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I Think I Can: Identity and Social Experiences of Adolescents with Physical Disabilities

A thesis

presented to

the faculty of the Department of Sociology and Anthropology

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Master of Arts in Sociology

by

Amy Sorensen

December 2007

Dr. Scott Beck, Chair

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Keywords: Disability, Adolescents, Social Experiences, Self-perception, Identity

ABSTRACT

I Think I Can: Identity and Social Experiences of Adolescents with Physical Disabilities

by

Amy Sorensen

An online survey was completed by 40 adolescents and young adults (ages 12 to 22) with physical disabilities for the purpose of exploring their social experiences. The survey focuses on key variables associated with individual identity, group identity, social relationships and activities, and future aspirations. Positive outcome variables were explored including: self-esteem, self-efficacy, body satisfaction, cultural identity, relationship quality, activity participation, and future orientation. Independent variables included sex, population size, ability level, and proximity to disability. Ability level proved to be the most predictive of positive outcomes. Sex, population size, and proximity to disability exhibited small associations to some of the outcome variables.

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DEDICATION

This is dedicated to my daughter, Autumn, who inspired me to understand her world.

ACKNOWLEDGMENTS

I would like to extend my appreciation to everyone who made this project possible. To my tireless thesis committee, thank you for letting me think big. To Dr. Kamolnick, thank you for your enthusiasm and open door. Thanks to my five children who endured many drive-thru meals and a mom living in her bedroom. Without my life partner, Lynn, there would be no thesis. Thank you for always being there to pick up the slack and always reminding me that I could do this. And thank you, mom, for teaching me to never play dumb, to always be inquisitive, and that nothing was truly out of reach. I also want to thank all my beautiful friends who listened attentively while I rambled on and on about this project.

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CHAPTER 1

INTRODUCTION

General Background

The identity formation process is a two-way communication between the individual and his or her social environment. It is perhaps the most important process in which all people participate, as it results in the person's sense of self. Identity is "a set of meanings applied to the self in a social role or situation defining what it means to be who one is" (Burke 1991:837). Identity formation is simultaneously social and individual, for while each person comes to self-cognition through socialization and interaction, no two people will have the exact same experience. For many people, the identity formation process is made more difficult, and perhaps more individualized, by stigmatized statuses (Goffman 1963).

People with disabilities occupy a unique place within society. They are part of a minority group containing a significant level of variance, and little cohesiveness. Throughout history, the idea of disablement and its related conditions have undergone many changes. It is, most notably, a subject of transience. Explanations of disablement have ranged from the supernatural to the medical to the social. Even today, the definition of disability is vague and non-universal (Trotter et al. 2001). Furthermore, conditions considered to be disabilities range from temporary injuries and illnesses to chronic conditions. They can occur at any time during the life cycle and can be physical or mental. The social issues related to disability are as variable as the conditions included within the classification (Barnartt 2005).

In order to more completely understand the social issues surrounding disability it is necessary to further narrow the subject to particular types of disability. For example, physical

and mental disabilities carry with them very different social implications. People living with physical disabilities have social experiences distinct from those with other types of disabilities. Perhaps the most important aspect of physical disability is its visibility. While certain types of mental impairments and illnesses may allow the individual to “pass” by managing others’ knowledge of their stigmatized status, most physical disabilities are distinctly visible to the public eye. This has a significant effect on the social experiences of people living with physical disabilities (Goffman 1963).

The socialization process for individuals with disabilities often varies according to the timing of the onset of disability. For those born with a disabling condition, primary socialization differs from the typical socialization experience (Barnartt 2005). Primary socialization for most other minorities is carried out by others with the same differentiating characteristics. However, for most individuals with disabilities, main socialization agents are all comprised of non-disabled “others,” people with significantly different, privileged characteristics. For those acquiring disabling conditions later in life, secondary socialization becomes an issue. After they have already established an intact identity, this identity is challenged and ultimately transformed into the new identity of disablement. Furthermore, they must begin the arduous task of learning the social expectations and roles associated with a disabled status (Englestrom 2003).

The status of disabled tends to become a person’s master status. A master status (often that of race, ethnicity, or gender) is the status that affects all areas of a person’s life (Barnartt 2001). Studies on disability as a status have found that it supersedes both race and gender (Barnartt 2001). Despite the importance of disability to a person’s identity, there is little evidence that a cultural identity based on disability exists. Previous research indicates that this type of cultural identity for people with disabilities is non-existent, and that they merely possess

a sense of disability consciousness (Barnartt 1996). With more and more literature pointing to the importance of cultural identity for people holding other minority master statuses (race, ethnicity, sex, and sexual orientation) (Negy et al. 1991, 1996; Rubin and Hewstone 1998; Sellers et al. 2003; Verkuyten 2005), it is difficult to know what effect this lack of cultural identity has on those with disabilities.

Accessibility is also often an issue for those with disabilities. While legal protections require some accessibility features, universal accessibility has not been a major focus within American society. Universal accessibility is a method of design that maximizes accessibility in buildings, products, and communities. While current legal protections require certain accessibility features on public buildings, there are many instances in which the interior is difficult or impossible to negotiate. Even fewer private dwellings are accessible, externally or internally. Restrictions go well beyond physically gaining access to locations for activities but occur within the activities themselves and how people commonly define them. For those without disabilities to understand how accessibility matters, input from those with disabilities and their allies is necessary.

Widespread inclusion in public schools has placed young people with disabilities in the mainstream classroom in the hopes of dismantling long-standing trends of inferior educational opportunities for those with disabilities. While this provides the student with a more normalized classroom environment, it may also place the student in a marginalized status within the classroom social group. “Fitting in” is a theme during adolescence. How a disabled status affects the social experiences of students within these mainstream classrooms is important to understand.

It is also vital to understand how a disability status affects a young person's future goals and aspirations. The complex negotiation of disability and anticipated endeavors must be understood if these young people are to be able to live successful and fulfilling lives.

Defining and Describing Disability

The subject of disability can be difficult to study. The term, itself, is poorly defined. This is partially due to definitions that range from "a condition which limits one's ability to perform necessary daily living activities," to "any perceived condition limiting one's abilities" (Barnartt 2005). While most definitions of disability have been created in order to ensure legal protection of those with disabilities, they have lacked universal application and appeal.

Another issue facing those who attempt to study disability is the evolution of the explanatory model (Barnartt 2005). As part of the human condition, disability has been an issue throughout history. In pre-modern societies disability was often viewed as a supernatural occurrence. Depending on the culture and condition in question, one could be viewed as cursed or blessed by the gods. This explanation often determined the social status of the person with a disability. It also influenced how others in the social group viewed the individual with a disability (Priestley 2001).

Later, in industrializing societies, disability began being viewed as a medical phenomenon. This change was driven by scientific advances and humanistic approaches to social issues. While the medicalization of disability allowed for treatment of the condition, it also placed the person with a disability in a new niche (Barnartt 2005). The goal of medicine is to cure and prevent illness. When disability is viewed as an illness, disablement places an individual in a sick role. This role is associated with subordinate status. It also places a heavy

emphasis on curative measures and behavior. For many people with permanent disabilities, this emphasis further marginalizes their position in society.

Finally, in recent years, the study of disability has taken another explanatory turn. The most recent trend is a cultural model of disability (much like recent trends in race and gender studies). This model defines disability as a cultural construct (Priestley 2001; Barnartt 2005). It finds disablement to be relative to the culture in which it is found. What is disabling in one society may not be so in another. This leads to further convolution in defining disability specifically. Some cross-cultural disability research supports the idea that disability is culturally defined (Priestley 2001). In a primarily agrarian society, mild mental retardation or mental illness is not considered a disabling condition. In more industrialized societies, these types of conditions can prevent an individual from independently making a living at all. Independence, itself, becomes an issue in the process of defining and categorizing disability. The heavy emphasis on independence in western societies marginalizes those with disabling conditions (Fine and Asch 2000). Societies that value interdependence often place those with disabilities in less marginalized positions, as no one is expected to be completely independent. The cultural explanatory model also lessens the emphasis on curing or erasing disabling conditions, which increases the social value of those who have disabilities.

The Current Problem

Current statistics paint a discouraging portrait for adults living with disabilities. According to 2004 Harris Poll Data on disability in the US, 74 percent of people with disabilities state that they are at least somewhat satisfied with their lives (versus 93 percent of people without disabilities). The same survey found that only 28 percent of respondents with

disabilities are employed, versus 68 percent of respondents without disabilities. Forty-six percent of disabled participants earn \$25,000 or less annually, compared to only 21 percent of non-disabled participants. People with disabilities participating in this study are nearly twice as likely as non-disabled respondents to have less than a high school education and almost half as likely to have a college or post-graduate degree (Harris Poll Data 2004). Table 1 illustrates the findings of the 2004 Harris Poll on educational attainment and disability.

Table 1. Educational Attainment from Harris Poll Data, 2004

<i>Educational Attainment</i>	<i>People with disabilities (percent)</i>	<i>People without disabilities (percent)</i>
Less than high school	21	11
High school	39	36
Some college	26	27
College graduate	9	17
Post-graduate	5	8

(Harris Poll Data, 2004)

It is difficult to distinguish how the type of disability affects outcomes such as these because the report does not differentiate by type of disability.

Background to this Study

This study is aimed at young people (12 to 22) with physical disabilities in the United States. In order to alleviate some of the negative experiences for people living with disabilities in the United States, a better understanding of their situation is necessary. By investigating adolescents with physical disabilities, it is possible to examine some of the issues they face that

will influence their subsequent experiences as adults. Because these adolescents acquire a disabled status early in life, we can learn about socialization factors and how they negotiate close social relationships in this important stage of their lives. Adolescence is an important time for creating a sense of self, group identities, and setting future goals. This population can potentially offer a vast wealth of information on how having a disability affects these processes.

To increase accessibility for data collection, the survey was made available online. The survey was designed to measure a large amount of information about the social experiences of the respondents, allowing this exploratory study to be a source of preliminary data with the potential of guiding future research efforts.

This study may also expose the internal and external barriers and strengths available to this particularly vulnerable group. Most importantly, this study can give voice to those who have previously been unable to raise their voices beyond those of professionals who, though earnest in their interest and desire to help, often lack the lived experience of disabilities. In hearing them, perhaps we can pave the way for a more positive adult life for all people who find themselves, at some point in their lives, living with a disabled status in our society.

This study focuses on several areas of importance: individual identity formation, group identity, social experiences, and future orientation. The survey collected information on all of these topics. While each area of focus included its own set of hypotheses, other relationships were investigated to ensure a broad overview of the subject matter. It was further thought that sex and size of place would affect the responses to items in the survey.

The hypotheses are primarily drawn from previous research, but not only research from the field of disability studies. Because so little research has been done on adolescents with physical disabilities, much of this research is based on existing general research on the main

topics. Chapter 2 explores this existent research. Chapter 3 describes the study's methodology, discusses the survey construction, defines the variables, lists the initial hypotheses, and explains the methods of analysis. The findings related to each of the main topics are discussed in depth in Chapter 4. Chapter 5 provides a summary of the findings, explores the questions raised, and discusses implications for future research. Appendices A, B, and C contain complete copies of the minor assent document and both versions of the survey.

CHAPTER 2

EXISTING RESEARCH

Identity Formation

The field of sociology has long examined the social foundations of identity formation. George Herbert Mead theorized on the social formation of the self. According to Mead, the “self” is formed through the conversation of gestures which is social life. An individual adjusts behavior according to the interpretation of social cues from others. Simultaneously, the individual formulates attitudes about the self and the world that are based on the cumulative effects of these social conversations. In order for one to have a sense of self, one must be capable of taking the role of “other.” The self is an ongoing, reflexive process rather than a pre-existing object/subject (Mead 1934). Charles Cooley remarked on this same process in his “Looking Glass Self” theory. According to Cooley, this has three requirements: The imagination of the appearance of the self to another, the imagination of the judgment of this other, and an internal feeling about this judgment (such as pride or embarrassment) (Cooley 1902).

Erving Goffman also made contributions to the study of self in a social context. Goffman’s interpretation of the self is based on the idea of dramaturgy, or behavior that is like a performance for an audience. According to Goffman (1959), successful social interactions depend on a convincing performance and, in turn, a successful viewing of the performance. Many social conditions can work against a successful performance. To succeed under trying conditions, both audience and actors must handle situations carefully. One such condition occurs when actors hold stigmatized identities.

A stigmatized identity is one that potentially discredits the actor in the eyes of the audience. In his powerful work, Stigma, Goffman (1963) theorizes about the implications of

stigmatized identities, including that of disability. Having a stigmatized identity alters the social processes for both actors and audiences and necessitates adaptive techniques. While many people who have potentially stigmatizing identities are able to negotiate the social world by “passing” (acting like a “normal” or hiding their stigmas), for others this is an impossibility. When people with visible disabilities or defects engage in face-to-face interaction, their interactions undergo altered social processes. The adapted process often includes a great deal of deference, by both parties, in an attempt to manage any discomfort stemming from the stigmatized identity (Goffman 1963). More recent research on the interactional processes for people with physical disabilities finds that they expend a significant amount of time and energy managing the emotions of others in response to their own disability (Cahill and Eggleston 1994).

Identity formation processes are part of the larger process of socialization. Primary socialization occurs during childhood and is carried out by various agents of socialization. Socialization agents include the family, peers, school, and the media. For most people, agents of socialization are characteristically similar to themselves. This is especially true within the family. Because of the genetic similarity that can be expected within biological families, the socialization agent and the socializing individual share a significant level of similarity (race, ethnicity, religion, and socioeconomic status, for example). For most children with disabilities, however, the socializing agent and the socializing child differ distinctly. In effect, the child is taught how to occupy the social position of one with a disability by those without disabilities. This is not true for around eight percent of children with hearing loss, whose parents are hearing impaired (Barnartt 2001). It is uncertain, at this point, what effect this prevailing dissimilarity has on the child. Perhaps they must base their identities on the reactions of others rather than through role modeling.

Another important agent of socialization during primary socialization is the school and peer group. Most children in the United States attend public schools. With the inception of The Education for All Handicapped Children Act (P.L. -94-142) in 1975, the United States adopted a stance of inclusion in its public schools. Inclusion is the practice of educating all children regardless of disability status in the same classroom. According to the Individuals with Disabilities Education Act (IDEA), all children have the right to a free and appropriate education in the least restrictive environment (Pub. L. No. 105-17, 111 Stat. 37). This law was intended to counteract the previously limited or nonexistent educational opportunities for young people with disabilities. While it has been largely successful in that aim, it has also brought social inequality in schools to the forefront. Having a physical disability during the ages associated with school years places the young person in a minority category. Because of low numbers and geographic dispersion, many students with disabilities will meet very few other young people with disabilities. The child with a disability may, in fact, be the only child with that status with whom able-bodied students come into contact. This makes the socialization that occurs within the peer group difficult for students with physical disabilities. They are once again involved in a socialization process in which they are different from those around them. Even teachers are often ill-equipped to handle the special needs of students with disabilities, for while federal law requires mainstreaming in classrooms, there is no equivalent requirement for teachers to have any significant special education background. Young people with disabilities may find themselves becoming the primary socialization agent for this situation in the classroom, as they are the only ones accustomed to their status (and they have acquired this understanding primarily from others without disabilities).

The final primary agent of socialization are the mass media. Young people today spend more time “plugged in” than ever before. They are bombarded with images in magazines, television programming, advertising, and internet sites on a daily basis. There have been volumes of recent research on the effects of media role models on young people. A primary focus of this research has been on the effects of unattainable body images presented by the mass media on young people, especially young women. Much of this research has shown that these images create a negative self-image for young people. Other research has focused on the representation of minorities in the media (Tuchman 1978; Collins 1991; van Zoonen 1994; Milkie 1999; Morrison, Kalin, and Morrison 2004). Little or no research has gone into the effects of media images on young people with disabilities. There is almost no representation of people with disabilities in mainstream media. Very few television shows depict people with disabilities, except in occasional bit parts. Movies are more likely to depict people with disabilities. However, disability is generally the focus point of the movie and becomes the central theme in these cases. Mass media outlets have been unable (or unwilling) to “normalize” disability in their programming. Thus, the body images presented in the mass media are truly unattainable for young viewers with disabilities.

All in all, the socialization experiences of young people with physical disabilities are almost exclusively with “others.” They rarely encounter a room of people just like them. They rarely get chances to model positive behavior and attitudes regarding their status as disabled. More often, they must base their self-perceptions on the responses of those around them who do not have disabilities.

Existing literature finds perceived physical appearance to be integral to self-esteem and self-efficacy in adolescents (Appleton et al. 1997; Davison and McCabe 2006). Some studies

exploring the relationship between self-esteem and disabilities suggest that disability, itself, is not the best predictor of self-esteem. Instead it is the cultural, social, and emotional impacts of the experience of disability that are most influential in determining self-esteem (Brooks and Matson 1982; Walsh and Walsh 1989; Craig, Hancock, and Chang 1994; Barnwell and Kavanagh 1997; Nosek et al. 2003;). A significant connection between social feedback and self-esteem has been reported by a number of researchers and theorists (Cooley 1902; Mead 1934; Adler 1979; Bednar and Peterson 1995; Nosek et al. 2003).

Previous research points to a complex method of negotiating in the social world with a disability. This research identifies a tight balancing act between claiming disability status when necessary and disclaiming it at other times (Taub, McLorg, and Fanflick 2004). Thus, the relationship between the person with a disability and his/her disabled status is not a simple acceptance of a physical condition but a more complex negotiation of physical condition as it affects and is affected by the social world.

Group Identity

Group identity is an important aspect of identity formation, especially during adolescence. Setting up group affiliations and in-group/out-group boundaries is an important aspect of social identity formation. Adolescence is the time in which individuals learn how to create group identity and group solidarity. These are the years when important networking skills begin to develop. During this stage of development, it also becomes more vital for the individual to be a part of a group.

Research has shown that young people with ethnic minority status are more likely to have positive outcomes when they have a high level of positive ethnic identity, while other studies

have shown that this, coupled with a positive opinion of the majority culture, results in more positive outcomes such as self-esteem, purpose in life, and self-confidence (Phinney 1991, 1996; Rubin and Hewstone 1998; Negy et al. 2003; Sellers et al. 2003; Verkuyten 2005). Disability has been shown to overshadow even gender or race in status hierarchies (Barnartt 1996). Because of this designation as a master status, establishing a positive group identity based on disability can perhaps be related to ethnic identity in its importance for the individual. This may prove difficult for individuals living with disabilities, for, while having a disability places a person in a minority status, the dispersion of the characteristic both genetically and geographically makes having a cultural identity nearly impossible.

While research has shown that disability status rivals that of gender or race for master status significance, the effects that the dispersion of the population has on group identity formation for people with disabilities is poorly understood. Some discussion has occurred on the subject of disability culture. According to Geertz, culture: "...denotes an historically transmitted pattern of meanings embodied in symbols...by means of which men...communicate, perpetuate, and develop their knowledge about and attitudes toward life (1973:89)." This leads us to the question of whether or not a disability culture can exist. It might more accurately be described as a sub-culture. A sub-culture "shares many elements from the larger culture but also contains cultural elements that are distinguishable from the larger culture (Barnartt 1996)." According to Barnartt, a disability culture is impossible and, in fact, what we find among those with disabilities in the United States is a disability consciousness (Barnartt 1996). While this status becomes the master status, there is, perhaps, no culture of disability. This may lead to feelings of loneliness and isolation.

According to previous research, a feeling of cultural identity has been found to be important in outcomes for other master status minority adolescents. Higher concentrations of cultural identity have been correlated with higher self-esteem, purpose in life, and self-confidence (Martinez and Dukes 1997; Negy et al. 2003; Sellers et al. 2003). Another important aspect of ethnic identity theory is the relationship between having a positive in-group opinion and positive outcomes. According to existing research, positive outcomes are found predominately in minority students who have positive ideas about both their own group and the majority group (Phinney 1991, 1996; Rubin and Hewstone 1998; Negy et al. 2003; Sellers et al. 2003; Verkuyten 2005).

Social Activities and Future Orientation

Previous research links some positive adolescent outcomes to friendship networks and social engagement (Tarrant, MacKenzie, and Hewitt 2006). During adolescence, people begin to create social networks of friends. Peers become more important to the status and social power of adolescents. Existing research shows that friendship groups and activities can have a huge impact on positive outcomes. These variables have been linked to increased feelings of self-worth, decreased feelings of loneliness and depression, and increased academic success (Jordan 1999; Tarrant, MacKenzie, and Hewitt 2006). Some studies have attempted to look at various groups of at-risk young people and their activities. One study found that increased sports activity (highly valued in our culture) provided a buffer against other negative influences in at-risk African American students (Jordan 1999). Another study found that young people with disabilities felt that they were part of a regular group of friends, though they felt that others viewed them differently. This study also found that peer relationships for these adolescents were

often defective or non-existent with few out-of-school opportunities for peer-led activities (Skar 2003).

Romantic relationships also become important during the adolescent years. For young people with disabilities, these types of relationships can be difficult to start or maintain. One of the main problems is that able-bodied people often view those who have disabilities as non-sexual (Crawford and Ostrove 2003; Nosek et al. 2003). Adolescents with disabilities have been found to have distinct relationship concerns. One study found that many students with disabilities had never been included in a sex education class. Of those who had been in a class, almost a quarter of them reported that the information was of no use to them, or that they were unsure of how relevant it was (Berman et al. 1999). This is not to say that young people with disabilities do not feel that they are able to take part in sexual relationships. According to existing literature, the majority of young people with disabilities believe that they are capable of having a sexual relationship and expect to be in one in the future (Cromer et al. 1990; Berman et al. 1999).

Existing research on young people with disabilities has found differing results on the subject of sexual activity. One study found no significant difference between adolescents with disabilities and those without in regards to frequency of sexual activity (Suris et al. 1996). However other studies have found that young people with disabilities have fewer romantic relationships than non-disabled peers (Dorner 1977; Borjeson and Lagergren 1990; Stevens et al. 1996; Berman et al. 1999).

Previous research has linked extra-curricular activities, sports, and active lifestyles to better health, higher academic performance, and higher self-esteem (Jordan 1999). These types of activities may be especially important to students who are considered high-risk. Future

orientation has been found to be important for all adolescents, but it has been found to be critical to at-risk youths (Pollard, Hawkins, and Arthur 1999; Kerpelman and Mosher 2004). Risk factors are those that have been shown to decrease the likelihood of attaining positive outcomes and have historically included impoverished youth and ethnic minorities.

Table 2 illustrates the findings from the Monitoring the Future: A Continuing Study of American Youth’s 2001 survey results regarding the post-secondary educational attainment desires of high school seniors. These results indicate all responses and not only the highest level indicated by respondents (thus, the total percentage does not equal 100).

Table 2. Desired Educational Attainment from “Monitoring the Future.”

<i>Post-secondary Educational Desire</i>	<i>Percentage</i>
None	5.5
Vocational/Technical school	17.9
Community college	24.2
Four-year college	77.8

(Johnston, Bachman, and O’Malley, 2001)

According to Wave II of the National Longitudinal Study of Adolescent Health (Add Health), 71.18 percent of respondents indicated that they would very likely or definitely attend college (Udry 2003). Using these national results, we are able to get an idea of how the respondents in this study of youth with physical disabilities compare to other groups of adolescents.

Comparisons between this study’s respondents and those participating in national surveys will be discussed in Chapter 4.

CHAPTER 3

METHODOLOGY

The Target Population

This study offers a glimpse into the social lives of adolescents with physical disabilities in the United States. In order to participate, respondents needed to be between the ages of 12 and 22, have a physical disability (with no significant accompanying cognitive delays), and live in the United States. Each of these population restrictions was chosen for specific reasons.

The age parameters were chosen based on a typical definition of adolescence, ages 12-18. However, young adults (ages 19-22) were included as well due to specific circumstances related to having a disability. Special education laws allow any student qualifying for special education services the option of remaining in the public school system through the age of 22. Furthermore, young people with disabilities may experience a prolonged adolescence due to their physical limitations for self-care and independence. They often remain at home with parents much longer than non-disabled young adults. This extended adolescence makes older respondents' experiences and attitudes vital to a better understanding of adolescents with physical disabilities.

The disability requirements for respondents were chosen based on research needs and researcher expertise. As mentioned earlier, physical disabilities are generally visible to the outside world and can lead to an automatically stigmatized identity (Goffman 1963). It is difficult for those with physical disabilities to hide their status or pass as another status, making this designation compelling for studying the potential effects of stigmatization. Adolescence is also a time in which most young people focus significant amounts of attention on their physical appearance. Having a physical disability may affect this aspect of adolescence. There also seems to be a need to focus on this particular population, as there is an obvious lack of literature

focusing on disabilities that do not include cognitive impairments. Furthermore, significant cognitive impairments affect a person's interpretation of the self and the social world. The lack of cognitive delays and severe mental illness places those with only physical disabilities in a particularly vulnerable position to hold an outsider status and remain *aware* of that designation. It was also a concern that those young people with significant cognitive delays and severe mental illness required a researcher with expertise in these areas. Given their heightened level of vulnerability, the researcher felt that it was in their best interest to be excluded from this study.

Because the target population is not a listed population, the researcher used organizations that specialize in providing services and information to families of young people with disabilities in the United States. These organizations were contacted via email with study details and contact information. These emails were sent to 240 such organizations. The organizations were asked to provide this information to any qualifying families. Organizational response was high, with almost universal participation in information provision. These organizations provide information to families in a number of ways: electronic newsletter, website, mail-out newsletter, and telephone. By using these organizations as gatekeepers, the researcher was able to provide information to a larger pool of potential participants while keeping costs low. Another important aspect of organizational gatekeepers is that they provided information to parents, who, in turn, provided information to adolescents. This allowed the researcher to forgo the costly and timely process of parental consent. Consent could be inferred by the adolescent's knowledge of the study. This method of contact, while offering a number of positives, may also affect who responded to the survey. Young people with parents who are very involved in the disability field may exhibit characteristics different from others.

The Instrument Format

For this study, an understanding of the specific needs of the population was a necessity. Adolescents with physical disabilities are often constrained by mobility issues, as well as accessibility issues. Because of the sensitive nature of the subject matter, privacy was also a consideration. It was necessary to design a study that would address these issues effectively. A survey was decidedly the best method for gathering the vast amount of information necessary to gain a broad understanding of the experiences of participants, as it allows for easily quantifiable responses. In order to offer the easiest form of response to participants, an internet design was chosen. This maximized accessibility for a wide-variety of physical limitations, as information technology has addressed accessibility with specific software components. An online format also allowed for a high level of privacy, as respondents could take the survey in the privacy of their own home with little or no interference from interviewers or family members. Of course, like a mail-out questionnaire, there was no way to control the conditions of the response process. This creates a minimal chance that someone other than the intended respondent filled out the survey, or that the respondent was unable to do so in private. The researcher also notified potential respondents that individual accommodations would be made for anyone wishing to participate but who lacked access to this technology. No such individual accommodations were requested.

The survey was designed on software provided by the hosting site, Survey Monkey. This site offers a large number of design options that minimize chances of programming error. It also provided free encryption of responses and internet protocol (IP) tracking. The availability of IP tracking meant that the researcher could minimize the chances of respondents taking the survey

multiple times. This also ensured that respondents could return to their last answered question if they lost connectivity or needed to return at another time.

The use of easily answered, primarily fixed-choice questions maximized the amount of information that could be ascertained from the questionnaire and also protected the respondents from fatigue. The survey included a few open-ended questions, but they required answers of only a few words.

Finally, in order to ensure age-appropriate content, two versions of the survey were designed with slight alterations in wording or questions. Version 1 was given to those listing their grade level as 5th through 8th grade. Version 2 included some more mature content, and was given to respondents listing their grade as 9th through 12th. In order to ensure that no younger respondent received the more mature version of the survey, any respondent failing to answer the question of grade level was also given the less mature version.

The Instrument Content

This survey was designed to get a broad overview of the social experiences of adolescents with physical disabilities. In order to do so, it was important to ensure that a wide variety of topics were covered adequately and efficiently. Copies of the minor participant assent document and both versions of the questionnaire are included in Appendices A, B, and C. The survey, itself, contained eight sections.

The first section of the survey (Items 1-5) consisted of basic information. Respondents first viewed an assent document to read and accept before beginning the survey. They were then asked whether or not they had a physical disability. Any respondents answering “no” to this question were excluded from the analysis. Participants were also asked for the city and state in

which they live. This information was used solely for geographic and population information. Population density was a consideration in the analysis of experiences of adolescents in this study, due to potential differences in available resources. Also included in this section were questions on age, sex, and grade level of respondents.

The second section of the survey (items 6-10) was designed to get an idea of each respondent's proximity to other people with disabilities and personal perceptions of people with disabilities in general. The first set of questions (items 6-7a) was used to discover how much contact the respondent has with others who have disabilities. The second set of questions in this section (items 8-10) was designed to ascertain how respondents felt about the effect of physical disability on attractiveness and relationship potential. This second set of questions was worded in a slightly different manner, depending on the survey version (the words "cute" and "pretty" were used in the less mature version of the survey, while the word "attractive" was used in the more mature version).

The third section of questions (items 11-18 on Version 1 and items 11-18d on Version 2) was designed to measure the respondents' level of ability. It consisted of a list of regular activities and for each the respondent was asked to mark whether this was something they could do alone, with some help or could not do at all. Each version of the survey contained some different options for these activities, believed to be more age-appropriate. Version 2 of the survey (grades 9-12) offered more activities than Version 1. It is natural for older teens to participate in more activities independently. While eight of the activities were considered similar, there were three unmatched activities offered in Version 2. These activities were: have a job, take care of a family, and have intimate relationships.

The next section of questions (items 19-55) was designed to get a picture of participants' self-perception. This section consisted of two sub-sets of items. The first subset (items 19-29) was designed to compare how respondents thought other people their age viewed them and then how they viewed themselves. This is particularly relevant when considering how self-perception and identity are formed. The survey listed 11 adjectives (some of which were positive and some of which were negative) as well as an open-ended "other" option. Respondents were asked to mark all of the adjectives they thought that others their own age would use to describe them. Then they were asked to mark all of the adjectives they felt to be true about themselves (items 30-40). The second sub-set of self-perception items (41-55) were taken from Rosenberg's Self-Esteem Scale (Rosenberg 1979), the Generalized Self-Efficacy scale (Schwarzer and Jerusalem 1995), and the Social Physique Anxiety Scale (SPAS) (Hart, Leary, and Rajeski 1989). All of these scales have been widely used, subjected to validity tests, and have proved to be highly reliable. There were six statements from Rosenberg's Self-esteem scale (items 41-46), five from the Self-efficacy scale (items 47-51), and four from SPAS (items 52-55).

The fifth section of the survey (items 56-68) was designed to get an overview of the group identity processes of the participants. These items were intended to look at whether or not participants have a strong group identity (sense of culture) and whether or not they were interested in increasing this feeling. The first 10 statements (items 56-65) were based on the Multi-group Ethnic Identity Measure (Phinney 1992) but were re-worded to apply to disability rather than to ethnicity. The final three items (66-68) were designed to ascertain the level of desire the respondent had for an increase in group identity.

The sixth section of the survey (items 69-79) was designed to measure the quality, quantity, and level of intimacy in participants' relationships. The first sub-section of questions

(69-74) dealt with the number and quality of friendships as well as the amount of time spent with peers outside of school. Each question offered four possible answers. The next set of questions (75-79) related specifically to frequency, duration, and level of intimacy in romantic relationships. It is important to note that each version of the survey offered slightly different intimacy level options (with the less mature version avoiding any sexual references). Version 2 of the survey offered the following two romantic activities not included in version 1: heavy petting and sex. In order to ensure accuracy regardless of age level, this section also offered an open-ended “other” option.

The next section of the survey (items 80-82) was designed to get a picture of the activities in which respondents participate. These items were categorized as: school activities (items 80a-80c), extra-curricular activities (items 81a-81c) and community activities (items 82a-82c). For each activity, the respondents were asked to mark whether or not they participate in the activity as well as whether it is available for their area or grade level. They are then asked if they have ever been unable to participate in any of these activities because of their disability. Those respondents who answer in the affirmative are prompted to mark all activities in which they have been unable to participate.

The final section of the survey (items 83-84) was designed to measure the respondents’ future orientation. In this section, participants were given a list of 12 normative adult roles and were asked to mark all that they planned to do in the future. The final item was an open-ended question in which the respondents were asked to list three careers they might be interested in.

Definitions of Variables

Many of the items in the questionnaire are evaluated individually. Some of these include the independent variables taken from the first five items on the survey: age, sex, and grade. Population size was believed to be an important measure in order to ascertain what effect living in rural areas might have on the social experiences of respondents. In order to ensure accurate categorization of population, respondents were asked to list their city and state. The researcher then correlated the location with population statistics from the United States Census Bureau. The categories used in this analysis were as follows: Rural areas with populations under 5,000 (coded 1), Towns with populations between 5,000 and 50,000 (coded 2), and Cities with populations over 50,000 (coded 3).

Items 6 through 7a were totaled to create the Proximity to Disability Scale score. This measure is intended to give an idea of how much contact the respondent has with others with disabilities. This measure is helpful in understanding the socialization process, the acquisition of a disabled status and identity, and the ease of group identification. The scale was tested using SPSS, resulting in a reliability coefficient of .746.

Items 11 through 18 dealt with how independently the respondent participates in certain normal activities. For each activity, the respondents were asked to mark whether they could do that activity alone (scored 3), with some help (scored 2), or cannot do it at all (scored 1). These scores were added together to form the Total Ability Index. This variable gives an indication of both the physical condition of the respondent as well as the level of independence the participant has attained. Given the wide array of potential effects of physical disability, this was decidedly the best way to ensure that accurate ability information was available. Higher scores on this index indicate more independence.

Items 41 through 46 were taken from Rosenberg's Self-esteem Scale (Rosenberg 1979) and together were found to have a reliability coefficient of .677. Self-esteem can be defined as a person's sense of worthiness, adequacy, and self-respect (Rosenberg 1979). These questions were presented in four point Likert scale format. For each statement, the respondents were asked to respond with the level at which they agree with the statement (Strongly agree, agree, disagree, and strongly disagree). These responses were positively scored on a scale of one to four (positive answers scored higher and negative answers scored lower).

Items 47 through 51 were taken from the Generalized Self-efficacy Scale (Schwarzer and Jerusalem 1995) and together were found to have a reliability coefficient of .864. Self-efficacy "refers to people's assessments of their effectiveness, competence and causal agency" (Gekas 1989). These items were scored in the same manner as items 41 through 46.

Items 52 through 55 were designed to measure body satisfaction. While the most widely used body satisfaction scales deal with weight, size, and shape of bodies, the researcher thought that these issues were less relevant for ascertaining how disability affects body satisfaction. Thus, these items were taken from the Social Physique Anxiety Scale (Hart, Leary, and Rajeski 1989) and were related to the overall comfort level the respondents feel about their bodies, both privately and in public. These items were scored in the same manner as the previous two subsections of questions (opposite their scoring on the original scale), providing an indication of how positively the respondents felt about their bodies. The decision to score these items opposite the original scale was based on the desire for a positively scored measure that would complement the other self-perception measures (self-esteem and self-efficacy), and led to the decision to refer to this variable as body satisfaction. These items were found to have a reliability coefficient of .732.

Items 56 through 65 were based on items from the Multi-group Ethnic Identity Scale (Phinney 1992). They were re-worded slightly to make them applicable to the experience of disability rather than race or ethnicity. These items were designed to measure the level of group identification the respondent feels. Four of the items referred to the respondents' feelings of group identification, two referred to any in-group bias the respondent might feel, two referred to the respondents' personal identification as disabled, and two referred to the level of knowledge the respondent felt about the experience of disablement. When totaled, these items were found to have a reliability coefficient of .805 and were used to create the variable "Cultural Identity."

Items 69 through 72 explored the number and intimacy of respondents' friendships. The respondents were given four options for answers (0, 1, 2, 3+) which were scored according to their numerical value (0, 1, 2, and 3). These answers related to number of friends meeting the criteria in the question, amount of time spent with friends, and the number of times certain friendship activities take place, depending upon the wording of the question. These scores were totaled to form the Friendship Quality score. This scale had a reliability coefficient of .791.

Item 79 contained a list of romantic activities and respondents were asked to mark all of these activities in which they had participated. The total number of marked activities was used to create the variable called "Total Romantic Activities." This variable helps describe the intimacy experiences of respondents.

Items 80a, 81a, and 82a are all lists of different types of activities. Item 80a refers to in-school activities, 81a to extra-curricular activities, and 82a to community-based activities. Each of these items is scored by adding the total number of activities marked by each respondent in that category of activities. These totals make up the three different activity scores for each respondent and help describe the activities in which respondents participate. Items 80c, 81c, and

82c relate to the same categories of activities but ask respondents to mark any activity in which they have ever been unable to participate due to their disability. These questions focus on cumulative experiences, and the totals do not equal 100 percent. When totaled they become the variables referred to as Inaccessible Activities for each category of activities, and are scored as such.

Finally, item 83 consists of a list of normative adult roles. Respondents were asked to mark all of the items in which they plan to participate in the future. Respondents were given five educational attainment options to choose from. While respondents were able to mark more than one answer in this section, responses were scored (0-5, 0 if they marked no post-secondary educational plans) based on the highest level of education indicated by the participant. This score was added to the total number of remaining items marked by the respondent. This total was used as the variable named, "Total Future Orientation." This score represents the level of the respondents' expected participation in normative adult activities and roles.

Initial Hypotheses

This study was designed to get an overall picture of the identity processes and social experiences of adolescents with physical disabilities. The main foci were individual identity, group identity, social activities, and future orientation. While the aim of this study was predominantly to look for relationships between all of the variables, there were a number of hypotheses to be specifically tested.

In looking at individual identity characteristics of respondents, the following hypotheses were made:

1. Respondents will exhibit very low levels of self-esteem, self-efficacy, and body satisfaction.
2. Female respondents will exhibit lower levels of self-esteem, self-efficacy, and body satisfaction than males.
3. Respondents from rural areas will exhibit lower levels of self-esteem, self-efficacy, and body satisfaction than respondents from other population categories.
4. Respondents will have negative ideas regarding peer perceptions of them.
5. Respondents' self-perceptions will mirror perceived peer perceptions.

This study also attempted to get an idea of the level of group identification the respondents felt towards the larger population of people with disabilities.

6. Respondents will exhibit low levels of cultural identification.
7. Cultural identity will be positively correlated with self-esteem, self-efficacy, and body satisfaction.
8. Proximity to disability will be positively correlated with cultural identification.

Another subject of study in this research is that of social activities for the respondents.

9. Respondents will report low numbers and levels of intimacy in all types of relationships.
10. Respondents will report a low number of social activities.
11. Respondents will report a high number of activities have been inaccessible to them due to disability.

12. Respondents from rural areas will report participating in fewer activities than those respondents from other population categories.

Finally, this study investigates the future orientation of the respondents.

13. Respondents will demonstrate limited expectations of normative adult roles.
14. Respondents from rural areas will demonstrate lower expectations of normative adult roles than those from other population categories.
15. Female respondents will demonstrate lower expectations of normative adult roles than male respondents.

In order to remain dedicated to the ideal of fully describing and understanding the unique experiences of the respondents, data analysis was not limited to testing hypotheses. Additional descriptive analyses and evaluations were performed in order to ensure the most comprehensive compilation of data possible. In analyzing the data, the following tests were used depending upon the type of data: cross-tabs, difference of means, and correlations. Tests of significance, such as chi-square and t-test, were not used due to the small self-selected sample. There was no attempt to generalize the results beyond this group of respondents. Substantive significance was determined by the size of differences found in categorical variables or the size of correlations. The results are meaningful in illuminating potential paths or directions for future research using more representative sampling techniques.

CHAPTER 4

FINDINGS

Basic Characteristics of Respondents

Forty respondents met the participation requirements. Because of the small, self-selected sample the results of this study cannot be generalized to the larger population of adolescents with physical disabilities. All results are assumed to be indicative only of this specific sample.

However, this snapshot of the lives of these young people living with physical disabilities can be an initial picture of the experiences of a marginalized group as well as a springboard for more research into the topics brought forth here. Because this is essentially a self-selected sample, the use of inferential statistical procedures is technically inappropriate and would have little or no practical use. Thus, procedures such as confidence intervals and tests of significance are not presented. Rather, brief descriptions of the patterns of responses for certain variables and the direction and size of measures of association or differences of means and proportions will be presented to address previously-stated hypotheses.

It is important to note that there are potential biases within this sample. As is the case with self-selected samples, it is possible that these respondents feel strongly (either positively or negatively) about disability. There is also the possibility that parental involvement with the referring organizations affects the level and nature of the respondents' response to and feelings about disability. Furthermore, the widespread use of internet technology by the referring organizations could have led to a bias based on easy access to this technology inside the home.

Of these 40 respondents, 15 identified themselves as males and 24 identified themselves as females. One respondent failed to answer this question. Ages of respondents ranged from 11 to 22. Of the respondents, 63.2 percent were between the ages of 16 and 18. Respondents were

in grades 5 through 12. Population sizes were split into three categories: Rural areas (population less than 5,000); Towns (population between 5,000 and 50,000); and Cities (population over 50,000). The majority of respondents (62.2 percent) listed small cities as their place of residence. A total of 47.3 percent of the respondents were either from Arkansas or Kentucky. This was partially because Kentucky’s Department of Special Education provided information about the study to its schools. Another contributing factor might have been that Kentucky and Arkansas rank second and third for highest percentage of disabled population in the United States (US Census Bureau 2003). Table 3 illustrates the basic characteristics of the respondents.

Table 3. Descriptive Statistics of Sample Population

Variables	Categories	Frequency	Valid Percent
Sex	Male	15	38.5
	Female	24	61.5
Age	11	1	2.5
	12	3	7.5
	13	3	7.5
	14	2	5
	15	2	5
	16	10	25
	17	7	17.5
	18	8	20
	19	2	5
	21	1	2.5
	22	1	2.5
Grade	5	2	5.4
	6	1	2.7
	7	2	5.4
	8	2	5.4
	9	2	5.4
	10	8	21.6
	11	11	29.7
	12	9	24.3
Population	Rural	8	21.6
	Town	23	62.2
	City	6	16.2

Individual Identity

Self-Esteem. In order to get a measurement of the self-esteem levels for this group of respondents, they were asked to note their level of agreement with six statements. On four of these items, a majority of respondents answered positively (in a manner that denoted positive esteem). However, there were two items that were answered negatively (in a manner that denoted negative esteem) by a majority of respondents. These items were: “I feel useless at times,” and “At times I think I am no good at all.” Furthermore, even though a majority of respondents answered in a positive manner to most items in this section, the fact that at least one-third of respondents answered negatively is of concern. The results from the six self-esteem items are detailed in Table 4 below.

Table 4. Responses to Self-esteem Items

<i>Item</i>	<i>Strongly Agree</i>		<i>Agree</i>		<i>Disagree</i>		<i>Strongly Disagree</i>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
I feel that I am equal to others my age	6	16.7	20	55.6	7	19.4	3	8.3
I feel I do not have much to be proud of	4	11.1	8	22.2	16	44.4	8	22.2
I take a positive attitude toward myself	6	17.1	17	48.6	10	28.6	2	5.7
On the whole, I am satisfied with myself	3	8.3	21	58.3	9	25.0	3	8.3
I feel useless at times	8	22.2	18	50.0	8	22.2	2	5.6
At times I think I am no good at all	6	16.7	20	55.6	8	22.2	2	5.6

The explanation for the differences between the primarily positive, though not convincing, responses to other self-esteem items and these two items is unclear. They are not the only negatively worded statements in the section, minimizing the possibility of response error. It is

perhaps logical to note the relationship these items have to physical utility. It may be that young people with disabilities feel less useful due to their limited physical abilities.

Self-Efficacy. The next five items on this section of the survey are taken from the Generalized Self-efficacy scale. Self-efficacy “refers to people’s assessments of their effectiveness, competence and causal agency” (Gekas 1989). Self-efficacy has been found to be a contributor to mental health in adolescents (Connolly 1989). These five items can be further categorized as being cognitively or actively oriented. Those scale items that were primarily cognitive were: “I can solve most problems if I try hard enough,” and “If I am in trouble I can usually think of a solution.” The other three items have an action component to the wording. A higher percentage of respondents answered the cognitive items in a positive manner than they did for the active items. This is possibly related to the physical limitations these respondents confront. Responses to the self-efficacy items are outlined in Table 5.

Table 5. Responses to Self-efficacy Items

<i>Item</i>	<i>Strongly Agree</i>		<i>Agree</i>		<i>Disagree</i>		<i>Strongly Disagree</i>	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
It is easy for me to stick to my aims and accomplish my goals	5	12.5	14	38.9	14	38.9	3	8.3
Thanks to my resourcefulness, I know how to handle difficult situations	4	11.1	16	44.4	11	30.6	5	13.9
I can solve most problems if I try hard enough	9	25.0	18	50.0	8	22.2	1	2.8
If I am in trouble, I can usually think of a solution	5	13.9	21	58.3	9	25.0	1	2.8
I can usually handle whatever comes my way	6	16.7	15	41.7	13	36.1	2	5.6

Body Satisfaction. Another important measure of self-perception is that of body satisfaction. This measure looks specifically at a person’s feelings about his or her physical body. Of these four items, only one received negative responses by a majority of the respondents. This item was: “When I am with other people, I am nervous about my body.” Twenty respondents (57.1 percent) agreed to some degree with this statement. The mean score for total body satisfaction was 10.03 (out of a possible range of 4 to 16). The mean for this score was only slightly lower than the means for self-esteem (15.22 out of a possible range of 6 to 24) and self-efficacy (13.61 out of a possible range of 5 to 20). These results seem to refute hypothesis number 1, that self-esteem, self-efficacy, and body satisfaction for this group of respondents would be significantly low.

Discussion. Existing literature has pointed to a discrepancy in self-esteem, self-efficacy and body satisfaction between males and females. In most studies females are reported to have lower scores on all of these measures (Murnen et al. 2003; Nosek et al. 2003; Skultety and Whitbourne 2004; Jones, Vigfusdottir and Lee 2004; Davison and McCabe 2006; Kinavey 2006). This group of respondents presented somewhat surprising results.

When the means for self-esteem, self-efficacy, and body satisfaction were compared by sex, the differences between male and female means were very small, with females scoring higher than males on self-efficacy. The means for male and female on each of these measures is outlined in Table 6.

Table 6. Means for Self-Esteem, Self-Efficacy, and Body Satisfaction by Sex

	<i>Self-esteem Mean</i>	<i>Self-efficacy Mean</i>	<i>Body Satisfaction Mean</i>
Male	15.58	13.33	10.08
Female	14.96	13.70	10.00
Difference in means	.62	-.37	.08

Ultimately, the sex differences on these measures were minimal for this sample, and refuted hypothesis number 2, that these scores would be lower for female respondents than male respondents. It is impossible to know the exact explanation for this variance from the population at large. It may be that the experience of disability during adolescent years outweighs sex as a predictive factor in self-perception measures. This may also illustrate a feeling of inadequacy by male respondents about exhibiting the hegemonic masculine qualities defined as desirable by our culture (Gerschick and Miller 2004).

The mean scores on these measures were compared by population size. Those living in rural areas (less than 5,000 people) had lower mean scores on self-esteem and self-efficacy. Mean scores for body satisfaction were somewhat lower for those living in cities, with a difference between the highest and lowest mean of only .76. This would indicate that hypothesis number 3 (that these measures would be lower for those living in rural areas) was only partially supported by these findings. These mean scores are outlined in Table 7.

Table 7. Means for Self-Esteem, Self-Efficacy, and Body Satisfaction by Population Size

	<i>Self-esteem Mean (possible range 6-24)</i>	<i>Self-efficacy Mean (possible range 5-20)</i>	<i>Body Satisfaction Mean (possible range 4-16)</i>
Rural	13.0	11.8	10.0
Town	15.77	14.23	10.09
City	15.5	13.00	9.33

While the mean differences in self-esteem, self-efficacy, and body satisfaction by sex or population size were minimal, a more substantial relationship was found between those variables and the measure of ability level.

The mean score for this measure was 23.13 out of a possible range of 11 to 33. When correlated with the self-perception measures, ability was associated with both self-esteem and self-efficacy. Despite its seemingly logical connection to body satisfaction, there was no empirical relationship found. These correlations are presented in Table 8.

Table 8. Correlations for Total Ability and Self-Perception Measures

	<i>Self-esteem</i>	<i>Self-efficacy</i>	<i>Body Satisfaction</i>
Total Ability Score	.329	.482	.051

These correlations may seem to represent a causal relationship between physical condition and self-perception, but this may not be the case. Other findings within this respondent group point to ability being a multi-faceted measure. Ability level correlated with several variables in this study. However, because causal attributions are difficult with questionnaire data, it is necessary to interpret these correlations carefully. Ability level (especially as measured within this survey) is not a purely physical condition. Much of what constitutes ability level is also social. Because of the high level of dependence and the effects of stigmatized identity, young people with disabilities may find themselves in social situations that hinder them from experiencing autonomy. They may encounter people who insist on helping/intervening in activities that they might otherwise be capable of learning to do independently (Cahill and Eggleston 1994). A lack of knowledgeable mentors may also contribute to situational helplessness. It is possible that they are, at times, unable to learn how to accomplish certain tasks due to the absence of people around them who could teach them how to do those things. This possibility was suggested by a correlation in the data between a respondent's total proximity to disability and ability level. The proximity to disability score is a

composite score based on the respondents' answers to several questions regarding their level of contact with others who have disabilities. In this sample, there is a positive correlation of .375 between this level of contact and ability level. This suggests that being around others who have disabilities allows one to reach a higher level of independent function.

Higher ability levels were also correlated with more numerous and intimate relationships and higher expectations for the future. Although they cannot be generalized to the population of disabled adolescents, these findings are important for this group of respondents. The apparent importance of ability level to so many other aspects of adolescent life points to a need to maximize independence and interdependence as much as possible. This is true for all adolescents but may be especially so for those adolescents who lack resources. Accomplishing this can be difficult as the disabled status tends to place able-bodied others into a helping role, potentially diminishing the level of independence possible. Over-helping may also lead to an intensified feeling of disablement and a more internalized feeling of helplessness.

Perceptions. Respondents were also given a list of adjectives and were asked to mark all the words they thought their peers would use to describe them. Then they were given the same list again and asked to mark which words they thought described themselves. The purpose of this part of the survey was to compare participants' ideas of themselves to the perceived ideas of their peers. These answers were analyzed individually as well as comparatively.

In looking at the individual adjectives offered to the respondents, several were marked more often than others. Existing theories of social identity, such as the Looking Glass Self theory, were also supported by the findings within this population, as answers to these sets of questions were very similar for what adjectives were marked for what the respondents thought

about themselves and what they perceived others to think about them. Table 9 outlines the findings on these items.

Table 9. Individual External and Internal Perceptions

<i>Item</i>	<i>Others think this</i>		<i>I think this</i>		<i>Marked both (Others think and I think)</i>	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Smart	25	65.8	27	71.1	21	55.3
Funny	27	71.1	31	81.6	25	65.8
Pretty	13	34.2	17	44.7	11	28.9
Strong	17	44.7	16	42.1	13	34.2
Fun	27	71.1	25	65.8	22	57.9
Popular	9	23.7	7	18.4	4	10.5
Dumb	7	18.4	3	17.9	3	17.9
Serious	15	39.5	15	39.5	10	26.3
Ugly	4	10.5	5	12.8	1	2.6
Boring	5	13.2	6	15.8	2	5.3
Weak	9	23.7	7	18.4	4	10.5

According to these answers, the respondents report having some negative ideas about themselves and how they think others view them. However, they are much more likely to use positive words to describe themselves than negative words. These results show no support for hypothesis number 4 (that respondents would have negative ideas about how their peers perceive them). There was strong indication that respondents' self-perceptions mirror perceived peers' opinions of them, supporting hypothesis number 5 (that respondents' self-perceptions would mirror perceived peer perceptions).

It is interesting to note that the most frequently marked adjectives are fun and funny. This finding supports other previous studies that have looked into the coping mechanisms of

people with disabilities. Humor has been cited as a primary mechanism to deal with embarrassing situations and social discomfort for adults with disabilities (Cahill and Eggleston 1994; Taub, et al. 2004). This method of coping has been used not only to alleviate discomfort on the part of the person with a disability but also to alleviate the discomfort of non-disabled people in social situations.

Disability Identity. While the participants in this study do not exhibit extraordinarily low levels of self-efficacy, self-esteem, or body satisfaction, they do overwhelmingly identify with their disabled status. When asked to mark how strongly they agreed with the statement: “Having a disability is a big part of who I am,” only six respondents disagreed. This level of agreement on the importance of this status re-affirms previous research that points to disability as a master status (Thomas 1966; Schaefer 2000; Barnartt 2001). As a master status, this identification has certain social implications which will be discussed in the following section.

Group Identity

Cultural Identity. Items 56 through 65 were designed to measure the level of cultural identity for each respondent. Four of the items referred to the respondents’ feelings of group identification, two referred to any in-group bias the respondent might feel, two referred to the respondents’ personal identification as disabled, and two referred to the level of knowledge the respondent felt about the experience of disablement.

According to the findings with this group of participants, their personal identification with the status of disabled is higher than their group identification or level of knowledge. This is potentially significant because it indicates that while these respondents have a high level of identification with a status of disability, they have much lower identification with a culture of disability. This finding partially supports hypothesis number 6 (that respondents would exhibit

low levels of cultural identification), although it was impossible to determine whether or not the respondents' overall cultural identification scores were high or low compared to other groups.

Cultural Identity Relationships. Using the cultural identity score, a variety of relationships were analyzed. The total culture index score was found to be positively correlated with both self-esteem and self-efficacy. However, this study found no relationship between cultural identity and body satisfaction. These findings support the first two parts of hypothesis number 7 (that cultural identity would be positively correlated with self-esteem and self-efficacy), while refuting the last part (that cultural identity would be positively correlated with body satisfaction). Total culture was also tested for any relationship to future orientation (an index score made up of normative adult behaviors the respondent selected as expecting to accomplish). The findings from these tests are found in Table 10.

Table 10. Culture and Self-perception and Future Orientation

	<i>Self-Esteem</i>	<i>Self-efficacy</i>	<i>Body Satisfaction</i>	<i>Future Orientation</i>
	Pearson Corr.	Pearson Corr.	Pearson Corr.	Pearson Corr.
Total Culture	.215	.335	.002	-.05

For this group of respondents there was a positive correlation between total culture and self-efficacy, a positive but weaker relationship between total culture and self-esteem, and no relationship between total culture and body satisfaction or Future Orientation. It may be that a cultural identity for disablement is not related to the same outcomes as that of ethnic identity, despite the similarities in the importance of the two statuses. However, it may also be that the specific characteristics of this group of respondents had an effect on these correlations. The high

degree of personal identification with the status and the low level of identification with the group itself may alter the effectiveness of the composite score.

Desire for Cultural Identity. When respondents were asked questions about whether or not they would like to experience some of the aspects of cultural identity, the responses were primarily positive. Participants were asked to mark their level of agreement to the following three statements: “I am interested in knowing more about people with disabilities,” “I am interested in knowing more about the issues that affect people with disabilities,” and “I would like to meet more people with disabilities.” The results of these questions are detailed in Table 11.

Table 11. Desire for Culture

	<i>Strongly Agree</i>		<i>Agree</i>		<i>Disagree</i>		<i>Strongly Disagree</i>	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%
Know more...								
About people	13	41.9	11	35.5	6	19.4	1	3.2
About issues	12	37.5	12	37.5	6	18.8	2	6.3
People w/ disabilities	12	37.5	14	43.8	5	15.6	1	3.1

A large majority of respondents answered each of these questions in the affirmative. This shows an interest in the cultural group in which these respondents find themselves, as well as a desire for more contact with others within this group.

Proximity to Disability. How much contact do these respondents currently have with other people with disabilities? One study found that adults with spina bifida mentioned the lack of contact with disabled peers during adolescence as an issue (Kinavey 2006). In order to investigate the number and intimacy level of these respondents’ relationships with other people with disabilities, items were included in the survey to measure their proximity to disability.

These items included questions about how many people they knew with disabilities and how close they are to these people as well as how much time they spend with them. On average, respondents know between three and four people with disabilities. The average number of friends who are disabled is between one and two and the average number of close friends listed as disabled is less than one. In fact, 18 respondents (45 percent) state that they have no close friends who have disabilities. The average number of hours spent socializing with others with disabilities each week is between 1 and 3 hours. When added together, the responses to these questions made up the Total Proximity to Disability score. These scores ranged between 1 and 12, with a mean score of 6.75.

Proximity to disability was found to have a positive correlation of .47 with the Total Cultural Identity score. Thus, for these respondents, having more contact with other people with disabilities increased the feeling of cultural identification. This finding supports hypothesis number 8, which stated that proximity to disability would be positively correlated with cultural identity.

Proximity to disability may also have some negative effects. For the respondents to this survey, there was a negative correlation of .28 between proximity to disability and body satisfaction. This may mean that by having regular contact with others who have disabilities, the respondents become more aware of their own physical condition or that those with a negative view of their bodies have more contact with other disabled teens.

In-Group Bias. This study looks briefly at the idea of negative in-group bias, partially in response to the existing literature on ethnic identity. In some situations, people with disabilities may attempt to normalize their own experiences by creating a negative idea about other disabled people, thus setting themselves apart from the group.

Within this survey there were several questions that were designed to get an idea of how the respondents felt about disabled people in general. Three questions dealt specifically with physical attractiveness and two questions (the bias questions found within the Cultural Identity section) dealt with the person's level of acceptance and comfort with others with disabilities. While these questions were overwhelmingly answered in a manner that indicated positive in-group opinions, some respondents displayed negative in-group bias.

When asked whether or not a person with a disability can be attractive, a large majority (72.5 percent) answered in the affirmative. However, 1 respondent answered "No," and 10 more answered "I don't know." When respondents were asked if they had ever been attracted to a person with a disability, once again a majority (52.5 percent) answered positively. In this case, there were 10 respondents who answered "No," and 9 who answered "I don't know." This shows a discrepancy between ideology and experience for these respondents. When asked whether or not they would consider dating a person with a disability, 66.7 percent said "Yes." There were 3 respondents who answered "No," and 10 who responded "I don't know." While these answers give us an idea of the level of negative in-group bias in relation to physical attractiveness, it also gives us insight into how these respondents may view their own attractiveness.

In the Cultural Identity section there were two questions aimed towards exploring negative in-group bias. Respondents were asked to report (on a 4-point scale) the level to which they agreed to the following items: "I try to hide being a part of a group of people like me," and "I feel uncomfortable with people with disabilities." Thirteen respondents (40.6 percent) marked some level of agreement with the first statement, and 11 respondents (34.4 percent) marked some level of agreement with the second statement. While certainly not overwhelming, this is

indicative of a significant amount of negative in-group bias within this group of respondents. This type of negative orientation about people with disabilities may not only limit the level of cultural identification possible but may also limit the positive feelings these respondents are capable of feeling for themselves.

Social Interaction

One of the main goals of this study was to investigate the social engagement patterns among young people with physical disabilities. In order to understand their social world, one must get an idea of the social patterns in their lives.

Friendships. The average number of friends reported was between four and six. The average number of close friends reported was between one and three. Respondents reported spending an average of between one and two hours per day talking to others outside of school. When asked how many times per month they spend time with friends outside of school settings, the average response was between one and two times. More detailed results can be found in Table 12.

Table 12. Time Spent with Friends

	<i>Hrs per day spent talking to friends</i>		<i>Times per month spend time with friends</i>	
	Frequency	Percentage	Frequency	Percentage
0	9	28.1	11	34.4
1	11	34.4	6	18.8
2	6	15.0	2	6.3
3 +	6	15.0	13	40.6

With no able-bodied respondents for comparison, it is impossible to tell how this compares to other adolescents. However, it is possible to get an idea of the typical social lives of adolescents from some statistics gleaned from other studies. A survey of American high school

seniors, conducted by the University of Michigan, found that the average high school senior goes out between two and three times per week. The same study found that less than 10 percent of respondents reported going out less than one time per week (Johnston, Bachman, and O'Malley 2001). Wave III of the National Longitudinal Study of Adolescent Health (Add Health) found that over half of the respondents reported having "hung out" with friends five or more times in the previous week, and less than 9 percent reported not having participated in that activity in the last week (Udry 2003). So it seems that this particular group of respondents may spend less time with friends outside of school than the average adolescent in the U.S. This finding seems to partially support hypothesis number 9, which stated that respondents would report low numbers and levels of intimacy in all types of relationships.

In analyzing the score for Total Friendship with other variables, it is possible to get an idea of how various characteristics affect the number and level of intimacy of friendships for this group of participants. A comparison of means indicates that there are differences in population size categories for Total Friendship scores. The mean for cities was 8.50. The means for other population categories were as follows: Rural areas = 5.6 and Towns = 7.58. According to this finding, living in a rural area is negatively related to Total Friendship. The Total Friendship scores for girls and boys were virtually identical (7.1 and 7.2, respectively).

Age also had a limited effect on this score. Those between the ages of 16 and 18 reported slightly higher mean Total Friendship scores (8.22). Being under 16 and 18 or older produced a lower Total Friendship score (6.78 and 3.0, respectively). Those over 18 reported the lowest mean Total Friendship score, pointing to a potential increase in isolation at the onset of adulthood for these respondents.

The variable exhibiting the strongest association with Total Friendship was Ability level. The correlation between these two variables was .591. It is difficult to know whether this is a uni-directional or a bi-directional relationship. A greater level of physical functioning may be an advantage to socializing outside of school, and a higher level of socializing may increase physical function. Increased social experiences may offer more frequent opportunities to acquire skills and the confidence to use them. Positive correlations between total friendships and both self-esteem and self-efficacy were found; however, there was virtually no correlation with body satisfaction. These findings are presented briefly in Table 13.

Table 13. Correlations between Friendship and Self-Perception Measures

	<i>Self-esteem</i>	<i>Self-efficacy</i>	<i>Body Satisfaction</i>
Friendship	.478	.287	.148

Romantic Relationships. For this survey, respondents were asked a series of questions about their romantic relationships. They were asked whether or not they had ever had a boyfriend or girlfriend, whether they had one in the last month, if they had one now, and how many such relationships they had in the last year. Twenty respondents (64.5 percent) reported having had a boyfriend or girlfriend at some point in time, 12 (38.7 percent) reported having one in the last month, and 9 (29 percent) reported having one currently. The participants were then provided an age-appropriate list of activities and were asked to mark any activities in which they had participated with romantic partners. The numbers of affirmative responses are detailed in Table 14. It is important to note that those filling out Version 1 of the survey did not receive

“Heavy petting,” or “Sex” as activities. However, all respondents were offered an open-ended “Other” option to add any other activities.

Table 14. Romantic Activities

<i>Activity</i>	<i>Frequency</i>	<i>Percentage of Total</i>
Write notes	12	37.5
Tell Secrets	10	31.3
Hold Hands	14	43.8
Hug	14	43.8
Kiss	13	40.6
Go out	11	34.4
Give each other gifts	11	34.4
Visit each other’s homes	11	34.4
Help each other	9	28.1
Heavy petting	4	12.5
Sex	2	6.3

On the “Other” option, two respondents mentioned that they had participated in online relationships, and another respondent stated that he/she had no such relationship since the eighth grade.

Ability level was positively correlated to Romantic Activities ($r = .482$), as were Total Friends scores ($r = .411$). Overall, it appears that Romantic Activities are related to other positive social experiences for these respondents.

Social Activities. This questionnaire also explores the number and types of activities in which respondents participate. Tables 15 through 17 illustrate these findings. Table 15 refers to in-school activities, Table 16 to extra-curricular activities, and Table 17 to community-based

activities. It is important to note that because of the comprehensive nature of these items, rows will not add up to 100 percent. There were also more missing data for community activities, making the number of respondents vary between items.

Table 15. In-school Activity Participation

<i>Activity</i>	<i>Yes</i>		<i>No</i>		<i>Not Offered</i>		<i>Can't due to disability</i>	
	Freq	Percent	Freq	Percent	Freq	Percent	Freq	Percent
Regular classes	26	83.9	5	16.1	0	0	0	0
Honors classes	10	32.3	20	64.5	1	3.2	7	21.9
Clubs	19	61.3	12	38.7	0	0	9	28.1
Science Fair	5	17.2	19	65.5	5	17.2	6	18.8
Special class	23	74.2	8	25.8	0	0	9	28.1
Field Trips	27	87.1	3	9.7	1	3.2	6	18.8
P.E.	18	58.1	12	38.7	1	3.2	13	40.6
Recess	4	12.5	2	6.3	26	81.3	1	3.1
Spelling Bees	1	3.1	6	18.8	25	78.1	1	3.1
Vocational Class	6	19.4	14	45.2	11	35.5	2	6.3
Driver's Ed	7	22.6	14	45.2	10	32.3	7	21.9

Table 16. Extra-curricular Activity Participation

<i>Activity</i>	<i>Yes</i>		<i>No</i>		<i>Not offered</i>		<i>Can't due to disability</i>	
	Freq	Percent	Freq	Percent	Freq	Percent	Freq	Percent
Sports	9	29.0	19	61.3	3	9.7	9	30.0
Cheerleading	2	6.5	27	87.1	2	6.5	13	43.3
Talent Show	6	19.4	23	74.2	2	6.5	6	20.0
Play	9	29.0	20	64.5	2	6.5	7	23.3
Extended	13	41.9	15	48.4	3	9.7	7	23.3
Band	7	22.6	20	64.5	4	12.9	8	26.7
Chorus	8	25.8	21	67.7	2	6.5	6	20

Fund-raiser	16	51.6	15	48.4	0	0	4	13.3
Clubs	18	58.1	13	41.9	0	0	6	20
Dances	14	45.2	15	37.5	2	6.5	4	13.3

Table 17. Community Activity Participation

<i>Activity</i>	<i>Yes</i>		<i>No</i>		<i>Not offered</i>		<i>Can't due to disability</i>	
	Freq	Percent	Freq	Percent	Freq	Percent	Freq	Percent
Festivals	15	53.6	9	32.1	4	14.3	4	14.8
Playgrounds	17	60.7	10	35.7	1	3.6	2	7.1
Parks	18	64.3	9	32.1	1	3.6	2	7.1
Restaurants	24	88.9	2	7.4	1	3.6	1	3.6
Concerts	17	60.7	11	39.3	0	0	2	7.1
Parties	15	53.6	12	42.9	1	3.6	5	18.5
Movies	23	82.1	3	10.7	2	7.1	1	3.6
Sports Events	14	50.0	13	46.4	1	3.6	2	7.1
Shopping	22	78.6	5	17.9	1	3.6	2	7.1
Trips	19	67.9	7	25.0	2	7.1	4	14.8
Camps	12	42.9	13	46.4	3	10.7	5	17.9
Carnivals	13	46.4	13	46.4	2	7.1	2	7.1
Bowling	18	64.3	8	28.6	2	7.1	1	3.6
Plays	12	42.9	14	50.0	2	7.1	3	10.7
Church	17	60.7	10	35.7	1	3.6	2	7.1

Responses to each type of activity were added together to create a score for the total number of activities in which each respondent reports participating. The total number of each type of activity in which the respondents reported not being able to participate were also totaled.

Respondents participated in an average of 4.77 school activities, 3.42 extra-curricular activities, and 9.14 community activities, and those totals were somewhat higher than expected.

This contradicts hypothesis number 10, which stated that respondents would report a low number of social activities.

According to these respondents, regular classes, spelling bees, and recess are the most accessible in-school activities. However, this may place older students at more of a disadvantage than younger ones, as recess and spelling bees typically are not available in higher grades. Dances and fund-raisers are the most accessible extra-curricular activities. However, for each extra-curricular activity, at least four students listed it as having been inaccessible to them due to their disability at some point in time. These respondents seem to find their community activities more accessible, with restaurants, movies, and bowling listed as the most accessible community activities. These findings seem to support hypothesis number 11 (that respondents would report a high number of activities have been inaccessible to them due to their disability) with the exception of community activities, which were listed as inaccessible less frequently.

This study did not support hypothesis number 12 (that there would be a more pronounced lack of participation opportunity in rural areas). When the mean scores for the total number of each type of activity were evaluated, there were actually some potential positive relationships between living in a rural area and all three activity areas. These results are laid out in Table 18.

Table 18. Mean Total Activity Scores by Type of Activity and Population

	<i>In-school Activities</i>	<i>Extra-curricular Activities</i>	<i>Community Activities</i>
Rural area	5.8	4.8	12.0
Town	4.6	2.8	8.4
City	3.7	3.0	9.9

For these respondents, population affected their participation rates in each of the types of activities. The results indicate that schools in rural areas offer a level of individual attention that allows for higher participation rates. However, it is impossible to truly know what made the difference for this group of respondents.

According to the results of this study, female respondents reported participation in more extra-curricular activities (mean score of 3.95) than male respondents (mean score of 2.3), and reported being unable to participate in fewer extra-curricular (mean score of 1.67 versus the male mean of 3.7) and community activities (mean score of .63 compared to the male mean of 3.25) due to disability. The data reveal negative correlations between Proximity to disability scores and the inability to participate in all three types of activities. These results are outlined in Table 19.

Table 19. Correlations between Proximity to Disability and Activity Inaccessibility Scores.

	<i>Number Inaccessible In-School Activities</i>	<i>Number Inaccessible Extra-curricular Activities</i>	<i>Number Inaccessible Community Activities</i>
Proximity to Disability	-.333	-.387	-.511

This may mean that being around others with disabilities has helped these respondents feel more able to participate in activities. It may also mean that locations in which there are more young people with disabilities are better equipped to provide accessible activities to these respondents. This also may mean that the more contact a person has with people *without* disabilities, the more accessibility issues they may face.

Future Orientation

One of the main questions that can be asked is whether or not the experience of disablement leads young people to have lowered expectations for their adult lives. They were given a list of normative adult behaviors and asked to mark the ones they expected to accomplish in the future.

Expected Educational Attainment. Respondents were given several educational attainment options to choose from. A majority of participants indicated that they expected to get at least some post-secondary education. The detailed results for expected educational attainment are presented in Table 20.

Table 20. Expected Educational Attainment

<i>Educational Expectation</i>	<i>Frequency</i>	<i>Percentage</i>
None listed	3	11.5
Graduate High School	5	19.2
Attend Vocational/Trade School	1	3.8
Go to Community College	1	3.8
Graduate from College	16	61.5

While these scores are seemingly positive, compared to the data from the national surveys (“Monitoring the Future” and “Add Health”) discussed in Chapter 2 (see Table 2), we see significant differences between this group of respondents and those from the national surveys. Over 70 percent of respondents in both national surveys report wanting or expecting to go to college. A lower percentage (65.3 percent) of participants in this study list college as their highest expected educational attainment. Less than 6 percent of participants in the “Monitoring the Future” survey intend to get a high school education or less, but 30.7 percent of participants in this study expect to get no more than a high school education.

The responses to this survey are still better than the statistics regarding adults with disabilities in the United States today, as reported by the Harris Poll data described in Chapter 1 (see Table 1). Given the optimistic responses from this survey (in comparison to the stark statistics for adults currently living with disabilities in the United States), it is possible that today's adolescents with disabilities see more potential for their futures. It is also possible that adolescents in general are overly optimistic about their post-secondary opportunities. According to a recent report by USA Today, 80 percent of high school sophomores in 2002 reported expecting to get a college degree, but only 64 percent of high school graduates actually enter college. Of those, only a fraction will actually graduate from their college program, although the percentage varies by type of college. About a quarter of students at two-year colleges and open-entrance universities will graduate, while 75 percent of students at more selective universities will graduate (Toppo and DeBarros 2005).

Expected Normative Adult Roles. Participants in this survey were also asked about several other expected normative adult accomplishments. The detailed results of these responses are listed in Table 21.

Table 21. Expected Normative Adult Roles

<i>Normative Role</i>	<i>Respondents Expecting to Accomplish This Expectation</i>	
	Total Frequency	Total Percentage
Get a job you like	26	96.3
Get married	20	74.1
Have a family	17	63.0
Travel	16	59.3
Live Independently	17	63.0
Drive a Car	17	63.0
Buy a Home	16	59.3

These percentages are higher than expected and seem to refute hypothesis number 13 (that participants would indicate low future expectations).

In order to get an idea of the overall future expectations of the respondents, these items were added together to create an index of Expected Adult Roles. A number of other variables were used for comparison in investigating the variation in this index.

One of the initial hypotheses for the Expected Adult Roles Index (hypothesis number 14) was that respondents from more rural areas would exhibit lower future expectations than those from urban areas. This hypothesis has been supported in the larger American population (Nurmi et al. 1993). For this index, respondents living in a rural area had a mean of 5.6. Those living in towns had a mean score of 8.75 and those in cities had a mean score of 9.11. This is especially interesting when city lifestyles are considered. In larger cities, driving is unnecessary and owning a home is often unaffordable. Hypothesis number 14 is supported by this data.

Another hypothesis (number 15) was that female respondents would list a smaller number of expected normative adult roles than would males. This hypothesis was supported, as female respondents had a mean of 7.16 whereas male respondents had a mean of 10.25. In order to better understand how sex of the respondent affected responses to individual Future Orientation items, crosstabs were run on all items (except educational expectations, which were scored differently and analyzed separately). The results from this analysis are contained in Table 22.

Table 22. Expected Normative Adult Roles by Sex

Expectation	Male positive responses (%)	Female positive responses (%)
Get a job you like	100.0	94.7
Get married	87.5	68.4
Have a family	62.5	63.2

Travel	87.5	42.1
Live Independently	75.0	57.9
Drive a car	87.5	52.6
Buy a home	87.5	47.4

A lower percentage of females than males marked a positive expectation on every item with the exception of “Have a family.” The females participating in this study exhibited a significantly lower expectation of their future accomplishments than the male respondents.

Other variables were found to have some relationship to the future orientation of respondents. Ability was found to have a significant positive relationship to future orientation for these respondents ($r = .659$). This was expected since it is logical that a higher level of physical independence will increase the expectation of normative adult behaviors. Self-esteem showed a positive correlation to future orientation (.222), and Self-efficacy also showed a positive correlation to future orientation (.286). This finding is consonant with existing literature on the subject of self-efficacy and future orientation (Nurmi 1991; McCabe and Barnett 2000).

CHAPTER 5

SUMMARY

While this study was comprised of a small number of respondents, it offered an important source of information on the issues and social experiences of these participants. Many of the original hypotheses were not supported by the results leading to an interesting discussion of the potential roots of the problems facing adults living with disabilities in the United States. In the end, this study provided an overview of the sample and numerous theoretically-relevant findings that need to be examined in a larger and more representative sample.

The sample is a limitation for this study. While the results are intriguing, they cannot be generalized to the larger population of adolescents with disabilities. The sample is small and concentrated. The majority of the respondents were female (61.5 percent) and nearly half were either 16 or 17 years old. Over 75 percent were in grades 10 through 12, and 62.2 percent lived in a town. These characteristics may have an impact on the results. However, according to this study, these characteristics have a smaller impact on other variables than was expected.

Discussion of Results

Fifteen hypotheses were explored in this study. Because the subject matter of this survey was so broad, it is important to revisit the major findings and their implications. Table 23 outlines these hypotheses and the correlated results, followed by an in-depth discussion of the findings and their implications.

Table 23. Summary of Hypotheses and Related Findings

Hypothesis	Results
1. Respondents will exhibit very low levels of self-esteem, self-efficacy, and body satisfaction.	Not supported
2. Female respondents will exhibit lower levels of self-esteem, self-efficacy, and body satisfaction.	Not supported
3. Respondents from rural areas will exhibit lower levels of self-esteem, self-efficacy, and body satisfaction than respondents from other population categories.	Partially supported
4. Respondents will have negative ideas regarding peer perceptions of them.	Not supported
5. Respondents' self-perceptions will mirror perceived peer perceptions.	Supported
6. Respondents will exhibit low levels of cultural identification.	Supported
7. Cultural identity will be positively correlated with self-esteem, self-efficacy and body satisfaction.	Partially supported
8. Proximity to disability will be positively correlated with cultural identification.	Supported
9. Respondents will report low numbers and levels of intimacy in all types of relationships.	Supported
10. Respondents will report a low number of social activities.	Not supported
11. Respondents will report a high number of activities have been inaccessible to them due to disability.	Partially supported
12. Respondents from rural areas will report participating in fewer activities than those from other population categories.	Not supported
13. Respondents will demonstrate limited expectations of normative adult roles.	Largely supported
14. Respondents from rural areas will demonstrate lower expectations of normative adult roles than those from other population categories.	Supported
15. Female respondents will demonstrate lower expectations of normative adult roles than male respondents.	Supported

Individual Identity Measures. Hypotheses 1 through 5 related to individual identity variables. Originally, it had been thought that this group of respondents would express negative feelings about themselves. They were expected to have low levels of self-esteem, self-efficacy,

and body satisfaction (hypothesis 1). It had been further hypothesized that being female and living in rural areas would further exacerbate these issues (hypotheses 2 and 3, respectively). The participants in this study did not exhibit overly negative self-perceptions, as was expected. This is, perhaps, one of the most important findings of this research. Positive self-evaluation is evident by the responses, despite a stigmatizing status. While the results were more positive than initially expected, the fact that negative answers were received from at least one-third of respondents on these items is still disturbing and warrants attention.

Furthermore, the sex differences found in the general population regarding these types of measures were not evident in this group of respondents. While this finding is surprising, it may provide support for other social research in the field of disability studies. One possible reason for this discrepancy between this group of respondents and the population at large is that the experience of disability has similar results for males and females, resulting in similar scores on self-perception. Another possible explanation is that the “de-sexing” of those with disabilities nullifies the effects of sex on self-perception measures. Finally, it is possible that the experience of disablement is particularly debilitating for the self-perception of males, ultimately dismantling the social structures that typically support male positive self-perceptions.

Respondents living in rural areas did report lower levels of self-esteem and self-efficacy, but not body satisfaction. It is difficult to ascertain how population size affects these self-perception measures. It is possible that this is true of the adolescent population in general, and it carries over into this group of respondents.

Hypotheses 4 and 5 projected that the respondents would have negative ideas regarding peer perceptions of them and that their own self-perceptions would mirror these perceived peer perceptions. Responses from this group of participants did not indicate that they felt their peers

held predominately negative ideas about them. However, the results do indicate that their self-perceptions mirror their assumptions about peer perception of them. The tendency for young people to mirror peer perceptions coupled with the unique nature of the socialization process for young people with disabilities makes this an important issue. Successful performances become acutely integral not only to interaction itself, but also to the identity creation process.

Using items from existing scales was both a strength and a limitation for this study. Although these measures were found to be reliable over a significant period of time, they raised questions about their applicability to this particular population of respondents. While alpha scores for the items used in this study were of acceptable strength, several items seemed to illustrate discrepancies. In all three self-perception measures, there were several items that elicited more negative responses than others. These items were related to activity and utility. In the end, it is uncertain whether or not these scales (based upon assumptions of a normative body) apply as strongly to this population as others.

Group Identity. The investigation of cultural identity stemmed from similarities between disability and ethnicity as an identity. Disability (like race or ethnicity) often becomes a person's master status, forming the foundation for the individual's identity. Both characteristics are also often visually discernable, allowing the characteristic to be an instantly stigmatized or privileged status. Because having a positive, intact cultural identity has been found to be correlated with positive outcomes for young people of color and other minority categories, the researcher felt that this might also be a buffer for young people with disabilities as well.

However, as expected in hypothesis 6, the respondents exhibited a low level of disability culture identification. The results indicate that the participants in this study have a stronger identification with the *status* of disability than with a *culture* of disability. This potentially

supports other research in the field that has shown a lack of disability culture. It also makes it difficult to ascertain whether or not a cultural identity based on disability would provide strong benefits for young people with disabilities. However, the results showed a positive correlation between cultural identity and self-esteem and self-efficacy (partially supporting hypothesis 7), pointing to a potential similarity between these different types of cultural identity.

Because physical disability, especially that in young people, is widely dispersed, it may prove difficult for adolescents with disabilities to have regular, meaningful contact with others who have disabilities. This lack of physical proximity may be a barrier to creating a feeling of cultural identity based on disability. Hypothesis number 8 projected that proximity to disability would be positively correlated with cultural identification. This was supported by the results of this study.

Social Activities. Exploring the social experiences and relationships of this group of respondents was integral to this study. Hypothesis 9 stated that respondents were expected to report low numbers and levels of intimacy in all types of relationships. Overall, this hypothesis was supported by the findings. Respondents reported what were considered to be fairly low numbers of friends (especially close friends) and romantic relationships, along with low frequencies of social time with others and romantic activities with others. It is important to recognize that the numbers of relationships and activities dropped sharply as they increased in intimacy level. This may point to a potential drawback for adolescents with disabilities. These results indicate a significant lack of close, intimate relationships in the lives of these adolescents. This lack of intimacy during this important stage in life carries potentially negative implications for adult relationships. If young people with disabilities are unable to learn to forge and sustain these intimate bonds, future relationships will more than likely suffer.

Hypotheses 10 through 12 dealt with participation in different types of social activities. These hypotheses projected that respondents would report participating in few activities (hypothesis 10) and be unable to participate in a high number of activities due to their disability (hypothesis 11). It was also projected that those living in rural areas would report participating in fewer activities (hypothesis 12). According to these respondents, participation in activities is not as low as expected. However, contrary to the inclusive stance taken by the educational system, a fairly significant number of school-based activities (both in-school and extra-curricular) were listed by respondents as inaccessible to them due to their disability. This inaccessibility may increase as students progress through grade levels, as the most accessible in-school activities were recess and spelling bees (not typically found in higher grades). This potentially points to areas in which schools are failing to provide equal and integrated opportunities to students with disabilities.

The respondents to this survey found their communities at large to be more accessible for activities than their schools, reporting that they participate in a higher percentage of the listed community activities than either school or extra-curricular activities. Increased legally-mandated accessibility in communities may play a part in this. Although school buildings and classrooms are required to be physically accessible, the sponsored activities at schools are not always so. These respondents listed a significant number of activities in which they were unable to participate because of their disability. Making more activities openly accessible and welcoming to students with disabilities may be difficult for schools that are already under-funded and anxiously focused on standardized test results. The progression from purely recreational activities to competitive activities in later grades may also create a barrier to the participation of students with disabilities in adolescence. How can schools increase the effectiveness of their in-

school and extra-curricular programs so that students with disabilities are more able to participate fully in their school environment?

Hypothesis 12 was contradicted by the findings of this study. According to these results, those living in rural areas reported higher participation in all three types of activities than did respondents from small or medium sized cities. The characteristics of rural areas may actually increase participation and minimize inaccessibility. It may be that in a more sparsely located area, more attention can be paid to the individual needs of people with disabilities. The fact that participation was significantly higher in large cities may or may not be truly indicative of the characteristics of these areas, due to the extremely low number of respondents from large cities.

Future Orientation. The final three hypotheses related to the expectations respondents hold about their future. It was expected that the participants would demonstrate low expectations of normative adult roles (hypothesis 13) and that these low expectations would be more pronounced in respondents from rural areas (hypothesis 14) and female respondents (hypothesis 15). Hypothesis 13 was based largely on the data available from the 2004 Harris Poll on disability, which indicates that adults with disabilities have unique adult experiences. While these respondents reported higher future expectations than the researcher expected (compared to adults with disabilities), they were still thought to be somewhat lower than what one would expect from a non-disabled population. Hypothesis 13 is largely supported by these findings. This was especially obvious in the comparisons of future educational goals from national surveys to the responses from this study. This is an important finding, as future earnings are related to educational achievement. This finding may indicate an area that can partially explain the financial difficulties faced by people with disabilities in the United States.

Mirroring findings in the general population, respondents living in rural areas reported significantly lower future expectations than those from other areas. This highlights an important problem for people in rural areas overall and perhaps for rural people with disabilities. Young people with disabilities from rural areas may feel less positive about their future endeavors than young people without disabilities and young people in other geographic locations. Having lower expectations of the future during adolescence may lead to lower achievement and further marginalization of people with disabilities in their adult lives. The fact that female respondents scored significantly lower than males on future orientation is also an important finding. Just as in the case of rural respondents, this points to a potential barrier to adult achievement and happiness for females with disabilities.

Other Findings

Proximity to Disability. Proximity to disability appears to have several interesting associations that necessitate discussion. For young people with disabilities, the level of contact with others who have disabilities may be correlated with other areas of their lives.

Proximity to disability had a negative relationship with the total number of inaccessible activities in all three categories of social activities. The potential sources of this relationship are worthy of discussion. It is possible that the explanation for this relationship is based on the creation of accessible activities and environments for people with disabilities. If proximity to disability is based on being geographically close to others with disabilities, activity locations may have experience with providing accessible activities. Schools with a higher number of students with disabilities may be better-equipped to provide activities in which these students can participate. It may also be that locations providing a large number of accessible activities

become a haven for families with a member who is disabled (creating a more concentrated population of people with disabilities). It is also possible that those young people who experience a closer proximity to other people with disabilities learn how to negotiate more activities, ultimately increasing the number of activities they find to be accessible to them.

Proximity to disability also exhibited a negative correlation with body satisfaction. This was unexpected, as it was assumed that proximity to disability would be a universally positive experience for adolescents with disabilities. The results of this study did not include any examination of the possible causes of this relationship. It is possible that through increased contact with other people who have disabilities, the respondents are made more aware of their own disability. It is also possible that those with more severe disabilities find themselves in contained environments with other people with disabilities. The severity of disability might have an effect on body satisfaction despite an increase in contact with people with disability. It is also possible that students with lower body satisfaction choose or are encouraged to spend more time with others with disabilities. It is difficult to know how much control young people with disabilities have over their social circles. Like anyone, adolescents with disabilities will gravitate towards social situations in which they are accepted. It is impossible to tell whether or not groups of students with disabilities are more or less accepting of these adolescents than other groups.

Ability Level. One of the most important and unexpected findings from this study was the importance of ability level to many positive outcomes for adolescents with disabilities. This measure showed a correlation with more variables than any other measure in this study, including age, sex, and population size. Table 24 describes all the correlations for ability level

found in this study, followed by a more in-depth discussion of the measure and its potential implications.

Table 24. Pearson Correlations of Selected Variables to Ability Level

	<i>Self-esteem</i>	<i>Self-efficacy</i>	<i>Proximity to Disability</i>	<i>Total Friendship</i>	<i>Romantic Activities</i>	<i>Future Orientation</i>
Ability Level	.329	.482	.375	.591	.482	.659

As mentioned in the previous chapter, this study attempted to measure ability level outside of the constraints of disability type. While knowing the type of disability can offer a limited understanding of physical functioning, it cannot fully explain the multi-faceted idea of ability. Within any type of disability, there is a wide variance of possible physical effects. When the various medical and rehabilitative interventions are taken into consideration, even more variation in physical functioning for a given disability is found.

Ability level, as defined in this study, refers to the level of independence a respondent has in accomplishing normative activities. The level of ability, then, is not purely based on the physical aspects of a particular disability, but encompasses a wide range of unique social experiences. Medical and rehabilitative interventions, assistive technology, the level of social support for independence, cultural constraints, and personality traits all factor into the level of autonomy for adolescents with disabilities.

Ability level was positively correlated with self-esteem, self-efficacy, total friendship, romantic activities, and future orientation. All of these variables can be considered positive outcomes for adolescents. Many of these variables are related to other positive outcomes,

including future successes. Thus, ability level may play an important indirect role in positive outcomes later in life.

The relationship between ability level and proximity to disability is also important. It is possible that by having more contact with others who have disabilities, these respondents gain important daily living skills and the confidence to use them. This increased contact may provide an understanding audience for attempts at autonomy. It is also possible that respondents with a higher ability level are able to spend more time with others who have disabilities.

Implications for the Future

While this study's small sample size does not allow for generalization, it does raise important questions. These questions may provide the necessary impetus for future social programs and research. With the potential theoretical implications of these findings, it is crucial that a larger, more representative study be conducted. Not only would we be able to discern whether or not the results from this study identify trends in the larger population of adolescents with disabilities, but generalizations to this larger population could be made.

Individual Identity. The results from this group of respondents regarding their self-perceptions raise important questions that should be addressed in future research. Are popular scales and measures of identity and self-esteem based on an assumption of a normative body? If so, how does this assumption affect the validity of these measures for this population? Can they be altered to be more applicable to the unique experiences of people with disabilities?

The results from this group of respondents varied on self-perception measures from the expectations. How do these scores compare with the able-bodied population? These results indicate that the experience of disability may level the playing field between males and females

on variables like self-esteem, self-efficacy, and body satisfaction. Do females with disabilities feel better about themselves or do males feel worse? Is there a way to recreate this level playing field for other adolescents?

Body satisfaction is an enigma in this study. While it was expected that it would mirror the patterns found for other measures (like self-esteem and self-efficacy), the results did not support this assumption of similarity. What are the implications of these differences? How can body satisfaction be best measured in this population? Would it be more appropriate to design a measure that deals specifically with disability issues as they relate to body satisfaction, or do adolescents with disabilities view their bodies by the same standards as able-bodied adolescents?

The participants in this study did not have primarily negative beliefs about their peers' perceptions of them. However, with no comparison group, it is not known how similar their perceptions are to reality. How do adolescents without disabilities actually view those with disabilities? How knowledgeable and understanding are they about the experiences and realities of disability? What types of reactions do they have to disability and their peers with disabilities? What sources do they cite for their conceptions about disability? Would it be beneficial to provide more information about people with disabilities to the non-disabled population?

Group Identity. Being a part of the disability community may be more of a political position than a social one. According to these respondents, there is a higher identification with an identity of disability than a culture of disability. While there may be no culture based on disability, what implications would cohesive, positive in-group identification have? Would this feeling of belonging provide similar buffers against the negative effects of minority status that have been documented in young people of color? Could this type of group identity increase independence while creating a positive feeling towards interdependence?

A strong majority of participants in this study exhibited a desire for a stronger group identity. At least three-quarters of these respondents indicated that they would like to have more information about people with disabilities and issues surrounding disability, and would like to know more people with disabilities. What information do they currently have? What information is easily accessible to them? Where do they get their information? What messages do they get from those around them and the media?

Perhaps proximity to disability would increase this feeling they seem to be looking for. There was, in this study, a correlation between cultural identity and proximity to disability. What effects does exposure to more people with disabilities have on adolescents with disabilities? If these effects are largely positive, what programs are available to offer this level of contact? Is mentorship a possibility or a desire?

These respondents indicate that there is some negative in-group bias. While the percentages may seem low on the surface, they are still disturbing. Imagine if a study found that nearly a third of African Americans would not date or were not sure they would date another African American. The fallout would be tremendous. What are the causes and effects of these negative feelings towards disabilities and others who have them? How can negative in-group feelings be minimized?

Social Activities. One of the goals of this study was to get a general idea about the social relationships and experiences of adolescents with physical disabilities. While the survey was able to get an overview of these experiences, the details are still largely unknown. It would be beneficial to do a more in-depth, qualitative study on the social patterns in the lives of these young people. The information from this study only begins to scratch the surface of their negotiation of social life during adolescence. How do their interaction patterns compare with

other teens? Do they spend more time participating in non-corporeal interaction (internet and telephone) than in physical interaction?

Having friends and romantic partners becomes increasingly important during adolescence. During this time, young people learn to negotiate intimate personal relationships. How much control do young people with disabilities have over their social networks? Are they pigeon-holed into certain groups of friends? How do their actual groups of friends compare to their desired groups of friends? How do their physical limitations affect their friendships and interpersonal bonds with non-family members? How do they negotiate romantic activities? What part does their physical condition play in their decisions regarding intimate behavior? How do these issues change as they get older? What information about their sexuality is available to them?

Participation in activities is sometimes problematic for young people with disabilities. Accessibility, ability, information, and transportation may all affect the participation patterns of adolescents with physical disabilities. The participants in this study did not exhibit extremely low participation in any category of activities. However, accessibility did seem to be an issue for most activities at some point in time for many respondents. How can schools provide participation opportunities for young people with disabilities? These respondents found community activities to be more accessible than either in-school or extra-curricular activities. What are communities doing that works?

Environmentally, different types of communities may offer different types of benefits for young people experiencing physical disability. What aspects of each type of community allow for these benefits to be meaningful? How can all communities embrace these aspects in order to maximize the positive experiences of people with disabilities? Is it possible for larger towns to

create a sense of intimacy and freedom that seems to be found in more rural communities? Can rural communities find a way to provide the opportunities found within larger cities? Can some non-participation be due to physical inaccessibility? If so, to what degree would embracing universal accessibility help? Universal accessibility is a method of design that uses accessible features in buildings and communities, doing away with physical barriers that people with disabilities encounter, including almost all of us who live to an old age.

Future Orientation. One of the most disturbing findings of this study is the low scores on future orientation. Respondents to this survey have lower expectations of future educational attainment than those found in national surveys of adolescents. They are also more likely to get less education according to current statistics on adults living with disabilities in the US. This is an important issue for adolescents with disabilities, as it has direct implications for their future financial stability. What information are they getting about post-secondary education? What colleges and universities have a good track record for working with students who have disabilities? What programs work? What specific issues do young people with disabilities have when entering college? What are the barriers to college completion?

Female respondents and those from rural areas exhibited much lower scores on future orientation. This is especially troubling. What are the factors leading to these findings? How can their expectations of their futures be increased? How can they be empowered in their aspirations?

Ability Level. As mentioned previously, ability level was, for this group of respondents, the most important variable for positive outcomes and warrants further investigation. Due to the interactional effects of many different variables, ability level is a complex concept. In order to understand how to maximize ability, many factors need to be investigated. Future research into

this would be extremely beneficial for people with disabilities as well as the organizations and professionals working with them. How do different types of medical and rehabilitative interventions affect ability and autonomy? How does insurance coverage affect the ability level a young person with a disability can attain? What training programs are available and what works? What impact do families and school personnel have on ability level? What skills can be gained from exposure to other people with disabilities? It would also seem logical that this type of research into ability level and autonomy would be beneficial for all young people, especially those who face barriers to success. A more complete understanding of the social aspects of autonomy and the effects of maximizing it would be applicable to many other groups.

Cross-Cultural Implications. Culture plays an important role in defining disability. In order to better understand the social experiences of adolescents with disability, cross-cultural studies would provide a wealth of information. Western society's emphasis on independence may prove to be a factor in the marginalization of people with disabilities. What differences are found in cultures and social groups that value interdependence? What implications does the move from the industrial age to the information age hold for people with physical disabilities? How do societal values affect how we define and treat people with disabilities? When the value of independence is decreased, is ability level still a major factor in positive outcomes?

In the End

While the goal of this study was to gain a better understanding of the experiences of adolescents with disabilities, in the end more questions are raised. Current statistics on adults living with disabilities are disturbing because they indicate inequality in the quality of life that people can enjoy. This project sought to find a correlation between the social experiences of

young people with disabilities and negative internal factors that could lead to difficulties later in life. Instead, internal measures (like self-perception) were not found to be as significant as expected. If this can be interpreted that internal issues (like low self-esteem) are not substantial barriers, then we must consider what external barriers are affecting the outcomes for people with physical disabilities.

Despite the small number of respondents, this study offered a fairly in-depth account of the social experiences of this group of adolescents with physical disabilities. It provided an overview of trends and issues affecting these young people, and offered an opportunity for further study. The findings that emerged from this thesis should be more fully investigated via more representative studies. Equality is often rooted in the willingness of social scientists to embrace the potential and discover the circumstances in which it can occur.

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APPENDICES

APPENDIX A

Minor Participant Assent Document

Principle Investigator: Amy Sorensen

Study Title: Social Experiences of Adolescents with Physical Disabilities

This page will explain about being a participant in a research study. It is important that you read this material carefully and then decide if you wish to be a volunteer.

PURPOSE:

The purpose of this research study is to better understand how having a physical disability affects how you feel about yourself, how you think others feel about you, how you feel about your disability and how it impacts your social activities. When your experiences are understood, changes can be made to make things better for you and other people with disabilities.

DURATION

This survey should take between one and two hours to complete.

PROCEDURES

In order to participate in this research study, you will use a computer to fill out a survey online. You should answer all the questions, if possible. If you feel uncomfortable with any questions, you can skip those questions and go on to the next question. After reaching the last question, you will be given the opportunity to share your contact information with the person conducting this research. If you choose to do this, the researcher will send you or your family the results of

the research. You will also be notified if this researcher does any more research in which you could participate in the future. You do NOT have to provide the researcher with this information if you don't wish to. It will not affect your ability to participate in this survey. The researcher will not know which answers are yours.

If you are unable for any reason to use the online survey, you can contact the researcher and accommodations will be made for you. The researcher will work with you individually to choose another way of completing the survey.

Participation in this study is voluntary. If at any time you decide not to participate, you can stop the survey.

ALTERNATIVE PROCEDURES/TREATMENTS

The alternative to participating in this study is simply to choose not to participate.

POSSIBLE RISKS/DISCOMFORTS

This survey may ask some questions that are very personal. Please answer all questions as honestly as you can. The researcher will not know which answers are yours. Your answers will be kept completely confidential. Not even your parents can see your answers. If any question makes you feel uncomfortable, you can skip it and go on to the next question.

POSSIBLE BENEFITS

Although some of the issues discussed in the survey are sensitive subjects, sharing your ideas and experiences may help you understand them better. Your answers may also help other people

understand what your experiences are like. This survey could also help people create programs and policies that help you and other people with disabilities.

COMPENSATION FOR MEDICAL TREATMENT:

East Tennessee State University (ETSU) will pay the cost of emergency first aid for any injury that may happen as a result of your being in this study. ETSU makes no commitment to pay for any other medical treatment. Claims against ETSU or any of its agents or employees may be submitted to the Tennessee Claims Commission. These claims will be settled to the extent allowable as provided under TCA Section 9-8-307. For more information about claims call the Chairman of the Institutional Review Board of ETSU at 423/439-6055.

VOLUNTARY PARTICIPATION

Participation in this research experiment is voluntary. You may refuse to participate. You can quit at any time. If you quit or refuse to participate, nothing will happen to you. If you wish to quit, you can choose to stop the survey at any time. If you change your mind and wish to complete the survey, you can do so by returning to the online survey. If you are unsure about your decision, you can contact Amy Sorensen at 423-523-2620 for more information.

CONTACT FOR QUESTIONS

If you have any questions, problems or research-related medical problems at any time, you may call Amy Sorensen at 423-523-2620, or Dr. Scott Beck at (423-439-6648). You may call the Chairman of the Institutional Review Board at 423/439-6054 for any questions you may have about your rights as a research subject. If you have any questions or concerns about the research and want to talk to someone independent of the research team or you can't reach the study staff, you may call an IRB Coordinator at 423/439-6055 or 423/439/6002.

CONFIDENTIALITY

Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored on a private disk in the care of the researcher for at least 10 years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, ETSU IRB, and personnel particular to this research (Amy Sorensen and the Department of Sociology and Anthropology at East Tennessee State University) have access to the study records. Your name will not be associated with your answers at any point in the research process.

By checking the box marked “I understand and accept” found below, you confirm that you have read or had this document read to you. You can print a copy of this page for your records. You have been given the chance to ask questions and to discuss your participation with the investigator. You freely and voluntarily choose to be in this research project.

I understand and accept

I have decided not to participate



APPENDIX B

Questionnaire Version 1 (grades 5-8)

1. Do you have a physical disability? Y N
2. City and State in which you live: _____
3. Sex: M F
4. Age:
5. Current grade level: 5 6 7 8 9 10 11 12
6. How many people with disabilities do you know?
 0 1-2 3-4 5 or more
- 6a. How many of your friends have disabilities?
 0 1-2 3-4 5 or more
- 6b. How many of your closest friends have disabilities?
 0 1 2 3 or more
- 7a. How much time do you usually spend socializing with people with disabilities each week?
 None 1-2 hours 3-4 hours 5 or more hours
- 7b. Where do you spend this time? (Mark all that apply)
 School Home Other
8. Do you think a person with a physical disability can be cute/pretty?
 Yes No I don't know
9. Have you ever seen a person with a physical disability who you thought was cute/pretty?
 Yes No
10. Would you ever consider dating a person with a physical disability?
 Yes No I don't know

Think about the things you frequently do. Look at the list of activities below and mark whether these are things you are able to do On your own, With some help, or are not able to do at all.

Can do alone

Can do with help

Can't do at all

11. Get dressed
12. Prepare food or snacks.
13. Play sports
14. Get in and out of vehicle
15. Play video games
16. Do household chores
17. Do school work
18. Go out with friends

Below is a list of qualities that describe people. Mark all of the qualities that you think other kids your age would say about you.

Other kids my age think I am:

19. Smart
20. Funny
21. Pretty
22. Strong
23. Fun to be around
24. Popular
25. Dumb
26. Serious
27. Ugly
28. Boring
29. Weak

Now place a mark next to all of the qualities **you** believe are true about you.

I think I am:

30. Smart
31. Funny
32. Pretty
33. Strong
34. Fun to be around
35. Popular
36. Dumb
37. Serious
38. Ugly
39. Boring
40. Weak

Here are several statements. After reading each one, mark how strongly you agree with each statement.

Strongly Agree Agree Disagree Strongly Disagree

41. I feel that I am equal to others my age.
42. I feel I do NOT have much to be proud of.
43. I take a positive attitude toward myself.
44. On the whole, I am satisfied with myself.
45. I feel useless at times.
46. At times I think I am no good at all.
47. It is easy for me to stick to my aims and accomplish my goals.
48. Thanks to my resourcefulness, I know how to handle difficult situations.
49. I can solve most problems if I try hard enough.
50. If I am in trouble, I can usually think of a solution.
51. I can usually handle whatever comes my way.
52. I am comfortable with how my body looks.

53. When I look in the mirror, I feel good about my body.

54. I am comfortable with how my body appears to others.

55. When I am with other people, I am nervous about my body.

Mark how strongly you agree or disagree with each statement.

Strongly Agree Agree Disagree Strongly Disagree

56. As a person with a disability, I feel that I am a part of a group of people like me.

57. I try to hide being a part of a group of people like me.

58. I have strong ties with a group of people like me.

59. I feel uncomfortable with people with disabilities.

60. Having a disability is a big part of who I am.

61. I feel like I have a connection with other people like me.

62. I feel like I have things in common with other people with disabilities.

63. I know a lot about people with disabilities.

64. I know a lot about issues that affect affect people with disabilities.

65. I feel like my life is like the lives of other people with disabilities.

66. I am interested in knowing more about people with disabilities.

67. I am interested in knowing more about the issues that affect people with disabilities.

68. I would like to meet more people with disabilities.

Now we are going to look at your friends and relationships. Please mark the correct response as it applies to you right now.

69. How many friends do you have?
 0 1-3 4-6 7 or more

70. How many really close friends do you have?
 0 1-3 4-6 7 or more

71. How much time do you spend talking to your friends, not counting time spent at school, each day?
 None 1 hour 2 hours 3 or more hours

72. How often do you spend time with your friends, not counting time spent at school, in a month?
 None 1 time 2 times 3 or more times

73. How many times have you spent the night with a friend in the last month?
 None 1 time 2 times 3 or more times

74. How many times has a friend spent the night with you in the last month?
 None 1 time 2 times 3 or more times

75. Have you ever had a boyfriend/girlfriend?
 No Yes

76. Do you have a boyfriend/girlfriend right now?

No Yes

77. Have you had a boyfriend/girlfriend in the last month?

No Yes

78. How many boyfriends/girlfriends have you had in the last year?

None 1 2 3 or more

79. Please think about the types of romantic activities you have shared with your current or past boyfriends/girlfriends. Please mark all that you have participated in.

Writing notes to each other

Sharing secrets

Holding hands

Hugging

Kissing

Dating

Giving gifts to each other

Going to each others' homes

Helping each other with problems

Finally we are going to look at all the activities you participate in on a regular basis. Read the list of activities and mark whether you do or don't participate in them, or if your school or grade does not offer this activity.

Yes No School/grade doesn't offer this

80a. Regular classes

Honors classes

Clubs

Science Fairs

Special activities in class

Field trips

P.E. Class

Recess play

Spelling Bee

Vocational classes

Driver's Education

80b. Have you ever been unable to participate in any of these activities because of your disability? Yes No (filter)

80c. If you answered yes, please mark any activities that you have been unable to participate in.

- Regular classes
- Honors classes
- Clubs
- Science Fairs
- Special activities in class
- Field trips
- P.E. Class
- Recess play
- Spelling Bee
- Vocational classes
- Driver's Education

81a. Extra-Curricular Activities. Read the list of activities and mark whether you do or don't participate in them, or if your school or grade does not offer this activity.

- | | Yes | No | School/grade doesn't offer this |
|-----------------------|-----|----|---------------------------------|
| Sports Teams | | | |
| Cheerleading | | | |
| Talent Show | | | |
| School Plays | | | |
| Extended School Trips | | | |
| Band | | | |
| Chorus/Choir | | | |
| School Clubs | | | |
| School Dances | | | |

81b. Have you ever been unable to participate in any of these activities because of your disability? Yes No (filter)

81c. If you answered yes, please mark any activities that you have been unable to participate in.

- Sports Teams
- Cheerleading
- Talent Show
- School Plays
- Extended School Trips
- Band
- Chorus/Choir
- Fundraisers
- School Clubs
- School Dances

82a. Other Activities. Read the list of activities and places to visit. For each, mark whether you do or don't participate in it, or if your community does not offer this

Yes No Community doesn't offer this

- Festivals
- Playgrounds
- Parks
- Restaurants
- Concerts
- Parties
- Movie Theaters
- Sports Events
- Shopping
- Trips
- Camps
- Carnivals
- Bowling
- Plays
- Church

82b. Have you ever been unable to participate in any of these activities because of your disability? Yes No (filter)

82c. If you answered yes, please mark any activities that you have been unable to participate in.

- Festivals
- Playgrounds
- Parks
- Restaurants
- Concerts
- Parties
- Movie Theaters
- Sports Events
- Shopping
- Trips
- Camps
- Carnivals
- Bowling
- Plays
- Church

These questions are designed to measure the future hopes and goals of students with disabilities.

83. Please indicate all the things you plan to do in the future.

Graduate high school

Go to vocational school/classes

Go to a community college

Go to a university

Graduate from college

Get a job you like

Get married

Have a family

Travel

Live independently

Drive a car

Buy a home

84. List up to three careers you think you would be interested in when you are an adult.

APPENDIX C

Questionnaire Version 2 (grades 9-12)

1. Do you have a physical disability? Y N
 2. City and State in which you live: _____
 3. Sex: M F
 4. Age:
 5. Current grade level: 5 6 7 8 9 10 11 12
 6. How many people with physical disabilities do you know? (filter)
 0 1-2 3-4 5 or more
 - 6a. How many of your friends have physical disabilities?
 0 1-2 3-4 5 or more
 - 6b. How many of your closest friends have physical disabilities?
 0 1 2 3 or more
 7. How much time do you usually spend socializing with people with physical disabilities each week?
 None 1-2 hours 3-4 hours 5 or more hours
 - 7a. Where do you spend this time? (Mark all that apply)
 School Home Other
 8. Do you think a person with a physical disability can be attractive?
 Yes No I don't know
 9. Have you ever seen a person with a physical disability who you thought was attractive?
 Yes No
 10. Would you ever consider dating a person with a physical disability?
 Yes No I don't know
- Think about the things you frequently do. Look at the list of activities below and mark whether these are things you are able to do On your own, With some help, or are not able to do at all.
- | | Can do alone | Can do with help | Can't do at all |
|--|--------------|------------------|-----------------|
|--|--------------|------------------|-----------------|

- 18a. Date
- 18b. Have intimate relationships
- 18c. Drive
- 18d. Shop

Below is a list of qualities that describe people. Mark all of the qualities that you think other young people your age would say about you.

Other people my age think I am:

- 19. Smart
- 22. Funny
- 23. Pretty
- 24. Strong
- 25. Fun to be around
- 26. Popular
- 27. Dumb
- 28. Serious
- 29. Ugly
- 30. Boring
- 31. Weak

Now place a mark next to all of the qualities **you** believe are true about you.

I think I am:

- 32. Smart
- 33. Funny
- 34. Pretty
- 35. Strong
- 36. Fun to be around
- 37. Popular
- 38. Dumb
- 39. Serious
- 40. Ugly
- 41. Boring
- 40. Weak

Here are several statements. After reading each one, mark how strongly you agree with each statement.

Strongly Agree Agree Disagree Strongly Disagree

41. I feel that I am equal to others my age.

42. I feel I do NOT have much to be proud of.

43. I take a positive attitude toward myself.
44. On the whole, I am satisfied with myself.
45. I feel useless at times.
46. At times I think I am no good at all.
47. It is easy for me to stick to my aims and accomplish my goals.
48. Thanks to my resourcefulness, I know how to handle difficult situations.
49. I can solve most problems if I try hard enough.
50. If I am in trouble, I can usually think of a solution.
51. I can usually handle whatever comes my way.
52. I am comfortable with how my body looks.
53. When I look in the mirror, I feel good about my body.
54. I am comfortable with how my body appears to others.
55. When I am with other people, I am nervous about my body.

Mark how strongly you agree or disagree with each statement.

- | | Strongly Agree | Agree | Disagree | Strongly Disagree |
|--|----------------|-------|----------|-------------------|
| 56. As a person with a disability, I feel that I am a part of a group of people like me. | | | | |
| 57. I try to hide being a part of a group of people like me. | | | | |
| 58. I have strong ties with a group of people like me. | | | | |
| 59. I feel uncomfortable with people with disabilities. | | | | |
| 60. Having a disability is a big part of who I am. | | | | |
| 61. I feel like I have a connection with other people like me. | | | | |
| 62. I feel like I have things in common with other people with disabilities. | | | | |
| 63. I know a lot about people with disabilities. | | | | |
| 64. I know a lot about issues that affect affect people with disabilities. | | | | |
| 65. I feel like my life is like the lives of other people with disabilities. | | | | |
| 66. I am interested in knowing more about people with disabilities. | | | | |

67. I am interested in knowing more about the issues that affect people with disabilities.

68. I would like to meet more people with disabilities.

Now we are going to look at your friends and relationships. Please mark the correct response as it applies to you right now.

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 None 1 time 2 times 3 or more times

74. How many times has a friend spent the night with you in the last month?
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75. Have you ever had a boyfriend/girlfriend?
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76. Do you have a boyfriend/girlfriend right now?
 No Yes

77. Have you had a boyfriend/girlfriend in the last month?
 No Yes

78. How many boyfriends/girlfriends have you had in the last year?
 None 1 2 3 or more

79. Please think about the types of romantic activities you have shared with your current or past boyfriends/girlfriends. Please mark all that you have participated in.

Writing notes to each other

Sharing secrets

Holding hands

Hugging

Kissing

Dating

Giving gifts to each other

Going to each others' homes

Helping each other with problems

Heavy petting

Having sex

Next we are going to look at all the activities you participate in on a regular basis. Read the list of activities and mark whether you do or don't participate in them, or if your school or grade does not offer this activity.

	Yes	No	School/grade doesn't offer this
80a. Regular classes			
Honors classes			
Clubs			
Science Fairs			
Special activities in class			
School trips			
P.E. Class			
Vocational classes			
Driver's Education			

80b. Have you ever been unable to participate in any of these activities because of your disability? Yes No (filter)

80c. If you answered yes, please mark any activities that you have been unable to participate in.

Regular classes

Honors classes

Clubs

Science Fairs

Special activities in class

School trips

P.E. Class

Vocational Classes

Driver's Education Class

81a. Extra-Curricular Activities. Read the list of activities and mark whether you do or don't participate in them, or if your school or grade does not offer this activity.

	Yes	No	School/grade doesn't offer this
Sports Teams			
Cheerleading			
Talent Show			
School Plays			
Extended School Trips			
Band			
Chorus/Choir			
Fundraisers			
School Clubs			
School Dances			

81b. Have you ever been unable to participate in any of these activities because of your disability? Yes No (filter)

81c. If you answered yes, please mark any activities that you have been unable to participate in.

	Yes	No	School/grade doesn't offer this
Sports Teams			
Cheerleading			
Talent Show			
School Plays			
Extended School Trips			
Band			
Chorus/Choir			
Fundraisers			
School Clubs			
School Dances			

82a. Other Activities. Read the list of activities and places to visit. For each, mark whether you do or don't participate in it, or if your community does not offer this

	Yes	No	Community doesn't offer this
Festivals			
Parks			
Restaurants			
Concerts			
Parties			

Movie Theaters
Sports Events
Shopping
Trips
Camps
Carnivals
Bowling
Plays
Church

82b. Have you ever been unable to participate in any of these activities because of your disability? __Yes __No

82c. If you answered yes, please mark any activities that you have been unable to participate in.

Festivals
Parks
Restaurants
Concerts
Parties
Movie Theaters
Sports Events
Shopping
Trips
Camps
Carnivals
Bowling
Plays
Church

83. Please indicate all the things you plan to do in the future.

Graduate high school
Go to vocational school/classes
Go to a community college
Go to a university
Graduate from college
Get a job you like
Get married
Have a family
Travel
Live independently

Drive a car
Buy a home

84. List up to three careers you think you would be interested in when you are an adult.

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