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Disability trajectories : disabled youths' identity development, negotiation of experience and expectation, and sense of agency during transition

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Publication Date

2010

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UNIVERSITY OF CALIFORNIA, SAN DIEGO

Disability trajectories: Disabled youths' identity development, negotiation of experience and expectation, and sense of agency during transition

A dissertation submitted in partial satisfaction of the

requirements for the degree Doctor of Education

in

Teaching and Learning

by

Suzanne Margaret Stolz

Committee in charge:

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      Professor Tom Humphries, Co-Chair
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2010

The dissertation of Suzanne Margaret Stolz is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

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Co-Chair

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Chair

University of California, San Diego

2010

DEDICATION

To the many young people and not-so-young people who have shared their stories and their disability experience. You have given me deeper understanding, greater purpose in my work, and stronger love for our community.

EPIGRAPH

If the music changes so does the dance…

—African Proverb

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EDUCATION

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University of California – San Diego Guest Speaker for classes on equitable education: *Disability and Education* and *Disability and a Teacher's Role in Creating Equity,* 2005-2009.

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Canadian Disability Studies Association Conference: *Confronting Ableist Conceptions in the High School Classroom.* Toronto, Canada, 2006.

Society for Disability Studies Conference Presentation: *Evacuating the Short Bus: Students' Understandings of Disability*. Washington DC, 2006.

Columbia University: The 30th Anniversary of I.D.E.A. Disability Studies In Education Conference Co- Presentation: *Integrating Disability Studies in Education.* New York, 2005

Society for Disability Studies Conference Presentation: *Ruptures, Disruptions and Practice*. St Louis, Missouri., 2004

American Educational Research Association Conference Presentation: *Integrating Disability Studies into the Humanities*. San Diego, California, 2004

Creative Writing Publication - *Physical Healing*. Disability Studies Quarterly, Summer 2006.

COMMUNITY INVOLVEMENT
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San Diego Service Inclusion Network, 2006-2009
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ABSTRACT OF THE DISSERTATION

Disability trajectories: Disabled youths' identity development, negotiation of
experience and expectations, and sense of agency during transition

by

Suzanne Margaret Stolz

Doctor of Education in Teaching and Learning

University of California, San Diego, 2010

Professor Brian Goldfarb, Chair
Professor Tom Humphries, Co-Chair

How do youth with orthopedic impairments negotiate expectations and
experiences as they transition from high school to college and from family-delivered
supports to independence? And what in the earlier periods of their individual
development/family life provides the context and frameworks for their negotiation of
transition to adulthood? The primary goal of this study was to better understand the
identity development of this subset of disabled youth. Data were collected through
youth and parent interviews, focus groups, and participant observation at a local
mentoring program for disabled youth, more specifically, youth with orthopedic
impairments. The researcher's status as a disabled person provided the benefit of

insider access. Several questions guided the research: What influences disabled youths' view of themselves? What discursive frameworks shape these views? How does the negotiation of physical and social barriers impact the relationships disabled youth develop? How do social barriers affect youths' development of agency?

Findings suggest that conceptions of disability have strong influence on the way youth view themselves; common disability discourses relating to normalcy and independence make claiming disability identity difficult; physical and social barriers require youth to use unique strategies in the development of relationships; and, disabled youth often do not find sufficient support in developing agency. Implications include incorporating critical disability studies into teacher education and in K-12 curriculum (and not isolated to special education contexts), recognizing bias and examining efforts to enforce norms, fostering classroom practices that promote seeing capability and support agency, and establishing strong mentorship relationships between disabled adults and youth.

I. Introduction

Imagining life as an adult was always difficult for me to do. Growing up, I did

not know any adults with orthopedic impairments. I saw people wearing leg braces

and using wheelchairs sometimes; but, I didn't see them working or doing the things I

saw other adults doing. My indistinct visions of the future relied on imagining that I

would someday inhabit a body quite unlike mine. From what I gathered, having a

disability was unacceptable. Disabled people[1] could not lead fulfilling lives or hold

important roles in the community.

My early sense of what society expected of people like me depicts fairly well

the reality that many disabled people face. High school drop-out rates for disabled

youth, at 28%, far exceeds that of the general population. Of those who do graduate,

less than one-third go on to some type of postsecondary education, less than half that

of their non-disabled peers. The employment rate for out-of-school disabled youth is

substantialley lower and the length of time they live with their parents is longer

(Wagner, Newman, Cameto, Levine, & Garza, 2006). With outcomes like these, I

cannot help but wonder how many disabled young people view themselves. What do

they want in life? What plans do they make? What do they believe is possible for

them?

As an adult looking back, I think about the messages I received about disability

and credit my family and some of my teachers for counteracting the expectations of

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[1] I have chosen to use "disabled people" rather than "people with disabilities." I acknowledge and respect that advocates of person-first language want to avoid using disability to define a person. However, I resist the idea that "disabled" must be a negative marker and have chosen to use it throughout the study.

society at large. With their support, I've managed to get beyond the statistical norm and build the life that I could hardly envision as an adolescent. Perhaps similar to most adolescents, my identity development was not without contention.

Our self-perceptions develop as we interact with the world around us; and, our primary perceptions begin within our own families. Early on, we are aware of what others expect of us. Large studies show that parent expectations for disabled youth are indeed low when it comes to postsecondary education and independent living (Wagner, Newman, Cameto, Garza, & Levine, 2005; Wagner, Newman, Cameto, Levine, & Marder, 2007). Less than thirty percent of parents of youth with orthopedic impairments expect their children to graduate with a 4-year degree, compared to 88% of parents of youth in the general population (Wagner et al, 2005). When it comes to living independently, the vast majority of parents of youth with orthopedic impairments do not expect their children to earn driver's licenses, to live without supervision, or to become financially self-sufficient (Wagner et al., 2007). Statistics regarding those with other types of impairments show similar patterns.

While parent expectations have great influence on student outcomes (Fan, 2001, Jodl, Malachuk, Eccles, & Sameroff,. 2001), other factors play into the success youth are able to achieve. Teacher expectations (Rist, 1970; Weinstein, Gregory & Strambler, 2004), school organization practices (Cicourel & Mehan, 1985), the presence of adult mentors (Snowden, 2003), student's own participation in goal setting (Karvonen, Test, Wood, Browder, & Algozzine, 2004), and many other factors can further influence the identity development of youth and impact their achievement. So,

even though parental support through youth's experiences with belonging, with self-esteem, and with independence and interdependence is important (Peterson, 2004), healthy identity development relies on many different types of support.

The expectations we hold for disabled youth are influenced by cultural views of disability, by our own experiences, and by our interactions with disability. Even when an adult has high expectations, he or she may lack the experience to know how a disabled youth will accomplish his or her goals. While my own parents and teachers encouraged and praised my academic work, they hesitated to talk to me about the aspects of adulthood they imagined would be different for me, aspects like driving, relationships, and parenting.

Although adults' expectations are important, it is crucial that educators recognize the ability of youth to act. Youth are active participants in their own identity development (Bandura, Barbaranelli, Caprara, & Pastorelli, 1996). Disabled youth, like other minority youth, must often go against adult expectations in order to live the lives they choose to live. Reaching a state of psychological empowerment by having a sense of personal control, a willingness to act, and an understanding of one's social environment, youth can affect change (Zimmerman, 1995). How do some youth develop the agency to do this?

Last spring, a seventeen-year-old with a spinal cord injury told me, 'My mom told my little brother that he needs to do well in school and go to college, because one day he will need to support me. Can you believe she said that right in front of me? " A senior in high school, the girl planned to go to college herself. A month after our

conversation, she affected change by convincing her hesitant mother to allow her to take a trip with her classmates to visit colleges in northern California.

As an educator, I've come to see how disabled youth can go beyond the expectations of their parents, their teachers, and other community members. Aware of the limited vision others have for them, some youth persevere. They have shown me that identity formation is more complex than just enacting what others expect. Rather, there is a negotiation of messages, interactions, and desires that youth employ as they make decisions about who they will become as adults. For youth with orthopedic impairments, careful negotiation is necessary for reaching beyond parents' and teachers' knowledge of how they made transitions to adulthood.

While I am interested in a broader category of disability and believe that my work has valuable implications for a wide variety of youth marked as different in some way, my study involves youth with low incidence orthopedic impairments, including but not limited to amputation, cerebral palsy, juvenile arthritis, muscular dystrophy, spina bifida, and spinal cord injury. Having grown up with a form of muscular dystrophy and having worked with disabled youth in a mentoring program, I recognize similarities between my experience and theirs, and find interaction between these youth and their parents particularly interesting. I remember struggles with my mother as she allowed me to take responsibilities within the family, times that she would give me a task and then take it over when it took me longer than what it would take her. The fine line between nurturing growth and holding unreasonable expectations becomes a tightrope walk for many parents and teachers. Parents,

teachers, and youth negotiate these ever-shifting relational dynamics, at times, with grace, at other times, quite awkwardly. These negotiations are part of the social interactions that shape youth's identity development.

By engaging in this research, I aim to encourage educators and policy makers to consider the changeable social conditions that often leave disabled youth to a continuing legacy of under-education, unemployment, and poverty. This project specifically will identify how youth with orthopedic impairments negotiate society's expectations and experiences and create goals for transition. This knowledge promises to inspire programs and policies that involve parents, teachers, and disabled youth in supportive communities that foster a broader conception of disability and increase the possibilities for youths' lives after high school.

Recently, a stranger in a coffee shop approached me to tell me about his 6-year-old son who has spina bifida and uses a wheelchair. He told me how the boy has changed his life, how he is doing in school, what his health issues are. He said, "We take things day by day, don't worry about next week or next year…just day by day." I had so much to tell him, but I just listened. He beamed with pride, "My son is awesome." I have, at times, been annoyed by unsolicited stories about how people are connected to disability; but this time, I was honored to hear the man's perspective and encouraged that he sought to connect with an adult who might somehow provide a glimpse of his son's future. As this man's son grows, they will learn from each other; they will reach next week and next year; and in the future, the boy will become a man.

With this project, I explored two main questions: 1. How do disabled youth negotiate expectations and experiences as they transition from high school to college and from family-delivered supports to independence? and 2. How can educators support these transitions? Sociocultural theory asserts that learning takes place in a social context, and is contextual and cultural. Social processes shape our cognition, how we act, and how we react to our surroundings (Wink & Putney, 2002). In my effort to understand how disabled youth think, act, and react to the social processes of their world, I examined several research areas. I consider work that explores identity development and how it is affected by multiple factors within an individual's social world, work that describes the relationship between culture and disability, and work that illustrates issues of power and voice. Through the research of these areas, I have found insight into the ways in which disabled youth make sense of their interactions with the world during transition to adulthood.

II. Literature Review

Theoretical Framework

In my dissertation study, I will combine theories of social constructionism and critical theory (especially, feminist and critical pedagogy) to examine the experience of disabled youth and how they come to understand and further construct their identities during transition from high school to college and from family-delivered supports to greater independence. Constructionists illustrate how value judgments made in the social world construct one's identity and career path (Cicourel & Mehan, 1985; McDermott, 2006; Erickson, 1987). Critical theorists critique context, representation, and language and aim for transformation (Guba & Lincoln, 1994). More specifically, critical disability theorists use these critiques in regard to disability (Thomas, 2002). In this project, I consider how the influences of the social world come together to construct disabled youths' identity and also critique contextual factors including historical representations of disability and common discourse used to make sense of disability experience. My critique is aimed at changing the ways schools interpret disability. An improved interpretation of disability can help shape the roles individuals take on as young people and carry out in adulthood after interacting with the social worlds of the family and of high school.

An individual's experience with disability becomes a significant factor in her identity formation. One's identity continually changes through the transmission of new understandings. Theories of the self develop from one's interaction with the world in which she lives and the histories that precede her. As she grows, the child

notices that much of the adult talk about her centers on her lack of ability, her deficits, and her difference. When she goes to school, a roomful of adults gather to decide what to do with her. In public, other children and adults stare and ask, "What is wrong with her?" In the same way that theories of Deaf selves are colored by beliefs held by others (Paddon & Humphries, 1988), theories of disabled selves also draw from beliefs of others (Siebers, 2008). From her social experience, the child begins to see herself as defective, isolated, disempowered, and mistreated (Davis, 2004). After internalizing these beliefs, how will she see herself as valuable and contributing part of the culture?

Although researchers have long studied individual behaviors, achievements and failures, and responses to interventions, this research has seldom considered the voice of disabled students as they come to make decisions about their futures. While recognizing that many influences, such as interactions with parents, teachers, and peers, social policies and barriers, come together in the identity development of disabled youth, I believe critical theory's dedication to agency and voice will be important in understanding how changes in existing school systems are possible. Efforts to transform the organization of power and to change consciousness show promise when "subjects' of the plan are invited to dialogue about their perspective (Freire, 1970). With the project, I insert my voice and the voices of my participants, to create dialogue about what our disability experience can offer to improve schooling. In consideration of a disability consciousness, Charlton (1998) and others involved in the disability rights movement demand, "Nothing about us without us." They assert

that although parents, families, friends, and passionate professionals have long advocated for the well-being of disabled individuals, true liberation from oppression must come from within the disability community.

The relationship between social constructionism and critical theory becomes complimentary in looking at the potential to transform the limited view of disability in schools. As we empower disabled youth to cross borders on an individual level, our hope is to disengage the cultural symbols commonly used in our society that promote low expectations (Peters, 1996). In a critique of cultural symbols relating to disability, interactions transform and new constructions of identity unfold. The lens of critical theory can provide hope when confronting the ways in which lives of disabled students are constructed (Ware, 2004). Through the careful negotiating of expectations, disabled youth can take part in a wider spectrum of cultural activities and can take on a wider variety of powerful identities.

Overview of Literature Review

The bodies of literature that inform this research relate to the identity development of disabled youth, if not specifically, then through the ideology of diversity. I break this literature into three groups, work involving: identity development in schools, the cultural framing of disability, and issue of power and voice.

Identity development in schools

Because transition to adulthood is known to be a tumultuous time for many youth as they make decisions about adult life, many scholars focus on various aspects of identity during this critical time and continue to make contributions to the way we think about identity. Parent expectations (Fan, 2001; Jodl, Michael, Malachuk, Eccles, & Sameroff, 2001; Kaplan, Liu, & Kaplan, 2001), teacher expectation (Rist, 1970; Weinstein, Gregory & Strambler, 2004) peer relationships (Chen, Chang & He, 2003), feelings of self-efficacy (Bandura, Barbaranelli, Caprara, & Pastorelli, 1996), and quality teachers and counselors (Rogers, Terriquez, Valladares, & Oakes, 2006) have important impact on youths' school achievement. Young people who go beyond high school to attend postsecondary school have often had access to adults who hold high expectations, encourage, provide interventions, and offer information about college (Oakes, Mendoza, & Silver, 2004). Various studies indicate that participation in service learning (Jones & Abes, 2004), in sports (Anderson, 2004), and in other activities help young people build a sense of purpose and sense of belonging. Educational researchers have given great importance to how culture influences learning and school identities, considering whether members of particular ethnic groups feel safe and supported in home schools (Onyekwuluje, 2000; Rodriguez, Jones, Pang, & Park, 2004), to how particular groups make meaning in discourse and situate their identities (Torres, 2004), and to what types of pedagogy will best serve a diverse population (Banks, 2001; Banks, 2008; Bennett, 2001). Few of these consider how disabled youth are impacted by cultural influences though. With evidence of how

isolation can have dangerous effects, researchers focus more and more on how pedagogy impacts school climate in regard to bullying (Lodge, & Frydenberg, 2005; San Antonio, & Salzfass, 2007) without considering that disabled students have often been involved in these interactions.

Although general findings about identity development may be pertinent to disabled individuals as well as nondisabled individuals, cultural factors associated with disability have been over-looked as educators continue to use deficit models to explain underachievement of this population. These cultural factors need exploration. Experiences and concerns of disabled youth differ from those of the general population. For example, disabled youth receive negative messages about their potential (Charlton, 1998; Priestley, 2003); disabled youth encounter more and different kinds of barriers to participation in school and work activities (Betz & Redcay, 2005; Dowling, & Dolan, 2001; Schuster, Timmons, & Moloney, 2003); and disabled youths' parents and teachers hold lower expectations for them (Grigal & Neubert, 2004).

In considering the nuances of identity development for disabled young people, some scholars criticize special education's segregation practices that humiliate and under-educate students (Fitch, 2003, Ware, 2004). Others analyze ableist practices within classrooms that contribute to negative perceptions of disability that make it unsafe for students to claim disability identity (Hehir, 2002). Many have come to see that, like other minority students, disabled students are categorized, labeled, segregated, judged as genetically inferior, and are seen as life-long children, as

financial drains, and as difficult to teach (Amos & Landers, 1984; Heard, 1999; Jones, 2004). Priestley (2003) advocates another approach in asking, "The 'problem' of transition for young disabled people has certainly attracted much attention and social investment, but to what extent do such investments envisage the attainment of future adult status, independent living, or participation in the adult labour market?" (94).

Cultural Framing of Disability

The cultural framing of disability impacts the way we think about, speak about, and interact with disability. Our view of what disability is, what causes disability, what disability means in the context of participation, learning, working, relating to others, and what disability experience might be holds tremendous power in shaping the trajectories of disabled youth. In this section, I introduce literature about models of disability and discursive frameworks for thinking about disability, including normalcy, dependency, disability hierarchies, and claiming disability identity.

Models of disability

What it means to be "disabled" is viewed differently by different social and cultural groups (Ingstad & Whyte, 1995).   So, how is disability culturally framed in the United States? Historically, disability has been framed in a variety of ways (Llewellyn, 2000; Scotch & Schriner, 1997; Smart, 2009; Terzi, 2005), some of which have had a stronger hold and a stronger influence on social policies and on individual thought.

Although some scholars consider only two models of disability, medical and social, Scotch and Schriner (1997) describe four different models: a medical model,

an economic model, a minority group model, and a human variation model. The medical model, the dominant view, characterizes disability as a defect or disease that must be "fixed" in order for the individual to be better accepted by society and lead a worthwhile life. The economic model centers efforts on providing support to individuals for overcoming disability and becoming part of the work force. Considering stigmatization, discrimination, and economic and social barriers, the minority group model recognizes that people with disabilities share many of the same experiences that other minority groups experience. This model anticipates that empowerment and self-determination will be gained through the legal system. The fourth model, the human variation model, suggests that adjustments be made within social institutions to account for natural differences. The three latter can be considered social models, models that lead us to see the problem of disability to lie in society rather than in the individual. The prevalence of the medical model has enabled schools to use deficit theories to explain the underachievement of disabled students.

Even though the medical model has been dominant, a growing acknowledgement of the profound social and cultural nature of disability is reshaping professional discourse on an international level. The World Health Organization (WHO), for one, has worked extensively to set guidelines for defining disability, carefully noting the social aspects of disablement as well as the medical aspects (Bickenbach, 1999).

In the way the WHO has challenged the validity of understandings based solely on a medical model, some disability studies theorists now complicate our

understanding of social models of disability. Amartya Sen and Martha Nussbaum theorize a "capability model," as a workable model in which to consider justice in terms of equitable education for all (Terzi 2005). This model, taking into account natural and social causal factors, places importance on enacting "the value of equal concern by aiming at equalizing people's 'capability to function'" (Terzi 2007, pg 758) and might be an effective model for schools to use.

Discursive Frameworks

Modern society has used defining difference as a way to mark "others" and hold them separate (Davis, 1995; Foucault & Khalfa, 2006). Understanding how normalcy frames conceptions of disability, Davis (1995) points to the absurdity of the common view of the disabled as the abnormal and asserts that impairment is a normal part of the human experience. He uses the example of eugenics policy to show how statistically "normal" bodies became the standard for what was considered acceptable. Others have noted the dangerous treads of eugenics in present-day enforcements of normalcy. For example, in an age of increased prenatal genetic testing, parents are encouraged to abort pregnancies that are not "perfect," and questioned about the decision to give birth to a disabled child (Russell, 1998).

Still, many efforts intended to give individuals agency are directed toward normalcy. Illustrating how people are constructed by relationships with their surroundings, Moser and Law (1998) looks at ways that communication technologies remove barriers for some individuals, but also notes limitations in the choices that are

afforded. The distinction between acts that remove barriers and those that enforce norms is, at times, difficult to make.

In and out of schools, political and economic systems have self-serving ways of valuing normalcy, and reinforcing what is "normal" (Charlton, 1998; Meekosha, 2002). Disabled young people strive for normalcy in a given area because of the threat of being condemned to be abnormal or substandard in other or all areas. Robert McRuer (2006) calls this threat "compulsory able-bodiedness." This threat is imposed by physical structures, cultural practices, common discourse, beginning with the early interactions between parents and children, and strengthened through the ongoing interactions in schools and communities. Within schools, normalcy is rewarded and disability is most commonly framed as deficit, as a condition needing to be fixed, or a problem to be overcome (Linton, 1998, Ware, 2003). Disabled students encounter prejudicial practices in schools due to the widely accepted medical model and the enforcement of normalcy (Hehir, 2002).

The ubiquitous role of dependency in the formation of disabled identities has been examined in two distinct ways, some questioning false assumptions of natural dependency and others considering independence to be mythical. In questioning dependency's natural place in the lives of disabled persons, some scholars have found evidence that families (Hussain, 2003) and schools (Benjamin, 2002) socialize disabled children to be dependent. These tendencies to infantilize disabled youth are often outside the awareness of the individuals involved (Robey, Beckley, & Kirschner, 2006). Coming into conflict with research that assumes immaturity is inherent to

disability (Galambos, Magill-Evans, & Darrah, 2008), these findings suggest that dependency is conditioned and needlessly becomes a part of disability identity. Although much of Western thought emphasizes the goal of independence, other scholars question the meaning of dependence and claim that true independence is unattainable for all of us (Fitch, 2009, Kittay et al., 2005). These scholars argue that personhood is based on one's relationships with others and that human experience is constituted by our dependence on each other. Recognizing the limits of true independence, they have made efforts to reframe and destigmatize dependence and interdependence, asserting that seeing relationships as symbiotic and interdependent is more realistic (Mintz & Young, 2008; Smith, 2001).

Attitudes toward different types of impairments vary greatly and are often hierarchical in nature (Caldwell, 2007). Disabled individuals, like nondisabled individuals, view those with various impairments to be better or worse than others based on a range of factors including stigma, sexual attraction, normalcy, competition for resources, "genuinely disabled," presumed emotional affect, way of acquiring the impairment, severity of impairment, etc. (Deal, 2003). This ableist tendency is often considered by scholars as a way for individuals to distance themselves from what is not their own experience and to avoid taking on the stigma associated with the specific impairment. Competition in schools serves to reinforce this tendency (Brantlinger, 2006).

Recognizing that dominant models of disability offer little hope for disabled individuals to lead worthwhile lives, Simi Linton (1998) advocates for disabled

individuals to redefine disability and embrace disability identity. She and others view

"claiming" disability to be similar to "coming out" as queer (McRuer, 2006). In doing

so, individuals not only find place among a group, but also change the way they

interact with the social world. However, many disabled people do not identify with

disability, either ignoring the impact disability makes on their lives or not wanting to

be categorized by it, as it usually brings no gain in social status (Watson, 2002). The

difficulty many disabled youth have in claiming disability identity can be seen as a

reflection of the discriminatory culture of schools. When schools continue to promote

deficit models of disability and lack an awareness of discursive frameworks that

devalue disability experience and belittle disabled students, we cannot expect students

to feel safe and supported in their identities.

Issues of Power and Voice

For disabled youth, the negotiation between cultural understandings of

disability and the creation of a strong sense of identity requires a degree of

empowerment many have not reached. As we aim to open space in schools where

claiming disability identity is possible, an understanding of disability representation

and of how voice acts to empower can provide insight into what separates those who

have access to the life they choose to live from those who do not.

Representation of disability

Media images influence perceptions of parents, professionals, peers,

and disabled individuals with stereotypical representations that create a narrow world

of possibilities for disabled people. Shapiro (1999) lists stereotypical images of

disability commonly seen: the object of pity; the sub-human organism; sinister or evil; the unspeakable object of dread; the holy innocent; the object of comedy, ridicule, and curiosity; or the burden. The entertainment industry has often exploited disabled individuals as freaks who reassure nondisabled individuals of their normal status (Thomson, 1996). Dominant depictions of disability are mediated through many layers and fail to represent the authentic voices of the disability community (Riley, 2005). These problems of disability representation are unlike those faced by other minority groups because these more often go unnoticed by the general public. In general, individuals do not receive instruction on identifying and critiquing disability stereotypes as they learn to critique stereotypes of other social groups.

These stereotypical representations are reproduced in schools, so that too few disabled young people have access to powerful models of disability in which to use as they develop their own identities. Disability representation in the media, in history, and in schools has in large part created barriers that keep many disabled individuals from acquiring power over their own lives. Recognition of this is not a new discovery. In the early 1900's, Vygotsky, working in a field then-called "defectology," recognized that using a deficit model in regard to disabled students would have harmful effects on their ability to acquire power, but still supported their segregation (Gindis, 1995; 2003).

A century later, a growing number of educators question the ways schools teach about disability. In recognizing that school curriculum usually "renders disability powerful and disabled people powerless" (112), Linton (1998) expressed the

need for schools to attend "to the active voice of the artist, writer, and theorist with a personal disability perspective" (113). In accordance with consulting those with direct disability experience, some have promoted mentoring programs for disabled youth. Despite the challenge of finding appropriate mentors, the need for powerful models is great (Daughtry, Gibson, & Abels, 2009). As beneficial as mentors can be for individual students, systemic change will require a wider "audience" and should consider incorporating critical disability content into the curriculum of K-12 schools and of post-secondary schools, including that of teacher education.

Scholars advocating for change in the K-12 curriculum have promoted new understanding of disability through history and art (Ware, 2008), through personal narrative (Solis & Connor, 2006), and through current events (Stolz, 2006). . These projects involved students' understanding the identity of others, learning about their own identity by understanding others, and exploring alternatives to negative images of disability. The teaching of critical perspective acknowledges that different bodies cause individuals to experience life in different ways, to see things, believe things, and know things that could not be known through life experienced within a different kind of body (Erevelles, 2000).

Efforts to engage teachers in changing curriculum have found that one of the difficulties teachers have in teaching a critical disability content is facing up to previously untouched perceptions and misconceptions (Ware 2001; 2003). Perspectives of the Disability Rights Movement and humanities-centered disability studies come in sharp contrast to conceptions of disability drawn from special

education and widely accepted stereotypes and still face substantial resistance (Ware, 2001).

With resistance to extending the scope of diversity work in schools to include disability, it should be no surprise that assuming a disability identity is fraught with conflict. Baynton (2001) would attribute this to the historical use of disability to justify inequalities. Within schools, these inequalities may range from giving less credibility to the perspective of disabled individuals and failing to critique disability stereotypes to providing inadequate resources for the education of disabled students and segregating them to certain areas of the campus. Due to oppression's historical nature, disabled individuals must conquer internalization, self-hate, and self-pity to change the consciousness of themselves and society (Charlton, 1998).

Too often, communities fail to question tradition and continue harmful practices instead of imagining new ways to structure school interaction. Ware (2004) showed how segregated social structures within a school facilitate internalization of oppression; and how unfortunately, disabled youth fulfill the expectations held for them. The failure to provide safe space for youth to claim disability identity can lead to students' personal humiliation, truancy, lack of belonging, lack of school achievement, and disconnect with other students.

Coming to voice

As schools work to open safe space for those of other marginalized groups, they recognize the value of perspective and encourage the voice of individuals. Several reasons make speaking one's voice, sharing one's perspective, a difficult feat

for disabled individuals. Clare (1997) describes the difficulty she had in learning to use her voice. As a child, she recognized the "blank faces" and "simple replies" others gave as she worked to be understood. For many, learning the act of speaking is laborious. However, in the process of coming to voice, one may hesitate in silence, endure gripping fear, and risk embarrassment and safety before finally having her voice heard. The intensity for many in coming to voice is the understanding that voice can serve as the keeper or the teller of our identity. When an individual's voice is not affirmed, feelings of illegitimacy and loneliness transpire (Anzaldúa, 1990). So, to put one's voice out there, she must risk rejection. Does our pedagogy give her the affirmation she will need? Anzaldúa (1990) describes her feelings in reading her first Chicano novel, the "pure joy," the surprise that a Chicano could accomplish the writing, and the thrill of "existing" (208). The presence or absence of multiple voices is monumental in establishing the value and expectation that society places on youth of diverse backgrounds; and so, we might want to consider how curriculum that includes disability perspective could affirm the experience of disabled students.

Rejection is not all one risks in coming to voice. In writing about the risks disabled writers take in voicing their perspectives, Fries (1997) considers that, when considering the situation described by a disabled writer, an audience reacts in unpredictable ways and might generalize the disability experience and consider it summed up in that one experience. A disabled student may also risk this misunderstanding as she uses her voice. And still, without authentic voices, truths cannot be discovered. Does our curriculum offer alternate disability voices or will she

hold the weight of being the only example? Since difficulties associated with having a minority status at school can contribute greatly to students' dissatisfaction with their school experience (Quiroz, 2001), we might imagine that disabled youths' school experience might improve when their voices are affirmed and their perspective is valued.   We might imagine how giving disabled youth voice can mean giving them the power to present their identities and create the futures they desire.

Not offending others has been particularly important for disabled youth who have often felt dependent on having good relationships with those around them. Often, voices remain silent in order "to make nice," to not offend, discredit, or challenge the privilege of others, to comply with the so-called "truths" to which the larger community adheres (Norris, 1992). When disability perspective is not considered in school, students may remain silent as opposed to uncovering what might be viewed as a "problem." How do we handle voices that may interrupt the "truths" of the larger school community?

If the content of speaking is more important than the act of speaking (hooks, 1990), we cannot assume that any act of speaking reflects the authentic voice of the individual. The liberatory voice is one that has addressed the problem of audience and is willing to place herself at the center of discourse. This voice is likely to "confront, disturb, demand that listeners even alter ways of hearing and being" (196). With this in mind, we cannot deny the risks youth must take in coming to voice. Students with disabilities risk confronting social norms and expectations when speaking and writing about their experience.

So rather than pushing disabled youth to talk, we might instead consider ways to encourage their participation in decision-making and in constructing their own futures. Humphries (1996) writes about the way Deaf persons have negotiated the views of others as they redefine their own identities; and in doing so, they have reshaped the views others have as well. While this process may be similar for disabled persons, cultural differences of these groups must cause this negotiation in identity development to play out in unique ways.

My Research Questions

With the knowledge of how identities are shaped by interactions in a social world, I consider the identity development of disabled youth to be substantially different from that of nondisabled youth. Conceptions of disability, produced by history and imagination, have tremendous power in the building of possibility for disabled youth. I believe deeper understanding of disability experience can lead educators to better support disabled youth before and during transition. In this study, I will bring together what I have learned from previous scholarship, from my own disability experience, and from the voices of disabled youth in transition to answer the following questions:

How do youth with orthopedic impairments negotiate expectations and experiences as they transition from high school to college and from family-delivered supports to independence? And what in the earlier periods of their individual development/family life provides the context and frameworks for their negotiation of transition to adulthood?

A. How is the identity development of disabled youth shaped by the social world?

B. How do disabled youths view themselves? What discursive frameworks shape these views?

C. How do social and physical barriers form a web that impact the relationships disabled youth face in their development?

D. How might we critically examine the most basic concepts of development that we apply to adolescent transition to autonomy such as "maturity", "friendship", dependence/assistance, etc? How are these concepts made to appear stable and universal even as they are fragile and diverse in their fit with so-called normal population (which is in fact varied in terms of ability)?

E. How do disabled youth develop agency? How can educators support the development of agency?

III. Methodology Chapter

Introduction

For many youth, making the decision about what to do after high school looms large as a task that can elicit both excitement and fear. Parents and educators often press youth to consider the long-term effects of their decisions. Disabled youth must often make decisions for their futures without having successful models to emulate. While non-disabled adults can provide guidance and support, these adults usually do not have access to the experience and knowledge that would be most helpful to disabled youth. Educators and parents of these youth want what is best for their children, but often have expectations and experiences that greatly differ from the experiences these youth encounter. This study considered how individual youth with orthopedic impairments, individuals who have had access to models with similar impairments, established goals for their own transitions to adulthood.

With this chapter, I outline my research questions and describe the contextual background of this study, including the sample, mentoring program as a whole, individual youth and their parents, as well as my positionality in relation to the work. I also give an account of my data collection and data analysis procedures. At the end of the chapter, I lay out the limitations of the study design.

Ethnographic research has proven valuable in examining issues of equity (LeCompte & Preissle, 2003) in ways that further understanding of the social processes that play into identity. I used ethnographic methods to produce detailed descriptions, suited for the particular questions of the study. The nature and diversity

of experience that constitutes disability requires observation of nuanced and context dependent processes, which would be difficult to articulate with quantitative tools.

Contextual Background

Sample

Participants in this study were urban parents and transition-aged youth, 16 to 22 years, who were involved or had been involved in a mentoring program for youth with low incidence orthopedic impairments in southern California. Low incidence refers to impairments that make up a small percentage of the total population of people with disabilities. Students with orthopedic impairments account for just 0.1% of students served nationally (U.S. Department of Education, 2009). This label includes students with Spina Bifida, Celebral Palsey, Juvenile Arthritis, Muscular Dystrophy, Spinal Cord Injury, and others, all impairments that vary in nature and severity. This purposive sample of youth had recently graduated or planned to graduate from high school within the next two years. By selecting participants from this group, I narrowed the sample to a subset of disabled youth who are typically mainstreamed in schools today and viewed as having decision-making capabilities. Even though disability studies critiques the classification of individuals, the challenge of considering all experience within bounded works has yet to be resolved. Although there is great need for transition research addressing the experience of youth with other types of impairments as well, my own disability experience has positioned me well as an insider with this group. Eight of the 32 youth who were mentees

participated in focus groups, seven youth and five parents participated in individual interviews. Although I was open to interviewing mothers or fathers, mothers were most accessible and willing. I selected particular youth for individual interviews because they appeared to be good informants. Although all of these youth belonged to the underrepresented group of people with disabilities, many also belonged to other underrepresented groups. Participants identified as: Caucasian, Mexican-American, Palestinian-American, and Multi-Racial. The racial breakdown of the parents closely resembled that of the youth. The parents of several youth participants used Spanish as their primary language and had limited English skills. The youth were currently or previously students who attended one of four nearby school districts.

The Mentoring Program

I decided to recruit participants from the mentoring program for several reasons. First of all, my familiarity with the youth gave me access to a group in which trust had already been established. This specific group had access to adult models with disabilities similar to their own. Because of their exposure to an array of possibilities for adult life with a disability, these individuals promised to provide interesting insight into the negotiation of expectations and experiences from multiple sources. The participants selected had the influence of parents and the influence of a community of other people with disabilities.

The grant-funded mentoring program from which participants for this study were selected was unusual in a couple ways. For one, it was designed specifically for youth with orthopedic impairments to encourage better post high school outcomes.

Mentees were recruited for the program through counselors, teachers, physical therapists, and through other community outreach events. Mentees had to meet the following criteria: be between the ages of 16 and 26, have an orthopedic impairment, and have or plan to get a high school diploma. Mentors for the program had to meet the following criteria: be an adult with an orthopedic impairment, have some post-secondary education, and have some employment experience. Youth were matched one-to-one with mentors on the basis of gender, similar functional ability, and interests. The mentoring program held events twice each month for mentors and youth and encouraged weekly phone or email contact between mentee and mentor pairs. The group interaction allowed the youth to meet and learn from the experience of a number of adults, to expand knowledge of resources, and build a social network.

Another component of the program, the college experience, provided an opportunity for youth to live in the dorms of a local college for four days and three nights. This gave many of them a space to be independent of their parents and families; for some, a rare opportunity. This also gave parents a chance to see how their children, now young adults, might manage to live away from them and still get their needs met. Program staff facilitated classes about self-advocacy, college survival, and communication skills, and accompanied youth as they toured campus and took part in some elective activities. At the time interviews were conducted, some of the youth interviewed had already attended the college experience while others had not.

Recruiting Participants

After receiving written permission from the mentoring program's director, I began to recruit participants. During mentoring program events, I individually told youth and parents about the study and asked if they would consider serving as interviewees. When I explained that I valued their experience and knowledge, individuals were eager to participate. In November of 2007, I mailed a letter explaining my research and asking for parent or guardian permission and youth permission for participation in the study. I selected six youth for individual interviews. One participant wanted to offer an individual interview even though her parents did not. I agreed. I later added one more individual interview when one young woman joined the group and proved to have a particularly interesting experience to share. So, in the end, three males and four females served as case studies. Of these, three were high school students and four were college students, with impairments varying in type and severity. Five mothers also served as individual interviewees. I selected 15 youth to participate in focus groups. Only 8 of those selected for focus groups participated, five females and three males. I believed these numbers would allow sufficient data to draw conclusions about patterns that emerged.

Positionality

Many scholars acknowledge the importance of positionality within research. Mertons (2005) speaks about the researcher as the instrument, naming speaking for the other, gaining permission, and negotiating entry (including establishing rapport) as potential challenges. One's positionality determines the ease or difficulty in which she

handles these processes. Freire (1970) asserts that efforts to change consciousness can succeed when "objects" of the plan are invited to dialogue about their perspectives. Charlton (1998) connects Freire's ideals with the disability community. His mantra "Nothing About Us, Without Us" is widely adopted by disability studies scholars and by disability community members. Although parents, families, friends, and passionate professionals have long advocated for the well-being of individuals with disabilities, Charlton (1998) claims true liberation from oppression must come from within the disability community. The inclusion of voices from within has come to be expected within progressive circles. Because of my status as a person with a disability, my positionality within my dissertation research illustrates Charlton's vision, creating a unique and meaningful context from which to study.

My involvement in this research was multi-dimensional. As an individual serving a number of different roles, I believe my positionality should be explained explicitly as recommended by Howe and Eisenhart (1990). First of all, I am a person with a disability, conducting research about people with disabilities. I was a mentor within the program from which participants were drawn. I was a member of the mentoring program staff, involved in creating and implementing program curriculum. I am a former high school teacher and administrator with knowledge of and opinions about institutional practices. And finally, I am a researcher. I must acknowledge my bias as an advocate, activist, and insider.

Person with a Disability

I consider disability to be a key aspect of my identity and a valuable perspective from which to conduct research. Having been diagnosed with a form of muscular dystrophy at age two, I believe much of my childhood social interaction was mediated around issues of disability. I did not embrace my disability identity while I was a child and adolescent, but instead tried to separate myself from all I had come to believe about disability. I saw that people with disabilities were devalued. I knew that my disability was a part of me others wanted to change. Over the years, I have learned to articulate some of the knowledge I have from living the experience. That knowledge includes the physical knowledge of inhabiting a body with specific kinds of limitations, but also includes a wealth of information about how the social world interacts with difference. This information includes experiences of discrimination and marginalization, experiences that were not shared by members of my family. As a student, I was not given access to certain courses taught in inaccessible spaces and, at times, was ostracized by peers. As a teacher, I was told by administration that I did not have a strong teacher presence because I did not stand above my students. I feel these experiences and others have given me an understanding of how these social practices affect identity and feelings of self worth.

Although I see my position as a person with a disability as critical, I want to acknowledge that I do not and cannot speak for all persons with disabilities, as the experience of disability is widely varied and intermingled with experiences of race, class, and gender. I believe my access to education, employment, and other social

capital, is not solely the result of my work and determination, but also the result of privilege. I grew up within a small community in which all students, more or less, including me, were expected to go to school and to work hard. The third of six children living on a farm, I was taught to contribute to the farm and household chores as I could. Even though my family survived on the single income of the farm for years and qualified for reduced lunches at school, my parents managed to always provide the necessities of food and clothing; and, we, as children, did not feel deprived, as we saw that many of our peers lacked the greater luxuries of the middle class as well. This economic position resulted from the values of my parents, who believed my mother's presence at home caring for children took precedence over being able to afford certain material luxuries. I considered this history as I interacted with youth and parents in this study. The extent to which I could understand the perspectives of those with experiences of race, class, gender, and variation of disability needed to continuously be questioned.

As a person with a disability and a student of disability studies, I have become greatly aware of the variation of disability perspectives within the larger disability community. I have considered the differing perspectives of those who have experienced disability throughout childhood and those who have acquired disability as adults, of those whose bodies are nearest the norm and those whose bodies are farthest from the norm, and of those who work to "pass" as non-disabled and those who call attention to what sets them apart. While I aim to affirm various perspectives, I struggle to do so as I hold a philosophy that can seem rigidly individualistic. I have

shown frustration when persons with disabilities rely on others for things they could do for themselves. While working with youth, I aimed to encourage self-reliance to whatever extent possible, as I believed it to be a key to empowerment.

Research conducted by individuals outside a group often is questioned for its lack of an insider's cultural knowledge. In this case, as a member of the underrepresented group of persons with disabilities, I had access to cultural knowledge and trust within the community. As a member of the disability community, I identified research questions that aimed to advance the position of people with disabilities in society. Although a member of the group, I used member checks and thick descriptions to ensure that assumptions were not based solely on my individual experience.

Mentor

When the mentoring program began in 2005, I was invited to serve as a mentor and attended an organizational meeting. There, I learned that the mission of the program was to create greater expectations for disabled youth, a mission in which I certainly believed. In January of 2006, I began to volunteer as a mentor for one youth. Even as my role expanded, I continued to individually mentor the young lady with whom I was originally matched.

After I began mentoring, the staff of the program asked me to assist with a summer project where the youth in the program moved into college dorms for four days and experienced life on campus. As I led a group of girls in campus activities, I

listened to their hopes and concerns; and, I decided I should speak to the director about my research interests.

Until I began interviews, I did not foresee how my role as a mentor would impact my data collection process as it did. Some parents asked for my ideas and experience in relation to concerns for their children. One mother followed me to my car as I left because she wanted to see how I got into my car. While I was there, I showed her my hand controls and explained how they worked. I included instances like this in my field notes.

Program Staff

Having learned that I was fascinated by the youth and interested in writing about them, the director asked if I would consider taking a position as the program's curriculum specialist. I accepted the position in August of 2006.

As the curriculum specialist, I worked with a team to identify topics that are important in supporting youth with orthopedic impairments as they transition to adulthood. I was responsible for developing events in which the various topics were addressed. Topics included: goal setting, transportation, money management, personal care management, going to college, interviewing for a job, dating and relationships, fitness, self-advocacy, community service, and community involvement. While addressing these topics, I planned opportunities for the mentors to share their experience and knowledge and for the youth to share in leadership of activities. In this position, I also provided training and support to the mentors in the program. During

the three years I worked for the program, a staff of five to six part-time members ran the program. Five of us were individuals with orthopedic impairments.

Youth of the program and their parents already knew me as the program's curriculum specialist and as a mentor. Having known many of the participants for over a year, I had some knowledge of their interests, personalities, and relationships with others. I interacted professionally and casually with the youth of the program. Because of my role as a leader in presenting program curriculum, I was concerned that youths' interviews might be colored by what they believed I expected of them. In my role as program staff, I often projected my beliefs that disabled youth must not let logistical and attitudinal obstacles stop them from attending the program, school, or community events. One of the mentors in the program told me the youth in the program thought I was a "hard ass." She said they knew not to give me excuses and knew I would not baby them. Although my familiarity with the group helped me gain access, I found myself wondering just how honest youth and parents would be, having knowledge of my role as a staff member. However, during the interviews, I sensed that interviewees felt an easiness or comfort in speaking to someone who understood disability experience.

Former Teacher and Administer

Having worked as a high school teacher and as a school administrator, I believe that disabled youth are often taught and treated unfairly by teachers, school staff, parents, and peers. I have witnessed teachers who have held low expectations, who have not provided instruction, and who were insecure about interacting with

disabled youth. I have also witnessed parents who have refused to give responsibility to their children, who have worked to protect their children from the sometimes harsh realities of social life, and who have spoken about their children mainly in terms of what they were unable to do.   Fortunately, I have seen the opposite in teachers and parents as well. I also recognize many of the constraints placed on parents and educators by social norms and the lack of quality resources. Therefore, I believe more knowledge generated about the social interactions of people with disabilities can improve unfair practices that often hinder youth as they make transitions to adulthood.

Researcher

My role as a researcher was interesting to negotiate as I had to uphold my responsibilities as a staff member and mentor. To uphold my responsibility as an individual mentor, I chose to not include my own mentee or her parents in individual interviews. My obligation to my mentee required me to provide mentoring without giving her the feeling that I am analyzing or judging her. In upholding my responsibility as a staff member, the majority of my data collection took place outside of program hours. In order to clarify my different roles to participants of the study, I told them that while my research coincides with the mission of the mentoring program, it was not a part of it. As a researcher and interviewer, I needed to refrain from offering my opinion like I often do as a staff member.

Data Collection Procedures

The study consisted of several data collection activities including document review of participant intake files, seven individual interviews with youth, five individual interviews with parents, focus group interviews with three small groups of youth, and field notes documenting my observation of the mentoring program. Remembering that Mertens (2005) warned that communication needs might present challenges when interviewing some people with disabilities, I foresaw having difficulty understanding the speech of a few of my participants. When speech was difficult to decipher in one case, I provided a transcript to the individual and asked her to clarify information.

I recruited participants from the mentoring program for which I work. Knowing the youth in the program, I approached those who I felt would be good informants. In order to recruit those under age 18 and their parents, I first approached their parents and explained my interest in learning from them and their sons and daughters. After having verbal agreement from parents, I then spoke to the youth. In order to recruit those 18 or older and their parents, I first approached the youth and explained my interest in learning from them and their parents. After having verbal agreement from youth, I then spoke to the parents. Most of these conversations happened in person at mentoring events; a few happened on the phone. Youth and parents were excited to participate.

Document Review

To begin data collection, I reviewed intake files, including the participants'
applications, intake interviews with youth and parents, and goals set by the youth.
Before conducting individual interviews, I read file documents and made notes
regarding each individual. These documents provided demographic information and
information about the parent goals at intake and about youth goals set at various times
of their participation in the program. I compared the goals stated in the intake
interview with goals stated at other intervals in order to note changes over time.
Review of individual files helped me design probes for individual interviews. I went
into the interviews with notes about the individuals' self-disclosed goals and reasons
for wanting a mentor.

Individual Interviews with Parents

I decided to begin with parent interview mainly because I wanted to have as
much background knowledge as possible when going into youth interviews.
Interviews of five parents investigated the family culture, the expectations they hold
for their children's education, employment, and independence, and experiences they
have had with their own transition to independence. Lasting from one hour to one and
a half hours, these interviews happened in their own homes. I used open-ended
questions to elicit stories and visions that revealed experience and expectations. A
translator was used as an interview assistant for one parent whose primary language
was Spanish. Interview questions are included in Appendix A.

Individual Interviews with Youth

After having interviewed a youth's parent, I set up a time, usually a week later, to meet with the youth. This gave me time to organize questions after learning from the parent. Interviews of seven youth explored the youths' individual family expectations, the youth's sense of what their parents expected, the youth's own plans for transition from high school, and the youth's ideas about how their own concerns compare to those of their parents. Two of the seven youth participants offered interviews even though their parents were not available. Lasting an hour, youth interviews took place at homes, libraries, or coffee shops. Again, open-ended questions were used to elicit stories from individuals of how they negotiate the experience and expectations of their parents and set goals to go to college and to live independently. Interview questions are included in Appendix A.

Focus Group Interviews

I piloted my focus group interview methods first with a group of five disabled adults. My aim was to gain experience facilitating a focus group and an idea of the types of responses my questions would elicit. After the interview, I received input about the questions in order to discover better ways to find what I was looking for. Through this process, I made substantial changes to my questions, moving toward questions that elicit thoughts about people's tendencies in general rather than specific experiences of individuals.

I invited fifteen youth to participate in one of three focus groups, explaining that I wanted to include their ideas about adult life in my writing. Eight were able to

participate. These groups gathered at various public locations. I grouped youth according to their comfort level with each other, hoping to provide a safe space for them all to contribute. Focus groups questions were used to identify beliefs that influence youths' goals and decisions about what they will do after high school. The topic of interviews revolved around youths' sense of what society expects of them, their sense of identity as people with disabilities, and their beliefs about what the future holds for them. Most questions had two parts, for example, "Describe what is most important to people when they are becoming adults. Tell me which of those things are important to people with disabilities." The main goal was to gain an understanding of how this group of youth with orthopedic impairments see themselves in the world and to elicit interesting points that could be compared to those made during individual interviews. I facilitated the focus group interviews and video recorded to make transcription possible. Portions of the videos were transcribed. Interview questions are included in the appendix.

Field Notes

I used field notes to document my observations of the mentoring program and, throughout the process of data collection and data reduction, to record my thinking about the process as I moved through the collecting and coding data. These notes helped provide thick description of the data and a transparency of my thinking related to data analysis. As a participant researcher, I had daily access to information regarding the youth and parents served in the mentoring program that could best be documented in field notes. I began taking field notes before I began any other form of

data collection. Field notes helped me record some of the general happenings of the

mentoring program and track related ideas that stemmed from my own experience and

interaction with the larger disability community.

Data Reduction and Analysis

I drew from grounded theory as a means for making meaning of the data

(Glaser & Strauss, 1967; Strauss & Corbin, 1990). Grounded theory uses a method

that allows the researcher to look for generalizations that emerge from the data. These

generalizations allowed me to develop a theory about how youth whose experience is

that of one marked by difference negotiate expectations and experience. With

grounded theory, I employed a constant comparison method in which concepts,

insights, and meaning-making occurred based on patterns in the data. This approach

to data reduction was necessary because the voice of disabled youth has been absent in

the literature. As educators seek to provide equity, it is critical to understand how

members of this minority negotiate various complexities that influence their goals and

decisions.

Specifically, the choice of a constant comparison analysis enabled me to

uncover how relationships with families, friends, and teachers have influenced the way

these youth construct their identities (Glaser & Strauss, 1967). I began by sorting data

in categories of expectations and experiences. To ensure that emergent theories

closely represented the data, I inductively analyzed the data using a cross-case

approach. I considered the particular expectations of parents and the particular goals

of youth, looking for patterns between the various cases. This allowed me to identify relationships between the goals and decisions of youth with orthopedic impairments and the expectations of their parents. These relationships provided insight into the ways youth think about and negotiate the expectations of others.

An inductive analysis approach was particularly important in this study as it allowed for a detailed and rich account of the interplay between transition-age youth and parents and allowed me to uncover the complex ties between social interactions and decision-making.

I analyzed data throughout the course of this study. Collection and analysis overlapped as I made collection decisions after seeing what was emerging. I used data collected from document review to prepare for individual interviews. I wrote a brief description of what I had learned about each youth from the contents of their mentoring program file, including demographic information, self-reported goals upon entering the program, and parent's report of youth's experience. I went into each interview with this knowledge. I also used this data to probe for deeper understanding of how the expectations and experiences of parents interplay with those of the youth. All interviews were transcribed by a research assistant and reviewed by me.

My research questions guided the coding and categorization of my data. For example, I categorized data from parent interviews by expectations, transition experience, and attitudes about disability, and then more specifically coded depending on what emerged. I categorized data from youth interviews by goals, beliefs about

parent's expectations, beliefs about potential challenges, and again more specifically depending on what emerged.

During open coding of interview data, I made notes of points I found interesting. I looked for themes that ran through stories of parents' own transitions to independence and of their visions for their children. Similarly, I looked for themes that ran through the youths' stories of how they have made plans for the future. After spending time thinking about the data, I created a "situational map" (Clarke, 2005), a picture of the many variables that seemed to make an impact on the youth I interviewed. I began by placing "youth conception of self" in the center and then surrounded it with human and nonhuman influences. I then placed those influences in the ordered situational map, shown in Figure 1. I used some of those variables as codes in the next phase of analysis.

Human actors—parents, caregivers, single parents, siblings, peers, teachers, mentors, medical professionals, disability commuity, other community members

Discursive construction of disability—normalcy, dependency, hierarchy, claiming

Political/Economic elements—family income, presence of IHSS, post-ADA

Major Issues/Debates during Transition—post-secondary education, transportation, independent living, employment, general health, and companionship

Nonhuman element actants—no ramp at home, no car/van, general access

Sociocultural/symbolic elements—variation of parent expectation, parent fears, sibling support, sibling jealousy, family cooperation, cultural background, gender roles, sexuality, materialism, ideals of beauty, health consciousness, onset of disability

Other elements—degree/severity of impairment

Figure 1: Ordered Situational Map of Variables

During axial coding, I focused on discursive constructions of disability and used "normalcy," "dependence," "hierarchy," and "claiming" as codes to group parts of the data together. I also focused on human interactions and coded "parents," "siblings," and "friendship." I began to make sense of how youth come to think about their own roles and their own possibilities. Then, I focused on relationships between the categories. I asked: How do youth view themselves? What kinds of interactions influence their thinking? How do different sets of ideas interplay as youth begin to transition? I looked for themes that ran through stories of how students interact with expectations and experience, of how they made their goals, and of how goals may have changed due to other mitigating factors. I examined demographic information and its relationship to the influential factors in an effort to potentially account for different relationships.

After focus interviews were transcribed, I began coding for factors that youth believe are different for disabled youth than the general population. When categories emerged from the focus group interviews, I used those to think about how the youth see the role of individuals with disabilities in society and compared those ideas with those that came from the interview transcripts. The following themes appeared again and again: acceptance of disability, rejection of disability, independence and dependence, hierarchy, and ideas of normalcy.

I created coding tables using Word to assist with the coding and organization of data. I imported my interview data to the tables and used it to help analyze the information. After creating a list of statements to describe my understandings, I

referred back to the coding tables to look for cases that supported and cases that countered those understandings. From that, I wrote my findings.

To increase the credibility of my study, I used member checks, peer debriefing, and triangulation. I wanted to ensure that others would see the situation in the same way, that my understanding was not dependent on my own biases. At the end of interviews, I summarized what was said to check that my understanding accurately represented the perspective of the interviewees. In some cases, I called participants to ask for clarification and further examples. As I began to make sense of the data, I discussed my analysis and accepted questions about my value judgments from peers who were distanced from my work and from disability community members. This process was invaluable in giving me confidence in my findings and in discovering other variables to consider. I sought triangulation of information through the collection of data from multiple sources: focus group interviews, individual interviews, and document review. This process helped me decide which emergent phenomenon could be most generalizable.

Limitations of the Study

This study had several limitations. The primary limitation of this study was the small sample size, the seven youth and five parents who interviewed individually and the eight youth who participated in focus groups. Although the sample had urban youth of various races, ethnicities, and genders, all of the youth in this study participated in a mentoring program that matches youth with orthopedic impairments with adults with similar impairments. A wider sample might have provided a wider

variety of youths' willingness to identify as people with disabilities. Despite the small sample size, I believe this research still valuable. It promises to be productive in expanding ways of thinking and generating further research questions about a topic that has been under-researched. While findings of this study might be used to inform parents and educators on ways to better support youth during transition, this study does not extensively examine the challenges that youth with orthopedic impairments often find in attending college. The results will not solve the many problems faced by youth who may want to go to college but lack proper academic preparation, adequate financial resources, or on-campus support. They will not wipe away the social barriers disabled youth face. However, the results may likely lead educators to consider better ways to support the development of disabled youths' sense of agency and consequently encourage more disabled youth to make the decision to go to college, to pursue independent living, and to envision lives they want to live.

IV. Beyond Physical Experience: An Introduction to My Findings

Youth with orthopedic impairments experience life differently than their non-disabled peers. They have a different physical experience and encounter a variety of physical barriers. However, this study assumes that the disability experience always goes beyond physical limitation, such that youth with orthopedic impairments have a different sociocultural experience and encounter a variety of sociocultural barriers. In this section, I begin to outline my findings related to the physical and sociocultural experiences of these youth. As I briefly describe the physical experience, I will show how the sociocultural experience overlaps. I begin by describing the physical experience and naturally slide into its effects on sociocultural experience. This is not to say that physical experience leads sociocultural experience, but rather that the two cannot rationally be separated. The section on physical experience is limited as it has not been the focus of my research. I briefly discuss it in order to acknowledge what otherwise could be seen as the elephant in the room. It is my belief that educators should be more concerned about sociocultural aspects than physical or medical aspects of disability.

In its International Classification of Functioning, the World Health Organization considers contextual factors rather than just medical conditions. The 2001 implementation of this classification system has created a multi-layered way to describe and measure the experience of disability (World Health Organization, 1999). This acknowledgment of how environment plays a role in the way individuals are able to function and participate in a society is not always apparent in the work of

professionals who serve disabled people. I argue that educators addressing issues of

disability in schools need to consider that disability experience includes contextual

factors, or sociocultural experiences, rather than solely medical conditions.

Medical Condition **+** Contextual Factors **=** Disability Expereience
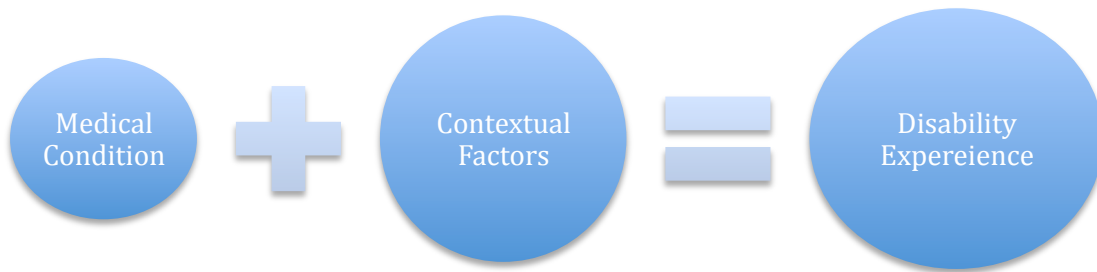
Figure 2: Relationship of Medical Condition and Contextual Factors

Educational theorist, Lev Vygotsky, propagated the concept that learning is a

social process, involving a learner's social, cultural, and historical perspective. Rather

than believing that individual ability is genetically determined and can be objectively

measured, as behaviorists did, Vygotsky saw that an individual's learning is shaped by

a wide variety of contextual factors (Wink & Putney, 2002, pg 63).   Today, most

educators would agree that understanding students' social experience is beneficial to

effective teaching.   However, in the case of disabled students, this is often forgotten

because dominant frames for viewing disability rely heavily on the medical model. In

other words, common conceptions of disability are often limited to medical

considerations, even within the realm of education. Society's tendency to medicalize

disability has crept into schools, creating structures that segregate disabled students

and perpetuate inequity. Within this tradition, students have often been viewed as

patients who need to be treated by specialized professionals (Shapiro, 1999).

Becoming objects of medicalization and pathologization, disabled students encounter experiences quite different than those of their peers. A medicalized view of disability focuses on deficit and devalues the experience of disability. If we begin to look at the interactions of youth, particularly disabled youth in this study, we can note how they gain specific knowledge, cultural knowledge that is different than that of nondisabled peers.

One of the important aspects of considering disability through a sociocultural lens is that it broadens our conception of disability, gives us space to consider the ways in which what we do as educators can impact the experience of young people. As educators, can we or should we work to impact the physical experience of disabled youth?   In most situations, no. First of all, we must not assume that our primary responsibility to students with disability is that of referrals to therapy or that of understanding how their bodies work. We must not assume impairment needs to "be fixed." Impairment is a natural part of life; and often, there is no elixir. However, I acknowledge physical changes or "fixes" can affect one's ability to learn.   Still, making referrals or suggestions about these concerns is not the sole responsibility we have to students with disability. Rather, our responsibility includes understanding what we can about students' sociocultural experiences, what lies beyond genetic predispositions and impairment.

Experience and Barriers

The experience of youth with orthopedic impairments is greatly impacted by having a physical body that differs from the average non-disabled body. Having a "different" type of body, youth with orthopedic impairments experience developmental tasks in a different way and have different feelings about the body. Some barriers youth encounter may be attributed to limits in the body's function; and other barriers may be attributed to limits in the structures created for a non-disabled population without regard for those with different kinds of bodies. But, all of these barriers exist within a sociocultural context. In this section, I introduce the six youth who participated in individual interviews, describe the experience of the youth, and show that this experience, dependent on its sociocultural context, is so much greater than what can be defined in medical terminology.

The physical bodies of the youth in my study varied quite a bit. The youths' characteristics that fall outside the physical norm include the absence of arms or legs, paralysis, and lack of muscle strength, coordination, or balance. From early on, the physical experience of youth with orthopedic impairments is different. Parent and youth interview data suggests that toddlers and children with orthopedic impairments struggle to become mobile, often undergo corrective surgeries, and sometimes lose function they once had. The physical is framed by and contributes to the social experience.

Joaquin

Joaquin learned to walk after intensive physical therapy and a surgery, learned to talk more clearly with speech therapy, and will continue to use concentration to manage other physical tasks that seem effortless to the average person.   The expectations of Joaquin's parents and therapists, sociocultural ideas, impact his physical experience. In learning to speak more clearly, Joaquin increases the likelihood that he will more easily access communication, an example of how his physical ability contributes to his social experience.

His mother, Teresa, learned that Joaquin had cerebral palsy only after relatives began asking why he did not hold his head up and why he did not sit up straight. She quit her job in order to devote her time to helping Joaquin's development. Her income was sacrificed as an investment in Joaquin's health. She described the effort it took to teach him to walk when he was four. Her attention and demands would truly impact the way Joaquin would learn to move. After he had taken his first steps during therapy, he went home and went back to his hands and knees. Teresa told him he was not allowed to crawl. She remembered telling him, "I'll hit you if you crawl." To avoid physical punishment, Joaquin worked to conform. This is yet another way that his physical experience is framed by the social.

When Joaquin was a middle-schooler, he had surgery that would eventually make walking easier for him. Teresa said it was "to straighten out his feet. They were going out. When he stepped, he stepped on the side. So they made 'em flat. Any little rock he stepped on, there he went 'cause it unbalanced him. So they straightened them out."

Before the surgery, Teresa said she told Joaquin to really concentrate on his walking. "Sometimes he's looking one way and walking the other and that's when he trips. I go, 'You gotta concentrate on where you're going.' And yeah since he had his operation, he hasn't been falling that much and he's been concentrating more on it." The physical ability to walk more steadily impacts how he socially interacts with his environment, including but not limited to the confidence he has, the way others view him, and the type of transportation that will work for him.

Teresa described Joaquin "holding a glass of water," needing to concentrate on not spilling it when others do it without even thinking. She said, as a person with a disability, "you have to concentrate more on things that come natural to you. Like if you hold a glass of water and drink it, it's easy. But if you have problems with your hands to get it, you have to concentrate and make sure it's not gonna spill." For Joaquin and many other youth with orthopedic impairments, the focus needed for physical tasks of walking, keeping balance, speaking clearly takes an extraordinary amount of attention.

To Joaquin, earning a degree, getting a driver's license, having a good social life, getting a job, and falling in love took on great importance. He also spoke about what his parents wanted for him:

> My parents want me to finish school, to get a nicer paying job so that I
> can make a good living all by myself. Then, meet someone special
> and get married and have a family… To buy a nice house…
> I seen my brother doing it and all my cousins. They actually tell me
> they want to see me like that. So, they kind of feel happy and relaxed
> about my future.

In a separate interview, Joaquin's mother outlined what she envisioned and then described conversations she had had with him about getting married. In the dialogue she imitated, Teresa laughed at the way Joaquin teased her about how he could have a baby before getting married.

> "Even if you don't have a high paying job," I told Joaquin, "As long as
> you are working and you enjoy the work you are doing then, you can
> concentrate on getting married."
> And he goes, "What if I give you a granddaughter right now..."
> And I go, "No that's OK. I don't need a granddaughter right now."
> The main thing is will he get married. "You think I'm gonna get
> married? You think I'm gonna have children? You think I'm gonna
> have a girlfriend?"
> I go, "Joaquin, you can…It's up to you. Don't think you're gonna
> have a girlfriend tomorrow or in two days, it takes time…Nobody
> knows if they're gonna get married or not. You know, nobody knows
> if they're gonna find a girlfriend or boyfriend or what not. So, it's no
> different with you."
> But he's been telling me, "In a week or so I'm gonna bring Marlene,"
> and I go, "Who?"
> "It's Marvelene. You'll find out in a week."

Teresa pointed out that her son's biggest concern about the future was wondering if he would get married. She said she advised him to first focus on making a living and then encouraged him to think positively about it. The conversation she

described painted a picture of her light-hearted encouragement and Joaquin's good-natured teasing in response. Although Joaquin addressed the topic with humor, his questions implied that he believed he might encounter barriers that would make reaching the goal more difficult for him.

While I set out here to describe Joaquin's physical experience, this description illustrates the importance of sociocultural context. Without the consideration of the demands, expectations, and attention of his mother, and of the messages he received about what it means to have a disability, our understanding of Joaquin's experience would be quite limited.

Salem

Nadia recalled that Salem's body changed dramatically during childhood. When a teacher noticed differences in the way Salem moved, his parents consulted specialists and learned that Salem had Duchenne Muscular Dystrophy, a condition that generally causes loss of muscle and a shortened life span. She recounted:

> It was hectic for me because for like two or three years I've been
> taking him to the doctor to find out what's going on and Kaiser said
> he's a normal kid. I knew something was wrong because between
> Ronnie and Salem are only eleven months. And I could tell Ronnie's
> younger than Salem and he can jump and climb and Salem can't.

Having been active in karate, soccer, and baseball, Salem experienced the loss of his ability to play sports. When Salem was 12, his soccer coaches said he was falling too much to continue playing. Nadia said, "He's stronger than other kids [with Duchenne] probably because we kept Salem active." Beyond feeling the loss of strength, Salem must have been crushed as the decision that he could no longer play

was made for him. Here, the physical impairment becomes the justification for social exclusion. Often, it's the social and emotional struggles following impairment that are more difficult than impairment itself.

Now, as a young adult, Salem uses a power wheelchair for mobility. His family helps him get in and out of bed, bathe, and dress. Salem said his physical experience is different "because I can't really live on my own without somebody else living with me to help me. So that's kinda the only thing that's different is that point of having to have help all the time and not being able to move out of the house." Aware of society's value on independence, I was not surprised when Salem told me he worries about becoming a burden.

Salem said he has an aide at school, "He just makes sure that I got all the papers I need and all the books and everything is in my reach. If I drop something, he can get it for me because I can't really reach it because the wheelchair is so high." Salem's physical reliance on his family and his school aide influenced his social interaction, his opportunities to establish new friendships, and the organization of his daily schedule.

In choosing a career path, Salem considered his physical ability. He explained his plan to become a graphic designer, a professional who uses a computer and needs not to have great physical strength, saying, "It's something I can do and it's something I enjoy doing." He worried some about losing the strength to write. This concern centered on what the loss of strength would mean for his career.

Like many disabled youth, Salem understood how surgeries impacted his physical ability. He reported on his back surgery, "Before the first surgery, I used to be able to move a lot. Like I could get from here to my bed or from here to the toilet; and then after the surgery, it cut everything. I can't get dressed anymore by myself. Sometimes I can't even scrub myself. I can't even do anything anymore like get out myself when I'm taking a shower. I need a lot of help getting my food or getting things set to the right height so I can reach it or whatever." This situation may warrant mistrust in the judgment of medical professionals or, in the least, a frustration at having lost mobility while undergoing a surgery intended to improve posture. In this, the advice of medical professionals impacts Salem's physical abilities, which in turn impact the social dynamics of his family as they come together to assist him.

He further described the attempts made to straighten his spine using rods, "The first surgery didn't go right because the rod broke, and then they had to do another surgery and still the screw, now the screw is broke or moved out of place. So, I don't know, that's about it." Salem said he still experiences back pain often.

Again, Salem's experience lay within a particular sociocultural context. In addition to having the experience of losing muscle strength and feeling back pain, Salem had to negotiate his mother's view that something was "wrong with him," the loss of the social connections he once shared in playing sports, the search for new interests and social connections, the development of relationships with care providers, and changes in what would be expected of him.

Thomas

Thomas's experience with becoming mobile has involved using particular tools and undergoing major surgeries. His parents described their efforts to help Thomas learn to walk. During the process, Thomas's dad crafted shoes with lifted soles that would compensate for the way one of his legs turned. As Thomas grew, new modifications were made. Aside from the shoes, Alice said, "Robert did a lot of building things, a stand for his computer, things to help him in the classroom, just little tools that would help him." Without arms, Thomas's ability to reach for things became possible with the use of a grabber.

When Thomas began school, an aide was appointed to help him within a regular classroom. Alice told, "By the time he was in third grade, at one point, he told the aide that he felt she was hovering too much, that he didn't need her and to go away." From that point, the only special education assistance he requested was in using the restroom. At this early age, Thomas rejected differential treatment that was not necessary. Thomas's physical differences qualified him for special education services in the form of a classroom aide. Perhaps his rejection of the aide's assistance created a space where he could further develop his own physical abilities.

Because of the difficulty he had with walking, his parents considered that removing the turned leg could improve mobility for him. After much deliberation, they decided to have the leg removed and have Thomas fitted for a prosthetic leg that would make walking more manageable. The deliberation of Thomas's parents and

doctors, a social interaction, had great effect on Thomas's physical experience in that he would undergo major surgery and learn to use a prosthesis to walk.

Years later, they saw his prosthesis as a source of independence, but also as the one thing he needed assistance with. Alice said, "You know, he needs help with putting on his prosthesis in the mornings. He's getting more and more independent, but that's one thing that he can't do. He can't take it off; he can't put it on. But he has friends that are learning how to do that. He does sleepovers a lot. He's got three friends that do that for him now."

Thomas also acknowledged having difficulty with the prosthetic. "I can put pants on and I can put a shirt on. Problem is, you gotta have legs on to do both of those things and I haven't figured that out yet." When Thomas considered his progress, he reported that personal care has been an important issue for him. As he has gotten older, he has learned ways to do more. He said:

> I'm able to take myself to the bathroom now. I could not do that for
> the longest time, 'cause one, I couldn't reach my pants, and two, I
> wasn't strong enough to pull down, even with a stick or something like
> that. I just wasn't strong enough to do it. Now that I am, I can go over
> to friends' houses and I don't have to call my mom, you know, or ask
> someone at the house, 'Hey, I need help with the bathroom!' You
> know? I don't have to do that anymore.

Having the physical strength and a strategy for using the restroom independently gave Thomas a new sense of liberty, a greater freedom to socialize with his friends. In addition to using prosthetics for walking, Thomas considered the power wheelchair he got when he was an eighth grader to greatly improve his mobility:

> With the chair I have now, I can do a lot of things. I've taken that thing
> probably five or six miles. No problem, it just does it. And that's a big

thing, 'cause I don't have to go, 'can I get a ride to this place?' I can take my chair. And I can walk with friends there, 'cause they can walk. They walk that far. So if they're doing something like walking down the street to Jack in the Box or something like that, I can go with them now, as to where usually I'd have to get a ride.

Thomas did not see the use of his wheelchair as the end-all solution to his mobility needs. "Driving," he said, "I think might be difficult. We've been trying at that for some time now and it's like they don't know we're around. People don't like to return phone calls or emails or any of that." He tried to begin the process of finding a driving specialist who would help determine what equipment he could get to drive his own vehicle. He said he didn't expect this process to be easy. "You have to find the adaptations and stuff like that, so that could be a problem." Finding specialized resources requires incredible persistence.

Thomas's experience, like that of the other two boys, happened within a particular sociocultural context. While functioning without arms and undergoing major surgeries, Thomas negotiated the use of personalized tools, feelings associated with depending on others for dressing and using the restroom, the development of friendships with youth who could walk farther than he could, and the need and hassle of specialized services.

Alejandra

At the age of nine, Alejandra acquired a spinal cord injury in a car accident that killed her father. Her experience since that time has been quite different than what her parents had imagined it would be. She has undergone surgeries and has dealt with ongoing pain. She has learned to become mobile again using a manual

wheelchair and has received assistance with personal care from her mother and from friends. Alejandra said one of the things she missed most about walking was being able to visit her cousins who lived up a long flight of stairs. The inability to walk upstairs becomes problematic when no elevators are available and when one's greatest social outlet is at the other end of the stairs.

For years after her injury, Alejandra relied on others pushing her wheelchair and then, as a teenager, worked to build strength to push herself. She listed "being independent" among her goals in life along with getting a bachelor's degree and a job, having a family and a house, and learning to drive. Mariana, her mother, an immigrant from Mexico, said she would like to see Alejandra be more independent, but imagined she would most likely always need help. She said:

> There does not always need to be somebody behind her pushing her.
> She's going to have to do it by herself. Because of her disability, I
> think that somebody's always going to be behind her; but, I want her
> to put in her mind that there isn't always going to be somebody behind
> her.

At this point though, Alejandra was not concerned about how she would get around. Instead, she wondered about how she would physically be able to cook and whether she could have children. Alejandra feared that her pain might be an issue when she wants to start a family, "I know you're not supposed to take medicine for pain when you're pregnant. But I don't know; then again, I've met people that have been in wheelchairs that have actually had kids, so that means I can do it too." Having knowledge of others' experience gave Alejandra reason to hope she too might have children. Alejandra's recent social access to disabled adults and knowledge of their

abilities changed her tendency to accept physical assistance without question. She instead tried more often to do physical tasks independently.

Mariana admitted that she helped Alejandra with tasks that she could do independently. She said she helped her get dressed, explaining, "When she does it, she takes a long time to do it. And I just can't stand to wait, so that's why I just do it, because I can't wait. She takes so long. And I understand with that disability that any person would take their time. That's the way it is." Rather than having Alejandra's ability determine what tasks she could do, her mother's inability to wait became the deciding factor.

"Sometimes she thinks I can't do certain things, but I can. It's just she likes doing them for me," Alejandra said about her mother. "I can push myself. I mean there are situations where I can't; but most of the time, I can." She continued to itemize her own personal care abilities, physical abilities that come head to head with her mother's cultural beliefs about giving assistance. "Also, I can cath [catheterize] myself and she insists that I can't, even though I do it at school every day. I need little assistance getting in and out of the shower… it's just that she wants to be there just in case because I have fallen before." She accepted her mother's desire to help as somewhat reasonable. Still, Alejandra saw new physical abilities, pulling up her pants, changing her clothing, showering, as progress she had made in becoming an adult.

As she looked forward to her upcoming high school graduation, Alejandra explained that she might have intestinal surgery. Losing abilities and having to regain them seemed to be Alejandra's biggest concern. She sighed, "And that's kinda scary. I'm kinda not sure 'cause I think, 'Surgery again to open up my stomach and my intestines again?' It's like going all through the whole process and so I'd have to start over." The unpredictability of the outcome and probability of losing strength with a surgery would make most of us feel perplexed and discouraged.

Alejandra and her mother have compared the similarities and differences in their lives as young women. Alejandra told:

> She said she had a lot of fun in her younger years. She used to dance a lot. That's one thing that she's like 'You're not gonna have that. I mean you can go to dances or whatever clubs, but it's not gonna be the same as when I did it. Then again, it's rock 'n roll.' Yeah, I don't know.

Her mother's physical ability differed, giving the two of them reason to initially imagine Alejandra's experience at dances and clubs would not be as much fun. Then, her mother considered "it's rock 'n roll," insinuating that even the type of music playing would change the context of dances and clubs anyway.

When Alejandra acquired her injury, her experience shifted within its sociocultural context. Her injury meant not walking, but also being closed off from regular interaction with her cousins. Alejandra had to negotiate building strength and skill to get around, to dress, and to bathe, but also had to negotiate her mother's concerns and her own ideas about independence signifying adulthood.

Erica

Erica's mother, Janice, recalls that her daughter, born prematurely, did not reach certain developmental tasks as typically expected. She did not sit up or crawl when other infants did. As a teenage mother, Janice says she did not worry that her daughter would not be able to walk.

> I'm not thinking she's gonna grow, that she's gonna get bigger, and she's gonna gain more weight. And so I'm not thinking about how, if I have to carry her for the rest of her life, how it's gonna affect me. I'm thinking, 'Oh my God, what if this child never speaks? How am I gonna know and meet her needs?'

To Janice's delight, Erica began putting sentences together when she was just a year old; and eventually, she learned to sit up on her own and to crawl. Doctors said that Erica had cerebral palsy, that her premature birth had caused it. Janice said, "If I had known that stress would have caused her to come early, maybe I would have taken more precautions on my stress level." After having a better understanding of what this diagnosis would mean for her daughter, Janice felt relief, "Once I realized that it wasn't that unbearable, I think I was okay with it. And when it's compared it to not having her at all, I was totally fine with it." Doctors used the social context of a stressful pregnancy to explain Erica's physical impairment. Her impairment would come to impact the social dynamics of her family life and her life beyond the family.

As a sixteen year old, Erica still had the ability to crawl, but mainly used a manual wheelchair for mobility. She dreamed of going to college and moving out of the house. The idea made her giggle. She said, "I don't want to live in my house no more. I want to be independent. I don't want to have my mom help me all the time,

especially now that she's getting older and its getting harder for her to help me and stuff. I just wanna move out on my own, and be independent and stuff."

While Erica's mother seemed slightly annoyed that her daughter did not have a specific career path in mind, Erica seemed more concerned about where she wanted to live. She told me, "Me and a friend are gonna share a dorm, so that's pretty cool. And then, prolly me—after me and my friends graduate from college, we're gonna get a three bedroom house and have our own place and just… live life, basically." In this, she acknowledged her goal without showing much understanding of what it would take to reach it.

Realizing that she relied on her mother's assistance, she hoped to someday have roommates who would help her. She did not know how she would manage transferring to the bathtub without her mother's help. "There might be some things at first that might get hard. But, maybe being, me getting in the tub or stuff like that might get hard at first. But I'll have to get used to it." She added doing dishes and laundry to the list of what might be difficult for her to do. Erica's social goals to move out and be independent of her mother loomed large as she thought about her physical abilities and the tasks with which she would need assistance.

Janice saw her daughter's dependence on her as a larger hurdle to jump. She questioned, "What if I was to drop off the face of the earth tomorrow, you know? I mean, that's just a daily concern." She imagined the barriers her daughter would face in moving out, "She'd have to get a handicapped accessible place; and, there's not a thousand of them around, you know." Aside from her knowledge of Erica's more

obvious needs, Janice shared her concern about more subtle needs. She described an

event where she had to exercise not fulfilling her daughter's need to have her food cut:

> I could see her through the window. And I'm going, 'Those are
> enchiladas. There's no way she can cut those herself!' And I'm like,
> 'I'm not allowed to go in there.' I was tapping my fingers on the table,
> and like finally, I see her go and ask somebody for help. Then they
> shut the blinds, and I was like, 'thank you' 'cause this was hard. She
> just needs help cutting her food, you know?

Janice's understanding of her daughter's physical needs led her to be always

ready to assist. Her ready assistance might have kept Erica from learning to advocate

for herself, save the social intervention of events like this one. As Erica gained

experience in asking others for assistance, she also gained experience in asking how

she could assist others when she took her first job, working at a toy store. She proudly

explained, "I do customer service and I unpack toys and I take them out to the shelves

and put them up on the shelves." The job was not easy. She described how difficult

some physical tasks could be:

> Trying to put the toys on my lap and trying to push at the same time
> with all the other toys on my lap, 'cause they drop all the time. And
> sometimes unpacking the boxes is kind of hard 'cause then the stickers
> rip or something. So I'm over here trying to hold it with one hand. I'm
> like, trying to— and it comes off and it rips. I'm like, 'Uhhhhgh!'

In this, Erica described the physical difficulties of holding the job. She later

told me about a more dramatic problem. When her mother received a call from a

teacher about Erica not turning in homework, she rashly demanded that she quit the

job. After her mother calmed down, Erica, embarrassed, called to ask if she could

return to work.

The physical characteristics used to describe Erica would tell little without the sociocultural context of her life. As Erica experienced a delay in some developmental tasks, she lived with love, acceptance, and often, emotional extremes of a teenage mother. As she became mobile using a wheelchair, she saw possibilities for gaining more independence and dreamed of moving out despite her mother's worries. Even though Erica juggled the physical tasks of her job and haphazardly negotiated her mother's demands, she gained pride through her ability to contribute.

Katie

As an infant, Katie acquired a spinal cord injury and has lived the majority of her life with quadriplegia. For Katie, becoming mobile, learning ways to negotiate physical tasks, and needing assistance are a large part of her physical experience. From the time she was small, her family found ways to include her in family outings to the beach. She participated in wheelchair sports, most loyal to her wheelchair soccer team. For mobility, she used a power chair and learned to take the trolley to the university when she began college. Her family's social desire to include her gave Katie physical access to many places. The close proximity to wheelchair sports team gave her the ability to play soccer. These physical abilities then contribute to her social world and her view of possibilities.

Relaying her dreams, Katie said she wanted to get a bachelor's degree in English and become a book editor or publisher, live on her own without parents, and travel on her own. When she thought about moving out, Katie said, "I just have to find ways to become independent first before I can do that." Katie's family provided

assistance to her with personal care: dressing, bathing, using the restroom. When she wanted to attend college away from home, her parents convinced her to stay close. She reasoned, "If my power chair broke down, it'd take six hours for them to come up and help me rather than just 20 minutes from work." Even though Katie bragged about how supportive her parents were, she understood that her experience was much different than her parents'. "Like my mom could live in the dorms when she was younger and I would have more difficulty with that."

Katie knew that living on her own and traveling on her own would mean hiring a personal assistant. She said, "No matter how much I want to be independent, I know that there are some things I cannot do without a person helping me." She felt good about a couple of trial runs she had. At one time, her family went out of town for a couple days and arranged for care attendants to assist her. Katie said she was hesitant to have strangers help her, so she asked a friend to sleep over. On another occasion, she hired an attendant to travel with her to New York for a soccer tournament. Katie said, "I had to make sure I found the right person and personally meet her and talk to her instead of just having my parents meet her and such. So that was interesting. And just being out on my own in New York was really fun, you know." Here, we can see how Katie's impairment gave her a sense of vulnerability, a sense that she would need to be extra cautious to protect herself from abuse or disaster.

Having listened to warnings from others, Katie and her parents worried about potential hazards of living alone. "I may have to have a roommate because what if there was a fire and I had no one to help me get out of bed or at least help open the

doors so I could crawl out or something. So that's another thing that's scary about independent living is that you have to face that stuff. You know that you can't live on your own 100%." Describing her parents' concern, she said, "Like they really worry about you know if I'm off somewhere and my chair flips over you know I'll be like stuck there in the middle of nowhere type thing."

In starting college, Katie found a number of physical barriers. Primarily, she found herself in classrooms and lecture halls that had inadequate accessible seating "where all of them are desks and there's no tables, so you have to kinda like use one of the desks as a table and hunch over." She said she learned that you have to tell people what you need rather than expect them to know. Katie found that she physically could not keep up with note-taking in her chemistry class. "Like I would try to do it by hand and he would say it'd be on the PowerPoint; but, the PowerPoint didn't have all his notes 'cause he would do some of them by hand…It was hard to pay attention and do the writing at the same time and that stuff." In addition to inventing ways the handle the classroom environment, Katie had to figure out what to do when she needed restroom assistance while on campus. These are prime examples of how the physical and social converge.

As Katie set out to find a summer job, she encountered challenges as employers did not see how she could do the jobs. Although she did not get hired at a retail store, she began to visualize how she could do the job. She argued, "I can't do cash registering, but I can still do other stuff in the store like fold clothes, you know, organize things. Especially with my new chair where I can go up and down too." She

saw that her new wheelchair, with its hydraulic lift, could make stocking merchandise easier for her.

Planning ahead for the day she has a career, Katie began asking Department of Rehabilitation to assist her with driving instruction and the conversion of a van. Like Thomas, Katie found resistance. "They won't do it right now, because they said they have to rule out every other mode of transportation." She knew the process of getting licensed would be extensive and expensive and complained, "I've heard just the evaluation is as expensive as a regular person's driving class, so that's not fair." Katie found that social bureaucracy and the availability of resources played a large part in determining whether she would someday have the ability to drive.

Like those of the other youth, Katie's physical experiences cannot be described outside of sociocultural context. This context mediated her experience of using a wheelchair and receiving personal assistance and gave place for negotiating situations that required self-advocacy, attention to safety concerns, and an understanding of policies and cultural practices that seem unfair.

Chapter Conclusion

As we can see in the brief descriptions of these youth, disability experience extends well-beyond impairment. We see how the physical is framed by and also contributes to the social experience. We see many ways that environment affects individuals' abilities to live well and participate in society. Although the experience of each of these six youth is unique, one cannot discount the commonalities, the various experiences shared by many youth with orthopedic impairments.

Many of these young people speak about their physical experiences in terms of dependence in doing activities or in terms of dangers of being unable to handle some disaster or accident. Of course, they do not recognize that independence is always a fiction. They rarely acknowledge that their dependencies are merely versions of the wide range of dependencies that all of us fail to acknowledge or learn to hide out of shame.

Many of these young people speak about learning to accomplish tasks in terms of overcoming barriers. While overcoming barriers in learning is not unique for disabled youth, it is the need to invent ways for their own particular abilities that makes this experience stand out. Although the modeling of parents and teachers is still beneficial to disabled youth, it often leaves youth to invent a new way that works for them.

Many of these young people speak about their relationships with family and friends and hint at the complexities in receiving assistance from them, and in finding access to the places where relationships typically develop. The give and take interactions of these relationships often fall outside of the norms of what friends and family typically do for each other. Negotiating these interactions marks yet another arena in which many youth lack effective models.

The findings and analysis in Chapters V, VI, and VII delve deeper into the sociocultural experiences of disabled youth. Chapter V., Conceptions of Disability in the Shaping of Youth's Identity: Why Educators Must Engage Modes and Discursive Frameworks explores the influences on youths' conceptions of disability and the

discursive frameworks commonly used to make sense of disability experience. In it, I examine the various influences on youths' conceptions of disability and discuss some of the discursive frameworks that help shape their conceptions. Conceptions of disability are always in process (for all of us—as people with varying abilities and people who interact with others whose abilities differ from ours). If we are conscious of this we can better see our conceptions of disability as a site for active engagement rather than unconscious acceptance. Some of the main contributors to how youth come to understand disability include parent beliefs, peer beliefs, medical professionals' advice, teacher practices, media depictions, social policies and practices, and disability community. Discourses of normalcy, independence, hierarchy, and claiming disability show considerable impact on youth. In this chapter, I consider ways we might teach students to be critical of this discourse.

Chapter VI. Negotiating Difference in the Development of Relationships offers a discussion of how the negotiation of physical and social barriers impacts the relationships disabled youth have with family and friends. For disabled youth, an awareness of one's own difference develops early and remains as a part of one's identity. This aspect of identity impacts youths' development of relationships with family and friends, in that youth and those they interact with perceive those marked as different to hold particular social roles. In this chapter, I explore some of the common understandings that develop within families of disabled youth, some of the strategies disabled youth use to navigate barriers to friendship, and the negotiation of assistance within these relationships.

Chapter VII., Seeing Capacity and Supporting Agency: The Impact on Disabled Youth provides an examination of potential outcomes for those who do and do not receive support in developing agency, followed by a discussion of how educators might work to support agency by seeing the capacity of disabled students.

As we work to create a more equitable system for all, including disabled youth, issues of power and agency must be examined and questioned. In my work with youth with orthopedic impairments, I have seen how the power of disabled people has been limited as others wrongly place them in positions of incompetence, inferiority, and submission. This chapter challenges schools to create environments of inclusion, interactive and interdependent places where everyone's experience and contributions are valued. I argue that we must create a pathway of seeing ability, an opportunity for all youth to know the abilities they possess.

V. Conceptions of Disability in the Shaping of Youth's Identity: Why Educators Must Engage Modes and Discursive Frameworks

How important is disability in the determination of a youth's identity? If she or others view her disability as "a defect" as opposed to "a variation," how can she, as a person with a disability, define herself? How much can one's conception of disability impact the life she lives?

For disabled youth, how one thinks about disability has heavy consequence. Figure 3 illustrates this consequence. Conceptions of disability color a youth's view of self and therefore influence self-expectations and life goals.
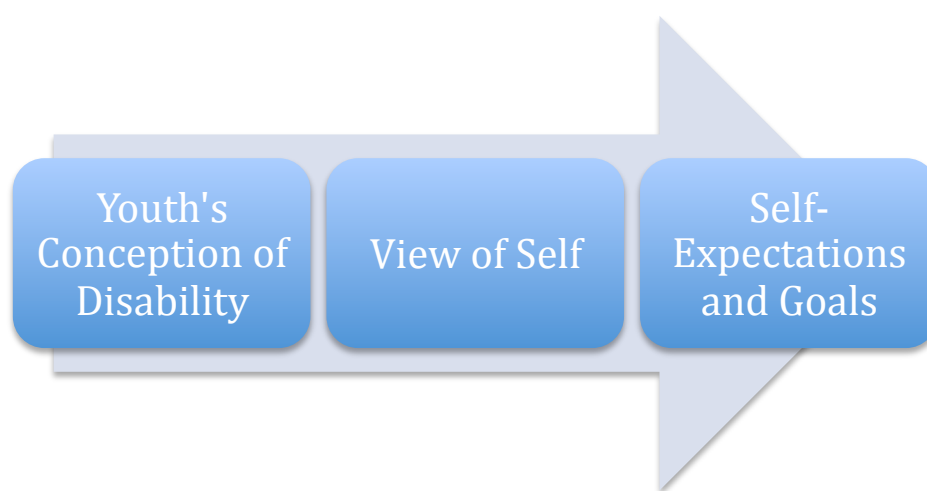
Figure 3: Progression of Identity Development for Disabled Youth

This chapter will examine the various influences on youths' conceptions of disability, discuss some of the prevalent themes that arise in their conceptions, and then explore the ways in which these themes must be critically examined as educators work to improve outcomes for disabled youth.

Influences on Youth's Conception of Disability

Disabled youth encounter a wide range of beliefs about disability; and, somewhere along the way, they develop their own conception of disability and what it means to be a person with a disability. An important corollary of this is that conceptions of disability are always in process (for all of us—as people with varying abilities and people who interact with others whose abilities differ from ours). If we are conscious of this we can better see our conceptions of disability as a site for active engagement rather than unconscious acceptance. As shown in Figure 4, some of the main contributors to how youth come to understand disability include parent beliefs, peer beliefs, medical professionals' advice, teacher practices, media depictions, social policies and practices, and disability community.
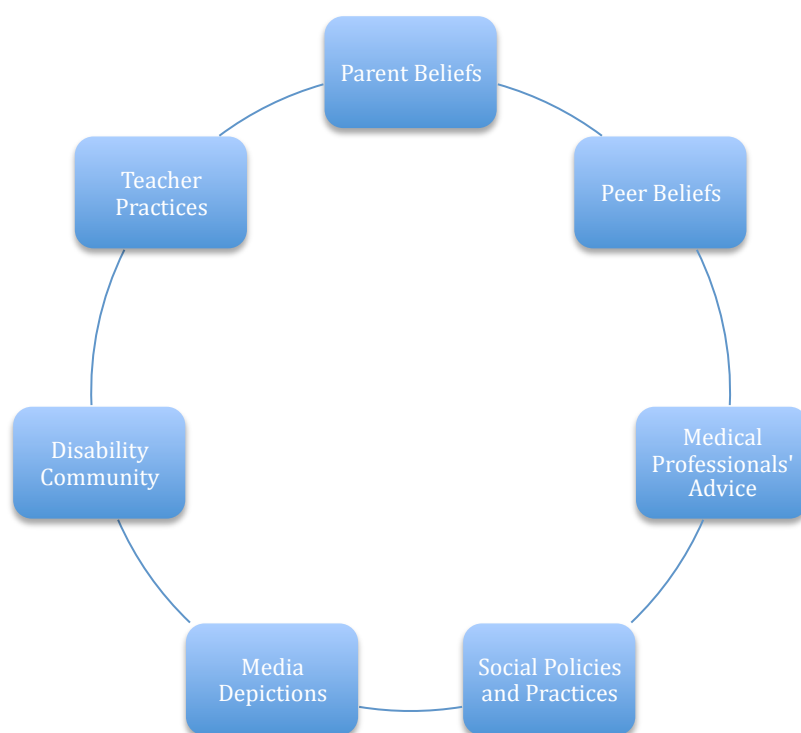
Figure 4: Influences on Disabled Youths' Conceptions

In looking at these seven influences, I believe what may be a strong influence on one individual may be a minor influence on another individual. Parent beliefs and social policies and practices seemed to be especially powerful to the youth I interviewed. I reserve teacher practices for last and give it special attention in an effort to highlight the impact that we, as educators, can make in the lives of disabled youth.

Parent beliefs

The beliefs of parents have a major influence on the conception of disability that youth develop. Although parent beliefs do not determine youth's conception, we cannot ignore the influence parents have on young people's self-concepts. With changing experiences and feelings, parents' beliefs and ways of interacting change. Youth can waver in their beliefs, as well, taking on some of their parents' beliefs as their own and/or rejecting some of those beliefs. Youth and parents interviewed in this study show a dynamic sense of disability and both agreement and disagreement in understanding. To illustrate, I will give a few examples:

Joaquin's mother, Teresa, has shown through many of her actions that she believed that disability is a part of life, that disabled youth need to learn to be tough, need to be responsible for including themselves, and that pity is not useful. Even as she tried to stress these beliefs in raising Joaquin, Teresa's daughter accused her of coddling Joaquin. Joaquin has seemed to develop a conception of disability as a natural part of life. He believed that even though disabled people needed to prove themselves, they could be independent. Still, he questioned whether others would

accept him and whether he would find someone to fall in love with, a goal he held as high priority.

Thomas's mother, Alice, expressed a belief that disability is a challenge to overcome. She conceived that disabled people must work extra hard because discrimination was a big issue. These views, like those of most parents, were not static. When Thomas was born, Alice briefly considered taking money from the ATM and running away. And over the years, she has shifted back and forth in figuring out how much attention to give her son. Thomas rolled his eyes as he considered his mother's worries. He believed that with persistence disabled people could become independent. He said disabled people should do "whatever works," should strive to function "no matter what it looks like."

Alejandra's mother, Mariana, conveyed her sense that disability means dependence, and yet, another sense that disabled people can lead full lives. In one conversation, she said that she would like disabled people to accept help from others. Shortly after, she said she did not want to hold her daughter back. Alejandra said her mother told her she could do whatever she wanted in life. Then, she complained that her mother wanted to do too much for her. Parents and youth can find it difficult to enact a consistent understanding, because our ideals and our everyday experiences do not always fit neatly together.

These are at best sketches of tendencies that certainly include many nuances and complexities that constitute familial negotiation of the meaning of disability that is difficult to disentangle from the fabric of domestic social life. What they make clear

is that discourse on disability in the home covers a spectrum of positions and is an important site for framing young people's views outside the home and as they transition to adulthood.

Peer beliefs

The beliefs of peers impact the conception of disability that youth develop. As peers influence youths' thinking on a wide variety of topics, their thoughts about disability largely contribute to youth's conception of how disabled people fit or don't fit in the world.   Disabled young people often field questions about ability from their peers, and learn from the various reactions (i.e. shrugs, wrinkled noses, smiles, frowns, shared stories, pats on the back) they receive. Some peers teach that disability is not grounds for exclusion within certain contexts, but that it is in other contexts, marking some activities as off-limits for disabled people.

Ali shared that, as a child, his peers made fun of him and often left him out. As a young adult, he described how he explained his disability to new friends as a way to make sure he doesn't "put them in a position where they get upset about my disability." The beliefs and actions of his childhood peers may have led Ali to believe that disability is not acceptable, but may also have given him strategies for finding acceptance. Ali views his disability as something that will not go away, and therefore, as something to be upfront about.

Thomas said that his childhood peers questioned him, but now "They don't notice anymore." He went on to say, "I don't think I've had anybody in high school come up to me and ask 'What's wrong?' But I've had people who keep a distance or

watch me when I go by or get out of the way when I'm going down the hall, different things. You can tell what they are doing; they just won't say it. It's kind of a nice way of alienating you." In this, Thomas saw disability as something that would commonly and subtly separate him from many of his peers.   The experience or appearance of rejection from peers, for Thomas and other disabled youth, can lead youth to withdraw, but can also lead youth to develop strategies for finding acceptance and making friends.

When Joaquin was in high school, he enjoyed the sense of protection he received from his group of friends. His mother warned his brother not to tease or pick on Joaquin at school; because, these friends might retaliate if they did not realize who he was. The support and respect given by friends can strengthen a young person's self-respect and confidence. If others believe he is worth defending, he can view himself as such.

Beyond feelings of acceptance and rejection, peers can show disabled youth their expected place in certain contexts. For example, when I was in high school and spoke to my friends about driving, they claimed that it was very difficult to do and required a lot of strength.   Amanda's high school friends told her that the boy who invited her to the homecoming dance must have felt sorry for her. In this, they tell her not to imagine that the boy liked her.   She later explained, "His parents loved me and I think they talked him into taking me."   In both cases, friends erected boundaries within certain contexts. While these situations appear limiting, others may open opportunities for contribution.   I observed a mural painting project in which a group

of young people divided the work according to who could reach certain places, leaving the lower portion for wheelchair users.

I further discuss relationships with peers in Chapter VI.   In this, I consider the challenges some youth face in building relationships and the strategies and narratives they develop in the process.

Medical professionals' advice

The advice of medical professionals impacts the conception of disability that disabled youth develop. Doctors, nurses, and therapists, viewed by many as experts on disability, are often trusted and left unquestioned in regard to what is to be expected of disabled people. Suggestions to avoid certain activities can create a view of limited possibilities. Conversely, suggestions to get involved in activities can create a view of wide possibilities. Therapies and surgeries can create a picture of disability as something that needs to be cured.   During any interaction, the attitudes of medical professionals can convey to those with disabilities and those without disabilities that disability is natural or abnormal, something to embrace or something to fear, manageable or unmanageable.

Medical professionals and institutions also play an important mediating role in the relationships among family members, setting up expectations and framing decisions in ways that suggest particular dynamics among parents and young people. Not insignificant in this respect is the centrality and visibility of issues of consent in medically mediated therapeutics and treatments. This overlaps with the next set of factors, social policies and practices.

Social policies and practices

Social policies and practices, including formal laws, informal rules, and everyday practices of people, influence the conceptions of disability that youth develop. Consciously and unconsciously, youth interact with these policies and practices and learn from them.

The youth who participated in this study have lived all or most of their lives after the passage of the Americans with Disabilities Act (ADA) of 1990. With this comes an expectation to be included and an understanding that disability is a category protected under the law. If youth see a lack of enforcement of the law, another understanding may develop.

Informal rules also govern the inclusion and exclusion of disabled people in social activities. For example, one youth told me that high school boys do not date girls who use wheelchairs. Another example, one mother explained to me that people with muscular dystrophy should not be left to cross the street alone. Other informal rules might include always being polite, offering help, or allowing cuts to the front of the line to disabled people. Whether benevolent or not, these rules send a message about what disability means. During one focus group, youth compared stories about the different ways people approach them. Amanda mentioned the way parents tell children not to ask her questions, "like you're an extraterrestrial from Mars," she said. Kelly told about someone giving her prayer beads, telling her if she really believed, she'd walk. Thomas laughed about comments he has heard, "It's really nice to see you out," and "I thought I had it bad, but I feel sorry for you."

Everyday practices can also be considered social policies that help construct what disability means. Some youth must adopt annoying practices like taking the long route due to a lack of accessibility. Some adopt the practice of caring for younger siblings after school. Yes, even those practices that seem to have nothing to do with disability can impact how youth come to understand disability. For example, if one cares for younger siblings, she may come to understand that disability does not take away one's sense of responsibility.

Media depictions

Media depictions, including books, magazines, TV programs, movies, and advertisements, can color the conceptions of disability that youth develop. Surrounded by media images, youth can see what is valued in our society, as well as what is not valued. Images of disability appear sometimes; and when they do, generally, the depictions are stereotypical. These depictions often portray disabled people as: objects of pity; sub-human organisms; sinister or evil; unspeakable objects of dread; the holy innocent; objects of comedy, ridicule, and curiosity; or burdens to others (Shapiro, 1999). Unfortunately, positive, nuanced and complex representations of disabled people are few and far between. The news media use disability as a metaphor, often depicting negative connotations. As one example, news media covering the Inauguration of Obama in 2009 focused some attention on the out-going Vice President Dick Cheney's use of a wheelchair at the ceremonies. Primetime news commentator Chris Matthews said, "And I can tell you again that metaphor here of the Vice President in that wheelchair – it is a metaphor for the low esteem with

which he's held in this country. His numbers are pathetically low." Too often, "low" is associated with disability. This is just one example of the many ableist messages that pervade the media and go unnoticed by the general population.

Disability community

And finally, if youth have access to it, disability community can positively impact the conception of disability that youth develop. While there may be many ways in which people define disability community, I refer to it as the interactions one has with others who have disabilities. There are a variety of ways youth might meet and take part in a community of disabled people, commonly childhood camps, wheelchair sports teams, activist groups, and in the case of these youth, a mentoring program. The youth who interviewed in this study said that meeting other disabled people changed their view of disability, made them feel like they were not "the only ones," and helped them to see more possibilities for themselves.

Important in this regard is the role that others with disabilities can play in supplementing the understandings that young people receive from parents and others that care for/about them, but who don't have access to experiences that would allow them to help these youth imagine a future for themselves.

Teacher practices

Teacher practices[2], a wide range of intentional and unintentional pedagogical tendencies, help create the conception of disability that youth develop. Teachers have an unlimited number of tasks and responsibilities each day through which they may interact with disability. Teachers are models of inclusive language and practice, or not. And teachers are also mediators of activities among peers. Chosen curriculum can include positive conceptions of disability, can include negative conceptions, or avoid disability issues altogether. A teacher's questioning of stereotypical depictions of disability in textbooks can show an understanding of variation in disability. During any interaction, teachers can convey a view that disability is a form of diversity to be valued or an unwelcome inconvenience, a need for accommodation or a need for kid gloves, something expected or an oddity. Teachers can suggest forms of interaction and participation and set up forms of organization or structure that avoid or preclude them.

Youth who participated in the focus group interviews in this study recalled interactions with teachers. Amanda remembered that, after telling her teacher she wanted to become a doctor, he replied, "I don't know if they have those, doctors in wheelchairs." Another youth, Paloma, said her elementary teachers, assuming her speech impairment signified an inability to learn, did not teach her to read. Both of

[2] Although I specifically discuss teacher practice here, it would be appropriate to consider school practice in general as having such an influence on youths' conceptions of disability. Baker & Donelly (2001) examine a wide range of school factors that impact disabled youth, including classroom seating arrangements, segregation to different classrooms or schools outside youths' neighborhoods, school ethos, the role of the principal and other support staff, etc.

these situations convey a view of disabled people as incapable, a view unforgivably passed on by those who are expected to nurture possibility in youth. However, Adam felt his teachers gave him a positive view. "My counselors and teachers have said good things. They have been helping me out a lot even though I don't really know, don't know exactly what kind of work I wanna do. They think I have good possibilities."

What might be surprising to some is how keen disabled youth can be to how their teachers seem to view disability. I share the following piece from one focus group because of its richness and its quality critique. The conversation revolved around what youth had noticed about the way their teachers viewed disability.

> Thomas: I've had teachers that have come up to me and said, "What do you need? Anything you need, you let me know and it'll happen."
>
> Amanda: Yes. (in agreement)
>
> Thomas: And others, like this year for example, I went into my history class, and the guy stuck me on like the opposite side of the classroom in the middle of the row. And well, that's alright, I can get up and walk. It's just you'd think he would stick me in the front maybe.
> Ya know what I mean? I don't think teachers really have a problem, per se. I just don't think they realize most of the time. It's just these problems are pretty common. You come across a student with a disability after how many years of teaching?

Thomas compared having teachers who communicated with him about his needs with having teachers who do not consider accessibility issues. Thomas did not believe teachers had a problem with disability; he felt they just did not have experience with it.

Amanda: I kinda have a lot to say. I've had some teachers that were absolutely awesome, like my AP English teacher. And luckily, in that class, AP students really want to learn, so I felt like in that class I was most at home. People didn't see my disability as one ounce of a difference. They would give me the same attention that they gave everyone else. They actually listened to me, which was like the most amazing thing that I have ever discovered. My teacher was awesome. He adapted everything I needed and never made a big deal out of it. He wasn't like, 'Oh my god, this person is taking notes for her,' or 'I wrote this off the board for her so she won't have to look up fifty million times and try to write.'"
Then, I've had teachers who have absolutely the worst problem with me. They can't stand to have me in their class. It like ruins their whole, entire day.

Kelly: Yep. (smiling, nods her head)

Insightfully, Amanda acknowledged that the way her teacher treated her impacted the way her fellow students treated her. Amanda and other disabled young people appreciate teachers who make accommodations and without making "a big deal out of it." The acceptance modeled by a teacher can affect the acceptance offered by peers.

Amanda: I had a teacher who used to tell me she wanted me to sit up at one of those really high lab tables and then park my chair across the room. And I was like, "But I can't walk." It was the most ridiculous thing ever.
I've had teachers that fear me.   When I had a physical therapist come to help me adapt the classroom a little bit better, she [the teacher] was shaking and trying to get through it as fast as possible.
And then, I have teachers that see me as mentally challenged, regardless of my IEP. Or I have teachers who never take a minute to read my IEP to figure out what's going on with me or ask.

The frustration of being misunderstood is apparent in Amanda's description. In one case, she was annoyed that her teacher asked her to do something she could not do. At other times, Amanda believed teachers assumed she had cognitive disabilities

too. Most of us have a desire to be understood.   The idea that a better understanding

could come in reading an I.E.P. can be debated. Individualized Education Plans tend

to focus on a student's limitations rather than abilities, and may color a teacher's view

of disability and of the particular student.

> Thomas: There's the teacher who won't stop asking if you need help.
> I mean, it's worse than them leaving you alone, it really is. It's awful,
> because they're like, "You need this? You need that? You need that?"
> If I need it, I'll ask, alright?

> Amanda: Then, that brings on what the class thinks about you. The
> teacher's reaction brings on the reaction of the other students. So it's
> kinda how the teacher acts is how the students are gonna act. It's like
> a whole chain reaction where it's either gonna be perfect or a horrible
> mess.

Thomas expressed frustration about a teacher who continually asked if he

needed help. These youth acknowledged there is a fine line between making sure

needs are met and patronizing students with too much attention. The problem with

offering too much assistance is the underlying assumption that the individual always

need help. And, as Amanda pointed out, these assumptions can then be taken on by

other students in the class.

As the conversation continued, Thomas told of a teacher who scolded a

student for coming to class late when the student, in Thomas's opinion, had good

reason to come late from the nurse's office. Amanda told how a teacher fussed about

giving her extended time on an AP exam and how it made her feel like "the problem

child" in the class. Throughout their discussion, participants critiqued ignorance,

assumptions, and the lack of effort made by teachers to understand them. Clearly,

teachers' conceptions of disability influence young people's conceptions. As models

of interaction in our schools, teachers' influence extends to help shape the beliefs of

peers as well.

With all those influences…

Young people's exposure to the various and likely, contradictory messages, no

doubt, creates complicated conceptions of disability.   Youth recognize contradictions

and find the negotiation of these messages challenging. In the following focus group

transcripts, participants question double standards and try to make sense of what

disability means to them.

> Micaela:
> I'm trying to think of how to put this. It's like when people that aren't
> disabled stay with their parents, one of the factors could be that they're
> just lazy that they're not independent. But when people with
> disabilities, when I see myself staying in my parents' house, it's not
> that I'm lazy, it's just that it's more difficult for me. And I don't like
> saying that. I don't like making an excuse for myself always because I
> have a disability.
> It is more difficult, but none of us want to admit it. Uh, because I
> think of it as an excuse! Then, other people are goona be looking at
> me like, "Oh, you're still living with your parents because you're
> disabled. But when you see someone else and they're like "Oh, it's
> okay, it's okay," I hate it when people say that to me. When other
> people are not disabled and they're with their parents, "Oh, they're just
> lazy, so it's not okay." Why can't you be like that, why can't you be
> that hard on me? Because it would motivate me to leave.

Here, we see that Micaela stated that expectations for her, as someone with a

disability, were different and should be different. She said that moving out of her

parents' house would be more difficult for her, and that she should not be considered

"lazy" for not having moved out yet. Then, we see that she was annoyed that people

cut her slack. She believed that if she were held to the same expectations as her

nondisabled peers, she would have had more motivation to move out. Here it might

be useful to have a way of articulating Micaela's apparently contradictory feelings. While she wants acknowledgement of her particular challenges to move out, it seems she wants motivating support and not critique. We might ask what role accepted social practices have in precluding adequate or nuanced response to Micaela by her peers.

> Thomas:
> "I don't know about you guys; but for me, it's good for me to be realistic. You know what I mean? Yeah, you shouldn't have any limits as a disabled person, but in reality, you do. You have a few select barriers that you just can't get over. And so, I think it's better sometimes to be more realistic than faithful."

> Kelly:
> "That's a fine line though, finding what's realistic and not selling yourself short. At least for me, here's what I do. I go "Well, I shouldn't go this far, but I don't wanna hold that back so much that…' It's finding that, like where is that boundary? What is enough but not limited?"

In this dialogue between Thomas and Kelly, we see them attempt to make sense of their beliefs about disability. Thomas wanted to acknowledge that limits are a reality for disabled people. But Kelly questioned where the boundary between realistic and "selling yourself short" was. To her, the contradictory "you can" and "you can't" messages still needed to be untangled. It is an essential fact of social experiences of disability, that negotiating possibility is already laden with critique vis a vis norms of accomplishment. While these norms apply, finding the perfect balance between reality and expectation is an impossible task. Within each of the aforementioned modes of influence, norms are held. In keeping up with norms, must one go to college? Must one get a job? Must one move away from parents? Must

one marry and have children? For disabled young people, these are nagging

ambiguities that will not go away. Straying from these norms is then experienced as a

personal lack or a failure, rather than a different experience. How can one convince

herself that she is not missing an essential ability or that she is not failing?   How can

we begin teaching that traditional norms of achievement are not markers of value?

Like Micaela, Thomas, and Kelly, whose views about disability have been

influenced by a variety of sources, many disabled youth have complex views of

disability. Measuring the individual significance and the tangled web of parent

beliefs, peer beliefs, medical professionals' advice, teacher practices, media

depictions, social policies and practices, and disability community may not be viable.

These influences cannot be disentangled. What doctors predict can affect what

parents expect. What parents expect and allow can affect how peers interact. What

policies mandate can affect how teachers respond. These influences simultaneously

make a difference in the way disabled youth conceive disability and view themselves.

Discursive Frameworks Apparent in Young People's Conceptions of Disability

Although most disabled youth are influenced by those same seven modes,

each has an experience that is unique and a conception of disability that is derived

from that unique experience. With that in mind, I write this section focusing on

discursive frameworks that often arise in conceptions of disability. These frameworks

involve the claiming and rejecting of disability identity and issues of normalcy,

dependence, and hierarchy that can interfere with individuals' ability to claim. The

examples I provide of young people's interaction with these frames illustrate how

individuals use the frames to find value or deficiency in their own experiences and the experiences of others. In order to encourage students to see value and think critically, we must better understand the discourses that shape thoughts about disability and disability experience.

Claiming: Is it okay to be disabled?

One theme that arises in youth conceptions of disability is the notion of claiming disability, a notion brought on by the disability rights movement of being able to view the self as belonging to a community of disabled people. Stigma regarding disability creates pressure for individuals to downplay disability or to make attempts to pass as nondisabled; so, while claiming may be freeing, it is not easy to do. To privately realize a connection to others of the group is one thing, to be public about that connection is another. In considering the spectrum or continuum of those who claim and reject disability identity, one's position on the continuum does not necessa rily indicate her achievement and growth. In fact, a youth's place on the scale would be extremely difficult to mark, as this is a dynamic factor that slides back and forth depending on the context of a situation. One is not just out or in, but develops nuanced approaches to the public and private aspects of identity. So, instead of making a claim that a particular place on the scale is most beneficial, I suggest that one's movement along the scale does indeed help shape one's view of the self and the way one interacts with her world. I argue that, as current systems make claiming disability identity quite difficult for young people, educators have a responsibility to open up space, to foster environments that value disability identity.

In *Claiming Disability*, Simi Linton (1998) advocates for embracing disability identity, not just to find place among a group, but to change the way we interact with the world, participating and demanding access. Some scholars compare "claiming disability" to "coming out" as queer (Linton, 1998; McRuer, 2006); it is not only asserting, "This is who I am," but "This is who I am and we're all going to be okay with it now!" Just as it is difficult for many LGBT youth to come out, it is difficult for many disabled youth to claim disability. Desires to not be one of "those" people are based on the negative stereotypes that pervade our society. Understandably, youth will reject any association with a group who is deemed weak, dependent, and weird.

Youth interviews reveal some of the difficulty in claiming disability status. In instances where youth reject disability identity, often they do so in an effort to separate themselves from the negative connotations they have learned about disability. Here, I will discuss how claiming disability has impacted two of my participants.

Alejandra remembers her reluctance to join a mentoring program for disabled youth. "I guess I did learn something from it… 'cause before, I didn't even want to be like, I don't want to say, people in wheelchairs." Almost saying she didn't want to be like people in wheelchairs, Alejandra implies she saw the life of disabled people as something she didn't want. After spending some time with the group, Alejandra felt a sense of community with the group as she came to know individuals and realized the group was more diverse than she had imagined. Having learned that she could find a place of belonging with this group would give Alejandra some resources she had not previously had access to, but it would not necessarily mean she would feel safe to

claim disability identity in other situations. The stigma attached to disability is strong enough to keep many disabled young people quiet about this aspect of their identity. They will avoid the topic, draw attention away from, and even deny connections they have to disability community. Although they may value interactions they have with disabled peers, they may not expect nondisabled others to value their disabled peers. Some disabled young people avoid making connections with other disabled people because they have internalized the negative stereotypes or because they believe it may interfere with their ability to make connections with nondisabled peers. Even though Alejandra made friends with disabled peers at the Saturday mentoring events, she kept these relationships separate from the friendships she had with nondisabled peers. Bringing the world of disability into daily interaction can seem too risky. Youth may fear that nondisabled youth might further view them as different, too different to associate with them.

Having had early exposure to disability community through wheelchair sports activities, Amanda reveled at mentoring events in having another space where she felt truly accepted. She liked to talk about the way people interacted with her and about how she fought for respect and for her rights. In a focus group interview, she spoke about proving herself to others. "I've had to prove a lot of people wrong and show them that I can do things." Even though Amanda would openly claim her disability identity, she struggled to be understood, feeling as though she needed to prove that being disabled did not mean being insufficient. While some disabled young people commonly reference their disability status and/or their membership in disability

community, they are often penalized for it with questioning looks, social distance, and patronizing responses. Some young people, like Amanda, want to be proud of who they are, be open; but they come up against dominant views which say disabled and proud do not go together. Some youth, like Amanda, take on the responsibility of disproving disability stereotypes, a feat that may have many small victories but no endpoint. The fact of there being a space to move into (not just out of) is key. That is, in order to claim disability, there needs to be a socially recognized identity to claim.

As many of us, disabled individuals, waver between rejecting and claiming our disability identity, we carry histories that prevent us from speaking at times and histories that enable us to claim at other times. We identify safe places and sometimes we push the boundaries. We do consider the risks we take.   If I bring attention to this difference, will I be respected? Will my ideas be heard? Will I be seen as one-dimensional? An unwillingness to claim disability identity does not denote a desire to live without impairment. More likely, it denotes a legitimate fear of the repercussions that follow such openness.   These repercussions often are connected to belief systems about normalcy, independence, and social hierarchies.

In recognizing and acknowledging the discourse of disability, schools have a responsibility to create and foster safe places to claim disability. As educators and models to students, our daily interactions with the discourse can have profound impact on the way disabled and nondisabled students view disability and themselves. We must continue to ask ourselves: How can we avoid enforcing a narrow conception of normalcy? How can we support independence and show the value of interdependence

as well? How can we stop perpetuating social hierarchies that leave some forever

devalued? The following sections delve deeper into why these questions are

important to consider in creating those safe places for claiming disability.

"I just want to lead as normal a life as possible."

To conceive a meaning of disability or to imagine having a disability identity,

Davis (1995)[3] argues that one must conceive normalcy.   Davis introduces disability

as a part of a social system, a system in which a person is considered normal or

disabled, seen as simply black or white, in or out, right or wrong. In an ableist

society, this hegemonic system creates absolute categories and makes disability

undesirable. Further, Davis shows that disability is not uncommon at all by

acknowledging the variety of ways in which one can be categorized as disabled and

by acknowledging the great number of people who fall into these categories. With

this, he asks us to consider then what being abnormal really is. He identifies function

and appearance to be the modalities by which disability is constructed. This

framework of how disability is conceived provides the shape to how people view

themselves and others.

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[3] Davis (1995) also creates a strong case for including disability in the spectrum of
diversity. He points out that "hundreds of texts claim to be rethinking the body; but
the body they are rethinking –black, female, queer— has rarely been rethought
disabled" (158).

People perceive that those who are "normal" fit in and do things "the" way they are supposed to be done. Disabled youth are pushed to be, act, and strive for what is normal. Many youth willingly take on this task, sometimes leading to achievement, sometimes leading to frustration. Many parents of disabled youth believe pushing normalcy will help their children achieve a good life. Alice described her and her husband's philosophy in raising Thomas:

> We have always felt, like any other parent, we've taught Thomas that school is his job; and, we required of him what any other family would require of their kids. Our expectations were that he would do anything anybody else was expected to do. Robert did a lot of building things…stand for his computer, things to help him in the classroom; just little tools that would help him. Other than that we tried to make his life as normal as possible.

For Thomas's parents, the semblance of normalcy became a priority. They believed that requiring "what any other family would require of their kids" was the best way to provide their son a good life. Still, some might question if it is "normal" for a child to receive so much help from his parents in this way. Regardless of the efforts made, Thomas's life would not be viewed as normal by most people.

Another mother, Teresa recalled pushing her son, Joaquin, to walk without consideration of his disability. She imitated their dialogue, beginning with her son's voice:

"I can't walk. I'm tired."
Eww, that would get me so mad. "Joaquin, why are you tired?"
"I walked a block."
"You already walked a block." And then, I would see someone with a wheelchair and I would say, "Do you think he is happy the way he is right now?"
"No, oh."
"Do you think he wish he can walk like you? Walk a whole block?"
"Yes."
"OK, so next time you tell me you're tired, think about somebody that cannot walk at all."
"Okay."
So that's my main thing I was always telling him. "Oh yeah? You're tired or you're lazy? You're tired or you're lazy? Okay."
"No, I'm not lazy."
"Well, then do it!" Sometimes people would probably hear me.

Teresa spoke about pushing Joaquin to be "normal" as if it was one of the difficult, but important tasks of parenting. She urged Joaquin to keep walking even when it was difficult for him by using his own sense of self, his desire to not be seen as lazy, ungrateful, or abnormal. Teresa acknowledged the harshness of her words in saying, "People would probably hear me." Several messages are clear in this: 1. Not walking is abnormal, and 2. Abnormal is unacceptable. Even in well-intentioned efforts to encourage children, these messages are prevalent. This contradiction structures my broader project as I question how expectations and motivations can be conveyed without adding to stigma and while positively and creatively engaging difference.

As young adults, Thomas, Joaquin, and other disabled youth internalize and take on the task of seeking normalcy. In describing what is most important for him to accomplish when he is an adult, Thomas said, "Drive, if I'm not already doing that.

Find my own place. Get a job somewhere that I like, pursue a career. Get into a

college. Be able to carry out as normal a life as possible." Since Thomas's interview,

he has pursued and succeeded in finding a means to drive. After an arduous search

for someone who had the expertise to work with him, Thomas travelled to Los

Angeles to try out a driving system that would work for him. Excitedly, he told me

that a van with proper controls was being built for him. He said, "Pretty cool, just

slower than normal." Although he could see himself within the normalized group of

those who drive, he could not acquire the tools in the normalized timeframe. His

situation shows how norms can be affected by one's socioeconomic status. Without

financial resources, driving would not have been an option for Thomas. This is a

prime example of the way various social conditions, beyond impairment, affect the

ability to meet established norms. Generally speaking, I hear that most parents, of all

children, need to have discussions with their children about the illusory nature of

norms at times when they are challenged by feelings of shortcoming in one area or

another. So, the compensatory embrace of norms I describe might counter

widespread, if covert, quotidian critique of the pressures of normalcy.

Although Joaquin never used the word "normal" in his interview, he alluded to

the importance it held for him. When Joaquin's parents purchased a power

wheelchair to make getting around a college campus easier for him, Joaquin tried it

for a short time and then refused to use it. Again, Teresa recounts her dialogue with

Joaquin:

He used it one month. And he said, "You know what, Mom? You
wanted a wheelchair. It's yours. You can have it."
I go, "Joaquin, no. Why don't you use it so you don't get tired?"
He goes, "I don't get tired. I don't wanna use a wheelchair and I'm
not gonna use a wheelchair."
I go, "What are we gonna do with it?"
"Well, pretty soon, you're gonna get old. You can use it."
"OK, we'll save it for when I get old."   So, he doesn't want to use it.

Ironically, Joaquin and his mother have changed positions. As she now

advocated for the use of a wheelchair, Joaquin rejected the idea. In a separate

interview, Joaquin explained, "I'm not really too good… Somewhere big like the

swap meet, I get tired. I know I get tired. But even though, like I go to school, go to a

friend's house, or something like that, I feel more comfortable walking." Even

though Joaquin admitted that he gets tired, following the norm of walking was more

comfortable for him than using a wheelchair. The stigma associated with using an

assistive device like a wheelchair, related to conceptions of normalcy, can cause

young people to reject what could be useful tools. Joaquin learned about this stigma

as a young child and carried it on with him as a young adult.

Many disabled youth are sensitive to the fact that others often view them as

abnormal. For Amanda, finding success was connected to proving her normalcy to

others. She said success for disabled people is the same as it is for those without

disabilities with some exceptions:

…except proving to people that despite your disability, you can still
achieve things that other people think you can't. I think there are a lot
of people who think because you have a disability, you're not…not
that you aren't worth as much, but it's different for you at least. I
know I've had to prove a lot of people wrong and show them that I can
do things.

Measuring oneself against norms is a broad part of modern social regimentation (Davis, 1995; Davis, 2002; Foucault & Khalfa, 2006). Disabled young people strive for normalcy in a given area because of the threat of being condemned to be abnormal or substandard in other or all areas. Robert McRuer (2006) calls this threat "compulsory able-bodiedness." This threat is imposed by physical structures, cultural practices, common discourse, beginning with the early interactions between parents and children, and strengthened by ongoing interactions in schools and communities. Interestingly, in an examination of how environments created by able bodies set barriers for disabled bodies, Breckenridge and Vogler (2001) claim that society is friendlier to disabled children than it is to disabled adults. Even though we might question that in light of some of the stories youth have shared, these scholars point out that finding a place in school is one thing and finding a place in the workforce is another. Their example hit home with me as it compared a typical school's treatment of disabled students to its treatment of disabled teachers. As a new K-12 teacher years ago, I came head to head with the "compulsory able-bodiedness" of the teaching profession when I was denied a job and told I did not have a "strong teacher presence" and that I was "disadvantaged" since I could not stand above my students.

The importance placed on self-image in southern California can especially create pressure for some youth to look good or feel self-conscious when they do not

meet society's norms for outward appearance.[4] Even though idealized images of beauty rarely, if ever, take the shape of disabled people, some young people search for creative ways to be noticed. A participant in one focus group, Micaela, left a message on my voice mail asking if I knew what company made cool parts for wheelchairs. "I really want to pimp my rims," she said. While her peers talked about "pimping rims" on their cars, Micaela, without a car, looked for a way to customize her own wheels. Is this a way to do what she believes everyone else is doing or to show uniqueness? While striving for normalcy, youth simultaneously face pressure to be unique individuals. The striving for these polarities, normalcy and uniqueness, can be difficult to balance. Although normalcy plays a part in development for most youth, its part in the development of disabled youth takes a different shape, a shape that makes balance particularly complicated.

Disabled youth are usually not afraid to admit that a main goal for them is to be normal. They are hyper-aware of the constructs that value ablebodiedness. With this awareness, Micaela and others try to appropriate and renegotiate their identities to situate themselves within a normalcy as defined by others. Disabled youth often compare all attributes and accomplishments against the attributes and accomplishments of the non-disabled norm. Disabled youth often feel pressure to choose what is normal over what is convenient, pressure to prove themselves, and pressure to look a certain way, a way that their bodies will not allow. For example, in

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[4] Priestley (2003) acknowledges that, because of deep-seeded perceptions of disabled bodies as genetically inferior, disability culture has a challenge in "reclaiming and redefining physical difference as beautiful" (95) in the way other minority cultures have.

making decisions about using mobility devices like canes, crutches, and wheelchairs, young people often select what looks good rather than what works best. As a young person myself, I rejected using forearm crutches, and instead chose to use underarm crutches, those with which I could more easily be seen as injured rather than disabled. For that slice of normalcy, I gave up a more versatile tool. I remember testing forearm crutches, feeling a sense of freedom and strength, and still reporting to my parents that the crutches would not work for me. I understood the different cultural meanings attached to these different tools. I wonder how my body may have better retained the strength I had in youth if I had chosen the other tool.

While some conforming to norms involves making a choice, conforming is not always an option one can choose or should choose. Now, I cannot simply choose to conform to the norm of mobility by walking; no, I use a wheelchair.   When we have limited control over our bodies' functioning, meeting the norm is just not viable in many cases. And still, the role models we see, the images of athletes and runway models, tell us we have no way of ever measuring up.

Recommendations

With the enormous pressure that is embedded in our society's practices to meet norms, schools can broaden youths' conceptions of what is acceptable and valuable:

1. Educators can be critical of their own conceptions of normalcy and the ways in which they enforce these norms.   In the same way we can be critical of our own biases in regard to race, class, gender, and sexual orientation, we can be critical of our

biases in regard to ability. Until we recognize these, we will not effectively change our interactions.

2. Educators can also teach students to be critical of pressure to conform to norms. If students gain an understanding of why people are driven to uphold norms and why norms should not always be upheld, they may be freer to know who they are and be who they are.

3. Educators can avoid making a big deal out of accommodations and can get rid of "special" language. Students are more likely to make use of accommodations that enhance access to learning if they get a sense that others believe it is reasonable and acceptable. When we tack on labels, students are more likely to feel disconnected from peers.

4. Schools can celebrate difference and provide models of variation. In the way we strive to celebrate cultural diversity, we can celebrate the various abilities of people and disability culture. As we teach, we can provide multiple models, show that individuals accomplish tasks in a wide variety of ways.

"As long as your brain works good…"

In making sense of themselves, disabled youth often place themselves within a hierarchy of ability as a way of assuming value. These assumptions are situational and relational. Often, those with physical disabilities will buy into the societal bias that places greater stigma on mental disabilities, in ways not dissimilar to the unconscious acceptance of privilege and entitlement afforded to more physically abled over themselves. The hierarchy of disability is complicated and dynamic.

Some groups within the population of people with physical disabilities will place value on either acquiring a disability or being born with a disability. Some will place value on severity of impairment or on the ability to pass as non-disabled. Members of ADAPT, a radical disability rights group, highly regard those with the most severe disabilities, assuming they are the ones who have real disability experience. Among the youth I interviewed, I noticed a tendency to value physical disability over mental disability and to value less severe impairment over more severe impairment.

As Alejandra spoke about her involvement in the mentoring program, she explained how she began to think about herself in comparison to other disabled people.

> It just taught me a lesson that I'm more independent than they are and there are people that actually do need more help than me.   I guess that made me feel good about myself. You know? I'm like, "Oh, there are more people that have it tougher or tough...". I talked to my friends about it. "You know there's people that have it, you know, harder." And then, they even tell me, "Yeah, but you don't have it that bad. Like you know, you actually are very independent." Because they're like, "We push you around campus because we want to push you, but we know you can do it."

In this, Alejandra told how she noticed she was more independent than some of the youth she met in the mentoring program and felt good about that. Seeing others who "have it tougher" made her feel good about herself, proud that she could do things on her own. Placing herself in a hierarchy of ability, she valued the abilities she had. Interestingly, her friends validated her assumed value as they spoke about her ability. They worked to convince her that they helped because they liked to, not because she needed it.

Similarly, Salem spoke about the severity of impairment in youth he met while participating in the mentoring program.   He said some things surprised him:

> For instance, how some people can't even … like how happy Joe is for instance. It's just amazing to me how happy of a kid he is. It's just, it's kind of surprising. Well not surprising. It's just surprising to me that I thought my life was hard and there's a lot of people that have a lot tougher situations to deal with.
> And with me, my situation is tough; but, it was a little easier because I knew that I was gonna be in a wheelchair at some time. But some people get paralyzed and they don't realize how tough it is; and, they don't want to be that way, but they have to deal with it. And it's hard. But I had a chance to deal with it, like to think twice and deal with it.

With his statement, Salem revealed his conception that severity of impairment impacts one's happiness. He compared his life with that of Joe, an intelligent and witty young man who has very limited control of his limbs, and considered that Joe's life was more difficult than his own. He then compared his experience of gradually losing physical ability to those who lose ability suddenly. In this way, he added value to his own experience, rationalizing that he did not have it bad.

In another part of Salem's interview, he placed himself hierarchically above those who have mental disabilities. He spoke about his plans, "Just do whatever you can. You know, 'cause of the disability, you gotta deal with things each day differently.... So, it's important to go to school and keep your brain." He chuckled, "As long as your brain works good, you got something important in life."   Without the intention of demeaning anyone else, Salem noted his own value, insinuating that being smart is what matters most.

Without realizing, Salem and Alejandra rationalized their own value by placing themselves within a hierarchy of disability. In this way, they subtly argued

that they deserve respect and that they have good lives. Often, disabled youth find an opportunity to do this when they interact with other disabled youth. They learn to use hierarchical comparisons to counteract the many messages they receive about their own lack of value. A number of disability studies scholars have begun to articulate this ableist tendency (Caldwell, 2007; Danforth & Rhodes, 1997; Deal 2003). They find that the negative attitudes of some disabled individuals about other disabled people are based on a variety of factors, and often express a fear of what is not their own experience and show a desire to set themselves apart.

Recommendations

Educational and social interventions can address this unproductive exercise of measuring self-worth by comparing to the assumed worth of others. Although deconstructing all social hierarchies may not be a feasible task, schools do have a role in promoting or demoting them. Schools can find ways to counteract the negative messages disabled youth receive.

1. Educators can teach students to be critical of hierarchical systems. If teachers explicitly question why certain groups hold power and privilege, students might learn to question and talk back to a system that devalues them.

2. Educators can give more attention to cooperation rather than competition. In cooperation, students might better learn to value each other rather than feeling pressure to be better than their peers. They might discover what unique contributions they can make.

3. Educators can provide students with opportunity to learn about the perspectives of various people, including perspectives of disabled people. Without an understanding of a variety of perspectives, students can easily make assumptions about the experience of others.

"I gotta do it on my own."

It's being more independent. Let me do what I need to do so I can succeed in life; because, my parents are not always going to be there. So, I gotta do it on my own. –Joaquin

They just always tell me, 'It would be good for you to get independent. That'd be good.' And I know that'd be awesome. That's the key to everything. –Thomas

She wants me to be totally independent. Well, I still get independence now 'cause she trusts me a lot." –Alejandra

I'm just gonna be independent when I can, you know? –Erica

Being able to support myself if something were to happen to my mom and dad and brothers. If it went to that extent, that's what's most important to me. –Salem

Unfortunately, no matter how much I want to be independent, I know that there are some things I cannot do without a person helping me. –Katie

Youth in America learn that independence is a priority, the best way to experience the American dream. They learn that good people are independent in particular visibly marked ways; they get jobs, pay their own way, and live away from their parents. Although many youth create goals for accomplishing these tasks, it is disabled youth who name their goal "to be independent." Disabled youth acknowledge the challenges they face in reaching a so-called independence, and sometimes realize the standard conception of independence is not realistic for them.

In this, I will discuss the way youth think about independence, the concessions some make, and potential applications of the reframing and destigmatizing of dependence.

How Valuable Is Independence?

Independence is at once a strongly embraced and recognized descriptive rubric, and a highly ambiguous ideological construction. Disabled youth view independence as highly valuable and a little frightening. Some see it as an event yet to come; some see it as a process in which they are engaged.

In reference to her mother, who became a teenage parent and moved out of her parents' home, Erica said, "She got independent at sixteen. I'm not gonna do that. I'm gonna be independent at the age of prolly eighteen or nineteen. So that way, I don't waste my whole childhood being worried at… you know… " By looking at her mother's experience, she considered independence to be the point in which one takes on a big responsibility, responsibility that would be worrisome to her.

Erica spoke about independence as an event, saying her mother "got independent." But in saying more, she revealed another view of independence, one in which it takes the shape of a process that she had begun to experience.

> My mom's giving me more independence now that I'm older. Letting me take my brother places, and ... Like tonight, I'm taking him to the movies. I mean, yeah, she gave me a little bit of independence, like walking to the corner store and going to get stuff, and walk back. But now, I can take the bus places and come here and hang out with my friends at the mall without her worrying about me and stuff. And, yeah. trying to graduate, getting good grades, trying to get my grades up for this year; I'm getting there.

Here, she described the way her mother had begun to give her space to go places without her parents and the way she worked to take responsibility for herself in

school. The value of the independence Erica's mother afforded her is noteworthy.

She was able to contribute by going to the store for her mother. Her options in

spending time with her friends increased as she was able to take the bus. She felt

pride in being trusted to care for her younger brother. But what happens when Erica

moves forward? She admitted expectations for further independence, "I just wanna

move out on my own, and be independent and stuff." Will she be able to maintain her

own personal care? Will she become successful in finding employment? Possibly. If

not, has she failed to reach her ultimate goal?

Even though the importance given to independence is large, its meaning is

somewhat amorphous. When an individual has the financial means to hire a

housekeeper, a gardener, and a driver, and comes to depend on them, is she

independent? When a youth moves from his parents' home into his first college

apartment and relies on his parents to pay his rent, is he independent? Under close

analysis, who among us is truly independent? Still, we value an individual's ability to

"take care of" herself.

The Closer the Better?

As Katie described her quest for independence, she noted the limits she'd

found. She recalled wanting to go away to college:

> But then my parents thought it'd be better if I went to a local college;
> because, you know, for independence, it'd be better. Because what if
> my power chair broke down? It'd take six hours for them to come up
> and help me rather than just 20 minutes from work.

In this, she decided that close proximity to her family would give her more

independence than distance would. This was not the only way in which Katie traded

one form of independence to maintain or obtain another. She said family members would usually plan to move out during college, but "Right now, I don't 'cause it's just so near the trolley. It's right there. But I do think about moving out sometimes. I just have to find ways to become independent first before I can do that." In order to obtain the independence of using public transportation to get to college, Katie chose to stay at her parents' home.

Katie said that she and her parents worry about the limits of her independence, that she might not be able to live on her own. She explained how she expected her independence to be different than her parents':

> It's gonna be hard. I have to not only just find an apartment; I have to find an apartment that's wheelchair accessible. I have to find a good roommate. I have to find good assistants to help. While for them, it's just easier 'cause they could just find an apartment. I have to find good health insurance 'cause I have to pay for most of my disability things. I have to find a good job that's willing to accept me despite my disability. I have more to prove than my mom and dad did.
> I say I want to work, but I'm limited transportation-wise. I can't just carpool with someone or get a ride…
> And also, being able to take care of your wheelchair and be more aware of disability, be more assertive and such. That's another thing. Where, as a kid, if you weren't able to do it, your parents would make sure that it'd be okay. While now, you need to be more assertive, like "Look I need this."

The limits to independence that Katie highlighted were not exaggerated. Finding a wheelchair accessible home, good personal assistants, transportation that accommodates a power wheelchair, and an open-minded employer will take determination, for sure. She also was aware that, for youth who have relied on the advocacy skills of parents to get their needs met, learning to be assertive enough to say, "I need this," is yet another move to make toward independence.

Although disabled youth see limits to their own independence, they still verbally maintain that it is a primary goal. Katie spoke about independence, but had really made concessions to rely on her family for shelter, for personal care, and other support. Is it so wrong for Katie to depend on her family? Why is dependency so stigmatized? When Katie helped care for her younger siblings, she engaged in a system of interdependence, in which her parents needed her and she needed them. So, for Katie, learning interdependence might make more sense. Why should she not make goals related to interdependence?

Recognizing the limits of true independence, many have made efforts to reframe and destigmatize dependence and interdependence (Kittay et al., 2005; Smith, 2001). The expectation for one to "care for oneself " is culturally and economically situated. The importance of independence varies depending on the culture within which she lives and on the economic situation of her family and community. Culturally, we might notice that children of immigrants do not feel the same pressure to move out of parents' homes. This is true of Alejandra and Salem. And, those who come from families of lower socioeconomic status may feel pressure to stay in their parents' homes to help contribute financially. So, within some societies and some communities, independence does not hold the highest value.

Although many scholars, service providers, and disabled people are aware of the problematic nature of drives for independence, disabled youth are pushed to strive for independence. In making sense of themselves, the youth I interviewed showed great concern about their goals and achievements in independence.

While making independence a primary goal, most disabled youth feel that dependency is a ubiquitous part of disability. In general, these young people were aware of limits to their independence and still proud of gains they had made toward independence. Even as they noted limits, they maintained an attitude that the closer to true independence they could get, the better.

Recommendations

With an awareness of the value placed on independence and the complexities it creates in the lives of disabled individuals, educators need to make a double move:

1. While facilitating independence and the sense of students' ability to achieve it, educators can give young people opportunity to realize their own capacities. This is crucial in developing agency.

2. Educators can also challenge the stigma of varied forms of interdependence. This challenge may involve questioning developmentalist frameworks that expect scaffolding to always lead to independent skill.

Detailed discussion of these practices continues with Chapter VII's notion of seeing capacity and supporting agency.

Chapter Conclusion

It is important that we recognize how one's view of disability is formed, how it impacts one's view of the self, and how it shapes the direction one chooses to take. Parent beliefs, peer beliefs, medical professionals' advice, teacher practices, media depictions, social policies and practices, and disability community all play into the

formation of one's conception of disability. Awareness of the problematic discourses that often construct conceptions of disability is crucial to helping frame more critical conceptions, conceptions that allow a broader range of positive outcomes for disabled youth. With an understanding of how the discourses of normalcy, disability hierarchy, and independence make claiming disability precarious, educators can begin to shift the direction of the discourse and open safer spaces for the positive identity development of disabled youth.

Our first responsibility in this effort is to allow disability identity to be an acceptable and respectable identity. Disabled youth should never need to feel ashamed to identify as disabled and to associate with disability community. Likewise, nondisabled youth should never need to feel ashamed to associate with and befriend disabled youth.   Ongoing critique of normalcy, hierarchies, and independence must be established and continued within schools in order to shift rigid and limited conceptions of disability.

As schools take on a more critical view, disabled students will benefit from the environmental and curricular changes. Students receiving accommodations will not feel as if their presence causes "trouble." Students who do not fit the narrow confines of normalcy will see their perspective and experience as a valued way of being. Students will learn to contribute their unique skills through cooperation and will not feel the burden of endless competition.   Students will be supported in building independence and still learn the value of interdependence.

VI. Negotiating Difference during the Development of Relationships

My mother told me that before I learned to walk at age four I used my younger brother to get what I needed. "You'd say, 'Jay, go get me that.' You'd point at a toy and he'd get it." I've always liked this image of a toddling boy gathering toys for his sister, without questioning why she could not get them herself, without questioning what she would in turn do for him. These were the early days of a brother/sister relationship that would grow from a simple awareness of our differences into something that could be both cooperative and antagonistic. The same brother would later sass back to our mother when she asked him to get something for me. "She has legs too," he would argue, "and she can walk!"

For disabled youth, an awareness of one's own difference develops early and remains as a part of one's identity. This aspect of identity impacts children and adolescent's development of relationships with family and friends, in that they and those they interact with perceive those marked as different to hold particular social roles.

In this chapter, I explore some of the common understandings that develop within families of disabled youth, some of the considerations disabled youth make in friendship, and the negotiation of assistance within these relationships. In conjunction with these sections, I suggest how educators might better understand and support disabled young people.

Family Relationships

Within the family, we begin to see the way the world works; we practice roles; we learn what our part is. Of course, a family's conception of disability shapes the roles of individuals in the family. If disability is viewed as tragedy, family members may see themselves as victims or heroes. If disability is viewed as a challenge to overcome, family members may see themselves as coaches, encouragers, or inspirational trainees. The family member with a disability follows the prescribed role, fights against it, or negotiates between the two. Likewise, other family members comply or resist, or work to recast the role.

In this section, I will draw upon interviews with participants in the study to discuss several key ideas related to family relationships: how the dynamics of family life can be impacted with the presence of impairment, how over-protection serves as a temptation for many parents and as a plague of disabled youth, and how many disabled youth find a desire to contribute to the well-being of their families.

Young people, parents and transition – "My parents are very supportive." Some scholars note that historically disabled people have often felt like outsiders within their own families (Mitchell & Snyder, 2001). However, the young people in this study described themselves as insiders with different roles. In large part, they described their families as very supportive. Families though can be limited by received social conceptions, having no alternative experience to lead to the idea that the social constrictions relative to disability may be wrong. So while the families of

disabled youth are often viewed as more caring and responsive, a certain depth of dependence can be built into disabled youth's identity (Hussain, 2003).

Several of the youth I interviewed indicated that relationships with their families took much more precedence than relationships with peers. Katie, a college student, showed enthusiasm for spending time with her family and expressed her pleasure in helping care for the younger children. She said it's "cool" that she is involved with her family and that she loves watching her younger siblings. "I'll leave school instead of hanging out here and go pick them up." She spoke at length about the support her family provided to her and about how much she considered her parents' perspective in her decision-making.

> My parents will tell me you should probably do this, or give me
> suggestions. Not so much tell me what to do, but they'll suggest
> things. Like, "Oh, this is better, you should probably do this. But you
> know, it's your choice."

She described her parents as supportive and useful in offering advice, not dictating her decision but strongly influencing. Katie's description of her family involvement is remarkable. At a time when many her age are seeking more autonomy from family, she seemed to prefer family time to time on campus with peers.

Salem implied that he spent the majority of his time with family. During his interview, he spoke about the ready involvement of his family and about his reliance on their support. Salem said that he told his parents "everything" except for the minor details they did not want to know. He chuckled as he told me how involved his parents are in his life.

>Sometimes when I go to the doctors, the doctors will say, "You want your parents coming in here with you?" I'm like, "They have to come in here or they're not gonna know what's wrong with me. And if they don't know, nobody's gonna be able to take care of me properly, you know? And, it kind of upsets me when people ask that kinda question.

He seemed annoyed that doctors sometimes offered him privacy and did not see the sense of not having his parents present during appointments since they were the ones who cared for his physical needs. Salem echoed this sentiment when he described how staff at his college's disability office offered privacy when he met with them also.

>"Do you want your parents in here with you?" Of course! It's common sense that you need your parents to be there to know what you need and what you think… It's important that they always keep posted on what you need. 'Cause they're the only ones that are gonna support you and help you in the future, so they gotta know everything.

The range of venues in which Salem expected to have his parents' involvement was quite broad. Even as a second year college student, he relied on his parents to best understand his medical needs and his learning needs. We might consider Salem's parents to be what some scholars call "helicopter parents," those who hover around their college-age children, afraid to allow them autonomy; however, Salem's younger brothers have been allowed more autonomy. He further explained their involvement:

>My parents want to know because they know it's hard for me to get help. Like sometimes I'm shy to ask for help when I'm places. I feel like I don't wanna ask for help but I really need the help. And then sometimes, I don't want the help and I just keep struggling until I get something done.

Salem said his parents knew that he was shy about asking for help. Rather than expecting Salem to learn how to communicate his needs, his parents remain

closely involved, offering any support he may need. Although Salem's disability did not limit his ability to make decisions and communicate, it is apparent that he and his parents had been affected by what some scholars refer to as "disability spread," (Van der Klift & Kunc, 1994) a phenomenon in which someone projects broad or generalized lack of ability onto someone based on a singular impairment; treating them as if disability pervades their whole being.

As some disabled youth do, both Katie and Salem saw parents as wise decision-makers and, at times, readily allowed parents to direct their choices. While many youth this age reject or downplay the role of their parents' input in decision-making, I imagine that embracing their input might signal one's own lack of confidence in making decisions for themselves. Salem said his parents helped him and his brothers "do the right thing." He was certain that his parents wanted life to be easier for their children than it had been for them. They had convinced Salem that he should continue living with them even as he is an adult. Salem explained:

> And I don't really see why there's a reason to move out you know? If they're willing to keep you here and give you all the money you need until you're finished with school and can support yourself. And my dad said he wants us to take advantage of that because when they were growing up…

> He's a welder; so, he has to go around and work with heat and know that it harms the eyes; and he doesn't want his kids to have to deal with that. We learn from what our parents have to deal with...

Interpreting disabled youths' and their parent's explanations of how they feel about dependence/parental support is challenging as it articulates a negotiation of multiple and contradictory expectations that exceed or lack normative models. In the

early 1970's, the independent living movement, through the work of disabled

individuals, began. The movement, based on the idea that disabled individuals could

best make decisions about their own lives and could integrate into the community,

continues to challenge normative models and pushes individuals to achieve non-

normative interdependency and relative autonomy (Shapiro, 1993). Although the

movement has largely spread and provides non-normative models, disabled youth and

their families rarely grow up with access to it since it is not part of the cultural

knowledge generally passed on in schools and communities.

Salem later told me he was unable to move out since he could not live without

someone there to help him, he reasoned here that staying with his parents would

simply give him an advantage that his parents did not have when they were young.

Salem seemed to find comfort in having a reason, aside from his disability, for living

with his parents, a reason that belonged to his brothers as well. In this reason, Salem

revealed a common immigrant story, a story of immigrant parents who would work

hard and expect their children to benefit from taking advantage of all the opportunities

they had not had in their homeland. I assumed that an immigrant story may be an

easier story to tell than a "disabled man stuck at home" story.

Similar to the way Salem spoke about his trust in his parents, Katie spoke

about getting advice from her parents:

> …whatever I have in mind, like [when] I want to do something else,
> I'll be like, 'Mom, Dad, what do you think about me doing this?' and
> I'll get their opinion.
> I mostly tell my parents everything… Well, like school stuff, if I had a
> bad grade or something, I'll be like 'What they don't know won't hurt
> them.' I don't hide major things from them or anything.

Katie said she tells her parents most things and likes to get their opinion on her decisions. Part of what seems to be at play is the competing values of intimacy and autonomy, interdependence and independence. How does one balance the two? This balancing act is one that all adolescents encounter, and likely begins when they are toddlers; but something makes it different for people who are perceived to have *radically* differing abilities from their parents. The differences in ability are articulated into conventions or patterns for non-normative or exceptionalist relationships. Rather than following the pattern set in the parents' experience, new patterns must be created. When Katie made plans to go to college, she wanted to go away to school. Her parents influenced her decision not to go. Katie said her parents helped convince her to stay close to home for college by discussing problems she might encounter if her wheelchair broke down. Having a power chair break down could be frightening, especially if those who have always solved the problem in the past are six hours away.

Salem and Katie exemplified a subset of disabled youth who frequently talk to their parents and rely heavily on them for advice when contemplating decisions often to the exclusion of other sources of information (perhaps placing their parents' feelings or intuitions before their own). Typically, these youth have heard their parents discuss important decisions many times and trust that they have youth's best interest in mind. Salem and Katie both told narratives to explain the rational behind their arrangements to continue living with their parents. What seemed to be missing from their stories were real options, workable possibilities to even consider. When

Katie explored the idea of moving, the risk of her wheelchair breaking down stopped her from imagining the possibility. Could she not have found a repairman in another city? The experiences of these youth and the questions they raise should set us up to consider how the work of other resources including mentorship or modeling by people could help families to performatively, conceptually, and creatively work through alternative forms of interdependence.

Not all of the youth I interviewed relied as exclusively on their family life in thinking about life decisions the ways Katie and Salem did. The difference could be related to the level of personal care needed or the person's success or lack of success with peers. Other youth did not accept their parents' input so readily. Seeking autonomy, some accepted parent ideas without feeling an obligation to follow them.

Thomas spoke respectfully of his parents, but did not talk much about enjoying family life. He said, "I'm outta here as much as I can be. I'm just off doing other things, whether it be with friends, or movies, or anything like that. They do what they do and I do what I do. That's just the way it goes. We don't bother each other too much." Although Thomas considered his parents advice when making decisions, he seemed to have a greater confidence in himself as a decision-maker. He was well-aware of his parents concerns.

> My mom's concerns are, "Will he get accepted to a school? How is he gonna find his own place? Is he gonna have to work while he's in college?" You know… keeping grades up so you can be accepted by a school that you want to go to. Stuff like that. How people will approach a disabled person. Walking into an office for an interview. You know, how are they gonna look at that?

He described his mothers concerns as a string of items, some disability-related, some not, without acknowledging that her concerns mainly involved his autonomy. Thomas answered a question about his father's concerns, saying "He doesn't talk much about it, you know? I think he has a little more faith in me than my mom does on that subject… He doesn't have many concerns. He's kinda like me, take it as it comes." To Thomas, it seemed that his father believed in him more than his mother did. It seems that silence could signify trust, a message of confidence, a willingness to let go of the details Thomas would handle. "I've always been told I can do whatever interests me…whatever college suits my needs, you know, what I can get into…set your limits at a reasonable amount." Even though his parents supported his interests, Thomas believed there were some things he preferred not to discuss with his parents.

> School, a lot of times. You see, I don't like to be under pressure, you know? If I'm just taking it as I go, I do fine. But when my mom starts, 'This grade isn't high enough…you know you need to do better at this…' I don't do as well when I'm asked to bring something up. I can do it by myself; it just takes longer. But I can get it there. But my mom, if she wants it in a hurry, you know, its *hard*. 'Cause it's hard to do anyway. And then the pressure of someone wanting it…

Quite different from Salem's reliance on his parents' involvement, Thomas wanted to take care of school on his own without the pressure of what his parents wanted. More importantly, he believed he could. Still, the description Thomas gave of his mother's concerns illustrates the non-normative aspects of his transition. She knew his experience would look quite different from her own; and until the family found useful models through the mentoring program, her ability to envision her son's future was understandably limited. Although the youth of this study participated in a

mentorship program that provided strong disabled adult models, such programs are not

common (Daughtry, Gibson, Abels, 2009).

Alejandra felt torn as she considered decisions she might make in the future,

torn between doing what she might like and doing what would most please her mother.

As Alejandra qualified to receive In-Home Support Services (IHSS), money to be paid

to someone providing care to her, she and her mother developed a symbiotic

relationship. Alejandra would continue to receive personal care from her mother; her

mother would be able to pay rent and support her family with the IHSS payments.

Speaking about her mother, Alejandra said:

> I'm pretty open with her. She knows, or at least I think she knows I
> won't leave her alone with my brother because we rely on each other
> so much. But then again, she supports me in whatever decision I
> make. I've told her before…that I have to go, as soon as I turn 18, I'm
> moving. And then I get there, and I'm like, "I want to stay here
> forever." But I think I'm able or capable of moving out and living
> with a roommate or a cousin. But I know in my heart that I wouldn't
> want to leave her alone, that I wouldn't do that to her, not yet.

For Alejandra and some other disabled youth, a decision to move out of their

parents' home can be much more complicated than feeling confident in supporting

oneself. Commonly, mothers of disabled youth become the primary personal care

providers, combining this and traditional homemaking as their work. Having the

benefit of government assistance in the form of IHSS, mothers can support their

families to the extent they would with some other low-wage job and also be present to

care for their disabled child. In Alejandra's case, she understood what her own

moving out might mean for her mother who would no longer have the income of

IHSS. Knowing that her mother's life had revolved around providing for her needs for

many years, Alejandra felt a sense of responsibility to her. How difficult it might be for her to move out and cut off her mother's source of income!

Recommendations

The tensions that arise with disabled young people and their parents may be similar to those other young people and their parents experience in the competition of intimacy and autonomy; but, conceptions of disability, levels of care needed, public disability service policies, and a lack of access to workable models create nuances that are important to note. To support disabled young people and families, we might consider the following:

1. As mentioned further in Chapter VII, we can encourage people to see capacity and support agency. We can avoid "disability spread" and allow individuals to find options within interdependence. If one is capable of communicating her own needs at school, she should become responsible for doing so, rather than expecting her mother to speak for her. I do not wish to extinguish the close connections of young people and their parents, but would like to extend support networks beyond the family. If one needs assistance, she should know that it can come from a variety of sources.

2. Educators and parents can expand the possibilities for adult relationships by considering the balance of concern and silence with which we offer support during transition. In some cases, it may be useful to share concern with young people, as a way to open conversation to concerns they may wish to discuss. At other times, it may be useful to offer silence, as a way to show confidence in a young person's ability to handle decision-making.

3. Changes in public policy regarding IHSS could play an important role in providing a transition plan for those, particularly parents, who have served as long-term care providers. While the existing structure may offer sufficient provisions for parents and children, it creates an unintentional co-dependency in which a young person's decision to move out might mean taking away the family's main source of income.

4. Mentorship programs for disabled youth and parents can provide a space for families to see others performatively, conceptually, and creatively work through alternative forms of interdependence. Building on the knowledge of valuable models can allow disabled youth to find workable strategies without always reinventing the wheel.

Sibling relationships – "Make sure they know he's your brother."

In general, sibling relationships can have great impact on one's identity development. These relationships tend to be people's longest-lasting relationships. Siblings can play a variety of roles in disabled youths' identity development and can impact their sense of belonging. Stereotypically, siblings of disabled youth can be seen as patient and caring individuals; and in some cases, this view is accurate. Although the dynamics of various families play out in unique ways, I noticed that many siblings of the participants in this study took on one or more roles that I would characterize in the following ways: the ready assistant, the questioner of parents' actions, the social connector, and the boss. In considering some of these common

sibling roles, I want to focus attention on how disabled youth interact with and what they might learn from their place among siblings.

Ready assistants

Parents oftentimes tell siblings of disabled youth to "take care of" or be mindful of their disabled siblings. While "taking care of" siblings, disabled or not, is a common expectation in many families, it is not as common that younger siblings are asked to care for the older ones. Usually, it is assumed that the older child has developed more responsibility. Many of the participants of this study had come to rely on the ready assistance of brothers and sisters, coincidentally younger brothers and sisters. In these situations, it seems the assumption is that a nondisabled child has the responsibility that a disabled child, even if older, cannot manage.

At various times during my research, I gave youth rides to meetings or rides home. Three individuals who participated in focus groups, Luciana, Diego, and Micaela, had siblings who, in a moment's notice, appeared to pull a wheelchair from the trunk of my car and assemble it. Diego spoke about his siblings, "If I need help, they help me. If I can't do it, they do it for me." Often, siblings have clear understandings of when help is needed and when it is not needed. Salem and his mother both spoke about the way Salem's two younger brothers assisted him on a daily basis with dressing and showering. For some, this helping relationship is easy and comfortable.

Adam said that his mother tells his younger sister to help him:

> When my parents go out, like running errands or going out for dinner,
> my mom's always like, "Now, be sure you help Adam with whatever
> he needs."
> And sometimes she [my sister] says "Okay"… Sometimes, she
> reminds me, "You know, you could…"
> Sometimes, I feel like I ask help for things I don't really need that
> much help with. And then I'm like "Yeah, you're right."
> She says, "Adam, you know how to do that."

Adam said that, although his sister was usually willing to help him, she questioned his need for help at times. He admitted that her questioning or telling him that he could do it made him realize that he sometimes expects to get help when he does not really need it. Like Adam, many who are continually told they need help begin to act as if there is no other way. If no one is critical of this tendency, the individual needlessly relies on assistance instead of practicing skills.

Alejandra said that her mother expected her younger brother to be the ready assistant. She often told him to focus on his schoolwork because one day he would need to take care of his sister.

> We always have fights over this. 'Cause she always tells him, 'Oh,
> you have to do good in school and then you can get a job and you can
> support your sister.' And that's when I told her, I'm like, 'He doesn't
> need to do that! I can support my own self.' That's something that
> really annoys me when she says that...

Alejandra wanted to be seen as capable of taking care of herself. She said her grandmother also believed her brother should be ready to take on the responsibility of providing for Alejandra. Alejandra agreed that cultural beliefs about gender were at play, along with beliefs about disability.

At least my grandma, she's old school. She thinks 'the man of the house.' 'Cause my dad's no longer here, she thinks that he's the one that has to take over. But my mom, I think she sees it as a disability type, that I'm not capable of doing things he can maybe.

Alejandra seemed to accept her grandmother's view as an old-fashioned view, based primarily on specified gender roles, that a brother should be prepared to take care of his sister. On the other hand, Alejandra did not accept her mother's view, which she believed came from an idea that someone who is disabled cannot care for herself.

Disabled youth commonly interact with ready assistants, self-selected or appointed, and through these exchanges, may learn to communicate needs, to accept and decline assistance, and to see themselves as receivers, contributors, or other types of members. It is often during transition that the results of this learning become apparent.

Questioners of parents

In many families, children question their parents' beliefs and actions; speaking from my general experience of working with school-age children and of talking with people about their relationships, this is not something exceptional in families of disabled children. What I intend to address though is the way children question their parents' beliefs and actions in regard to disability, the practices that hint at parents' views of how a person with a disability is to live her life. This questioning differs from other questioning in that it comes at the differing experiences of parents and disabled children.

In the section above, Alejandra questioned her mother's expectations for her. In regard to how disability is viewed, disabled youth and their siblings sometimes become critics of their parents' views and actions.

Aside from questioning why her mother expects her brother to support her, Alejandra questioned her mother's idea that her brother would learn to drive first. Alejandra complained, "Like, she told him before, 'As soon as you turn sixteen, you're learning how to drive so you can get a car, so you can take us wherever.' And I'm all, 'How come I can't? You know, take driving lessons so I can get my car?'" In both instances, Alejandra criticized her mother's more narrow view of possibilities. Alejandra understood this to create unnecessary limitations, limitations on what she was capable of accomplishing.

While Alejandra had good reason to question her mother's expectations, these expectations were hardly surprising for several reasons. First, knowledge about how disabled people drive is not common, and not often available to parents. Second, the cost of adaptive driving equipment can prohibit low-income families from acquiring it. Third, access to adaptive driving instructors can be difficult to find. And fourth, the process of learning, licensing, and acquiring equipment is full of hoops and misinformation that create real barriers. Still, if Alejandra and other disabled young people could identify the limitation in resources, they would not need to carry the weight of identifying the limitation in themselves.

In some cases, siblings are active in critiquing parents' views. Teresa, Joaquin's mother spoke about the way Joaquin's younger sister questioned her when she did things for Joaquin. She laughed:

> My daughter would say, "Why aren't you letting him do that? Why are you doing it for him? He can do it himself."
> I go, "Oh yeah."
> So, I keep forgetting. And Joaquin, like always, he takes advantage of it. "Mom will do it. Mom will do it."

In this, Teresa implied that her daughter was right to question her and that the questioning helped her remember that she did not want to coddle Joaquin. Although one may recognize her son's acceptance of more help than is needed, distinguishing between supportive and overindulgent actions and changing patterns can be difficult. Teresa imitated the way her daughter scolded her for giving Joaquin more attention and the response she offered:

> "He's already going to college. He's an adult. Why are you concentrating? Why are you doing things for him? He should be out. He should be out of the house, he's already 18." You know, she's the baby so she wants all the attention.
> I go, "No. As long as he's living here, he's gonna get my attention and you [will] too."
> "Well, you do more things for him than me." She would say, "Why are you giving him that?"
> "Lorena, because if he does it, he's gonna spill it."
> "Well, let him learn."
> So I go, "Oh my God, she's become like I was before. She's telling me what to do." Maybe I am doing more things for him right now than I used to. I don't know. But maybe, she's just a little bit jealous that he's still here and that she's not the baby, I mean the only one.

This dialogue Teresa recreated did not show full acceptance of her daughter's critique. Parents of disabled youth sometimes notice their children's vying for attention and feel conflicted, in the way Teresa showed. Giving equal attention to all

children can be especially challenging for parents as some children seem to have more pressing or obvious needs. Making judgments about how much attention to give, how many spills to allow, and what kind of chances to take is the on-going work of families. Lorena's voice, like that of many siblings, rightfully served to bring these judgments into question.

Disabled youth often interact with questioners of parents and can learn to become critical themselves, to voice their own opinions, to think about their place in the family and the impact they have on others lives. It is often during transition that this learning becomes apparent.

Social connectors

Many people's first social connections involve siblings. In discussing how some siblings of disabled youth take on the role of social connectors, I consider the meaning this gives to disability. Individuals may take on this role if they notice a sister or brother's shyness or lack of friends. Some will push siblings to make friends, to join groups, and to get out of the house. Some invite siblings to go out with them or initiate friendship on their behalf. And even when they do not intend to help siblings make friends, many serve as a model to others on how to interact with a disabled person.

As one teenaged girl joined the mentoring program, her older sister accompanied her to our office. There, the sister confided that she wanted to help her sister get involved and make connections; she noticed her sister lacked friends and didn't understand why. "She talks to a few people at school, but she never wants to do

anything with them outside of school," the sister told me. With continued encouragement, the high school student attended mentoring events including a four-day/three-night stay in college dorms in which she made strong connections with other disabled young people.

Another mentee wrote in his blog about his sister taking him and his friend to a strip club. Aware that her brother relied on nurses for personal care, had limited access to privacy and fewer opportunities to socialize with young people his age, she encouraged him to participate in activities she believed others his age engaged in. He wrote about how she drove him in the family van, convinced him to get a lap dance, and then initiated interactions for her brother. Although we might question the value of an interaction within this context, the sister's ploy might have greatly expanded her brother's view of possibilities.

In both of these cases, the disabled young people expressed some hesitation in following their social connecting sisters, but complied with the sisters' ideas. The efforts made to involve them might have been crucial to helping youth recognize possibilities, to supporting and validating their sense of belonging and their sense of being out in the world. On the other hand, the social expectations of siblings may be hard to live up to for some.

Some siblings find they do not need to help a disabled sister or brother make friends. Teresa said Joaquin had friends throughout his school years who stood up for him. She explained what would happen if anyone made fun of Joaquin:

He would always have a little group saying, "Nope, you better not talk to Joaquin like that."
...he went to high school first and then his brother went to high school. I told his brother very seriously, "You make sure when you go to Joaquin, you make sure that your friends know he's your brother. Because if you start teasing him or you hit him or something…"
He goes, "No, I can take care of it."
And I go, "I don't care. He's got lots of friends."

She told Steven, her younger son, to make sure others knew he was Joaquin's brother before teasing him or hitting him. In this, she asked Steven to be conscious of the messages about disability he could teach through his actions. She didn't want him to be known for picking on a disabled kid and didn't want Joaquin's friends to retaliate if they didn't know who Steven was. Without volunteering, siblings act as examples to peers about what is acceptable or what is status quo when it comes to interacting with disabled peers.

These examples serve to illustrate a couple ways that siblings educate people about disability. They invite interaction. Their perspective about disability seems to be valued by others, as it is a nondisabled view of close proximity.

Disabled youth often interact with social connectors, those who take an active role in facilitating their siblings' social lives and those who serve as social models to peers, and learn to negotiate the meetings with people, to see the ways they fit in or do not fit in, to play into the positive or negative ways peers view disability. It is during transition that this learning often becomes apparent.

Bosses

It is not uncommon for siblings to boss each other around. Some siblings of disabled youth take on the role of a boss too, acting as one who dictates how others are to act. Some set rules for their siblings to follow and harshly judge what their siblings do and say. In my study, I observed a variety of ways in which sibling bosses set rules based on their own view of disability and how a disabled sibling must act.

One focus group participant, Paloma, said her older sisters always told her what to do and said that, often, their instructions were based on the fact that she was "handicapped." Paloma called one sister a hypocrite and said, "She yelled at me and told me I can't drink alcohol because I'm handicapped! I don't even drink much. I've never been drunk." The antagonistic and paternalistic role her sisters took had created much tension in the family. "I'm staying with my sister until I can find my own place. She won't even let me do my own dishes." Recently, Paloma sought the assistance of a social worker to move out on her own and is now living in her own apartment while attending college.

Disabled youth sometimes interact with sibling bosses, trying to direct their actions and decisions, and learn how to act, how to view themselves, when to fight, when to give in, how to speak, and how to be silent. It is during transition that much of this learning becomes apparent.

The situations and roles I have characterized cannot encompass all of the many possibilities that play out in sibling relationships, but can give us a glimpse of how young people's identities are impacted by these relationships. The learning that results

from sibling interactions can affect one's feelings about receiving assistance, one's skill within social networks, one's ability to be critical, and one's decision-making. Further exploration may help us better understand the impact sibling relationships make. Although I recognize that siblings of disabled youth often make sacrifices for their families and I commend scholarship that considers ways to support them, I focus my work on the identities of disabled young people. In this vein though, I would argue that support given to siblings would in turn benefit entire families.

Over-protection –"There's no way she can cut those herself."

The line between what is supportive and what is over-protective is blurry. We would like parents to offer encouragement and assistance that promotes learning and growth; but, at times, parents offer so much assistance that they prevent learning and growth[5]. Too much assistance, too much supervision, and too many restrictions can thwart a youth's development of autonomy, responsibility, and risk-taking ability. But really, the question is not just quantitative; what is important is how types or structures of interdependence are staged in relation to imagined future possibilities. This includes willingness or resistance to imagining eventual separation and whether the exceptionality of disability gives parents and their children an excuse to avoid or avert confronting this.

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[5] Benjamin (2006) found that schools can also participate in over-protection or what some consider coddling. She examined the reproduction of traditional femininities like that of "the sweet girl" in girls with special education placements. While the girls of her study took on identities that could easily attract help, they also saw themselves as perpetually needy.

The tendency of some parents and other family members to overprotect disabled youth can create significant challenges to gaining independence during transition. If we assume that parents and other family members care and want what is best for youth, it is not difficult to fathom how care habits form and, at times, turn into over-protection. In Joaquin's case, his mother carries his glass to protect him from a potential spill. In Adam's case, his parents assigned his sister to his service to protect him from struggling to do something himself. In Katie's case, her parents convince her to not move away to protect her from having to build a new network of support.

Often, parents believe that no one can care for their child as well as they can. In Chapter IV, I provided an example of this as Erica's mother, Janice described her discomfort with a situation that happened at a mentoring event when parents were seated for lunch in a room away from their teenaged children. When Janice foresaw that Erica needed help cutting her food, she wanted to jump to assist her. Even though Janice had been told that assistance would be available if Erica needed it, she was not confident her daughter would ask for help. In this case, Janice allowed Erica a chance to ask for assistance. As the exercise proved difficult for Janice, many other parents also struggle with letting go of roles they have needed to fill in other contexts. If parents do not resist the urge to help at some point, or break the habit, young people will not gain the experience asking someone outside the family for assistance, a task that is often difficult for disabled youth.

Katie's parents worried that she could not get adequate assistance if she moved away from home for college. Their concerns affected Katie's decision about which

college to attend. Rather than going to her first-choice school and living in a dorm,

she attended a local college and lived with her family. Katie, like many disabled

youth, was used to the built-in support of family and postponed taking on more

responsibility for herself and gaining more personal autonomy.

Although Katie and Erica may have been restricted from some independence

because of their parents' tendency to over-protect, other disabled youth experience

more severe limitations.   Salem's mother, Nadia, spoke about her wishes for a

program that would provide care for him and other disabled adults, specifically a

program that would help them be "safer."

> The other day, one kid in the wheelchair, he couldn't cross the street
> because the cars are going back and forth. It [the program] should be
> for everyone, the adults 21 or older. They need somebody to support
> them, to stay with them. That's my opinion. Some other people
> can…and walk on their own; but with the muscular dystrophy people,
> I think they need help.

Nadia was upset to see a wheelchair user crossing the street. She believed that persons

with muscular dystrophy should not be alone, should always have someone with them,

should be escorted safely across the street. Although beliefs like this come from a

desire to protect, they shows disregard for the capabilities of many individuals.

Without the use of glasses, Nadia's son had the eyesight to see traffic. Her son had an

understanding of physics needed to gauge how fast traffic would approach. Her son

had the ability to maneuver his power wheelchair across the street with precision.

Despite these abilities, Nadia would not allow Salem to perform such a task

independently.

This illustration of Nadia's over-protection could help us understand Salem's feelings of dependence. When parents believe a youth needs assistance all the time, he is likely to "need" more assistance, creating a greater dependency than is necessary. When Salem spoke about going to doctor's appointments and school meetings, he said he needed his mother or another family member to go along so they would know how to take care of him. In reality, Salem had the capacity to go to appointments on his own and then communicate results or needs to his family later; but he did not see this capacity. In other words, his perceived limitations greatly outweighed actual limitations.

When parents or others do tasks for disabled youth, they can prohibit the youth's development of responsibility. If they allow youth a chance to try to do tasks, they can develop responsibility. Thomas acknowledged changes in his own awareness and responsibility when he learned to accomplish more on his own.

> I think to myself, "Ahh, I'm gonna do this tomorrow. Never done it like this before, but I'm gonna give it a shot."
> Yeah, it's better to do it yourself, I think, 'cause you learn, you know, if you make a mistake you learn from it. When someone does something for me, I forget about it. Like, "Hey, I put your wallet and your phone here, get it in the morning." I leave without it, hah! But if I put it there, I'm gonna remember that. "M'kay, I'm gonna get that in the morning…"

In this, Thomas described the way he felt confident about trying new tasks. Having a chance to make mistakes can help one learn. Taking care of one's own belongings, wallet, phone, book bag, whatever it may be, can make him more responsible, help him remember to pick them up again. In the way that Salem's beliefs about his abilities mirrored his mother's, Thomas's beliefs about his abilities

reflected those of his parents. Thomas said, "Yeah, my dad kinda worked it in a little bit, you know. He said, 'You need to start doing this stuff on your own and you'll get better at it; and eventually, it'll just become a habit.'" When parents offer chances for young people to take responsibility, they are more likely to see their potential.

Helping the family – "I'll help you, Mom."

Disabled youth, like nondisabled youth, who contribute within the family gain confidence and skills that benefit them during transition. Seeing oneself as a contributor, as someone who has abilities, is a great advantage, especially during a time when activities, responsibilities, and routines are shifting. Disabled youth find a variety of ways to help the family: doing chores, watching siblings, caring for their own things, or even applying for and receiving government assistance. In some cases, they may even take on the emotional role of parenting their parents. These realities run counter to the notion of disabled youth taking on greater roles of dependence and create a more nuanced view of how interdependence more accurately describes relationships (Smith, 2001).

As Alejandra talked about sacrifices her mother had made for her, she said, "I just want a car so I can drive wherever and drive my mom wherever she wants to go." Being able to contribute was important to Alejandra. She said she sometimes argued with her brother about who helped more. She bragged to him that she used her SSI check to help pay rent. "I'm all 'You don't pay rent.' 'Cause in a way, I do pay rent 'cause, my check, I give it to her, so I don't get none of it. So it's, whatever I want, I have to ask for the money. I tell my brother, 'I pay rent here now.'"

Disabled youth are often aware of their parents' worries, and sometimes feel

burdened by their parents' worries or feel pressure to ease parents' worry. Youth

notice that parents often question how life will treat their disabled children. Even if

youth do not share the worries of their parents, they may feel responsible for the extra

stress their parents carry. Many disabled youth want to relieve parents' stress and be

seen as contributors to the family rather than burdens. Other disabled youth see what

their parents have done for them and feel like they want to help, contribute, follow

their parents' wishes.

As Joaquin considered the future, he was aware that his parents sometimes

worried about him:

> My parents are concerned that I will, not mess up, but make mistakes
> on my own. Like could I do this on my own? "I know he's gonna do
> it on his own, but can he keep it up and do it on his own everyday?
> Can he do this on his own, do that on his own?"

He believed they worried about how he would manage as an adult and he felt some

sense of responsibility to relieve their worries. Many youth understand that their

parents will not always be there and they may need to "do it" on their own. Joaquin

felt he should, "Let them know I can do it. Like go to the store by myself, pay my

bills on time; pay my credit card, my bank, and all that on my own." He wanted them

to be comforted knowing he could do it, that he could be responsible.

Many disabled youth take extra pride or get extra enjoyment from taking on

responsibilities within the family. Confidently, Katie told me that she loved taking

care of her younger siblings. She said she had taken care of them, "Since they were

born. Not with my 18-year-old [sister], she's like one year different, so not too much

babysitting. The eight and nine-year-old, I watch."

Similarly, Joaquin spoke proudly of his contribution "I pick up the living

room. I clean the bathroom. I clean my room, clean the yard, a lot of the things inside

the house, house chores."

Joaquin's mother, Teresa, said he always has wanted to help around the house.

She said, "He tries to do everything himself. He washes dishes when I tell him to

wash the dishes. Pick up his room. Take out the trash, the little one because he can't

take the heavy ones." Later, she described the way she expected to get more help

from her older son and the efforts Joaquin made to do his share:

> Here in the house, his brother used to do a lot of things. He used to
> help me more, with the heavy things, the trash and moving the
> furniture around. "Cris can you help me move the furniture? I don't
> want it like this. Let's change it this way." "OK." I couldn't ask
> Joaquin for that, he can't push. But sometimes, he would come, "I'll
> help you mom." "Are you sure?" "Yeah." A little, he helped a little;
> so you know, he's always been like that.

Although Teresa relied on her nondisabled son to do heavy chores, Joaquin also

offered to help move furniture when his brother was not available. When parents

allow youth to help, they are able to recognize and more fully use their abilities.

Connecting Joaquin's willingness to help and his desire to try whatever his brother

did, Teresa linked his abilities to her pushing him to always try.

> He always wanted to do what his brother did; so in a way, they helped
> each other. So if he [Cris] was climbing up something, he [Joaquin]
> wanted to climb up something. But I had to help him. That's the
> difference, his brother just jumped. But he had to go and do what his
> brother did. So I think that helped Joaquin a lot too. "If he can do it, I
> can do it." "Mom I can't do it." "But try. Try again. If you can't do

it, then do something else."   So yep, but at least he knew that he tried. That's the main thing.

This illustration provides a picture of a young Joaquin, active in following the movements of his brother, receiving assistance from his mother to keep up, and accepting the encouragement to try. In receiving encouragement and having opportunity to explore his own abilities, a young person can grow to see possibilities and strength in himself. With awareness of his abilities, he may want to use these abilities to help his family, perhaps continuing to prove what he can do, still pushing the limits of his strength.

Relationships within the family and the roles individuals take on do not determine one's outcomes, but do take part in shaping the identity of disabled youth. Interactions with parents, siblings, and other family members can provide experiences that empower or disempower, experiences that open doors or shut off opportunity. I included sections on overprotection and on helping the family because I think the ramifications of both have significant influence during transition. As I illustrate in Chapter V., common conceptions of disability uncritically support tendencies to overprotect disabled youth and also mask the importance of learning to contribute. So, a family's opportunity to see beyond a medical view of disability and beyond what scholars call the "myth of independence" could greatly impact the success of disabled youth.

Making Friends

Establishing and maintaining friendships can be a challenge for some disabled youth and a well-developed art for other youth with disabilities. The development of friendships is a particularly sensitive and sometimes complicated task, in which a failure to accomplish can lead to great disadvantage. In general, our institutions of learning and teacher training devote little attention to the problem of friendship beyond preschool years. In fact one could say the issue is patently avoided, and this is reinforced by the focus on standards and teaching only what can be quantitatively assessed. So with the lack of models for the non-normative aspects of negotiating friendships for disabled youth, this problem is further exacerbated. Lack of friendship cannot always be attributed to an individual's social skill; many external factors are at play (Baker & Donelly, 2001, Priestley, 2003). In my work with the mentoring program, I spoke to many parents who expressed concern that their sons and daughters did not have friends or did not interact with friends outside of school. In this section, I discuss some particular challenges disabled youth encounter in making friends and some strategies used to beat those challenges.

Real and perceived discomfort with difference – "They're staring at me."

One of the primary challenges for disabled youth in making friends comes in the form of real and perceived discomfort with difference. While children are often open to accepting difference or, in the least, curious about it, they may be prone to following the example of adults. If adults show discomfort with difference, in this case, disability, children may learn to show discomfort as well. Disabled children

become aware of others' discomfort, curiosity in the form of starring, and avoidance.

In some instances, they come to expect this kind of response from others, and may

learn to perceive these responses even when they are not there.

Joaquin's mother, Teresa, spoke at length about her efforts to help Joaquin

learn to socialize effectively when he was young. She used a direct approach,

speaking openly with her young son about how to handle starring and questions about

disability.

> "So, all you have to do is tell them what happened to you and why you
> can't talk." Before he couldn't talk, you know; with the speech, he
> talks better.
>
> They couldn't understand what he was saying… "Why are you on the
> floor? Can't you get up? Why are you crawling?"
>
> And I told him, "…Explain to them what happened, why you're like
> that; and if they don't accept it, that's their problem. You go and play.
> And if they keep teasing you, if they keep starring at you, just…turn
> around and say, 'What you looking at?'" And he did it!
>
> "What you looking at." Even [to] adults. You know, adults would –
> "What you looking at?" –they would get embarrassed. He would get
> mad because they were starring at him; and then when he would say
> that, they'd get embarrassed. And I'd go, "You asked for it! Sorry,
> that's my kid."

Although some parents might decide to shelter their children from the hurtful reactions

and comments peers sometimes make, children with disabilities can learn ways to

handle these situations without completely withdrawing. When Joaquin cried to

Teresa about the way other children responded to him, she told him to tell the children

why he moved and spoke differently. She offered him a backup plan, a way to handle

a situation when the explanation did not work. She suggested that he question people about their actions toward him with "What you looking at?"

With encouragement, children can learn to resolve differences and demand respect. Teresa was proud that her son took her advice and laughed at the thought of adults feeling embarrassed when he questioned them about why they were looking at him. She remembered that young Joaquin would say, "I can't walk very well. I can't move very well because I was born like that." Parents are often surprised by the effectiveness of their children's own communication skills. Teresa said she would never forget a time she had taken her sons to a McDonald's playground. She said three children were looking at Joaquin.

> He came over and said, "I don't think they like me, Mom. They're just starring at me and they don't wanna play with me."
> I go, "Joaquin, did you explain it to them? Did you talk to them?"
> "No."
> "Okay. Talk to them or tell them, you know, 'Leave me alone.'"…And he went over there and started talking, and I thought, "Oh my God, this kid is gonna hit him." Just…you know, the expression on his face like…saying…you know, talking to him, talking back to him! And I go, "Ohhh, my kid is gonna be crying right now." Five minutes later, they were all playing together…
> And I saw him, you know, making his face like this… I go, "Instead of [Cris] defending his brother, the other one [Joaquin] is defending himself." Yeah, they started playing together.

By talking to peers about disability, children can successfully negotiate a conflict. In this example, a mother's worry that her child could be assaulted is relieved as she allows him to negotiate the interaction. The expectation that a sibling could defend his disabled brother may ease a parent's fear, but will do little to prepare the child for future encounters. Teresa believed that the advice she had received from therapists to

not do everything for Joaquin, to not "feel sorry" for him, had helped her to teach

Joaquin how to interact with others.

Many parents of disabled youth have concerns about how their children will be

treated by their peers. They are not alone with these concerns. Research and efforts to

curb bullying in general have grown as a result of school violence. Scholars advocate

for curriculum to give youth coping strategies (Lodge & Frydenberg, 2005), and for

educators to promote accepting campus climates for all youth (San Antonio &

Salzfass, 2007), including those with disabilities (McDougall, DeWit, King, Miller, &

Killip, 2004). Some parents, like Teresa, do what they can to prepare their children

for difficult peer interactions. Others, like Thomas's parents, Alice and Robert, take a

different approach. Instead, they worked to prepare the community, to create a more

friendly community for their son. Alice explained that, on the teacher's request, her

husband went to Thomas's first day of kindergarten:

> Robert did a presentation to all the parents and told them about
> Thomas…what he could do and what he couldn't do. Kind of trying to
> prepare the parents to know that Thomas was just like any other kid,
> just had physical differences. The hope was that the parents…when
> their kids came home and started talking about Thomas, they would
> have answers.

Rather than arming the child with strategies for interacting with his peers, some

parents and teachers choose to prepare the school community to be accepting of the

child's differences. Like Thomas's parents, they act in hopes that they can help other

children come to see their child "like any other kid." Even though this strategy is

likely beneficial, it may not have the same strength as giving the child tools for

interaction. As Alice spoke about her efforts to help Thomas make friends, she

indicated that she may have gotten in the way more than she helped. She said Thomas had once angrily told her to leave him alone at one youth activity.

Although Joaquin received good coaching from his mother on how to handle others' discomfort with difference and Thomas received support from his parents' efforts to educate the community, many disabled youth are on their own in figuring out how to handle difficult interactions. Some parents work to protect their children from difficult interactions, keeping them isolated or encouraging them to retreat from not-so-welcoming situations. In Salem's case, the later onset of his disability created a social situation quite different than those of Joaquin and Thomas. As a young child, Salem had opportunity to interact with peers in school and on his soccer and baseball teams without the influence of disability. But these established relationships, based largely on the shared experience of sports, changed as Salem's muscles weakened and he no longer could play on the teams. Nadia, Salem's mother, said his soccer coach told them when Salem was 12 that he could not continue to play anymore since he was falling. Aside from losing physical strength, Salem began to lose the easy interaction he had enjoyed as a small child. Salem said that, when he was younger, he often got frustrated when his peers made fun of him because of the way he walked.

As Salem's social life changed, his family offered the support of their companionship. Nadia said, "We don't have him feel like he's left home alone or this or that. He's always with us. If we go to eat, he's with us. If we go to soccer, he's with us. If we go travel anywhere, he's with us." Certain that Salem should not feel alone, his parents took responsibility for spending time with him, offering a refuge

from the difficulty he experienced with peers. While parents' intentions are often to

protect, this sheltering does little to help one develop deeper relationships outside the

family. Parents then come to believe the young person is unable to initiate social

interaction. When Salem graduated from the two-year mentoring program, Nadia said

she wished there was another group he could join. She told me I should start a group:

> See, the problem, I think, is those people are scared to go on their own.
> They want a group to go. Let's say that Suzanne is responsible for that
> group. Suzanne will tell everybody what's going on and she'll take
> them there. They go.   But if you tell them go on their own, they
> won't.

Even though Nadia advocated for the creation of a group that would give her son a

new social outlet, she placed him in a category of "those people" who would be too

scared to initiate a social activity, unable or unwilling to make plans to get together

with friends. While my first suspicion was that Nadia meant "disabled people" when

she said "those people," I noticed that she did not include me in the group. Perhaps

she believed it was young, disabled people who needed assistance in making social

connections.

As the three youth discussed in this portion learned differing strategies for

negotiating others' discomfort with disability, they also experienced differing social

outcomes. Still, all three saw a need to develop ways to put friends at ease with

disability.

Even with his mother's early encouragement, Joaquin carried some social

insecurity with him into early adulthood. He told me, "Personally, I'm afraid that I

won't fit in. Like they're gonna judge me because I have a disability." Although

Joaquin had friends in high school, friends who served as his "backup" if anyone

bothered him, he did not spend much time with them outside of the school day. His

mother said he has gained friends through his participation in the mentoring program.

She explained:

> Before, I would go, "Why don't you call one of your friends from high
> school?"
> "Oh, maybe later. Maybe later." He was always here watching TV or
> he likes music. But now, he's calling –"Where are we gonna go?" --
> Beto or the other one. "Where you gonna go? What are you gonna
> do?" Or with the football, they met over here; they met over at his
> house or his brother's house. Now, they're meeting every other
> weekend.

Despite parents' encouragement to call friends, some young people spend much of

their time at home watching TV or listening to music. For parents who have

encouraged interaction and have witnessed their childrens' social skill, this can be

difficult to understand. Teresa seemed relieved that, after finishing high school,

Joaquin often called friends from the mentoring program and initiated getting together.

As a young adult, Thomas said, "I'm outta here as much as I can be." He

claimed that he was "pretty shy for the most part," but had found it easier to talk to

people lately. Thomas had three friends who were close enough that they knew how

to assist him with putting on his prosthetic leg. With practice, many disabled young

people become comfortable telling friends what they need. As a teenager, Thomas

went with his friends to the movies, to ball games, and to each other's houses. Alice,

his mother, imagined his future:

> He's an outgoing person. He really enjoys friendships, so I think that
> he will find people that have the same interests as him. Right now, it's
> video games and computers. Maybe that will continue to be it. But as

he gets into his career, he'll find people that have the same interests…
He won't be a person that stays home a lot. He never has been. I don't
think he will be.

The early worries parents have about their children being accepted by peers can fade or change shape. Some no longer worry about them lacking friends, but lacking the right kind of friends. When Alice persuaded Thomas to join the mentoring program, one of her main goals was for him to meet people who were more focused on going to college than his high school friends seemed to be.

Generally, Salem connects with friends, from high school and college, online to play video games. He does not see his high school friends anymore, unless it is online. Some of them moved away for college. Salem said, when high school is over, "It's very hard. You gotta keep in touch in different ways… computer, internet." PlayStation 3 had features he found useful, like messaging and voice chat. He said, "Like just turn on the machine and you're talking to them and it's kinda like they're here again."

Regardless of whether he met someone at school or during an online video game, Salem believed it was important to talk to friends about his disability.

Right now, a lot of my friends, we play online video games; and, they
know it's kinda hard for me to always be playing with them the whole
time because I need somebody to help me get in my bed and stuff.

So, they don't get mad if we're in the middle of a game and I just
leave them all of a sudden. They understand it's because I really need
help…

When I first get a friend, usually, I tell them about my disability
because I don't wanna surprise them at the end and be like, "Oh I have
this kind of disability and my muscles are dying off or my muscles
don't grow properly and they're weaker." So, I don't put them in a

position where they get upset about my disability. I make them think
it's OK. You know, life's gonna go on no matter what we do or
what's happening with me.

Although some disabled young people enjoy not having to disclose disability status in

online friendships, Salem saw importance in his friends knowing that he might leave a

game unexpectedly to receive assistance getting to bed. Some disabled young people

place high importance on putting friends at ease. Salem's effort to ease others'

discomfort represents a common sense of duty felt by many disabled youth, a duty to

quell any hesitation of those who may be judging the value of his or her friendship.

This social/emotional skill set, developed by some disabled youth, might be compared

to the skill set youth with other radical differences employ.

Experience with "give and take"

Friendship often relies on the ability of friends to find a balance of give and

take, to create a relationship in which both parties benefit. When many disabled youth

are socialized to be recipients, it can be difficult for them to see how they can

contribute. So, when disabled youth do make friends, some feel lucky or view their

friends as especially generous. With this belief, some youth believe being nice is the

best way they can contribute to friendship and often go to greater lengths to keep

peace.

Having heard from a number of disabled youth and parents about the youths'

lack of friendship, I gave considerable thought to the problem. As they participated in

the mentoring program, they acted quite sociable, greeting and conversing with

mentors and other youth.   At one point, I called one of the youth who had missed

several meetings. She told me she wanted to quit because she had not made friends

her own age, but instead spoke more to the adults. I counseled her that making friends

with adults was good and suggested that her maturity might make that quite

reasonable. However, I began to consider the different dynamics of her friendships

with adults. First, her mentor initiated contact with her; secondly, other adults

welcomed her and asked her questions without the expectation of reciprocation. I saw

this with other disabled youth, relying on adult friendships because of the fear of

initiating interaction with peers who may reject them. Within the confines of the

mentoring program and in many other situations where youth befriend adults, the

needs of the youth are privileged and the need for youth to include themselves is

limited. The problems of exclusion are exacerbated when disabled youth fail to

include themselves, perhaps fearing rejection, rejection they have previously

experienced.

Because disabled youth are often recipients of service, many miss

opportunities to learn how to reciprocate and experience difficulty in establishing

friendship. For this reason, a mentor relationship does not replace or fill the need for

disabled youth to find friendship among peers. Imagine how lonely it must be to not

have friends in high school! How can youth discover what they can contribute to

friendship? How can we teach youth to interact effectively, to have the confidence to

initiate interactions even when risking rejection?

Katie spoke about having more success with friendship as an adult. Her account connected her early difficulty with her peers' lack of acceptance and her own shyness. She said:

> I've gained more friends when I became an adult. Because when you're a kid, kids are less OK at first if you're different. And they're a little more immature about that stuff. And then when you get to adult, they're more accepting of you and they're more mature about it than that and they even try and help.
>
> The problem was, in high school, I was really shy. So, I don't know if that would have made a difference or not if I wasn't so shy. Freshman year and sophomore year, I was really shy because I was more into my books than social skills. And sometimes, the teachers would be more my friends and have to drag me out of the books to kind of socialize, you know.
>
> But my senior year, I got more friends and became more and more social. So it became a lot easier. And in college too, I was like I'm tired of being shy, toss the book aside and be like more outgoing and such.

Some youth use their transition from high school to mark a transition from being isolated to being more social. We might ask if making this later transition contributes to a different approach to relationships. Does it lead to a more self-conscious or thoughtful approach to interdependence, give and take, and the core basis of friendship? It is not uncommon for teachers, like Katie's, dragging her "out of her books," to befriend students who lack friends. Some youth use their transition from high school to mark a transition from being isolated to being more social. With this decision, Katie learned to be more outgoing, to contribute to interactions, and found success.

Accessibility of the environment – "They just stay in her room."

When Alejandra was a small child, her cousins always invited her over to their upstairs apartment to play. They were her best friends at the time. After Alejandra acquired a spinal cord injury at age nine, the visits to her cousins' apartment ceased and their friendship diminished. Ten years later, Alejandra still remembered how hurt she was by the loss. She said accessibility has continued to be an issue that affects her relationships. When she went out with friends to their houses, stairs would prevent her from going in some places; and when she could get in, she could not stay too long if the bathroom was not accessible.

Lack of accessibility in places where friendships tend to develop creates another challenge that has profound effects on disabled youth. Playgrounds with sand surfaces are only the beginning of exclusion for many disabled children. As they grow, they will likely find many parts of their homes, schools, and communities that are off-limits to them. Time with peers can be limited because of lack of accessibility. In school and outside of school, sports are the most common of extracurricular activities for youth; and, most sports communities have not found ways to include disabled youth. Visiting others' homes can be difficult or unrealistic. (This limits social life, but also limits the youth's chances of seeing how other households operate.) A lack of accessible transportation can prohibit disabled youth from going to the places where they could make friends and can prohibit nondisabled friends from inviting disabled youth to join in activities.

Mariana, Alejandra's mother, found a strategy that allowed her to maintain friendships and romances outside of school. She welcomed Alejandra's friends and boyfriends to their home. Alejandra said, "My mom's a really good cook. She makes food for me and my friends."

Erica's mother, Janice, noticed that her daughter never received invitations to her friends' homes. She had not considered accessibility. She only knew that Erica had just one friend who came to their house and that Erica had never been to the friend's house. As she spoke to me about it, she said, "They don't ever go anywhere. They just stay in her room. Oh my God, I never thought about it, but I could let them take the bus down to the mall." In this, Janice realized that there were reasons apart from her daughter's social skill that contributed to her lack of social activity.

Accessible transportation has impacted Thomas's ability to spend time with his friends. He recalled two breakthroughs for him; one, getting a power wheelchair, two, having access to the trolley. With a prosthetic leg, Thomas could walk, but not as far as his friends could. He explained:

> With the chair I have now, I can do a lot of things. I've taken that thing probably five or six miles. No problem, it just does it. And that's a big thing, 'cause I don't have to go, "Can I get a ride to this place?" I can take my chair. And I can walk with friends there, 'cause they can walk. They walk that far. So if they're doing something like walking down the street to Jack in the Box or something like that, I can go with them now, as to where usually I'd have to get a ride.

Having a power wheelchair or not can determine the ability of some young people to meet up with friends. Previously, Thomas would need to get a ride from his parents to go to places that his friends could walk to. Able to go with them now, he would more

easily make plans with his friends. Thomas situation provides an example of how some disabled youth can be excluded from or challenged in hanging out in their own neighborhood with friends. Katie, a college student who lived with her family, happily used public transportation to get to and from school, but found it would not take her to all the places she wanted to go. When her friends made plans to go to a karaoke bar, they could not offer her a ride in their cars; her power wheelchair could not be transported in a car. Katie said she was still working to convince her parents to allow her friends to drive her family's van. While Thomas and Katie needed access to mobility in order to go where their friends went, some disabled youth get stuck at their own inaccessible front doors.

  While working on this project, I noticed the prevalence of home inaccessibility. I documented this in my fieldnotes:

> I called to make sure I was at the right place. I told Alejandra I saw a "beware of dog" sign and heard a rooster crowing. She directed me to a steep ramp that led to her front door.   I doubted that I could push up the incline and doubted that Alejandra could either.

I visited Alejandra's house twice; and both times, her mother pushed me up and down the ramp as I came and went. She was available and helpful to me, but I was aware that I was not in control, that my decision to leave would get me nowhere without her assistance. This was Alejandra's reality every time she came and went. There was a time I could not get in and out of my parents' house; so, I understand the acceptance of this predicament. I was an adult before I ever expressed my frustration about the lack of access at what had been my own home. I imagined that Alejandra would never complain about how steep the ramp to her house was. Many of us have recognized the

extra things our parents have done for us, so complaining about imperfections or asking them to exert more effort just doesn't seem reasonable. . However, the lack of home accessibility can ruin one's chances to build friendships in one's own neighborhood.

Perceptions of maturity – "It helped me mature much faster."

Within families of disabled and nondisabled children and within conversations about disabled people, I have noticed a perception that disabled people tend to rest on one of two extremes, that of the extremely mature or that of the extremely immature. On one hand, some disabled youth are considered to have a particular type of social maturity or social awareness, perhaps a heightened sense of what others think of them, of how others react to disability. They often have dealt with taunting and rejection of some sort. On the other hand, some disabled youth are considered to have a peculiar type of social immaturity, a naïveté that may come from being sheltered or being left out of conversations. They too have dealt with taunting and rejection. My intention is not to prove these perceptions true or false, but to consider how maturity is conceptualized and how these conceptions impact people's relationships.

Maturity is often gauged in relation to normative aspects of development and it is not uncommon for researchers to attempt to measure it (Galambos, Magill-Evans, & Darrah, 2008). While certain abilities that are part of disabled youth's trajectory toward maturity escape the notice of others, we do not feel the need to confront these challenges or barriers. Robey, Beckley, and Kirschner (2006) claim that infantilizing attitudes about disability are common and largely outside most individuals' awareness.

So, not only do we fail to see disabled youths' abilities, but also fail to recognize the ways in which we act as if they are perpetual children.

Salem though viewed himself as someone who had matured faster than his peers and saw this as a benefit of being disabled. He said:

> Being in the wheelchair, it helped me mature much faster 'cause I had to deal with people when I was young…laughing or making fun of me as a person…how I walked or how I was… I used to get really frustrated with myself when I was really young; but now, I don't.

> I don't care what people think about me. I just care that they think I'm a good person. I don't care what they think about my disability. Like if they don't like me because of that, then there's no need to be their friend… Even if somebody makes fun of me, I never…I don't care.

Some disabled young people feel they have gained maturity as a result of being treated poorly by peers. When an individual views himself as more mature than his peers, does that make connecting with them more difficult? Salem felt proud that he had learned to not care what people thought of him and to see offenders as ignorant.

> They [classmates] changed and they're not getting in trouble anymore. They're doing something right in their life. It's always interesting to see somebody grow that way. A lot of my friends, they look up to me as like a role model for them; because, they know I'm a good person…

Here, Salem exemplifies the way some disabled young people feel as if they are not in the same place as their age peers. As Salem went on to talk about his high school peers, "getting in trouble," "doing something right," he referred to them as if they are children in his eyes. He placed himself as a more mature person, one who would watch others grow. Even though being mature may be viewed as an asset, in some cases, viewing oneself on a different level may be another challenge in establishing peer relationships.

Aside from impacting friendships, the perception of maturity or immaturity can also impact one's opportunities for risk-taking in transition. It can be a source of frustration for parents. Janice, a mother with concerns about her daughter's limited social life, felt frustrated by what she considered Erica's naïveté and lack of initiative in finding out how the world works. Janice said she tried to encourage Erica to ask her mentor, a disabled woman, questions:

> She keeps telling me, "I forgot. I forgot." I'm like…how was it that she began driving, and what types of things did she do to study for her driver's license test? And how many hours of on the road driving did she do beforehand? You know, does your disability require you to do more hours than another person? But she doesn't come back with any questions or answers or anything. And I think she just thinks the information is going to come to her without her asking. And that's what I mean when I say that she's naïve.

Sensing that Erica did not ask questions or was not receptive of the information her mentor offered, Janice called her "naïve and lazy," with the social maturity of an eighth grader. Although the frustration Janice experienced may have been quite typical of any parent whose teenager failed to take much initiative in planning for the future, it may have been amplified by her sense that her daughter's path to adulthood would be quite different than her own. Some parents presume that immaturity is related to disability. They wonder how they can safely let go of some responsibility when their teenager does not seem to have a grasp of it yet:

> It's maybe just the maturity level, and I don't honestly know if it comes with the disability or… I just don't see her at the level that she needs to be at. But maybe the job is kinda helping her a little bit, you know, because I see some growth in her. I don't know if it's the job or maybe the mentoring program even; but, she's starting to express her needs. And that's what I'm talking about. She doesn't express herself the way she needs to. She steps back and just expects people to know

what she needs. And I'm just hoping that changes. She does it with me too. Not just with everybody else...

Some parents, awaiting the day when their children move from expecting others to know their needs to expressing their own needs, search for signs of improvement. Janice thought she saw "some growth" since Erica had gotten a job and had been participating in the mentoring program. Without social opportunities, like having a job or being connected to a group, this growth may be quite difficult for youth to realize. But beyond that, a parent's perception that her daughter is immature will negatively impact the responsibility she is allowed to hold. Is it fair to withhold responsibility from her or is it necessary? Erica's story illustrates what may be all too common. When disabled youth near a transition point, adults begin to realize what skills they lack, and often find that self-advocacy, the expression of one's needs, has not been developed. Systemically, and more often than nondisabled children, disabled children are told what they need and are offered unsolicited assistance. How does this teaching against self-advocacy play into our perceptions of what maturity is? How often do we question the way institutional practice reproduces infantilization of disabled individuals (Priestley, 2003)?

Recommendations

Considering some of the particularities disabled youth experience in making friends, educators can think about how we might better support them. While we understand the value of peer networks during transition, we could offer better guidance in establishing them (Schuster, Timmons, & Moloney, 2003).

1. We can learn from Teresa's approach to teaching Joaquin to interact with peers. Directly instructing disabled children to confront discomfort with difference and expecting them to negotiate difficult interactions might help them understand and develop their own social abilities.

2. We can learn from Alice and Robert's approach to creating a friendlier community environment for Thomas. Efforts to build welcoming communities that understand and accept difference can be beneficial for all students as they need to feel a sense of belonging.

3. With cooperative activities, we can help disabled youth and their peers establish and value interdependencies.

4. If we take time to consider the accessibility of spaces where friendships tend to develop, we can realize that barriers to meaningful relationships are not always internal. We can work to create better access.

5. We can benefit from new frames for understanding maturity that exceed the often simplistic and uncritical ones that exert a great deal of social impact. New frames can account for the radical differences in social skills that people develop and find necessary in transitioning to adulthood.

The Role of Assistance

"Like, when I was a child, people would just do things for me,
especially my parents." –Katie

Within the above sections about family and friends, the topic of assistance

appeared in a number of places. This section expands on ideas about support, over-

protection, and give and take in relationships, looking closer at what assistance means

in the lives of disabled young people. As humans, we all experience needing

assistance, asking for assistance, accepting assistance, and declining assistance of

some kind; but assistance plays a much larger part in the lives and relationships of

most disabled youth. Although all people have needs, the needs of disabled people in

our society have long been deemed "special." What constitutes "special" needs? We

can assume they are needs that the average nondisabled person does not have. Having

needs that are considered unusual or exceptional, disabled individuals can experience

a myriad of uncomfortable feelings and can struggle with developing strategies for

both obtaining and resisting assistance in the midst of negotiating relationships with

family and friends. This section illustrates a need for a more open and flexible

language or discursive conventions for communicating about

assistance/interdependence in a culture that communicates very indirectly about the

radically varied needs for assistance among its constituents.

Several variables make communicating about assistance difficult for many

disabled youth. Often, family members who regularly provide care assistance come to

predict a youth's needs and will act without provocation. Consequently, some youth

expect that their needs will be met without any effort on their part. Still, many youth

who have come to understand society's negative view of dependence often avoid admitting need and become determined to be independent. Youth who have come to believe that being different is not acceptable fear what others will say, and then do what they can to blend in. Some youth confront the feelings of parents who "want to be there," who have supported their children and have come to rely on them as well. And, some youth, who find occasion to transition from the personal care of family to that of others, must develop strategies for maintaining safety and well-being, strategies that most people need not consider. In addition, disabled youth rarely have models for learning how to ask for and how to decline assistance while maintaining pride. These variables are considered in the following four subsections.

"I'm shy to ask for help."

Some disabled young people rely on their families for any and all assistance because it is difficult for them to ask others. Salem said his parents understand that it is hard for him to get help. He explained, "Sometimes, I'm shy to ask for help when I'm places. I feel like I don't wanna ask for help, but I really need the help." Most disabled individuals will hesitate to ask for assistance in some circumstances; and, many will forego what they desire to avoid the discomfort they feel in asking. Why is asking for assistance so uncomfortable? Most likely, commonly held views of dependence make us presume we will be devalued by those who assist us and by those who witness the act.

In some cases, individuals use these circumstances to test their own independence, to try out different methods, and gauge what is possible. Salem spoke

about wanting to do things on his own, "Sometimes, I don't want the help and I just keep struggling until I get something done. Usually I do. Sometimes, I can't open a door…but I always find a way to get it open even if I don't wanna ask somebody." By struggling with it, he knows that he can open a door independently.

Aside from concerns about being dependent, most disabled youth are sensitive to, or at least aware of the feelings of those who assist them. Some disabled youth become concerned about burdening their parents or burdening others with their needs. Describing the tasks that she expected to be difficult for her when she would move out of her mother's house, Erica said:

> Getting in and out of the bathtub… Washing dishes maybe, or doing laundry. Or um, that house type stuff might be hard. That's why I'm gonna have roommates with me. So I…at least if I need help, they're there when I need it… I don't want to have my mom help me all the time, especially now that she's getting older and it's getting harder for her to help me and stuff. I just wanna move out on my own, and be independent.

As transition nears, many disabled young people begin to consider what their parents have assisted them with. Erica believed that it was getting more difficult for her mother to assist her. Knowing that a number of tasks would be difficult without help, Erica said she did not want her mother to always have to help her.

Thinking about what his parents had done for him, Thomas said that a disabled child is "a little more work than a normal kid is." Thomas spoke about not being able to use the restroom independently when he was younger. He said, "I just wasn't strong enough to do it. Now that I am, I can go over to friends' houses and I don't have to call my mom or ask someone at the house, "Hey, I need help with the

bathroom!" you know?" Part of his delight in gaining the strength to get his pants up and down came in not needing to ask his mother to come get him and not needing to bother someone at his friend's house with the task.

"It's just that she wants to be there."

In a world of mixed messages, disabled youth try to balance the ideas that asking for help is okay and that being independent is key to success. These youth waver in decisions to accept assistance or decline assistance.

Sometimes, disabled youth allow others to do things for them because they believe others like to feel needed. It can be difficult to decline assistance that is offered. Alejandra offered an example as she spoke about her mother:

> Sometimes, she thinks I can't do certain things, but I can. It's just she likes doing them for me. …pushing me around. I can push myself. I mean, there's situations where I can't; but most of the time, I can. Also, I can cath [catheterize] myself and she insists that I can't, even though I do it at school every day… She knows now that I'm actually more independent and that I can do it all. It's just that she wants to be there just in case…

Many times, youth accept assistance because they do not know how or do not want to tell someone no. Some youth, like Alejandra, learn that others "want" to help, and as a result, will sometimes give up their independence to let others feel needed.

If one allows her mother or someone else to over-assist, she gives up opportunity to build her own capacities. Without practice, skills will not be fully developed. A reliance on assistance can limit one's view of possibilities. To open possibilities, one must learn to manage the assistance she needs, especially when assistance is needed to get up in the morning, to move from place to place, and to get

to bed at night. Rather than managing one's own behaviors, she must also communicate and coordinate with a care provider.

Receiving assistance from outside the family can often build one's confidence and sense of independence. During Alejandra's senior year of high school, she travelled to northern California with classmates to visit colleges.   In preparation for the trip, Alejandra asked a friend to assist her while they would be away from home for three days. She explained why having a friend in place of family was important:

> Because I get to do things on my own. And even though my friend
> was there to help me, she really didn't do much, you know… We had
> fun and we still talk about it. We even tell each other, "Maybe when
> you turn 18, we can take another one." We just need to learn to how to
> drive first… [laughter] And my mom wouldn't say no, because she
> knows I'm capable of doing it.

She was able to go on a field trip with her peers, take an opportunity that she would not take for granted. In imagining her future and considering the assistance she may need, Alejandra could now use this experience to broaden her view of possibilities. She imagined that she might someday live away from her mother and might need to live without her mother's assistance.

> My mom works with me to help me to cook and stuff like that. I
> mean, obviously, I don't want somebody to be there to help me out so
> that I will give up, but I have to learn how to do it first. [laughter] And
> if I have a husband, he can help me out; and if I have kids, then they
> can too.

Although Alejandra was accustomed to having her mother's ready assistance, Alejandra had begun to see that she could rely on others as well. She imagined that she might one day receive assistance from a husband and children of her own.

Oftentimes, disabled youth seeking more independence find themselves in conflict with parents or other family members about how much they should do on their own. This can be a precarious position, in which one may or may not consider the position of the other. Nondisabled youth also experience this type of conflict, but usually without the same degree of assistance-related attachment. Some disabled youth feel indebted to parents who have provided much physical assistance over the years; saying "I don't need your help" has potential to be particularly hurtful. Like Alejandra, they can work to balance their appreciation of parents and their experimentation with independence. Some choose rebellion; some choose compromise; others choose submission to their parents' lead.

"I need assistance in that."

When disabled youth realize they can live away from family if they like, they think about what they will need assistance with. "Like for me," explained Joaquin, "if I move out, I need assistance in how to do laundry, how to cook, clean the dishes." In making a transition from their parents' homes, disabled youth often need to learn to manage the care they receive. For some, this means knowing who to call when something is out of reach. For some, this means making arrangements with roommates to assist with certain tasks. For some, this means hiring attendant care and creating a workable schedule.

Learning to hire and manage attendant care, no small feat, could be compared to running a small business. One must learn to negotiate pay, set expectations, train, create and follow a schedule, and at times, to resolve conflicts and even terminate

employees. Along with learning these skills, one must negotiate questions of trust.

Will I be treated with respect? Can I trust that this person will show up? Am I safe in

this person's care?

Although Katie had not yet moved out of her parents' home, she had an

opportunity to hire an attendant to travel with her to a wheelchair sports event.

> No matter how much I want to be independent, I know that there are
> some things I cannot do without a person helping me. Especially at
> night and in the morning… I had to go through some connections…
> He helped me find a person that he knew through a group, I guess.
> And she was really good.
>
> She had reliable recommendations… I had to make sure I found the
> right person and personally meet her and talk to her instead of just
> having my parents meet her and such. So that was interesting. And
> just being out on my own in New York was really fun, you know…

Making an arrangement for one's own personal care is an important step, one that can

bring confidence and freedom to expand boundaries, if the outcome is as successful as

it was in Katie's experience. Unfortunately, many youth and families do not have

access to disabled adults who have experience with finding care attendants. Without

some guidance, having a successful outcome on a first attempt may require luck.

Along with receiving good advice, one also would benefit from experiences that

would lead up to this step. Prior to this experience, Katie said she had received

personal care assistance from outside her family on another occasion. She explained:

> One week, my family went on vacation and I had to stay home because
> I had school… So, I had a lady for a day, that was, two separate
> ladies. One came in the morning and one came at night…

> I'm a little hesitant just because of strange people…but as long as they have good recommendations and I practiced with them before, like the New York person, then yeah, I'm fine with that. But I was kind of hesitant with the two ladies… which is why I had my friend sleep over with me.

In this, Katie's parents arranged for two attendants to assist her while they were away, paying them with IHSS funding. Katie said that, although she was comfortable with having met the attendant who assisted her in New York, she was hesitant about the two her family had arranged for her. Having a say in who will be assisting with personal needs can make a significant difference in one's comfort and security.

When one needs daily personal care assistance, the reality of moving out of her parents' home will require careful planning. Considering her need for assistance, Katie said she and her parents thought it would be best for her to live with a roommate if she moved out. They worried about her inability to escape a fire without assistance getting out of bed. In many cases like Katie's, disabled youth needing assistance must consider the risks involved in living more independently and decide if the potential benefits are worth the potential costs.

"This bus driver didn't let me get on the bus on my own; he pushed me!"

Learning to communicate about needing or not needing assistance is a skill that many disabled youth work for years to sharpen. Unfortunately, good examples are not readily available. Even though, most people learn to communicate needs, different cultural meanings make this a different task for disabled people. As many disabled youth learn ways to ask for help or learn ways to survive without help, they find it's a real trick to learn to do this gracefully, to be effective and maintain pride. On the

other hand, disabled youth often encounter people who assume they need help and who sometimes step in to help without communicating. Handling these situations can be challenging as well.

Asking for and accepting assistance are skills that must be developed. The fears associated with asking for help may be as varied as the situations that require it. Fears of being denied, of looking helpless, of inconveniencing someone, of calling attention to the self, of being seen as different, of feeling humiliated are some common blocks for those needing to request assistance. Salem said that getting assistance became easier for him when he dismissed fear that he was "gonna trouble them too much." As young people practice this type of communication, a willingness to face their fears is only one step in the process. Ease and grace come as one moves toward knowing and accepting where her abilities lie. Accepting assistance for what one does not have the ability to do, while practical, threatens one's sense of pride until she reaches a certain awareness and skillfulness. With my own experience, I can illustrate this development. When I was a college freshman, I skipped meals in the cafeteria when my roommates would not be there, because I did not want to ask someone else to carry my tray. I had not yet learned how to balance a tray of food on my lap. I was afraid of the way others might see me. Years later, I accompanied my students to a college cafeteria. I held a tray on my lap, but knew that balancing a full glass of water with it was beyond my strength. In this situation, I did not hesitate to ask, "Would you carry this water for me?" I had gained an awareness of my own skills and had become comfortable in admitting what I could not do in that context. During

transition, youth often must work toward realizing skill and comfort in new social contexts.

During transition, disabled young people seek strategies for declining assistance as well. When Micaela began to use public transportation to get to school, she often told me about the way people interacted with her on the bus. One day, she complained, "This bus driver didn't let me get on the bus on my own; he pushed me!" Often, disabled people encounter others who make assumptions about what they need. Well-meaning others step in and give assistance, leaving disabled people feeling powerless or confused about how to react. In the midst of frustration from being misunderstood, many wonder how to decline assistance with clarity and without insult. Again, having a clear view of one's own skills and comfort in a particular context are helpful in developing a strategy for declining unwanted assistance.

Chapter Conclusion

A primary difference in the experience of the disabled and the nondisabled in developing and maintaining relationships is the negotiation of assistance-related interactions. As educators seek to promote healthy relationships and self-advocacy of disabled youth, an awareness of how family support impacts decision-making, how sibling interactions affect identity, and how youth negotiate barriers to friendship is useful to broadening our understandings.

Family support, in a wide variety of forms, often has great impact in disabled youths' decision-making, that is in ability to make decisions and in what they choose. An array of sibling roles offer youth interactions that inform the identities youth take

on for themselves. Tendencies toward over-protection can impede growth opportunity, but youths' desires to help their families can facilitate that opportunity.

The barriers to friendship, although numerous for disabled youth, can be circumvented. Strategies for handling discomfort with difference, for understanding how to participate in give and take, for achieving environmental access, and for managing perceptions of maturity must be developed and utilized.

In and out of transition times, and within particular contexts, disabled youth must negotiate assistance-related interactions with family, friends, and others. Learning to communicate needs while balancing feelings, hesitations, and cultural meanings is a complex task that must often be tackled with little or no guidance.

These important strands of relationship development intersect again and again in real and messy ways. Family interactions, friend interactions, and the real and perceived assistance needs are unique and dynamic threads that create colorful result in the weave of individual identity development.

VII. Seeing Capacity and Supporting Agency: The Impact on Disabled Youth

I am powerful. I make choices that take my life in directions I want to go. I imagine the many possibilities and ways I can access the world around me. Without my own individual agency, I wonder what unfortunate place I might be.

What happens when 13 disabled young adults—individuals who have come to believe they are powerless—convene in a circle with a problem to collectively resolve? *Silence…* Feminist and educational scholars have explored the notion of silencing in regard to women and other marginalized groups, referring to the way dominant groups or ideologies create barriers in which others feel unable to speak or act outside of their perceived role (Fine, 1991; Fine, Weis, Centrie, & Roberts, 2000). This chapter describes one component of an ongoing mentoring project with youth (ages 16-26) as participants in research designed to better understand how they approached the construction of their futures in anticipation of continued education in post-secondary educational settings and beyond. Observation and interview data reveal that for some of these youth, the opportunity to shape realistic goals for independence, education, and the freedom to choose viable means to independence had yet to occur. Prior educational experiences for these youth failed to include the opportunity to *Imagine if,* much less the opportunity to plan for such opportunity—as mandated by the Individuals with Disabilities Education Act (IDEA)[6]. In describing circumstances in which disabled youth meet opportunity with stillness and silence, I

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[6] The Individuals with Disabilities Act (IDEA) of 1975 mandated that public schools provide appropriate education to disabled children in the least-restrictive environment.

explore a failure of current educational systems and imagine how we can build on

critical teaching practices. Educational efforts to "empower" and "give voice" aim to

break the silence of particular minority groups, but too often reinforce students'

tendency to rely on facilitators. Within a disability context, this is especially

problematic as disabled individuals time and again are taught to see themselves as

always reliant on the good deeds and assumed better judgment of others. The failure

of schools to foster attitudes that enable individual agency among disabled youth is a

failure that allows gross injustice to continue, as it relegates too many youth to live

lives they have not chosen to live.

As we work to create a more equitable system for all, including disabled youth,

issues of power and agency must be examined and questioned. In my work with youth

with orthopedic impairments, I have repeatedly observed how the power of disabled

people has been limited as others wrongly place them in positions of incompetence,

inferiority, and submission. Terzi (2005) examines a "capability model," theorized by

Amartya Sen and Martha Nussbaum, as a workable model in which to consider justice

in terms of equitable education for all. The model takes into account natural and

social causal factors. Terzi (2007) discusses what justice is for disabled students,

asserting that education is a primary concern of equality in that it is crucial to well-

being. She insists that a lack of education is a fundamental disadvantage and

acknowledges that education involves both formal schooling and informal learning

through social interactions. By her analysis, a fundamental basic education would

promote literacy, numeracy, and scientific understanding, and nurture attitudes to

sociality, participation, learning functioning, exercise, play, practical reasoning, and deliberation. The emphasis she gives to a broader understanding of the role of sociality and life beyond typical literacy and academic skills within education is seemingly lacking in the education of many disabled youth. To build this broader understanding, we must consider how we view students' needs and help them learn to get those needs met, how we create environments that are interactive and interdependent, how we assess student learning, questioning meritocratic practices and achievement-centered assessment, and how we provide scaffolds and learn to critically judge when scaffolds should be removed.

At this time, I look at functionings that enable individual agency, or more specifically, the injustice that comes when these functionings are not promoted. I focus my attention on just a part of what Terzi defined as fundamental basic education, that of the development of attitudes to sociality and participation. I consider these attitudes to be those that give individuals a sense of belonging, contributing, having responsibility, being involved –not just letting the world happen around you. As Terzi writes about the just distribution of resources, she considers a number of complications including the controversy around limits on provisions that might take away from what is needed by others. She argues that provisions for fundamental basic education should be offered "as a matter of justice." Despite the educational debates surrounding the cost of educating disabled students, a large part of education is not zero sum, but instead improves learning opportunities for all. The provisions for which I argue in this chapter, the nurturing of attitudes that enable individual agency,

promise to benefit society as a whole. These attitudes could effectively be nurtured through widespread implementation of DSE in schools, and more specifically, by changing the way we imagine disability.

"Don't Touch Me": An Illustration of Undeveloped Agency:

In July of 2008, 13 youth from the mentoring program participated in "College Days," an opportunity to live in college dorms and learn about college life. For some of the participants, this was their first chance to spend nights away from the support and comfort of their families. Within the bounds of program policy, many of the participants would have new freedoms and opportunities to practice independence. Although youth knew each other from previous mentoring events, they usually had interacted with each other alongside their adult mentors. Educational and still unlike school, this context offered the support of personal care assistants and of staff members with disabilities who would see capacity in the youth that others educators do not.

On the first day of the event, members of the university's recreation staff facilitated a 3-hour team-building event with the participating youth. This particular event gave me greater insight into some serious challenges these youth encounter in particular contexts in regard to responsibility, problem-solving, and decision-making, challenges directly related to agency. Below I describe the participants' hesitation in taking active roles in the team-building activities and question the development of youths' agency.

The first set of activities, designed to warm participants up to communicating with each other, consisted of introductions, silly handshakes, and sharing about what risks make us comfortable or uncomfortable. All 13 youth actively participated at this point doing "elbow bumps" and "salmon handshakes" [7] while telling each other about their goals to go to college, earn degrees, have meaningful careers and relationships, goals that will not be reached in the absence of agency.

After the warm-up activities, the youth gathered in a circle as the facilitators presented the first challenge, a game called "Don't Touch Me," designed to give groups a chance to creatively solve a problem together. The game is often used to illustrate the barriers we place on ourselves and encourage thinking outside the box. The facilitators instructed, "You must all touch the center ring. You must all change positions. You must not touch each other. And when you're in motion, you must say, 'Don't touch me, don't touch me, don't touch me.'"

With time to plan and problem-solve, the youth all remained silent, waiting for someone else to take the lead. Eyes looked up, down, meeting the gaze of others, avoiding the gaze of others. Eyebrows rose. Minutes dragged in silence and finally Thomas suggested, "Let's take turns crossing one at a time?" More silence followed.

"Is anyone going to tell him what you think of his plan?" the instructor pushed. Watching in anticipation, the staff remained silently confused by the silence; and finally, some discussion ensued between two of the youth. The group, without a

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[7] Both refer to various types of handshakes youth learned as informal greetings. "Elbow bumps" described when two individuals each bent an arm and touched elbows togethers. "Salmon handshakes" described when individuals extended a hand to each other and wiggled their fingers and palms to imitate the way a fish moves.

complete plan, made an attempt. Without dictating a particular order, they planned to take turns crossing the center ring. Several youth touched the center ring and moved back to the outer ring. Some youth hesitated before taking a turn. Three youth remained in their original positions. Those who had taken their turns looked at the three who had not yet taken a turn and remained quiet, not offering any direction to those who waited to be told. After 2 ½ minutes, all of the participants had moved, but few had followed the "Don't touch me" rule and several failed to touch the center ring. Given a second chance, the group tried again and decreased their time, but still did little to cooperate or communicate with each other.

During the next challenge, a human-sized checkerboard lay as a maze in which the youth were to navigate. One at a time, the youth entered the maze with the goal of finding the way and leading everyone to the other side. At any misstep, the individual was sent out and another was sent in to try another way. The challenge required youth to watch each other and to help guide the next person. In the beginning, when one was expelled from the maze, he or she would not pay attention to the next attempt. From the sidelines, I hollered, "Help each other. Pay attention." I was frustrated that few took responsibility to help their fellow teammates or to learn from them. The game was half complete before the group began to work together and give advice to individuals in the maze.

I was surprised by the time it took to complete these two activities. More than that though, the youth's lack of initiative, hesitance in communicating ideas, and unwillingness to lead others troubled me greatly. I wondered, "Is this about problem-

solving or decision-making or communication or leadership?" The facilitators concluded the 3-hour session and packed up the props they had planned to use in additional activities, activities that had been cut from the session given that the activities described above took so much longer than anticipated.

Why the silence?

Why were these 13 intelligent youth unable or unwilling to share ideas? What silenced them? Thinking about the many team-building activities I'd participated in, I could not remember any that resembled what we witnessed here. The facilitator would later admit that these youth were incredibly difficult to engage, and that most groups warm up to sharing and implementing ideas. She said people need to feel very comfortable with their own abilities and with the potential reaction of the group before they will share ideas. I considered the possibility that the youth in my program were uncomfortable with their own abilities and the potential reaction of others. Yet my previous experience told me otherwise. These same youth had interacted with each other on numerous occasions; and among the group, recognition of individual ability was common. Within a community of disabled people, shared experience often creates a place where people can be quite comfortable with their own abilities. The "Don't Touch Me" activity required something else. It required a type of agency that would move youth beyond agreeing to participate or not, beyond agreeing to follow directions, to the realm of making the plan and directing the movement of self and others.

Minority youth are often socialized to be followers rather than leaders (Rist, 1970; Wilcox, 1982). This is certainly the case for disabled youth, as illustrated in this story; but few educators recognize or acknowledge how this happens. Like other minorities, disabled youth internalize messages that are given in formal and informal learning experiences, messages that place false limits on the potential of disabled people (Shapiro, 1999). These learning experiences work to further exclude youth from places in which attitudes toward participation can grow. In many cases, families of disabled youth partake in excluding them from activities that nurture attitudes toward participation. During the team building activities I observed, youth embodied a number of attitudes that indicated powerlessness:

- I am not a leader

- I must wait for directions specific to me

- Someone will tell me what to do

- Directions to the group do not pertain to me

- Minimal effort and less output is enough for me

- I do not need to help my peers

- I cannot help my peers

As silence plagued the group, their behavior suggested that they did not see themselves as leaders capable of using independent motivation, willing to take risks, willing to expose themselves to vulnerability. When several youth hesitated to move in turn and others remained in place, it was as if they expected someone to call them by name and give instructions to them. In seeing that most of the youth did not say

"Don't touch me," that some did not touch the center ring, and most did not contribute ideas, I wondered, did they not think that the directions were intended for them? Did they assume they could "get away" with minimal effort. When those who had crossed the circle offered no instruction to their peers, I believed they did not feel responsible or capable of helping others. Did these youth miss the part of fundamental basic education that nurtures attitudes to sociality and participation? Or rather, can we assume that educators have viewed this as fundamental to education? My sense is that educators view the nurturing of attitudes to sociality and participation as fundamental only for certain youth.

With support of special education services in schools, the youth in this group attended general education classes; and, I speculate they learned to participate by following along, but rarely had opportunity to lead. Without opportunity to make decisions, problem-solve, and lead action, one's agency is greatly limited. Terzi (2007) argues that "...an education consistent with enabling people to achieve well-being and allowing the exercise of agency, entails the promotion of functionings and capabilities pertaining to abilities and knowledge that enable them to become participants in dominant social frameworks..." Although I would hesitate to claim that these individuals lacked the ability and knowledge that could enable participation in all social situations, I do believe the illustration of silence indicated real limits, limits that resulted from lack of a fundamental part of education. And further, because the cues of this type of activity likely signaled a school or classroom-like context, these observed limits could be viewed as the

outcome of reinforcing passivity through positive or neutral feedback, and even more, of a lack of proactive training or modeling of independent initiative. Rather than completely lacking leadership-type agency or skills, these young people have internalized a practice of repressing these skills in particular types of supervised contexts. Although there are many ways to interpret the observation of this game and my judgments as speculative, my judgments are linked to a broader set of experiences that I have observed. With this in mind, I believe a nurtured attitude of sociality and participation in schools would ideally give students a broader view of their own potential roles as contributors in society and an idea that they might be more than followers when participating in activities. This research probed more deeply. The section below describes one participant's experience at "College Days" and her struggle with the expectation that she should actively engage in directing her own movement in social and physical space.

An individual case study of unsupported agency: Lori's experience

Without a nurtured attitude of sociality and participation, the development of agency among disabled youth can be severely limited. In this section, I illustrate the pervasiveness of these limits into all aspects of life for an individual. Lori, who didn't remember having any responsibilities in school or at home when she was a child, provided a vivid example. Her example, drawn from the group of youth with varied experience, could be considered extreme; however, it is important to note that the group from which she was chosen was an elite group, those who had graduated high

school or who were on track to graduate. At age 22, Lori joined the mentoring program with her mother's full support. Having attended community college for some time, she wanted to transfer to a 4-year college which would require moving away from home and closer to the college. Having relied on her family for attendant care, Lori did not see how it could work for her and said she wasn't sure if it was "God's will" for her to make the move.

As she participated in mentoring events, Lori did very little for herself and did not hesitate to ask for assistance with tasks she could otherwise do on her own. After one of the events, she hesitated to proceed fifty feet down the sidewalk where her family's van waited for her. "They're waiting. You'll be fine. Go!" I pushed. At another event, she feared getting in an elevator without a non-disabled companion.

Having convinced Lori to attend "College Days," an opportunity for mentees to stay three-nights in college dorms, the hope was that four days away from home would be challenging and good for her. Recognizing Lori's positive attitude, I felt certain that she would grow and we would get to witness something exciting. Before the event, Lori said she was excited but also was afraid to be left alone. We assured her she would not be left alone during the event.

During the team building activities on day one, Lori was one of the most passive participants. In the "Don't Touch Me" game, she not only remained silent, she remained immobile until directed. When she moved, she was not careful to touch the center ring, a central part of the whole endeavor. For the most part though, she stayed with the group throughout the day.

Later that evening, I heard that Lori was upset, that she had cried when two female assistants helped her get in bed. I decided to check on her and take her a walkie-talkie that she could use to call for help if she needed anything. Lori turned her head toward me, revealing tear-streaked cheeks, as I entered her dorm room. She had calmed down and was able to talk to me about what had happened. She described getting help from one personal assistant earlier in the day by saying, "She did it the right way." She then said the two personal assistants who helped her get in bed did not know "the right way." She said she worried that they could have dropped her on the floor.

I asked Lori if she told them how to best assist her. She said she did not. I asked her to tell me what the right way would be. She was not able to tell me; yet, she was angry that they did not know the right way. When I said, "Lori, you are an adult now. You should pay attention to how your mom and your sister assist you, so you can give directions to others who assist you. Others won't know what is best for you if you don't tell them," she began to cry loudly.

"I want to go home. I've never felt this way before. My mom wouldn't want me to stay if she thought someone might drop me. I don't want to stay here," she wailed. I wondered which took precedence, what she wanted or what her mom wanted.

I realized that my comments about being an adult sparked this crying reaction. I apologized, telling her I did not mean to hurt her feelings. Just as her crying ceased, two other staff members rushed into the room. Lori and I had forgotten the walkie-

talkie was on. "Well Lori, at least we know it works," I consoled and we both
chuckled.

When the other staff members left the room, I told Lori that it was all up to her.
"If you still want to go home in the morning, you will. I would like you to stay and
work through this, but you can go if you want to. I know your mom wants you to be
safe; but, I'd like you to think more about what you'd like instead of thinking about
what your mom would like. If you'd like, I can come back in the morning to help you
figure out how to talk to the assistants about how to best help you."

In the morning, I arrived back at Lori's room just after one of the morning
assistants reached her. From outside the door, I heard Lori giving instructions. I then
heard the assistant tell her, "No, that won't work. I'm gonna do something else."
They decided to wait for another person to help. I went in as the assistant left to help
someone else in the meantime. Lori said, "Suzanne, I want to stay. I'm sorry for
crying last night. I was just scared they would drop me and I was really tired."

Describing the actions of a care routine to attendant staff can be difficult, but if
you have never been in charge of directing personal care, it is made more difficult.
Describing how someone can help you when you are outside of your regular, familiar
limited space can be difficult. Communicating your needs when you have been living
with family who has always anticipated your needs can be difficult. How might Lori
have had the occasion to practice these skills? In high school? I later wonder.

When we, staff and youth, moved into the dorms together, Lori took notice of
the differing levels of independence each of us had. She asked individuals about help

they needed and then frowned, "Does that make you feel sad?" She watched me carry

a box of supplies and asked, "Do you live by yourself? Does anybody help you?"

"Yes, I live by myself. I have friends I can call if I need any help," I answered.

She said, "Aww, you're lucky. I have to have someone help me."

"Different people need different things. That's how the world works," I added.

Lori's questions revealed her awareness and feelings about her lack of agency. Her

comments suggested that she considered her lack of agency to be fixed, unchangeable,

resulting solely from her body's limitations. She seemed to have no awareness of the

great potential she had, no idea that her greatest limitations came in lacking an attitude

of sociality and participation.

As Lori began the new day at "College Days" having decided she did not want

to go home, I watched closely to see how she engaged in activities. During one

presentation, I sat beside her. Five minutes in, she leaned in and said, "Will you get

someone to help me go to the bathroom?"

I whispered back, "We just had a 15 minute break and you didn't use it. I will

get someone to help you this time. Next time, I want you to pay attention to when the

breaks are."

Her eyes got big and she said, "I don't have to go. I can wait."

"No, next time. You can go now. I don't want you to be uncomfortable," I

told her.

She shook her head and repeated that she would wait. She waited two hours

before asking again. I assumed that her initial expectation to leave class during an

important presentation came from her previous classroom experience. Did her

teachers ever question her need to leave class? Did they assume she did not have

bladder control? Did they not worry about her missing important instructional time?

Was this Lori's attempt at asserting the little power she believed she held? During the

remainder of College Days, Lori did not leave during instructional time.

Accustomed to having someone with her at all times, the absence of a one-on-

one assistant challenged Lori in several ways. I noticed that her facial expressions

could go from full smiling and laughing to frowning within a short amount of time.

Whenever she was receiving direct attention, she was all smiles. Whenever she was

not being engaged, her head lowered and she frowned. Given the fact that she

received one-on-one care at home and at school with someone assigned to be there for

her, Lori had learned to let others do any task that might comparatively be more

difficult for her. As a result, she believed she was unable to do most things. The

growth opportunity at "College Days" was great because assistants gave attention only

when it was needed. Another challenge of surviving without one-on-one care

followed having to wait for assistance. As Lori waited one evening for assistance with

her nightly routine, she seemed impatient. I asked her what part of her routine she

could start without help. "Can you get out your toothbrush? Can you put toothpaste

on your toothbrush?" I asked. I believed she could. She proudly told me that she

could brush her teeth after someone else put on the toothpaste. I can imagine that Lori

could have once attempted putting toothpaste on her toothbrush, missed the target, and

heard something like, "Oh no, let me do that!"

Lori, like some others, was uncomfortable including herself in groups of her peers or among those with whom she would have to initiate the conversation. I noticed that when Lori entered a room where groups were socializing, she chose to place herself with the staff instead of with her peers. She had learned that she would receive more attention, with less effort, from the staff. Other students have done this too, claiming they get along better with people who are older than them. Within schools, students sometimes are instructed to include others; but, how often are disabled students taught how to include themselves? Although inserting oneself into a group of staff members may have been a way to avoid the risk of rejection, it would not give the same rewards as sharing time with those who are not being paid to be with you.

At the conclusion of the four-day experience, students reported their biggest accomplishments during their stay. Lori proudly stated that she had learned to cross the street by herself and use the elevator by herself. At age 22, she finally had the opportunity to take these baby steps perhaps because it was the first time she was with a group of adults who assumed she could direct her body in both social and physical space. Unfortunately, four days in a different environment would not provide the learning she had missed over the course of many years.

Less than two months after her stay on campus, I learned that Lori had followed through with her plan to move away from home into an apartment of her own. I called Lori and asked if I could visit. She was so proud to welcome me into her own place and tell me about the personal assistants who worked for her. In the

months that followed, she quit coming to mentoring events, reporting that her care

attendants did not know where to bring her, never mind that we had sent directions. I

contacted her to schedule a follow-up interview more than ten times. Repeatedly, we

scheduled times; and when I'd call just before leaving, she would apologetically

cancel. One week, she cancelled and rescheduled three times. About to give up, I

realized that Lori likely had little control of her own schedule. When we finally met,

Lori told me that decisions she felt most comfortable making included choosing what

to wear and deciding what she likes and where she likes to go. As she described what

things in her life she was most proud of, Lori began to list, "I'm happy I live here and

that I go to college; I'm happy that my sister lives with me now and helps me; I'm

happy…" The rest of her list did not include anything that resulted from her

individual agency.

Lori told me that her tutor had not made it over that weekend and that when

she went to class without her homework, her instructor would understand. She said

she could not do the work without a tutor. She asked me what jobs she would be able

to do with a degree in communication. In order to receive tuition money from

Department of Rehabilitation (DOR)[8], Lori had to give up her desire to major in

psychology. Even that choice was taken away from her. How will Lori finish her

degree? How will she convince someone to hire her? Without the experience of

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[8] The Department of Rehabilitation (DOR) offers funding for education and training to
prepare disabled individuals for employment. Decisions about what program should
be funded for individual clients is often based on a counselor's view of the
individual's capacity and employability in the field.

making decisions beyond what to wear, how will she handle job responsibilities? How will she live the life she wants to live?

In describing Lori's lack of individual agency, I fear that some may read it as an illustration that depicts the powerlessness ascribed to disabled people. Instead, it should be viewed as one point along a continuum of power, neither the highest nor lowest point in the realm of possibilities for disabled people. Overall, it should be viewed as an example of how our schools systematically fail to provide fundamental basic education to some students.

An individual case study of supported agency: Thomas's experience

The spectrum of power, the realm of possibilities for disabled people, proves to be wider than that with which most people imagine. Some make many choices in how to live their lives, while others have few opportunities to choose their own direction. This spectrum also has multiple layers. The various layers, some of which are personal care, household chores, school achievement, financial management, relationships, and community involvement, are not always neatly connected. An individual can have a limited sense of agency in regard to her own personal care and, at the same time, have a great sense of agency in regard to schooling. Likewise, an individual can have an unlimited sense of agency in regard to her personal care and a restricted sense of agency in participating in the community.

To provide another example, I will describe another place along the continuum of power, a higher place, exemplified through Thomas's involvement in the mentoring program. Thomas, a high school junior with an impairment that affects his limbs, also

began the program with the full support of his parents. When we first spoke, Thomas told me about his goal to be a sports writer. Born without arms, Thomas leaned his right shoulder forward and used his small hand to give his signature. His parents told me about difficult medical decisions they had made and about how they tried to include Thomas in the decision-making process. They told me about his dad's ingenuity in designing tools that would help Thomas be more independent, shoes with angled soles to make walking possible and grabbers to make reaching without arms possible.

As we prepared for the "College Experience," I learned that Thomas would need daily assistance with putting on and taking off his prosthetic leg. Thomas was comfortable receiving assistance from non-family members as he had taught a few of his friends how to assist him when he wanted to stay the night at their houses. During our event, he would receive assistance from personal assistants hired by the mentoring program. However, Thomas was concerned about how he could manage attending a week-long journalism workshop a month earlier. His parents considered taking him and picking him up each day, a plan that would work, but would exclude him from the social experience of living in the dorms with his peers. Instead, they arranged to hire a personal assistant that Thomas knew through the mentoring program who would go to the dorms in the morning and then again in the evening. Thomas's success at the journalism workshop spanned multiple domains. Not only did he earn the highest scholarship award and write three articles in the group's youth publication, he also managed his first experience with hiring an assistant for personal care needs.

After his success at the journalism workshop, Thomas arrived at the "College Experience" with confidence. When he finished his own moving in process, he volunteered to direct others to the appropriate dorms.

During the team building activities, Thomas stood out as the leader. He seemed to understand more than others that he could be a contributor. Although he had a laid back style and was not a big talker, he broke the silence of the "Don't Touch Me" game by offering an idea on how to manage the task. At free times, he brought out his football and initiated outdoor games. He involved other youths who were not yet engaged in the casual interactions of free time. In addition, he offered to help wherever he noticed a need. He delivered messages for staff members, used his grabber to retrieve articles dropped by others, and accompanied those who did not know their way around.

During lunch one day, Thomas and another young man included me in a conversation about wrestling with siblings. Thomas said that although he did not have siblings, he had wrestled with friends. "I quit though because I didn't want to kick anyone in the head," he said.

"Kick anyone in the head?" I laughingly questioned. Thomas explained that his prosthetic leg could potentially injure someone seriously. He did not express worry about getting hurt by a non-disabled peer or about not being able to defend himself. I was amused and grateful that Thomas instead recognized, within his own strength, an ability to hurt someone and consciously chose to not use that ability.

Because Thomas is five years younger than Lori and still in high school, I cannot yet compare the effect his confidence will make on his transition to independence. However, I can say that Thomas's earlier experience with decision-making and problem-solving have already allowed him to achieve some independence that Lori has yet to feel. The road for him will most likely not be frightening in the way it has been for someone who has lacked these early growth opportunities. It is difficult to locate the complex processes that result in the different sense of agency represented by Thomas and Lori. How do we sort out the role of schooling, home, and other informal learning experiences in developing their sense of agency? How do these learning experiences come together?

How did this touch me?

As I wrote about the "Don't Touch Me" activity and about the vastly different experiences of Lori and Thomas in the sections above, I felt as though my own anger could not be adequately expressed. I described the way many of my people, people like me, had unfairly been held back, held back from establishing the individual agency to visualize and choose the life they lived. I described the stark contrast between one who has been given opportunity to see his own capacity and one who has not. Society's failure to see individuals beyond the labels of impairment has prohibited too many disabled people from accessing what Terzi (2007) calls "effective freedoms." Even while I illustrated some very unfortunate and sad situations, I believe I failed to express the overwhelming disappointment I feel about those who participate in this system. How can so many families fail to see and nurture the abilities of their

children? How can they neglect teaching responsibility? How is it that they give so much time to caring for without considering what a child can do for herself? How can teachers hold disabled students so separate from others that they fail to teach them decision-making, fail to allow them opportunities to lead, to grow, to speak up? How is it that so many school administrators leave educating disabled students to special educators who have such little expectation for "these kids"? How is it that a system with legal mandates for inclusion and I.E.P.'s, set up to consider individual learning needs, so miserably prepares students for life after high school? How is it that no one in the system wants to be accountable for the learning and outcomes of disabled students? And finally, why are so few people ready to acknowledge the extent of this injustice?

I want to offer suggestions for change. In this section, I reflect on my positionality as a woman with disabilities and think about my own privilege being a result of my access to learning experiences that fostered an attitude toward sociality and participation. I begin by describing my positionality and then discuss some of my own formal and informal learning experiences that have contributed to my own sense of agency.

Like the youth in my study, I lack certain functionings that the average person my age has. Specifically, I am not ambulatory and I have other muscle weaknesses as well. Although I have experienced disability discrimination, I have been able to make decisions that have helped me to lead the life I want to live. I moved from Kansas to California. I became a teacher. I have assumed positions of leadership in places I

have worked. I have pursued graduate degrees. I am the one who makes the decisions that most affect my life. Now, as I work with youth with orthopedic impairments, I often compare my experience to theirs. I see similarities at times, but often see differences that result from privileges I have been given. Strangely, that privilege is having had the fundamental basic education Terzi deems necessary for social justice. My education has had its flaws. I could write a book about them. But here, I will focus on the experiences that I believe were just. I see a number of ways that my parents and teachers gave me opportunities to develop individual agency.

I remember as a small child being given the task of folding washcloths and the task of setting the table for dinner. My mother would place the plates and glasses on the table and I would place them around the table. She allowed me to pour or dump ingredients into recipes as she cooked, telling me I was helping. As I grew, I learned to take on more. With a chair pushed up to the sink, I could kneel on it and wash dishes or wash vegetables. At age 9 or 10, I was responsible for gathering chicken eggs from the nests and washing the eggs to sell.

I was 12 when my mother returned to work, dividing more of the household chores to my siblings and me. Summertime meant time away from school and more responsibility at home. My two older siblings had already taken jobs away from home, my sister babysat and my brother worked in the field. This left me in charge of watching the younger kids, including my two-year-old sister, making lunch, and doing the family's laundry. For this, my parents gave me an allowance in which I could use to pay my way into the public pool and to buy my own school clothes in the fall.

I remember getting angry when I'd hear my mother talking to someone on the phone about my impairment or anything related to it. However, I remember feeling proud when I heard her mention what I did for the family or how well I did in school. I know it was not easy for my mother to let me do chores and try to do them independently. After burning myself with the iron while doing a craft project, she forbade me from using the iron. On several occasions, she lost patience with how long it took me to do dishes. She would say, "You're done, I'm gonna finish," and I would snap back, "You gave me a job, I'm gonna finish it."

In school, I was not segregated from my peers and learned to make friends easily. When I needed help carrying my books or getting to another classroom, teachers left it up to me to ask other students. Teachers came to see me as a good student. They asked me to help other students and told me I was good at explaining things. I remember taking my turn at being "in charge" when a teacher stepped out for a phone call. I remember teachers asking me to deliver messages, to retrieve supplies, to help grade papers. They helped me see that I was a contributor. Teachers helped me feel confident in my abilities. When I began high school, I decided I did not want to have physical or occupational therapy anymore and told counselors I no longer needed an IEP. My parents and teachers supported me in that decision and my special education services were discontinued. In high school, I was encouraged to take part in school activities and student leadership. I am certain that the space to take responsibility, to problem-solve, and to make decisions on a daily basis helped build my sense of agency.

Recommendations

Although I do not want to claim that my educational experience can be or should be replicated for other disabled students, I do want to use my experiences and the experiences of the youth I work with to identify some keys to nurturing attitudes to sociality and participation and make recommendations for change. These keys depend on challenging and changing dominant views of disability. While I cannot specify exactly what the implementations would look like, I expect educators to engage in this discourse and begin to make change. Below, I offer seven recommendations:

1. Schools can offer disabled youth opportunities to lead. By allowing youth to assist with classroom tasks, teachers can help them view themselves as capable contributors.

Teachers are challenged with the often-complex task of dealing with difference within the classroom. Recognizing the various ways in which individuals can contribute may take time, especially since many teachers have been taught to focus on inability of disabled students. Working with a class of teacher interns this year, I asked them to read a letter pulled from the file of a disabled student. We talked about the images the letter created; they said, "bed-ridden," "a death sentence," and "maybe the girl can't walk or move her arms." One intern said, "It's a neurological condition, so maybe the disability will be physical and not cognitive. Oh, or maybe it will be cognitive." The well-intentioned group decided that if this student attended their class, they would speak to the mother about the girl's abilities, but would not expect too much from the student. When I told the interns that this particular letter came

from my own student file, they were surprised. "This is you?" they asked. The image created when one focused on my impairment was an image that was quite different from the image these interns had come to know through their interaction with me as their instructor. With a focus on impairment, how can teachers view their students as contributors with potential to lead?

The need for teachers and schools to change the way they see disability is crucial. Current systems reinforce ableist conceptions that make it difficult for individual teachers to rethink the way they interact with disabled students, to see the real capacity for learning that each student has.

When teachers do see beyond impairment, they can find potential for all students to lead and contribute. What does it mean to lead? Our conception of leading should be broad and should grow from the abilities our students have. Leading, for any student, may be making decisions about what she wants to learn, offering a solution to a problem, collecting materials for a group, or listening to a classmate practice a skill. As I have planned activities for cooperative learning groups in my own teaching, I have stopped myself from choosing group leaders who I perceive to be the most skilled at managing a group. Instead, I have offered support in the form of oral and written instructions to group leaders to help them build on their own abilities. Javier, a student with a speech impairment, might learn that his listening skills can help him facilitate turn-taking during his group's discussion. Alicia, a student with a cognitive disability, might learn that she can lead a group in learning by asking questions even when she does not have all the answers.

In some situations, teachers may need to negotiate some students' tendencies to take over the leadership or decision-making roles when it is not their turn. Their prior experiences may have taught them that they are the appropriate leaders. In these cases, teachers have an opportunity to model for students how leadership can be shared, how all contributions should be valued, how various abilities can be utilized, and how the status quo can be interrupted.

It's not possible to prescribe exactly how these leadership opportunities should unfold in every classroom; but it is crucial that we make a priority of giving leadership opportunities to disabled youth. Teachers can take ownership of how it will happen in their own classrooms. If teachers want it to happen and make it a priority, they can find unique ways to do it.

2. Schools can offer disabled youth opportunities to act without always having direct instructions. Without the chance, youth cannot practice decision-making skills.

In efforts to make sure disabled youth keep up, understand, and feel included, sometimes teachers inadvertently provide scaffolds that they forget to take away. There seems to be a difference in the shape and dimensions of scaffolding for people with differing abilities. For some, permanent reinforcement is used instead of temporary scaffolds. The fine lines of what functions as scaffolding and what functions as infantilization need to continually be examined. When it comes to giving instructions, teachers often make it part of their routine to repeat instructions to certain youth, giving them just one step at a time. While this may be necessary in some cases,

it should not be an ending point. If youth come to expect this repetition, they need not take on the task of seeing the whole picture or understanding the whole process as connected. In cases where students receive one-on-one assistance from a classroom aide, students learn that they do not need to understand directions because someone else has that responsibility covered.

If we consider a student's zone of proximal development, we might see her ability to work with the support of a more capable peer and imagine that, with time, she will be able to complete the task with less support. Moving from direct instruction to indirect instruction is a way to begin taking scaffolds away, allowing her to work with less support. Indirect instructions, as opposed to direct instruction, might be those students read in a book, those taught through the act of modeling, and those that could be assumed after having previously completed a similar assignment. In Lori's case, she learned to cross the street independently during "College Days" when scaffolds were given and then taken away. She followed the direct instructions of a more capable peer who modeled how to stop, assess the traffic, and proceed together when crossing was safe. Later, she was intentionally left far enough behind that she would need to try the steps without the support of someone right next to her. Previously, when Lori believed that someone would always be with her crossing the street, she saw no need in learning to decide if it was safe to cross, as that responsibility belonged to someone else. In this, she had failed to realize that she could be as capable as someone else. In believing that someone else is always more capable, one becomes powerless in decision-making and in taking action.

3. Schools can offer disabled youth opportunities to identify their own needs and their own solutions. When youth need assistance, they can learn to articulate their needs and direct the assistance they receive. One-on-one assistants should not take-over tasks that the students can do.

Schools often focus on students' inabilities and label those with disabilities as having "special needs." The approach has negative consequences for the students, including the assumption that disabled students are not able to identify their own needs or find their own solutions. This recommendation, like the others, is something that should be considered for all students. I propose that the guidance and encouragement to articulate needs, which is more often given the non-disabled population, be given to disabled students as well.

Those offering assistance to disabled students should be critical, considering whether the students need assistance or desire assistance. When students become accustomed to unnecessary or excessive assistance, they may begin to view themselves as incapable. They may find themselves waiting for assistance on tasks they could do on their own. I visited Lori on a day her college math tutor was unable to work with her. I offered to help and was not surprised that Lori wanted me to write the problems in her notebook. However, when I handed her the textbook and asked her to read the problems to me, she had difficulty finding the correct numbered problem to read. Could it be that her tutors had not expected her to participate in that way before? When it comes to an individual's learning, shouldn't we ask for

maximum participation? In distinguishing between needs and desires, we should see a student's capacity and avoid underutilizing her ability.

Perhaps we could differentiate the types of assistance we give, rather than lumping all types of assistance into what can be seen as a patronizing mass of help. What if we coded assistance as "temporary," "remedial," "instructive," etc.? What if we were direct in acknowledging the context of assistance? How might this make a difference in the affect of students? How might it aid in removing the stigma of needing assistance? If one receives "temporary" assistance, will she be more likely to take responsibility? If she receives "instructive" assistance, will she be more likely to visualize the expansion of her own abilities? How might this coding help those providing assistance refrain from giving more assistance than the individual needs, a well-meaning but patronizing tendency?

As we teach all youth to advocate for their own needs and their own desires, we can and should include disabled youth. Why is it so often assumed that disabled students cannot learn to find their own answers? Disabled students can be given opportunities to identify the way things work for them. How can they learn to make decisions if someone else always makes the decisions for them? I vividly remember an instance from my own childhood in which my 5th grade teacher decided that I could not walk the distance my peers would walk on a field trip. I was not only angry that I was separated from my peers, but also that I was not allowed to decide for myself. Now, I wonder how encouragement to articulate what I thought was best could have better served me. As a young person who could recognize when a distance was too far for

me to walk, I did not learn to tell others, but instead waited for others to offer solutions

to problems they may or may not have realized. This left me in many difficult

situations, smart enough to visualize answers and unable to communicate them.

During transition, many disabled youth encounter situations in which their ability to

communicate their needs is tested. Leake & Cholymay (2004) found that this

becomes a significant challenge for disabled college students. After attending

secondary schools that are responsible for identifying the needs of students under

IDEA, they find themselves following new rules in which they must become

responsible for communicating their needs.

When adults allow disabled youth to take on responsibilities related to getting

their own needs met, outcomes can be unpredictable. What happens when youth make

poor decisions? We must question tendencies to protect, or over-protect disabled

youth and consider making mistakes as part of development, a way to learn. A high

school student I know received his first power wheelchair and enjoyed the freedom of

independent mobility in his neighborhood. Having forgotten to charge the battery, he

ventured to a nearby park on his own and ran his battery dead. I don't know the details

of his rescue, but heard that his mother grounded him from going to the park. I wish

we could recognize what was a great lesson with built-in consequences –you don't

charge the battery, you get stuck!

Within the discourse of special needs, teachers accept and perpetuate the

position that disabled youth need assistance and usually need the assistance of

specialists. We should recognize that "special needs" are imposed by a framework of

"normal needs" and that a special need is usually viewed as an excessive lack. Must disabled students feel that their needs are abnormal? Must they take on the belief that their "special needs" signify a timeless and unchanging lack? What other beliefs do students gradually take on with the prevalence of imposed assistance? By contrast, we might consider the contextual nature of needs. Do we recognize how existing structures create needs? While I was a college student learning to teach years ago, I observed and tutored at two different high schools. At one school, I came and went and was known as a contributor. At the other school, I was known as a college student with special needs because there was no ramp at the school's entrance. Did the lack belong to me or to the school building?

We might also think about using the term "special desires or wants." Would this language be enough to highlight individuals' agency and move us away from seeing lack? In this sense, what makes my needs any more special than those of my non-disabled peers? But, we often consider meeting "needs" as priority and meeting "wants" as a luxury. How could we learn to prioritize what should happen if we do not use "needs" language? If we move away from the discourse of special needs, might we expect a wider range of students to communicate their needs and participate in finding solutions? Too often, when we consider needs to be so "special," we create an atmosphere where people believe that no one is "specialized" enough to meet the needs. Rather, can we be open to viewing needs as needs and help youth learn how to get their needs met?

4. Schools can hold disabled youth accountable to following classroom rules and instructions. Without being denied accommodation, youth should not be taught to expect exceptions to always be made for them. If accommodations require individualized instructions, these instructions can build on the instructions given to the entire class, keeping the youth connected to the group.

"Here's how we're all going to do this. Well, except for you." This is one sure way to push someone out of a community of learners. In establishing classroom rules, all individuals should be considered. Rather than exceptions, it may be useful to think of accommodations as creative transformations of learning opportunities. When possible, coming up with an accommodation can be treated as an interactive or participatory challenge (that involves at least the affected student, but perhaps their peers). If youth believe exceptions will always be made for them, they may not contribute what they are capable of contributing, they may disregard lessons as not applicable to them, they may accept the status of an outsider. That said, there should be room for accommodation when it is reasonable and when it enhances learning.

Many teachers question the difference between a "crutch" and an accommodation. This is a difficult question to answer. Rather than considering accommodations to be good or bad, we might think about accommodations as a way of being flexible. In this, accommodations need not be what a teacher does for a student. I've heard a yoga instructor say to her students: "If you are unable to do this position, make an adjustment that works for you." What a great way to say I

understand individual difference, but I still expect you to work. The same instructor will offer alternative suggestions on how to accomplish the same end.

Finding balance between hard and fast rules and excessive exceptions is crucial in developing an inclusive classroom. All students can be held accountable to participating in the community as they can.

5. Schools can provide disabled youth with opportunities to contribute their own ideas and to share their perspective. They need to believe their ideas and perspectives are valued.

Part of the willingness to share ideas comes in the knowledge of how those ideas will be received. Disabled students often learn that their perspective is not valued and not desired. With this perception, many are unwilling to contribute what they know.

Although many schools of education now teach about student-centered pedagogy, few recognize disability as an important and valuable identity marker. Curriculum often leaves out or marginalizes disability experience. When we do find disability in the curriculum, it usually reflects a deficit model of disability, which causes students to deny their own disability status or to internalize negative perceptions.

As an elementary and high school student, I understood that disability was not a respected piece of my own identity. No one ever questioned the stereotypical depictions of disabled people in the literature we read; no one taught about disabled people in history. So, I learned to never share my own experience with disability.

When I wrote true stories of the disabled people I knew, I erased any details that showed disability. Why should students feel a need to hide what they know, what they experience?

Critical pedagogy teaches us to question power structures, to unlearn, to relearn, to reflect. We need to use critical pedagogy to question what we teach and do not teach about disability. We need to open up space for students to recognize and claim what they know. And we need to spend some time learning about their experience. In the same way that teachers inadvertently legitimize whiteness by silencing conversations about race (Castagno, 2008), we tend to privilege and normalize the experience of nondisabled students by avoiding conversations about disability. We need to consider how to validate the experience of disabled students as well.

6. Schools can offer disabled youth opportunities to do tasks "imperfectly" and with some extra time without someone taking over and doing the task for them. Without the chance to perform, youth might believe they are incapable. They can be given some room for error in order to reduce the fear of risk-taking.

I consider my own experience with being given real tasks that I am sure I did imperfectly. Without these, how could I have learned what I was capable of? How could I have learned to perfect some of these tasks? I remember my mother's tendency to want to take over when something took me longer to accomplish; and, I understand her position as benevolent. However, had she not resisted the desire to do it for me, there are many things I would not have learned.

The example of doing dishes at a slower speed can speak to the question of time limitations. When the dishes need to be cleaned, how long is too long to spend on the task? Is not the end result of clean dishes what we want? In classrooms, keeping twenty or thirty students working at the same pace is impossible, and still we try to do it. We often consider time as a benchmark without stopping to question if faster is always better. Can we somehow change a system of comparison to one that acknowledges the value of knowing even when it does not happen so quickly?

In a meritocratic system, we offer rewards for accomplishments, and give grades and assess achievement based on norms. When do we stop to question whether expecting all students to reach the same goals in the same timeframe is the right thing to do? And if we do not necessarily expect such homogeneity, then why do we subject students to comparative grading? Could we instead reward progress toward goals? Beyond this how can we validate activity in terms of process, motivation, participation and their affective dimensions rather than standardized outcomes? Feminist scholars have noted that the creation of learning spaces that use cooperation rather than competition can raise academic achievement and enhance participation (Fine, 1991). If schools do reduce competition and make space for all students to do tasks "imperfectly" without the risk of being marked as inferior, students could most likely build a greater arsenal of capabilities.

7. Schools can support disabled youth in finding opportunities to build friendships outside of contrived socializations like "Circle of Friends." The passive and patriarchal impulse of these arrangements does not serve them.

Youth may need encouragement in initiating friendships and in contributing to friendships.

I cannot deny the difficulty some disabled youth experience in making friends. Educators have long been sensitive to this problem and have often questioned their role in finding solutions. Some educators have gone to lengths to create special clubs that specifically pair disabled and non-disabled youth together as buddies. On the surface, these may seem successful. But these contrived interactions do not mirror the way friendships tend to develop and few of these friendships continue beyond the artificial circumstances.

Most schools believe they share responsibility with families and communities in teaching social skills. Developing friendship is one of many social skills that youth are expected to develop during their school years. However, their success in this development may be difficult to assess. How can we judge intentions, loyalty, depth, and mutual respect? A student might be polite and friendly to peers and still not have friends. Likewise, a student might to rude and inconsiderate of peers and still have friends.

Although it may be difficult to assess, we can look critically at the culture of interaction within our schools and classrooms and consider the potential ways this culture impacts youths' development of friendship. For example, do we somehow promote an acceptance of excluding certain people? Do we forget to model an acceptance of diversity? In establishing positive and inclusive learning communities, we might denaturalize antagonisms, increase cooperation and decrease competition.

Opportunities to work together on common goals might do wonders. Do we need to wonder why many students who are segregated into separate classrooms have difficulty making friends with those in the general population? We know how important proximity is in building relationships. What messages do we give about how different people contribute or do not contribute to friendships? How often do we instruct non-disabled youth on how to interact with disabled youth? We say things like, "Offer her help" or "Be patient." Do we offer disabled youth these instructions? Not as often, I imagine. Do we help them see how they can contribute to peer interactions? More broadly, what space is given for the articulation of friendship within the sanctioned activities of a classroom? There is a wide variety in the ways in which school activities are structured; and in many more traditional approaches, friendship-like communication falls mostly outside the regimented forms of communication and contact that is allowed most of the time (sitting in rows, facing the teacher, speaking only with permission, etc). Friendships are not reflected upon or "recognized" in any public or open way by teachers or the institution.

Chapter Conclusion

Fine (1991) uses the phrase "being wrapped too tight" to describe the confines on adolescent girls in poor neighborhoods, trappings that keep them from seeing options and exercising choice. In this chapter, we see how disabled youth can also get "wrapped too tight" within a system that fails to recognize the capacity the youth have.

I imagine how we can make this shift, begin to view disability without the grossly limited lens of incompetence and allow individuals to develop to their real

potential. I know that changing the way we think about disability is so much more than a simple task. The prevalence of ableist conceptions will prove hard to beat. And yet, we cannot allow silence to follow the call for change.

Will educators need special training to make the same considerations for disabled youth that they make for other students they teach? At this time in history, perhaps they do. The status quo perpetuates the view of disability as deficit and schools fail to offer disabled students the opportunities that are afforded to other students.

Basically, the implementation of the above recommendations requires educators to radically change the way they think about disability and the way they teach about disability.   Attempts made to engage teachers and students in exploring alternatives to negative images of disability have proven to be complicated, as individuals must unlearn what they have previously learned about disability (Ware, 2003; Ware, 2001). Implementing disability studies in education would serve to work at just that, at providing alternative views and at starting critical conversations about disability. It is crucial that we recognize that the common reluctance of teachers to embrace the ideals of an inclusive classroom likely comes with the challenges of reflecting on and rethinking long-standing practices, and is not a simple dismissal of those in the classroom. As need necessitates change, we must encourage this reflection and support teachers in creating new practices.

Until disabled youth receive the basic fundamental education complete with the promotion of what Terzi calls "attitudes toward sociality and participation," we

have failed. Merely allowing disabled students entrance in classrooms is not enough.

Schools must create environments of inclusion, interactive and interdependent places

where everyone's experience and contributions are valued. We must create a pathway

of seeing ability, opportunity for all youth to know the abilities they possess. We must

learn to locate barriers that people imagine and create as enactments of institutions in

culture.   Imagined barriers can be taken down and goals can be reached when we stop

thinking there is only one way to reach them. With such an expanse of uncharted

territory, there are no simple solutions and the radical diversity of what we call

disabilities (and these contexts with) resist the establishment of any comprehensive

way of articulating a set of fixes. Therefore, this is ongoing work for all constituents

in learning communities that needs to be encouraged, acknowledged, and rewarded.

And perhaps most importantly, it is creative work—characterized by invention and

openness.

I imagine that with this education, youth participating in the "Don't Touch

Me" activity will speak, share ideas, solve problems, make decisions, offer support to

each other, and complete tasks at hand. They will carry these skills to all of the other

activities that they no longer hesitate to join.   They will be responsible for

propagating the new conception of disability, their contributions making the old view

impossible to continue. I imagine that Lori and other individuals will put fears aside,

give directions, and choose the lives they want to live.

They will be powerful. They will make choices that take their lives in

directions they want to go. They will imagine the many possibilities and ways they

can access the world around them. With their own individual agency, I know what

fabulous places they might find.

VIII. Conclusion: Pathways to Seeing Ability

When I studied to be a teacher, just fifteen years ago, I planned to teach general education students and imagined that my presence in the classroom would affect the way people saw me. At the time, I did not consider how I might affect disabled students. In fact, I steered clear of making any connection with special education programs and students of those programs. I believed that people expected me to connect there; and consciously, I did not want to fit the mold of what others expected for me. I knew that connection to special education and to disability was devalued and patronized. My perception was not wrong, but was limited. Today, I still do believe my presence as an educator impacts the general population of students; however, I now see making that impact as a responsibility to disabled students, and I imagine the ways I might help them view themselves differently.

Schools, like other institutions, have historically viewed disability through a medical lens. They have worked to diagnose and treat problems, often without giving much thought to social ramifications. This study primarily assumes that the disability experience always goes beyond physical limitation, such that disabled youth have a different sociocultural experience and encounter a variety of sociocultural barriers. Without consideration of the sociocultural experience, educators lack a great deal of understanding that could help them be more effective in teaching and including disabled youth. During the 1990's, a number of education scholars began organizing to form what would become the field of

Disability Studies in Education (D.S.E.); and in 2000, the Disability Studies SIG of

the American Educational Research Association (A.E.R.A) Conference was

established. This growing field has begun to bring a more critical perspective to

understanding disability in schools.

As a part of understanding sociocultural experience, we must consider

conceptions of disability and the discursive frameworks commonly used to make

sense of disability experience. Always in process, our conceptions of disability

can be sites for unconscious acceptance or for active engagement. If we see

conceptions of disability, for disabled youth, to be conceptions of the self, we

must recognize the importance they hold in identity development. Parent beliefs,

peer beliefs, medical professionals' advice, teacher practices, media depictions,

social policies and practices, and disability community intertwine to build these

conceptions. From these locations, discourses of normalcy, independence, and

hierarchy show considerable impact on youths' ability to claim disability identity.

Our contributions to these discourses, promoting the status quo or engaging

critically, must be examined and improved. Teaching students to be critical of

this discourse will also help us transform outcomes for youth whose previous

failure reflected the expectations of common discourse.

The negotiation of relationships with family and friends further impacts

the way individuals view themselves. Disabled youth's need for assistance,

perceived to be different than the need of nondisabled youth, works its way into

the threads of these relationships and creates unique barriers. Often, youth and

those they interact with perceive those marked as different to hold particular

social roles.   Within families, conceptions of disability –often linked to assistance

needs– influence the roles individuals take and the opportunities that are given.

Depth of family involvement and acceptance or rejection of "disability spread"

make tremendous difference in one's identity. In developing and maintaining

friendship, individuals' conceptions of disability and issues of access must often

be mediated.   Although maintaining relationships and getting needs met can be

difficult to balance, few disabled youth receive guidance or encounter models to

obtain the skills. Again, if educators have knowledge of and consider the

common intricacies of these interactions, they may better support youth in

developing relationships and skills that will make their transitions more

successful.

Ideally, we want disabled youth to become disabled adults who have

choices, make decisions, and advocate for themselves and others. Unfortunately,

the power of disabled people has been limited as others wrongly place them in

positions of incompetence, inferiority, and dependence. Close examination of

outcomes for those who do and do not receive support in developing agency

reveals what should not be surprising, that educators need to see the true

capacity of disabled students in order to support agency. Schools must work to

create environments of inclusion, interactive and interdependent places where

everyone's experience and contributions are valued. We must create a pathway

of seeing ability outside of normative frames, creating an opportunity for all youth to know the abilities they possess.

Implications for practice

The implications of this study largely relate to school and teacher practice, but can also inform parent support programs and other social programs and policies pertaining to disability.

Broadening our views

Primarily, educator's recognition that disability experience extends well-beyond impairment may be the key to improving outcomes for disabled youth. The physical is framed by and also contributes to the social experience. In many ways, environment affects individuals' abilities to live well and participate in society. Incorporation of critical disability studies in teacher education can broaden educators' understanding of disability and schools' role in creating safe social spaces for disability identity development.

Creating safe space

In addition, schools have a responsibility to create safe places to claim disability. This is an ethical imperative that goes beyond compliance with exceptionalist logic of accommodation articulated by special education to express a social ideal for the entire learning community. As educators and models to students, our daily interactions with the discourse can have profound impact on the way disabled and nondisabled students view disability and themselves.

As educators, we articulate this ethical position as we become critical of our own conceptions of normalcy and the ways in which they enforce these norms. In the same way we must be critical of our own biases in regard to race, class, gender, and sexual orientation, we must be critical of our biases in regard to ability.

Educators can teach students to be critical of pressure to conform to norms. If students gain an understanding of why people are driven to uphold norms and why norms should not always be upheld, they may be freer to know who they are and be who they are. We can find ways to teach that traditional norms of achievement are not markers of value.

By recognizing learning as a radically diverse and variegated process for all students, educators will avoid making a big deal out of accommodations, which includes getting rid of "special" language. Students are more likely to make use of accommodations that enhance access to learning if they get a sense that others believe it is reasonable and acceptable, and when learning itself is not centrally defined by standards. When we tack on labels, students are more likely to feel disconnected from peers.

Schools can celebrate difference and provide models of variation. In the way we strive to celebrate cultural diversity, we can celebrate the various abilities of people and disability culture. As we teach, we can provide multiple models, show that individuals accomplish tasks in a wide variety of ways. Educators can provide students with opportunity to learn about the perspectives of various people, including perspectives of disabled people. Without an understanding a variety of perspectives,

students easily make assumptions about the experience of others. Interestingly, Illinois passed state legislation in 2010, Public Act 96-0191, which requires school districts to teach about disability history and the disability rights movement.

A key aspect of promoting this ethical model is for educators to teach students to be critical of hierarchical systems. If teachers explicitly question why certain groups hold power and privilege, students can learn to question and talk back to a system that devalues them.

Educators who give more attention to cooperation rather than to competition promote productive exchange and healthy forms of interdependence. In cooperation, students can learn to value each other rather than feeling pressure to be better than their peers. They can discover what unique contributions they can make.

At the same time, educators can facilitate relative forms of independence (or autonomy from subservience) and the sense of one's ability to achieve it. Giving young people opportunity to realize their own capacities is crucial in developing agency.

Educators can challenge the stigma of varied forms of interdependence. This challenge may involve questioning developmentalist frameworks that expect scaffolding to always lead to independent skill.

Understanding interactions

Educators might gain insight by thinking about the ways in which interactions with families, friends, and caregivers influence identity development. With this insight, educators may better promote healthy relationships and self-advocacy of disabled youth.

To build this understanding, educators can consider how families impact decision-making, how family interactions inform the identities youth take on for themselves, how tendencies toward over-protection can impede growth opportunity, and how opportunities to help their own families can facilitate growth.

The support of mentorship programs for disabled youth and parents can allow families to find valuable resources and workable strategies for working through alternative forms of interdependence. Adults with disabilities can offer their experience and help disabled youth imagine a wider range of potential futures.

Teachers might be comforted to know that the barriers to friendship for disabled youth can be circumvented. Strategies for handling discomfort with difference, for understanding how to participate in give and take, for achieving environmental access, and for managing perceptions of maturity can be developed and utilized.

Disabled youth might benefit from support in negotiating assistance-related interactions with family, friends, and others. We can consider ways to support youth as they learn to communicate needs while balancing feelings, hesitations, and cultural meanings.

Development of agency

To justly educate disabled students, we can challenge and change dominant views of disability. In this, we can allow youth to see their potential and develop the agency needed to lead the lives they choose.

With opportunities to contribute their own ideas and to share their perspective, disabled youth might come to believe their ideas and perspectives are valued. By allowing youth to assist with classroom tasks, teachers can offer disabled youth opportunities to lead and can help them view themselves as capable contributors. Likewise, schools can offer disabled youth opportunities to act without always having direct instructions. With the chance, youth can practice decision-making skills.

Having opportunities to identify one's own needs and one's own solutions is important. When youth need assistance, learning to articulate their needs and direct the assistance they receive can be empowering. When schools can offer disabled youth opportunities to do tasks "imperfectly" and with some extra time without someone taking over and doing the task for them, youth might see themselves as capable.

While holding disabled youth accountable to following classroom rules and instructions and without denying accommodation, schools might teach youth to not expect exceptions to always be made for them. If accommodations require individualized instructions, these instructions could be build on the instructions given to the entire class, keeping the youth connected to the group.

Schools could better support disabled youth in finding opportunities to build friendships outside of contrived socializations like "Circle of Friends." Rather than relying on the passive and patriarchal impulse of these arrangements, we might find better ways to support friendships.

Future Research

Although the main participants of this study were youth with orthopedic impairments, I believe the implications of many of my findings extend to practices in educating a broader population of disabled youth as well as other students whose experiences exceed a variety of social norms. Other disabled youth negotiate conceptions of disability and difference in social interactions. I imagine that youth with cognitive disabilities, learning disabilities, emotional disabilities, and other types of physical disabilities form conceptions of disability through the same modes that youth in my study do. However, the cultural messages they must negotiate and the strategies they develop most likely vary. Future research should investigate the nuances of how other disability groups and youth of various cultures negotiate transition and disability experience.

My research questions lead me to investigate youths' conceptions of disability, their experiences with family, friends, and educators, and their plans for the future. Bits of data revealed interesting identity issues in regard to disability and sexuality; and unfortunately, this area is beyond the scope of this study. Further research should consider the impact that assumed vulnerability has on the sexual identity development of disabled youth.

Beyond this study of identity development, educational research should further investigate how schools might contribute to broader conceptions of disability and how a critical view of what inclusion means could lead to different outcomes for disabled youth. This work should connect to the larger scope of research on equity in schools, focusing on improving school outcomes and access to postsecondary education for all students, including disabled students. It is high time we include the futures of disabled youth in our list of utmost priorities, in the critical goals of our educational system.

VIV. Appendix

Focus Group Interview Questions

Intro: This is a focus group interview that should last about an hour. My goal is to learn about the experiences of the group. I will ask a question and you may answer in any order. Feel free to add to your comments if someone in the group reminds you of something else you'd like to add. Please take turns though, so that everyone's comments can be heard.
I'm interested in your ideas about life after high school and want to know about how you think it might be different for people with disabilities.

1. Describe what is most important to people when they are becoming adults.
Are any of these things more important to people with disabilities? Why or why not?

2. What kind of support do most people need when they becoming adults? What support do people with disabilities need?

3. How do most people decide what to do with their lives? How do people with disabilities decide what to do with their lives?

4. What does living independently mean? Is living independently different for people with and without disabilities and why?

5. What is college life like for most people? What about college life might be different for people with disabilities?

6. People without disabilities are four times as likely to go to college as people with disabilities. Why do you think that is?

7. Sometimes, people don't talk to their parents about their plans for the future. Why do you think that is?

8. If you met an 8th grader with a disability similar to yours and he or she asked you for advice on how to handle parents, what would you tell him or her?

9. If someone told you going to college would be too hard for you, what would you say?

10. Many young people believe having intimate relationships is part of growing up and many people find it challenging. Is this a bigger challenge for people with disabilities?

11. If you could give advice about becoming an adult to a group of 8th graders with disabilities, what would you tell them?

12. Sometimes, people don't talk to their parents about their plans for the future. Why do you think that is?

13. Sometimes, people with disabilities notice how various people think about disability. What have you noticed from the following people: parents, siblings, peers, teachers, mentors, therapists, doctors, religious groups?

14. The mentoring program was started to give you a wider view of possibilities for your future. Do you think it has done that? What do you think is different about your life because of your participation in the program?

Youth Interview Questions

First of all, I want to thank you for agreeing to participate. I'm very interested in how youth with disabilities make decisions as they are becoming adults. Your perspective is important to me. I don't want you to think there is a right or wrong answer for any of the questions. I want to learn from you, so please be honest. Let me know if there is a question you do not want to answer.

A.
1. Tell me about your family and about your role in the family.
2. What happens when someone turns 18 in your family?
3. At what point do individuals in your family move out of their parents' home?
4. In your family, how do people decide what to do after high school?

B.
5. What do your parents want most for you in life?
6. How do you know?
7. How does that compare to what they want for your siblings?

C.
8. What 5 things are most important for you to accomplish once you are an adult?
9. Tell me about your plans after high school.
10. You've made the goal to ---; tell me what makes you interested in that. Why is this important to you?

D.
11. How do you think life will change for you as you move into adulthood?
12. What do you think might be exciting for you personally?
13. What do you think might be difficult for you personally?
14. What support systems would most help you accomplish your goals?

E.
15. What do your parents know about your plans for life as an adult?
16. Tell me about conversations you've had with your parents in regards to your future.
17. What do they think about your plans?
18. What worries or concerns do your parents have about how you will accomplish your goals? How do you know?
19. What can you talk to your parents about?
20. What things do you choose not to discuss with your parents?
21. Do you have any concerns about your future they would not understand?
22. Do your parents have concerns about your future that you don't understand?

F.

23. How is your experience growing up different than your parent's experience?

24. Regarding independence, how do you expect things will be different for you than they were for your parents?

25. In becoming independent, what might you worry about losing or giving up? .

26. Tell me about the progress you've made in becoming an adult.

G.

27. What did you hope you would get from participating in the mentoring program?

28. What has surprised you?

29. Tell me about your relationship with your mentor.

30. What have you learned?

Parent Interview Questions

First of all, I want to thank you for agreeing to participate. I'm very interested in how youth with disabilities make decisions as they are becoming adults. I believe you may know a lot about this; and, your perspective as a parent is important to me. I don't want you to think there is a right or wrong answer for any of the questions. I want to learn from you, so please be honest. Let me know if there is a question you do not want to answer.

A.
1. How would you describe your family?
2. What happens when someone turns 18 in your family?
3. At what point do individuals in your family usually move out of their parents' home?
4. What determines what family members do when they graduate from high school?

B.
5. Tell me about the time when you were becoming an adult.
6. What did you want in life?
7. What concerns did you have?
8. Tell me about your relationship with your parents at that time.

C
9. Tell me the gender and ages of your children. Let's talk about each one specifically.
10. What do you envision for his/her future?
11. As an adult, how do you think he/she will spend time?
12. How do you think his/her financial needs will be met?
13. Where will he/she live?

D.
14. Let's talk more about (name).
15. What challenges do you think (name) may face in becoming an adult?
16. What support systems will (name) need?
17. Do you think (name) is prepared for the challenges? Why or why not?
18. What concerns do you have about (name)'s transition to adulthood? How do your concerns about transition to adulthood for him/her differ from (name)'s concerns? (do they?)

E
19. How is becoming an adult different for people with disabilities?
20. Tell me about people you have known with disabilities similar to your child's. Are there any within your family?

F.
21. How is parenting disabled youth different than parenting non-disabled youth?
22. If you met a parent who just found out his or her child was disabled, what advice would you give?
23. What was it like for you when you learned your child had a disability?
24. What do you wish you'd have known?

G.
25. What did you hope your child would get from participating in the mentoring program?
26. What has surprised you?
27. Tell me about your child's relationship with her/his mentor.

Table --: Youth Goals Compared to What Parents Envision

What five things do you most want to accomplish in life?

ERICA	SALEM	THOMAS	KATIE	ALEJANDRA	JOAQUIN
•-graduate high school •-choose a major •-graduate college •-learn to live on my own •-get my own place	•-finish college with good degree •-get a good career •-deal with life and not get upset •-be able to support myself if I lost my family	•-drive -find my own place •-get a job…pursue career •-get into college •-carry out as normal a life as possible	•-get a BA in English •-live on my own •-become a book publisher or editor •-travel on my own •-have a family	•-get a bachelor's degree, a job, and career •-have a family •-get a house •-learn to drive •-be independent	•-get an associate's degree in electronics •-get a driver's license •-have a good time •-get a job •-fall in love

What do you envision for your son/daughter's future?

ERICA	SALEM	THOMAS	KATIE	ALEJANDRA	JOAQUIN
•-choosing a career •-going to college •-continue making friends	•-staying healthy •-completing college •-becoming a graphic designer •-living at home	•-living independently •-going to college •-becoming a journalist	Not available	•-finishing a college degree •-getting a job •-having a family •-getting help from others	•-finishing college •-getting a job he enjoys •-getting married

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