project is grounded in the concept that people with disabilities should have more control over the choices made in their lives; choices regarding where to live, whom to hire as support staff members, and the type of work they want to do. Funding is individualized and portable, and choices are made with a Circle of Support (Falvey et al., 2000) (friends, neighbors, family members, service coordinators, etc.). Planning is person-centered. My initial concerns centered on questions of access. Why was Britany the only participant afforded the opportunity to make these important life choices? Is it a matter inequity that a family with cultural and
financial capital is provided with access to this individualized service? But after researching the service more, I began to ask other questions.

According to the State’s Office for Persons with Developmental Disabilities (OPWDD; 2013), participants are provided with the “freedom to develop a personal life plan, the authority to control a targeted amount of resources, the support needed to obtain goals, and the responsibility for contributing to one’s community and using public dollars wisely” (¶ 1). According to the State’s Self-Advocacy Association (2011), the Self-Determination Project is a good fit for “families who are willing to take on more direction, more control of their lives, and more responsibilities” (¶ 1). These descriptions beg the following questions: (a) what families are excluded from this conception of “good fit,” (b) who controls this particular definition of self-determination and, (c) what cultural values shape this service?

The task of taking on more responsibilities and negotiating the paperwork and planning process for this service can be daunting for many families and students. Waiting lists are oftentimes quite long for receiving this particular consolidated support service and the time commitment alone can make this particular service an impossibility for some families. One must also look to the underlying cultural values of freedom, control, choice, and responsibility. Does this formulation of adult service provision meet the needs of diverse students and families?

According to Kalyanpur and Harry (1997), “professionals need to be aware that service delivery systems in the United States are defined by the underlying cultural values and social practices of mainstream America, and identify the culture-bound assumptions that have determined them” (p. 488). The emphasis on choice and control “is based on the American ideal of freedom of choice” (p. 491). Is this ideal shared by all families? Smith and Routel (2010) would argue, “no.”
In their critical analysis of current policies and practices of self-determination, Smith and Routel (2010) provide vast theoretical and research-based evidence to support the centrality of White, middle-class values to transition planning and formulations of self-determination:

The culture of Western special education, focused as it is on the dominating discourse of Anglo-American beliefs, places value on certain settings, such as independent living and work environments, denying as it does so, all too often, the importance of interdependence, reciprocity, and inclusion. (¶ 35)

It is important to note that the enactment of Britany’s self-determined, consolidated support services reflects the discursive policies of adult services: to live on her own in a supported apartment, to work in the food service industry, and to give back to her community through volunteering with her local community. The directions chosen are situated within the framework of mainstream definitions of successful transitions: independent living and productivity. This said, texting her friends, talking on the phone with her mother, and having fun are important life aspects that Britany hopes to enact as well. She appears to have successfully negotiated this particular transition, but how is the transition enacted by a young woman who’s cultural and financial capital may not make her a “good fit?”

Although Aminah does not qualify for the State’s Self-Determination Project given her learning disability label, her experiences with transition planning provide a narrative that diverges and converges in interesting ways when compared to Britany’s narrative. Transition “planning” in the traditional sense does not occur with Aminah and her family. Aminah has shared her desire to attend the local private university to pursue a health-related career, and several times throughout our interviews she shared how important it was to her family that she would be the first to attend college.
Danielle: And why did you pick the word family?

Aminah: I was just thinking about it. I don’t know, I just… ‘Cause everyone talks about how I’m the first person in the family to go to college.

Danielle: What do you think about that?

Aminah: I think that’s a good thing, yeah.

The college pathway to a health-care related field was also reflected in Aminah’s IEP, but a disconnect had occurred. Neither Aminah nor her family members had attended her IEP meeting that year. Due to a scheduling conflict, the planning meeting was held without them and Aminah was told she could attend next year instead. I was left questioning what sort of relationship building had occurred between the school and Aminah’s family. Although Aminah had not attended an IEP meeting and was not aware of the transition goals outlined on that IEP, the women in her life are supportive of Aminah’s choices for furthering her education, living near her family, and pursuing a healthcare-related career. This said, the school-family link is not established yet. What could Aminah’s teachers learn from the fact that she will be a first-generation college student? This identity-maker is something important to Aminah, yet it is not reflected in her IEP. This single piece of information could be used to shape a more culturally-responsive transition planning process.

The IDEIA (2004) mandates that professionals involve students and parents in educational decision-making processes. Involving students and families becomes even more important throughout the transition to post-school life. But as Kalyanpur, Harry, and Skrtic (2000) contend, the “realization of this vision of collaborative relationships and family-centered practice continues to remain elusive, particularly for low-income and culturally diverse families” (p. 119). Barriers such as scheduled meeting times, information conveyed at a high reading level or inaccessible format, lack of transportation, or a wariness of school officials based on past
histories can all contribute poor collaboration. The authors argue that both the hierarchal positioning of special education professionals and parents, as well as issues related to cultural capital are at play. Members of mainstream culture have acquired the tools and resources necessary to operate within the mainstream culture, but “for outsiders to the culture, however, this knowledge has to be learned as a conscious process at the point and time of contact – and, indeed, may never acquire it” (p. 125). Without a process of relationship building, cultural reciprocity, and self-reflection can transition planning be an equitable experience? What might be the consequences to Aminah’s college pathway if she and her family remain marginalized partners in her transition?

**Surrogate choice making.** Parents and family members are not the only ones to experience marginalization in the transition planning progress. Students can experience transition planning at the periphery as well. Victoria, who is 16-years-old, had yet to attend an IEP meeting, for reasons that also reflect, like Aminah, scheduling issues.

   Danielle: And have you had any meetings at school about this kind of stuff?

   Victoria: No, definitely not.

   Danielle: Do you ever go to meetings about school?

   Victoria: Meetings? No.

   Danielle: Have you seen your IEP?

   Victoria: Oh my IEP’s, yeah. I mean I don’t think? Yes, no, maybe. I’ll say yes.

   Victoria has heard of an IEP, but appears confused about what exactly an IEP is and what the meetings entail, so I tried to take her through an IEP meeting as something that occurs during the school year with teachers.

   Danielle: And so you have an IEP and at the end of the year or the beginning of the year. Have you ever gone to any meetings with your teachers about your IEP?
Victoria: My mom does, definitely. We did that like last year. She had to meet my teacher Ms… What’s her name? Ms. Brown, last year’s teacher.

Victoria’s mother is a high school teacher in a neighboring suburban school district and shared with me that she didn’t want Victoria to miss class time to attend her IEP meetings. Typically IEP meetings are held during school hours, which may not be convenient for parents nor students. The result is a teenage girl who is aware of and able to express choices regarding her future, but does not have the opportunity to fully make those choices. Victoria’s mother has taken up that work of choice making. This is not to vilify her mother, Victoria’s educational plan reflects some of the narrative she shared with me, but to bring attention to the consequences of enacting policies (i.e., transition planning) in ways that at worst, keep students out and at best, result in surrogate choice-making.

The consequences of surrogate choice-making were also present throughout interviews with Hope. During our interviews Hope frequently shared ideas she had about her future such as wanting to attend the local community college to taking nursing-related courses and securing work that involved caring for others. This said, she had never shared these ideas with her school or family. Hope is a young woman with more limited expressive communication skills, which makes it even more unacceptable that the adults in her life are not actively seeking out her opinion on things that are important for her future. Hope also indicated that she was not aware of her IEP or any goals that the school is working on for her future. Hope and I did talk about meetings that she has at school with her Special Education teacher and her legal guardian, Joyce. Below, Hope describes the topics typically shared at her school meetings.

Danielle: What kinds of things do you talk about at those meetings?

Hope: Ummm… Ummm… That’s a hard question.

Danielle: Is it?
Hope: [laughs]

Danielle: Does anyone else usually go to those meetings with you?

Hope: Joyce.

Danielle: Oh ok, Joyce. Do you remember what kind of stuff Joyce talks about at those?

Hope: I walk.

Danielle: What kinds of things does your teacher talk about?

Hope: That I stand.

Danielle: And why do you do that stuff?

Hope: To get stronger.

Danielle: To get stronger. So, is there anything else you can remember that you guys talk about at your school meetings?

Hope: Hmmm… No.

Hope uses a wheelchair and her legal guardian has expressed concerns that she will not be able to walk across the stage at graduation and will not be able to dance at her senior prom if she doesn’t build physical strength. Standing and walking have been placed as priority goals for Hope and her transition, even though Hope had expressed during our interviews two salient goals related to college and employment. She did not refer to standing or walking until we began discussing topics that the adults discussed at her IEP meeting. Building strength is important for Hope’s access to the community, because her guardian does not have wheelchair accessible transportation. Being able to pivot makes accessing the community easier, but why is this one goal (grounded in problematic and limited constructions of ableism and normalcy) at the center of Hope’s transition?

For Hope, planning that is centered specifically on her personal dreams and goals will be essential to the realization of those dreams. Transition planning falls under the one of just many
areas of Hope’s life that can be considered institutionalized. Hope is not positioned as an active participant throughout her transition planning. She is 21-years-old and has attended one meeting about her future. Teachers do appear to be listening to Hope’s ideas about her future, because her IEP reflected her desire to work with children or in the area of care work, and her preference to take courses at the local community college. In addition, her current job placement through the school district was in the area of caring for older citizens. According to her IEP, Hope was to be provided with the opportunity to engage in career activities related to working with children, and to visit the community college. During the time of this study these activities had not occurred. Hope’s residential service manager was preparing for her summer employment at a sheltered work center. Somewhere along the lines, communication and collaboration for Hope’s post-school dreams broke down.

**Accessing Meaningful Work**

The second primary area of inequity that I examined through the participants’ narratives was in relation to their experiences with accessing meaningful work. Participants such as Victoria and Aminah shared interests in following paths of employment held by immediate and extended family members. These family members provided a frame of reference for understanding the world of work and allowed the participants to explore varied interests. Britany’s family also provided her with important career connections through the business of a family friend. Aminah and Victoria still have a few years of schooling left before they enter post-secondary education and/or employment so it is difficult to discuss the actualization of their employment dreams. However, Britany and Hope are both in their final years of schooling and will enter the world of adult services soon. In the following sections I contrast Hope’s narrative of sheltered work with the narratives of the other three participants, all of which center on
families providing career connections.

**Family career connections.** As previously mentioned, Aminah is very close with the female members of her immediate and extended family. She often goes to her grandmother or godmother for advice and wants to remain close to her family after graduation. During our conversations Aminah and I began talking about her general plans for after she graduates from high school. Aminah’s desire for a future healthcare-related field appeared to be shaped, in part, by her grandmother’s career in nursing.

Danielle: What do you have to do? Like if you wanna be a pediatrician, what kind of stuff do you have to do?

Aminah: You gotta go to school. I think they said four or eight years. That’s too much school, but I can do it. I [emphasis on I] think I can do it.

Danielle: Have you told anybody that’s what you wanna do?

Aminah: Uh huh, my mom.

Danielle: What’s she think?

Aminah: She’s happy. She was happy I guess, ‘cause my grandmother talked to her. She was a doctor or a nurse.

Aminah recognizes the years of study it will take to pursue her career choice, but demonstrates confidence in her ability to complete that task. She emphasized that she believed she could accomplish the necessary schooling, but her emphasis on the word I indicated that someone might not agree with her assessment. Even so, Aminah is supported by her grandmother and appears ready for the challenge.

Aminah also discussed the importance of graduating high school and how she would not only be the first in her immediate family to receive a high school diploma, but would also be the first to attend college. Aminah’s family frequent shared this observation, and it appears to have become an important part of her identity. In their study of the academic performance of first-
generation college students with disabilities, Lombardi, Murray, and Gerdes (2012) found that the intersection of disability and first-generation status placed students at risk for post-secondary education completion. First-generation students who had disabilities experienced lower GPAs, less family support, and greater financial stress. The authors suggest implications for disability services providers including more individualized supports, opportunities to discuss stress, and facilitating social support from families. Aminah’s dream of becoming a pediatrician or working in a health-care related field is reflected in her IEP. It will be important for Aminah’s circle of supports to discuss both her first-generation student status and her disability label in order to facilitate a successful transition to post-secondary education.

Like Aminah and references to her grandmother, Victoria also identified a successful female role model when discussing her future career choices. During an interview with Victoria, she mentioned her dream of becoming a chef and indicated that she would like to pursue post-secondary education to learn more about cooking. Oftentimes my conversations with Victoria centered on food; the types of foods she liked to eat at school, what she had for lunch that particular day, or things she could cook at home. Her collages were also filled with more food images than any of the other participants (burgers, sandwiches, ravioli, meatball subs, etc.). When finishing up her collage about the future, Victoria made a list of 14 things that were important to her. Numbers one through three were as follows: (1) college, (2) chef and, (3) work in restaurant. Family connections to Victoria’s culinary interests came into play when she discussed a restaurant at which she could work.

Danielle: Is that a restaurant?

Victoria: Yeah it’s a restaurant. My friend Kerri of my family works there.

Danielle: Ok. So, you can be a chef and work in a restaurant where one of your family friends works.
Victoria: Yeah, my family yeah.

Danielle: And so, why do you wanna be a chef?

Victoria: I wanna be a chef because, I wanna be a chef because, my friend that’s of my family’s is a chef so, that’s why I wanna be a chef. ‘Cause she’s being a chef.

Victoria’s strong interest in food has led her to understanding the culinary arts as a possible career choice, as well the experience of an adult female family friend who has success in the same field. Victoria’s food interests intersected with her access to family friends working in her desired industry. She has been provided with a model of a successful female chef, whom is close to her family and may be able to provide guidance at some point during Victoria’s post-school transition planning. After an interview with Britany, also about the culinary arts, I began to understand how family connections not only provide models for various employment opportunities, but also reflect the discourses of financial and cultural capital.

Like Victoria, Britany also has strong interests in food and the culinary arts. Britany described one of her favorite parts of her current job at Rob’s BBQ as tasting the food with the chefs, and bringing food to guests so she could see the “wonderful” items they ordered. Britany also discussed stocking shelves at her other job placement (a large retail store) with gourmet chocolates and pastas. In addition, Britany was involved in cooking classes through her local adult service agency. Through her involvement in statewide self-determination planning, Britany will soon be taking courses at her local community college related to the culinary arts.

Britany: I really want to be a part of the culinary arts there [community college], ‘cause I love to cook.

Danielle: And what kind of stuff did they do at the culinary…

Britany: They make like foods like, I can’t remember what foods exactly, but there’s like hamburgers or something.
Britany also “loves” her current job placement at Rob’s BBQ and is planning to continue her work there after she finishes high school. Britany feels a sense of belonging at Rob’s BBQ and has experienced a variety of job duties from serving, to cleaning, to interacting with customers. Britany and her self-determination broker have arranged for her continued employment at Rob’s after graduation. Britany shared that she needed to be aware of her budget and to not work too many hours. She was also expressed a desire to change her work schedule to every-other-day, so that she would have free time to spend with friends, take college classes, and relax.

Britany will experience the realization of inclusive, community employment. She will continue working for an employer who respects her and understands the value Britany brings to his restaurant. Through extensive collaboration and student-driven transition planning, she has found a job site that she enjoys and will be able to continue with her community employment after graduation. Although I cannot predict the future, it appears that Britany will realize a successful post-school transition, at least in regard to the world of work.

Access to opportunities has also shaped Britany’s post-school employment. As previously mentioned, Rob’s BBQ is owned by a family friend. Britany’s mother is a special educator, adept in the world of adult services for people with disabilities and the statewide person-centered planning initiative. Britany’s success cannot be attributed entirely to financial and cultural capital, but these privileges cannot be ignored. Unfortunately post-school transitions are not an equitable process. Hope’s post-school narrative does not reflect access to such inclusive employment opportunities.

Traditional “employment” and persons with intellectual disabilities. Segregation, institutionalization, and limited access to opportunity shaped Hope’s actualization of post-
secondary employment. I must admit it is ironic that she had chosen this particular pseudonym in light of our various conversations. Early during one of our interviews, Hope indicated that she would like to pursue care work in the form of nursing. Hope shared that she wanted to work with babies and could take courses at a community college to support her learning. As described in Chapter Five, these dreams are an unlikely reality for Hope. Her residential manager has arranged for Hope to begin employment at a local sheltered work center. Each of Hope’s six housemates is “employed” at either this or another sheltered work center in the area.

Hope believes she will be handling paperwork and answering telephones while at the sheltered work center, but her Medicaid Service Coordinator described the employment for persons with disabilities as involving piece-rated work. While I cannot say with 100% certainty, my thoughts are that it is likely Hope’s employment will involve segregation and piece-rate work. Hope’s situation is not unique among young adults with intellectual disabilities. Even with the availability of supported community employment, the instances of people with intellectual disabilities engaging in segregated work is actually increasing (Rogan & Rinne, 2011). Based on data from the 2010 Kessler Foundation/National Organization on Disability survey, Rogan and Rinne report that only 21% of people with disabilities in the U.S. are currently employed full- or part-time. 76% of adults with developmental disabilities spend their days in congregate settings with segregated employment.

The Olmstead decision of 1999 requires states to place “qualified” individuals with mental disabilities in community settings instead of institutions. The decision places a legal preference on community inclusion and requires services and programs to be implemented in the most integrated setting possible. Even with the establishment of the Olmstead Act (1999), “our federal and state governments continue to uphold an apartheid system of mass congregation and
segregation of adults with intellectual and developmental disabilities in sheltered workshops and 
day activity centers” (Rogan & Rinne, 2011, p. 248). In recent news, Diament (2012) highlighted 
the class-action lawsuit of 2,300 adults with developmental disabilities in Oregon indicating, 
“they’re being relegated to sheltered workshops even though they’re capable of working in the 
community” (¶1). The U.S. Department of Justice even weighed in on the this particular lawsuit 
arguing the similarity of sheltered workshops to institutions, and stated that the unjustified 
placement of people with disabilities in congregate work settings when a person could be 
employed in the community is a sufficient to file claim under the Americans with Disabilities 
Act.

Leaders in the field of employment for people with intellectual disabilities have also 
issued a call for change. Rogan and Rinne (2011) argue for a shift from sheltered to integrated 
employment and suggest a viable transformation with the support of federal and state agencies. 
The authors posit that National and State Employment First initiatives should be established to 
provide greater funding support, and resources to enable more individuals to pursue competitive 
employment. In addition, Taylor (2002) cites both pragmatic and philosophical grounds to 
relegate sheltered workshops to the history books. Citing low pay, the virtually nonexistent 
likelihood of securing community employment once placed in a segregated setting, and the need 
for workshops to retain high producing workers, Taylor calls for an end to sheltered work. 
Taylor’s call to end sheltered work began over 10 years ago. There is no reason for Hope to 
become another statistic of a segregated worker. She has aspirations for community employment 
surrounding care work and has the right to proudly be accepted into the ranks of real 
employment.
In this chapter I describe the transition experiences for the four adolescent girls in this study. The participants share their dreams for the future including post-secondary education, employment, friendship and intimate relationships, and interdependent living. It was striking to examine the ways in which the participants accessed opportunities to realize these dreams in inequitable ways. Privilege such as being labeled learning disabled and being provided with greater access to general education, did not guarantee greater access to transition planning. However, financial and cultural capital appeared to greatly shape student access. More than 10 years after the call to end sheltered workshops by Taylor (2002) and the enactment of the Olmstead Act (1999), young women with disabilities continue to have their employment options ignored and are still placed in congregate work settings. In the concluding chapter I will discuss the implications of these narratives for their family members, teachers, future students, and ultimately policy and practice regarding culturally responsive transition planning.
CHAPTER 6: CONCLUSION

In this dissertation I explored the experience of schooling and transitions for four adolescent girls with intellectual and learning disability labels, through multiple in-depth interviews, supported collage, document review, and the AIR Self-Determination Scale (Wolman et al., 1994). In this conclusion, I summarize and review each data chapter describing the divergent and convergent participant narratives. I then highlight methodological (i.e. the use of supported collage in qualitative research) and theoretical implications (i.e., self-determination theory). Lastly I provide recommendations for high school administrators and teachers, university teacher preparation programs, and students with disabilities and their families.

Driving my recommendations is the need for culturally responsive transition planning and strategies for addressing the inequities uncovered by this dissertation. As Gay (2002) notes, Individuals are socialized to devalue, suspect, and pretend to ignore differences, especially those that derive from class, race, ethnicity, and culture. Much of this socialization equates differences with deficiencies that should be eradicated. The ultimate goal seems to be to make everyone believe, value, and act the same. The standard of this sameness is mainstream, European-American cultural norms. (p. 614)

It is my hope that by paying attention to differences, including disability, and conceptualizing diversity as valuable and of great resource, more adolescent girls with disabilities will experience the reality of their post-school dreams and greater access to opportunity.
Key Themes and Implications

Negotiating the Borders of Adolescent Girlhood

In Chapter Three, I examined the participants’ constructions of gender and the ways in which they negotiated the simultaneous experiences of girlhood and womanhood. Anzaldua’s (1987) conceptualization of the borderlands was central to this chapter. Each of the participants negotiated the liminal space between girlhood and womanhood, actively claiming each and both identities throughout adolescent narratives. Anzaldua argues that identities are constructed in a hybrid, pluralist manner in response to the creation of borders. Anzaldua created the borderlands in response to Mestiza identity, but I found her conceptualization particularly useful for understanding the borders between girlhood and womanhood as well.

In this dissertation, the borderlands were produced by both the culture of special education (through segregation, limited opportunities for authentic friendships, and extensions on graduation age) and mothers (through limited choices and protection). The participants struggled at times with creating a non-contradictory female identity, but also demonstrated agency by locating themselves within certain identity spaces when it benefited them. In addition to negotiating the borders of girlhood and womanhood, the participants shared their experiences with friendship and sexuality and reconfigured adolescent girlhood through sexual expression and divergent interests.

Each of the participants described the experience of friendship, but experienced friendships in differing ways. For example, Britany struggled with high school cliques, but vacationed and participated in Special Olympic activities with a few close friends. Victoria also participated in Special Olympics and sports clubs such as cheerleading, with a few close friends, but relied on her mother for organizing social activities as well. Aminah, who was fully included
in her high school, was never at a loss for friends to chat with during our interviews, to attend parties with, or to simply hang out at the mall. Hope, who experienced the greatest amount of segregation, was not able to name any school-aged friends, did not attend events with people her own age, but created collages that were replete with representations of people she called friends.

Aminah was the only participant to attend an urban high school. She was also the only participant to be fully included in all aspects of the high school experience (from her academic classes, to sports, to social events). Her cell phone was full of the phone numbers of friends and acquaintances, she did not rely on her family to organize opportunities for socialization, and she described rather wild teenage parties where bloody fights occurred. My intention is not to claim that the experiences of the other participants are any less valuable, simply that they are categorically different.

Doesn’t Hope also deserve the chance to experience these realities of adolescence? Hope’s “social scene” included watching television with her housemates and eating dinner with her housemates. She went shopping and ate lunch with classmates during school hours as part of the activities of her self-contained classroom. The only friend whose name she shared was also a staff member in her group home. Throughout Hope’s narrative was a discourse of safety and protection, but what are the unintended consequences of this discourse? Doesn’t she deserve to experience risk as well? Given Hope’s structured day at her group home (pre-planning menus, organized group activities, limited access to community settings, hourly schedules followed by all housemates, etc.) there is little opportunity for her to experience risk. Segregated special education and her institutionalized living arrangements contributed to a lack of access to friendship development, particularly with non-disabled peers.
Rossetti (2011) found that the structured environments of special education were not congruent with the spontaneous nature of social interaction in high school. Aminah’s social interactions occurred within the spontaneous nature of her general education classes and throughout her high school building. Passing notes with friends, laughing behind the teacher’s back, or chatting with many people in the hallways on her way to class. Hope, Victoria, and Britany experienced social interaction and friendship through organized events such as Special Olympics, outings initiated by parents, or the structured environments of special education.

Inclusive education can provide students like Hope, Victoria, and Britany with more opportunities for authentic friendships. Rossetti (2011) argues that organized friendship groups perpetuate charitable relationships between students with and without disabilities. This is not to say that educators should not facilitate friendships, but that the facilitation should be based on common likes and interests. In addition, facilitation cannot occur if students do not learn in the same places. Although Aminah’s friendship narrative diverged from the friendship narratives of the other three participants, they did share similar experiences regarding heterosexual relationships and counternarratives to hegemonic femininity.

Contrary to research demonstrating silence in the area of sexuality and people with intellectual disabilities, all participants in this study shared stories of heterosexual relationships. In the case of Aminah, this meant speaking on the phone late at night to boys or taking pride in ignoring their texts. For other students like Britany and Victoria, this included sharing first kisses and intimate relationships. And for Hope, this meant attending school dances with a former boyfriend. Family members and residential staff appeared supportive of the girls’ relationships and the ways in which the girls actually talked about their relationships mirrored typical
adolescent discussions: sometimes giggling, sometimes excitement, and sometimes simply a matter-of-fact tone.

Confident sexual expression could be considered a counternarrative to they ways in which people with disabilities are typically understood by parents and caregivers. Sexual agency provides young women with opportunities to choose how to experience sexuality. Wilkerson (2011) argues that sexuality is nonetheless a culturally feared aspect of the body, with especially serious implications for those whose bodies are perceived as falling outside a fairly narrow and rigid norm” (p. 193). Although the adults in the participants’ lives did not appear to consider the participants asexual people, some parents were overprotective regarding their daughters’ recreation and leisure time. There was a tension between sexuality and restriction that I am not able to fully explain. Each of the participants shared stories of intimate relationships, but some experiences restrictions on their access to social media outlets, such as Facebook, and “tween” television programs such as Pretty Little Liars. Other participants had less control over their recreation activities, which were oftentimes arranged by adults.

The participants also did not automatically accept the most stereotypical gender roles, but recreated their own definition of femininity that included sports and food interests and discussions of physical altercations. These transgressions, however small, were exciting for me to hear but were not substantially reflected in the participants’ IEP (Aminah’s IEP reflected her interests in sports and Britany’s IEP listed Rob’s BBQ as a future place of employment). At other times the participants actively inserted themselves into a hegemonic discourse of traditional femininity.

This was most readily seen through the participants’ collages, heterosexual relationships, and job choices. These insertions could be considered political acts when positioned against
sexist and ableist discourses of women with disabilities as asexual or childlike. The participants created collages of “tween” heartthrobs, feminine clothing, and sexualized female models, while specifically Britany shared an interest in sex and Victoria discussed marriage as an important part of her future. In addition, Hope identified caring for young children as an interesting area of future employment. Early work by Asch and Fine (1988) discusses disabled women’s claims to traditional gender norms as a political act, because they are perpetually denied access to femininity because of disability. These hegemonic discourses of traditional femininity were not created for women with disabilities, but the young women in this dissertation have actively taken up these cultural narratives, again, creating their own definitions of femininity.

A lesson learned from this study was the need for educators to support diverse experiences of adolescent girlhood. Sexuality was not discussed in any of the students’ IEPs, perhaps because educators assume that sexuality is not important to the lives of students with disabilities, or perhaps they are uncomfortable tackling this topic. Even if educators are uncomfortable, they must be reflective and consider the dangers of positioning young women with disabilities outside of the discourse of sexuality. As previously discussed, I myself experienced discomfort when Victoria began sharing the more intimate details of her relationship with Geoff. I, other educators, and much of society have been inundated with messages that people with intellectual disabilities are either asexual individuals or are in need of protection from predators. We are not often exposed to discourses of sexual agency (Wilkerson, 2011). It is important to recognize when these cultural messages are reflected in our personal thoughts and behaviors in order to resist and counter this discourse.

The goal of sex education is not to perpetuate a discourse of protection, but to provide people with disabilities access to the same opportunities as people without disabilities. Sex
education materials should be made accessible to students with disabilities and can include modified curriculum, alternative formats, and auxiliary aids. Components of an inclusive sex education course should include trusting relationships, diverse communication modes, a focus on generalizing skills, respecting student choice, and administrative support (Belote, 1997).

The tension between sex education and protective parents is an area I have not yet resolved in my mind. Even throughout this study, I would find myself, at times, limiting my follow-up questions when the participants’ mothers were present during more sensitive topics. In the future I would be sure to take note of areas for potential follow-up and come back to those topics when the participants could be more open with their responses. The tension of protective parents and sex education is an area I have thought about extensively, but have not been able to formulate a specific strategy to address this tension. However, I believe that not offering sex education to students with disabilities is discriminatory and ableist, and in fact, illegal in some states. In the state of California, if a school district chooses to offer a comprehensive sex education program, it must adhere to state guidelines such as medical accuracy, teaching both abstinence and contraception use, and bias-free curriculum. In addition, if comprehensive sex education is offered to students with disabilities, it must be made available to students with disabilities as well and should be accessible and modified as needed (California Department of Education, 2012). By offering sex education to students with disabilities and reflecting the importance of the topic in a student’s IEP, perhaps educators and parents will become more comfortable and supportive of this aspect of their students’ and children’s lives.

Constructing Self-Determination

In Chapter Four, I explored the ways in which the participants constructed and experienced self-determination. Although the phrase, “self-determination,” was not used by the
participants throughout their many interviews, each young woman shared stories of choices, decision-making, and control. Honoring Smith and Routel’s (2010) call for diverse understandings of self-determination, I began by presenting each participant’s narrative: Victoria, the anti-bullying activist; Aminah, an ninth grader who makes “good choices” as a means to an end; Hope, a young woman who leads an institutionalized life; and Britany, who demonstrates control through cultural capital. I also explored the IEP as a document with its own self-determination narrative. In some cases the IEP rearticulated the participants’ narratives, but often key information, such as the need for financial aid to attend higher education or employment preferences, was absent.

In Chapter Four, I also co-analyzed the qualitative data from interviews, document review, and supported collages with the quantitative data from the AIR Self-Determination Scale (Wolman et al., 1994). One of the more interesting trends from mixing qualitative and quantitative data was that the participants, whose narratives reflected the greatest access to opportunities for self-determination, reported the least opportunities for self-determination on their quantitative survey. Drawing on Lareau’s (2003) ethnography of class and childhood, I posited that class culture might have shaped how the participants rated their opportunities for self-determination on the AIR Self-Determination Scale.

In addition, the more time participants spent in the general education classroom, the lower they rated their opportunities for self-determination. Aminah, who is labeled with a learning disability, experienced the greatest amount of inclusion, but self-reported the same dissatisfaction with opportunities for self-determination as Britany, who is labeled with an intellectual disability and is more included at her school than Victoria and Hope. I do not believe that Aminah’s “less significant” disability label necessarily provided her with greater skill in
making friends or self-determination. Aminah presented her narrative in a similar manner as Britany and when reviewing the data, Britany (who was labeled with an intellectual disability) appeared to be just as talkative, confident, and self-directed as Aminah. Rather, this label provided her with greater opportunities for inclusion at her school. Victoria, Hope, and Britany all attend suburban schools (although in different suburbs) and all experienced the same disability label, but Britany’s narrative demonstrated a greater amount of access to self-determination and socialization. It appears that the participants who experienced more privilege in relation to subject position (socio-economic, educational, and disability label), more readily verbalized their dissatisfaction with their opportunities for self-determination.

It is important to note, however, that Britany’s opportunities for socialization did operate within the constraints of parental protection. She resented not having opportunities to engage with social media or choose the television programs she wanted to watch. She chose not to have a boyfriend at the time of this study, but resented having the option of sex taken away from her. This frustrated Britany and she indicated that she “just wanted to be treated like everyone else.” Britany recognized the differential treatment she received at home due to her disability. There appeared to be differences in how choices were constrained for each of the participants (institutional constraints v. family constraints).

Britany faced limited choices in her personal life, but her academic and employment opportunities are much greater. Both Britany and Victoria come from families with cultural capital and there appeared to be more family involvement. At times during my interviews, both of their mothers even seemed to feel like a background presence throughout. Along with greater family involvement, came greater control over choice making. For Aminah and Hope,
institutional policies and practices (such as segregation, sheltered employment, and lack of IEP involvement) framed their opportunities for choices making.

The most striking finding from this chapter related to issues of inequity. Similar to their experiences with transitioning to post-school life, the ways in which the participants experienced self-determination were quite diverse and were shaped by their access to opportunities. When I first sat down to talk about advocacy with Victoria I was excited by her experience travelling to New York City to participate in a public service announcement for a campaign to end the use of the r-word. Victoria loved singing and acting, so this experience not only represented a significant act of advocacy, but also reflected genuine interests of hers. She had also been the victim of bullying, so the cause personally resonated with her as well.

But I soon came to recognize how this extraordinary opportunity was also shaped by financial and cultural capital. The access needed to participate in a national anti-bullying campaign, filmed in New York City required a personal and familial awareness of this particular campaign, a vested personal and family interest, the financial means to travel to and stay in a rather expensive city, and the cultural capital of a mother who effectively navigated this opportunity and supported her daughter throughout. I also became struck by the ways in which access to opportunity shaped Britany’s experiences with self-determination.

Britany has a job, at a restaurant owned by a family friend, that she thoroughly enjoys, fully participates in her transition planning meetings and has so for several years, and is in the early stages of preparing for self-directed, adult support services. Britany’s family and educational planning team are aware of her desire to attend post-secondary education and have identified two local institutes of higher education that she can attend with support. Given that, in part, this was a study about experiencing self-determination I was thrilled to hear this narrative of
a young woman who controls, and will continue to control the course of her future. Britany has the right to choose a place of employment she enjoys, to hire a support staff person who best matches her interests and needs, and attend the college of her choice. But again, I was left with a sense of unease. In stark contrast to these two narratives of self-determination was Hope.

What about Hope? Does she not also deserve the right to such autonomy and self-direction? Hope’s experiences with self-determination were shaped by her institutionalized life. One of her closest friends was her agency-appointed advocate who is also a paid support staff in her group home. Hope has limited access to friends her own age and limited access to her community due to inaccessible transportation. Hope’s meals are planned for her and even through she expressed a strong interest in cooking, this experience is limited to stirring juice. Hope’s school day and time at home is very structured and she is in bed by 7:00pm. Hope shared with me that she wanted to attend the local community college for nursing and is interested in working with young children. Yet, Hope will begin her piece-rated job at a sheltered work center very soon, a job that was chosen for her by her residential manager. It was quite distressing to see how a 21-year-old young woman’s life has unfolded in such an institutionalized manner.

I wondered how young women could experience self-determination and choice in such a disparate, inequitable manner? Britany’s access to opportunities for self-determination is shaped by the ways in which her intellectual disability label intersects with her cultural and socio-economic locations. Her Whiteness and upper-middle socio-economic status grant her a certain amount of privilege that may not be experienced by other young women with intellectual disability labels. Given that two of the participants were African American students both from low socioeconomic backgrounds, it is difficult to separate out differences between race and class. The two subject positions are intertwined in important ways.
Also, this is not to say that Britany does not experience oppression. She will not receive a high school diploma, spends a great deal of her high school day segregated from her non-disabled peers, and is restricted in the choices she makes regarding clothing, television, and relationships. But I could not ignore the privilege she experienced as well. What would self-determination look like for Britany if her family friend did not own the restaurant where she completes her job placement? What would self-determination look like if Britany did not have the financial capital to travel with her family? What would self-determination look like if her mother was not a highly educated special education teacher with knowledge of adult services? It is my hope that studies such as this one can further the conversations of access to opportunity for students with disabilities and the consequences of ignoring the importance of social and cultural capital.

**Narrating Transitions**

Perhaps the greatest lessons learned from this study came from uncovering the disparate experiences of transitions. In Chapter five, I explored the post-school dreams of the participants and situated the realization of these dreams within the larger context of opportunity. My study shows that adolescent girls with disabilities have ideas for what they want their post-school life to look like. This post-school life most often reflected a desire for community inclusion. Aminah wished to attend a local university to play sports and study medicine, and live on her own near her family. Britany wanted to take courses at the local community college, continue working at Rob’s BBQ, and eventually (not without trepidation) share an apartment with a roommate. Victoria shared the dream of culinary arts and marrying her current boyfriend. Hope wished to
take courses at the community college, enter the care-work field, and continue living in her current group home. All of these dreams reflect inclusion in the larger community and, with support, could be realized. I cannot say which dreams will become a reality for the participants, but for one participant, Hope, transition planning has failed and has taken her down a segregated path instead. Part of this can be explained by inadequacies in the transition planning process itself.

For many of the participants, transition planning appeared to be an add-on activity and did not drive their schooling. In addition, I uncovered several mismatches between the participants’ narratives and their IEPs. For example, pursuing culinary arts and attending college were not reflected in Victoria’s IEP, Aminah’s IEP (the participant who experienced the most educational privilege in regard to inclusion) did not reflect any transition activities to support her in reaching her goal of attending college, and Hope’s IEP indicates an interest in caring for children, but did not indicate what steps would be needed to help her reach this goal. The one participant who experienced a transition-driven education also experienced a great deal of cultural capital was, of course, Britany.

Similar to Britany’s experience with living a self-determined life, her transition planning was also shaped by the social and cultural capital she and her family possessed. Trainor (2008) argues that much of the work in post-school transitions for students with disabilities focuses on the individual and fails to examine social and cultural capital as a key unit of analysis. Long have disability studies scholars argued that disability is not the inherent result of impairments, but is rather a socially constructed category and, in the case of learning and intellectual disabilities, is produced by social and institutional factors. By paying attention to these social factors, rather than the impact of perceived individual deficits on post-school transition, I was better able to
recognize when issues of inequity or opportunities and barriers related to social and cultural capital were at play. My belief is that this dissertation contributes to this gap in the literature by providing stark examples of how social and cultural capital are used during the transition process and how by ignoring the importance of capital, inequities are perpetuated. I propose that culturally responsive transition planning may begin to address these inequities. At the end of this chapter, I provide a framework and considerations for this planning process.

**Methodological and Theoretical Implications**

**Supported Collage Making**

Supported collage making proved to be a useful tool for accessing the narratives of adolescent girls with disabilities, building trust, and creating a sense of pride. None of the participants knew me prior to this study and the idea of creating a collage fostered both trust and buy-in for this study. Many of the participants had not previously shared their thoughts on schooling and transitions with an adult, and the use of collage helped to build trust. In addition, some of the participants experienced expressive communication differences, so the act of creating images (through magazines and artwork) provided them with a point of access. This method worked particularly well when discussing aspects of high school and adolescent girlhood, topics that were familiar to the participants. The participants also experienced a sense of pride in their creations. Hope hung her collages around the dining room of her group home, while Victoria taped them to the walls of her bedroom and even brought one to school to post on the walls of her self-contained special education classroom.

The method was not without its problems though and there are things I would do differently in the future. For example, I would not shy away from probing the participants further on their questions. I felt I made attempts to navigate this skill, but did not want to lead the
participants either. Ways to gather more explanation from participants without leading them include, asking a related question, asking for examples, or seeing if the participant has other words to describe her experience. I believe that in some instances, such as with describing goals or choices, some of the participants simply did have these ideas in their available discourse. Some participants may have never been asked about their goals for the future or have never been in a position to decide. Others may have not experienced many opportunities for choice making and, therefore, did not have the available language to discuss that particular topic in great detail. In addition, it is important to acknowledge the potential dangers of using anything resembling arts and crafts with young adults with intellectual disabilities, given the history of child-like assumptions about people with intellectual disabilities. One must proceed with caution and an awareness of this history in order for this method to be both accessible and emancipatory.

This adapted method is an important starting point for making qualitative inquiry more accessible to students and adults with disabilities. I intend to continue exploring methods for adapting qualitative inquiry and believe this to be a potentially useful strategy for any qualitative researcher interested in the experiences of adolescents, and for qualitative researchers who wish to fill the literature gap of research prioritizing the voices of people with disabilities.

**Re-thinking Self-Determination Theory**

A skill-based understanding of self-determination was not reflected throughout the participants’ narratives. Each of them shared diverse experiences with choice and control in their lives. Some choices were seemingly mundane, such as choosing what clothes to wear, while others were more significant such as choosing a place of employment or to transfer to a different school. The ways in which the participants enacted self-determination was shaped by their social
locations and access to opportunity. Cowley and Bacon (in press) outline several recommendations for researchers in the field of self-determination including, (a) shifting from skill-based understandings to opportunity-based understandings of self-determination, (b) infusing self-determination into the general education curriculum for all students, (c) examining segregation as a barrier to self-determination and, (d) valuing disability as diversity.

In Ratner’s (2000) analysis of agency and culture, he noted how “agency always operates within and through a social structure” (p. 421). Self-determination skills mean little if students are not provided with the opportunity to enact those skills. At the end of this study I actually felt anger at the idea that a concept such as self-determination, where a person has the right to direct her life, has been diminished to a set of skills. I was also angered that so many researchers believe that self-determination is a concept for students with disabilities alone.

As discussed in Chapter four, I found that the questions asked on the AIR Self-Determination Scale (Wolman, et al., 1994) did not reflect the barriers and opportunities experienced by the participants. I am not in a position at this point to create a new tool to assess how well schools and families are doing at providing opportunities for self-determination, but I have developed some potential items that highlight school climate and the tensions experienced by the participants. These include, (a) people have asked me about my goals for the future and have discussed them with me in a meeting at least once this school year, (b) I feel as though I have control over my leisure, recreation, and social time and, (c) someone has shown me my IEP and I feel that my personal strengths and needs are seen throughout it. These questions represent a more disability studies orientation to self-determination in that they are not addressing skill building or simply opportunities to build skills, but reflect the importance of the environment and institutional structures when considering who or what needs to change.
By re-thinking self-determination as a concept important to all students, it can be more readily infused into the general education curriculum by encouraging cooperative learning, supporting self-advocacy for all students, and infusing positive disability representations throughout the curriculum (Cowley & Bacon, in press). When inclusive classrooms are embraced, self-determination may be effortlessly represented, and both special educators and general educators may come to see the importance for advocacy, choice, control, self-esteem, and self-awareness for all students. Creating opportunities for advocacy for students with disability may require accommodations and modifications, but not does require segregated practices.

**Limitations and Future Research**

For some readers, the small sample size of this study may be viewed as a limitation. I purposefully chose to focus on a small number of participants in order to delve deep into their experiences with schooling, self-determination, and transitions. Some readers may find similarities to their lives or the lives of students they work with and care about, but I am not able to make universal claims on the experience of adolescent girlhood and disability. This said, by including culturally and economically diverse participants in this study, I was able to make comparisons within various aspects of their lives. In addition, the variety of methodological tools I used allowed me to provide a multi-layered understanding of the participants’ experiences. Although my ability to generalize my findings may be limited, I intend to pursue future research into the experiences of diverse adolescent girls with disabilities in order to continually narrow the literature gap in this field of study.

One extension of this study I would like to pursue includes a more ethnographic approach to the schooling and transition experiences of adolescent girls with disabilities. The purpose of
this dissertation was narrative in nature, but I believe participant observation (in addition to in-depth interviews and supported-collage) would add another layer of depth to understanding the experience of schooling. Bettie’s (2003) practice of “hanging out” with adolescent girls may provide additional insights into the practices of friendships and sexuality, while Kusenbach’s (2003) use of participant observation would add the environment as a key site of analysis. It would be particularly useful to observe participants at their IEP meetings.

Due to the varied times of year in which their IEP meetings occurred and the inconsistency in student attendance, I chose not to observe these meetings for this particular study. In future studies, I would request to observe IEP meetings whether or not the participant attended in order to add yet another layer of data. Potential questions I would like to explore include, (a) Do various educational settings (self-contained classrooms v. general education classrooms) impact self-determination, post-school transitions, and the borders between girlhood and womanhood and how? and, (b) How is adolescent girlhood enacted during unstructured school and family times?

I would also like to pursue a longitudinal study of transitions and self-determination. To date, there are no studies that approach the transitions experiences of adolescent girls with disabilities through a longitudinal lens. It would be informative to study a small group of students during their early high school years, their final year of schooling, and then a year after graduation. The participants in my study all shared their dreams for what they wanted their future to look like, but to collect data on the realization of those dreams would significantly add to the transitions literature, particularly from the perspective of diverse adolescent girls with disabilities.
A final venue I would like to pursue has both practical and research-based implications. I would like to identify schools, families, and students who engage in culturally responsive transition planning. I would like to further explore best practices for culturally responsive transition planning and examine the outcomes of developing a cultural responsive IEP that attempts to address the inequities displayed throughout my dissertation.

**Culturally Responsive Transition Planning**

Researchers using transformative paradigms are guided by a desire for social change. The results of transformative research elucidate power relationships and facilitate social change and action (Creswell & Pano Clark, 2011). It is not enough for me to report that a student like Hope, a student of color from a low socioeconomic background, will likely continue living in a seven-person, supported group home with housemates 20 years her elder while earning less than minimum wage at a sheltered work center. While a student like Britany, a White student from a mid-high socio-economic background, will likely continue with her consumer-directed services, live in a supported apartment, and continue working at her favorite restaurant. I am driven to suggest specific changes to schooling and transitions in order to improve social justice for students like the participants in this study. Keeping in the spirit of research demanding social action, I draw on Gay’s (2002) and Ladson-Billings’ (2004) work in culturally responsive teaching, as well as educational equity researchers such as Artiles, Kozleski, Trent, Osher, and Ortiz (2010), Harry, Klinger, and Hart (2005), and Klinger, et al. (2005), in order to provide a framework for culturally responsive transition planning.

Culturally responsive teaching is guided by the principles of accessing students’ prior knowledge, valuing and representing diverse cultural experiences, prioritizing home-school connections, and connecting with local communities (Gay, 2002; Ladson-Billings, 2004). In
addition, Ladson-Billings (2004) argues that educators who use culturally responsive teaching practices encourage a community of learners and cooperative learning, work to establish equitable student-teacher relationships, and understand that all students can learn. Due to the disparity seen in the four participants’ experiences with schooling and transitions, I believe culturally responsive transition practices may serve as a way to counter such inequity. My framework for culturally responsive transition planning targets three different constituencies: high school teachers and administrators, university teacher preparation programs, and students with disabilities and their families.

**Recommendations for high school teachers and administrators.** Klinger, et al. (2005) indicate that, “mainstream educators generally interpret culturally diverse students’ performance through white middle-class normative parameters of competence” (p. 6). As a result, many culturally and linguistically diverse students are viewed as deficient. The authors argue that instead of fixing the students’ perceived deficits, educational systems that are responsive to cultural differences must be created. In culturally responsive educational systems, students’ culture, heritage, and family experiences are valued and used to facilitate learning. Educators and administrators working in secondary education and postsecondary transitions must be culturally responsive as well. Below I outline several recommendations that will enable teachers and administrators to create more culturally responsive transition practices.

1. School leaders and personnel must create a vision that embraces diversity of culture, language, economic background, and ability. This includes building cultural competency, creating positive relationships between the school and families/ communities of color, and integrating multi-cultural resources and materials across the general education and special education curriculum.
Embracing diversity cannot occur in name only, but should be reflected in classroom assignments, community outreach, and the recruitment of culturally and linguistically diverse teachers.

2. Teachers and administrators should practice cultural reciprocity (Harry, 1997) when interrogating their personal beliefs about groups of people, the meaning of disability, parenting styles, and goal setting. Cultural reciprocity involves self-reflection and social action by collaborating around shared values. Examples include re-thinking the Americanized ideal of independence and leaving the family home, using gentle advocacy with families who may not be comfortable occupying a position of expertise or control over educational programming, and understanding that parents’ apprehensions toward school involvement may stem from a personal history of educational marginalization. Building reciprocity will take time and trust, but leaning toward a family’s values can build collaboration and make the institution of schooling a more welcoming place for both families and students.

3. Administrators and teachers should rethink the ways students with disabilities spend their final years of schooling. If a student chooses to extend her education until age 21, a variety of post-high school options should be provided. One option can include linkages to community colleges or other college-experiences. Another option can be to expand vocational opportunities by providing students with a variety of interesting volunteer and/or paid work opportunities. Temporary supports can be faded as students gain more work experience. In addition, post-secondary education and employment
experiences can be combined to create an individualized learning experience. Students who do not have family supports or who are simply interested in expanding their community experiences should also be provided with opportunities to navigate public transportation systems, open bank accounts, and explore their local libraries and museums.

4. When creating an IEP and activities/resources to support transition goals, educators must consider student culture, socio-economic background, and home experiences. Some questions to consider include: Who is a student close to within her family and what valuable information and support can that family member provide? What are the transportation needs of students and how can these be addressed? Will a student require the support of scholarships or financial aid to attend postsecondary education? It is also important to consider the importance of interdependence in post-school life and to recognize that goals such as moving away from family to an independent, supported apartment may not reflect the values of all families and students.

5. Teachers and administrators should reconsider the processes of IEP and transition planning. Compromises must be made to accommodate not only the many educators and professionals who attend transition planning meetings, but students and families as well. Considerations should be made to hold planning meetings before or after school, during lunch periods, or student study hall times. In addition, pre-planning meetings may help families become more familiar with transitions, can serve as an informal time to share
information and resources, and can be held off-campus to accommodate family schedules and comfort.

6. Student-centered planning is key to student involvement throughout the transition process. Students should not only be invited to each of their IEP meetings, but should be allowed to invite others such as friends, neighbors, and favorite teachers. If a student is comfortable, she can lead her IEP meeting through the use of PowerPoint, note-cards, or person-centered planning tools such as MAPS and PATHS (Pearpoint et al., 1998; Falvey et al., 2000). Student-led IEPs should focus on strengths, interests, and post-school dreams and should not begin in the student’s final year of schooling. Transition planning can occur as soon as middle school, while student-led IEPs can be creatively implemented in elementary school as well. The key to student-centered transition planning is that the dreams and goals of the student drive the process. Adult support is provided and the efforts are collaborative in nature, but information about the future that is important to the student should be reflected throughout the IEP.

7. Develop mechanisms to connect students with disabilities with “transition mentors.” A student like Britany may be able to provide valuable support and mentorship to younger students with disabilities, by sharing her experiences with self-determination planning. In addition, young adults with disabilities who have graduated may be interested in developing mentor relationships with high school students as well. Sharing success stories can be empowering
and can provide students, families, and educators with strategies for supporting a student-driven transition.

8. Pay attention to gender stereotypes that may be reflected throughout the IEP and transition planning process. Even though adolescent girls may express an interest in areas such as care work, nursing, or administrative assistant work, be sure to provide young women with a variety of volunteer experiences and career options outside of traditional female roles. In addition, consider the use of language throughout the IEP. Language reflecting desirable behaviors such as politeness, compliance, and good manners can do more harm than good. When “non-compliance” occurs, what are young women trying to communicate? How can this be reframed as advocacy?

**Best practices for university teacher preparation programs.**

1. Well-supported practicum placements in urban schools where pre-service teachers can interact with culturally and linguistically diverse students and teachers. The pre-service teachers’ experiences in urban school placements should guide university classroom discussions, coursework, and future teacher preparation curriculum decisions.

2. All pre-service teachers should be given the opportunity to observe IEP meetings and work with secondary special education/transition teachers. This will not only help future special educators develop greater comfort with their future roles, but will give future general educators the opportunity to gain first-hand knowledge of transition planning and their potential roles in IEP meetings.
3. Acknowledging the value of students and their families is central to any culturally responsive strategy. When completing fieldwork hours, pre-service teachers should be encouraged to collaborate and communicate with families and students whenever possible/ appropriate. Pre-service teachers should attend parent-teacher conferences or Parent Teacher Association meetings, participate in afterschool events or student clubs, interview parents or engage in a home visit, and communicate to parents (with the support of the special education teacher) through progress reports, newsletters, phone calls, or communication journals.

4. Coursework should reflect culturally responsive pedagogy, teaching for social justice, and disability studies frameworks. Pre-service teachers should be encouraged and appropriately supported to discuss current issues of race, class, gender, sexuality, and dis/ability and to engage in self-reflection. In addition, multicultural curriculum and issues of diversity should be infused throughout the special education curriculum. Hegemony, normalcy, and inequity should all be discussed. In addition, it will be important to use texts written by people with disabilities as a means to disrupt the centrality of able-bodiedness in special education.

5. All pre-service teachers, both general educators and special educators, should receive coursework in transition planning. With federal preference for the involvement of general educators in IEP meetings, it is imperative that teacher preparation programs provide them with the information they need to be successful members of an IEP team. Given the importance of transition
planning on post-school outcomes it would be ideal for one entire course to be devoted to this area. Topics can include writing meaningful transition goals, infusing self-determination into the general education curriculum, and student-centered transition planning. Adaptations to coursework may need to be made for elementary pre-service teachers, but activities such as student-led IEPs benefit students of all ages.

6. All pre-service teachers should be exposed to and prepared to use age-appropriate curriculum. Young adults with disabilities should not be playing children’s games in high school classrooms. When students with disabilities are not provided the opportunity to be educated in general education classrooms, the curriculum in self-contained classrooms should reflect the general education curriculum and modifications should be provided as needed.

**Recommendations for students and parents.** When I began working with Hannah and her family on transition planning, she had never before attended an IEP meeting. Her parents were strong advocates who actively participated in such meetings, but they were unsure of how to include Hannah in a meaningfully way. After brainstorming over several weeks, we developed several strategies for Hannah to actively participate in the development of her IEP and to make IEP meetings more creative and engaging for her. Several of the strategies we collaboratively developed are outlined below. After two years of actively participating in developing her IEP goals, transition goals, choosing job sites, and leading her IEP meetings, Hannah and I (along with her parents) presented her transition planning process at the TASH (formerly The Association for Persons with Severe Handicaps) national conference. Hannah stole the show and was even recruited by an inclusive university program in the state of North Carolina, which she
is now considering attending. Student and family participation in the transition planning process can and should vary, depending on family history, comfort, and cultural expectations. Below I outline several recommendations for students and families that can be considered throughout the transition planning process.

1. When participating in an IEP meeting students and families can determine what level of participation makes them most comfortable. A student may enjoy creating a PowerPoint presentation highlighting her strengths, interests, and goals, while others may be more comfortable inviting a friend and discussing what they like and dislike about school. Students who enjoy expressing their creativity may like creating a script where the two friends “act out” their plans for the future. Even the act of all participants writing three positive adjectives about a student and sharing these at the beginning of the meeting can change the dynamics and make both students and families more comfortable. If a student is embarrassed or uncomfortable initially participating in IEP meetings, provide the student with a disposable camera to take pictures of things in her life that are important to her or her thoughts about future employment, places to live, etc.

2. Students should participate in developing their transition goals. Although the student may not be able to write a measurable goal, she can provide the framework. This may mean families and educators listening more carefully to students’ wishes, in addition to what is not said. If a student is asked to share all the things she enjoys about school and never discusses her self-contained math class, this may be a sign of something amiss. Another strategy is to
compromise on transition goals. Perhaps for each area of transition (employment, education, and independent living) the student chooses one goal and the parents or teacher choose another.

3. Families, and other adults, should be aware of their use of airtime at IEP meetings. Prior to the meeting, appoint one person to redirect questions to the student or offer support for student involvement. An important, yet often overlooked, time for student involvement can relate to reporting progress on goals. Rather than relying on adults to report on transition progress, students can share their thoughts and any activities they participated in related to transition goals. After practice, these meetings, redirecting airtime, and reporting on progress will be a great opportunity for the student to express her self-advocacy, control the direction of her future, and create a sense of empowerment.

4. Families should be encouraged and supported when recognizing when acts of perceived non-compliance may be a sign that their daughter is making a choice, self-advocating, and trying to exert a degree of control over her life. In addition, young women should not only be praised for “good behavior” and the ability to follow directions, but when she shares her opinion, expresses disagreement with an aspect of schooling or transitions, or comes to parents for help with struggles in life or school.

5. Families should also provide their children with opportunities for engaging in age-appropriate social activities. Facebook and Twitter can be intimidating outlets for parents, but many high school students without disabilities engage
with this social media. Social media can be monitored and often is for students without disabilities. Other activities can include athletic teams (with students with and without disabilities), band, choir, high school musicals, and school clubs such as film club or comic book clubs. Families can help their daughters “fit” into peer groups by encouraging such age-appropriate activities.

My intention for this dissertation was to better understand the schooling and transition experiences of adolescent girls with disabilities. I purposefully chose not to interview the adults in the participants’ lives in the hope of taking an epistemological stance on the representation of students with disabilities in the research literature. I purposefully chose to interview a diverse group of young women: White students from mid-high socio-economic backgrounds attending suburban high schools, African American students from low socio-economic backgrounds attending urban high schools, and students of color from low socio-economic backgrounds, attending suburban schools and living in residential group homes. I knew that disparate post-school outcomes were occurring across the United States and believed I would glean some insight into inequity. But, I never imagined the anger and sadness I would feel when listening to Hope’s story. I never thought I would discover how clear the impact social and cultural capital had on transitions. At the same time, I never imagined I would find myself laughing aloud when I would replay Aminah’s stories of young women, “bein’ grown” or driving the wrong way down a one-way street. I will always imagine how her grandmother’s face looked at that moment.

Of course I would rather remember the laughter and the funny stories, but it is the frustration that pushes me to continue researching transitions and girls with disabilities. Hope and Britany are graduating. Aminah and Victoria have at least three more years of schooling left.
Perhaps the lessons learned from this study will create more opportunities for student-centered, culturally responsive transitions. I like to think that future adolescent girls with disabilities will have teachers who include the female mentors in their educational programming, will find meaningful, inclusive employment opportunities, and will understand that choice does not mean compliance, but oftentimes quite the opposite. I like to think that if Hope had another try at high school she would be getting ready to take those college-level nursing classes she is so interested in, rather than getting ready to package travel toiletries.
Appendix A

One-Page Description of Research Study

My name is Danielle Cowley. I am a Ph.D. student in the department of Special Education at Syracuse University. With the support of my advisor Dr. Steve Taylor at Syracuse University, I am looking for volunteers to participate in a research study about high school girls with intellectual disabilities. I have been working with a young woman with Down syndrome and her family over the past two years on self-advocacy, self-determination, and inclusion at her high school. It has been an amazing experience for me and has made me interested in what high school and transitioning is like for other girls with intellectual disabilities.

Who?
- I am looking for girls with intellectual disabilities who are between the ages of 15-21, who are currently attending high school, and who live with a parent or legal guardian.

What do you need to do?
- Participate in up to 3 interviews (1-2 hours each) at Syracuse University or location of your choice
- Complete a short paper-and-pencil survey (parents as well)
- Parents will be asked to provide a copy of their daughter’s Individualized Educational Plan (IEP) for purposes of transition-related goals.

This is an opportunity for parents and their daughters with intellectual disabilities to help us to understand what it means to make choices about life. By taking part in this study parents and their daughters may benefit from talking about school and friends, as well as thinking and talking about the future.

If you and your daughter are interested in participating (or if you know of anyone who may be interested) I would love to hear your story. Also, if you have any questions or comments please contact me at:

Danielle Cowley
dmcowley@syr.edu
315-436-7471
Appendix B

Sample Questions from Interview Guide

1. Can you walk me through a day at school?
   a. What classes are you taking?
   b. What do you do in class?

2. What do you like about school?

3. What are some things you don’t like about school?

4. What kinds of things do you like to do at home? On the weekends?

5. What are your dreams for after graduation? What kinds of things would you like to do?
   a. Where would you like to live?
   b. Do you want a job? Where would you like to work?
   c. Would you like to go to college? What classes would you like to take?

6. What worries do you have about graduation? Or what to do after school is done?

7. Do you talk about these things with your parents or teachers?

8. What kinds of transition goals do you have?

9. Do you get to go to meetings at school to plan for the future?
   a. Could you walk me through one of those meetings?

10. What choices do you get to make at school and home?

11. Can you tell me about your teachers?

12. What has been the hardest thing about being in high school?

13. What is the best thing?
Appendix C

Opportunities for Self-Determination Student Form
Adapted from the AIR Self-Determination Scale, Student Form

Name: ________________________________ Date: ____________

School Name: __________________________ Grade: __________

Date of Birth: _________________________

HOW TO FILL OUT THIS FORM

Please answer these questions about how you go about getting what you want or need. This may occur at school, or after school, or it could be related to your friends, your family, or a job or hobby you have. This is not a test. There are no right or wrong answers.

| Goal | You may not be sure what some of the words in the questions mean. For example, the word goal is used a lot. A goal is something you want to get or achieve, either now or next week or in the distant future, like when you are an adult. You can have many different kinds of goal. You could have a goal that has to do with school (like getting a good grade on a test or graduating from high school). You could have a goal of saving money to buy something (a new iPod or new sneakers), or doing better in sports (getting on the basketball team). Each person's goals are different because each person has different things that they want or need or that they are good at. |
| Plan | Another word that is used in some questions is plan. A plan is the way you decide to meet your goal, or the steps you need to take in order to get what you want or need. Like goal, you can have many different kinds of plans. An example of a plan to meet the goal of getting on the basketball team would be: to get better by shooting more baskets at home after school, to play basketball with friends on the weekend, to listen to the coach when the team practices, and to watch the pros play basketball on TV. |

HOW TO MARK YOUR ANSWERS

Example question: I check for errors after completing a project.

Example answer: Circle the number of the answer which tells what you are most like: (Circle only ONE number).

1 Never ........................................................ I never check for errors
2 Almost Never ............................................... I almost never check for errors
3 Sometimes ................................................ I sometimes check for errors
4 Almost Always .......................................... I almost always check for errors
5 Always ....................................................... I always check for errors

Remember: There are NO right or wrong answers. This will not affect your grade in school, so please think about each question carefully before you circle your answer.
### WHAT HAPPENS AT SCHOOL

1. **People at school listen to me when I talk about what I want, what I need, or what I’m good at.**
   - Never □
   - Almost Never □
   - Sometimes □
   - Almost Always □
   - Always □

2. **People at school let me know that I can set my own goals to get what I want or need.**
   - Never □
   - Almost Never □
   - Sometimes □
   - Almost Always □
   - Always □

3. **At school, I have learned how to make plans to meet my goals and to feel good about them.**
   - Never □
   - Almost Never □
   - Sometimes □
   - Almost Always □
   - Always □

4. **People at school encourage me to start working on my plans right away.**
   - Never □
   - Almost Never □
   - Sometimes □
   - Almost Always □
   - Always □

5. **I have someone at school who can tell me if I am meeting my goals.**
   - Never □
   - Almost Never □
   - Sometimes □
   - Almost Always □
   - Always □

6. **People at school understand when I have to change my plans to meet my goals. They offer advice and encourage me when I’m doing this.**
   - Never □
   - Almost Never □
   - Sometimes □
   - Almost Always □
   - Always □
## WHAT HAPPENS AT HOME

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People at home listen to me when I talk about what I want, what I need, or what I’m good at.</td>
<td>Never □ 1</td>
</tr>
<tr>
<td>2. People at home let me know that I can set my own goals to get what I want or need.</td>
<td>Never □ 1</td>
</tr>
<tr>
<td>3. At home, I have learned how to make plans to meet my goals and to feel good about them.</td>
<td>Never □ 1</td>
</tr>
<tr>
<td>4. People at home encourage me to start working on my plans right away.</td>
<td>Never □ 1</td>
</tr>
<tr>
<td>5. I have someone at home who can tell me if I am meeting my goals.</td>
<td>Never □ 1</td>
</tr>
<tr>
<td>6. People at home understand when I have to change my plans to meet my goals. They offer advice and encourage me when I’m doing this.</td>
<td>Never □ 1</td>
</tr>
</tbody>
</table>

THANK YOU!
Appendix D

Opportunities for Self-Determination Parent Form
Adapted from the AIR Self-Determination Scale, Parent Form

Child’s Name: ____________________________ Date: _____________

Date of Birth: _____________ Grade: _____________

Disability Label: ____________________________

My child’s ethnic/cultural background:
☐ African American   ☐ Asian American   ☐ Latina/o   ☐ Native American
☐ White   ☐ Other (please specify): ________________________________________

My child receives free or reduced lunch at school: ☐ Yes   ☐ No

My education level attained:
☐ Some high school   ☐ GED   ☐ High School Diploma   ☐ Some college
☐ 2-year degree   ☐ 4-year degree   ☐ Masters degree   ☐ PhD

Services:    ☐ Special Education   ☐ Paraprofessional   ☐ Program modifications
☐ Assistive Technology   ☐ Speech/Language   ☐ OT   ☐ PT

Time spent in the general education classroom: Expected Year of Graduation: ____________________________
☐ 80%
☐ 60%
☐ 40%
☐ 20%
☐ None

Graduation Track: ☐ Regents Diploma
☐ Local Diploma
☐ IEP Diploma

School Name: ______________________________________________________________________

Parent’s Name: _____________________________________________________________________

HOW TO FILL OUT THIS FORM

Each page of this form lists characteristics and behaviors that indicate the degree to which the people influencing this student provide opportunities that foster self-determination. For each item, select the appropriate rating code based on what you have observed about this student.

Here is an example of how you should mark your answers.

Example question: Student check for errors after completing a project.

Example answer: Check the box of the rating code which tells what your student is most like: (Check only one box per question).
1 Never…………………………………… student never checks for errors
2 Almost Never………………………… student almost never checks for errors
3 Sometimes…………………………... student sometimes checks for errors
4 Almost Always………………………. student almost always checks for errors
5 Always………………………………… student always checks for errors

### WHAT HAPPENS AT HOME

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>7. At home, people listen to when my child talks about what she is good at.</td>
<td>Never</td>
<td>Almost Never</td>
<td>Sometimes</td>
<td>Almost Always</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

| 8. At home, people let my child know that she can set his or her own goals to get what she wants or needs. | Never | Almost Never | Sometimes | Almost Always | Always |
|   | 1 | 2 | 3 | 4 | 5 |

| 9. At home, my child has learned how to make plans to meet her own goals and to feel good about them. | Never | Almost Never | Sometimes | Almost Always | Always |
|   | 1 | 2 | 3 | 4 | 5 |

| 10. At home, my child is allowed to act her plans right away. | Never | Almost Never | Sometimes | Almost Always | Always |
|   | 1 | 2 | 3 | 4 | 5 |

| 11. At home, my child has someone to tell her when she is meeting her own goals. | Never | Almost Never | Sometimes | Almost Always | Always |
|   | 1 | 2 | 3 | 4 | 5 |

| 12. At home, people understand my child when she has to change plans to meet her own goals. They offer advice and encouragement. | Never | Almost Never | Sometimes | Almost Always | Always |
|   | 1 | 2 | 3 | 4 | 5 |
### WHAT HAPPENS AT SCHOOL

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>7.</td>
<td>At school, people listen to when my child talks about what she is good at.</td>
<td>Never</td>
<td>Almost Never</td>
<td>Sometimes</td>
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<td></td>
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<td>8.</td>
<td>At school, people let my child know that she can set his or her own goals to get what she wants or needs.</td>
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<td>Sometimes</td>
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<td></td>
</tr>
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<td>9.</td>
<td>At school, my child has learned how to make plans to meet her own goals and to feel good about them.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>At school, my child is allowed to act her plans right away.</td>
<td>Never</td>
<td>Almost Never</td>
<td>Sometimes</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>11.</td>
<td>At school, my child has someone to tell her when she is meeting her own goals.</td>
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<tr>
<td>12.</td>
<td>At school, people understand my child when she has to change plans to meet her own goals. They offer advice and encouragement.</td>
<td>Never</td>
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<td></td>
</tr>
</tbody>
</table>

**THANK YOU!**
REFERENCES


*Theorizing at the intersections of race and dis/ability. Race, Ethnicity and Education, 16*(1), 1-31.


Curriculum Vita

DANIELLE M. COWLEY, M.S., C.A.S

ACADEMIC PREPARATION

Syracuse University, Syracuse, NY
    Doctor of Philosophy in Special Education, Anticipated Spring 2013
    Advisor: Dr. Julie Causton-Theoharis
    Dissertation Topic: “Being grown”: How adolescent girls with disabilities narrate self-determination and transitions (Chair: Dr. Steven Taylor)

Syracuse University, Syracuse, NY
    Certificate of University Teaching, Spring 2012

Syracuse University, Syracuse, NY
    Certificate of Advanced Study in Disability Studies, Spring 2010

Ithaca College, Ithaca, NY
    Master of Science in Sport Psychology, Summer 2004

Morningside College, Sioux City, IA
    Bachelor of Science in Counseling Psychology and Physical Education, Spring 2002

UNIVERSITY TEACHING EXPERIENCE

Instructor
San Francisco State University
    Department of Special Education
    Courses: SPED 745/Environmental Design for Students with Moderate/Severe Disabilities
    SPED 787/Advanced Assessment and Instructional Design for Students with Moderate/Severe Disabilities
    SPED 788/Law, Ethics, and Instructional Planning

Instructor
Syracuse University
    Department of Teaching and Leadership
    Courses: SPE 412/Adapting Instruction for Diverse Student Needs (Spring 2012)
    SPE 634/Collaboration and Cooperation in the Inclusive Classroom (Fall 2010; co-Instructor)
    SPE 300/Methods and Curriculum for Teaching Students with Significant Disabilities (Spring 2010)
    EDU 203/Introduction to Inclusive Schooling (Spring 2009)
    SPE 348/Seminar in Severe Disabilities (Spring 2008)

Teaching Assistant
Syracuse University
Department of Teaching and Leadership

**Courses:**
- EDU 203/Introduction to Inclusive Schooling (Fall 2008; Fall 2011)
- SPE 705/Psychoeducational Evaluation and Planning for Exceptional Children (Spring 2011)
- SPE 324/Differentiation for Inclusive Education (Fall 2009)
- SPE 346/Methods and Curriculum for Teaching Students with Significant Disabilities (Fall 2007; Spring 2008)
- SPE 348/Seminar in Severe Disabilities (Fall 2007)

### PRE-SERVICE TEACHER SUPERVISION

<table>
<thead>
<tr>
<th>Practicum and Student Teaching Field Supervisor</th>
<th>2012-present</th>
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<tbody>
<tr>
<td>San Francisco State University, Department of Special Education</td>
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<tr>
<td>• Graduate Moderate/Severe Disabilities Program</td>
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<tr>
<td>• Graduate Mild/Moderate Disabilities Program</td>
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<table>
<thead>
<tr>
<th>Practicum and Student Teaching Field Supervisor</th>
<th>2007-2009</th>
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<tbody>
<tr>
<td>Syracuse University, Department of Teaching and Leadership</td>
<td></td>
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<tr>
<td>• Undergraduate Inclusive Elementary Education Program</td>
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<tr>
<td>• Graduate Elementary Education Program</td>
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### RESEARCH-RELATED EXPERIENCE

<table>
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<tr>
<th>Graduate Trainee at Syracuse University</th>
<th>2007-2012</th>
</tr>
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<tr>
<td>Preparation of Leadership Personnel: Preparing Future Teacher Preparation Faculty for Outcomes-Based, Inclusive Education</td>
<td></td>
</tr>
<tr>
<td><em>Funded by U.S. Department of Education: Grant CFDA #84.325D (P.I.: Dr. Beth Ferri)</em></td>
<td></td>
</tr>
<tr>
<td>• Prepared to support pre-service special educators in providing meaningful access to general education curriculum for students with disabilities.</td>
<td></td>
</tr>
<tr>
<td>• Engaged in social-justice oriented qualitative and quantitative research in urban public schools.</td>
<td></td>
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<table>
<thead>
<tr>
<th>Research Assistant/Inclusion Facilitator at Syracuse University</th>
<th>2010-2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promising Practices: Identifying and Cultivating Inclusive Practices</td>
<td></td>
</tr>
<tr>
<td><em>Funded by New York State Department of Education/VESID: School Personnel Development Grant (P.I.: Julie Causton-Theoharis and George Theoharis)</em></td>
<td></td>
</tr>
<tr>
<td>• Conducted qualitative and quantitative research on inclusive school reform, promising practices, and student achievement in urban public schools.</td>
<td></td>
</tr>
<tr>
<td>• Provided in-service trainings and classroom observations on the inclusion of students with disabilities.</td>
<td></td>
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<table>
<thead>
<tr>
<th>Research Apprenticeship at Syracuse University</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Silenced Stories, Silenced Labor: The Collision of Discursive (Her)stories</td>
<td></td>
</tr>
<tr>
<td>• Conducted qualitative observations in order to explore student participation and agency in multiple middle-school classrooms.</td>
<td></td>
</tr>
<tr>
<td>• Engaged in a feminist examination of the relationship between gender, participation, and academic labor.</td>
<td></td>
</tr>
</tbody>
</table>
Grant Writer at Syracuse University  
Summer 2008
NIDRR Center Grant Application: Post-Secondary Education for Students with Intellectual Disabilities. Unfunded.

- Worked with faculty and staff on conducting literature review of inclusive post-secondary educational opportunities for students with intellectual disabilities.

PUBLICATIONS


PRESENTATIONS  *indicates competitively selected*

International/National


*Cowley, D. M.* (June, 2010). *Shifting the conversation: How the social model of disability can be used to (re)theorize self-determination and transitions for students labeled as intellectually disabled.* Society for Disability Studies Annual Conference, Philadelphia, PA.


**PROFESSIONAL DEVELOPMENT TO TEACHERS & PARENTS**

Bacon, J., & Cowley, D. M.  (September 2011).  *Accommodations, modifications, and adaptations.*  Presentation made to the Arc Oneida-Lewis Chapter, Utica, NY.


EDUCATIONAL CONSULTANCIES

Shaker High School
North Colonie Central School District, Latham, NY
2010-2012

---

Shaker High School
Educational Consultant

• Facilitated McGill Action Planning (MAPS) and Planning Alternative Tomorrows with Hope (PATH) for a transition-aged student, while advising and training staff on person-centered planning, self-determination, and inclusion.

Greene Elementary School
Greene Central School District, Greene, NY
November 2010; October 2011

---

Greene Elementary School
Independent Educational Evaluator

• Observed an elementary student with a disability in various educational settings and assisted in writing a report of educational findings for due process hearing. Co-facilitated staff training regarding inclusive practices for the student.

Monroe County BOCES (K-12)
Fairport, NY
May 2010

---

Monroe County BOCES (K-12)
Educational Consultant

• Observed various classrooms throughout the county, assisted in providing an independent evaluation of the county’s educational service delivery system, and writing a report of findings. Findings used to develop strategies for providing education to students with disabilities at their home schools.

Woodland Elementary School
East Syracuse Minoa School District, East Syracuse, NY
2009-2010

---

Woodland Elementary School
Educational Consultant

• Assisted in providing professional development to Kindergarten classroom teachers and paraprofessionals on inclusive education and supports for students with disabilities. Provided educational evaluation, written report of strategies, and training regarding a student with challenging behavior.

OTHER DISABILITY-RELATED EXPERIENCE

Projects Manager
JM Murray Center, Inc., Cortland, NY
2004-2007

• Developed and implemented person-centered intake, assessment, and evaluation processes for non-profit agency providing services to youth and adults with disabilities.
• Served as agency’s Lead Incident Investigator responsible for investigating all incidents and allegations of abuse, and developing and training staff members on rights-based policies and procedures.

Residence Counselor
Opportunities Unlimited, Sioux City, IA
2001-2002
• Provided support services for young adults with traumatic brain injuries and
developmental disabilities in residential, rehabilitation, and community settings.

SERVICE

Profession
• Invited Manuscript Reviewer: *Intellectual and Developmental Disabilities*, 2010

University
• Member, Beyond Compliance Coordinating Committee, 2007-2012
  o President (2009-2010)
  o Secretary (2008-2009)
• Member, Student Subcommittee of the Chancellor’s Task Force on Disability, 2008-2010
• Board Member, Educational Rights Advocacy Board, 2008-2010
• Senator, Graduate Student Organization, 2008-2009
  o Finance Committee (2008-2009)
• Panel Moderator, *Including Samuel*, Syracuse University MayFest, 2008

College
• NCATE Program Report for Inclusive Elementary and Special Education, 2011
  o Assisted in data analysis and synthesis, and program report writing
• Panel Moderator, *Creating Campus Change through the Law and Politics*, Syracuse University Disabled & Proud National Conference, 2011
• Panel Moderator, *Through the Same Door: Inclusion Includes College*, Syracuse University Annual Summer Leadership Institute, 2011
• Graduate Student Member, School of Education Third Year Faculty Review Committee, 2009
• Planning Committee Member, Disability Studies in Education National Conference, 2009

Community
• Member, San Francisco Unified School District’s Inclusion Task Force, 2012-present
• Presenter, *Parent University Series*, Syracuse University Parent Advocacy Center, 2010-2012

PROFESSIONAL MEMBERSHIPS
• American Educational Research Association
  o Disability Studies in Education Special Interest Group
• TASH (formerly known as The Association for Persons with Severe Handicaps)

AWARDS
• Teaching Associate, Future Professoriate Program, 2010-2012
• Preparation for Leadership Personnel Traineeship, 2007-2012