"WE JUST STICK TOGETHER": CENTERING THE FRIENDSHIPS
OF DISABLED YOUTH

by

Nancy Salmon

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DEDICATION PAGE

For two of my most precious friends
Colby and Una

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ABSTRACT

Friendship matters. Practical support, caring, moral guidance, enjoyment, improved health and greater life expectancy are but a few of its benefits. Despite living in a stigmatizing social environment where isolation is common among disabled youth, some disabled teens establish strong friendships. A nuanced understanding of these meaningful friendships from the perspective of disabled teens was constructed through this qualitative study. Teens aged 15 to 20 who self-identified as experiencing stigma due to disability were recruited from urban, suburban and rural areas of Nova Scotia, Canada. Each teen was involved in a friendship of at least six months' duration and had a close friend (with or without a disability) who was also willing to participate. Seven boys and seven girls, all but one of whom were disabled teens, took part in the study. These seven sets of friends engaged in research interviews and participant observation sessions. Nine adults who witnessed the friendships develop over time were also interviewed. Preliminary coding was completed using Atlas.ti. This was followed by a deeper, critical approach to analysis which generated three inter-connected themes. The first theme outlines how stigma disrupts the friendships of disabled youth though a range of processes (labeling, stereotyping, status loss, separation) that arise from and contribute to ableism – discrimination against disabled people. The second theme, finding a balance between adult support and surveillance, emphasizes the crucial role adults play in facilitating the friendships of disabled youth. The final theme, disrupting oppression to create enduring friendship, highlights the strategies used by these disabled teens to make and keep friends in a stigmatizing society. Strategies most often used that appeared to be effective for participants were disrupting norms about friendship, coming out as disabled, connecting through stigma, and choosing self-exclusion. Two strategies – horizontal hostility and passing as nondisabled – were potentially harmful to disabled youth and in some ways limited friendship opportunities. Ideas to counter the harmful effects of ableism while creating lasting friendships are addressed to disabled teens, to their families, to allies in the education system, and to the broader community.

ACKNOWLEDGEMENTS

CHAPTER 1   INTRODUCTION

"Children who live with a physical, sensory, intellectual or mental health disability are among the most stigmatized and marginalized of all the world's children" (UNICEF, 2005, p.4). As Canadians we like to imagine ourselves to be an inclusive society; yet this statement made in a United Nations report implicates both first world and third world countries. News reports on violence against disabled youth frequently surface in the media. Consider the story of Brian McKay, a fourteen year old disabled boy who was roughly pushed into a wooden shed by four neighborhood children in Winnipeg (CBC, October 16, 2006). The nondisabled children then locked the door and set the building on fire. After being rescued by an adult who heard his cries, Brian offered the following interpretation of the actions of his peers, "They knew I was weak. I was born different, so they made fun of me." For Brian and many other youth with disabilities, the rhetoric of inclusion and valuing diversity is hollow. Brian's experience demonstrates not only exclusion, but also the extraordinary violence of attempted erasure of embodied difference. The children involved did not act alone. The larger society in which they learned their values and ways of being is complicit in designating disability as undesirable difference (Goffman, 1963).

For youth, disability often leads to loneliness, frustration, low self-concept, dropping out of school, unemployment, underemployment, lack of independence and mental health problems (Brown, Higgins, Pierce, Hong, & Thoma, 2003; Heiman, 2000). Adolescents with emotional, learning, and physical disabilities are more likely to be exposed to sexual abuse, smoking and alcohol use and have less access to protective factors such as enduring friendship than are nondisabled peers (Blum, Kelly, & Ireland, 2001). Carbonell and colleagues (2002) suggested that age 15 is a critical window for establishing the protective factors against depression, one of which is friendship (Public Health Agency of Canada, 2004). The value of friendship for youth is clear, however, little is known about the friendships of disabled youth.

Friendship concerns figured heavily in my earlier research where almost every disabled teen participant described episodes of verbal abuse and physical aggression by peers while simultaneously reporting few, if any, enduring friendships (Salmon & Kinnealey, 2007). These thoughtful, articulate disabled teens spoke of feeling rejected in their

classrooms and communities. They longed for the friendships that eluded them. Their accounts echoed the experiences of most of the disabled children with whom I worked during sixteen years of occupational therapy practice. My concern with the intersection of disability, friendship and youth finds its roots in the stories of these teens. Priestley (1998) and Shakespeare (2006) agree that engaging disabled youth in research about meaningful friendships is timely. Numerous scholars argue that much of the work in the field of disability studies has focused on the experiences of adults, inadvertently silencing teens (Connors & Stalker, 2003; Davis & Watson, 2001; Priestley, 1998). Additionally, much of the research that does attend to disabled youth, relies heavily on interviews with parents, teachers, and other adults instead of directly involving teens in the research process (Connors & Stalker, 2003).

In conceptualizing this study two particular routes were supportable. I could have followed a well-traveled research path by concentrating on the barriers to friendship as experienced by disabled youth. Although that approach has merit and there is much to be learned from examining hindrances to meaningful friendship, this option was set aside in favor of attending to friendships that were flourishing. In essence this study begins where others end – at stigma. The current study concerns the stories of disabled teenagers who engage in long term, reciprocal friendships despite the interference of stigma in their lives. There is tremendous hope available in understanding how some disabled teens create sustainable friendships in a society where the difference associated with disability is stigmatized and excluded. Their experiences can make it possible for other disabled teens to see that friendship is possible, that social calendars can be filled, that they can be the recipients of virtual pokes, and that text messages can continually flow.

1.1   Research Questions

The aim of this study was to compile a richly textured account of the friendships of disabled youth from their perspectives. It was designed to offer a response to the question: *How is friendship understood and experienced by disabled youth?* Related questions included: How did the youth involved in this study negotiate around stigma to create enduring friendships? What constituted a meaningful friendship for participants? What contributed to positive friendship experiences? What was the context within which

these friendships developed (e.g., community, school, policy)? How did that context sustain or hamper friendships for disabled youth?

1.2   Interdisciplinarity

Interdisciplinary research involves the process of addressing a complex phenomenon by synthesizing the perspectives of multiple disciplines, creating a unique contribution to the field of study (Repko, 2008). Thus, the arguments typically used to defend interdisciplinarity include three aspects: (1) the complexity of the research question or problem mandates an interdisciplinary approach, (2) at least two disciplines offer meaningful contributions to the current understandings of the problem or question, and (3) the research question addresses a societal issue that has defied explanation or resolution from a disciplinary perspective (Repko, 2008). Friendship is a multi-faceted relationship that has eluded definition by researchers for decades (Allan, 2008). It has been of interest to philosophers for centuries. Ancient scholars, notably Aristotle in *Nicomachean Ethics* and *Eudemian Ethics* (as cited in Brewer, 2005), and present day philosophers (Fehr, 1996; Hay, 1988) offer the foundations for how one might begin to understand the meanings of friendship in our lives. Psychologists have investigated dimensions of adult friendship for several decades (Crosnoe, 2000); however, in recent years friendships of children and youth have garnered attention from both sociologists and psychologists. Although overly simplistic, broad brush strokes indicate that sociologists focus on the systems and structures that shape the friendship experiences of individuals and groups (Allan, 2008; Pahl, 2000); whereas psychologists generally concentrate on developmental stages and the interactions involved in creating and sustaining friendship (Crosnoe, 2000).

This study was designed around the friendships of disabled teens, hence the range of disciplines that could contribute to the work was substantial (e.g. sociology, psychology, education, social policy, history, social work, rehabilitation science); therefore, the epistemological commitments within the inherently interdisciplinary field of disability studies were used to guide all aspects of the research process, including the selection of the most relevant disciplines and theories used. Historically, political science, policy studies and sociology comprised the academic disciplines that were first integrated to establish the field of disability studies (Longmore & Umansky, 2001). The scope of disability issues included in this field proliferated in recent years as contributors to the

field expanded dramatically. Disability studies is now situated at the intersection of social sciences, the humanities and the sciences, combining a wide range of disciplines, theories, and methods (Albrecht, Seelman, & Bury, 2001; Longmore & Umansky, 2001; Linton, 1998).

The ontological and epistemological commitments of academics within this wide-ranging field of study are varied; however there are basic tenets that wind through the writings of disability scholars. Disability scholars agree that disabled people share the experience of oppression. Many disability scholars argue that oppression is rooted in the socially constructed categories of ability and disability; however, there are very real material consequences in the lives of disabled people (Linton, 1998; Wendell, 1996). At the heart of disability studies epistemology, regardless of a theorist's paradigmatic commitment, is the knowledge of disabled people. The knowledge arising from the embodied position of disabled people is a powerful site for inquiry (Abberly, 1996; Michalko, 2002; Zola, 1979). Linton (1998) included the following commitments in a summary of an epistemology of disability: (1) acknowledge that disability and ability co-exist; (2) centralize disability in analysis; and (3) link the social sciences and humanities within an interdisciplinary field of inquiry. These commitments are commensurate with the definition of interdisciplinary research offered above and are clearly present in the paradigm of inquiry that provides the scaffolding for this project: critical theory.

Critical theory, like disability studies and interdisciplinary research, is a term that applies to a vast field of theory and research praxis with the goal of social transformation resulting in equity and social justice (Guba & Lincoln, 2005). It is a nuanced, evolving, diverse field that defies simple definition (Kincheloe & McLaren, 2005); however, there is a set of core beliefs that connects critical theorists. For example, critical theorists generally agree that power and knowledge are inextricably linked and that knowledge is socially situated (Kincheloe & McLaren, 2005). There is a fluid relationship between the knower and the known as they interact and shape one another (Denzin & Lincoln, 2005). Privilege and oppression occur along a range of social locations (e.g. race, class, gender, age, ability). If only one dimension of oppression is attended to then researchers can inadvertently reproduce the very hierarchies they meant to critique and dismantle (Kincheloe & McLaren, 2005). Olesen (2005) argues that research informed by critical theory must instead "interrogate power, privilege, and multiple hierarchies" (p.255). Research within this paradigm thus asks questions about why particular social structures

exist, what keeps them in place, and whose purposes are served by them (Kincheloe & McLaren, 2005).

Critical theorists argue that positivist claims to objectivity are untenable in a world brimming with multiple realities (Denzin & Lincoln, 2005) and partial truths (Haraway, 1988) where all findings are value-mediated (Guba & Lincoln, 2005). The perspectives of researchers and participants are fore-grounded within this paradigm (Guba & Lincoln, 2005; Olesen, 2005). To address these commitments in this doctoral study, Donna Haraway's (1988) work on situated knowledges and Sandra Harding's (1991) thoughts on strong objectivity were incorporated into the theoretical framework. Reflexivity is a cornerstone of critical theory research praxis, thus the reflexive methodology proposed by Alvesson and Sköldberg (2000) was used to further strengthen the theoretical framework. A detailed description of this interdisciplinary, critical theory framework is presented in Chapter 3. Loppie (2004) offered a thoughtful position on interdisciplinarity, one that concisely summarizes my own stance, "Ultimately interdisciplinarity is not so much an attempt to embrace divergent philosophers, as it is a philosophical position that has its roots in many disciplines of thought" (Loppie, 2004, p.266).

1.3   Language Use

> Language is not a mirror of society. It is an unstable social practice whose meaning shifts, depending on the context in which it is used… language is not a neutral and objective conduit of description of the 'real world.' Rather, from a critical perspective, linguistic descriptions are not simply about the world but serve to construct it (Kincheloe & McLaren, 2005, p.310).

Before proceeding, it is important to offer a clarification of terminology. Medical understandings of disability start with an underlying pathological condition that leads to some type of physical, psychological, cognitive or sensory impairment that affects function, as exemplified in texts such as the *Diagnostic and Statistical Manual of Mental Disorders* (2000). This disruption of 'normal' activity is then considered a disability that requires a remedy (Altman, 2001). Conversely, the *International Classification of Functioning, Disability, and Health* (*ICF*, World Health Organization, 2007) extends the definition of disability beyond body functions and structures. The ICF describes disability as a 'universal human experience' that occurs when a medical condition interferes with a person's ability to participate in a particular socio-political and cultural environment (World Health Organization, 2007). From a legal perspective people with mental and

physical disability are protected from discrimination in Section 5(1) of the Canadian Charter of Rights and Freedoms (1982). It is clear that disability is a word that is taken up by particular people, in particular contexts, to make particular claims. In this project I contend that disability has no central core that exists outside of our interpretations of embodied difference (Linton, 1998). Disability is created around individual traits that are devalued within a given sociopolitical moment (Pothier & Devlin, 2006). Although its definition is by no means unified within disability studies, I will take the position that disability is a marker of embodied difference (Linton, 1998; Michalko, 2002). This indicates a conscious move away from the use of diagnostic labels to describe disability, and in this case disabled youth. Youth who self-identified as experiencing social stigma based on disability status were invited to participate in this study.

The term "disabled youth" in this text is deliberately invoked. Like many disability studies scholars, I started this work from the position that disability is imposed upon people who live with a medical diagnosis. Disabling experiences are created by environments and attitudes that exclude bodies of difference (Oliver, 1990). Yet disability is, in part, rooted in the physical experience of embodied difference that exists outside of the social constructions of disability (Thomas, 1999; Thomson, 2002; Siebers, 2001; Wendell, 1996). The debate in disability studies around the social model of disability and the embodied experience of impairment is ongoing. Although it contributes to the background of this study, this debate was not the focus of this dissertation. The stigma surrounding disability is clearly a social construction (Goffman, 1963; Link & Phalen, 1999). Impairment in a range of embodied forms was described by participants as an integral part of their lives. The exact site of impairment (e.g., legs, arms, neurological system, or sensory system) was not centralized in this study; rather, this research started with the assumption that disabled teens experience stigma.

Deciding which terminology to incorporate into the dissertation was troubling. Should the person or the disability be given primacy? People-first language – the common use of the phrase "people with disabilities" – creates a pleasant image. Yet it is the experience of many people that disability is responded to first, not their personhood (Titchkosky, 2001). In fact, the personhood of disabled people is frequently called into question by normative society (Davis, 1995). Thus, person-first language may help nondisabled people feel they are being respectful, but it does not change – and may even deny – the reality of those who live disability. Putting disability first in this text underscores the belief

that disability is constructed by our society around embodied difference and becomes a dominant, marked status. This project does not deny the individual experience of impairment; however, the focus is on the shared experience of stigma and social oppression among disabled people (Thomas, 1999; Wendell, 1996).

Within the context of academic writing I used the term "disabled youth" given my philosophical commitment to disability studies; however, when I communicated with participants and the broader community, I used people-first language. Although this move was uncomfortable from a disability studies perspective, it was important for me to use language that was readily understood by the community with whom I sought connection – school age youth, their friends, families, educators, and eventually politicians. Participants and their families all preferred people-first language.

1.4   Getting Situated

There appears to be a mandatory line in most published qualitative research where the author lists a series of identifiers in an effort to demonstrate social location. This typically includes a statement of gender, race, educational background, class and perhaps age and sexual orientation. In disability studies there is also an implicit requirement that one's disability status be claimed. Using this format my identity statement would include being a temporarily able-bodied 43 year old, English speaking Canadian woman most likely of Irish and Scottish descent who grew up in poverty before completing Bachelor's and Master's degrees in occupational therapy, permitting my transition into the middle class. The list of identifiers could go on *ad infinitum*, but does that help the reader understand the dialectical relationship between me and the research?

This position statement serves both as a claim to knowledge and as a political act – identifying as an insider or outsider in relation to the research question. Unfortunately a researcher's identity statement rarely includes how the researcher's location at the intersection of multiple identities shaped the research project or how the project shaped the researcher. That is indeed a daunting task, one that can never be fully accomplished, yet the responsibility to try remains if one is to demonstrate a commitment to the kind of accountability advocated for by disability scholars. For example, Tregaskis & Goodley (2005) offer another example of this accountability in their exploration of the complexities of engaging in research together as disabled and

nondisabled scholars. They present excerpts from fieldnotes that expose tensions and vulnerabilities while simultaneously offering an interpretation of these interactions in an effort to connect as research partners. Consciously and reflexively situating oneself in the research process can help break through the binary of disabled/nondisabled, instead recognizing that as human beings we are all vulnerable and interdependent (Tregaskis & Goodley).

Efforts to situate myself in this project were guided by the doctoral dissertations of Judy MacDonald (2006), *Untold stories: Women in the helping professions as sufferers of chronic pain, (Re)storying (dis)Ability*, and Charlotte Loppie (2004), *Grandmothers' voices: Mi'kmaq women and menopause*. Both scholars offered a personal accounting of elements of their identities that were directly related to the research they were involved in. Loppie offered an intimate portrait of her family life including the importance of story-telling and shared memories. She then described her first hot flash that took place at the outset of data collection moving her to being an 'insider,' sharing the experience of menopause with participants in her work. Years of living with chronic pain and (dis)Ability positioned MacDonald as an insider in her study as well, one who intimately understood the "emotional vulnerability associated with publicly claiming voice" (p. 4) that she was asking of her participants. These women went far beyond the two line identity statement, opening relevant aspects of their lives to the reader, without straying into the realm of self-indulgent disclosure. The tone and content of my personal account was shaped by theirs.

Five years ago I started reading the works of disability scholars. These writers contest traditional medical understandings of disability and instead talk about how disability is created by a society that does not welcome the full range of human embodiment (e.g., Davis, 1995; Goodley, 2001; Hehir, 2002; Linton, 1998; Oliver, 1990; Shakespeare, 2006; Thomson, 1997; Ware, 2002; Wendell, 1996). The ideas and theories spoke to my personal experience while raising serious concerns about my professional practice in occupational therapy. What about my exposure to the writings of disability scholars made "business as usual" untenable?

Disability has been my companion for many years, initially as a therapist, and more recently as a daughter. My relationship with disability shifted dramatically from the safe distance of employee/employer when I moved in with my mother and dementia ten years

ago. Throughout these years I felt invaded and overwhelmed by medical interpretations of disability as I negotiated her care with healthcare professionals, personal care workers, and institutions. This intense experience brought my background as a therapist into sharp relief, creating an opportunity for critical reflection.

In my nearly two decades as an occupational therapist I engaged in what I believed was client-centred practice. It is possible that this goal was achieved in some situations, but what of the many times where my values as a therapist grated against the values of clients? What was going on? A number of scholars have looked specifically at the barriers to client-centred care. Some suggest that systemic forces, like resources, policies and time constraints, limit therapists' ability to engage in client-centred practice (Dodd, Saggers, Wildy, 2009; Mullaly, 2007). Others point to factors within the therapist such as inexperience with negotiation or collaboration, or to client characteristics like cognitive impairment, depression, or the inability to communicate (MacDonald & Friars, 2009). Although these ideas are worth consideration, I contend that when one peels back the layers, each of these explanations can be traced to the same source: ableism (this term is addressed in more detail in Chapter 2). Within my professional practice those with impairments were required (and themselves often hoped) to return to or more closely approximate 'normal' – meaning nondisabled– people. Normalcy is contested territory between the nondisabled and disabled (Davis, 1995). My livelihood as a therapist depended on its existence; yet it remains a source of pain and frustration to me as a daughter. The bell curve, so revered in statistics, was one dimension of this conflict (Davis, 1995). If a person's score is too far away from the summit, the elusive point of normality, then they are out of bounds. In physical and cognitive terms it was exciting to have clients whose scores indicated intellectual abilities and physical skills that were on the right hand side of that magical summit – 'above average.' But those who strayed too far to the left of that peak into the realm of 'below average' were on unstable ground. Their ability to contribute to society – and sometimes even their personhood – was questioned.

During my years of clinical experience, I was not required to explain my ability to walk, get dressed, or eat breakfast. Possessing these skills was a given; it was natural. This established the dominance, power and privilege of the nondisabled. In contrast, the disabled were scrutinized to a cellular level to identify (and correct or eliminate) what physically interfered with participation. Disabled bodies were out of bounds, 'proving' that

disabled people were in need of rehabilitation, in need of my 'expertise.' Such services have exploded into a multibillion dollar industry (Albrecht, 1992). Extraordinary resources have been deployed to 'improve the quality of life' of disabled people, inspired by the quest for normalcy. Each effort toward normalization causes disability to be masked or denied as disabled people are encouraged to 'pass' as normal. Many disability theorists (e.g. Abberly, 2002; Albrecht, 1992; Albrecht & Bury, 2001) argue that disability is continually constructed in order to employ a vast 'army' of health professionals, like me.

If ability and disability are constructed as two distinct, mutually exclusive territories, then there must be a border between them. One feminist writer, Gloria Anzaldùa, referred to the US/Mexico border as a place "where the Third world grates against the First and bleeds" (p.2). The border between nondisabled and disabled historically involved a scalpel and only the disabled bled. For example, Borsay (2002) noted that the knowledge and skill of orthopedic surgeons was built upon the backs and bodies of children with orthopedic 'deformities.' In the mid-twentieth century many children in the United Kingdom with orthopedic impairments were taken from their parents to reside in institutions where they underwent multiple, unnecessary surgeries to make their bodies more closely approximate 'normal' as new surgical techniques were developed. At different points throughout my career as a therapist, I worked in post-surgical units at hospitals in Canada an in the United States with no awareness of the oppressive history embedded in these medical interventions. I am not proposing that medical interventions that address specific dimensions of impairment be discontinued, only that we understand their origins; that we take into account the oppression that gave rise to our medical knowledge.

So, who polices the borders of 'normal'? I agree with disability theorists that this role is filled by health care professionals, like me. In my work I supported the return of disabled people to 'normalcy' through rehabilitation or adaptation – often using test-retest comparisons to demonstrate the effectiveness of my practice. Setting goals and measuring improvement by aspiring toward the centre of the bell curve. I want to be clear that I am not rejecting orthopedic surgery, standardized testing, evidence-based practice and rehabilitation services; however, these historical roots must be acknowledged before I can tentatively establish a new way of engaging with disability.

In my doctoral studies, these musings caused a key epistemological question to surface – who can claim ownership of the knowledge surrounding impaired bodies? Health professionals learn vast amounts about how bodies function. Doctors use clinical skills and advanced medical technology to identify the source of physical complaints. Remarkable advances extend the lives of millions of people. I studied for years, spent endless hours in the library, worked with thousands of clients and families. My professional knowledge is legitimated through research, evidence-based practices, quality assurance audits, supervision and mentoring. In my work I was committed to advocacy and issues of social justice; I knew through my training, reading, and work experience. But this was not enough to claim a practice free of ableism.

Disabled people possess an alternative perspective. This knowledge is learned through the body, through oppression, through systematic exclusion. It involves knowing that university doors are hard to open, that the sexuality of disabled people is oft erased, that families are often dismissed, that averted gazes dehumanize and that being left out leaves deep scars. These two sources of knowledge, often set up in opposition to one another, exist jointly in the lives of people like me who live on the border between ability and disability. In the vast 'armies' of health professionals are scores of people who live more personally with disability. This point of contact punctures the border between ability and disability; giving hope that ableism can be dislocated. By living and working in this space between – an occupational therapist who is also the daughter of a woman with dementia – I am intimately acquainted with partial perspectives. It is from this place of bringing together multiple perspectives that I started this study. My interpretation of the friendships of disabled teens is documented in the upcoming chapters, yet the words and stories of the teens themselves are included, opening up the text to alternate readings. What follows is not the whole story of the friendships of disabled teens, but it is a place to open a constructive dialogue among disabled teens, their families, researchers, educators, policy makers and health care professionals.

1.5   Overview of Chapters

Again, the research question explored in this qualitative study is *How is friendship understood and experienced by disabled youth?* The stories of meaningful friendship will be presented in the upcoming 6 chapters. Chapter 2 orients the reader to the literature surrounding the foundations of friendship and what friendship contributes to our lives. It

then narrows to describing the friendships of teens before specifically focusing on some of the unique forces that shape the friendships of disabled youth. These influences include the history of segregation, educational policy and practice, accessibility issues, individual skills, helping relationships, and who counts as acceptable friendship partners. Attention then turns to stigma, a dominant force affecting disabled teens. Stigma will first be described and then directly connected to the friendships of disabled youth, clearly demonstrating the timeliness and significance of the research question.

Chapter 3, *Methodology*, weaves together the theoretical framework and research approach introduced by Alvesson and Sköldberg (2000), reflexive methodology. The methods used for gathering and interpreting data are then explained with specific attention to ethical implications. A series of guiding questions are presented that enable the reader to evaluate the quality of this research.

Participants in this study offered varied, lively accounts of enduring friendship. The possibilities for representing their stories knew no bounds. The guiding question was returned to time and again, leading to the account of how disabled teens were able to negotiate around stigma to create lasting friendship that is developed in Chapters 4, 5, and 6. The concept map presented in Appendix A offers a visual guide to the interconnections among the three main themes identified during data analysis. The first theme, *Negotiating stigma to create enduring friendship*, describes the common process of making friends in a stigmatizing society. The second theme, *Finding a balance: Adult support and surveillance*, speaks to the complex dynamics between disabled teens and their parents as they all engage in the quest for friendship. The final theme chapter, *Disrupting oppression*, addresses the strategies used by participants to respond to the stigmatizing forces in their lives. Connections between this study and existing literature are embedded in each of these three chapters.

In the conclusion, Chapter 7, key elements flowing through the literature review, methodology, and research findings are drawn together. A review of the quality of the research based on the criteria presented in Chapter 3 is offered, with particular attention given to how the stories of disabled teens were represented in this text. Implications of these findings are presented followed by recommendations for knowledge translation and future research.

CHAPTER 2   LITERATURE REVIEW

How might you fill in the blank: my friends are _____? One could speak about the qualities embodied by friends – *my friends are kind, thoughtful, caring, funny*. The blank could be filled by activities friends share – *my friends are into sports, hanging out at the mall, or Facebook*. Perhaps attributes could be brought forward – *my friends are all close to my age, live in my neighborhood, from diverse backgrounds*. The statement could also be fraught with tension – *my friends are too demanding, always asking me for money*. Or it could conclude with a list of names of people identified as being friends – *my friends are Kiya, Chenise, Colby, and Paulo*. These responses allude to some of the commonly held meanings of friendship. In this section the concept of friendship is examined as the context for this study.

2.1   Foundations of Friendship

The meaning of the term 'relationship' has defied definition for decades (Allan, 2008). Given that friendship has the greatest variation of any human relationship (Allan, 1998; Krappman, 1996), it is not surprising that it too has resisted attempts to establish an all-encompassing definition. Most scholars agree that friendship is a voluntary relationship between two people (Friedman, 1993; Hartup, 1975, Wright, 1984). Duck (2008), a well-established academic in the field of relationships, noted the starting point of inquiry can simply be that friendship is a shared interaction between two people. Others take the definition further, stating that those involved in enduring friendships demonstrate caring, commitment, and loyalty to one another (Bukowski & Sippola, 1996; Collins, 1997; Friedman, 1993). Trust is frequently cited as crucial to lasting friendship (Bukowski & Sippola, 1996; Cotterell, 1996; Schneider, Wiener, & Murphy, 1994). Rather than attempting to explicitly define friendship, some scholars have developed typologies that place friendship along a continuum. For example, Hays (1984) described friendship as ranging from superficial through casual, to intimate connection between people. This typology, like many others, appears to find its roots in Aristotle's writings on friendship.

Aristotle differentiated between three specific forms of friendship based on what motivated people to engage in this relationship: utility, pleasure, moral goodness (Bukowski & Sippola, 1996). Prus (2007) interpreting Aristotle, notes that all these forms of friendship share the common ingredient of mutuality in that each person has a

particular affinity for the friend; however, the reason for the interest in the other person varies dramatically among Aristotle's forms of friendship. Utility-based and pleasure-based friendships are both focused on what one person gets from the other; however, friendships based on moral goodness concentrate on 'virtuous caring' where each person is primarily concerned about the well-being of the other (Prus, 2007).

Aristotle believed that these forms of friendship were closely linked to the life course (Prus, 2007). Pleasure-based friendships, for example, are focused on self-centred enjoyment and were thought to be exemplified by the affiliations between young people. In utility-based friendships two people connect based on their ability to meet each other's needs. Many friendships among elderly people were thought by Aristotle to align closely with this form of friendship. Moral goodness-based friendships seem to be reserved for the most socially conscious and ethically informed citizens. Since Aristotle argued that this was a very small group of people, friendships based in moral goodness are assumed to be far less common than utility or pleasure friendships (Prus, 2007).

Aristotle's most complete and thus most rare form of friendship is based in recognizing and appreciating the goodness in the other person. Utilitarian and pleasure-based friendships make important contributions to our lives; however, Aristotle argued that the mutuality and shared concern for the other establish 'moral goodness' friendship as the most desirable of the three forms. Valuing the goodness in one's friend was believed to be at the heart of long lasting, close friendship according to Aristotle's writings (Bukowski & Sippola, 1996), Today this form of affiliation is commonly understood to refer to close or intimate friendship (Rawlins, 2009). Moral goodness friendships are characterized by trust, commitment, mutual self-disclosure, caring, concern for the needs or desires of the friend, willingness to make sacrifices on behalf of the other, and the desire to work through conflict in respectful ways (Bukowski & Sippola, 1996).

Each form of friendship has unique threats to sustainability. Although Prus (2007) established that friendship is possible between people of unequal social status, he clearly states that these friendships can be difficult to maintain because of entrenched beliefs about balance. When a perceived imbalance occurs a moral friendship devolves into more of a utility-based friendship where people focus on what they deserve from the friendship rather than on what they can do to benefit their friend. Utility-based friendships are particularly susceptible to perceptions of imbalance in the amount of help given and

received. In this scenario people become more concerned with what they are getting in return for what they offer to the friendship. When these material concerns become the focus, the friendship is likely to become ridden with conflict and result in dissatisfaction for both people. Pleasure-based friendships are threatened by minor shifts in attitude and interest, given that enjoyment is the only thing that binds the two parties together. If one person loses interest in the shared activity that connected them or decides that engaging with the other person is no longer enjoyable, the friendship quickly fades.

This sense of balance or reciprocity appears to be fundamental to all forms of friendship (Krappmann, 1996; Turnbull, Blue-Banning & Pereira, 2000) – whether it is a balance between help given and received (utility), a balance in pleasure experienced compared to pleasure offered, or a balance in concern between the two friends (moral goodness). Balance can be understood in terms of similarity as well, particularly in terms of shared interests, beliefs, life situation, attitudes, and demographics (Berndt, 1982; Fehr, 1996; Friedman, 1993; Hartup, 1995; Kupersmidt, DeRosier, & Patterson, 1995; Urberg, Degirmenciolgy, & Tolson, 1998).

Allan (1998) argues that when there is a substantial discrepancy in social position, sustaining the friendship can be incredibly challenging. Others note that enduring friendship is only possible between equals (Allan, 1998; Bukowski & Sippola, 1996). Prus (2007) on the other hand understands Aristotle's writings in a slightly different way. Although he agrees with Bukowski and Sippola that friendship between people who do not share the same social status is complex, Prus argues that it is possible to find an alternate point of balance in the relationship rather than the more direct equivalency often seen in friendship. This latter interpretation seems to be more closely aligned with the spirit of a moral friendship – where inequality based on social structures can be contested and friendship is viable between people from across the social spectrum.

2.2   Value of Meaningful Friendship

In addition to the varied circumstances surrounding friendship, what people want out of a friendship is also diverse. Practical help and companionship are considered integral to friendship (Adams & Plaut, 2003; Bauminger, Shulman, & Agam, 2004; Fehr, 1996).Turnbull and colleagues (2000) extend the functions of friendship to include affection, emotional and informational supports. Hays (1988) synthesized these qualities,

describing friendship as, "voluntary interdependence between two persons over time, that is intended to facilitate social-emotional goals of the participants, and may involve varying types and degrees of companionship, intimacy, affection, and mutual assistance" (p.395). Hays' nuanced but fluid definition notes that friendship is a chosen relationship where the boundaries of duration, intensity, intimacy, and level of commitment are flexible. These elements provide a general framework to begin thinking about the friendships of disabled youth in this study without being overly prescriptive. To add substance to this definition the meanings of friendship is now considered. What does friendship contribute to our lives? Why is it something that many people value so highly?

As humans we are inherently social beings. Most people pursue meaningful connections with others from our earliest moments to the closing days of our lives. Outside of family (and sometimes in spite of family) friends become our closest allies and confidantes. Friendship is described by some researchers as the most important of human relationships (Berndt & Perry, 1986; Bukowski, Newcomb, & Hartup, 1996; Newcomb & Bagwell, 1996). Friendship enriches our lives in many ways, ranging from improving overall health and well-being (Duck, 1991; Marmot & Wilkinson, 1999; Sarason et al 1997) to endorsing or critiquing our moral commitments (Fehr, 1996).

Consider the health benefits connected to high quality friendships. Although few people consider the immediate health benefits of friendship, for women simply talking to a close friend increases levels of progesterone, a hormone known to boost the sense of well-being, and to reduce anxiety and stress (Brown, 2009). Friendship is also reported to boost the immune system (Pahl, 2000). People with well-established social networks live longer than those who are isolated (Giles, Glonek, Luszcz, & Andrews, 2005). In a 2006 study on breast cancer, women who had 10 or more friends were four times more likely to survive compared to those with no friends. Adams (2009) argued that friendships are more protective than family relationships. Friendship also serves a protective function in terms of emotional and social health. In long term friendships frequent exchanges of support can create a sense of belonging and acceptance. This in turn reduces the experience of loneliness while simultaneously diminishing the risk for serious depression or anxiety disorder (Cotterell, 1996). Hartup (1996) along with Collins and Laursen (1999) agree that there is a strong connection between the quality of friendships and a sense of personal well-being. People who experience strong friendships as children have a greater sense of self worth as young adults (Crosnoe, 2000). Rebecca Adams, a

sociologist well known for her contributions to friendship research, was quoted in a New York Times article stating, "In general, the role of friendship in our lives isn't terribly well appreciated. There is just scads of stuff on families and marriage, but very little on friendship. It baffles me. Friendship has a bigger impact on our psychological well-being than family relationships" (Parker-Pope, 2009).

Beyond the bounds of physical and emotional health, the mutual assistance provided within even the most basic of Aristotle's forms of friendship, utility, encourages the development of social skills across the life course (Crosnoe, 2000). The physical assistance involved in utilitarian friendship could include preschoolers sharing toys, a teenager offering to drive a friend to a sports event, helping a young adult prepare for a job interview, taking care of a friend's children, picking up groceries, or taking someone to doctor's appointments. These exchanges offer important opportunities for learning how to become effective social beings (Pahl, 2000). We learn that sharing with others is quite likely to result in new experiences being made available to us. Offering assistance to someone else may in turn create the possibility of our receiving support at a critical moment later in our own lives. In some sense this is reflected in the phrase 'one good turn deserves another' or in the 'pay it forward' principle where it is expected that an act of kindness will eventually return to the actor. On some level perhaps we learn to engage in social relationships to ensure self preservation (Pahl, 2000).

The enjoyment of shared activities in friendship is a crucial aspect of overall well-being. This moves into the realm of Aristotle's *pleasure friendships* where people interact with one another for sheer enjoyment. Many friendships begin and are sustained within the context of recreation (Passmore & French, 2003), whether that be via participating on a competitive sports team, spending an evening gaming, watching a movie, having a few drinks at the pub, or sharing a meal. Brown (1997) noted that leisure activities build and strengthen friendships and expand personal networks. Friendship offers participants a sense of belonging and acceptance as they engage in mutually valued activities (Doubt & McColl, 2003). According to Specht, King, Brown, and Foris (2002), in addition to a wide array of health benefits ascribed to engaging in leisure activities (e.g. improved coping, reduced stress, relaxation, improved sense of well-being) participating in recreation also creates opportunities for establishing friendships.

The third type in Aristotle's taxonomy of friendships focuses on *moral goodness* or *virtue*. He envisioned this as the highest form of friendship, one that was only available to moral equals (Pahl, 2000). Virtuous friendship is not about what friends can do for one another, nor is it about what friends do together. It is about friendship for its own sake; about a deep, voluntary, and altruistic commitment (Rawlins, 2009). Virtuous friendship expand one's moral understandings, with each friend offering the other a moral mirror or compass (Pahl). This form of friendship always seeks out what is best for the friend and will make personal sacrifices to that end (Rawlins). In essence achieving this form of friendship is perhaps the highest moral accomplishment one can attain (Pahl). It has been argued that the foundation of moral friendships develop in the early years, and are referred to in the literature as relationships where prosocial behavior can flourish. In addition to the material concerns of providing assistance, sharing and volunteering, a key element of prosocial behavior is voluntary engagement in conflict resolution (Bergin, Talley, & Hamer, 2003). Upon these early skills one builds the capacity to engage in moral friendships. Yet the early moral commitments learned within one's family or community do not necessarily remain fixed over the life course (Friedman, 1989). Indeed, friendship can also prompt moral growth. One's moral universe expands dramatically via the experiences and dilemmas encountered by one's friends. We begin to understand the world from alternate moral perspectives, thus increasing our ability to reflect on our own set of moral commitments (Friedman, 1989). Yet what happens to this kind of friendship when the moral commitments of the friends conflict? Some can negotiate through this tension, while other friendships dissolve. This leads us into some of the morally unstable aspects of friendship, the place where friends can lead one another into dangerous territory.

Although it is much more hopeful and encouraging to concentrate on all the wonderful contributions the various forms of friendship make to our lives, it is important to consider its shadow side. Many children, young people, and adults gravitate toward those who are committed to a set of principles that may be rooted in loyalty while simultaneously rejecting the notion of a greater good (Melde, Taylor, Esbensen, 2009). Friendship is not always about learning to be prosocial. Friendship can be self-serving, unbalanced, and damaging to one or both parties or even harmful to broader society. Much research focuses on the negative dimensions of friendship. Consider gang affiliations that require enacting violence on others in order to gain credibility or acceptance within the group

(Gatti, Tremblay, Vitaro, McDuff, 2005). Burns and colleagues (2008) argue that among youth the influence of the peer group can be in the prosocial domain, or can just as readily promote and reinforce negative social behaviors (e.g., bullying, smoking, drug use, high risk sexual encounters). Thus, depending on one's moral commitments, friendship can help people connect with others in responding to social norms, whether that be engagement with those norms, rejection of them, or outright violation of them.

2.3 Friendship and Youth

2.3.1 Developmental Dimensions of Friendship

Although there is great diversity in how people meet, who we choose as friends and how close those relationships become, friendships seem to have a general flow. Gottman (1983) described six processes that seem to occur sequentially in friendship formation during childhood: (a) establishing clear communication, (b) sharing information, (c) identifying common interests or values, (d) expressing personal feelings, (e) establishing a balance in the give and take of the relationship, and (f) resolving conflicts that arise. Particular processes have greater salience as children move though developmental stages into adolescence and later into adulthood. These are now considered.

The many incarnations of friendship change over the life course. Preschoolers tend to choose friends based on who is readily available to play with. Children in this age group seem to base their friendships in the shared activity of the moment (Doll, 1996). Although these connections form easily, they are also transient, fading quickly when the activity ends. During the elementary school years children start to become aware of the responsibility of friendship. It is at this stage that the rules about balanced give and take become established (Doll). Children start doing favors for one another. Friends will defend each other at times of conflict with other children or with adults. This sense of loyalty and commitment becomes even more pronounced in later elementary years when cliques start to loosely form (Cotterell, 1996).

Friendships in the teen years become much more complex (Hartup & Stevens, 1997). During this stage of development, friends become the focal point of life and have more influence than parents in terms of immediate decisions like what to wear and plans for the weekend (Thornberry et al 1994). Between the ages of 12 and 16 shared secrets, trust and empathy begin to emerge in friendships (Berndt & Perry, 1986; Cotterell, 1996;

Crosnoe, 2000). Teens in this age group tend to spend more time away from the perceived surveillance of adults where they feel more at ease to experiment with a range of identities along with their friends (Crosnoe, 2000; Travis & Violato, 2001). Since more time is spent away from family, parents often do not know who is part of a teen's social network (Hay, Payne, & Chadwick, 2004). Claes (1994) reported that Canadian adolescents have an average of 36 acquaintances, 17 friends, and 4 close friends. More than half of his sample reported having the same best friends for more than 3 years, indicating stability in these friendships over time.

Teens spend more time connecting with friends than they spend in any other leisure activity during the day and describe themselves as happiest when spending time with friends (Hurrelmann, 1996). This includes face to face contact and virtual connections via telephones, cell phones, texting, emails, chatrooms, or online social networking sites (Duck, 2008). The focus in the early teen years is on becoming affiliated with a clique and remaining connected to this group (Cotterell, 1996). Often cliques are gender-specific in early years, but gradually become mixed as teens get older (Crosnoe, 2000). Groups often develop based on neighborhood, grade, and shared activities and become more exclusive in older grades (Urberg, Degirmenciolgy, Tolson, Halliday-Scher, 1995). Teens connect based on particular aspects of identity. Many high schools have groups of athletes that hang out together. There is also likely to be a substantial pool of 'geeks' who are drawn together by their affinity for technology. There is the notorious group of beautiful people who wear all the right clothes and spend hours preening every morning before rushing out the door to school. No doubt most high schools have clusters of friends who share a social activist agenda around environmental issues. No matter where the high school is, the 'druggies' and more recently the 'gangstas' create a niche for themselves as well. All of these groups set clear parameters around who is and is not included. The formation of cliques in early adolescence is about both belonging and marginalization.

Connecting with a particular clique establishes social status while also providing a sense of emotional safety (Cotterell, 1996). The peer group provides an opportunity for social and emotional stability outside the family (Hurrelmann, 1996). Through the group processes of teasing, approval, physical contact, laughter, and gossip, adolescents learn about themselves, their worth, and the society of which they are a part (Giordano, 2003). Although being part of a clique offers substantial benefits, there are also risks associated

with group membership. For example, Cotterell (1996) points out that if a group member breaks with the values of the clique, that person is often viewed as a traitor and can be treated with intense hostility. Each microculture creates its own norms around clothing, language, and the kinds of activities they endorse (Kinney, 1999). Peer groups provide an efficient mechanism for learning how to function within social structures, yet they also convey clear messages about conforming and excluding those who don't adhere to the group norms (Crosnoe, 2000). Unfortunately, peer groups often recreate the negative aspects of a given society as well – like sexism, racism, heterosexism, and ableism.

As teens age they generally become less concerned about conforming to the peer group (Brown et al 1986). By the time youth reach 18 years of age they are primarily concerned with establishing individual identity and future goals (Cotterell, 1996). Thus, the influence of cliques starts to fade and is replaced by closer friendships with just a few peers. Intimacy characterizes the friendships of teens as they mature (Gordon, Feldman, & Chriboga, 2005). A series of milestones characterize the transition from adolescence into young adulthood: young people learn to demonstrate individual autonomy, construct a viable social network, refine social skills, establish an identity including a sexual role, take on greater responsibility, and make preliminary decisions about what to do for work (Marn & Koch, 1999). Hurrelman (1996) agreed that adolescence is the time to move away from the family of origin – emotionally, socially, economically. All of these tasks of adolescence are intimately connected with the friendship experiences of teens. By spending time with friends, teens are able to establish a sense of personal worth, explore a range of social skills and potential identities, and modify their performance based on feedback from these trusted companions (Bukowski, 2001). Friendship is thus central to establishing both identity and meaning in one's life (Allan, 1998; Fehr, 1996).

The experiences of teen friendship appear to differ significantly by gender (Crosnoe, 2000). Research indicates that girls tend to have smaller clusters of friends with less connection between cliques and different rules around power and influence when compared to boys (Graham, Cohen, Zbikowskim & Secrist, 1998) Boys, on the other hand, have larger numbers of good friendships that are less exclusive (Branje, 2007). Girls highly value communication, demand emotional intimacy, and demonstrate similar behaviors and attitudes (Crosnoe, 2000; Graham, 2004). In contrast, boys are more interested in shared activities and linking to others who share the same social status (Black, 2000). Even when girls are intensely emotionally invested in their friendships,

these relationships are fluid, becoming closer or more distant over time (Way, Cowal, Gingold, Pahl, & Bissessar, 2001). Indeed, girls' friendships are particularly prone to change, compared to those of boys, during the transitions from junior high to high school, yet girls are more adept at creating new relationships (Hardy, Bukowski, & Sippola, 2002). Some of this change has to do with shifting interests and the effects of proximity on friendship; however, conflict plays a substantial role in how the friendships of both boys and girls evolve over time. Working through conflict is foundational to sustaining friendship. When faced with conflict, adolescent girls tend to engage in prosocial resolution, while boys opt for more aggressive strategies (Black, 2000). Interpersonal dynamics clearly shape the friendships of teens, yet these relationships are also dramatically shaped by broader social influences.

Although most adolescents are compassionate, thoughtful, and have a well-developed set of moral commitments, they are frequently viewed as dangerous and unpredictable by adults (Graham, 2004). The experience of stigma by teens is something they share at this stage of development. Respondents to a 2001 Canadian survey conducted by Reginald Bibby described many examples of discrimination based on their age. One teen from that study commented,

> An important issue is how adults treat me just because I'm a teenager. Sure there are bad ones out there but I'm not one of them and it doesn't just hurt but it's disrespectful when security figures follow me around like I'm some kind of loser or criminal. I'm 17 years old and I hope you'll consider my opinions (p. 70).

In contrast to the broad, negative stereotype ascribed to youth, Giordano (2003) argues that teens continue to value the perspective and support of their parents, though this is balanced by the influence of friends and the need for teens to express personal autonomy. Among its many other functions, friendship can help mitigate the harmful effects of stigma.

2.3.2   Value of Meaningful Friendship in Youth

Researchers believe that friendship is crucial to the social and emotional development of youth (Crosnoe, 2000). It is through the interactions made available in the friendship that children and youth gradually sort out how to cooperate with others, a skill that is highly valued across multiple domains including home, school, community, and work (Giordano, 2003). Friendship, according to Rubin, Bukowski, and Parker (1998),

provides experiences that enable teens to view a situation or problem from alternative perspectives, promoting empathy, compassion and other prosocial behaviors. Meaningful friendships during adolescence offer a foundation upon which to explore future relationships (Giordano, 2003). The conflict that often surfaces in collaborative tasks is an important dimension of friendship. Children are typically more comfortable expressing authentic feedback and contributing original ideas with friends than with acquaintances (Bukowski, 2001). Conflict provides an excellent opportunity for learning the skills of negotiation and self-management. It is through negotiating resolution to conflict that youth friendships deepen and become more stable (Matheson, Olsen, & Weisner, 2007).

The benefits of friendship specific to the teen years are substantial. Research indicates that teens who have friends possess more confidence, have greater concern about others, become more involved in school and have increased focus on employment trajectories compared to isolated teens (Fletcher et al 1995; Hartup & Stevens, 1997). Companionship and feeling a sense of belonging are important to all teens (Cotterell, 1996). The connection between friendship and self-esteem is well-established (Bauminger, Shulman, & Agam, 2004; Swain & French, 2000; Pitt, 2003). The presence of one close friendship can counter some of the negative effects of peer rejection (Berendgen, Little, & Krappman, 2000; Doll, 1996). Such close ties provide emotional stability, enjoyment, and relaxation for teens while simultaneously protecting them from loneliness (Rook, 1987) and depression (Bagwell, Newcomb, & Bukowski, 1998; Ueno, 2005). In contrast, a literature review conducted by Brown and colleagues (2003) noted that teens who experienced alienation were more likely to engage in violence, participate in gangs, experience failure at school and be at high risk for dropping out of the education system altogether. Bearman and Moody (2003) found that teens who reported few peer relationships demonstrated higher levels of suicidal thoughts and attempted suicide more often than teens who reported having friends. Nonetheless, initiating friendship is not always easy for youth, and is highly dependent on context.

2.3.3   Initiating Friendship: Forces that Shape Youth Friendship

Crosnoe (2000) pointed out that friendships are not random. Many structural forces shape the friendship experiences of youth. For example, families tend to live in neighborhoods or regions based on the work and income level of the parents. This then

sets particular parameters on what schools children will attend, what recreational options are available, whether public transportation is accessible and who lives nearby (Hartup & Stevens, 1997). Clearly there are multiple contextual influences on friendship formation (Adams & Allan, 1998; Urberg, Degirmenciolgy, Tolson, & Halliday-Scher, 1995). Proximity and similarity are two of the main factors that determine who will connect as friends and whether that relationship will endure. Spending time near the same people during one's regular daily or weekly routine increases the chances that friendship will develop. Thus, where teens live (geographical location is often outside their control) sets boundaries around who they are likely to connect with (Crosnoe, 2000). A large number of high school students take school buses or public transit to get to campus, thus they mingle with a group of peers from their neighborhood for the drive to and from school every week day. Most teens spend at least 6 hours of each weekday at school, thus their pool of potential friends extends beyond their neighborhood into peers who are in the same class(es). Teens involved in organized recreation at school or in their community expand the number of potential friendship partners within their range. Part-time paid employment is yet another avenue for teens to extend their social networks. Sharing these spaces (home, school, work, recreation) places teens near a variety of people from whom they can select friends (Allan, 1998; Crosnoe, 2000). But proximity alone does not ensure connections will form among teens.

Crosnoe (2000), like many others (e.g. Cotterell, 1996; Hartup, 1995; Urberg, 1998) points out that similarity is one of the key mechanisms that determine who will become friends. Similarity is needed for teens to move from being acquaintances into a closer form of friendship. This may be based on a similar social location including cultural identity (Hartup & Stevens, 1997), a shared language, age, gender (Bukowski, 2001) or academic performance (Akers, Jones, & Coyl, 1998; Berndt, 1982). It is well-established that although some cross-sex friendships occur, during the teen years most friendships occur between same-sex pairs/groups (Hartup & Stevens, 1997).

Similarity can also be understood in terms of shared interests. Enjoying similar recreational activities forms strong connections among peers. Often teens will connect through extracurricular activities on or off school property (e.g. student council, sports teams, clubs and committees). Engagement in shared activity creates an opportunity for companionship while providing a sense of acceptance and affirmation (Cotterell, 1996). This is similar for both sexes, although different activities may be the focal point of

interaction (Urberg et al., 1998). Consider the vast amount of time committed to texting, MSNing or Facebooking short comments about clothing choices, make-up, sports, cars, and how ridiculous parents are. These activities are all about sustaining friendships, trying on a range of identities and expanding social networks (Duck, 2008). Sharing interests or aspects of identity builds upon proximity, but another ingredient seems to be crucial in forming lasting friendships – the relationship needs to move beyond its point of origin (Asher, Parker, & Walker, 1996).

2.3.4 Sustaining Friendship

Extending a friendship outside the situation where people first meet demonstrates a clear preference to spend time with that person. This demands further orchestration, friends need to make plans and adjust schedules to get together. This is a commitment to shift one's daily routine to accommodate plans with a new person (Matheson, Olsen, & Weisner, 2007). This might involve a teen inviting a friend over to play videogames, meeting at the mall to do some shopping, or volunteering together at the food bank. Until teens are able to organize their own transportation, this stage of friendship development tends to require a great deal of support from adults. Making plans with a friend outside of a typical routine has to be arranged among several parties – the teens, one or more parents – and is often negotiated among competing transportation demands of siblings. Getting to know each other across multiple contexts over time strengthens friendship, creating a history of shared experiences, demonstrating the ongoing commitment between friends (Asher, Parker, & Walker, 1996; Matheson, Olsen, Weisner, 2007)

Early on, friends need adult supports to sustain the connection, most often in the form of transportation to and from friends' homes or community events. The kinds of supports shift dramatically as children mature into adolescence when teens distance themselves from parents and spend more time with their friends (Crosnoe, 2000). In rural areas teens may still rely on parents for transportation; however, in urban and suburban areas teens often access public transportation, or walk, to enable them to connect more freely with friends outside the purview of parents. The friendships of teens are closely aligned with earlier comments made about friendship broadly with three notable exceptions: (1) teens most often connect with friends at school initially; (2) these friendships change as children mature into adolescence and young adulthood; and (3) teens often need to

negotiate at least some aspects of their friendships with parents, like transportation, time frames, and destinations (Berndt, 1982; Bukowski, 2001; Crosnoe, 2000).

2.4   Friendships of Disabled Youth

When disability is added into the mix, the permutations of friendships shift. According to the Participation and Activity Limitation Survey (PALS, 2006) 4.7% of adolescents in Canada between the ages of 15 and 18 experience some form of disability. Some studies indicate that disabled youth fare reasonably well in terms of making and keeping friends (Alderson & Goodey, 1998; Bax, 1999; Sebba & Sachdev, 1997). However, most research involving the social experiences of disabled youth raises concerns about social isolation and bullying (Dorries & Haller, 2001; Llewellyn, 2000; Pijl, Frostad, Flem, 2008; Yude & Goodman, 1999). In studies that have considered the friendships of disabled youth, challenges with initiating and sustaining friendships are reported across the spectrum of medical diagnoses (e.g. Blachman & Hinshaw, 2002; Church, Alinsanski, & Amanullah, 2000; Doubt & McColl, 2003; Elbaum, & Boardman, 2001; Evans & Meyer, 2001; Howlin et al. 2004; Koning and Magill-Evans 2001; Orsmond, Krauss, & Seltzer, 2004; Panacek & Dunlap, 2003; Vaughn, Wiener & Schneider, 2002;). Hogan, McLellan, and Bauman (2000) found that disabled students described feeling a sense of belonging, safety, and acceptance half as often as nondisabled peers. Skar (2003) found that adolescents who had mobility impairments tended to have fewer friends than teens who had typical mobility skills. Barron (1997) reported that disabled teens were often excluded from peer groups.

In addition to having fewer friendships than nondisabled peers, research indicates that the friendships of disabled children are also of lower quality, in that disabled youth go out with friends less often, have no identified best friend, and are involved in fewer activities with friends (Timmons, 1993; Vaughn & Elbaum, 1999; Wenz-Gross & Siperstein, 1997; Weiner & Schneider, 2002). This difference in self-reported friendship quality increases as children get older (Vaughn & Elbaum, 1999). Conflict in friendship further compromises the quality of these relationships (Wiener & Schneider, 2002). Disabled youth reported feeling powerless and alienated more often than nondisabled peers (Brown, Higgins, Pierce, Hong, & Thoma, 2003). Children with learning disabilities had fewer friends than nondisabled peers at the beginning of a school year and more mutual enemies at the end of the same year (Tur-Kaspa, Margalit, & Most, 1999).

These findings around social isolation and low quality friendships are particularly troubling since this indicates that disabled teens have less access to the protective functions of friendship described in Section 2.3.2 (e.g., confidence, self-esteem, emotional stability, and sense of belonging). For example, research has shown that disabled youth experience higher rates of physical and sexual abuse than their nondisabled peers (Atlshuler, Mackelprang, & Baker, 2008). This concern is heightened further when it is understood that there are also higher rates of substance abuse, sexual risk-taking, and smoking in youth who identify as experiencing emotional, mobility-based, or learning disabilities (Blum, Kelly, Ireland, 2001). Friendship mitigates these risks (Bukowski, 2001; Pahl, 2000). Why is it that disabled teens struggle more around friendship than their nondisabled peers?

2.4.1   Additional Forces that Shape the Friendships of Disabled Youth

Although there are similarities between the factors that influence friendships for disabled and nondisabled youth (e.g. neighborhood, school, parent support) there are forces that uniquely shape the friendships of disabled teens. Existing literature describes multiple factors that intersect to make creating enduring friendships challenging for disabled youth. These range from the individual characteristics of disabled youth to broad social issues (Baker & Donnelly, 2001; Connors & Stalker, 2003; Priestley, Corker, & Watson, 1999; Shakespeare, 2006). All of these forces combine in a particular historical moment, one where the tendrils of a history of segregation still wind their way into the lives of disabled teens.

a)   History of Segregation

Although Canadians pride ourselves on being an inclusive society, our history is riddled with segregation and eugenics. Because that history continues to shape the social lives of disabled teens today, it will be reviewed briefly here. Canada did not escape (nor did we seem to resist) the wave of eugenics, moral hygiene and institutionalization that swept through North America and Europe in the late nineteenth and early twentieth centuries (Snyder & Mitchell, 2006). Within a few short decades, intellectually disabled people, along with other 'undesirables' like poor people, unwed mothers, and people with mental illness were being sterilized and warehoused *en masse* in an effort to protect the general population from 'moral contagion' (Thomson, 2006). In our infancy as a nation, we needed to demonstrate that we were indeed made of the 'right stuff,' that we

were as strong and intelligent as our European ancestors and as our neighbors to the South. The eugenics movement was concerned with statistical measurement of bodies and minds, identifying those that were subnormal, and proceeding to segregate those so labeled (Thomson, 2006). Thus arose the era of institutionalization and sterilization of disabled people – both endorsed by progressive thinkers in Canada like Alexander Graham Bell (Davis, 1995), Tommy Douglas and Josephine Dauphinee (Thomson, 2006).

From as early as 1910 educators in Canada followed the lead of their counterparts in the United States and started evaluating children, placing those designated as subnormal in special classes that focused on manual labour and improving social skills (Thomson, 2006). Those who did not show improvement were sent to institutions, warehouses that quickly became overcrowded and rife with brutality (Strong-Boag, 2007). It was only after the world witnessed the horrendous power of eugenics as enacted by the Nazi regime during World War II that this 'scientific' approach to 'improving' humanity fell out of favor. The social climate shifted dramatically beginning in the 1960s with the advent of the disability rights movement, when institutions were vilified as unlawful incarceration of disabled people (Shapiro, 1994). The era of de-institutionalization and community integration began (Strong-Boag, 2007). In Canada the Charter of Rights and Freedoms (1982) enshrined the rights of disabled people into law as a recognized minority group.

These social changes, reflecting the mainstreaming agenda, meant that disabled youth – who had been warehoused in schools for the deaf, the blind, the disabled, or the 'incompetent' – were mandated to be educated in the same buildings as nondisabled peers in 1980 in the United States (Shapiro, 1994). Similarly in provincial education systems across Canada, steps were taken to integrate disabled students into mainstream education during the late 1970s and early 1980s (Udistsky, 1992). During this period disabled students shared the same institutional space as nondisabled peers (same building or same classroom), yet interaction rarely occurred and inequality between disabled and nondisabled students remained pervasive (Shapiro, 1994). Physical room was available, yet social spaces and curriculum continued to be inaccessible to many disabled youth. Thus, parents and other advocates demanded that disabled students be integrated into the classrooms of their nondisabled peers, making cross-ability friendships possible for the first time in nearly a century (Shapiro, 1994). Decades were spent preparing schools and communities to include disabled people, yet

according to Meyer (2001) many disabled children and youth spend their whole lives waiting to be accepted. While they waited, it seems that policy makers concerned about balancing budgets here in Nova Scotia diverted resources from community support back to institutions (CACL, 2009). It was at this critical moment, the moment of this research, a moment full of the possibility for inclusion and simultaneously fraught with the very real danger of re-institutionalization that disabled youth were trying to make and keep good friends.

b)   Educational Policy and Practice

The philosophy of inclusion informs much of current educational policy and practice; however, tendrils from the history of segregation and integration continue to shape the friendship experiences of disabled youth. At present there is no uniform approach to educating disabled students. In schools segregation, integration, and inclusion all continue to be practiced, thus it is difficult to discern how inclusion may be shaping the friendships of disabled teens (Fitch, 2003). Segregation and integration are both described as 'traditionalist approaches' to education (Fitch). According to Fitch segregation involves the complete isolation of disabled youth from nondisabled peers via institutionalization or spending the entire school day separated from nondisabled peers in a self-contained classroom. Integration refers to scenarios where at least some portion of the day is spent sharing space with nondisabled youth; however, meaningful interaction between disabled and nondisabled youth is unlikely to occur (Fitch).

After an intensive review of how inclusion, integration, and segregation were understood across Canada, Bunch and his colleagues (2004) compiled the following definition.

> Inclusive philosophy refers to a belief or value system focused on education of learners with disabilities. As such, it involves recognition of the need to support development of full citizenship and recognition of rights of learners with disabilities. When translated to practice inclusive philosophy emphasizes full participation in classroom activities by all learners, social interaction across levels of abilities, appropriate supports, development of friendships across levels of abilities, and development of a diverse community of individually contributing learners (p.42).

This definition served as a touchstone throughout the project. Despite the continued presence of both segregation and integration within the education system, advocates for inclusion argue that the potential to form lasting friendships is a key reason to endorse inclusive policies and practices (Graves & Tracey, 1998; Pitt, 2003). The overarching

school policy around how or to what degree disability is included (or not) plays a key role in how friendship is experienced by disabled teens in the school context. This establishes which other students will have close, frequent contact with disabled teens – two of the key elements to friendship formation (Zetlin & Murtaugh, 1988).

As with nondisabled peers, school is often the initial point of contact for many potential friendships among disabled youth, given the consistent contact over time. Research indicates that disabled children in elementary school generally do well in their early social relationships. A large portion of the curriculum in elementary school is designed for collaborative learning (Cuckle & Wilson, 2002). This provides extensive opportunities for children to become comfortable spending time with a variety of classmates. Others note that most friendships during the elementary school years are activity-based and do not yet have the demand for increased emotional intimacy required of older children (Crosnoe, 2000). This may contribute to greater acceptance of disabled children during early elementary school compared to later elementary, junior high and high school experiences. For all children, the presence of adults is pervasive throughout the early years of school. Teachers, parent volunteers, and education assistants are readily available to facilitate the formation of friendships (Borntrager, 2005; Giangreco, 1997; Middleton, 1999). There are also frequent invitations to the homes of friends, though these may be initiated by parents (Cuckle & Wilson, 2002). These provide the proximity and consistency needed to establish meaningful connections in younger age groups

A substantial change takes place when students move into junior high school. Although developmental changes that affect friendship certainly happen during this transition (see section 2.3.1 above), this is not the only reason that there is less engagement between disabled students and their nondisabled peers. The semester system, content area teachers, larger class groupings, presentation and format of course material, and constantly shifting classroom configurations all contribute to structural barriers to sustainable friendship in high school (Priestley & Rabiee, 2002; V. Timmons, personal communication, June 5, 2006; VanRuesen, Shoho, & Barker, 2001). Additionally, many disabled students are transported to school on a completely separate transit system from their nondisabled peers. The combination of different transportation systems and separate classrooms in high school mean there are few opportunities for disabled teens and nondisabled teens to get to know one another, and become friends (Doll, 1996; Fisher, 1999; Llewellyn, 2000; McDougall, DeWit, King, Miller, & Phillips, 2004).

Educational practices surrounding disabled students have been a research priority in the United States since the 1980s. Inclusive classrooms particularly emphasize the social relationships among young children (Grenot-Scheyer, Staub , Peck, & Schwartz, 1998). Most research in this area focuses on peer acceptance, friendship, and support networks in children from 5 to14 years of age (e.g., Bauminger, Shulman, & Agam, 2004; Blachman & Hinshaw, 2002; Rosenblum, 1998; Meyer, 2001; Wiener & Schneider, 2002). Although this is a large body of literature comparing the friendships of disabled students in inclusive and segregated placements, results vary dramatically (Webster & Carter, 2007). Some researchers have found that disabled students report more satisfying friendships when they are in segregated classrooms (Cuckle & Wilson, 2002; Matheson et al., 2007) while others note friendship is more likely to happen when disabled students are in inclusive settings (Buysse, Goldman, & Skinner, 2002; Fryxell & Kennedy, 1995; Vaughn, Elbaum, Boardman, 2001).

Research findings highlight the influence of educational policy and how that policy is enacted in the classrooms, on the playground, in the cafeteria, and on the school bus (Bunch & Valeo, 2004; Priestley & Rabiee, 2002). For example, Weiner and Tardif (2004) compared the friendship experiences of students with learning disabilities across a range of educational placements ranging from full inclusion with nondisabled peers to full segregation (self-contained classrooms). They found that students who left the classroom to receive support services in a resource room were less accepted by their peers, perhaps due to the stigmatization associated with this model of support. When structures are set up to support consistent contact, then friendships can develop between disabled and nondisabled students. However, when disabled and nondisabled students are systematically separated by curriculum and schedules, friendships rarely form (Bunch & Valeo, 2004). The separation between disabled and nondisabled youth evident at school is reproduced in many recreational venues in the community (Collins & Kay, 2003; Murray, 2002; King, Petremchik, Law, Hurly 2009).

c) *Limited Accessibility of Recreation Options*

When disabled youth do establish friendships at school, few of these relationships move beyond the boundaries of the classroom or the school campus (Buttimer & Tierney, 2005; DHaem, 2008). Extending friendships into the community is crucial for creating sustainable relationships and establishing the network needed to live interdependently

as young adults (Curtin & Clarke, 2005; DHaem, 2008; Johnstone 1995; Matheson, Olsen, & Weisner, 2007; Skar & Tamm, 2001). Recreation is often the link that bridges the school to community shift for friendships. Friends become more connected by participating in a range of shared leisure activities at home (e.g. second life, Facebook, chat rooms) or in community venues (e.g. walking the dog in local park, volunteering, going out to catch a band at a bar). Unfortunately, engaging in leisure activities with peers appears to be problematic for some disabled youth (Fisher, 1999; Murray, 2002). Leisure pursuits for many disabled youth tend to be passive: watching television, listening to music, and reading (Doubt & McColl, 2003; Specht, Kind, Brown, & Foris, 2002). This perpetuates the experience of isolation.

Teens who use alternative forms of mobility (e.g. walkers, wheelchairs) face additional barriers to leisure participation since many gathering spaces are inaccessible (Connors & Stalker, 2007; Murray, 2001). Limited access to recreation venues can directly interfere with the friendships of disabled youth. This includes physical barriers (stairs, heavy doors, no lifts available, poorly designed signs, inaccessible bathrooms) and inadequate information about options (Collins & Kay, 2003). Likewise, if there is no one available to support disabled teens during recreational activities or there are negative attitudes from facility staff members toward disability greater social isolation results (Baker & Donnelly, 2001; Collins & Kay, 2003; Rosenblum, 1998). Costs of recreation can also be prohibitive when families are already struggling with the extra costs often associated with having a disabled family member (Collins & Kay, 2003).

Spontaneity characterizes the social lives of many teens. Plans made by teens appear to happen quickly and can change with little notice. Many disabled teens need to have plenty of lead time to make or change plans since they often need to rely on adults for transportation or other forms of support (Murray, 2002). Often disabled students are not given as much leeway to travel independently and may be perceived as being more vulnerable, so they don't have the same amount of freedom as their peers (Cuckle & Wilson, 2002). This creates another layer of inaccessibility in terms of entry into the social worlds of nondisabled peers.

d)   Individual Skills

Although the history of segregation, the structure of the education system, and accessibility issues all shape the friendships of disabled youth, individual experiences of

impairment must also be taken into account. Bringing impairment into the discussion does not give primacy to medical understandings of disability; rather, it offers a more balanced account of the range of influences on the lives of disabled people (Goodley, 2001; Shakespeare, 2006; Wendell, 1996).

There is a clear focus on the social skills or competencies of disabled teens in the friendship literature. Meyer and her colleagues (1998) note that social skills are critical for establishing early connections with peers that could develop into friendships. Many researchers suggest individual differences in these skills explain why disabled youth have fewer friends and are more isolated than nondisabled peers. Consider the situation of teens with autism, many of whom prefer solitary activities, struggle with communication and are unclear about social rules around establishing friendships (Carrington, Templeton, Papinczak, 2003; Koning & Magill-Evans, 2001; Orsmond, Krauss, & Seltzer, 2004; Tager-Flusberg 2001; Waterhouse & Fein 1997). Bauminger, Shulman, and Agam (2004) found that children with autism experienced less companionship and greater loneliness than nondisabled peers. Similarly, teens with low vision or blindness spent more time alone than nondisabled peers (Rosenblum, 1997). Problems with connecting socially for teens with visual impairments was attributed to the inability to immediately recognize people when they come into the room, to miss visual cues in the conversation, or not follow social conventions like turning toward the person speaking with them (Rosenblum, 1998). Wiener and Schneider (2002) noted that children with learning disabilities may struggle with friendships because of limited social skill development and poor impulse control – both of which alienate them from their peers. Others have argued that developmental differences in interests interfere with establishing friendships between disabled and nondisabled youth (e.g. Harry & Day, 1999; Cuckle & Wilson, 2002). Students who use alternative communication strategies (sign language, picture exchange communication systems, voice output communication systems) often struggle with making and keeping friends compared to teens who are able to engage others in fluid verbal communication (Overton & Rausch, 2002).

e)   Helping Relationships Dominate

Most teens require some degree of support from adults to make their friendships work – whether it be agreeing to host a sleepover, driving teens to meet friends at the mall, or paying for tickets to the latest blockbuster movie. Because of their specific impairments,

some disabled teens need more extensive help from others at home, school, and in the community. Educational assistants and respite workers play a key role in the academic and social lives of disabled children and youth (MacKay, 2006). Some research suggests that many of these workers inadvertently interfere with the friendships of disabled youth in schools because of their constant presence and the tendency to over protect the children (Giangreco, Edelman, Luiselli, McFarland, 1997; Meyer, 2001). The focus of professionals on addressing limitations in the physical function of disabled youth often interferes with both educational attainment and the development of lasting friendships (Middleton, 1999). Yet, receiving help is part of all of our lives as interdependent social beings. Striking balance between appropriate amounts of support and overprotection requires an intellectual flexibility since an action that is supportive of one youth can be stifling to another.

Friendships of disabled youth involving nondisabled peers are frequently conflated with helping relationships (Harry, Park, & Day, 1998; Meyer et al, 1998; Turnbull, Blue-Banning, & Pereira, 2000). Nondisabled peers emulate adult behaviors or are encouraged to become helpers/caregivers to disabled youth (Kishi & Meyer, 1994; Staub et al 1994). In many schools disabled teens have minimal access to nondisabled peers during school hours, except those who are volunteer 'helpers' in the learning centre during their free periods or at lunch time. Many nondisabled students (particularly girls) will say that they 'work with' disabled peers (Kishi & Meyer, 1994). The 'helping' approach may have contributed to the finding by Heiman (2000) that disabled students valued help in friendships whereas their nondisabled peers rated intimacy as the key element in friendship. Numerous programs appear to advocate helping as a foundation of friendship such as 'Circle of Friends' and 'Best Buddies.' Although altruism is a moral attribute to be encouraged in teens, it does not necessarily contribute to long lasting friendships (Meyer et al, 1998). Most of the peer relationship programs do not extend outside the school environment or involve only time-limited commitments by nondisabled peers (Shakespeare, 2006). Helping is an integral part of friendship; however, if it is the only defining feature, the relationship will almost certainly fade (Meyer et al, 1998). Frederich Neitzche (1978/2008) highlighted the need for friendship to move beyond altruism or help when he wrote, "Shared joy, not compassion makes a friend" (entry 499).

f)   *Who Counts as Acceptable Friendship Partners*

Turnbull and colleagues (2000) report that the friendships of children with disabilities have great potential for both quantity and high quality with diverse partners: relatives, nondisabled peers, mentors, those who share the experience of disability, and partners of different ages. But is this range and quality of friendship realized for disabled youth? Although these researchers recognize the value of a range of friendship partners, much of the research on the friendships of disabled youth is directed toward the friendships between disabled children and their nondisabled peers in school (Overton & Rausch, 2002). This connection between disabled youth and nondisabled peers appears to be the gold standard against which all other friendships are evaluated by adults. This may be related to the value-based social policy of inclusion (Meyer, 2001) that is grounded in the disability rights movement and informed by commitments to equality between disabled and nondisabled people (MacKay, 2006). When approached from the perspective of equality then the focus of parents, policy makers and researchers is placed solidly on the friendships between disabled and nondisabled youth to the exclusion of friendships among disabled youth (Harry, Park, & Day, 1998; Turnbull, Blue-Banning & Periera, 2000). Countless studies have focused exclusively on the friendships between disabled youth and their nondisabled peers (e.g., Alderson & Goodey, 1998; Bax, 1999; Carter & Hughes, 2005; Sebba & Sachdev, 1997; Siperstein, Parker, Bardon, Widaman, 2007).

Not recognizing the full range of friendship options for disabled youth can produce many unintended consequences. For example, it may create a negative valuation of disability, falsely narrow choices of friendship partners, or dismiss long lasting friendships (Meyer et al, 1998). More recently a handful of projects included disability-disability friendships among youth and young adults. For example, Curtin and Clarke (2005) and Rosenblum (1998) found that many disabled participants in their studies selected other disabled youth as their friends even though they were involved in classes with nondisabled peers. Matheson and colleagues (2007) indicated that friendships between disabled teens appear to be more stable and consistent and suggested that the most stable friendships were between disabled peers who attended the same segregated classes together over several years.

Despite these hopeful findings, two disturbing trends in the literature remain. There is strong evidence that relations with nondisabled youth are not always positive. Research highlights the harm that ensues in the form of bullying, social isolation, discrimination, and stigmatization when disabled and nondisabled youth interact (Dorries & Haller, 2001; Llewellyn, 2000; Yude & Goodman, 1999). Although generally children select friends based on demographic similarity, this does not appear to be the case for those who share the experience of disability. Just as children who are not popular do not choose each other as companions, rather pursuing friendships with more popular students (Kupersmidt, DeRosier, & Patterson, 1995), so children with physical disabilities have negative perceptions of other disabled peers and would not select them as friends (Cuksts, 1988). Some authors suggest that disability to disability friendships are avoided in order to reduce or manage the level of stigma experienced by disabled youth (Low, 1996). The risk involved in connecting with another disabled youth may exceed the potential benefit. I was recently told of two boys who befriended each other in elementary school. Both were diagnosed with particular impairments that stigmatize them as disabled. They had not rejected each other as predicted by the above research; rather, they consistently sought each other out as friends. Much to the disappointment of the children, both sets of parents requested that the students be separated at school and that the friendship be discouraged. Each set of parents did not want their child to have a disabled friend. What messages does this convey to the disabled children involved? It is not okay to be friends with another disabled child? Disabled children don't make good friends? If this is true, then how is each child to understand this? Does that mean that he is also devalued as a potential friend? That he should expect to be rejected by others as well? Stigma, whether assigned by other students, adults, or the broader society, has a dramatic influence on the friendship opportunities of disabled youth.

2.4.2   Focus on Stigma

Friendship is elusive for many disabled teens. This may be in part due to the way the education system is structured or how inclusive policy is enacted. The lack of friends is also attributed to the effects of specific impairments. Yet when you trace these experiences back to their historical roots, the problem of friendship and disabled youth appears to be heavily influenced by the connection between disability and stigma in our society (Middleton, 1999). Thus, in addition to any other sources of stigma, disabled youth experience at least a doubled stigmatization – the generalized stigma assigned to

teens by adults (Graham, 2004; Travis & Violato, 2001), and the stigma assigned to disability within an ableist society. Although McDougall and colleagues (2004) found that most grade 9 students held either neutral or positive attitudes toward disabled classmates, a solid 21% of respondents held markedly negative attitudes. Tomlinson (2001) argued that segregation within the education system both mirrors and reinforces the stigmatization of disabled people in broader society. There is a well established pattern of hierarchical preference for specific types of disability in society. For example, Gordon and colleagues (2005) found that people with physical disabilities including diabetes, arthritis, or asthma are preferred by nondisabled others over people who have mental illness or intellectual disability. Stigma affects all disabled people, including youth; however, particular dimensions of disability are assigned different degrees of stigma, with less stigma ascribed to those who are perceived as closer to 'normal' (Davis, 1995; Linton, 1998; Michalko, 2002).

Erving Goffman (1963) was the first to use the concept of stigma to describe the structures within society that define and impose normative expectations. He argued, quite convincingly, that labeling particular human attributes as undesirable was an arbitrary process informed by historical context. Consider the history of segregation of disabled youth where the color of one's hair could be discrediting and result in removal from the education system and potentially institutionalization. Strong-Boag (2007) quoted a member of the Canadian Council for Child Welfare who in 1929 described those relegated to institutions as

> Children with bow legs, cross eyes, ugly brick red hair, jug-handle ears, near-sighted children, half caste children, the child who stutters, the child with the frowning countenance, the bad complexion, the birth mark or those whose hair stands straight on end, the child who, through physical weakness or lack of training, has not acquired clean personal habits and perhaps the most pitiful of all, the child with bad heritage (p.422).

This quote clearly exemplifies the situations Goffman identified as stigmatizing: devalued forms of embodiment, character, or beliefs. This devaluation places the stigmatized person in the category of Other and opens the door to a whole range of discriminatory acts. Goffman went on to describe phases of stigmatization that included recognizing normative expectations, realizing that one is rejected/stigmatized because of not fitting with those norms, and finally finding ways to manage the experience of stigmatization. Goffman's work was ground-breaking; however, it has been criticized for attending to the

individual experience of stigma without explicitly drawing the connection to broader social structures or to how power shapes and interacts with stigma (Link & Phalen, 2001).

Link and Phalen (2001) clarify and extend Goffman's work, describing stigma as occurring at the intersection of four specific processes that occur within a socio-political context imbued with power: (1) identifying and labeling differences; (2) ascribing negative social value to these differences via stereotyping; (3) creating specific categories to distinguish a normal 'us' from the abnormal 'them'; and (4) loss of social status for those assigned into the category of the Other via discrimination that creates inequalities. Each of these is considered in turn.

a)   Labeling

We all receive strong normative messages throughout our lives. These become unquestioned beliefs and inform our actions. We resist challenges to our system of values and beliefs. Ware (2002) argues that the norms surrounding ability/disability that permeate our childhoods are difficult to cast aside. What comes to mind when you are asked what we value at this moment in time? Picture Sidney Crosby or Michael Phelps: tall, handsome, young, athletic, bright, competitive, dominant in their sports. Although there are countless variations and expressions of humanity, we end up idealizing particular attributes (e.g. strength, youth) while simultaneously vilifying what we consider the polar opposites (e.g. weakness, age). According to Link and Phalen (2001) creating these oversimplified categories conveniently leads to placing people into them. People are men or women, gay or straight, nondisabled or disabled. One side of the dualism is favored or used as the standard while the other is labeled as different. When this difference is determined to be undesirable, then stigmatization is at work.

Disabled teens are typically labeled according to a set of norms about what intelligence means, how communication happens and 'proper' ways to move through the world. This way of understanding ability shapes the education experiences of disabled teens (Hehir, 2002) and thus significantly shapes the friendships that are available to them. Confirming Goffman's (1963) assertion that most children do not experience stigma until they enter the formal education system, Antle (2004) found that self-esteem in children born disabled was comparable to that of nondisabled peers until they were old enough to recognize stigma. It appears that school-aged children learn very quickly that disability is

stigmatized and devalued. Additionally, Skar (2003) raised concerns about the attitudinal barriers faced by disabled teens. Disabled teens believed that people responded to their disability first rather than getting to know them as individuals, thus disability designated them as different. Many teens were reluctant to talk about aspects of their disability with peers due to fears about social repercussions. Participants in Skar's study described tense and unsatisfying relationships with nondisabled peers because of the negative meaning assigned to the difference of disability.

b)   Stereotypes

When the differences identified are assigned a negative social value, stereotyping results, according to Link and Phalen (2001). Some psychologists argue that stereotyping is a cognitive strategy that enables greater efficiency in thinking (Link & Phalen); however, attaching a negative meaning to particular attributes moves things dangerously past efficient thinking and comes at tremendous cost for those who are stereotyped. Disabled youth are often presented as two-dimensional characters in the media. Children with particular cognitive impairments are commonly stereotyped as gregarious and perpetually happy; kids with autism seem to all line up toy cars and watch the Price is Right; teens with schizophrenia are dangerous. Overall disabled youth are characterized as helpless, vulnerable care receivers (Davis & Watson, 2002). These sweeping generalizations rarely connect with the particular lives of disabled teens, yet the stereotypes persist.

Grenot-Scheyer and Leonard-Giesen (1998) point out that stereotyping plays a key role in the decisions about where disabled students spend their time in school. Segregation of disabled students, particularly those from racialized minority groups, persists in the US despite legal and advocacy efforts over three decades (Grenot-Scheyer & Leonard Giesen). Students identified as somehow more disabled than others are less likely to be educated along with nondisabled peers. If, for example, a teen is identified as having multiple disabilities, she is very likely to be placed in a segregated setting within the school building and may rarely spend time with nondisabled peers (Hehir, 2002; Middleton, 1999). This administrative decision may be based on a stereotype about what it means to live with multiple disabilities. It then determines who this student will spend time with during the day and thus who is available as potential friends.

c)   Separation

Inclusive educational policies set the expectation that disabled children will spend the majority of the school day in the classroom, cafeteria and on the playground with their nondisabled peers. But is this happening? A recent review indicated that in the US fewer than 50% of disabled children were spending the majority of their day (over 80% of the school day) in the 'regular' class with nondisabled peers (Hehir, 2007). Being in a classroom or in a community does not directly translate into being part of it (Shakespeare, 2006). Link and Phalen (2001) refer to this separation as a mechanism that makes a clear distinction between us and them. Reducing disabled youth to the position of Other creates the opportunity for the more powerful nondisabled group to enact violence against the less powerful.

One participant in a study completed by Curtin and Clarke (2005) described her experience of being separated from her peers because of her physical impairment.

> I have tried really hard to make friends. I used to go to hell for leather and would smile and be nice but no one made any effort back towards me… They thought that I was going to tarnish their reputation or something because I was in a wheelchair or because I was a complete boff at most things.

This story demonstrates how nondisabled peers may attempt to create social distance between themselves and the disabled youth. This girl felt she went to extraordinary lengths to fulfill the expected role of a disabled person by "go(ing) to hell for leather" in her efforts to connect with nondisabled peers, yet the separation remained. She attributed this distancing to the nondisabled peers not wanting to be tainted by association. They did not want to risk losing their social status by befriending her.

d)   Status Loss

As humans we consistently organize ourselves in structural hierarchies both in society at large and in transient groups (Link & Phalen, 2001). The status of any one individual depends largely on what is valued within a particular context. Religious leaders and politicians hold high status positions in some societies; healers or physicians are honored in others; people with artistic skills or great orators are highly valued in certain communities. Social status can also be something you are simply born into (e.g. royal families, aristocracy, wealthy families). One can also be born into disadvantageous situations like poverty and thus automatically be assigned a low social status (Gould,

2002). Clear distinctions exist between those assigned low status and high status; yet it may not be readily apparent why particular people or attributes are given higher or lower status. What is clear is that low status positions are almost always assigned to conditions of stigma. Once a person is labeled as embodying undesirable difference and relegated to the position of Other she is simultaneously placed in a lower status group in the social hierarchy. This devalued status leads to inequalities at the individual level (Link & Phalen, 2001).

Status loss is about social comparison; it is about where one person is located in the hierarchy in relation to another (Coleman, 2006). Although the loss of status is an inevitable consequence of stigmatization, certain people experience more deleterious consequences (Coleman, 2006). Return again to Michael Phelps for a moment. Although he attained fame by winning a record number of gold medals, it took one photo to move him into a stigmatized category of 'drug user' resulting in censure and the loss of more than one sponsorship deal. The adage, 'how the mighty have fallen' comes to mind – indicating that no one is immune from the effects of stigmatization. Yet Phelps' experience of stigma is not the same as that experienced by people with mental illness. Although Phelps lost some income and was denounced by some for his actions, he remains wealthy and popular as opposed to many young disabled people who are socially and economically marginalized, not based upon anything they have done, but upon who they are believed to be.

Many disabled youth are always embedded in the experience of stigma. Even when this is the case, disabled teens continually face the risk of "downward mobility" (Coleman, 2006, p.142) in the social hierarchy. Middleton (1999) presented the following quote from a young man who was intimately acquainted with this loss,

> Children at my school were categorized by staff… put into boxes. You had to be partially sighted or you had to be blind. Partially sighted pupils had guide duties. My sight deteriorated, and I was moved from one box to another. This meant I lost friends and I lost status, and although I could still find my way around, and I learned to use a guide cane, I was no longer allowed to guide visitors. My loss of sight meant loss of status automatically: no one assessed either my willingness nor my ability to continue to act as a guide (p. 20).

This richly layered quote identified the structural issue of labeling, the stereotyping of particular disabilities (blind students can not guide sighted people), and the loss of status

that ensued. The young man clearly stated that losing his social status, a status that hinged on being partially sighted, had the immediate consequence of losing friends.

e)   Discrimination

According to Link and Phalen (2001) losing social status opens people up to discrimination based on the negative stereotyping described above. The person or group discriminated against has fewer opportunities and typically experiences more negative health outcomes, lower income, poor housing, lower life expectancy, and fewer educational opportunities than those in higher status positions in society (Link & Phalen, 2001). Stigma tends to focus on the individual or group experience of being ascribed a negative label or stereotype; whereas discrimination focuses on those who are actively engaged in ascribing the label (Sayce, 1998).

Discrimination is commonly reported by disabled youth. Curtin and Clarke (2005) note that mainstream schools often have deeply rooted discrimination against disabled students and have not created accessible curriculum, resources, or friendship. Cooney and colleagues (2006) note that students involved in their study who were educated in mainstreamed classrooms experienced discrimination both in school and off campus by nondisabled peers. Ableism is discrimination based on disability. Like its counterparts racism, sexism, heterosexism, ableism is based in deeply entrenched cultural assumptions about what is 'normal.' From an ableist perspective, walking is always better than wheeling, speaking is better than signing, reading print is better than reading Braille, and people with higher IQs always make more of a contribution to society than those with cognitive impairments (Hehir, 2002). Rauscher and McLintock (1996) note that ableism is

> a pervasive system of discrimination and exclusion that oppresses people who have mental, emotional and physical disabilities… Deeply rooted beliefs about health, productivity, beauty, and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities… fall out of the scope of what is currently defined as socially acceptable (p.198).

In recent years there has been a focus in the disability rights community on access to healthcare for disabled people. Many disabled people are denied medical services based on negative stereotypes that guide the actions of healthcare professionals. Middleton (1999) included comments made by a prominent transplant surgeon in the

United Kingdom who systematically discriminates against disabled people. Although Middleton argued that children with Down syndrome are the largest single group of children with heart problems, this physician stated, "It is not just Down's we are discriminating against. It is anybody with a disability. We take, when faced with a choice, the person who is the most whole, as it were" (p.37). Discrimination is rarely so explicit; often ableism takes subtle forms that are difficult to name and address (Connors & Stalker, 2007), yet it substantially reduces the friendship opportunities of disabled youth. Another participant from a mining community in Middleton's study on social exclusion offered the following experience,

> My early education, if you can call it that, sitting at the back of the classroom and being given crayons to play with due to my sight problem. I do not know if this was deliberate discrimination or just, 'why teach someone who could not work down in the (mining) pit and would end up with a menial job anyway?'(p.15).

In this situation discrimination was enacted via the curriculum and placement at the back of the room. The belief that he would never be a productive (read employed) member of society, relegated him to scribbling with crayons. Although this teen was in the same classroom as his nondisabled peers, he did not participate in the same learning activities. Shared engagement in classroom activities provides the opportunity for students to get to know one another and may be the starting point for a friendship. Thus in addition to reducing his life chances overall due to lack of education, ableist beliefs and practices reduced his chances of making friends.

f) Exercising Power

The presence of stigma is predicated on one group having the social, economic and/or political power to stigmatize another (Link & Phalen, 2001). Stigmatization involves the power of the dominant group to decide which attributes become discrediting. Link and Phalen contend that stigma and discrimination can only exist in a hierarchy – where the lower status group is stigmatized, but cannot in turn discriminate against the higher status group due to the power differential. People can move in and out of situations where they experience stigma. Zola (1979) argued that everyone, at some point in life would experience stigma either in a transient or more permanent way. For disabled youth the experience of stigma in the context of the social power relations of ableism, is constant, and affects the ability to establish and sustain friendship.

Doubt and McColl (2003) incorporated a disturbing narrative from a young man in high school who had a physical impairment. Brad told the following story about the way power was enacted around the difference of his disability:

> I have a mild stroke on my left arm and my leg… They laugh if my arm's up in a weird way or… if I walk real funny… The kids say mobie and weird names like that to me. The grade 12s grabbed a hold of me and they dragged me down and this one guy kicked me between the legs (p. 143).

This comment was included under the heading 'exclusionary peer reactions' in the article, which seems a vast understatement for the violence Brad was subjected to. This example includes all of the interactive elements of stigma. Brad describes a physical difference in his body compared to the normative standard describing his arm as 'weird' and his gait as 'real funny.' This difference is clearly defined as negative by his peers given that he is called names because of how he moves through the world. Brad's non-normative body marked him as low status, one who was stereotyped as a helpless, emasculated victim by those of higher status (the physically nondisabled grade 12 students). These intersecting processes culminated in the violent exchange based in discrimination. This assault was a physical demonstration of the power differential between Brad and his higher status peers. Most stories of stigmatization from disabled youth are not as physically violent as this example, yet they all mark disabled youth as embodying undesirable difference and relegate them to low status positions (Susinos, 2007; Cooney, Jahoda, Gumley, & Knott, 2006). These damaging interactions make it incredibly difficult for disabled teens to make and keep friends.

To stop at this point implies that the stigmatized group has no recourse; that they must simply bear the burden. This is not my intent. Where power exists, the possibility for resisting it also abides. The disability rights movement is filled with examples of stigmatized groups who pushed back against imposed norms and oppressive laws. ADAPT, a disability rights organization in the United States, was key in shifting disability policy around accessibility and self-managed care (Shapiro, 1994). There are countless disability scholars and organizations across Canada, including People First and the Canadian Association for Community Living, who work tirelessly toward deinstitutionalization and community participation.

Resistance is not limited to the large political stage or to academic writing; it happens in the small exchanges of disabled youth every day. One young man who attended a

segregated school pushed back against what he perceived as over-protectiveness by adults (Davis & Watson, 2001).

> The people here are too protected. I can do a lot more things than they give me credit for. For example, a few months ago I got a pass to go to the back shops and the access person and I agreed that I can go through there, that I've got the confidence to do it. But for the first few times they kept on checking up, following me… I can't understand why they want to check up on me, but they do and they keep doing it. You get this awful feeling you're over protected. At home I negotiate my way round the local town OK. I'm capable of doing lots. My mother never had any quibbles about it. I just do what I can do, and I just wish here they wouldn't be so over protective (p.683).

In this excerpt adults seemed to perpetuate the stereotype that disabled youth are vulnerable and constantly need support. This young man clearly disputes their position, demonstrating that he is completely capable of being on his own in public spaces. He goes on to point out the discrepancy between the beliefs held by education staff (i.e., that he needs adult surveillance) and his mother's approach (i.e., that he is fine being out in the community on his own). Not only does he recognize this difference, he uses the counter narrative offered by another adult, his mother, to resist the practices of over protection at school.

2.5   Chapter Summary

Friendship is a highly valued relationship throughout our lives. It takes multiple forms providing us with companionship, assistance, guidance and support. Friends enter and leave our lives in countless ways, yet the desire to have and keep friends remains constant for most people. Having good friends gives us a sense of connection, promotes health and well-being, and in some situations encourages moral growth. The form and elements of friendship gradually shift from loose associations based on shared activity to having greater depth and intimacy as children move through developmental stages into adulthood.

All the forces that shape the experiences of nondisabled youth also structure the friendships of disabled teens (e.g., proximity, similarity, consistency), yet there are additional factors that are unique to disabled youth. For example, the history of institutionalization continues to wind its way through the lives and friendships of disabled teens. Educational policies and practices determine who will be available as potential friendship partners. Accessibility issues set parameters around recreational spaces

where friends can spend time together outside of the school setting. Beliefs about dependency and vulnerability of disabled youth seem to encourage imbalanced helping relationships instead of enduring friendships. There are also implicit messages about who makes a good friend based in the stigmatization of disability in our culture. Researchers suggest that being stigmatized reduces one's life chances in terms of employment, income, longevity, and social connection (Cooney, Jahoda, Gumley, & Knott, 2006; Green, Davis, Karshmer, Marsh, & Straight, 2005; Lundberg, Hansson, Wentz, Björkman, 2008). We know that disabled youth experience fewer and lower quality friendships than their nondisabled peers, yet this is not the case for everyone. There are some disabled teens who have figured out how to establish enduring friendship despite the presence of stigmatization. The current study specifically seeks to understand their stories.

In the past decade many disability scholars have called for researchers to engage in more balanced, respectful projects that centralize the stories of disabled youth (e.g., Davis & Watson, 2001; Middleton, 1999; Priestley, 1998). McVilly (2006) clearly demonstrates this move in his participatory study involving the friendships of adults with intellectual disability. Members of the expert panel in McVilly's research described friends in the following ways:

> 'you've got to be able to trust them if they are going to be a friend'; 'a friend must be honest …like they got to tell the truth or they're not a good friend'; 'I have to be able to count on them …, like know that they will be there'; 'friends stick by you …through thick and thin… you can rely on friends'; 'they respect you… for who you are … like the stuff you like and its OK if you like different stuff too'. Also, people who were considered friends were those who were seen to be 'caring' and 'understanding': 'you know, understand each other … what you need and… stuff you like doing' (p. 698).

This is a strong beginning for understanding friendship from the perspective of disabled people. The reflexive approach to research endorsed by McVilly (2006), Shakespeare (2006), and Priestley (1998) guided the current study. The following chapter presents the theoretical and methodological framework that informed this project from recruitment of participants through to selection of methods and data analysis processes.

CHAPTER 3   RESEARCH METHODOLOGY

Methodology is the distinctive way that theory and epistemology merge within research practice (Fontana, 2004). The research methods used in different projects may be quite similar but how the researcher employs them depends on her philosophical orientation – the conceptual framework that guides the research process. This project was developed as a critical ethnography, demonstrating my commitment to using critical disability theory to think through the experience of stigma as it relates to the friendships of disabled youth. This approach also recognized that the research itself is dialectical, jointly created through interactions between me and the participants (Anderson, 1991). Extended fieldwork was a key feature of the project. This particular research method enabled me to gradually understand friendships from the perspective of disabled youth, an emic worldview (Pike, 1967). Extensive use of researcher reflexivity was a hallmark of the study, where I continually moved among the partial perspectives of participants and my (partial) interpretations of their experiences (Alvesson & Sköldberg, 2000; Emerson, Fretz, & Shaw, 1995; Harding, 1991). Although substantially revised, portions of Sections 3.1 and 3.2 were accepted for publication (Salmon & Bassett, 2009).

3.1   Theoretical Orientation: The Celtic Knot

The image of a Celtic knot invokes Nova Scotia's history while simultaneously organizing the theoretical framework of this research. The interconnected spirals represent the ontological, epistemological and methodological underpinnings that inform this study. My work blends critical theory with complementary paradigmatic elements of constructivism. The research begins from the position that disabled youth constitute an oppressed group within society, hence the connection to critical disability theory (Charlton, 1998/2006; Oliver, 1990; Priestley, 1998). To begin to appreciate the complex interactions that contribute to the experience of disability, we must acknowledge both the construction of 'disability' as a social category (Davis, 1995) and the embodied experience of impairment (Wendell, 1996). I describe my paradigm of inquiry by first considering the ontological and epistemological underpinnings of this work. It seems somehow false to tease these concepts apart since they are all so intimately connected; hence, they are addressed synergistically after each is briefly defined. These ideas then inform the

presentation of research methodology, which then flows back into the paradigm of inquiry – completing the Celtic knot.

Denzin and Lincoln (2005) note that ontology describes a researcher's stance on the nature of reality. I take the position that multiple interpretations of reality exist; however, I do not believe this unravels into relativism where we can only know ourselves. When many alternative understandings of reality are given an opportunity to coalesce we develop a greater awareness of the complexity of the phenomenon and our experiences. Returning to the Celtic knot whose lines weave and flow together, we can acknowledge multiple realities as contributing to a larger, unknown (and perhaps unknowable) whole where the intimacy of individual experience combines with others to become a fluid construction that evolves as our understandings deepen.

Consider the Mother's Against Drunk Driving commercial that played repeatedly on television in 2007. It opened with a view out a second or third storey window. The camera looked down onto a lovely garden scene where a young woman sits on a park bench. Text appeared at the bottom of the screen "your girlfriend.' She smiled at someone approaching. The camera followed her gaze, introducing the viewer to a handsome young man walking over to greet her. The script at the bottom of the screen read, 'your best friend.' To the surprise of the audience the two then embraced, kissed, and walked away from the camera hand in hand. The camera then panned back from the upper window, past the person through whom we witnessed the exchange below. It was quickly revealed that the onlooker sat motionless in a wheelchair with a headrest, perhaps to indicate that he (presumably) had a high level spinal cord injury incurred after an accident involving alcohol. The script read, 'don't drink and drive.'

There are many ways to interpret this 30 second public service message. From the perspective of disability rights, it is startling that the faceless disabled character in the clip watches his life unravel through the window of a residential facility of some kind. In direct opposition to the commitments of the People First movement in Canada, this commercial brought the violent history of imposed institutionalization of disabled people into the present. An alternate reading of this commercial could focus on how disability was constructed as an undesirable Other. The isolated, excluded disabled guy is cast as sexually undesirable. His girlfriend chose the nondisabled friend to kiss and walk away into the sunset with, not once looking back toward the window. Why doesn't this choice

surprise the audience? When approached from the perspective of power relations, the disabled guy sat powerless and inert; the silent observer. The girlfriend and best friend were the ones who had the power to choose because they had the ability to move. And what of these relationships? Our friends are supposed to be the people we can trust and rely upon; people who have our best interests at heart. Why were the actions of girlfriend and best friend not vilified? Their actions constituted a dramatic breach of trust, yet this was somehow acceptable because of the presence of disability? When this sampling of interpretations is combined, a more nuanced understanding emerges about how ableist assumptions shape the experiences of disabled people via stereotyping, social isolation, and discrimination. Whether or not these interpretations contribute to a unified holistic reality is uncertain. Whether or to what degree disability and discrimination are socially constructed is not the primary concern of this dissertation. What matters is that discrimination against disabled people negatively affects their life chances (Davis, 1995; Goffman, 1963; Linton, 1998; Shakespeare, 2006).

Epistemology is concerned with what can be known, how and by whom (Denzin & Lincoln, 2005). There are multiple complementary ways of knowing that include our sensory perceptions of the world, experiences, intuitions, spirituality, history, and context. In other words we know through our embodied location. I contend that disabled youth are able to understand and interpret friendship from their particular social locations in ways that simply cannot be arrived at without having experienced friendship as a disabled teen. These teens have unique contributions to make to the friendship literature that are quite likely to contest current beliefs about what knowledge is privileged (i.e., medical and educational knowledge), and who creates this knowledge (i.e., adults). Thus, knowledge is recognized as situated in the lives of these youth. For this study, disabled youth with established friendships are posited as the experts on knowing about their own friendships. A conceptual framework that respects these beliefs is informed by three substantive bodies of work: critical disability theory, situated knowledges (Haraway, 1988), and strong objectivity (Harding, 1991).

3.1.1   Critical Disability Theory

In 1975, as the disability movement gained strength in Britain, the Union of the Physically Impaired Against Segregation (UPIAS) presented their stance on disability:

In our view, it is society which disables physically impaired people. Disability is… imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (p.4).

The social model of disability, and indeed much of critical disability theory, finds its roots in this position statement. The social model postulates that disability does not exist outside of social constructions that constitute it (Oliver, 1990). Disability is created by our values, perceptions, and the design of the physical environment. The social model offers an alternative to the traditional medical conceptualizations that present disability as a personal problem, often viewed as a tragedy, which can only be addressed at the level of the individual. The social model moves away from this position and instead highlights the historical and socio-political factors that shape the experience of disability (Oliver, 1990). In the three decades since the UPIAS publication numerous scholars have supported, contested, and extended the social model of disability, creating a new discourse: critical disability theory. The proposed study draws from this body of work in order to understand the processes through which disabled youth are both constructed and stigmatized in our society.

3.1.2   Social Construction of Disability

Disability is created by the interaction between the dominant group of the nondisabled and the 'others' it constructs (Thomson, 2002). The social and political exclusion of disability is mediated by institutional, economic, attitudinal, legislative, and architectural barriers. Thomson (1997, 2002) and other disability scholars interrogate historical and current media representations of the body to reveal the substrate of value-laden normativity (e.g., Davis, 1995; Michalko, 2002; Snyder & Mitchell, 2006). Normalcy, and hence disability, is primarily constructed through function and appearance (Davis, 1995). To adequately respond to the social construction of disabled youth, both disability and its twin, normalcy, must be traced back through time. Both find their roots in the eugenics movement that was started in the middle of the nineteenth century by scientists and politicians in the United Kingdom and United States, reaching its horrifying climax in World War II (Davis, 1995). At that time untold thousands whose bodies were labeled as statistically outside the 'norm' as defined by the bell curve were deemed 'undesirable' and killed in concentration camps in Germany (Laing & French, 2005; Snyder & Mitchell, 2006).

Today, disability theory is one of the few places where we are encouraged to think about the influence of the eugenics movement on the construction of disability. Consider how rehabilitation services are provided. Before services are provided to disabled students, educators and health professionals are often required to subject them to standardized testing – to 'objectively' identify the ones whose skills are two standard deviations below the mean of the 'normal' population. We then assign labels like autism, learning disability and motor impairment. These labels then permit the students to receive particular support services. The links between standardized testing, normative references, labeling, and ascription of disability status are clear (Davis, 1995; Wendell, 1996, Linton, 1998). Research that draws upon diagnostic categories starts from within a paradigm that arose from eugenics; therefore this study does not employ these labels. Instead it explores experiences of stigma and friendship across the extraordinary diversity of impairments experienced by disabled youth.

Attending to the historical, cultural, political, and medical forces that shape the disability experience is crucial if I am to assume a critical disability perspective, one that contests the notion that disability is inferior to ability in some 'real' or 'objective' way. The imagined objectivity of standardized tests and traditional science more broadly is incomplete; yet it does offer a form of accountability that is important to carry forward. Many disability scholars argue that research that comes from the standpoint of disabled children and youth is both timely and necessary (Connors & Stalker, 2007; Davis, 1998; Davis & Watson, 2001; Middleton, 1999; Priestley, 1998). Thus, the work of two standpoint feminist theorists, Sandra Harding and Donna Haraway, were used as guideposts in this study. Harding's (1991) work on strong objectivity and Donna Haraway's (1988) writing on situated knowledges offer important guideposts to promote accountability in research practice involving disabled people.

3.1.3 Strong Objectivity

Traditional conceptions of objectivity demand that a researcher display detached neutrality in her work. Without this standard, it is argued, science dissembles into relativism – where every opinion is given equal weight and there is no way to assess the worth of a project. Harding (1991) contests this stance, noting that a researcher must move out of the safety afforded by privilege and acknowledge the bias inherent in her own social location as part of the academy. This can be accomplished, at least in part,

by recognizing that each researcher approaches her work from a very particular place created by personal identity, social location, academic training, and the historical moment in which she pursues a project. Harding is concerned that traditional methods in science are not sensitive or rigorous enough to detect sexism, racism, and heterosexism inherent in the normative centre of society; they detect deviations away from the norms of science, away from normative standards, but do not detect when 'normal,' standard approaches rest on entrenched collective biases. Therefore, these approaches offer only 'weak' objectivity – a kind of objectivity after the fact. As long as the researcher remains committed to researching the 'other' from an unexamined position of normative centre, she leaves her own position of privilege intact. Harding argues that this markedly limits the objectivity claimed by the researcher.

When one concedes that she holds particular beliefs that will inevitably influence the research, it becomes counter intuitive to subscribe to traditional conceptions of objectivity. I cannot dispute that my subjectivity influences my reading of a situation (e.g., what I attend to, how I perceive a particular interaction), yet this is not the primary concern of strong objectivity. Strong objectivity disrupts the dualism that places objectivity and subjectivity on opposite ends of an imagined continuum. It moves me into an unfamiliar location that Harding (1991) argues will intensify objectivity.

Harding (1991) believes that a researcher can begin her project with a commitment to the knowledge held by people who have been marginalized by the dominant groups in society. She argues that people on the fringe of society are not committed to maintaining the status quo that locates both power and knowledge in dominant perspectives. Their worldviews employ different lenses. Strong objectivity can disrupt dominant perceptions and stereotypes by questioning the background assumptions that inform research practice. When applied to the project of assembling a careful account of friendships experienced by disabled youth, strong objectivity means attending closely to the social forces of ableism and adult-centred social policy that construct these experiences.

Ableism – like its counterparts sexism, racism, ageism, heterosexism to name but a few – is rooted in the faulty belief that one form of embodiment, nondisabled, is taken for granted as superior to another, disabled in this case (Linton, 1998) . This is the root of beliefs that privilege speech over sign language, walking over wheeling, independence over interdependence and care giving over care receiving. The older disabled children

get, the more disadvantaged they become since their peers gradually adopt the ableist assumptions entrenched within society that perpetuate discrimination against disabled people (Hehir, 2002; Priestley, 1998). To counter and de-centre the foundations of ableism, the knowledge of disabled youth is the focal point of this project. This move to privilege the situated knowledge of disabled youth is supported by the work of Donna Haraway (1988).

3.1.4 Situated Knowledges

Harding (1991/2004) opens her essay on strong objectivity by quoting Haraway, "Feminist objectivity means quite simply situated knowledges" (p.49). This alludes to the respectful debate between these feminist scholars over the past two decades. Haraway (1988) believes there are multiple, culturally determined, yet individualized ways of perceiving the world. She argues that starting inquiry from the position of marginalization makes it possible to unmask domination and oppression in the everyday world. To engage in such a project, one must be able to recognize the structures that exist within society. How is this possible? She, like Harding, contends that the reflective, self-critical position often used in research is inadequate because it starts (and remains) in the privileged position. Haraway gestures toward reflexivity and commitment to multiple perspectives as possible ways to move forward with the research project of representing the stories of others.

Haraway argues that embracing partial perspectives offers the only supportable route to objectivity. This approach does not advocate for engaging in the violent act of colonizing the Other by attempting to assume that identity or take up that worldview; instead, Haraway recommends the accountability possible when one is able to understand the world from both marginal and dominant perspectives. She recognizes that we have access to many partial understandings and interpretations (i.e. situated knowledges), some of which may be complementary, while others may present radical contradictions. Take for example the range of perspectives on making friends offered during a focus group of participants with intellectual disabilities in McVilly (2006).

> "People stick in their groups … like people with intellectual disability stick
> together"… "Yer, even when they got a physical disability, people with intellectual
> disability can't get a say … like when they just got a physical disability they don't
> want to be friends"… "You can be friends if they ain't got a disability,
> sometimes"… "Not much' to which others in the group nodded in approval. When

asked 'why' this was so, one participant stated 'its stigma …like you're different … like when they call you names and stuff"… "'its because you need to be equal …you need to have an equal say in what you are going to do"…"you need to be on the same level"… "its hard to be friends if they ain't got disability, they just don't understand…don't know, guess that's why you stick to your friends that got disability" (p.699).

This series of quotes demonstrates positions that work well together – people with intellectual disability need to stick together, needing to be equal, people without disabilities don't understand the disability experience. Yet another perspective opposed this stance – you can have nondisabled friends. Someone else noted that even within the broad category of disability, there is a distinctive hierarchy where physically disabled people reject intellectually disabled people as friends. McVilly did not attempt to unify these interpretations; instead, he presented them as partial perspectives on who makes a good friend.

Haraway (1988) argues that people in marginalized positions are more likely to have access to a split screen, where both the dominant and marginalized perspectives are paradoxically available. Because disabled teens face discrimination they may have an understanding both of the world of disability and of the nondisabled world. Many participants in this study reflected on both what it meant to be disabled and how that made them acutely aware of the meanings of ability. Yet their friends and classmates who were nondisabled had little or no awareness of what it meant to be disabled. They could easily engage in a world designed for them. For their nondisabled peers doors were rarely too heavy to open, stairs too steep to climb, print too small to read, language too difficult to decipher, or social rules too unpredictable to sort out. They didn't encounter abrupt messages about which kinds of bodies spaces were designed for, thus ability never surfaced as an issue. Haraway does not contend that everyone from a marginalized position understands both their own world and that of the dominant group, only that it is more likely that less powerful people are aware of both worlds.

When a researcher is able to access the tension that exists among these situated knowledges, Harding and Haraway posit that she is able to become more accountable. The marginalized position provides a more objective location from which to view the world since it simultaneously changes both what can be seen and how the world is viewed. Yet Haraway (1998) expressed her concern that powerful people could use her work to appropriate the knowledges of those in less powerful positions in society.

Seeking out the view from below can be both difficult to achieve and problematic (Haraway). The commitment to situated knowledges can take many forms in research. To begin to understand the world from the perspective of disabled teens, participants were invited to bring along a set of photographs that depicted aspects of their friendship. Rather than imposing a scripted set of interview questions grounded in my understandings of friendship, the participants focused the interview on stories and activities that were meaningful to them. Another strategy used to shift out of ableist assumptions around friendship involved not imposing a particular ability status on the friends of participants. Much educational research concentrates on the friendships between disabled children and nondisabled peers. Had this been used as a criterion for participation, only one set of friends would have been eligible to participate in this study.

I share Haraway's worry that the powerful (i.e., the researcher) can exploit the marginalized even further by appropriating their situated knowledges. It takes a great deal of effort to ethically engage with participants; to avoid simply taking their stories and representing them in ways that serve the interests of the researcher (e.g., publications, tenure, promotion). Davis (1998) suggests that reflexivity helps mitigate this concern. He recommends that researchers attend to tensions that arise during the research process, noting that these are spaces where the worldviews of the researcher and participants may be colliding. To illustrate this point, a clash of assumptions took place over what inclusive recreation meant to those involved in the study. At the outset of the project I understood inclusive recreation to mean leisure activities where disabled youth could readily participate alongside nondisabled peers. Yet nearly everyone involved in the study engaged in what I would have described as segregated settings such as Special Olympics or disability-specific social clubs. After much discussion with participants, my supervisor, my colleagues, my assumptions about what inclusion meant became more apparent. I was immediately dismissing disability-to-disability connections as a throw back to the era of segregation. What I came to understand was that when viewed from the perspective of disabled teens, these venues were self-selected havens; places where they could relax and be themselves. Teasing apart the 'meta-languages' of the academic training of a researcher, her personal history, and the multi-voiced cultural languages of participants can be helpful in unpacking the assumptions one brings to the project. To address this concern a set of questions, included in section 3.10, was developed to guide the research process. The reader can use these questions to judge

the alignment of the study with the ethical commitments made in the conceptual framework.

3.1.5 Moving Forward

Harding (1991) and Haraway (1988) agree that beginning from marginalized knowledges is required in order to counter the weak objectivity they argue is inherent in the positivist paradigm. Positivism, with its conceptions of a singular truth, limits what can be known by and about the privileged group because it does not critique the dominant perspective typically held by the researcher. The objectivity of traditional science is described by Harding as 'weak' since it does not acknowledge, let alone question the ontological and epistemological assumptions held by the researcher or within the research community. Strong objectivity, on the other hand, offers a critical assessment from the position of subjugated knowledges, carefully deconstructing dominant values and beliefs.

Without arguing that the knowledges and experiences of oppressed groups are the singular way to really understand the world, strong objectivity works to shift the power in research, recognizing the value of partial perspectives. This can be realized, at least in part, by spending the time required in the 'field' to come to understand the world from the point of view of those who are marginalized relative to the issue being studied. So in this research, it means coming to understand the (partial, situated) worldviews of disabled youth and actively engaging disabled youth in conversations about their experiences. But these two strategies are not enough. The fieldwork and interviews must then be interrogated through a process of critical reflexivity that is informed by disability theory – another partial perspective that begins from the margins.

Neither of the constructs presented here, situated knowledges and strong objectivity, hold that the non-dominant position is the only perspective one must attend to. The 'view from below' is not presented as the only real way of understanding the world or knowing the truth of a story. That would link both philosophers back to positivism – something they clearly set themselves against. They contend that it is through moving among the multiple partial perspectives made available through situated knowledges that we create more meaningful knowledge in research. When research proceeds only from a dominant perspective, its inherently partial views become constructed as Truth; acknowledging and navigating multiple partial perspectives makes transparent the socially located nature of all knowledge claims.

Like Haraway (1988), Harding (1991) believes that knowledge and politics are core factors in feminist epistemology. They agree that knowledge is available from multiple locations; however, they contend that particular locations offer a more productive/informative place to start inquiry. In this study, strong objectivity requires active engagement with disabled youth, detailed observation, and critical reflection. I understand the appeal of positivism's standards of control, generalizability and reliability; however, my work is informed by the embodied and heterogeneous agents presented by Harding and Haraway. Disabled youth cannot be made one-dimensional and imagined to constitute a homogeneous group based on the ascription of a medical label, IQ score, or functional status. There are infinite combinations of identity, ability and perspectives (Priestley, 1998). How did I move beyond the typical positivist research strategy of including only youth who share a diagnostic label? Inviting the participation of youth who identify as experiencing social stigma based on disability status began to address this concern. Employing the work of Harding and Haraway indicates where to begin inquiry, yet they offer little concrete guidance in terms of enacting the process of research. Their work is congruent with the theoretical underpinnings of critical ethnography. These connections are now explained. The analytical project of reflexive interpretation is then considered using the work of Alvesson and Sköldberg (2000).

3.2   Methodology

Alvesson and Sköldberg (2000) argue that all knowledge is socially constructed and inseparable from the 'knower,' the context, and the process of knowledge production. These authors recommend that empirical data be approached using four interactive aspects of analysis that wind through the research process. First, they suggest data gathering and interpretation using a well-supported methodological approach like ethnography. Second, they insist upon in-depth interpretation regarding the authenticity of the interview, assessment of bias and analysis of the relationship between researcher and participants. The third element entails political and ideological interpretation, understanding data through political lenses. In this study, this meant drawing on critical disability theories, thus linking the methodology back to the ontological and epistemological underpinnings of this work. The fourth strand of this approach prompts the researcher to interrogate representation and authority in writing up the research text. Alvesson and Sköldberg do not prescribe a linear movement through a hierarchy of

layers; rather, they encourage the researcher to wind through these interpretive sites as theoretical understandings of the participants' experiences are created. Strong objectivity and situated knowledges inform each interpretive element.

This approach appears to be congruent with the strategies employed by a 'reflexive practitioner' (Davis, 1998). Davis argued that qualitative research can represent divergent perspectives of many children, rather than representing children's experiences as a unified whole. This demands that researchers question the approach used and the assumptions that underpin their work. He suggested that a researcher be open to re-negotiating her role, ethical commitments, and methods. To draw on an example from my work, consider the range of methods used. About half of the participants moved easily through all aspects of the study as laid out in the research proposal (e.g., individual interviews, joint interviews, participant observation session). To include the stories of disabled teens who used alternative communication strategies, the methods had to change. One participant was interviewed with the help of an interpreter (parent). Two others could not tolerate the intensity of an interview with someone unfamiliar, so more extensive periods of participant observation were completed. Yet another disabled youth asked that all interview questions be sent in advance so he could prepare for our conversation. These accommodations were based on a reflexive review of the data collection methods before, during and after the interactive sessions with participants.

Alvesson and Sköldberg (2000) note that the epistemological position taken at the outset of a project guides the work in particular directions, while simultaneously closing other avenues. Taking an epistemological position is necessary before advancing through the interpretive processes of research. Consider the first stage of data gathering within a methodological approach as recommended by Alvesson and Sköldberg. It is at this point that a researcher makes a decision to engage with strong objectivity. If this decision is not consciously made, I would argue that the researcher, by default, advances with weak objectivity.

The research question itself originates in one's epistemological orientation and is thus saturated with values and beliefs. It immediately speaks to who can know and what knowledge is legitimate. Over my life course I learned much around friendship, disability and youth; yet, I have no direct knowledge about how disabled teens negotiate meaningful friendships. In my professional practice I witnessed the challenges that many

disabled teens face in making and keeping friends. As an aunt I hear about the sometimes tumultuous but consistent friendships of my nieces and nephews. As someone who found and kept one good friend since grade 8, I remember how tenuous the line between isolation and belonging can be. Acknowledging my lack of experience and knowledge about the intersection of disability, youth, and friendship disrupts the expectation of researcher expertise. Starting from this point of vulnerability, of not knowing, creates an opportunity for inquiry to begin from the position and interests of disabled youth. The study explored the question: *How is friendship understood and experienced by disabled youth?* This question presumes that friendship is important to disabled teens; however, it does not suggest the form(s) or meaning(s) of friendship. Related questions include: What constitutes meaningful friendship from the viewpoint of disabled youth? How do disabled youth and their friends negotiate their relationship over time? What is the context within which these friendships develop? How does that context influence friendship?

Using ethnographic case studies (Emerson, Fretz, & Shaw 1995; Hammersley & Atkinson,1995) that begin in the lives of youth with disabilities fits well with these research questions. Strong objectivity and situated knowledges counter the colonial history of this research methodology. An ethnography informed by Harding, Haraway and Alvesson and Sköldberg respects youth as a distinct culture within society while simultaneously acknowledging the experience of stigma among youth with disabilities. Data collection began by asking youth to represent their experiences of friendship with photographs. Interviews then opened with their perspectives on and interpretations of these images.

Alvesson and Sköldberg (2000) encourage the researcher to explore the underlying meanings of the data using instructive theoretical positions. It takes constant vigilance and willingness to be vulnerable to persistently question the theoretical positions we consciously and not-so-consciously bring to research (Tregaskis & Goodley, 2005). This process was guided by asking what ableist assumptions might be present in my text? How well does the analysis stay with the experiences of the teens? Whose understandings and interpretations are privileged in the analysis?

Critical interpretation, the third element of Alvesson and Sköldberg's work, focuses on thinking through the data using multiple theoretical frames. While Alvesson and

Sköldberg (2000) suggest that critical interpretation moves the analysis further from the original statements and observations, I remained closely in touch with disabled youths' accounts while exploring theoretical perspectives; working back and forth between them. For example, after several weeks of intensive analysis a concept map (Appendix A) was developed outlining how disabled youth established enduring friendships. It incorporated elements of ethnographic analysis, interpretations of how power was exercised, and simultaneously attended to structures that shaped the friendships of disabled teens. I then returned to each account of friendship in the study, revising the map to ensure that it reflected the experiences of all the participants. It was possible to engage in this third interpretive process as described by Alvesson and Sköldberg without expecting to resolve the tensions that inevitably arose when using multiple interpretive processes. Instead, all of these elements were incorporated into the concept map.

To continue from the perspective of disabled youth in this third phase, I drew from the writings of critical disability scholars. For example, Davis and Watson (2001, 2002) note the absence of the voices of disabled children in a body of literature that privileges health professionals, educators, parents and policy makers. They contend that this is an indication of how society views the lives of disabled youth: as a problem to be eradicated or assimilated. Their work challenges the ableist assumptions embedded in my health professional background and the historical baggage that accompanies it. Priestley (1998) also highlights the importance of the situated knowledge of disabled teens. He is concerned that the cultural quest for health, autonomy and beauty exclude disabled teens from youth culture. Priestley's work prompted me to consider the messages that shape the experiences of disabled youth. These disability scholars constantly reminded me to stay with the teens' understandings as theory is constructed in the research process. For example, when reviewing a government policy Davis and Watson might ask: Whose voice is represented in this text? Were disabled teens consulted? If so, how were their stories included? Who is missing? How is the 'problem' of disability framed in the text? Who does disability belong to? In the same text Priestley might wonder how the policy shapes the experiences of disabled youth. What are the unintended consequences of this document? How is the text understood by disabled teens? How does this differ from how adults enact the policy?

The fourth interpretative process recommended by Alvesson and Sköldberg (2000) weaves in a critical exploration of authority and the ethics of representation, from data

collection through to construction of the final text. Alvesson and Sköldberg believe that engaging with/in the multiple interpretive dimensions works toward addressing this concern. They encourage the researcher to question and explore her ability to represent the stories of others. Here I reflected on how the participants chose to represent themselves. How did I position myself in terms of the stories told? Rather than ask whose interpretation takes precedence, how did I intertwine both our partial perspectives so as not to fuse our understandings, but allow them to inform and trouble each other? Although power relations are present throughout the research process, they erupt with volcanic force when considering issues of representation, given the permanency and immediate worldwide dispersal of text.

Harding (1991) and Haraway's (1988) work offer landmarks through the treacherous terrain of representation. They do not demand that *only* the voices of disabled youth be acknowledged in the final text; however, I believe they would both agree that the document be presented as a partial perspective, not the whole story of friendship. Our best hope is to provide a situated, relational account that acknowledges what is both lost and made possible in our awkward and fumbling attempts to represent another (Davis,1998; Prout, 2001). Transforming the friendships of disabled teens from embodied, vibrant, engaging, conflicted, joyful experience into two dimensional text continues to be troublesome for me. Having to make choices about which aspects of their stories to tell and which to leave in the background was the source of much uncertainty. One approach used to address this concern involved presenting the three main themes to a group of about 50 parents and young disabled people who attended a workshop session at a local conference. None of those in attendance were participants in the study. This was not done as a member check; rather, it was an opportunity to see if my interpretations made sense to people who had also experienced stigmatization. They overwhelmingly supported the content of the findings and reported that the stories were represented in a respectful way. A focus group was not pursued given that it would have completely compromised the anonymity of participants. Those involved in the study told very personal stories. The potential benefit to the analysis for bringing participants together in this public way did not outweigh the risks of this kind of exposure. Additionally, there were ongoing tensions among a few participants that would have been exacerbated had a focus group been attempted. I followed the example of McVilly (2006) in that I did not bring the participants together into a focus group to review the

findings, instead, I presented the three key themes to a group with similar interests and experiences.

Given that written text is not accessible to most participants, writing this dissertation meant having to grapple with leaving participants out of this stage of the research process. This was incredibly uncomfortable. It felt as though I stole their stories and revoked my commitment to accountability in research practice. In an effort to resolve this tension the dissertation is viewed as a preliminary document, one that was written for the academy. The more important works will be published out of the dissertation and will include parallel text that can be enjoyed and critiqued by participants. These publications will be prepared in the spring of 2010. The format and content will be designed in collaboration with disabled youth. Participants from the study will be invited via email to be involved in this process. If they are not interested or available, then other disabled teens will be recruited to assist in the knowledge translation activities.

Weaving together the theories of Harding (1991), Haraway (1988), and Alvesson and Sköldberg (2000) creates a conceptual framework that can disrupt ableist assumptions while simultaneously promoting respectful engagement with disabled youth in this study. Alvesson and Sköldberg support the critical reflexivity advocated by Harding, agreeing that this move disrupts traditional beliefs about objectivity, and demands that researchers be more accountable for the positions they hold in their projects. Reflexive methodology creates space for Haraway's diffracted, partial perspectives in the analysis and representation of disabled youth. This conceptual framework guided all aspects of the study, from devising research methods to completing data analysis to representation of research results that flowed from the multiple friendship stories of disabled youth.

3.3   Study Design and Research Methods

The research proposal was approved by the Dalhousie Research Ethics Board in October, 2007. This study was designed to address the primary question: *How is friendship understood and experienced by disabled youth?* A research map is depicted in Appendix B. Ethnography was identified as the research approach most suited to this question. According to Emerson, Fretz, and Shaw (1995) the core elements of an ethnographic study include entering a social environment that is unfamiliar and creating a written record of interactions and observations made. The friendships of disabled

youth certainly met the first criteria. As a nondisabled researcher in my early forties their world was unknown to me. Fieldnotes created a detailed account of my interpretations and experiences, informed by my conceptual framework. Even though these three basic criteria were met, it was clear that the study would not follow a traditional ethnographic path of complete immersion in the daily routines of a culture for an extended period of time (Emerson, Fretz, & Shaw). A traditional ethnographic approach would have been too intrusive, placing a high burden on participants and their families. But how was I to answer the question, one that closely aligned with ethnographic methods?

Engaging in an ethnography guided by the conceptual framework described earlier in this chapter demanded that the research approach itself be carefully scrutinized to address concerns about power relations and about whose stories would be privileged. When critical theory was applied to ethnography it became apparent that the tradional approach of embedding myself in a particular community was not supportable on a number of fronts. First, there was no distinct community of disabled youth *per se* with whom I could live and work for several months. There are numerous diagnosis-specific groups that meet regularly for social events and to provide mutual support; however, in this study I sought to resist medical understandings of disability (Priestley, 1998). Diagnosis is a force that structures the experiences of disabled youth (Connors & Stalker, 2003). The ascription of a medical diagnosis is often part of the stigmatizing process experienced by disabled youth, thus it would have been incommensurable with the conceptual framework to proceed with a diagnosis-specific study. Beyond philosophical concerns about medical diagnosis, social policy mandates that inclusion be understood as the disabled mingling with the nondisabled across social contexts. For example, the educational policy of inclusion typically requires that disabled youth be labeled and then acts to place disabled youth with nondisabled peers. The flip side of this particular coin is that disabled youth are separated from one another, hence a distinct community of disabled youth is not readily formed, and thus was not a viable way to address the research question.

One could argue that despite the efforts to create inclusive education systems, constructed communities of disabled youth continue to exist within the school system – consider learning centres and resource classes attended by many disabled teens in high schools in Nova Scotia. Although most disabled students are assigned to a homeroom class and go there for attendance and morning announcements, students identified as

having high support needs often spend most of the day in a classroom with a designated special education teacher and several Education Program Assistants (EPAs) for the rest of the day. They receive one-on-one or small group instruction based on the learning objectives outlined in their Individualized Program Plan (IPP). These segregated classrooms are not communities that are necessarily freely chosen, thus I did not choose to use the classroom environment as a backdrop for an ethnographic study about friendships. There is also the added complication that students who attend school together can come from a large geographic area in this province. When disabled youth leave school (whether they participate in the learning centre or inclusive classrooms) they may have little contact with their friends. This absence of any 'real' community of disabled youth thus required a reflexive modification of ethnography.

Rather than doing an in-depth foray into a community of disabled youth, this research design allowed me to spend time with several sets of friends from different areas of the province, in different grades who all found ways to negotiate around stigma to create enduring friendships that extended beyond the boundaries of the education system. The immersion was into friendships, rather than communities. Generally speaking, the research design entailed individual interviews, joint interviews with friendship partners, interviews with adult witnesses to the friendships, and observations with the friends during social interactions.

3.3.1   Participants

Purposeful sampling guided the recruitment process, given that particular parameters were predetermined to establish who could participate in the study (Cutcliffe, 2001). Originally I hoped to recruit ten sets of friends that would include primary participants ages 15–19 (five female, five male) from Halifax and Lunenburg counties who identified as experiencing social stigma due to the presence of disability. Upon receiving the first few email replies to the initial round of recruitment it became apparent that many of the disabled youth interested in participating in the study had friends who were also disabled. For the most part, parents initiated contact with me about their children becoming participants. Only one participant contacted me herself after I handed out brochures at a recreational event for disabled teens. My first contact with the remaining 13 participants occurred at the time of reviewing the consent form. In the end there were seven disabled girls, six disabled boys, and one nondisabled male friend who

participated in the study. Six of the seven sets of friends involved two people, one set included two boys and a girl. One disabled teen was part of two different friendships included in the study. Because his two friends were not friends with each other, these were treated as separate sets of friends. The length of friendships ranged from six months to over five years. In four of the friendships, the friends had similar medical diagnoses and abilities, while in the remaining three friendships, the friends had diverse diagnoses and abilities. Participants identified 10 adults to be interviewed as witnesses to the development of their friendship. Most of these adults were mothers, however, two were female education program assistants, one was a male education program assistant and respite worker, and one was a male respite worker.

Most participants were able to engage in verbal discussions about their friendships to ensure that the perspective of disabled youth remained centralized in the study. Few participants explicitly used the word 'stigma' to describe their experience; instead they described experiences where they were treated differently from other youth and attributed this difference to the presence of disability. A number of people indicated an interest in the study, but did not meet the criteria to participate (e.g., out of age range, had no long term friends). The first few disabled youth who met the basic criteria became participants. Ongoing data analysis created a set of theoretical questions that guided decisions about who to specifically recruit as participants. Variation in friendship partners was deliberately sought out. Disabled youth determined who their friends were, instead of the study imposing restrictions on who they could claim as long term friends. This approach also broadened the scope of the research and challenged some of the preliminary interpretations in the analysis. For example, I intentionally included disabled youth whose friend also had a disability, a male/ female set of friends, another whose friend lives outside her neighborhood.

Halifax county was selected to represent urban and suburban experiences of disabled youth. Lunenburg county offered a more rural element to the study. These areas were chosen above other regions of the province since I have established networks in these counties. The rural county was within 1.5 hours of Halifax, thus reducing the burden of transportation. All primary participants were enrolled in high school. Each participant identified at least one longterm friend (secondary participant) who was also willing to participate in this study. No restrictions were imposed on who the youth identified as a

friendship partner (e.g., age, disability status, gender). Tertiary participants included adults who witnessed the friendship evolve over time.

Given that the project was based on the experience of stigma related to disability, rather than on a specific impairment, primary participants were diagnosed with a wide range of medical conditions. This diversity enriched the study and resulted in policy recommendations to promote the well-being of disabled youth without the boundaries of diagnosis limiting how they might be applied. Three participants used alternative or augmentative communication strategies. Extra time was spent with these participants compared to their more verbal counterparts. This time was invested at the outset of the study, after initial consent forms were signed. The preliminary visits with participants who used alternative communication strategies were directed toward establishing a trusting relationship and identifying specific ways that the participant communicated assent/dissent to continued involvement in the study. These included, but were not limited to behavioral expression (e.g., falling asleep, averting gaze, leaving room) and vocalizations of distress or irritation. For disabled teens who struggle with meeting new people, initial reluctance to interact was not interpreted to mean they refused to participate in the study. Rather than assuming what particular behaviors meant, I relied heavily on their friends and on the adults who knew them best to interpret their communication strategies. For example, when one participant left the room during an interview, I asked her mother if this meant she wanted to end the session. Her mother stated that this teen often leaves a room briefly to take a break and will then return to the activity when she is ready. Within a few moments the participant returned and completed the interview.

At the outset of the study, friendship was defined as a reciprocal relationship where each identifies the other as fitting into the 'best friends' category as described by Meyers and her colleagues (1998). These friendships were of at least six months duration between two people who voluntarily spent time together outside of school. This could mean that the friends hung out in person, on the phone, or virtually at least once every two weeks. Paid support staff (unless spending time with the participant outside paid work time) and immediate family members were excluded as friendship partners. The parents, paid support staff or other adults who witnessed the friendship develop were invited by the friends to be involved in the study as tertiary participants.

a)   Recruitment Strategies

Previous work in this province both as a therapist and as a researcher provided access to a substantial pool of potential research participants. Recruitment proceeded through multiple networks including disability support groups, technology resource centers, health professional networks, academic networks, a rural school district, disability listservs and recreation programs. I offered information that introduced me and the study to my contacts and asked that it be passed along to potential participants. Because both my clinical experience and the literature indicated that it would be challenging to find teens who met the inclusion criteria, snowball sampling was used in the early phases of recruitment to maximize the number of people who would receive information about the study. When using this sampling strategy, I specifically asked participants, their parents and teachers to refer me to another disabled youth who also had at least one close friend.

I arranged to meet with individuals, organizations and professionals who expressed an interest in the study to explain the parameters of the proposed study and discuss the time commitment required of potential participants. When someone attending these information sessions was aware of young people who fit the proposed study's inclusion criteria, they were asked to contact these teens to pass along the letter of introduction wherein the teen or parent was invited to contact me. One teen contacted me directly. All other participants initially contacted me via their parents.

The poster advertising the study, provided in Appendix C, was placed with permission in community centres, technology resource centres, disability organizations, and libraries. A more detailed description of the project, written to potential participants, was offered to administrators at each of these locations (Appendix D). A small article was placed in the local paper in Lunenburg County about the study (Appendix E). Potential participants were invited to contact me directly to discuss the project. Alternatively, they could visit the accessible website for the project. This site offered information about me (e.g., photo, work CV, links to websites of committee members) and the project as a whole (e.g., information letter, consent form, and poster). This site was advertised on the research poster, through disability listservs and via my network of contacts around the province. Local disability organizations interested in supporting this study were asked to post a link to my website on their homepages.

Choosing a community focused recruitment strategy limited my access to some disabled youth. I recognize that most friendships start in the school environment; however, at first I did not approach the regional school boards to recruit participants. I chose to stay outside educational institutions since the study concentrated on friendships that extended beyond that environment. About 4 months into recruitment I contacted the rural school board in an effort to boost recruitment in that region. The participants were also limited to disabled youth, or parents of disabled youth, who were willing to initiate contact with me. In this work I was interested in specificity, detail, and the nuances of friendships.

The recruitment process began in January 2008 and continued through September 2008. There was an immediate response to the first round of emails via listservs. This resulted in two sets of friends joining the study. Throughout the winter intensive recruitment efforts were to no avail. Given that recruitment was very slow during this period, the methods were revisited. The time commitment required for participation was reduced in an effort to boost recruitment. By May the next set of friends agreed to get involved in the study. The remaining 4 sets of friends were recruited over the summer. The recruitment strategies outlined above provided access to youth with a diverse range of positive friendship experiences. In total 7 sets of friends participated in the study. The decision to end recruitment was made in consultation with my doctoral supervisor. We were guided by the following question, was there sufficient information upon which to confidently make knowledge claim(s)? We reviewed the data collected with careful attention to both the breadth and depth of the friendship experiences included. The quality of the interviews, depth of the participant observation sessions, and the preliminary data analysis (in the form of newsletters about each set of friends) demonstrated that the stories of friendship brought forward by participants were varied and nuanced. These newsletters are not included as appendices to the dissertation since they could readily be used to identify particular participants. They were used for internal communication with my committee only.

b)   Consent and Assent

Everyone who expressed interest in this study was provided with the introductory letter (Appendix D). For those who required alternative formats, arrangements were made to enable potential participants to review the information letter. For example, someone read

the letter to the interested party or an electronic copy of the letter was available to access using screen reading software. I arranged to meet with each potential participant and his/her parent/guardian at their preferred location once they reviewed the information letter. At this first meeting we discussed the purpose, process and time commitment involved in this project. The participant(s) were then asked to sign the appropriate consent form as described below. At the beginning of each interaction (e.g. interview, observation) I reviewed the purpose of the meeting and the rights of the participants, including the right to stop participating at any time during the data gathering process. Participants could withdraw consent for me to use quotations from interviews, audio, or digital images until the first full draft of the dissertation was prepared.

c)   Primary Participants

Four participants were able to understand and sign the consent form; however, others required proxy consent signed by a parent or guardian. Primary participants who were not identified as experiencing a cognitive impairment were provided with the information letter to review. They were then asked to sign a consent form before participating in the study (Appendix F). The decision of a disabled youth to participate in research necessarily involved family members or carers in many ways (e.g., scheduling, providing communication support, transportation, and emotional support); therefore, including families in the assent/consent process was critical. Parents of these participants were asked to sign an acknowledgement that they understood the youth was involved in the proposed study (Appendix G). In the initial meeting I facilitated a discussion with the primary participant and the parent about the strategies the participant uses to communicate discomfort or dissent. These individual strategies were recorded carefully and referred to throughout the project. Some individual sessions ended after a brief interaction based on participants indicating they did not want to continue at that time; however, no participants completely withdrew from the study.

d)   Secondary Participants

The friends identified by the primary participant were referred to as secondary participants. Since all but one friend also identified as experiencing disability and all friends spent equal time engaged in research activities, their contribution was comparable to the primary participants. These individuals were asked to contact me via the primary participant. Once they initiated contact, the same process of consent/assent

was followed as described above (Appendices C & E). In one case the secondary participant was an emancipated minor; therefore, parents were not asked to sign the acknowledgement form (Appendix G).

e)   Tertiary Participants

The friends were all asked to identify an adult who witnessed their friendship develop over time. This could include a parent, support staff, therapist, teacher, coach, or an educational assistant. Once the friends agreed on who the tertiary participant would be, that individual was contacted for an interview. Because this interview happened near the end of the study, I already had relationships with all of the adults identified by the teens, so I was able to approach the adult myself to discuss their potential involvement in the study. Everyone approached as a tertiary participant agreed to be interviewed. Each adult signed the tertiary participant consent form before the interview proceeded (Appendix H).

3.3.2   Research Methods

The purpose of this project was to create a thick description and multidimensional analysis of the friendships of disabled youth from their perspectives (Rock, 2001). Bloor (2001) notes that ethnographic methodology hinges on the relationship that evolves between researcher and participants. To this end multiple data collection methods were employed over a period lasting between 2 days and 6 months depending on the preference of the friends or imposed timelines: interviews (joint and individual), observation, and fieldnotes. The purpose of these methods are each described in turn. Most interviews were audiotaped if participants used speech as their preferred method of communication. One participant requested that his interview not be recorded; therefore, notes were taken during the session and details were filled in immediately following the interview. One of the three participants who used alternative communication strategies opted to participate in an interview that drew heavily on images of the friends and included someone who was very familiar with her communication style to act as an interpreter. The other two participants who employed alternative approaches to communication were not comfortable with any type of interview format. In these situations, in lieu of an interview, I opted to increase the time spent in participant observation to be able to get a sense of how they understood and

engaged in their friendships. My observations were then reviewed with an adult who knew these participants well to review my interpretations.

A summary of research activities is presented as Appendix I. Two sets of friends agreed to complete all the research activities laid out in the original research proposal (Jay and Brandon; Emma and Lauren). This included two joint interviews, two individual interviews with the primary participant, one individual interview with the friend, at least one interview with an adult witness to the friendship, and two participant observation sessions for a total of at least eight contacts with the researcher. Five sets of friends were recruited after the methods were condensed. Participants in three of these sets of friends completed individual interviews, one joint interview, at least one adult interview, and at least one participant observation session for a minimum of five contacts with the researcher over the course of the study. The remaining two sets of friends (Jared and Timothy; Jared and Gavin) included at least one participant who could not be interviewed directly, thus extensive periods of time were committed to participant observation (approximately 25 hours) in addition to two adult interviews and one individual interview with the friend. Because Jared, Timothy, and Gavin were all involved in the same summer camp the 25 hours was spent simultaneously with all three participants involved in these two distinct friendships. Table 1 summarizes basic information about each set of friends, including an estimate of the time spent engaged in research related activities.

Table 1

Description of Friendship Pairs

Friends	Age	Sex	Disability status	Time as Friends	Region	Time Shared with Researcher
Jay	19	Male	disabled	6 years	urban	14 hours
Brandon	20	Male	disabled		urban	
Emma	17	Female	disabled	5 years	urban	10.5 hours
Lauren	18	Female	disabled		urban	
Amanda	15	Female	disabled	1 year	suburban	7 hours
Rachel	16	Female	disabled		rural	

Table 1 (continued)

Friends	Age	Sex	Disability status	Time as Friends	Region	Time Shared with Researcher
Jared	18	Male	disabled	4 years	suburban	25 hours
Timothy	18	Male	nondisabled		suburban	
Jared	18	Male	disabled	3 years	suburban	25 hours
Gavin	17	Male	disabled		suburban	
Jesse	17	Male	disabled	3 years	suburban	
Sean	17	Male	disabled		suburban	9 hours
Alexandra	18	Female	disabled		suburban	
Sabrina	16	Female	disabled	6 months	rural	8 hours
Cassidy	16	Female	disabled		rural	

All together 46 research contacts were included in the data set. This included eight joint interviews with friends, 13 individual interviews with disabled youth, one interview with a nondisabled friend, 14 participant observation sessions each lasting from two to nine hours, and 10 interviews with adults who witnessed the development of the friendships over time.

a)   *Joint Interviews*

The first two sets of friends agreed to participate in the full version of the study even when they were given the option of reducing the number of interviews and observation sessions. These two friendship pairs completed two joint interviews, one at the outset of the study and one six months into the study. One participant could only tolerate having a few questions asked at one time, and the joint interview was completed over two sessions. Two participants were not able to be involved in a verbal interview. The remaining 2 sets of friends completed one joint interview. The purpose of the first interview was to develop a broad understanding of the friendship; how it was interpreted and experienced by the friends. Locations for interviews were determined by the participants. They chose to meet at their homes, convenient community locations, or at my office at Dalhousie University. These interviews generally followed the guide presented in Appendix J and were audiotaped with the participants' consent, and later transcribed. Participants were asked to collect several photos taken when they have

been together and bring those along to the first joint interview. These images were used as a starting point for the conversation. The initial probe involved inquiring about the photos. This was followed with more questions about how the friends met and what they enjoyed doing together. In a few situations photos were not available. These interviews all took place after an initial participant observation session; therefore we had a recent activity to draw on as the starting point for the interview.

The second joint interview, completed by two sets of friends, took place near the end of the study at a location selected by participants (Appendix K). This interview focused on the overall account of the friendship that evolved through the course of the study. Originally participants were given the option of preparing some kind of representation of their friendship to discuss during this session (e.g. musical montage, slide show, poem, painting, collage of momentos from a favorite activity); however, it became apparent that this was too time intensive and placed too great a burden on participants and their parents. Instead, we reviewed the information gathered over the course of the study about their friendship. Questions were asked to clarify particular aspects of their friendship to add more depth to the account of friendship compiled to that point in the study via interviews and observation sessions.

b)   Individual Interviews with Youth

Recognizing that we respond differently across situations and time, participants and friends were interviewed separately over the course of the study to further discuss the dynamics of the friendship (Fontana & Frey, 2005; Holstein & Gubrium, 2003; Kvale, 1996). All the friends were interviewed separately once with the exception of the primary participant from the first two sets of friends who engaged in two individual interviews each. During the first individual interview, conducted within the first 2 months of the study, the focus was on deepening the friendship narrative that was offered in the first joint interview. The interview guide, presented in Appendix L, was used for both friends. Participants were asked about the history of their friendship in terms of how it began, what strengthened the connection and who supported the friendship. They were also asked to compare this friendship history to others they had. This process was facilitated by having participants map out all their friendships using a diagram (Appendix M).

The second individual interview, completed only with disabled youth from the first two pairs of friends, took place about six months into the project (Appendix N). This interview

concentrated on friendship sustainability. We talked about similarities and differences among their various friendships. Participants were then asked what made the friendship at the heart of the study last.

c)   *Interview with Adult Witness*

Interviews were arranged with people who observed the evolution of the friendship such as parents, guardians, support staff, recreation coordinators. The interview guide is available in Appendix O. This person was recommended by the friends as someone who was around to see the friendship develop. Interviews with adults were scheduled after the teens had time to express their perspectives in this project, giving primacy to the knowledge of the youth. I was not concerned about how closely aligned the adult and youth accounts of friendship were. The alternative perspective available from the adults was sought out to add another dimension to the analysis, another partial perspective, not as a method of triangulation. This aspect of the study was included in the introductory letter that was provided to potential participants and their families and was defined in the time commitment required of participants. Interviews were audiotaped and transcribed.

For four of the sets of friends I interviewed two adult witnesses each. In two friendship pairs the teens were not able to agree on a single person for me to interview. When it became clear that they would not reach a compromise I suggested that both adults be inteviewed. The other two situations where two adults were interviewed involved disabled teens who were not able to participate in an individual interview due to the intense stress such an interaction would create for them. Rather than proxy interviews, these conversations were used as a time to talk through the participant observation sessions. It was a wonderful opportunity to talk to adults who knew these participants well and were able to explain some of the behaviors and interactions observed. They did not speak for these disabled teens; however, the adults interviewed were able to read the subtle communication signals with great precision. They were highly skilled interpreters who offered insight into how these participants understood the social world, and particularly their friendships.

The ethnographic interview is considered to be a co-construction involving interviewer and participant (Sherman Heyl, 2001). To respect this collaboration all participants were given the opportunity to review their transcript(s) once all identifying information was removed. No copies were requested by participants, so transcripts were reviewed once

by the researcher then entered into Atlas.ti. One set of friends asked for and were provided with an audio copy of their first joint interview because they found the whole conversation very entertaining and wanted to listen back to their jokes. Interviews are not the only (or sometimes even the primary) source of ethnographic data. Participant observation offered another avenue for including the subjugated knowledge of disabled youth, especially from those who experience cognitive and language impairments (James, 2001; Lewis & Kellett, 2004).

d)   Participant Observation

Two options were offered to all friends around participant observation – in person sessions or digital recordings created by participants. One option involved my spending time with the friends while they engaged in preferred activities where having an adult available was appropriate and felt comfortable for everyone. For example, if the friends often went to movies with adults or out for pizza I might join them in these excursions. A second observational strategy in the fieldwork component of the project focused on activities that the friends participated in together where an adult would not typically join them (e.g., hanging out in community skate park, meeting up with larger group of teens at the mall). A digital recorder was made available to all sets of friends should they choose to record such no-adults interactions; however, no one pursued this option. All participant observation sessions happened in person. No notes were taken during these sessions since I was often fully engaged in the activities (e.g. swimming, watching movies, eating pizza). When the sessions ended I was typically quite fatigued; therefore, I immediately recorded point form notes to jog my memory when I wrote up the full notes within 2 days of the session. When I returned to the jotted notes I first filled in as much detail as possible. When I ran out of descriptive details, I took another sip of coffee and referred to Spradley (1980). His set of queries was used to elicit further detail, adding both more depth and breadth to the fieldnotes. The fieldnotes were then cleaned and entered into Atlas.ti as primary documents.

3.4   Analysis

Analysis was embedded in all dimensions of this project and proceeded as described by Emerson, Fretz, and Shaw (1995). Data analysis began as the first fieldnote was recorded after the first session where I reviewed the introduction letter and consent form with a participant and his mother. In the act of writing that note I began to make

decisions about which parts of the interaction I would record and which would be allowed to fade into the background, eventually disappearing. I was acutely aware that I was already engaged in representing the friendships of disabled youth, enacting the power of the researcher by recording my perspective on the interaction. These fieldnotes were recorded first in point form immediately after each interaction. Within 2 days I returned to those first jottings and filled in as much detail as possible, often referring back to Spradley's (1980) matrix when I needed a new topic to ellicit more in-depth description. His work prompted me to consider space, actors, activities, objects, acts, events, time, goal and feelings as key elements when recording observations. Fieldnotes based on partipant observation sessions were included as primary documents in Atlas.ti along with the transcribed interviews. Fieldnotes based on interviews with participants were considered secondary data; therefore, they were attached to the interview transcript as a memo in the software.

I transcribed all of the interviews. This was not done because of a belief that completing one's own transcription brings the researcher closer to the data. In my experience cleaning the transcripts while simultaneously listening to the interview accomplishes a similar intimacy. While transcribing interviews I listened to basic phrases and attended to how many more minutes I need to finish typing until my next break. Transcription and analysis were two very different cognitive tasks. I chose to do the transcriptions as a cost-saving measure, not because of a commitment to this approach as essential to a strong analysis.

Given that a great deal of the complexity of an interview is lost in the process of transcription, I simultaneously reviewed both the written text and audiofile of each interview as I proceeded with the preliminary ethnographic analysis. This involved reviewing each interview and the fieldnotes from interviews and observations several times. When all the interactions were completed with a set of friends and all of the transcription was complete I listened and simultaneously read back through all the data brought forward by participants. At that point I developed a memo, in the form of a newsletter to summarize the key elements from each friendship. Because these memos were still quite close to the data and described particular sets of friends, certain participants could be identifiable. Thus, they were only sent to my doctoral committee as a mechanism for keeping members up to date as I progressed through this stage of analysis.

There was a large volume of data to work with; therefore, Atlas.ti was used to help manage and support the analysis. Initially open coding was employed with 4 transcripts, reflecting the key ideas presented in each segment of the document. These segments sometimes consisted of a single line but on other occasions included entire paragraphs, depending on the content and meaning conveyed. This approach generated the initial code list and a series of broad early themes (e.g. disrupting normative expectations, marginalized mentors, paradox of experiencing inclusion in an exclusive group, conflict in friendship, caring and invisible reciprocity, adult power, disability as a master status). With the conceptual framework ever-present and the memos freshly written, the original research question was revisited with my supervisor to further refine the code list in Atlas.ti. Through a dialogical process we developed a code list that drew from the preliminary analysis while remaining closely aligned with the conceptual framework. Some of the broader codes included: aspects of conflict, adult support, disability organizations, discourse, elements of friendship, friendship development, location (school, home, community), mentorship, Othering, policy, processes of inclusion, processes of exclusion, recreation, resistance, rites of passage, stigma management, technology, and transitions. Elements of the code list shifted slightly as I assigned codes to all of the primary documents; however, the broader codes listed above remained intact. In the end there was a total of 68 codes used to deconstruct the primary documents, so that connections among the friendships of disabled youth could be understood.

After the intensive coding stage was completed I struggled to figure out how to put all of these fragmented accounts of friendship back together in a way that would maintain the integrity of the stories while simultaneously offering a response to the research questions. I created a visual map that incorporated the main themes from the analysis: how inclusion is defined, exclusion, norms, resistance, stigma, and adult support, adult surveillance, developmental processes, and creating safe spaces. Massaging these concepts into a diagram that could speak to thematic analysis that fit onto one page forced me to make difficult decisions about which stories would be brought forward into the dissertation and which would be left for another day (e.g. negotiating conflict in friendship, rites of passage for disabled teens). The visual map was discussed with my supervisor on several occasions. It gradually evolved into three interconnected themes: negotiating around stigma to become friends, adult support and surveillance, and

disrupting oppression. This image, available as Appendix A, proved invaluable in the next stage of analysis.

With a printed version of the thematic diagram close at hand I returned to Atlas.ti. I carefully considered each element of the map and asked, 'which combination of codes would help me think through this aspect of the analysis?' I then used the query tool in Atlas.ti to collect segments of text that were related to the themes. For example, to identify what participants had to say about adult support and surveillance I ran the following single code queries: conflict with adults; conflict with professionals; resisting adult direction; resisting protection. I then looked for combinations of codes that would contribute to my understanding of participants' perspectives on adult surveillance and support: support, community, processes of exclusion; support, community, processes of inclusion; support, disability organizations, processes of exclusion; support, disability organizations, processes of inclusion. Each of these queries was exported and saved as a Word document ranging from 4 to over 60 pages in length.

Every excerpt contained in these documents was carefully reviewed with the ever-present concept map helping maintain the thematic focus. Using an iterative process, the interview segments were gradually clustered based on the main ideas they contained. Returning to the example of adult support, some of the ways that adults were contributing to the friendships of disabled teens included: practical support, dismantling stigma and stereotypes, mentoring. Over a period of several weeks the first drafts of the three themes chapters were developed using this approach. Returning to a close reading of interview segments through this process was informed by the concept map; yet it simultaneoulsy reshaped the map. At one point it became apparent that not only were disabled youth stigmatized, they were in turn stigmatizing other disabled teens, in a process of horizontal hostility. This realization created a shift in the map. The map was thus viewed as a fluid guide, one that could maintain the focus of the analysis, while having the flexibility to respond to new directions as they surfaced.

Data analysis was guided by the conceptual framework, specifically by the reflexive interpretation recommended by Alvesson and Skoldberg (2000). They recommend that a traditional approach to data analysis be followed by moving through the data using other interpretive approaches. They don't envision this as a linear movement, but as a series of processes that can happen together or in response to the developing analysis. The

third element of reflexive interpretation, attending to the power relations within aspects of the analysis, informed the development of the second theme – adult support and surveillance. This aspect of reflexive interpretation also prompted me to consider whose stories were given primacy in the analysis. For example, at one point in the analysis it became apparent that the quotes used to demonstrate particular aspects of the analysis were most often coming from adults. This ran counter to the ethical commitment made in the conceptual framework, thus this aspect of the analysis had to be revisited to foreground the stories of disabled youth. My default position as a researcher appeared to be listening to sequentially organized stories that adults learn to construct over a lifetime. The disrupted, partially developed stories told by disabled teens who sometimes used words but often used alternative communication strategies required much closer attention since they challenged the boundaries of what adults tend to identify as a 'good' story.

3.5   Confidentiality and Anonymity

Pseudonyms were either selected by participants or assigned by the researcher. These pseudonyms were used from the initial transcript and will be maintained through to any publication or presentation of their experiences of friendship. If information provided was completely unique to one participant the risks involved were discussed with the participant and their parent/guardian. Unless both signed consent/assent to use information that could reveal the participant's identity, then that identifying information was not used; rather, they were represented in aggregate data and in theory development about friendships and disabled youth.

Individual and joint interviews with disabled teens were offered only to these participants on request. No transcripts from these interviews were given to parents. Parents had the opportunity to review aggregate data once any individual identifiers were removed. For example, summaries of data analysis were offered to all participants.

The importance of confidentiality during joint interviews was highlighted at the outset of each session involving the disabled youth and their friendship partners; however, it is not possible to guarantee confidentiality in this situation. This was described both in the consent/assent form and verbally at the beginning of each of these sessions. It was only

after participants confirmed that they were comfortable with this limitation that the interviews began.

All text-based materials were held in secure storage in my office in the School of Occupational Therapy. The researcher and committee members had access to the data during the course of the study and will continue to do so during knowledge translation in the upcoming months. Identifiers were deleted from digital audio files and text files (e.g. transcripts, fieldnotes, supporting documents). All files were password protected within Atlas.ti on my laptop. Back-up copies of digital information were burned onto an external hard drive and maintained in secure storage as described above. If any participants would like to be involved in the knowledge translation aspects of this research, they will be asked to sign a waiver of confidentiality. This would permit them to be involved in presentations about this study locally and nationally if they choose and if we are able to secure funding for this joint venture. This option will be presented to them at the end of the project when the knowledge translation strategy is more definitive.

Quotations were, and will continue to be, used in publications and presentations of this work. All identifying information was removed and pseudonyms selected by participants were used to protect their privacy. Participants were able to withdraw permission to use direct quotations until the first full draft of the dissertation was complete. One publication went forward before the dissertation was fully developed; therefore, permission to use segments of text was obtained from participants for the first manuscript that was prepared for the Centre of Excellence for Children and Adolescents with Special Needs (Salmon, 2009). This document was based on the preliminary analysis of how recreation was used as a form of resistance by disabled teens. An email message with the draft manuscript attached was sent out to all participants whose quotes were included. Participants were asked to review the quotes. They had one month to ask for their quotes to be removed. If they did not respond to this request for feedback within one month, then it was assumed that they did not want to have the document altered. This was a demanding process for participants, especially those who do not read. It meant that their parents had to sit down and read through the text with them, a task that was not particularly motivating for most participants. It added significant burden to participants and their families. It also potentially compromised the anonymity of the participants since their parents would know without a doubt which pseudonym applied to their child. After reviewing this process, it was determined that no further requests would

be made of participants in this regard. As knowledge translation activities continue, copies of all texts including a research summary, the dissertation, any publications and power point presentations will be made available to all participants as they are produced.

3.6 Financial Information

If participants needed to travel to a selected location, a travel allowance of $15 for gas money was provided to the driver. As compensation for their time and expertise, each participant (disabled youth and friendship partner) was provided with a gift certificate valued at $20 to engage in their preferred activity (e.g. movie theatre, sports complex, technology store, music store, and restaurant). The two sets of friends who went through the long version of data collection each received two gift certificates – one half way through the study and one at the end of their participation to acknowledge their contribution to the project. All other youth involved in the study participated in the shorter version, thus they were each provided with one gift certificate to demonstrate my appreciation for their participation.

3.7 Potential Risks

The greatest risk posed to participants involved discussing the challenges with creating friendships. This may have been emotionally painful given the level of social rejection experienced by many disabled youth. When a participant appeared to be distressed in any way during an interview or observation session by the line of questioning or the activity, I first tried to understand the source of the participant's discomfort either by asking questions of the teen or an adult who knew the youth well (in the case of disabled youth who used alternative communication strategies). If the teen indicated that he or she was uncomfortable, then the topic or activity was quickly changed. For example, during one interview a participant talked about an experience of being bullied by her nondisabled peers. Her body language indicated that this was a very stressful memory to her (e.g. shoulders raised, gaze went toward the floor, hunched forward slightly in the chair). Noting that she looked uncomfortable, I asked if she wanted to change the subject. She thought that was a good idea, so we moved on to a lighter topic. Later that same day I called her mother, who was present for most of this interview, to make sure the participant had no adverse effects from that part of our interview. No harm was reported.

Another example of potential risk was raised by the participation of one of the disabled teens who used alternative communication strategies. He communicated primarily through his behaviors. When he disliked someone he could become quite upset and was known to harm himself or lash out at his support staff. It was well-established that he does not like to be approached by strangers. If anyone spoke to him without his consent, this young man became very distressed. His mother contacted me about this young disabled man and his best friend participating in the study. When she explained the situation to me, we decided that I would simply go and hang out at the summer camp he was attending at the time. If he seemed comfortable with my presence, then we would proceed with a modified approach to the research methods – one that would have no individual or joint interview with this teen. I had no verbal contact with him during the first session nor at any time during his involvement in the study because of the risk involved in such an interaction. This approach appeared to be effective in that the participant demonstrated no signs of stress or discomfort when I participated in activities near him and talked with those around him during multiple participant observation sessions. His mother and support staff all confirmed that my presence was not disruptive; therefore, this teen's unique friendships were included in the study.

Potential risks of participation extended into the friendships themselves. This intensive exploration of friendships could have created conflict in the relationship. Discussing the friendship may have influenced the evolution of the friendship and could have potentially disrupted it. Agreeing to participate in the study could have prompted people to feel that they had to remain in the friendship even if the relationship was no longer working for them. Friendships are fluid. If a friendship were to dissolve before the end of the study, it was decided that an effort would be made to interview both the disabled youth and the friendship partner to understand the decision. This did not become an issue; at the end of data collection, all of the friendships remained intact.

At the outset of this project I held the assumption (perhaps ableist) that friendships were somehow different for disabled teens compared to nondisabled peers. This could potentially be damaging to self-esteem and re-inscribe a disability label. Some participants were keen to identify as disabled in a political, disability rights sense, while others were conscious of the stigmatizing force of disability in their lives and preferred not to discuss disability-related topics. This topic was approached with caution. Like other moments when participants appeared to be uncomfortable described earlier in this

section, if a participant showed any sign of stress or discomfort when discussing the topic of disability, I asked them if they wanted to continue with that topic or to move on to a new question. If they indicated any reluctance to continue with the topic, we moved on. I was not able to identify a strategy outside of participant observation to tap into the issue of disability labels with participants who used alternative communication strategies; therefore this concern did not arise with several participants.

3.8   Potential Benefits

Participation in this study created an opportunity to reflect on what makes friendships work and thus may have provided greater potential for more meaningful friendships in the future for participants and other disabled youth. Engaging in a project that centralizes critical disability theory promotes disability rights awareness. Those who express interest in becoming involved in knowledge translation will be included in that process (e.g. writing brochures, talking with policy makers). This may increase the research capacity of the disability community in Nova Scotia. Adults (except me) are included only peripherally in this work to raise awareness within the disability community of the abilities, insights, and contributions of youth.

3.9   Potential Conflicts of Interest

I have not practiced as an occupational therapist in Nova Scotia for over a decade. I did not recruit any disabled youth with whom I worked in the past. The youngest clients I worked with when practicing here are all now in their early 20s and outside the age range of this study. A close friend has a disabled child in the age range for participation in this study. I was involved in some advocacy work involving this young man. At one point his mother, my friend, approached me about his potential involvement in the study. This possibility was discussed with my supervisor. It was decided that his friendship story could make a valuable contribution to the study without raising ethical concerns given that his mother approached me, indicating no undue influence on my part to pressure participation. His participation was not solicited, nor was my advocacy work payment in kind for his involvement in the study. These were completely separate aspects of our relationship and of my own work.

3.10 Evaluating This Project

Evaluating qualitative research is acknowledged as a crucial aspect of the research process (Lincoln, 1995). How one goes about completing such an assessment is contentious (Seale, 1999). There are numerous checklists available to evaluate qualitative research such as the Critical Appraisal Skills Program (CASP, 2006). Many of these assessment tools were developed within a post-positivist paradigm; therefore, extending these same standards to qualitative research developed within a critical, postmodern, participatory action, or constructivist paradigm is unsupportable (Lather, 2007; Torrance, 2008). Given the range of ontological and epistemological perspectives, it is important to evaluate a project from within its own paradigm of inquiry (Guba & Lincoln, 2005). Although universal criteria cannot be applied to all qualitative projects, Richardson (2000) argued that it is important to maintain high standards in ethnographic research. To this end a set of questions were developed reflecting the commitments to research practice within critical theory raised in the first three chapters of this dissertation. Richardson's (2000) framework guided this reflexive process.

3.10.1 Substantive Contribution

1. How do these findings connect with the experiences of disabled teens not involved in the study?

2. What is the utility of these findings? Can they confidently be used to inform social or educational policy? If so, what kind of recommendations would those be?

3.10.2 Structure

1. Upon reviewing the findings, does anything give cause for alarm? Can any negative consequences for disabled teens (either those in the study or disabled youth more generally) be anticipated as a result of this interpretation of their friendships? Could these findings inadvertently harm disabled youth?

2. Is there sufficient depth and breadth to the account provided with respect to the friendships of disabled teens? What examples from the study support this?

3.10.3 Engagement of Reader

1. Does the text engage a reader at an emotional level? Does it evoke surprise? Anger? Frustration? Hope?

2. Does reading the text inspire new ideas about future directions for research?

3.10.4 Representation

1. In what ways was power between researcher and participants negotiated in this study? Were these efforts adequate given the commitment to accountability?

2. Whose knowledge was privileged in this dissertation?

3. How were the partial/multiple perspectives brought forward into the findings chapters and discussion?

3.10.5 Reflexivity

1. How did the research(er) engage in reflexive practice during data gathering, analysis and representation? Were these measures enough to counter the ableist tendencies of research and interpretation? How might these effects have been further reduced?

2. Did the researcher provide an account of herself that was relevant to the project? In what ways did this 'position statement' help the reader understand the lens through which the research was interpreted?

In Chapter 7 I return to these questions, inviting assessment of this qualitative study.

3.11   Chapter Summary

This study included 14 youths between the ages of 15 and 20 with diverse disabilities who have at least one positive, long term friendship. A reflexive ethnographic approach allowed the researcher to develop a nuanced understanding of the history and shared activities of the successful friendships over a period lasting up to 6 months. Research methods included interviews with friendship partners and witnesses to the friendship history (e.g., parents, support staff, teachers). Using participant observation allowed the researcher to participate with friends in preferred activities. Analysis methods identified

the foundations for initiating and maintaining friendships in a society where stigma is ascribed to disabled youth.

In the next three chapters I present the key findings from the study and discuss the connections with related research. Chapter 4 introduces the friends and maps out how participants negotiated around stigma to create lasting friendships. Adults were an integral part of these friendships. Their work to strike a balance between surveillance and support is discussed in Chapter 5. Transforming stigma through resistance is the topic of the final theme, presented in Chapter 6. In the upcoming chapters all quotes from participants in the current study are italicized to highlight their voices. Quotations drawn from relevant literature are presented in regular font.

CHAPTER 4   NEGOTIATING STIGMA TO CREATE ENDURING FRIENDSHIP

4.1   Introduction(s)

Before presenting how participants negotiated around stigma to create lasting friendships I offer a glimpse into the friendships that informed this study. Writing the series of seven brief summaries posed an ethical challenge – how might these unique relationships be represented in a way that would protect the anonymity of the teens and their families? Nova Scotia has a small population. Many disabled teens and their parents know each other through school, disability organizations, and advocacy work. To address this concern only basic information about the friends is incorporated into the summaries. Each set of friends was sent a draft of their summary for review. It was not possible to contact one family. All other participants or their parents approved the following introductions.

4.1.1   Amanda and Rachel

Most teens in the study met at school or through adult organized recreational activities. Rachel and Amanda's story started in an unusual place—a newsletter! Rachel read an article about Amanda while in the waiting room at her doctor's office and decided that she wanted to meet this girl she had so much in common with. Contact was facilitated through healthcare workers and emails were exchanged. One year later it was still hard to get these two away from MSN. They chatted daily on-line and saw each other every few weeks even though they live more than two hours apart. Music, sports, shopping, Facebook and Tim Horton's figured heavily in making this friendship work.

Amanda was 15 and Rachel was 16 years old. They shared the same medical diagnosis and both grew up with their disabilities. Their mothers described the girls as having similar temperaments as well. Amanda used a wheelchair for community mobility. Rachel used a walker. Amanda was just about to enter high school at the time of this study. Rachel was one year ahead in school. Both girls were struggling to make and keep friends at school at the outset of their friendship. Their mothers were very supportive of this friendship, driving long distances so the girls could spend time together.

4.1.2   Lauren and Emma

This was one of the longest running friendships in the study. Emma and Lauren connected 5 years ago at a point in time when both girls were looking for new friends in junior high. Each had experienced stressful rejection by peers. For Lauren this was in grade three but for Emma it happened in grade seven. They both needed a relationship where they felt accepted and valued.

The girls spent time together very often as part of their school routine and in community-based recreation. They traveled to school together on the accessible bus and shared lunch with several other students in the cafeteria three days each week. Adult-mediated recreation was the primary venue for connecting away from school. They enjoyed basketball, soccer, skating, and especially swimming. 'Traditions' were established around holidays. For example, they went trick-or-treating together every year, exchanged Christmas gifts, and enjoyed the excitement of dressing up for Special Olympics dances.

At the beginning of the study Lauren was 18 years old and Emma was 17. They both grew up with their medical diagnoses. Emma's impairment was stable; Lauren's was less predictable. Lauren was articulate and easily participated in the research interviews. Emma used alternative communication strategies including some sign language, lots of vocalizations, and was very expressive with her body language. Both girls lived in two parent homes about two kilometres apart. Their parents were in frequent contact to organize outings with the girls.

4.1.3   Jay and Brandon

Hip hop dance, movies, videogames, shared jokes, and relentless teasing created the cornerstone for this long lasting friendship. Jay (19 years old) and Brandon (20 years old) both grew up with disability and share the same medical diagnosis. These two guys go way back—to preschool in fact. Although their parents tried to foster a friendship between these guys at different points in time, it wasn't until Jay and Brandon took control of their relationship in grade 7 that a strong connection developed. They have sustained this friendship for over 6 years, through the transition out of high school. Their moms were both committed to helping these friends stay in contact. They lived in the same neighborhood and spent a great deal of time together just hanging out at home.

Conflict was constant in their interactions. They argued about everything from who had the best hair color to whether life was better as a Catholic or as an atheist. Most of these contentious conversations ended with some kind of pithy punch line. The guys then 'just move on.' Dating, women, sex and sexual orientation were endlessly fascinating for Jay and Brandon. This reached a crescendo when Jay was involved in a tumultuous relationship with a young disabled woman. Jealousy ran high, but the guys found a way to work that out as well.

The lines between family and friends were quite blurred in this relationship. Over the years each has become a valued member of the other's family and are invited along to supper, vacations and everything in between. Adult protection played a key role in their lives. The guys resisted this surveillance in many ways—breaking rules, disputing social norms, rapping, and of course through dance. Having graduated from high school Jay and Brandon were waiting for space to open at a vocational training program.

4.1.4   Jared and Timothy

Jared was a charming 19 year old guy who grew up with his disability. He had a great sense of humor and a deep affection for those close to him. It is a high honor for anyone to be counted (literally) as Jared's friend. Jared is a man of few words, but he clearly communicates about whether or not he will accept new people into his personal space. If there are four people in the room and he only says, "one, two, three" then someone, typically the new person, needs to make a quick exit.

The friendship between Jared & Timothy developed gradually. In elementary school Jared briefly zoomed into Timothy's classroom. Later they did high fives in the hallway. In junior high Jared decided Timothy needed to share his seat on the bus. Since then the guys have become close friends. They spend time together at school, at home, and in the community. Their interaction style is playful with Timothy doing lots of verbal imitation to keep Jared happy. One of Jared's favorite things to do is poke Tim in the belly.

This friendship is the only one in the study where one of the partners does not identify as having a disability, although Timothy may have experienced some discrimination earlier in his school career. He skimmed by with his grades and wasn't sure he cared to graduate. Timothy was 18 years old and had returned to high school to complete one

last course in order to graduate. Connecting with Jared offered Timothy wonderful mentors including Jared's Education Program Assistant (EPA). Timothy's network of friends and his future plans were shaped dramatically by this friendship.

4.1.5   Jared and Gavin

While engaging in participant observation with Jared and Timothy at a diagnosis-specific summer camp, I noticed that something quite remarkable appeared to be happening between Jared and Gavin (18 years old). Although Jared typically became distressed when anyone invaded his personal space, he consistently let Gavin sit really close to him, poke him, and put his arm around him. If anyone else approached Jared in a similar way he became extremely upset and would hit himself and scream. He typically accepted Gavin's presence with a smile. This reaction captured my attention, so I shared my impressions with a parent and support staff involved in the camp program. They believed that this was a longstanding friendship – one that did not rely on words.

These friends were one grade apart in school but spent time together outside of school for at least three years. Both of these guys shared the same medical diagnosis. Jared relied primarily on alternative communication strategies. Gavin could talk when he was comfortable with people, but did not like to be asked questions. Rather than doing interviews with these friends, I spent several days with them at camp over a three week period. I also interviewed three adults who knew both guys very well and spent time with them across a variety of settings (e.g., at home, at school, swimming, bowling, eating out at restaurants).

4.1.6   Sabrina and Cassidy

When I met Cassidy and Sabrina they were friends for 6 months, having connected on their first day of high school. Since then they experienced a continuous cycle of conflict and closeness. Their friendship was in the upswing during my visit. These friends have very different temperaments. One is relaxed and outgoing while the other is more emotionally intense. Both girls were 16 years old. I spent three days with them at school in a rural area of the province. I went to classes with them, hung out during lunch, and joined them on a class trip to the swimming pool. Sabrina and Cassidy both grew up with their disabilities. Although neither had a specific medical diagnosis that I was aware of, they were both identified as needing small group learning support by the school system.

The girls lived quite a distance apart in a rural area of the province, so they never saw each other outside of school. These friends are the only ones in the study who use the phone as their primary mode of communication. Most of their face-to-face contact happened at school under almost constant adult supervision. Sabrina was an only child who lived with her mother. Cassidy lived in a blended family with two brothers and two step-siblings all of whom were in their teens.

4.1.7   Jesse, Alexandra and Sean

Jesse, Alexandra, and Sean, the self-titled 'three amigos,' made a unique and exciting contribution to this study for many reasons: (1) three teens were involved in this friendship; (2) this was the only mixed gender set of friends participating (3) Jesse's EPA was the same person all through his school years. Jesse and Sean were 17 while Alexandra was 18. They were all friends for over three years. Disability was understood and explained differently by each friend in this group. Jesse grew up with his disability. He likes life to be predictable. He communicates well when he feels comfortable. Sean described himself as someone with a learning disability; although he only 'comes out' as disabled after his connections with new people are well-established. Alexandra experienced a chronic illness that intermittently causes her to experience disability.

Safety figured heavily in this friendship. Both Sean and Alexandra described experiences of rejection in elementary and junior high school. They both noted that they were drawn to Jesse because they knew he would never be unkind to them. Alexandra and Sean became friends because each of them enjoyed spending lunch times with Jesse. With the support of Jesse's mom and his EPA these friendships gradually extended outside the confines of the school to many community locations. Although all three friends spent time together on a regular basis, there were activities that Alexandra and Jesse did on their own (e.g., playing badminton, going to the animal farm) and times when Sean and Jesse hung out on their own (e.g., watching movies or playing video games at Jesse's home). Alexandra and Sean were Facebook friends. Jesse hoped to get a Facebook account set up as well so that he could more easily stay in touch with his friends outside of school. The friendship was flexible enough to incorporate all these configurations. These friends were confident that their friendship would survive the upcoming transition from high school.

4.2   Meanings of Inclusion

For many disabled teens life both inside and outside of school is characterized by loneliness (Bauminger, Shulman, & Agam 2004; Brown, Higgins, Pierce, Hong, & Thoma, 2003; Heiman, 2000); however, this was not the case for the disabled youth involved in this study. Each participant was engaged in complex, fulfilling friendships that spanned many months or years. In this chapter I present my understanding about how the disabled youth were able to establish these enduring friendships. Tracing the origins of these friendships consistently lead back to the social and educational policy of inclusion, but not in the way one might expect. It wasn't that inclusive education set the stage for these friendships; if anything these friendships formed in spite of practices attributed to inclusive policy. The experiences of participants disrupted idealized versions of inclusion.

The rhetoric of inclusion around disability permeates all public venues in Western society, but it is particularly salient in the education system. Putting this value-based philosophy into practice involves systematically placing a group of diverse learners in the same classroom with the resources needed to make both the curriculum and social connections accessible to everyone (Bunch & Finnegan, 2005). In Canada, each province has a working definition of inclusion to guide classroom practices. The policy from Manitoba Education (2001) is an example of a carefully constructed, thoughtful definition of inclusion:

> We believe inclusive education to be much more of a process than a destination, but that the goal of inclusive education is the achievement of consistently better student outcomes for all students, in all areas (academically, emotionally, socially, and physically) while providing a satisfying and supportive work environment for educators and staff. Inclusion is a way of thinking and acting that permits individuals to feel accepted, valued and secure. An inclusive community evolves constantly to respond to the needs of its members. An inclusive community concerns itself with improving the well-being of each member. Inclusion goes farther than the idea of physical location, it is a value system based on beliefs that promote participation, belonging and interaction (p.23–24).

This definition focuses on inclusion as a process that extends far beyond academic performance by emphasizing the importance of building social connections within a flexible, responsive community. In the ideal version of inclusion, disabled youth are embedded within an egalitarian community where everyone is valued and feels a sense of belonging (MacKay, 2006). In this safe and supportive space friendships form readily

between disabled youth and their nondisabled peers. This imagined trajectory for friendship did not happen for a single participant in the current study. They all arrived at a sense of belonging and friendship, yet it was only after a circuitous route that for most took years to traverse.

To some extent this may be due to inclusion being a vague and controversial term (Ware, 2002). Its meaning shifts dramatically across people, contexts, and time. The research participants presented a wide array of interpretations about the meaning of inclusion. Few teens made explicit comments about inclusion. Perhaps they had not yet reflected on this aspect of their lives. Adults, on the other hand, frequently spoke about this subject. Some felt that inclusion was about academic gains for disabled teens; however, most adults talked about how inclusion provided social benefits to everyone involved, especially disabled youth. For example, the mother of one disabled youth downplayed the academic aspect of inclusion while emphasizing the social value of disabled children and youth being immersed among nondisabled peers.

> *[Inclusion's] not learning about how to do the 10 times table or… how to write a story. Inclusion is about learning how to be a person in the real world, outside your family. How to have a conversation with somebody you're not related to; how to interact… And it takes it up a notch. Because, 'If the other kids can do that, why can't I do that?'*

This mother recognized that inclusion is at its core relational. It was about connecting to other people in a meaningful way. In this interpretation of inclusion, academic tasks form the backdrop against which the process of inclusion happens. Sharing the learning environment can set higher expectations of disabled youth from teachers, parents, and from themselves compared to learning in a segregated site. She seemed to believe that inclusion can be accomplished by first getting disabled and nondisabled people in the same space, then supporting all parties as they learn to connect to one another in meaningful ways. This definition centralized shared experience and relationships, echoing the values underpinning most inclusive policies.

All participants described positive experiences of social and academic inclusion in the first few years of elementary school. Disabled children were part of the classroom community. There were plenty of invitations to spend time with friends on the playground and outside of school. The hopefulness of these early experiences was dramatically disrupted by the emergence of stigma. Based on the accounts of some disabled teens

and many parents in the current study, the difference of disability became evident as soon as disabled and nondisabled youth entered the same environment. For many these interactions happened in daycare, preschool, and kindergarten where the difference of disability was noticed but not devalued. Similarly, Diamond (1996) found that most nondisabled preschoolers who attended inclusive programs were aware of the presence of disability, but did not appear to devalue disability. Dyson (2005) reported comparable findings in her research with nondisabled kindergarteners. Placing people in categories appears to be a strategy to streamline our thinking (Link & Phalen, 2001); hence we place people in a range of categories like male/female, child/adult, short/tall, walk/wheel, verbal/nonverbal. On their own these categories are simply about difference. They are not hierarchical. As discussed in Chapter 2, stigma arises when one aspect of a particular category is favored over the other. According to disabled teens and their parents, stigmatization of disability surfaced within a four year range for disabled youth involved in the study, between grades three and seven.

One mother acknowledged a distinct moment of separation based on difference that occurred at the end of grade three for her son. She felt that this was the point when the intellectual development of nondisabled peers surpassed his cognitive skills, thus making a 'real' friendship unlikely.

> *It wasn't that Brandon had a lot of other friends. He always had– he went to [an accessible elementary school] and kids in the school were very supportive of him, but I found… the summer after grade 3 it's like the kids went to another level. And like he couldn't play the games. He wasn't competitive enough to play the football, to kick the ball around, to play the basketball, or do– So everybody says hello and chit chats, but nobody comes to play. Or nobody – it's a little tousle as you walk by, you know how boys… But you know, that's what guys do, a little friendship tousle, but you know, no real [friendship]. They're nice to him.*

Brandon didn't experience the overt rejection and ridicule other disabled youth were subjected to at this same age; however, he was no longer part of the group. Shared space and kindness was no longer enough to maintain the social connections between Brandon and his nondisabled peers in or out of school.

Another parent described a sequence similar to Brandon's gradual isolation, though it occurred a few years later for her daughter, in grade seven.

> *I think the cognitive, the change in the cognitive level and interests. At that age kids are very involved in themselves and what's important to them and just kind*

of can't see beyond themselves. They were really helpful in elementary school and concerned about others. And then, they all become so central that you know they don't really care about anybody but themselves, so. I think, yeah, that's what happened then. [sighing] So we had to find some new buddies.

Here again, this mother attributes the change in friendships to a developmental shift in cognition. Other parents echoed this experience, noting that inclusion worked very well in the early elementary years then gradually disintegrated. Another mother said, *"The first two years were wonderful because difference wasn't as noticeable. As soon as the difference became noticeable that's when problems began."* Without exception, each participant experienced rejection by nondisabled peers at some point in mid to late elementary school. The difference of disability was there all along, but suddenly it was imbued with negative meanings. Disabled children were no longer recognized as potential friends by the nondisabled peers who inhabited their social lives. What interfered with the inclusion of disability?

One of the core problems with the translation of the idealized policy of inclusion into its practical application is that it does not account for the stigmatization of disability. When the stigma around disability in our society is not explicitly acknowledged in policy then, by default, stigma is likely to be reproduced. This results in disabled youth *sharing space* with nondisabled peers instead of actively participating in *shared experiences* that facilitate belonging and community. When inclusion is defined as shared space it requires almost nothing of nondisabled people beyond physically making room for another body. Granted, this may demand that the physical environment be altered in some way since the disabled person may use a wheelchair or perhaps have an alternative communication system. This does not require the nondisabled to change values and beliefs about disability and disabled people. This chapter focuses on how the experiences of research participants reflect the power of stigma within our society. Analysis indicates that unless policy begins to address stigma, inclusion will continue to be interpreted narrowly as shared space only, thus leading to segregation and social isolation for disabled youth.

4.3   The Power of Normative Demands

As Canadians we identify as being an inclusive society. We imagine ourselves to be 'multicultural' and are proud of our commitment to 'celebrating difference' – that is as long as this difference does not disrupt our fundamental belief systems. But the moment

that difference forces the centre of society to shift, difference is no longer greeted with characteristic warmth and hospitality. It is resisted since it requires that we change the existing norms (Davis, 1995; Snyder & Mitchell, 2006). Hence, stigma remains firmly rooted, separating Us (nondisabled) from Them (disabled). It carries the weight of history, of oppression, of discrimination, and of guilt. Few nondisabled people consider how oppression is reproduced in our daily interactions (Hehir, 2002). Conversations that expose discrimination create discomfort in nondisabled people and are thus typically avoided.

When stigma is not named, and actively challenged, it is inevitably perpetuated. Thus in schools, in communities, and in recreational venues disabled youth are continually faced with something that is unspoken. One participant made a clear connection between discrimination based on race and discrimination based on ability.

> *Like I have a kid in my class who's black… And once… he had to go out of class for something and um [the teacher] said to him, "well you better get going– us white folk need to get back to work"… It's not just me, like it's any kind of 'difference' [using air quotes].*

This participant clearly saw that the thing that separated her from her nondisabled peers was akin to racism, it connected around stigma and discrimination. One mother described a conversation she had with her son, a young disabled man. He noted that racism names the experience of discrimination against people from particular racial or cultural backgrounds, sexism is used to identify discrimination based on gender, ageism names discrimination based on chronological age. After describing all these 'isms' he asked his mother if there was a word to describe the discrimination he constantly faced around his disability. The oppressive force he identified and experienced is ableism.

Ableism is rooted in the widely held belief that one form of embodiment, nondisabled, is superior to another, disabled in this case (Linton, 1998). As discussed earlier, ableism privileges speech over sign language, walking over wheeling, independence over interdependence and care giving over care receiving. Ableism can be overt, but more often is very subtle. It is there every time someone says 'falling on deaf ears,' 'the blind leading the blind,' 'what an idiot,' 'stand up for yourself,' or 'that drives me crazy.' Think about how often disabled people are prompted to 'pass as normal.' Children and youth with autism are required to follow the rules of social engagement, people with visual impairments are encouraged to 'look' at the person speaking to them; many people with

hearing impairments are trained in lip reading. Pressure to identify with the nondisabled denies the 'normalcy' of disability. The implicit message is that being disabled is not acceptable. One disabled teen, Lauren, described a situation at her school where normative expectations quietly resulted in segregation of one of her good friends.

> *We have lunch with all the kids that go to the cafeteria, but um, but some kids are still upstairs eating because they have more dysfunctional and they [can't] eat properly in the cafeteria. Like our friend Joan, we want her to come to the cafeteria, but she makes a lot of mess with her food.*

Joan's meal time routine was determined by adults to be too far outside the norm; therefore, she stayed in a separate space, segregated from both her disabled friends and her nondisabled peers. Lauren wanted Joan to join her in the cafeteria for meals. She did not express any discomfort with Joan's unorthodox approach to eating; however, the adults would not allow Joan to eat in the cafeteria because her eating violated their standards. This clearly demonstrates that adults have the power to determine who enters particular social spaces. Enacting adult and nondisabled power in this way meant that Lauren was unable to spend time with someone she identified as a good friend. It limited the opportunity for both girls to strengthen their friendship. This story reflects Stiker's (1999) core argument that those with impairments are required to 'become', 'return to' or be 'integrated with' normal. If someone in a position of power decides that a disabled teen cannot 'become,' 'return to' or be 'integrated with' normal peers, then segregation seems to be the alternative that is imposed.

The process of stigmatization is embedded in a complex web of power (Link & Phalen, 2001). Only those in more powerful positions can ascribe stigma on the less powerful. In the ability hierarchy it is clear that the dominant nondisabled group has the power to stigmatize disability. Although this happens in multiple ways, one of the most apparent mechanisms for enacting this power is by enforcing normative demands (Davis, 1995). Ability is defined as normal while the difference of disability is stigmatized as abnormal. It seems that until someone overtly breaks a social rule, normative expectations rarely move into the realm of conscious thought. The presence of disability brings the norms of society to the forefront. Norms surround almost every aspect of social life: communication, behavior, intelligence, clothing, body shape and size, and ways of moving through the world. Although society has always been shaped by (and shapes) human behavior through an intricate network of rules and social structures, our

obsession with "normal" as both a concept and a term emerged around 1840 (Davis, 2006). What is 'normal'? Typically normal is defined by what it is not. It is not disabled. Normal has a voice and can be heard; it walks and *maybe* it wheels; it has moments of discomfort but not chronic pain or illness; it sees you; it has a predictable trajectory; it is emotionally stable; it is definitely reasonable and logical (Hehir, 2002). The demand for normalcy constructs the disabled Other (Michalko, 2002). Those who do not fit into the charted territory of normal are labeled as deviant and become stigmatized (Goffman, 1963).

Lauren was a pleasant, shy child who did not meet the normative expectations of her nondisabled peers when she was in elementary school. Her embodied difference was stigmatized by her peers and escalated into violent discrimination followed by a lengthy period of social isolation. Her mother explained:

> *Then grade 3, HOLY COW! The girls grew horns! Oh my gosh! Awful! It was the most god awful year of my entire life… Grade three. First of all, all these things started happening to Lauren… She started developing quite early. Plus she was a year older than the kids. Then she had started seizuring. So it was a traumatic year that way… but the kids grew horns. That's the only thing I can attribute it to, hormones or something… Lauren was picked on maliciously… Girls would corner her in the bathroom and say she stuffed her bra. They were writing things on the bathroom wall about her. She was constantly called this, that, the other thing. It was just an awful time. Every day. And the teacher was doing nothing, absolutely nothing.*

This excerpt demonstrates the power of nondisabled peers over the life of a disabled child. The power differential in this situation moved Lauren from being an included student and friend into social exile. The nondisabled children enacted an extraordinary amount of normative power, while Lauren became a vulnerable and frightened disabled child. When Lauren's mother intervened to address this situation, the power of adults over children came into play. Once the parents of the nondisabled children were informed about this violence the dynamics changed. Then the nondisabled children pushed back, another power play. They refused to interact with Lauren at all, leaving her completely isolated.

This damaging group reaction to the presence of disability became even more evident in junior high for many participants. Groups of teens establish a set of norms that identify who can belong to the group and how group insiders will interact. These norms and the power of group leaders interact to maintain clear boundaries about who belongs. The

story of systematic exclusion by a group of nondisabled peers was emotionally recounted by the mother of another participant. On a class trip her daughter was constantly set aside by girls she had been friends with in school for many months.

> *That's like so sad. If kids have to think that other kids will think badly of them because they have some compassion for somebody that doesn't fit in with the definition of the group, then like that's just so sad to be ruled by, you know. [My older daughter] said, 'The other friends in the group might not let you back into the group as their friend if you deviate from the rules of the group, whatever.' And I'm saying, I said, 'Please tell me that when you were in grade 9 that if you had seen a kid in that position you would have been able to step out of the circle and help.' And she said, 'When I was in grade 9 my, I did not have a position of authority to make those decisions.' And that was a tough pill to swallow.*

This mother believed that in order to be accepted, or to maintain their social status as insiders, teens have to *'fit in with the definition of the group.'* If someone deviates from these norms by demonstrating kindness to an outsider (i.e. disabled youth) then they risk rejection by the group (Berndt, 1982).

Although many participants in this study tried to meet normative demands, they were constantly met with rejection and social isolation, aptly described by this mother.

> *Again, not to say that there aren't nice kids who will acknowledge him in the hall, who will give him a high five and all that…It's not that there isn't a value to that larger community including him, but in a way, I've come round to think that in many ways we have done our kids a disservice through mainstreaming and integration and everything. Because in a way we've isolated them. Like it means that they are the one special needs kid in the class.*

Jay, like all of the other participants in the study, experienced the effects of stigma that led to imposed segregation within shared spaces (i.e. classrooms), and long periods of painful social isolation before finding ways to resist and transform the experience of stigma. Jay described several friendships that faded over the years. He was not sure why his nondisabled elementary school friends no longer spent time with him. He spent much time in a range of leisure activities with nondisabled peers, yet none of these relationships transcended the location of the organized activity. Inclusion, the very policy that was meant to promote a sense of belonging, seemed to have the paradoxical effect of isolating disabled youth amid nondisabled peers.

4.4   Dimensions of Stigma

To better understand how stigma disrupted the experience of inclusion, and thus of friendships, each of the intersecting elements of stigma set out by Link and Phalen (2001) will be considered – labeling, separation, stereotyping, status loss and discrimination. These were not used as *a priori* categories in the analysis; rather, they are employed here as an organizing framework for presenting participants' experiences of stigmatization.

4.4.1   Labeling

Among humans, some degree of difference is apparently acceptable, given that we don't reject everyone who is not like us on some dimension. At some point however, the difference of disability gets labeled as unacceptable. Most disabled youth are labeled early in their lives by health professionals or educators, or psychologists. This administrative process marks difference in a public way and is evident to their friends and classmates as soon as physical or educational accommodations are required (Priestley, Corker, & Watson, 1999). Disabled children undergo multiple standardized tests to compare their performance to normative standards. Those who do not meet these expectations are often labeled abnormal and are referred on to other professionals to address the identified problems. Parents interviewed as part of the current study made reference to volumes of reports written about the disabled youth, labeling them medically or educationally as non-normative. Labeling by professionals goes back to the historical roots of eugenics and segregation in North America and Europe (Stiker, 1999; Davis, 1995; Snyder & Mitchell, 2006; Davis & Watson, 2001).

Norms now permeate our culture. Most of us carefully scrutinize one another to identify any aberrations, and don't hesitate to assign stigmatizing labels. One of the most overt examples of labeling in this study arose in Cassidy's story. She was identified as a visible (racial) minority when she arrived in high school. It seemed that for several weeks the students from the small-town area perceived her difference as exotic and interesting. As soon as it became clear that she also embodied the difference of disability all emerging friendships collapsed. Her Education Program Assistant (EPA) described her perspective on what happened:

EPA: I know when Cassidy first came here she, people were being friends or something, but then it kind of phased out because people realized she was kind of different…

Interviewer: So when she first came was it that they liked her because she was from away?

EPA: I think.

Interviewer: And then recognized that she had a disability and then kind of backed off a bit?

EPA: Mmmhmm.

Interviewer: Ok. That's interesting.

EPA: There was a boy here that took a very good interest into her. But that soon phased out when he realized. Cassidy's a very pretty girl... And this guy is very nice. He's nice to everybody…And I think he realized, 'Oh, this isn't what I think it is' you know. They remained friends and it phased out. And now I don't think they even speak now.

Initially the difference Cassidy embodied was desirable. It was exciting for her peers to connect with the new girl who was from another country. Cassidy was thought to be charming as she learned to speak English. Her eventual transition out of the spotlight could have a variety of explanations. Perhaps her novelty simply wore off. Maybe the boy's romantic interest shifted to someone else. Having witnessed the sequence of events, the EPA believed that once Cassidy was identified as disabled she moved into the category of Other, an Other that is not sought after as a girlfriend, nor as a friend. Eventually she was not even spoken to by the same peers who had so admired her before the label of disability was assigned.

Labeling was often followed by acts of violence directed toward disabled youth. Examples ranged from verbal teasing, to accusations of cheating, to writing obscene messages on bathroom walls, to complete erasure by treating disabled youth as invisible. Sean said he always struggled to be accepted by his nondisabled peers. Like several other participants, Sean was negatively labeled then isolated. This led to his parents pulling him out of one elementary school since he was so distressed by the ongoing rejection.

Interviewer: What was going on for you at that point with other kids.

Sean: Um it wasn't really until like down at [elementary school] I got labeled very easily.

Interviewer: Labeled?

Sean: There was a lot of kids that didn't like me down there – picked on me. That's why I left that school. So I started at the new school. I got a lot of friends there. I went to a new school, no labeling or anything. So they just knew me. I met all kind of friends there. I met friends in junior high and I'm meeting people here now.

Interviewer: Ok. So that's why you changed schools.

Sean: Yeah because I wasn't being accepted there and my needs weren't being fully met either.

Sean's experience of being labeled and stigmatized by his nondisabled peers led his parents to remove him from his elementary school several years earlier. For Sean changing schools offered him the opportunity to start with a fresh slate. This strategy seemed to counter the effects of stigma that characterized his early school years. His label was not carried forward into his new school settings; therefore Sean was able to establish good friendships.

Many disabled teens in the current study viewed the Individual Program Plan (IPP) as a document that marks them as different from their classmates; a document imbued with stigma. Amanda was especially resistant to being on an IPP since it meant she would have different work from her peers. For years she insisted on trying to do the same work as her nondisabled peers even though she had to put in very long hours of homework. She believed that being on an IPP meant that she would be treated differently by her nondisabled classmates. She was right. There was an extended period of time where her nondisabled peers accused Amanda of cheating in math because her IPP allowed her to use a calculator. The IPP marked her as disabled and the curriculum modifications included in the IPP additionally resulted in her being labeled as a 'cheater.' This double stigmatization created more social distance between Amanda and her nondisabled peers, making friendships even more difficult to sustain. Amanda recognized the stigma that being on an IPP would bring – little wonder that she resisted it.

Comparable stories were presented by disabled teens in a study by Doubt and McColl (2003). They described being labeled as less competent by nondisabled peers and were

subsequently verbally teased or physically assaulted. These negative responses to disability were attributed to the inexperience of nondisabled youth; however, when re-interpreted through the lens of stigmatization, these accounts of violence can be understood as part of a much larger social process that marginalizes disabled youth.

4.4.2 Stereotyping

Teens are moody and impulsive – these are perhaps two of the most commonly held stereotypes for people from 13–19 years of age (Bibby, 2001). Perhaps this is true of some, but our deeply held beliefs about typical teens shape our responses to individuals. How often have you casually crossed the street upon noticing a group of teens approaching in the distance? How many teens complain about how ridiculous and restrictive adults are? Likewise, there are clear stereotypes about how disabled teens should behave – dependent, helpless, vulnerable, and appreciative (Priestley, 1998; Davis & Watson, 2001). When disabled teens in the study fit within these stereotypes, nondisabled peers and adults responded quite well. Disabled youth were offered consistent support and encouragement. Cassidy was cheerful, willing to receive assistance from her nondisabled peers and readily acquiesced to adult demands that her flirtatious behavior be abandoned. Her best friend Sabrina was not about to conform to these stereotypes. She did not hesitate to voice her displeasure. When Sabrina was in a bad mood she resembled a rugby player plowing through the halls at school, demanding that people get out of her way. Cassidy was charming and endearing; whereas Sabrina, like many other disabled teens in this study, had no interest in conforming to stereotypes.

Benjamin (2002) presents the stories of two girls who resemble Cassidy and Sabrina. She argues that nondisabled people value the diversity embodied by disabled people who, like Cassidy, acquiesce to stereotypes and quietly allow the nondisabled to care for them. When Sabrina makes her entrance, the rhetoric of 'valuing diversity' suddenly is less palatable. She, along with several other participants in the current study, were so radically different that adults and nondisabled peers viewed them as dangerous and sought to protect themselves and others from the disabled teens. Cassidy's compliance with disability stereotypes meant that helping relationships dominated her social landscape. Sabrina's nonconformist approach led to separation or social distancing from nondisabled peers. Diversity is only valued within a narrow frame (Benjamin, 2002).

Stereotyping was rampant and multi-directional, thus it was not surprising that educational spaces associated with disability were stigmatized. For example, most learning centres in junior high and high schools were riddled with stigma. Disabled teens in the current study did not want to be identified as needing learning support, even when help from learning centre staff could promote academic success. The social price was simply too high. Amanda's mother explained,

> *Amanda herself until this year didn't want to go to learning centre for anything because there was a stigma, even herself, right. A stigma associated with that group. And she did not want to go until this year, the whole grade 9, kids who weren't in band had to go there anyway for a study period, so then it was just a regular classroom after that. But up until then there was, when she was younger yes, but after a while she noticed the kids were attaching a stigma with this group and she did not want to have anything to do with it herself.*

Amanda, like her nondisabled peers, stereotyped students who access support from the learning centre. They were discredited (Goffman, 1963). Students who went to the learning centre were discredited as not being smart enough to work independently. They are thus stereotyped as the weaker, less intellectually able. This practice of disabled teens stereotyping one another was evident in a study by Curtin and Clarke (2005). A disabled participant from that study described how he stereotyped his disabled classmates.

> In my class there were five [disabled children] who sat on my table. They were all "brain damaged"… I didn't like being on the table with the other disabled children. It was uncool and I hated it because I was showing myself up every day…. When I was in the playground I played with undisabled children. I would have been really angry if they had made me stay with the other disabled children (p. 204).

Like Amanda in the current study, this boy in Curtin and Clarke's study recognized that sharing a space with disabled students identified him in the same way. He did not want to be stereotyped as "brain damaged" and "uncool." He had no intention of being "shown up" in such a way. He therefore acted to distance himself from the other disabled youth, clearly directing his social energy toward making friends with nondisabled classmates.

4.4.3   Separation

Stigmatization of disability creates a pronounced division between Us, nondisabled, and Them, disabled (Link & Phalen, 2001). Elementary years were difficult for a number of participants, while for others junior high was a particularly difficult window of time for

initiating or maintaining friendship connections. One participant briefly mentioned her experience of being rejected by her peers during junior high. An EPA expanded on her story.

> *She was teased a lot because she was a little bit slower maybe. Yeah. There were some girls that were pretty mean to her through the internet sources and at school. And so that first year at junior high was really difficult and it continued although she gradually found a safer place to be. And when she got here to the high school it's like it stopped. It was like a junior high thing and when they got to high school it's like they grew up [laughing] and they had other interests and they didn't have to make Alexandra feel bad in order to make themselves feel good. So she had a difficult time. And I think a little bit of her difficulty would have been she was trying to fit into groups that really weren't suited for her. And so people she was trying to fit in with really weren't accepting. So they might have felt like, enough's enough, but weren't skilled enough to know how to go about it.*

Being labeled as different by Alexandra's nondisabled peers was followed by distancing. No matter how much effort she put into connecting with them, they consistently distanced themselves, leaving Alexandra isolated and friendless in junior high. Green and colleagues (2005) brought forward the experiences of several disabled participants that echoed Alexandra's. One person in that study said,

> I was the only disabled student in a student body of 1,000 people, so there I stuck out even more like a sore thumb… even the ones I knew from church were standoffish… nobody ever talked to me unless they had to and I was too shy to initiate conversations with them. So I was completely ignored and that's painful (p. 205).

Separation was initiated by the more powerful actors, the nondisabled. Alexandra and the participant from Green's study both wanted to be included, but were set aside by their nondisabled peers. Social distancing is an effective, though subtle tool. Those who are distanced, the disabled youth, cannot claim overt discrimination (Green et al.), yet the pain of being left out is very real.

Separation did not happen only between those designated as nondisabled and disabled. There were also clear distinctions made within a perceived hierarchy of impairments among disabled youth. According to Priestley, Corker and Watson (1999) how impairments are relatively situated in this hierarchy depends upon the perspective of the person in charge of constructing it. One participant in their study stated, "there's a lot more things that could be a lot worse than dyslexia, now I could have been disabled in a wheelchair" (p.93). Another participant in the same project felt that people who walk are

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higher up on the hierarchy than wheelchair users. In the current study, these hierarchical relationships were also constructed among forms of impairment, with walking being 'better' than wheeling. It was apparent in the documentary film *Murderball* (2005), that wheelchair users have substantially higher status than people with intellectual disabilities. In the current study differences in communication approaches were raised as a primary concern for one parent. She wondered if the social distance created by alternative approaches to communication would become too difficult to negotiate over time.

> *I knew [daughter's best friend] was nonverbal so I was always worried [about] How do you deal? well I, because I can't understand her. I don't know any of the signs and stuff. And I was always worried you know, what if she needs to use the bathroom and I don't know?*

This mother felt her daughter was more able than her best friend because the daughter could communicate verbally. This social distancing is another element of stigma according to Link and Phalen (2001). If one girl could speak and the other used signs and body language, how could they have an authentic, balanced friendship? This concern appears to have been mitigated by the strong affinity these girls have for one another. They found ways to understand and appreciate each other that transcend normative reliance on verbal communication. This took a great deal of effort and a willingness to learn an alternative communication style (mother and daughter), and patience on the best friend's part to wait for others to gradually get to know how she expresses herself.

Separation can happen in many ways. Most commonly it is initiated by nondisabled peers as they distance themselves from the stigmatized disabled youth. The social distance between Rachel and her nondisabled friends erupted as she moved through grade eight. Her mother described the transition:

> *In elementary school she had two or three really close friends. One really close friend who was at our house a lot. And they were back and forth at each other's houses. Really were together. Did all the things that elementary kids do. And then she got into junior high and they were still together a lot, but as, I think the separation probably was around grade 8… just gradually they grew apart. All her friends were going places. They were walking over town. They were doing things that she just wasn't able to do easily and she really got left behind. And it was very lonesome, very, very lonesome.*

At first it seemed that Rachel's physical impairment got in the way of sustaining her friendships. Like some participants in the study by Doubt and McColl (2003), Rachel found it difficult to physically keep up with her nondisabled peers. Rachel's friends also wanted to hang out in places that were not readily accessible to her, resulting in social separation. As the interviews progressed it became apparent that, to some extent, Rachel engaged in pre-emptive distancing from her nondisabled friends. Rachel appeared to recognize her social status was already in jeopardy because of her disability. She then chose not to divulge personal information to avoid further stigmatization. This seemed to have the effect of further isolating her, though in some ways it protected her sense of personal dignity. Her mother reflected on this choice:

> *There's a lot of partying going on and she hears all the stories on Monday when she would get back to school. 'So and so's out partying. So and so did this.' They all get together. They have girls' night out parties. And sleepovers. And she was just never included in those anymore. And of course when you get back to school on Monday and hear all that, you feel bad… She, I don't think it bothers her anymore. I think she's hardened to it.*

What an incredibly difficult decision to make. Rachel was uncertain about how her nondisabled peers would respond to her physical impairment, thus she withheld personal information. She had impairments of bodily function that would have caused her embarrassment with peers. Telling her nondisabled peers about how her body worked would have risked even further isolation. In the transition into junior high she had lost the out-of-school connections with nondisabled peers. Perhaps the tenuous in-school connections would also be lost. Rachel could not afford to risk further separation from her nondisabled peers, especially since she was the only physically disabled teen in her school. Reflecting again on the work of Doubt and McColl (2003), disabled teens indicated that they refrained from particular activities because they were concerned about further social separation. One disabled girl in that study said, "I substituted (physical education) for another class… I would have liked it but I also would have felt really different because they would have to change things so I could do them" (p. 144). Like Rachel, this girl appeared to weigh out the risk involved in participating and felt it wasn't worth the potential cost of further separation from her nondisabled peers because she was 'really different.'

One participant in the current study identified a moment where she felt particularly stigmatized because she used a mobility device. "*Like I said, like being included – might*

feel a bit like an outcast kind of, like especially in school if they don't know. Or just walking in a crowd and people staring at you as you're walking down the hall." This reference to feeling like an 'outcast' indicates a dramatic form of stigmatization – one that hearkens back to the institutional era around disability – where those who embodied difference were designated an unacceptable Other and removed from the community (Snyder & Mitchell, 2006). Here the casting out is less tangible, yet clear enough to be noticed and felt. This young woman found the stares of strangers conveyed clear messages of not belonging. Carnevale (2007) reported that children requiring mechanical ventilation at home experienced unwelcoming and unwelcomed stares because they didn't fit into normative expectations as they breathe and move through the world via specialized equipment. For participants in Carnevale's study, staring was equated directly with separation, with being discredited in Goffman's (1963) terms. Yet Shakespeare (2006) described his personal experience of being on the receiving end of stares. He wrote,

> I have restricted growth. This is a very visible impairment, but it is comparatively minor. The main effect in daily life is that people stare at me. This is because the vast majority of people do not have restricted growth and are unfamiliar with people with restricted growth. For them, and particularly for children, dwarfs are fascinating. Education can reduce but will never eliminate this natural curiosity. Therefore, I will always be stared at. This is not pleasant, even if people are not actually hostile. I cannot escape the awareness of my abnormal embodiment, however much I am happy and successful as an individual. But I do not think these reactions can easily be explained away as oppression (p.63).

It is agreed that staring is not always about oppression; however, the relationship between ability and disability during the act of staring is much more complex than can be accounted for by mere curiosity. Thomson (2002) argued that the act of staring by the nondisabled establishes the disabled body as fundamentally different. This act "creates an awkward partnership that estranges and discomforts both the viewer and the viewed… even supposedly invisible disabilities always threaten to disclose some stigma, however subtle, that disrupts the social order by its presence" (p.57). Whatever the root cause of the stare, the act of nondisabled people staring at disabled people effectively establishes a separation, and thus contributes to ascribing stigma to disability.

Several participants described another separation that seemed to take place in the transition from junior high to high school. Most of the adults attributed this change to maturity on the part of nondisabled teens. One EPA said, "*Especially when you get to*

junior high and then to high school, there are different things to take your interests. You branch out." This branching out meant leaving particular friends behind and establishing new friendships with people who shared the same passion. This can lead to unintended exclusion, where a change of interest could mean that friends who spent a lot of time together around a particular recreational pursuit gradually lose touch. At the same time, this 'branching out' can also be a more subtle form of social distancing. In high school it seemed that nondisabled peers returned to a kind, almost compassionate style of interaction with disabled youth. For many participants nondisabled peers shifted back into the 'helping' forms of friendship that were ubiquitous in elementary school. In this mode, while connection is maintained, it is a truncated connection, one that positions the disabled youth as lesser, not a full participant in friendship, always a recipient of charity. A long time EPA offered this analysis,

> *When they're younger and they're in lower elementary, they're included no matter what. I have seen kids from primary all the way through grade 12. And I have seen as they get older when they [nondisabled] break away, they break away from the ones with disabilities. Kind of outgrow. It's not that they're not accepting, but it's the peer pressure I think. You know, and the ones that have had good friendship with the ones with disabilities are sort of left alone. But I don't know how that affects them or if they realize it. But they're just sort of left out.*

Disabled youth are not choosing to be apart from their nondisabled peers, they are actively 'left out.' The reference to nondisabled teens 'outgrowing' disabled youth was echoed by parents and disabled participants. This EPA briefly mentions the 'peer pressure' experienced by nondisabled teens to distance disabled Others. If nondisabled peers don't engage in this distancing, they run the risk of being separated from the peer group as well. One disabled teen described nondisabled friends from elementary school passing him in the hall and saying, "*Yo! What's up dog?"* There was acknowledgement, but nothing beyond a greeting. This subtle distancing was not lost on the disabled teens. Meyer (2001) described a comparable experience for a participant from the five year study she was involved in around the friendships of disabled children and youth in the US. A boy identified as 'severely disabled,' was greeted by many nondisabled peers in the hallway and many people offered to help him by pushing his wheelchair to his next destination, but no one ever really talked to him. Although he was acknowledged, the social distance between him and his peers was imagined to be so vast that no good friendships ever formed for him.

In the current study, adults tended to speak about this distancing as a process of exclusion, as one without a negative intent, yet disabled teens understood it as having discriminatory undertones. During one interview Jay described a friendship he valued from elementary school, noting that he rarely interacts with this nondisabled guy any more. When asked what he thought changed about their friendship, Jay said, *"I guess he just grew up."* But is Jay not growing up as well? The discourse that uses development and diverging interests seemed to thinly veil the underlying social process of separation based on the difference of (and stigma attached to) disability. Jay did not choose to end the friendship, but was instead left behind by someone who was able to "*grow up*." Jay, because of the presence of disability, was separated from those who grow up. He remains somehow forever childlike. Consider the tasks adolescents must accomplish to move into adulthood as laid out by Marn and Koch (1999): establish individual autonomy, construct a viable social network, refine social skills, establish an identity including a sexual role, take on greater responsibility, make preliminary decisions about what to do for work. Jay was doing all of these things, yet like many disabled youth, he was not framed as someone who could grow up – at least not grow up 'normal.' The range of ways of growing up was not recognized, thus nondisabled peers distanced themselves from Jay, terminating their friendships.

The social distancing of disabled by nondisabled teens in high school is also influenced by administrative structures (Bunch & Valeo, 2004). Most of the disabled teens in this study attended segregated classes for at least part of their day in high school. When they were in classes with nondisabled peers, disabled teens were typically accompanied by an EPA for learning support. Few opportunities for connecting with nondisabled peers – especially unaccompanied by an adult – were identified by participants. In a focus group from Meyer's (2001) study, nondisabled peers said that one of the main reasons disabled students had few friends was because they were rarely around. There were few opportunities to get to know them. Since initiating and sustaining friendships are heavily influenced by proximity and consistency it is not surprising that disabled teens in the current study made friends with other disabled teens who also experienced separation from nondisabled peers. This does not imply that friendships between disabled teens were somehow of lower quality than friendships between disabled and nondisabled peers, rather, the intent was to demonstrate how labeling and separation of disabled youth determines who will be available as friendship partners. There are clear messages

about who makes an acceptable friend – from adults about 'growing up' and from a system that differentiates between disabled and nondisabled students.

4.4.4   Status Loss

By the time participants in the study reached high school they were already part of a marginalized tier in the social hierarchy at school. Some adults in the study attributed this to nondisabled people feeling uncertain about particular medical diagnoses or accessibility, thus invitations were not forthcoming. One parent commented,

> *I think people are afraid. I think they worry that something will happen to her, you know in their home, or their home won't be accessible enough and she won't be able to get around, so why invite the kid over. Or, that would be from the parents, the fear would be from the parents, right. Um, and then as they get older the kids would make their own decisions about who they want to have as friends and who they want to invite over.*

Although disabled teens had already been labeled and separated from nondisabled peers, they remained under considerable threat of further stigmatization. Take Rachel for example. In elementary school and early junior high she was occasionally invited to stay overnight at the home of a friend from school. This invitation could have extended the friendship with her nondisabled peer outside the domain of school and into personal, familial space. It is expected that teens both accept and reciprocate such invitations. For disabled teens like Rachel accepting such invitations came with the risk of further disrupting normative expectations. In the following example Rachel's mother described how Rachel declined a number of invitations for sleepovers. Later on in the interview it became apparent that Rachel turned down the invitations because she was concerned that the other kids would react negatively to aspects of her personal care routine. Her mother said,

> *Another thing I believe that separated her – she was invited a lot to go to sleepovers and mainly sleepovers, girls night out. And she never wanted to do it because she didn't want to leave the house and go anywhere over night… She had been invited and didn't want to go. And I think it's like anything else – if you get invited so many times and you decline, eventually the invitation is lost. You don't get invited back.*

Perhaps Rachel recognized the potential to lose even her marginal social status. There was great risk involved in sharing information about how her body works, how her body defies normative expectations. Llewellyn's (2000) findings echo Rachel's position about

her tenuous social status. Both of the participants in Llewellyn's qualitative study who had non-normative bodily functions for daily routines experienced significant bullying by nondisabled peers. Telling others about her body could have opened Rachel up to the very real possibility of ridicule and rejection. Because Rachel didn't follow the norms for accepting invitations the invitations stopped coming. This lack of invitations then cycled into further isolation, since Rachel wasn't included in the weekend social events. She chose social isolation rather than risking the harm that could come from further status loss.

Another poignant example of status loss involved a recent end of year class trip for one participant. The entire trip was emotionally devastating for both Amanda and her mother. Amanda had school-based friendships with three nondisabled girls. This trip seemed to catalyze a steep decline in her status, resulting in social distancing by her nondisabled friends. This story revolved around meals, idealized as a space for sharing stories and laughter. For Amanda they became the backdrop for discrimination. Although the tour company that was contracted to organize the trip knew one student used a wheelchair, they did not adjust the travel itinerary or destinations. This meant that most venues were physically inaccessible, so Amanda and her wheelchair became the focus of much negative attention. The wheelchair, and hence Amanda were identified as a problem. After being humiliated by being carried up flights of stairs by her male classmates, Amanda was typically met with hostility from frazzled serving staff at crowded restaurants. After multiple failed attempts to share a meal with her friends, Amanda was thrilled to finally be able to sit with them for one meal. Imagine her distress when all three girls got up and left the table to move to a different location, leaving her completely alone in a crowded restaurant.

This situation could be read in a number of ways. Amanda's mother attributed the behavior of the friends to the stage of social development and peer pressure. The constant negative attention directed toward Amanda was something her friends were embarrassed by, so they distanced themselves from it. Yet from another perspective this experience can be understood as a scenario where the 'problem' of disability was individualized instead of attending to the problem of inaccessibility and poor planning by the tour company. This lead to Amanda losing her position in the social hierarchy in a way that constructed her as an undesirable Other, thus her friends literally distanced themselves from her in order to maintain their own social status. A mother in Overton

and Rausch's (2002) study described an incident where a peer who befriended her disabled child was subsequently shunned by classmates. This story supports the belief Amanda's classmates may have had – that the risk of being assigned courtesy stigma (Goffman, 1963) by associating with a disabled youth was substantial. Goffman described courtesy stigma as a label assigned to people who associated with discredited individuals, in this case disabled youth. Perhaps the behavior of Amanda's nondisabled peers was an attempt to avoid losing their own social status via courtesy stigma.

4.4.5 Discrimination

All of these aspects of stigma – labeling, stereotyping, separation, and status loss – culminate in discrimination and form the backdrop against which disabled youth create their friendships. For some participants discrimination was experienced as a sideways slur as evidenced in the following fieldnote excerpt:

> *Rachel's teacher divided the class in half, asking one group to do a walking activity around the auditorium. The other half of the class was asked to participate in a seated activity. When another student asked why their group was doing a seated activity, the teacher said it was because Rachel couldn't walk*.

More directly, however, this same teacher planned a class trip to a local beach, one where the only point of access comprised a steep ladder down a cliff to the shore. This meant that Rachel could not participate. This teacher used an ableist approach to instruction. Her actions sent a clear message about what kinds of bodies were welcome in the classroom and on the beach. Rachel's experience is reflected in findings presented by Doubt and McColl (2003) that suggest disabled teens view themselves as having secondary status in the social hierarchy at school in large part because of inaccessible physical spaces and inflexible curricula. Llewellyn (2000) also notes that disabled teens endure a cycle of discrimination that limits their access to resources, to the curriculum, and to meaningful friendships.

Many disabled teens raised concerns about adults being oblivious to issues around accessibility, thus barriers prevented these teens from connecting with their friends. The inflexible nondisabled gaze did not anticipate the participation of disabled youth especially during outings, resulting in discrimination. Consider Rachel's story about the teacher planning a class trip to a local beach where the only point of access was a ladder down a cliff face. Think about Amanda having to be carried up flights of stairs in

her wheelchair to get into the same restaurant as her classmates. The adults expected the nondisabled norms to be upheld; therefore, the barriers to mobility that these environments created did not occur to them. Rachel, clearly frustrated with being left out, stated *"the older I get, the more they think that I can take it, that I can handle it. I shouldn't have to handle it."* The commitment to normative standards for how people move through the world mark disabled youth as having undesirable difference, separating them from classmates and friends. Instead of having opportunities to share recreational experiences with classmates both girls experienced incredible disappointment and were further stigmatized. Clearly, they "*shouldn't have to handle it."*

Inclusion of physically disabled people does not require the normative group to change in any substantive way. It demands changes to the physical environment – widening a doorway, lowering a counter, using a voice activated computer interface, incorporating environmental controls. Universal design is the mantra for engineers and designers in the 21st century with many of the concepts filtering down into everyday conversation. Universal design is becoming the new 'norm' for public spaces in the first/Northern/Western world. Our response to intellectual disability creates a stark contrast. Most of the teens involved in this study identified as experiencing some form of intellectual disability. Non-normative cognition comes with a long history of stigmatization and discrimination (Davis, 1995; Goodley, 2001; Snyder & Mitchell, 2006; Stiker, 1999). For the person who experiences a physical disability, modifications and adaptations are readily available. Many technologies such as word prediction software, are now standard on every cell phone or Blackberry. To include someone with an intellectual disability, however, requires a massive shift in attitudes and the value systems that inform them.

Although policies imagine inclusion as shared *experience*, in the lives of disabled youth inclusion is often interpreted as shared *space* only (Doubt & McColl, 2003). In the current study, many teens who identified as having intellectual disability found that sharing space can be fraught with tension due to the presence of stigma. One mother offered an account of discrimination that involved a group of disabled young people going for a swim at a public beach as part of their community based summer camp. The disabled youth were not welcomed by other beach-goers:

> *One of our problems that we still get – we can go to parks and people will ask us why we're there. They'll ask staff, 'Why are you here? This is my outing with my family today. Why do you have these kids here?' Well actually your [nondisabled]*

kids are acting worse than mine! We went down to… the beach. And the school psychologist… put in a huge complaint about how bad the [disabled] kids were. Now, it had nothing to do with the kids. The kids were one-on-one. The kids were not the problem… But this lady put in a big complaint about that our kids – that our staff was terrible, our kids were poorly behaved. And when I asked some other people, that was not true. But I mean that's the kind of environment you're going out into.

All of the elements of stigma converge in this scenario. The complaint was made by a school psychologist – the very discipline associated with the historical assessment, labeling and segregation of disabled people. Her power both as an adult and as a professional was substantial. It not only gave her the authority to confront the disabled teens and their support staff directly, but also to launch a formal complaint against them with the city, hearkening back to the era of 'ugly laws' in the United States (Schweik, 2009; Snyder & Mitchell, 2006). These ordinances, dating back to the early 1880s, made it a felony for disabled people to appear in public (Schweik, 2009). Simply being present in a public venue exposed disabled people to the threat of arrest and institutionalization. The last known arrest made under the auspices of 'ugly laws' reportedly took place in 1974 (Schweik), yet the response of the psychologist to disabled teens implies that the effects of these laws transcended both time (nineteenth century) and place (United States).

"Why are you [disabled] here? This is my outing with my [normal] family. Why do you have these (abnormal) kids here?" This brief statement was enough to diminish the social status of the entire group of disabled teens, stereotyping all disabled youth as badly behaved. She effectively created social distance between her 'normal' children and the undesirable disabled youth who disrupted her position of nondisabled privilege. Stigma, fueled by ableism, permeates the social worlds of disabled teens, defining who is valued as potential friendship partners and what spaces are physically and socially accessible.

4.5 Responding to Stigmatization: Choosing Self-exclusion

Discrimination and the resulting social isolation were commonly reported by participants, yet ableism is not where this story ends. It was where the friendships of participants began. For example, Alexandra said that her experience of being identified as 'weird' by her nondisabled peers lead her to connect with the two guys she now hangs out with at school every day.

Interviewer: What kind of drew you to them?

Alexandra: Mine's pretty much the same reason and also because I pretty much got pushed aside in junior high…. Let's just say some people thought I was weird. And it really hurt. And Jesse isn't like that. He's a good friend [both laughing quietly].

The experience of labeling and separation from nondisabled peers prompted many disabled youth to push back against this rejection. It was at this point that they started to connect with other disabled youth who shared the experience of stigma. One EPA suggested that friendships between disabled youth were forged through the trauma of rejection by nondisabled peers. She noted, *"I found that what really brought them together was the conflicts of junior high."* With one exception, participants selected other disabled teens as close friends. In the case identified as an exception, the nondisabled peer selected as a good friend also experienced stigmatization, though it was not based on his ability status. Marcus (2005) found that disabled youth feel a greater sense of belonging when they spend time with peers who share the disability experience. Self-exclusion, whether at school or in the community, was the eventual route taken by all participants to circumvent stigma in the quest for friendship. Unlike the findings presented by Doubt and McColl (2003), where disabled teens seemed to blame themselves for being segregated and tried to fit in with normative expectations, participants in the current study (or sometimes their parents) chose self-exclusion as a viable strategy for creating sustainable friendships. For at least two sets of friends in the current study, this was a conscious decision on the part of disabled teens. Parents of some participants – primarily those who used alternative approaches to communication – made the decision to be exclusive while carefully attending to the responses of disabled teens to ensure they were comfortable with this choice.

4.6   Meanings of Friendship

In order to describe what friendship means to disabled youth the query tool in Atlas was used to pull quotes together from all interviews with disabled teens and their friends. The only adult perspectives included in this aspect of the analysis were excerpts from fieldnotes based on participant observation sessions with disabled youth who use alternative forms of communication. There was nothing dramatically different in the meanings of friendship presented by disabled youth compared to those described in the literature. For example, proximity and similarity were both essential to initiating

friendship.

Most disabled teens recognized that their friendships started because they lived near one another, shared the same school bus, or were in the same home room class. In the one friendship where the teens met in a nontraditional way (via a newspaper article) Rachel spoke of her desire to live closer to her good friend.

> *Interviewer: So is there any thing you would change about your friendship?*
>
> *Rachel: I would like it if we lived closer together.*
>
> *Interviewer: You guys do have quite a distance.*
>
> *Rachel: I feel like that kind of – I don't want to say hurts our relationship – but we don't get to spend much time together because we live so far apart.*

Having the opportunity to be near one another on a consistent basis made it possible for disabled teens to gradually get to know one another, easing into their friendships. However, simply being near other teens was not enough to foster friendships, as demonstrated by the segregation and isolation all of the participants experienced before finding good friends.

Similarity was identified as particularly important when first meeting potential friends. They talked about understanding each other because of being the same age or sharing a similar medical diagnosis. Many participants described a sense of relief at meeting someone who also experienced disability. Rachel and Amanda's friendship started because they shared a similar medical diagnosis. Rachel stated, *"We go through some of the same stuff – or most of the same stuff. So I can tell her different things that go on. So I just find it easier to talk to her."* Sharing a common diagnosis or the experience of marginalization was the point of initial contact; however, engaging in meaningful friendships required a substantial commitment over time.

In one of the last data collection sessions with Jesse, Alexandra and Sean it occurred to me to ask teens who constantly use technology what they would post on Wikipedia as a definition of friendship. They made the following comments,

> *Alexandra: Oh! Friends are people who stick together no matter what.*
>
> *Sean: Friends are people who help you cheer up when you are down… Jesse?*

Interviewer: Jesse what would you put on Wikipedia?

Jesse: Fun.

In this brief exchange participants identified one of the core elements of friendship presented in Chapter 2. Trustworthiness and loyalty appeared to be the focus of Alexandra's comment. Sean indicated that demonstrating emotional support ("cheer you up") was integral to the meaning of friendship. Jesse alluded to the companionship friends provide. Like these participants, the stories of disabled teens involved in this study demonstrated how much they valued the practical support, emotional support and the companionship that friendship provided.

4.6.1 Practical Support

Reciprocity demonstrated through giving and receiving of practical support was integral to all of the friendships included in this study. Participants described scenarios where they delivered homework to a friend if school was missed, loaned money for bus fare, offered dating advice, made lunch, helped shy friends meet new people, or told friends about exciting recreation opportunities. The importance of each person contributing to the friendship was evident. Many friends seemed to expect that each time they made a contribution, the friend would then respond in kind. The importance of reciprocity was clear in the following discussion,

Rachel: Like I had a friend who it was, I was doing everything and that's pretty much what it ended.

Amanda: But I do a lot of stuff too.

Rachel: Yeah. It's more 50/50 not one way.

Interviewer: Yeah. Cause you said that sometimes you'll tell her things that are frustrating you and then you'll do the same.

Amanda: Oh dude, I'm doing that right now.

Rachel: Yeah.

Interviewer: Ok, so you kind of give each other some support and listen?

Amanda: Yeah it's either there's something wrong with her. And when there's nothing wrong with her, there's something wrong with me!

Although this example indicated an expectation that practical support be mirrored by the

friend, other friends were not as concerned about precisely matching the contributions of friends. For example, Lauren was pleased to be on the receiving end of Emma's adoration stating, *"I have a friend who really, really needs me and who really, really, really wants me to be there."* Lauren offered practical help, while Emma responded with complete devotion. The constant positive attention seemed to give Lauren an incredible boost in self esteem and a strong sense of purpose. Although the point of balance was unique to each set of friends, practical support was consistently present.

4.6.2   Companionship

Frequent and consistent participation in shared interests was crucial to establishing friendships. Most participants mentioned how important it was for them to see their best friend several times a week. In addition to seeing each other every morning on the school bus Lauren and Emma saw *"each other on Tuesdays and Thursdays. And on Monday... But Wednesday I take a break. And on Friday we have basketball. And Saturdays were figure skating days. So most [days]."* For participants who lived at a distance, telephones and social networking sites on the Web made staying in touch simple and accessible. Amanda said, *"We both love Facebook too…Facebook is our best subject."* Some of these exchanges were only a few key strokes long, while other web-based interactions lasted several hours.

A big part of spending time together was simply having fun. Participants liked to have a good time together whether engaging in recreational activities during the school day, at home, or out in the community.

> *Interviewer: And what makes you really close friends?*
>
> *Emma: [sharp, excited exhale; huge smile as she looked over at Lauren]*
>
> *Lauren: I'd say because… Emma just enjoys me, having fun with me. I guess because we're just interested in each other.*

Joy and laughter were ever-present in these friendships. Participants enjoyed each other's sense of humor, teased one another, shared jokes, and found many situations they faced incredibly amusing. When asked what he liked about his best friend, Jay replied,

> *Jay: Because he's kind of like me in a way.*

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Interviewer: In what way?

Jay: You've seen me and Brandon together and all of those jokes we do together. All of those jokes that I came up with, that I came up with I gave them to him.

Interviewer: Oh, so you share your jokes.

Jay: Yeah. Like, 'Oliver. Oliver who? Oliver clothes off.' I gave him that one myself actually… All of the ones I gave him are mostly the ones that are inappropriate [laughing].

In the early days of the friendship between Jay and Brandon were characterized by telling and retelling the same jokes, and sharing laughter each time. A shared sense of fun was not limited to verbal jokes. Two participants who rarely communicated verbally still shared a great sense of fun. For example, Jared and Gavin grinned mischievously and laughed uproariously when they teamed up to tackle their support staff in a bouncing castle. Actions, gestures, facial expressions were all fundamental to sharing entertaining experiences.

Transcending the point of origin was another key aspect of sustaining friendship. After meeting, gradually getting to know each other, and deciding that there was a mutual affinity these friendships literally took off – to malls, swimming pools, bowling alleys, movie theatres, friends' homes, restaurants. When asked what made his relationship with Brandon different from his other friendships Jay replied,

> *It's that we knew each other a lot and being together and stuff… I see other friends at school, but me and Brandon, it's not just in school and out of school we see each other, but I had a sleepover at his place that day. And he has sleepovers at my place. And Brandon's parents take me to their cottage. And I would take Brandon to me and my mom's cottage. Brandon's the only friend I have to really do that kind of stuff with.*

Friendship moving beyond the first point of contact was also reported in many recent studies (e.g., Overton & Rausch, 2002; Rabiee, Sloper, & Beresford, 2005). In particular, Matheson, Olsen and Weisner (2007) found that transcending context deepened the friendships of disabled teens. Like participants in the current study, disabled youth in the ethnographic research of Matheson and her colleagues relied heavily on parents to provide transportation to and from these alternative locations.

4.6.3 Conflict within Friendship

Conflict was referred to and witnessed in every set of friends involved in the study. Some teens talked about the stress they experienced when friends did not recognize the need to spend time apart. Others argued about religion, musical preferences, or what to do on Saturday night. Much of the conflict observed in the study took place at the nonverbal level – through facial expressions, body language, and tone of voice. This was highlighted in disputes involving disabled teens who use alternative forms of communication. For example, Timothy described his irritation when Jared kept demanding he say the number '10' dozens of times in a row. After so many repetitions Timothy said he couldn't stand it any more so he started saying other numbers such as 50, 100 or one billion. This in turn annoyed Jared, so he stopped requesting that Timothy repeat numbers. This was a definite moment of tension in the friendship, but it was something they resolved. Each expressed his frustration – one verbally, one via alternative communication. They moved away from each other briefly and then regrouped without any reference to the earlier dispute. Other participants described how friends became jealous when disabled teens hung out with other friends.

> *Participant: Oh, [my friend] gets mad… Ok we had this party at Special Olympics and I started dancing with Marcus who's in our school. [She] got really, really, jealous. She tried to pull me away from Marcus! [laughing].*

Participants who were friends for 6 months and those who were friends for several years all regularly experienced conflict. In one friendship characterized by frequent conflict, a participant stated that the friendship remained vibrant because *"we like each other. That is why we're still friends."* Disagreements were understood to be part of what it means to be friends. Mutual liking made sorting out the disputes worthwhile.

4.6.4 Emotional Support

Feeling accepted made it possible for these friendships to flourish. For most participants these friendships were the first time they experienced an unconditional sense of belonging outside their family. One participant captured this well stating,

> *I've never had a really, really, really best friend before. And also because now since we're friends… we get to have fun together and we don't have to worry about our disability. We don't have to worry about… having something wrong with us. We just stick together.*

Participants described the relief they felt at not having to fight stereotypes and

judgments about disability. This open acceptance seemed to create a deep affection among friends. Perhaps because they lived outside the realm of words, the emotional attachment between disabled youth who use alternative communication strategies and their best friends was readily observed via hugs, gentle touches, and huge smiles. When asked how she was able to understand Emma's communication style Lauren replied,

> *Lauren: I think her laughter, her joy, and her hugs and high fives.*
>
> *Emma: [reached over and gave Lauren a big hug].*
>
> *N: Nice demo there!*
>
> *Lauren & Emma: [both laughing].*

The friends in the study cared deeply about one another. They demonstrated this by doing thoughtful things such as remembering to ask for an autograph from a famous singer for the friend, throwing a party for a friend before surgery, talking the friend through an emotional crisis, or taking the time to learn how someone else communicated. Friends seemed to understand each other in ways that extended far beyond language. Participants were able to read and respond effectively to their friends' nonverbal communication. Lauren thought that she and Emma were best friends because *"we're nice to one another [and] because we're lonely and sad and we just want a friend to talk to."* These acts of kindness solidified the friendship, moving into the territory of Aristotle's moral goodness friendships. Each friend was concerned about the well-being of the other.

A commitment to remaining friends after graduating from high school was described by all participants who could be interviewed, although there was a realization that aspects of the relationship were likely to change. For example, Sean said that after graduation, *"it might look like a little more distance because we won't be able to see each other every day or every week. But I think we'll still be able to hold on to our friendship."* This sentiment reflected the vision of most participants. Again, this is not unlike the expectations of any teen leaving high school to move on to whatever life holds in store.

4.7   Chapter Summary

Despite the rhetoric and the laudable intentions of inclusive policies, the friendships of participants in this study were all forged in a social climate rife with stigma. For some the

elements of stigmatization – labeling, separation, stereotyping, status loss, and discrimination – started as early as grade three; for most these damaging interactions peaked during the junior high school years. All of the disabled teens involved in this study went through a period where segregation was imposed on them, either by their nondisabled peers, or by administrative structures within the education system. This separation was sometimes overt, taking the form of mandatory segregation based on an educational policy. A number of students involved in the study spend at least part of their day in a learning centre or quiet work area away from nondisabled peers. Nondisabled peers were described as demonstrating outright rejection of disabled teens via ignoring, verbal aggression, or acts of physical violence. Yet a direct approach was not needed to segregate disabled youth. Subtle forms of discrimination were also effective at distancing disabled teens from nondisabled peers. Gradually drifting apart due to changing interests resulted in good friends from elementary school or junior high becoming acquaintances who just gave a high five in the high school hallways.

This drift in friendship was not unusual as teens move through high school, yet it seemed to leave disabled youth in isolation whereas nondisabled youth readily established new friendships. Bunch and Valeo (2004) asked nondisabled teens about why they no longer connected with disabled peers at school. Participants in that study reported that the school policy of educating disabled youth in separate classrooms created this distance. There was not enough consistent contact for relationships to form and gradually evolve into friendship.

Whether discrimination was rooted in educational policy or in individual actions, the outcome of social isolation for disabled youth was constant. It was at this point that either parents or disabled teens themselves started to actively seek out relationships with other disabled youth. The friendship between Amanda and Rachel was a typical example from the current study. These girls lived in different regions of the province and specifically sought each other out because of sharing the experience of disability. Rachel's mother supported her decision to pursue an exclusive friendship with another disabled teen because "*Everybody needs that one good friend.*" The choice to exclude themselves from normative expectations about who makes a good friend (i.e. nondisabled peers) gave these disabled girls the opportunity to feel a sense of belonging, to finally make good friends.

As alluded to throughout this chapter, adults play a crucial role in facilitating or thwarting the friendships of disabled teens. The power of adult support and surveillance is addressed in Chapter 5. A more detailed analysis about how disabled youth disrupted oppression to create lasting friendships is the subject of Chapter 6.

CHAPTER 5   FINDING A BALANCE: ADULT SUPPORT AND SURVEILLANCE

5.1   Introduction

Social support is known to promote overall well-being (Wallander & Varni,1989). It has many forms including instrumental or practical support, emotional support, providing information, companionship, and affection (LaGreca, Bearman, & Moore, 2002; Turnbull, Blue-Banning, & Pereira, 2000). Although the companionship and affection of adults including parents, teachers, recreation staff, and Education Program Assistants is of great importance to the lives of most disabled teens (Antle, Montgomery, & Stapleford, 2009), this study focused only on the companionship offered through friendship. In the current study adult support was heavily weighted toward instrumental or practical support; however, there were also elements of advocacy that extended far beyond the standard definition of practical support. This chapter presents the types of support offered at two particular phases of friendship – initiating friendships and maintaining friendships. The slippage of support into surveillance is discussed. The analysis then addresses the tenuous relationship between support and surveillance of disabled teens. The chapter closes with a review of the strategies used by adults in the study to strike a balance between support and surveillance in their efforts to help disabled teens engage in meaningful friendships.

5.2   Adult Support

This section discusses in turn, practical or instrumental supports, advocacy of adults and the mentorship provided by adults that support the friendships of disabled youth. In each of these areas, I explore how the support provided differed at particular stages of friendship development.

5.2.1   Practical/Instrumental Support

Among the families in the study, practical support for friendship included activities like driving teens to meet specific friends or to go to events where disabled teens had a chance of connecting to some people they might like. It also involved identifying potential friends, gently providing feedback to disabled teens about their interaction style,

organizing recreational activities and arranging times to connect that fit with the schedules of other teens and their parents or support staff. The adults most involved in supporting the friendships of disabled youth were mothers and Education Program Assistants from the schools. The forms of instrumental support they offered were crucial both for initiating new friendships and sustaining the ongoing friendships of disabled teens.

a)   Initiating Friendship

Most participants in the study met in fairly traditional ways. They were in the same classroom at school or attended recreational activities together. Rachel and Amanda's story was unique in that they connected via a newsletter posted in the office of a doctor they both see. Rachel's mother described making this connection as follows,

> *We were at the [children's hospital]… and I was in the waiting room and saw this article, read this [newsletter] about this girl and how…the family modified the house…I was just quite taken with her and I thought 'wow, she's so independent and her parents are just so proactive.' And I just thought it was great. So I showed it to Rachel and she really wanted to meet this girl because she was really struggling with friends. She had lost a lot of the friends she had in junior high. And she was at a place where she sort of got left behind. So I called the [children's hospital] and talked to the nurses at the… clinic. I knew that they would know Amanda's family. I said to Rachel, 'I didn't want to appear like a stalker.' [laughing], and just call the family and say 'I saw you in the paper'… So I called and talked to one of the nurses and said, 'Could you kind of be a liaison and touch base and see if they want to get to know Rachel?' And she did so and they called us back and said, "They would love to hear from Rachel." And gave us her email address. And Rachel sent her an email and they were on MSN and that was the beginning of it. It was awesome!*

As soon as this mother read the article she recognized the potential for Rachel and Amanda to click as friends. She felt a sort of kinship with Amanda's parents. She saw them as people who may have shared a similar life experience and perhaps had similar values to those her family held. This, combined with Rachel's struggles around maintaining friends in the transition to high school, prompted both Rachel and her mother to take a risk, to see if Amanda and her family wanted to initiate contact.

In the stage of initiating friendships, looking at who the adults viewed as viable friendship partners revealed a fascinating pattern. The teens identified as viable friends were not the people typically targeted in the school system to befriend disabled youth. The schools often look to nondisabled, high-achieving students who are adult-oriented and

want to bolster their resumes with volunteer activities. This is not meant as a criticism of these adults or teens; rather, it is important to note that the nondisabled peers who appeared to be viable friendship partners in this study were youth who understood the experience of stigma. These were the teens who gravitated toward the safety of friendship with a disabled teen. In these relationships they felt a sense of belonging, of knowing they could trust that the disabled teen would not further exploit them. One mother gave the example of an Education Program Assistant (EPA) from school sending home a note suggesting that Amanda contact one particular girl who signed her year book.

> *Now there is– we had a little girl over the other day that the EPA said this kid put her name in the year book and she said, 'call me.' And the EPA said that she really should call, so we did. And we had her over for a full day. And I would say she doesn't have any siblings this kid. They're not very well off. Very nice family. And I think this person would have had a little more compassion.*

The EPA identified a nondisabled peer who also experienced marginalization based on living in poverty. Amanda's mother noted that this relationship had more possibility for 'compassion' given that the other child understood what it felt like to be left out.

Similarly, an EPA at school was also instrumental in connecting Lauren and Emma. By the end of grade seven Emma had experienced a dramatic decline in the contact she had with friends outside of school. It became clear to her parents that they needed to support Emma to establish meaningful relationships. Her mother explained,

> *So we started looking at who was out there and who was at school with her who– new friends that we didn't know from junior high, or didn't know from elementary. And Lauren was an automatic. She was so helpful and the teachers and the EPAs would mention that there was a natural friendship starting there. So that's where we started. We went in that direction because it was a natural.*

Emma's mother talked about the affinity the girls had for one another at school. This mutual liking was apparent to the EPAs at school, who then communicated this to Emma's parents. This act of sharing information was crucial since parents have little access to the school environment after elementary school. Information about which disabled youth seem to enjoy spending time together was only available to school staff. Passing this observation along to Emma's parents was the starting point of a friendship that lasted over 4 years.

EPAs figured heavily in many friendships included in this study. Another mother described her sense of surprise when her son's EPA told her about a few guys at school who enjoyed hanging out with her son Jared.

> *When [the EPA] went to school with him in grade 9 he was telling me about these kids that hung around with Jared. And I'm like, 'what kids?' He said, 'Well this guy named Timothy and a couple of other guys.' And I said, 'Well what's wrong with them?' Like they're coming to the learning centre, the resource centre, so what's wrong with them? You know, clearly [there must be something wrong with them]. He said, "nothing, they just like to hang around with Jared.' I said, 'well clearly they're not the most popular kids at school.' [small laugh] and I can say that because you know the most popular kids is not going to necessarily hang around with Jared all day you know.*

After years of Jared being rejected and isolated by his peers, this mother had no expectation that popular, nondisabled peers would seek out his company. Thus, her immediate response to the surprise that Jared had connected with some classmates was to question the disability status of these peers. If his friends weren't disabled, then she reasoned, they must have been of low social status in the school – "*clearly they're not the most popular kids.*" This comment indicated that supporting the connections among teens who share a common experience of marginalization can be fruitful.

An EPA described her process of identifying possible friendship partners for a disabled youth as attending to needs and interests. "*If you find a student who has similar needs or similar interests then it turns into more of a– less of a one person give, and everybody giving and taking.*" Here she makes an excellent point – one that is well established in the literature around the importance of shared interests and reciprocity (Shakespeare, 2006). She clearly differentiates between helping relationships and friendship. When a relationship is perceived as imbalanced by one of the parties involved, then it may be more of a helping relationship. These kinds of relationships are important; however, they are not the same as friendship because of the dramatic difference in how each party sees the other (Meyer, 2001; Turnbull, Blue-Banning, & Pereira, 2000). Time and again in the current study adults who spent a lot of time in school or recreation with disabled youth recognized peers who had the potential to be a good fit in friendship. The peers they identified were often not the high achievers. Quite on the contrary, they are the youth who struggled to fit in; those who needed additional support to be successful in school; or those who were stigmatized by their more popular peers for reasons other than disability (e.g. income, clothing, weight).

b) *Sustaining Friendship*

Although making initial connections posed many challenges for participants, sustaining those tenuous relationships over time required substantial adult support. There were multiple examples of parents who spent countless hours investigating recreational opportunities. Comparable findings were reported by Turnbull, Pereira, and Blue-Banning (1999) where finding opportunities to connect with friends was the most frequent form of adult support offered to disabled youth. In the current study, if adults could not find venues that fit well for their children, then several parents established new spaces for disabled teens to connect. These venues tended to be diagnosis-specific and the activities were more available during the summer months when school programs were not running. This enabled disabled teens to connect with friends outside of school and to get to know a few new people as well. For example, Jay noted that he really enjoys the diagnosis-specific Friday night social club he attends: *"Most of those people are my friends, but I only see them at [social club]."* Without the adult support to structure this venue, Jay would not have any opportunity to relax and just hang out with these friends.

Invitations to spend time with peers at home or in the community solidified friendship, given that this moves the relationship out of the domain of school and into the personal sphere, making it more likely that the friendship will be sustained. Supporting teens in the early stages of friendship formation also involved encouraging them to take the risk of inviting someone new over to the house for a visit. This also helped to dispel any assumptions the friend had about disability or how the disabled youth functions. One parent suggested that this approach reduced the risk of rejection for the disabled youth and simultaneously reduced the stigma attached to disability. She stated that spending time together in a supportive atmosphere made disabled teens and their friends feel, *"more comfortable and the fear thing kind of goes away a little bit."* Instead of waiting to be invited to someone else's home, this mom encouraged her disabled daughter to invite new acquaintances over to dispel the myths about her disability. These friends were able to enjoy spending time with Amanda and can see how she moved around in her own home. This allowed them to more easily imagine Amanda spending time in their homes.

When disabled teens in the study used alternative communication strategies, adults needed to be even more attentive to sustaining connections. These participants did not

directly ask to spend time with one of their friends, nor will they invite friends over. This was not out of lack of interest; rather, it was because of limited communication systems. None of the participants in the study who used alternative communication approaches seemed to have a mechanism in place for explicitly asking to spend time with their friends. They relied on the adults around them to offer them this option. When it was presented, these participants eagerly agreed to joining their friends in a variety of activities. Jared's mother expected that because Jared and Gavin's support staff get along well together it is quite likely that they will continue to invite each other to outings after the guys graduate from high school. Jared's EPA noted that a great deal rests on how committed support staff are to maintaining already established friendships between disabled youth. This is clearly the case for disabled teens who are unable to drive. Jared and Gavin for example will always need someone else to chauffeur them to events. At the time of this study, they see each other several times a week at school, swimming, bowling, and the occasional meal out. Neither Jared nor Gavin ask to spend time together, but they consistently enjoy engaging in shared recreation. Respite workers coordinated all of these activities so that the guys could hang out together. They also arranged for Gavin to drop over to visit Jared at home– extending the contact across multiple environments in ways that are comfortable for everyone involved (parents, guys, support staff).

Transportation was not readily available to all participants. There were a number of friends who lived quite a distance apart and could only see each other either at school or during occasional weekend activities. This did not pose a significant barrier to forming lasting friendships. When parents were not able to provide consistent transit for disabled youth to spend time with friends, the teens adapted nicely to using whatever technologies were available. They spent time together 'virtually' outside of school on standard phones, cell phones, MSN chat, and Facebook. Because so many teens use social networking websites and other technologies to connect (even when they are in the same room!) a number of parents recognized the need for them to become more technically savvy. For example, Jesse said that his mom was encouraging him to get an account set up on Facebook so that his friends can poke him, write on his wall, and share photos. Many of the parents of participants involved in the study were in their 50s, had computers in their homes, and were comfortable setting up the technologies for their teens to enjoy – that is if the teens did not already have it set up on their own.

A key role adults filled in friendship development involved gentle guidance for disabled youth to support ongoing friendships at home, school, and out in the community. This requires fairly close observation of what is happening between friends. When not handled with caution, this form of support easily shifted into 'policing' the teen's behaviour. One female EPA demonstrated wonderful ways of deftly moving in and out of Jesse's friendships. She busied herself in the same general area where Jesse and his friends hung out for lunch and often left the room to do errands when things seemed to be going well. She also engaged in debriefing sessions with Jesse to explain confusing parts of interactions that he had trouble interpreting. Another EPA noted that when a misunderstanding was brewing she offered the disabled teens suggestions about how to adjust their behavior to maintain the friendship. A male support worker frequently offered guidance to Gavin about how to initiate conversations with new people when out in the community. All of these approaches support disabled youth as they work to develop an understanding of how friendships work and how to sustain the relationships that matter most to them.

Encouraging acceptable behaviors was a common point of discussion in conversations with adults involved in the study. One mother was very direct with her daughter about demonstrating more mature behavior. For Amanda junior high was full of many interpersonal tensions. She was wrongly accused by her peers of cheating because she used a calculator for her math assignments. Her mother recommended that Amanda think of high school as a fresh start,

> *You know this is going to be your chance… [a] clean slate, start fresh and improve some of your behaviors a little bit. To be a little bit more mature thinking. The best thing to do is say nothing. Wait. Think. And then maybe another time, another day once you've thought it through maybe there's something to respond to a comment. But the best thing would be to not react with a behavior that would tag you as a little kid, or an immature person. Because nobody at that age group is going to want to hang out with somebody who behaves immaturely. You're going to have to really think long and hard about how you're going to react to the accusations of cheating or whatever. You're going to have to be able to let a lot of that stuff go too, right?*

Amanda's mother explained to her that the transition to high school was a terrific opportunity for Amanda to establish a new way of engaging with her nondisabled peers at school. This was a very direct form of guidance on how to negotiate with peers.

In these examples – Amanda acting more maturely, Gavin approaching others respectfully, Jesse understanding his friends' actions – adults encouraged disabled teens to change their behaviors. The adults involved were not trying to change who the disabled teens were; instead, they helped the teens understand situations that did not make sense to them. This support encouraged the disabled teens work through moments of conflict in friendships and thus contributed to friendships enduring over time.

For some of the long-standing friendships, each friend became embedded in the family of the other. One mother described this dynamic with Jay and Brandon.

> *Well I guess if the families are doing something, they'll often– we'll just include them. I mean I make a point. There's just things we do now. If we're going to a movie we'll almost always call and ask if Brandon wants to come. They, their family will frequently– but Brandon will certainly, aside from that, particularly in the summer where there's more unstructured time, Brandon will call and say "what are you doing? Do you want to come over?"*

These friends were constantly inviting one another to spend time together at home or out in the community. Each was consistently invited to join the friend's family on vacations. The guys understood that different rules applied when they were in the company of the friend's family. In fact, they took great pleasure in pointing out the differences between their families during interviews for this study, often making jokes and laughing about the rules of their friend's parents. Although the friends saw their families as very different from one another, each family was willing to open themselves up to including the friend in almost all aspects of their lives. The trust demonstrated by these families played a key role in creating a lasting friendship for these young men.

*c)	Transportation*

Transportation, as almost any parent of a pre-licensed teen will understand, was critical to friends connecting outside of school. Most recreational activities and the transportation required to engage in them looked very much the same as among nondisabled teens: trips to the mall, nights out at the movies, meals at fast food restaurants, and of course the inevitable coffee talk at Tim Horton's! Driving sometimes involved short commutes between homes; however, given the distance between many of the friends in the study, some parents drove between one and three hours each direction for disabled teens to spend time with their friends. This was a substantial financial and

time commitment for adults, especially in homes where both parents work full time or in single parent homes where work schedules were not flexible.

Rachel felt that the most significant contribution her parents made to her friendship with Amanda was chauffeuring. Given that Rachel and Amanda live quite a distance apart, this was indeed a crucial contribution. Both girls are tech savvy and constantly sent each other messages on MSN; however, they both frequently asked to spend time together in person. This required parent-assisted transit. There were a few exceptions regarding transportation for some participants. For example, one set of friends used the city buses regularly, although they were notorious for missing their stops because they were too engrossed in conversation.

The challenges of transportation were raised by participants in many studies involving disabled youth (Cavet, 1998; Harry, Park, & Day, 1998; Murray, 2002; Turnbull, Pereira, & Blue-Banning, 1999). In the current study these issues ranged from physical access, costs of transit, reduced ability to make spontaneous plans with friends, competing demands of siblings' recreational schedules, and distances between friends' homes. But transportation was only an issue if people actually have somewhere to go. Several parents in the study reported that venues that support the participation of disabled youth have been limited in Nova Scotia for many years. It is only recently that several programs began to address the need for accessible recreation. Finding these organized activities proved challenging for disabled teens and their parents. Many parents spent a great deal of time making phone calls, checking in with organizations and surfing the web for recreational opportunities.

d)   *Organizing Recreation*

Due to the recruitment criteria, all of the friendships represented in this study extended outside the boundaries of school. Numerous disability organizations arranged for social gatherings in the community such as pizza parties, dances and movie nights. All of these social adventures were organized by nondisabled adult volunteers. The commitment of many parents to support disabled teens in establishing strong friendship networks was remarkable. Some parents focused on the specific friendship, while others established formal social clubs where disabled teens could connect. For example, one small group of parents organized a social club that runs one evening session and one afternoon activity each week.

We only started last fall, so it's only just coming up on a year. And we're still just figuring out lots and lots of things about how to do stuff. So we feel– we're still working through policies and stuff in our own minds. So we feel that until things have gelled a bit more for us we don't want to [open up the group to people outside one medical diagnosis]. But we've talked about things like maybe hosting a dance for the wider community.

Parents tended to organize diagnosis-specific groups in an attempt to establish connections between disabled teens who may share a similar life experience. When asked to describe the pros and cons of creating diagnosis-specific social clubs, one mother said,

I think it could well be that Jay could form a similar kind of friendship with somebody who had a different intellectual disability…I think there are certain similarities but, you know when we first started the group I thought, great the kids will all be on the same wavelength. But now I see, no, that there's some big, big differences within the group. Big differences you know…I can well imagine that maybe say in the wider community of Special Olympics or something that Jay could well meet someone else who.. would be sufficiently similar that they could have a genuine relationship. So I think there's sort of value in both.

After limiting group entry to one specific disability, it became apparent to the organizers that this did not limit the range of disability experiences embodied within the group. After completing biographical interviews with physically disabled young people Curtin and Clarke (2005) supported this parent's experience, noting that essentializing disabled youth based on a diagnostic category discounts the dramatic individual variations within a particular group. Diagnosis may be one potential point of connection, but like nondisabled youth, in order for a lasting friendship to develop similarity needed to extend into other dimensions such as recreational interests, location, and age.

Parents organized cooking groups and drama clubs. One mother set up a diagnosis-specific summer camp because no summer camps designated as 'inclusive' throughout the city could actually accommodate her son Jared. She explained,

We started it out with the inclusion camps at HRM and it was just not going to work because those things changed way too often for it to work for kids like Jared. Because there is always new kids. The staff stays the same but the staff was too young, so they couldn't deal with the problems and the issues that were faced.

The unpredictability of the 'inclusive' summer camp and its inexperienced staff meant that Jared was not part of the group. Creating an exclusive, diagnosis-specific venue was identified as the only option by this parent. Pursuing this alternative meant devoting

countless hours to fundraising, organizing the camp, training staff, and intervening as needed during summer program. The energy required for these disability-specific groups – social club and summer camp – was incredible. The commitment of parents to promoting the friendships of their disabled children by organizing recreational options was reflected in many other studies (e.g., Antle, Montgomery, & Stapleford, 2009; Overton & Rausch, 2002; Turnbull, Pereira and Blue-Banning, 1999). The time, energy, and financial costs involved in orchestrating these activities appeared to be viewed by the mothers in the current study as an investment in the future for their disabled children, both in terms of establishing a wider social network and encouraging participation in an active lifestyle.

It was at one of these parent-organized, disability-specific venues where one of my favorite memories from all the participant observation sessions in this study occurred. It involved the disability-specific summer camp, Jared, Gavin and a bouncing castle. The following excerpt from a fieldnote demonstrates what can happen with just the right amount of adult support.

> *Initially Jared and Gavin just went in the castle, bounced a few times and then sat or laid on the striped floor…Timothy (Jared's friend and his support staff at camp) said that this was Jared's favorite spot. Jared kept an eye on everyone and had a little grin on his face. He kept note of where Gavin was, but didn't approach him at all. After about 5 minutes Josh (Gavin's support staff) decided to take the plunge, removed his shoes and charged in to tackle Gavin. Jared had a huge smile on his face when this happened. Josh then tackled him and they all tumbled into a big pile at the side of the castle. This tumbling, tackling and rolling about carried on for several minutes before they all got really tired and needed a break. Because they were all in one big pile it made that part of the castle sink down, so it was actually pretty hard for any of them to get out of the valley they all created. After a few minutes one by one they rolled out of the groove for a rest.*

This entire scene was one of engagement, interaction and sheer joy. Gavin and Jared had a wonderful time because (1) the adults who organized the event created an environment ripe with possibility for connecting in meaningful ways as friends; (2) the adults paid attention to what the teens enjoyed and the timing needed; and (3) the adults were willing to engage in exactly the ways the teens wanted them to. This appeared to be adult support for friendship at its best.

5.2.2 Emotional Support: Setting the Stage for Meaningful Friendship

Adults can only be supportive to disabled teens when they know the teens well and understand what kind of supports work for them across a variety of settings. Setting up safe, calming spaces or activities was a commonly used strategy for disabled teens who found engaging with others stressful. That might mean playing a particular video, doing a quiet project in a secluded space, or spending some time alone to play computer games or listen to a few favorite tunes. Other adults gave disabled teens plenty of warning about what was coming up next so that they could emotionally prepare for the interactions. One EPA offered this example,

> *[Jesse's] parents, God bless them, fight [for him]. And they've been very vocal about what they feel is best for him. And it's made a big difference. Getting a quiet space for him. A place of comfort that he can go to school and know that 'I have a place that I can go.' That's made the difference between being in school and not being in school.*

Having the reassurance of a safe space to unwind at school made it possible for Jesse to remain in school and thus engage with others in a meaningful way. In addition to promoting Jesse's educational attainment, this protected space meant he was able to participate in meaningful friendships.

When someone prepared both the environment and the teens for connecting, the possibility of creating lasting friendships increased dramatically. For example, consider the following depiction of Lauren's first day in the learning centre in junior high, after several traumatic years of cruel treatment and rejection by nondisabled peers. Her mother stated,

> *And so off she went her first day of school. And I said more prayers that day than I think I ever said in my life. And she came home thrilled. THRILLED! Absolutely thrilled. Loved it! Marcus was there. First time she had met Marcus really. Joan was there…A few others. And Lauren was in heaven… And she had an absolutely wonderful learning centre teacher… Grade 7, 8 were wonderful in that Lauren was taught mostly in the learning centre, except for gym, those particular– and math. Her math teacher was actually fantastic. So she benefited very well from being secluded. She was able to develop her friendship with the kids because of that.*

The teacher in this account created an environment that felt welcoming and comfortable for Lauren. Adults who attended to the needs of disabled teens were able to facilitate the experience of belonging. When teachers set the expectation that the diversity of

disability is both normal and welcomed in their classroom friendships are more likely to develop for disabled youth (Baker & Donelly, 2001; Llewellyn, 2000; McDougall, DeWit, King, Miller, & Killip, 2004; Meyer, 2001).

In the current study adults discussed the importance of sharing personal information in order to support positive interactions. In particular, parents believed that nondisabled peers needed information about ways that disabled youth interact so that they could more easily interpret nontraditional behaviors. This was raised most often by parents of teens who use nontraditional approaches to communication. Jesse's EPA noted that his parents were very supportive of nondisabled peers having access to information about how Jesse understands the world:

> *Jesse's family is really quite comfortable with you saying to somebody, "These are Jesse's needs. You might see Jesse doing this or you might"… And because of their comfort level in doing that, Alexandra and Sean have information that other friendships maybe don't necessarily start out with.*

Having this information made it much easier for Alexandra and Sean, Jesse's friends, to understand when Jesse needed some time away from them. This averted conflict and hurt feelings that could easily have disrupted their friendships. Instead, having this 'confidential' knowledge strengthened their friendship. Jesse's EPA offered the following example.

> *Jesse was upset one day here not long ago and they walked in and then he sort of blurted, 'I need to be alone.' Had they not had the information [about Jesse's communication style], some people would have been quite slighted by that, hurt. But they knew that it wasn't him reacting. It was how he was feeling at the time reacting. And when they come back later, everything's fine. So I think information, in my opinion, is quite vital.*

The policy around confidentiality of student information in schools had a surprising consequence for several disabled teens in this study. Although developed to protect privacy, the confidentiality policy seemed to suggest that disability is a secret, making it mysterious and unknown.

There were many examples identified in the literature where disabled youth were isolated because peers did not understand how to interact with them, or how to interpret certain behaviors. Participants in Middleton's (1999) study described looking at the floor while they moved through the environment in order to prevent wiping out because of an unexpected obstacle. Their peers seemed to assume that this lack of eye contact as a

social snub. Meyer (2001) highlighted the importance of peers understanding how to interact with disabled youth who use alternative communication strategies, like learning how to use a communication system or being guided to speak directly to the disabled youth instead of to the adult assistant. Because school policy prevented teachers and support staff in the current project from sharing information about disabled students, nondisabled peers often misinterpreted behaviors and then rejected disabled teens. Jared's mother was not prepared to give up all aspects of confidentiality, but she recognized the need for classmates to understand his communication style.

> *I think you can do a lot to change the confidentiality issues and talking about it in a more open sense. And sort of giving people the ok to talk about these kids and to give information. I don't necessarily want to tell them all about my family or anything, but you can say that Jared has [medical diagnosis] and these are his needs. These are the things that would help. When I would talk to kids I would say, 'Here are the things that you need to know about Jared. This is what would make him mad. This is what he would really enjoy.' It gives them some clues.*

The school policy around confidentiality may inadvertently reduce the chances for some disabled teens to establish strong friendships.

Adults in this study demonstrated a wide range of instrumental supports that are comparable to those of nondisabled teens including coordinating activities with friend's parents, transportation, and setting the stage for meaningful friendship. However, these parents went to extraordinary lengths to offer their children a chance to belong. They established diagnosis-specific non-profit organizations that focused on recreation and social engagement. The parents were also willing to openly talk about disability and what it meant in the lives of disabled teens who struggled with social demands or used alternative communication strategies.

5.2.3   Advocacy as Support

Another form of support for the friendships of disabled teens demonstrated by adults involved in the current study was that of advocacy. Advocacy took many forms in this study such as parents lobbying for consistent EPA support, quiet work areas at school, or more recreational opportunities so that disabled teens could connect with potential friends. In 2007 the Department of Education in Nova Scotia attempted (unsuccessfully) to lower the age at which students had to exit in the school system – reducing it from 21 to 18. This dramatically affected all of the teens involved in this study. Most of the

parents interviewed described their strong advocacy against this policy given that it would mean social isolation for many disabled teens. Few vocational or recreational options exist for people aged 18 to 21 outside the school system. The massive push back by parents forced the school board to keep the existing age policy in place, thus the teens involved in this study had a few more years to establish long term friendships in structured educational settings. Brandon's mother described investing much more time in her advocacy efforts when he transitioned into high school.

> *I really wanted them to focus on things like money skills. And I wanted him to be in certain classes. And that was you know, I really had to push that. I had to work harder at the high school. I had to work harder. I had to go down to the principal's office. I had to go down to sit in the office. I had to say [sigh] how can I put this politely? You have to dress in a nice suit. You have to go down there and be you know, have your blackberry and your tools, your briefcase and go in there and say, 'we're going to deal with this.' And be very calm, but 'this is the way it's going to be.' You have to take your best business high profile you know.*

Although Brandon's mother did not hesitate to advocate on his behalf, she expressed concern about families who were not able to engage with the school system confidently or who were burnt out by the time their teens reached high school. She said,

> *What happens to the mother or the single parent who has, who is afraid to, who has had bad school experiences themselves, and they just– the thought of going into the principal's office brings back every bad memory they've ever had. You know, it's not fair, but unfortunately we all fight for our own kid.*

Brandon's mother raised a key point about advocacy and disability here. As long as advocacy remains at the individual level, then only people with lots of support like Brandon will benefit. Disabled teens who are not able to advocate for themselves or who do not have someone to advocate for them may continue to experience segregation and social isolation, with few opportunities to make good friends.

Three EPAs were interviewed on the recommendation of the disabled teens involved in the study. They each engaged in advocacy efforts in support of the students with whom they worked. For example, one EPA was concerned that expectations change for all students when they enter high school; everyone is required to function much more independently than they did in junior high. She stated,

> *Expectations do change for everybody. But I guess the others, a lot of the [nondisabled] others, have the skills to make that transition. I think sometimes*

we… forget that those transition years are when they need the support… Not when we need to drop it away. And I don't think everybody's on the same page.

Because she recognized that more support was needed for all teens, this EPA found creative ways to support Jesse's two good friends, who were not officially designated as eligible for EPA support. The informal chats at lunch break, advice, and occasional spare change for a nutritious lunch that this EPA provided simultaneously promoted both friendship and successful transition into high school for all three teens.

There are a range of approaches to advocacy. For example, Jesse's EPA was subtle, yet effective. Jared's EPA, on the other hand, was more direct in his approach. He spoke up on behalf of Jared and Gavin, making it possible for them to actually spend time in the same space at school. Originally the administration wanted to keep the two guys apart, fearful that they would interact in negative or disruptive ways. Jared's EPA pursued many opportunities for the guys to hang out. This created a unique friendship where Jared and Gavin can comfortably be in the same space. This move required the EPA to take a substantial risk given that he is not in a powerful position in the school hierarchy. Adult support often takes courage. This EPA refused to accept Jared's longstanding reputation as being one of the most difficult students in the entire school system. He actively contested this belief, conveying his opinion in a large meeting where he felt Jared was being labeled unfairly.

> *I said, 'You know what, that's bullshit.' Right in front of everybody. I didn't mean to say it, it just come out. And they're like [gasping sound]… I was really frustrated. He's not the worst kid in [the school system]. He's not at all. Not even close. I said he's a kid that everybody's afraid of because of what happened in elementary because they didn't have the resources to help in elementary. I said, 'that's what you fellas are afraid of.' And then [the specialist] kind of backed that up. But I kind of took heat for that afterwards. Like, you know, I was told when I come to meetings like that I should just sit there and listen because that's what EPAs do.*

This act of advocacy took incredible courage. The efforts of both these EPAs (Jesse's and Jared's) extend beyond the students they were officially paid to support. Voicing concerns about how inclusive policy is practiced within the education system was another form of advocacy. Jared's EPA described his perspective as follows, "*So can inclusion work? Depends on how it's done. Does it work? 50 percent of the time. Does it work on everybody? No. Everybody's different… Does it only include the student and the EPA? No, everybody has to be on board.*" If inclusion in schools is supposed to be, at

least in part, about creating social connections between disabled and nondisabled people, it seemed to be failing. Friendships between disabled and nondisabled youth were the exception, rather than the rule for participants in this study. When adult support moved into the realm of advocacy and extended beyond the needs of an individual teen, it necessarily meant taking on the stigmatization of disability more broadly.

5.2.4   Mentoring as Support

Adults in the study devoted much time and effort to supporting the friendships of disabled youth, in part through differing forms of mentorship. For example, Jared's EPA was at the centre of a large network of male support workers. This informal group of 8 men, ranging in age from 18 to 50, worked in schools, homes and in community venues. It seemed that Jared's EPA made caregiving cool to an unlikely group of young guys in high school who then pursued paid support roles after finishing school. When asked about what drew this group of men together, Jared's EPA wondered if the commonality of struggling with learning experienced by the younger men in the group was a factor. Connecting to disabled teens and their support staff during the high school years gave these young men access to learning support as well, promoted their confidence, and thus encouraged them to pursue paid work in the field. When asked specifically why he thought so many young men at the high school gravitated toward him, and thus toward disabled teens, this EPA replied,

> *As for me, I think it's because they just feel comfortable. I mean, I'm no typical EPA. I'm not really a book person, to go by the book. I will tell you what's on my mind and expect you to tell me what's on your mind. Cursing and swearing – excessive cursing and swearing I don't deal with you know – but people curse and swear all the time. If you judge them by what they wear or how they act, then you're not going to really get to know them. But if you judge them on what they're telling you, how they're acting towards other teachers and how they're acting towards the choices that you give them for a positive day – because you can only go day by day for some of these children. Then, will they respect you? They will respect you to a point where they will come and get directions. And then not only will they respect you, they will respect you for what you do and ask questions about what you do with other children.*

This EPA was a magnet for many young guys at the high school. He had many opportunities to talk to these nondisabled teens – many of whom are struggling with their courses but receive no official support – about skipping classes and making choices that will help them stay in school. He often ended up with a group of 8 or 9 students working with him in the learning centre at the high school, even though only a couple of them

were officially on Individual Program Plans (IPPs). He found a way to remove the stigma associated with the learning centre that plagues so many high schools. He noted that these students felt a sense of belonging when they were with him. This EPA created an equitable learning environment, where it is understood that everyone needs support, but that those supports varied from person to person. Each person felt comfortable and was recognized as making a valuable contribution to the learning of others in the group. He described the responses of the teens who drop by the learning centre to work with him and with Jared.

> *Jared and them fellas you can see why we're with them…Now those [unlabeled] kids see the abilities to rise even just one step so they can get through their day when they come with some of us, right? Not that they feel they're above this person, but if Jared's looking at them, they think that's a huge accomplishment. So they feel like they accomplished something in this whole day. And then there's questions that get asked.*

Many of the students who hang out with this EPA and the disabled students were very curious and felt comfortable enough to ask questions about Jared's communication style. Once this EPA believed the nondisabled teens established a good rapport with Jared, he left the room for periods of time, excusing himself to go do some photocopying. This gave them the chance to establish a stronger connection without the oversight of an adult. He felt this approach promoted the development of real friendships between Jared and his peers.

Others also recognized the mentoring role this EPA embodied. Another support worker commented on the relationship between Jared and his nondisabled friend Timothy. She said that Timothy sees Jared's EPA as a mentor. Timothy received lots of positive feedback from this EPA. Being connected to Jared and to his EPA appeared to give Timothy a strong sense of belonging and connection. It motivated him to stay in school and offered him a way to emulate the EPA imagining a career involving disabled youth. This EPA understood that he was not Jared's friend himself; instead, he worked to facilitate connections between students. Jared's EPA demonstrated this when he described how these two friends met.

> *I think they [Jared and Timothy] met on the bus. And Timothy just kept looking at him and kept looking at him and stuff like that. And then when we moved [to the high school] – I was only there three times and then I became friends with Timothy by just – we were doing the puzzle and I was joking around saying 'don't touch my puzzle or you're going to get it' type thing.*

This EPA created an environment that enabled Timothy and Jared to pursue their friendship. He did not ask a nondisabled peer to do volunteer work by befriending Jared. This EPA treated all students as deserving of respect. He did not treat all teens exactly the same way – he joked around with Timothy, was firm and consistent with Jared – nor did he treat anyone as though they were fragile. This EPA found a way to engage with all teens in ways that demonstrated his belief that all of them are normal, regardless of the role disability plays in their lives. This kind of equitable support was crucial to the friendship between Timothy and Jared.

The same EPA was also instrumental in supporting the friendship between Jared and Gavin. He recognized the many forms friendship can take, especially between disabled youth who use alternative communication strategies. He understood the nonverbal signs that are conveyed when people enjoy spending time together. Because Gavin was often around when Jared and Timothy spent time together at school and in the community, Gavin and Timothy also developed a relationship. So the network of friendship and support continues to expand for everyone involved. It was impressive to witness this intricate web of support.

Participants in this study highlighted a variety of ways that adults support the friendships of disabled youth. Instrumental support was key; however, advocacy and mentorship also made important contributions to establishing a climate of acceptance where friendships could flourish. Yet this was not the only role adults played in terms of the friendships of disabled teens. Each set of friends offered examples of adults who inadvertently crossed the line from support into surveillance.

5.3   Adult Surveillance

"They have similar experiences you know. They have similar rules placed on their lives" (parent). Adult surveillance seemed to find its roots in support, but shifted when the adults did not respond to changing landscapes in the lives of disabled youth. Nondisabled teens experience increasing amounts of time away from the gaze of parents, but disabled youth, particularly intellectually disabled youth, do not have access to the same level of privacy (Giangreco, Edelman, Luiselli, McFarland, 1997; Middleton, 1999; Morgan, 2005; Skar, 2003). One mother described her experience of negotiating the line between surveillance and support in this way,

Our kids are monitored all the time! And you know what I have really wanted to do with the Friday nights is give them a little bit more control. A little bit more of their own space. But some parents are opposed to it. And I don't know how we're going to cross that line. 'Cause some parents want there to be a no touching policy. And I think – a social group with a no touching policy? But, but, then I think if this is the only way we can have it am I willing to give on that? So it's difficult.

The tension between adult surveillance and support appears to be most contentious over issues of dating and sexuality. Although these are crucial topics for disabled youth (Shakespeare, 2006), they are beyond the scope of the current study. Analysis indicated that adult surveillance interfered with the development of friendships involving disabled youth. Surveillance was often couched in the discourse of safety and vulnerability.

In the context of this study, surveillance is used to describe situations where adults imposed rules or restrictions on the lives of disabled youth that were not in keeping with the demonstrated abilities of the teens. Adults in other studies were overprotective, imposing restrictions that impeded the friendships of disabled youth (Middleton, 1999; Turnbull, Blue-Banning, & Pereira, 2000). Meyer (2001) found that at times adults facilitated friendships, while at other times they unintentionally set up barriers to friendship by blocking connections or simply missed opportunities for disabled youth to interact with potential friends.

Most participants in the current study worked closely with EPAs during the school day. This relationship can slide easily from support into surveillance, or the perception of adult surveillance by classmates. For example, Rachel and her EPA worked together throughout her school years. Rachel's mother expressed some concern over their relationship.

[The EPA] is a wonderful woman and we are so fortunate to have her. And she knows Rachel inside and out and she doesn't let Rachel get away with anything. And she knows exactly what she, what her capabilities are with school. But they would be in school together a lot. In classes, walking through the halls together. Somebody pointed it out. 'Do you think teenagers want to be with Rachel where she has an adult with her all the time?' I said, 'you know I never [thought of that] – it wasn't an issue in primary because little kids love to be near an adult.' But I said in hindsight, I said, 'you're right.' We didn't see it. These are things that nobody tells you about until after it's over with.

Because this EPA was Rachel's constant companion no one questioned how their relationship needed to adjust to Rachel's evolving need for greater autonomy. Although

done with the best of intentions, this relationship may have interfered with Rachel forming closer relationships with her peers. In effect, having an adult constantly present marked Rachel as different from her nondisabled peers and may have contributed to Rachel's social isolation. Other parents in the study agreed that having an adult as a constant presence at school acts to isolate disabled students, in effect segregating them, even when they participate in mainstream classes.

Rather than forming relationships with other teens, some disabled youth create comfortable, safe relationships with their EPAs. Both Curtin and Clarke (2005) and Meyer (2001) expressed similar concerns, highlighting the distance created between disabled teens and their peers when an EPA acts more like a friend. During a focus group in that study it became apparent to Meyer (2001) that

> By adolescence, the other teenagers seem almost envious of the relationship between the student with disabilities and the teacher aide. Rather than seeing [the disabled teen] as disadvantaged in any way, they told us it must be great having an adult with you to do everything for you and be with you all the time – mentoring you and caring about you. They do not see that there is any space or need for them as peers or friends" (p. 27).

Although having a strong relationship with an EPA is important to disabled teens' academic and social success, that relationship does not and should not replace the friendships among peers (Giangreco, Edelman, Luiselli, & McFarland, 1997).

In the current study teachers were frequently identified as being too protective of disabled students, thus hindering their opportunities to engage in friendships. One teacher's overzealous desire to protect disabled students was described by a parent as follows,

> *She certainly did not have a mean bone in her body. I don't want anyone thinking that. I think she really felt she had to shelter the kids. She felt the high school kids would mutilate the kids. And I really had to push for her to give Lauren some independence. Lauren loved choir. Lauren wanted to eat in the lunch room. Lauren wanted to be able to take regular courses. So like any good mother, what Lauren wanted, Lauren got (parent).*

Lauren's mother advocated for a change in her school program, resisting the pressure from the teacher to segregate Lauren. The teacher was well-intended, but was not responsive to Lauren's expressed wishes, thus her actions – her adult surveillance – interfered with friendship.

Out of concern that Rachel would be further stigmatized at school, her mother chose not to disclose certain aspects of Rachel's medical condition to others. This constituted a form of surveillance, or at least adult control.

> *We didn't encourage Rachel to be open about that [personal care] because we thought that these were kids and they'd be cruel. And they wouldn't understand... I guess that's a personal preference, but I think that maybe I didn't give her friends, and her one good friend, enough credit for maturity. Maybe she could have accepted it. I think if that had've been a little more open she would have stayed in touch with that group instead of getting pushed to the side.*

Rachel and her mother both wondered if friendships would have been able to endure the transition to high school had they been willing to take the risk involved with disclosing personal information. This again demonstrates that desire to protect disabled youth from harm may inadvertently exacerbate social isolation. Meyer (2001) offered a similar example from her research, noting that teachers and EPAs often inadvertently blocked disabled youth from connecting with potential friends. One nondisabled peer in that study stated, "Some kids that would be [the disabled girl's] friend don't go near her because [the EPA] is always there" (p.26).

Perhaps erring on the side of caution on the part of education staff can be understood, in part, when one considers the risk of litigation if a disabled youth is placed in harm's way while at school. An EPA in the study completed by Davis and Watson (2001) described her concerns as follows,

> We're under a lot of pressure to teach [disabled students] properly, we can't let them out of the school on their own if we're unhappy about safety. There's a real fear of, there was a teacher at a school down south and she was sued because a child of hers was in an accident. She apparently hadn't taught the child how to cross the road properly. So that sort of thing is like a big axe hanging over you all the time (p. 680).

Although no one in the current study explicitly commented on fear of litigation, there were a number of instances when EPAs talked about needing to closely attend to disabled teens, particularly when in public spaces and around heavy traffic areas. When considered from this perspective the question arises about whose safety is served by such close attention – disabled youth or the adults paid to support them?

The sense of needing to protect disabled teens from experiences common to youth was raised in almost every interview with adults in the current study. One mother led her son

to believe that people with his medical diagnosis were not able to drink, nor were they able to get a driver's license. *"I don't want him to think that you have to drink to socialize."* This clearly crossed the line into surveillance. She argued that her son did not have the level of maturity required to engage in either drinking or driving (clearly not both simultaneously!), *"He still has a lot of maturing to do. And if it comes, fine. It may never come. And I'd rather that he didn't drink because I just think it's too dangerous."* This inclination to (over)protect is supported by research findings that report the increased vulnerability of disabled youth to financial abuse, to injury in pedestrian accidents, and to becoming victims of crime (Almack, Clegg, & Murphy, 2009). Typically as children transition into adulthood the responsibility for protection shifts from parents onto young adults themselves; however, this does not seem to happen as readily in the case of disabled youth (Almack, Clegg, & Murphy). The discourse around risk and vulnerability encourages parents to maintain a protective stance, while the disability rights movement promotes self-determination and autonomy (Sapis, 1999, Shakespeare, 2006). This clash of perspectives seems to further complicate the transition into greater autonomy for disabled youth (Almack, Clegg, & Murphy; Goodley, 2003).

5.3.1   Enforcing Norms

Surveillance involves clearly supporting a normative standard and taking action to ensure that the norm is not disturbed by the presence of disability. Enforcing norms was reported across all environments (home, school, community). Most of the examples invoked earlier to demonstrate aspects of stigma (Chapter 4) can also be seen as aspects of adult surveillance. Take for example Lauren's story about her friend not being allowed to eat in the cafeteria because "*she makes a lot of mess with her food.*" There is a tacit understanding about how much "mess" a person is allowed to make when they eat. As small children we are incredibly messy and that is seen as endearing, demonstrating how much the small ones need the adults' care. Yet as we grow up, dropping food, spilling things, or dribbling a bit on our chins invokes disgust. In the case of Lauren's friend, this meant eating in a completely separate space, away from the students who ate "normally." The adults involved clearly demonstrated surveillance by first deciding that the teen's eating behavior was unacceptable and then segregating her. This choice to enforce norms limited the time Lauren could spend establishing a stronger relationship with her friend.

The isolation that occurred for Lauren's friend did not come as a surprise to the adults who decided to separate her from her friends during meal times; however, there were many examples in the current study of unexpected consequences. When adults intervened on behalf of disabled youth, it sometimes had the paradoxical effect of further isolation. Many teens, perhaps in an effort to establish autonomy, react in opposition to adult directives. When Lauren's mother intervened to stop nondisabled peers from treating her badly, Lauren in effect became invisible: *"It [bullying] certainly decreased after that. But then it unfortunately put that Lauren was untouchable. So the complete opposite. So Lauren was basically ignored."* Her mother's intervention served to protect Lauren, but it also resulted in significant social distancing by her nondisabled peers. Instead of risking getting into more trouble, Lauren's classmates simply avoided interacting with her at all.

A similar story was raised by Amanda's mother regarding her year end class trip, demonstrating the complex dance between support and surveillance. Each time Sandra tried to close the physical gap between Amanda and her classmates at mealtimes, the nondisabled peers withdrew further. This spiraled uncontrollably throughout the trip. At one restaurant Amanda's mother approached a few of her classmates to arrange for a seat at their table.

> *So the tables there were crammed, crammed, crammed...Her friends, these friends that she thinks are her friends, are sitting right across from her looking me in the eye knowing they are not going to move and sit with her or let her sit with them. No one's going to shuffle… But not one of them would have sacrificed the others to be with her right? Not ONE of them. So she's in tears again.*

All attempts to intervene were met with resistance from nondisabled peers and seemed to have the unfortunate consequence of increasing the stigma Amanda experienced. Was the resistance of the nondisabled peers about excluding Amanda based on her disability? Was it about pushing back against an adult's interference in their social world? Did it originate in the embarrassment of unwanted attention? What informed the actions of the nondisabled girls in this scenario was difficult, if not impossible, to ascertain. Regardless of the intentions of these nondisabled girls, Amanda and her mother interpreted their actions as rejection. Direct adult interference in everyday youth conflict seemed to complicate the situation by further isolating the disabled youth from their peers. Meyer (2001) recommended that adults find ways to restrain themselves from mediating during uncomfortable peer interactions, though each situation must be

considered in terms of weighing out the potential risks and benefits from the perspective of the disabled youth involved.

5.3.2 Resisting Adult Surveillance

The same action by an adult can be perceived as surveillance in one context and as support in another. How can this difference be understood? Perhaps one of the most obvious ways of defining the boundary between these two concepts is by attending to resistance expressed by teens. It is possible that teens react negatively to support as in the example where Sandra supported Amanda by literally trying to find her a seat at the table. The nondisabled teens she approached perceived this same action as surveillance and resisted her efforts. If teens feel they are under surveillance, many will respond with acts of resistance (Watson & Davis, 2002). Disabled teens involved in this study indicated that they wanted to have more time away from the well-intended gaze of adults, especially at school and in community-based recreation activities.

The rules that exist in many recreational venues were troublesome to a number of the participants. When asked why they preferred one recreational venue over another Brandon and Jay were quick to identify rules as the biggest problem. They were particularly resistant to rules that diminished their autonomy. Any interactions where disabled teens felt their maturity was called into question were contested. In the following excerpt Jay disputed the notion that a man would have to ask anyone for permission to go to the bathroom, as youth were required to do in one social club. He clearly identified himself as a man who does not require this kind of surveillance.

> *Interviewer: What do they have rules about?*
>
> *Brandon: Work! Safety… It's safety rules.*
>
> *Jay: Brandon the basic rule is that you can't use the washroom without asking for permission.*
>
> *Brandon: That's a huge safety issue.*
>
> *Jay: I don't get that. 'Cause there's a saying that when a man's got to go he's got to go. When they say you only can go with their permission, then that doesn't really work.*

Adult concerns about safety collided with Jay's need to be an autonomous person, capable of making his own decisions, especially about something so fundamental as when and how to access the bathroom. Rules infantilized (and infuriated) him.

Reminiscent of Jay's comment about being a man, Rachel wanted to be seen as an independent young woman, especially during a trip to attend a concert where she met one of her favorite musicians. Although she appreciated the support of her family in getting her to the concert in another province, she wanted them far away when she met the singer:

> Rachel: I didn't want my family to be anything. I wanted it to be me. Like it was my thing. But they wanted my family in [the photos]. They wanted them to be part of it, which was great. Which was fine. But I wanted to do it myself!
>
> Interviewer: At the time it was a little irritating? You didn't want to share?
>
> Rachel: Even if they could have just dropped me off and then gone to their seats.
>
> N: [laughing] 'leave me be!'
>
> Rachel: But that was kind of one of my concerns when I found out I was going, was am I going to do this myself? 'Cause I want to do it myself.

The desire to establish oneself as an autonomous agent surfaced in all of the interviews with disabled youth and in all of the observation sessions completed as part of this study. This is consistent with the Skar's (2003) research where participants described their frustration at being treated as children by parents and personal assistants. A young woman in Skar's study described her desire for greater freedom then added "after all I'm 18 years old" (p.642). Like Rachel and Jay, this young woman felt ready to establish more distance from her parents and to take on greater responsibility, resisting the messages that disabled teens are vulnerable and in need of protection (Davis & Watson, 2002).

People react to surveillance in different ways. Some participants used humor as a form of protest against what they perceived as surveillance. One EPA laughed as she recalled a reference to the Simpson's animated sit-com on television, *"Jesse told me at times that I need to stop nagging him or my hair will turn blue like Marge's."* In addition to having EPAs at school, a number of participants have in-home support staff who spend time with them when their parents are out. Gavin, a guy with a devious sense of humor,

seemed to get fed up with this constant surveillance, so he decided to go undercover – literally. His respite worker told this story.

> *Respite worker: He still talks about one time I was looking after him years ago and he hid. I couldn't find him.*
>
> *Interviewer: Where was he?*
>
> *Respite worker: He was under the bed. I ran down to the lake. I ran up the side. I was just – sometimes he wanders off in the woods. He's fine enough that he used to go down to the lake to look for frogs. So I booted 'er down there and I ran back and searched the yard, searched the house.*
>
> *Interviewer: How long did he stay hidden?*
>
> *Respite worker: Only 10 minutes [laughing]… I was just like, "I can't believe I lost him"… I came back and he was sitting on his bed. He laughed and laughed. I said, "What were you doing?" So if you ever hear him say, "Were you hiding from me?" or "Were you hiding from [respite worker]?"–*
>
> *Interviewer: that's what he's talking about!*

Humor proved an effective tool for prompting support staff at home and at school to ease up on the amount of direction they were providing. Normative expectations can be disrupted by a humorous comment or action in a way that does not elicit a defensive response in the person whose behavior may be the object of the joke (Meyer, 2000). In the case of the above scenarios humor served the dual purpose of expressing dissatisfaction about surveillance and simultaneously creating an opening for the adults to reflect on the amount of surveillance they were imposing on these disabled teens.

Then there is the age old strategy of withholding information from adults to pre-empt surveillance. A classic example was offered by Jay's mother.

> *One day when Jay was taking the bus to swimming on his own... He fell asleep and he went way, way past his stop. And he had his cell phone with him and he knows he's supposed to call when he gets to [the pool], which usually he gets there at about 5 to 5 or so. So he still called me at about 5 to 5 and he said, 'ok I'm at the pool.' I didn't find out until days later that he was nowhere near the pool. But he knew enough to call me, reassure me that he had gotten there, and then just walk back…He got to the pool. He was 10 or 15 minutes late, but he had already called me and told me he was at the pool, so that was ok. We sort of discussed that. I said, 'you handled it really well, but the reason you have the cell phone is so you can call me and tell me when you're in trouble.' 'But I wasn't in trouble mom. I knew how to deal with it.'*

Jay was perfectly capable of handling an unexpected situation. Once he woke up and got his bearings, Jay addressed the priority item – contacting his mom so that she wouldn't be worried about him. Once that was dealt with he made his way to the pool. Jay clearly showed the ability to problem solve without consulting with an adult. He discerned between a real problem (being lost) and a simple inconvenience (walking an extra kilometer).

When Jay's mother reflected on the incident she framed his strategy as what one would expect from a nondisabled teen.

> *I thought, how normal that is, you know. How absolutely normal. We discussed the whole thing but, but really I thought, 'that's not bad.' That's not bad. He handled it. He handled it in a pretty normal way. He tried to minimize the stress on me [both laughing]… But then the interesting thing is that he did tell me about the whole thing a few days later. You know, after it was all over.*

Jay's resistance to surveillance in this situation made it possible for his mother to reconsider the amount of surveillance she was comfortable with. Jay's success at handling an unexpected event demonstrated that his abilities exceeded his mother's expectations. This act of resistance led to a greater experience of autonomy for Jay, and to his mom's ability to reduce the level of surveillance she offered. The ability to access the transit system on his own opened up destinations around the entire city to Jay. He could arrange to meet up with his friends or go out to a whole array of recreational venues without relying on his mother for transportation. This gave Jay an incredible sense of freedom.

One of the most subtle forms of resistance was avoidance. Cassidy often stepped outside at lunch time instead of staying in the lunch room at her high school in what appeared to be an effort to move away from the close supervision of adults at school. Similarly Brandon stopped attending an adult-organized recreational venue. It seemed that his decision not to stay involved was based on his aversion to people pushing him to perform. Although all teens used avoidance, it was perhaps most apparent among participants who used alternative communication strategies. They simply stayed away from people who were too forceful or demanding. For example, both Jared and Emma would both simply walk away from people who were too directive. Silence speaks volumes once people learn to listen.

Although resistance can be quite subtle, there were many examples of disabled teens explicitly voicing their displeasure with adult surveillance. Brandon's mother reported his demands that she leave immediately after dropping him off at his weekly social gathering. Much to his dismay she occasionally volunteered as a chaperone. She described one incident of resistance as follows,

> *I was sitting at a table and I was playing cards with Frank…Brandon came over, and made me change seats with Frank so my back was to them dancing. Because he would not dance if I was looking. He just didn't like the way I was looking over there and checking things out. You know like, 'you have to be here, but–'… he'd rather I just stayed in the car and dropped him off. But you know, if I go downstairs he said, 'ok you can go now. Get lost.'*

Although chaperones are common at junior high and even high school dances, many people attending this social club were over 19 years old. They expressed much interest in exploring sex and sexuality. Constant surveillance interfered not only with friendships but also with romantic relationships. Organizers of the social club faced incredible pressures to provide a safe environment where disabled young people could connect in meaningful ways. The demands for privacy and autonomy by disabled youth had to be balanced against the concerns about safety from parents. This scenario captures the essence of the struggle to find a balance between surveillance and support – a strained negotiation between adults and disabled youth.

> *Everybody's comfort level is different. I mean my feeling in thinking about it a lot these days is we need to talk to the kids about it. And we need to say, 'does this make you uncomfortable? Are you ok with this? When you are not, when you are seeing Jay and Terri with their arms draped over each other's shoulders on the couch, do you mind that? Does it make you uncomfortable? If somebody else comes and drapes their arm over your shoulder, do you mind that? Does it make you uncomfortable?'… I think we need to start empowering them to say what's ok with them and what's not ok with them… I appreciate that the line needs to be drawn somewhere, but I think we help the kids draw it. We say, 'ok in this social setting, what's ok. What's not ok?' And we work it out. But that's somewhere a little cozier than absolutely no touching, but short of anything overtly sexual. You know, what's appropriate in a group social setting?*

This balance between surveillance and support often involves sorting through different adult perspectives. For example, if one parent believes the social group is the only viable opportunity for an intellectually disabled teen to have to establish dating relationships, then she might be more open to teens dancing close, hugging or holding hands. Other parents might be incredibly uncomfortable with any level of physical

contact and view it as potentially exploitive. Sorting out the balance between adult support or control presented an ethical dilemma that ultimately shaped the friendships of disabled teens.

5.4   Reflecting on the Balance Between Surveillance and Support

"It's a really difficult balance, giving them independence and keeping them safe"
(parent). Many situations that arose during the course of data collection demonstrated how blurred the line between surveillance and support can be. For example, all the guys attending a disability specific camp wore identical brightly colored shirts with the name of the group stamped on the back. On one level this could be viewed as surveillance given that the shirts identified the guys as a group. This made it easy for the adults to keep track of everyone when they were out in the community. At the same time the shirts could be interpreted as overt labeling of disabled teens that could contribute to further stigmatization. Yet these same shirts helped to diffuse the negative reactions many people have upon encountering the group. Not only was this a group of teenagers – something many people dread – but they were a bunch of guys who were not concerned about normative expectations. They were sometimes quite energetic and enjoyed playing on equipment that most teens only visit under the cover of darkness, such as swings and climbing structures on playgrounds. The arrival of these young men created tension in people they encountered on their outings. In this respect, wearing the brightly colored shirts seemed to shift the expectations. Boisterousness seemed to be more readily excused. When nondisabled people recognized that the guys were part of a disability group, the defensive body language typically (though not always) appeared to ease. When approached from this perspective, wearing the labeled shirts can be understood as support rather than as a mechanism for surveillance.

Finding this balance between surveillance and support happened at a group level as described above, but it was also part of ongoing discussions between disabled teens and their families. Brandon and Jay clearly wanted to be viewed as mature, autonomous individuals. They were involved in intricate negotiations with their parents around what level of support fits in different situations. Their parents had no problem leaving each guy at home on his own, yet they were reluctant to leave them unsupervised when they were together, *"just because the two of them together have just a little bit less sense than either of them individually [laughing]."* Brandon's mother explained that this

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decision was based on their maturity level. When the friends were together they tended to come up with some interesting ideas and needed a bit of redirection. Jay's mother told the story of how the guys each did well catching the city buses on their own, but when they are together on the bus, they get completely engrossed in their conversations and often miss their intended destinations.

> *They used to take the bus home from [high school] one day a week and I would meet them at the bus stop. And there were SO MANY TIMES when they did not get off the bus. They'd be talking away. I'm standing at the bus stop. I see the bus coming. I see the bus go by. I see their two heads and I'm running after the bus. And usually, well always, they'd realize it within a stop or two and then I'd see them trudging back towards me, still talking a mile a minute.*

Why did this mother wait for them at the bus stop? If they always recognized they went too far within one or two stops, could they not have been left to sort out missing the stop on their own? Yet when one puts this situation into context, the bus travels along a very busy city street where several vehicle-pedestrian accidents happen each year. The guys tended to take the path of least resistance (or the path of fewer footsteps), so their parents were justifiably concerned that they would cross the four lane street somewhere other than the cross walk. Finding the balance between the safety associated with surveillance and the freedom of support was challenging for everyone involved.

The need for teens to have time away from watchful adults is broadly recognized (Murray, 2002; Middleton, 1999; Shakespeare, 2006). All of the participants in this study sought out time alone, both at home and at school. For example, Sabrina and Cassidy enjoyed the time they were able to spend away from adults during lunch break.

> *Sabrina: We're alone at our lunch hour now.*
>
> *Interviewer: Yeah. And that's really good?*
>
> *Sabrina: Yeah.*
>
> *Interviewer: So, is, does it make a difference when there's adults around and when you're alone at lunch time?*
>
> *Sabrina: Yeah.*
>
> *Interviewer: So how is that different?*
>
> *Sabrina: Because it's quiet and we can be on our own.*

Interviewer: Yup. And so what do you do when you're on your own. Just the two of you at lunch time?

Sabrina: Mmm. Just our own little privacy thing, like emails.

The importance of moments of privacy cannot be underestimated. For Sabrina, having a few minutes to read and respond to emails gave her a sense of being mature, of being acknowledged as someone who has a private life. The guys at summer camp needed to experience the freedom only available through the provision of supportive staff. Brandon and Jay wanted to have greater privacy and autonomy both in their friendship and in exploring dating relationships.

5.5   Negotiating a Balance Between Surveillance and Support

How did adults and teens in this study work through these differences? Including disabled teens in the decision making process was one strategy used to help balance the power in the relationship between teens and adults. Teens involved in the social club engaged in collaborative decision making around how the evenings would be set up, what activities would be available. One parent described the importance of disabled teens participating in making decisions:

> *I sort of see it in a way as a little bit like hanging out at the mall. These kids never got to hang out at the mall with their peer group. And this is the closest thing to that. And again you know we've got to structure it and their parents have to bring them, drop them off and pick them up. And we have to have an activity and all of that. But that, particularly the Friday night social, as much as possible I've tried to let them take the lead in organizing what they want to do. It's the closest thing they have to a sort of loosely structured peer group where they kind of get to choose who they want to hang out with.*

Allowing lots of room and time for teens to connect at their own pace and in ways that feel comfortable to them was an important strategy. Having a critical mass of people also contributed to the success of the social events— meaning that there were enough people involved in an activity so that each person had a good chance of finding someone they enjoyed spending time with. All of these factors helped create supportive social situations where friendships could become established.

5.5.1   Getting Out of the Way

One of the most effective strategies to remain supportive of disabled youth and their friends was simply for adults to get out of the way. Meyer (2001) stated, "Adult mediation

[of friendship] does not necessarily involve teaching adults to do a lot of different things, but may instead involve teaching adults to restrain themselves so that they do not interrupt or interfere with natural peer interactions" (p.25). Although it sounds straight forward, getting out of the way required incredible skill, a great deal of self control and trust. Adults who were able to do this managed stress well and were comfortable letting disabled youth fail. They viewed failure as a necessary part of growing up and maturing. Adults able to stay in the background also demonstrated a high level of trust in disabled youth. The very act of making room for failure (or success) communicated volumes to disabled youth about how the adults in their lives viewed their abilities. If adults stayed out of the way it conveyed a sense of confidence in the ability of the teen to handle the situation they were in.

Many adults carefully observed at a distance, staying out of the way, while remaining close enough to guide the disabled youth to the next stage in friendship formation. Jesse's EPA noted that most of the initial interactions between Jesse, Alexandra and Sean involved computer games where the rules were clear and the activity defined.

> *It started with 'we're playing a game.' Very little conversation passed back and forth. And then it slowly grew into talking to each other and then teasing each other and then we reached the point where it was time to take it out of the space.*

Because this EPA was in the background surreptitiously observing the early stages of this friendship, she could see how relaxed Jesse was with his friends in the safe environment. Once the friendship was well-established she then prompted the friends to join Jesse for lunch. Here again, she remained close at hand to support the developing friendship. When it became clear that the teens were doing well on their own the EPA came up with lots of reasons to give them their privacy. Eventually the friendship extended well beyond the boundaries of school into home and community venues using this same approach – moving closer to provide support during the transition, then getting out of the way to give the friendship room to grow.

Jared's EPA had a unique approach to negotiating this boundary in that he often let things unfold between disabled teens and their friends, trusting they would work things out. He offered this example,

> *Let's take my lunch crew. When my lunch crew's there, there's no adult supervision that will sit there and go 'don't do that. Stop doing that. Leave him*

alone. Don't bug him. You shouldn't be talking to him like that because he doesn't like it. Gavin you should leave him alone.' Because that makes no sense. We're in there and if Gavin's being a goof, if Timothy's being a goof, if Jacob and all the other kids plus the special needs are all being goofs together that's the reality of school. I'm not going to sit there – and hey, I'm the goof too. I mean there's a good many times that we wrestled and we tickled people and we make a mess of the place. But if it's only me and the kids who don't have the special needs who are doing it, then I'd find something wrong, then I'd say no we can't do that because it's not appropriate. But if it's me and the other kids and the special needs kids and everybody's all – there's eight of us there and we're all carrying on and we're all being loud and we're all getting in trouble and everybody's doing this. Yeah, that's reality.

Here the EPA created a space where disabled teens could actually get into trouble with school administration. He viewed this as something that happens to all teens in school, so why should disabled teens be excluded from getting into trouble and getting kicked out of class by teachers for being rowdy or disrupting classmates by flirting. This EPA stepped back and allowed – or perhaps sometimes encouraged – teens to be teens.

Both of these EPAs established welcoming environments for disabled teens and their friends. They used humor and offered the friends lots of support as well. The following exchange between Jesse's EPA and his friend Alexandra clearly demonstrated their mutual affection and the kind of support the EPA offered everyone connected to Jesse. In this group interview excerpt the EPA and Jesse's friends discussed an incident from gym class earlier that day.

Alexandra: Please don't tell me you saw my wipe out [to EPA].

EPA: I did Alexandra.

Interviewer: she's still fairly traumatized by that [laughing]

EPA: it was a very gentle wipe out: It was like a slow motion, falling to the ground. It was very–

Interviewer: elegant?

EPA: Yes! Like a ballerina [laughter].

Alexandra: Well let's just say –

Interviewer: It didn't feel like a ballerina?

Alexandra: Let's just say Ben, Aisha, and Jesse seemed to have found it funny.

EPA: Oh well.

Sean: Aisha would find anything funny!

EPA: Yeah, but Alexandra let's be honest. If Jesse had fallen and you knew that he was ok, what would you have done? [all laughing].

Although Jesse's EPA was more cautious in her approach, there were many things she and Jared's EPA had in common. They both espoused the same philosophy. She described it this way,

> *If you want them to be treated by their peers as anybody else then you have to step back and let them take their lumps…You have to stop and think about what your job really is. And really somebody once said this to me and they're right, our job is to work ourselves out of a job.*

Both of these EPAs were well on their way to accomplishing this goal. The young men they supported were establishing strong connections to others and were gradually moving away from the one– on– one support they needed earlier in their lives– in no small part due to adults giving them room to succeed. This required also having room to fail.

Siblings were an incredible resource to parents in terms of helping the adults get out of the way of friendships. There were many instances when nondisabled siblings prompted adults to shift out of surveillance mode.

> *Parent: As they've often told me, 'he's not a baby anymore.' But you know, we do tend to baby our special needs kids…You know, you just tend to do those little things, like you know, you tie the shoelaces longer. You're zippering up his jacket and like, 'Mom, I hope you're not doing that at school.'*
>
> *Interviewer: [laughing] So they're also telling you what the rules are. "These are the rules of behavior mom."*
>
> *Parent: You know, that sort of thing. I was just very fortunate that he had siblings I think. Because they tell you, this is not something you would ever do in public.*

It was crucial for parents to recognize the limits of their knowledge. There was so much about youth culture that was not accessible to most adults – the language, the quickly shifting clothes trends, the music, and the cutting edge technologies. Siblings and their friends were an invaluable resource about how to be cool. One mother acknowledged that this insider information was an incredible opportunity to be supportive – again by getting out of the way and letting the experts on youth culture work their magic.

Parent: You know I can teach him things. I can teach him how to be cool to [a point], but your head space is just not there… And you can never be there. I just think a parent who tries to be the best friend, you just don't – I mean it's good to be friends – you just don't, you can't know what the conversation is, or what the little secret things that happen. They're not secret, they're just –

Interviewer: The inside knowledge.

Finding this elusive point of balance, providing support without straying into surveillance was an extraordinary challenge for adults involved in this study, as it is for most adults involved in the lives of all teens (Alles– Jardel, Fourdrinier, Roux, & Schneider, 2002). Much of the research addressing the involvement of EPAs describes the negative implications for friendships of disabled youth associated with this constant adult presence (Davis & Watson, 2001; Giangreco, Edelman, Luiselli, & McFarland, 1997). Yet this was not the case for most participants in the current study. The EPAs in their lives were the adults who identified potential friendship partners and then found many innovative ways to support those friendships, including getting out of the way once the friendship became established.

5.5.2   Characteristics of Support

What were the main characteristics that defined adult support in this study? How can it be differentiated from surveillance given that these two actions are so easily blurred? As noted earlier, support does not tend to evoke the resistance of disabled youth. A number of other factors also appeared to be specifically associated with support. These included: being responsive, being proactive, collaborating, demonstrating respect, and offering gentle guidance.

a)   Being Responsive

Support was responsive or flexible. For example, Emma's mother talked about how she had to shift her perspective on inclusion in response to Emma's experiences. In junior high Emma's parents wanted her to remain in regular classes, but Emma was very unhappy in this situation. Emma experienced difficulty sleeping and cried constantly. Although Emma could not verbally tell them what was wrong, it didn't take long for her parents to identify the source of her distress – being completely isolated in a regular classroom where she didn't feel accepted by her peers. Emma's mother reported that her daughter preferred the learning centre where she met many other disabled students who remained close friends years later.

She seems happier. Junior high was not that happy. It was just trying to figure out where you belong. Like we were trying to, we as parents were trying to get her into the regular classroom more and she wasn't all that happy. But by high school you realize that she's just happier [in the learning centre class]. Definitely.

Similarly, participant's in Middleton's (1999) research described aspects of emotional support provided by adults in their lives. They felt it was important for adults to recognize when disabled youth were unhappy and then take the time to listen to their concerns. Youth in that study wanted to talk about what it meant to be disabled with trusted adults who would take their concerns seriously. Emma's mother followed Emma's lead, paying attention to what was important to Emma – feeling relaxed and happy. This was not a simple decision for Emma's parents since they wanted her to remain in the 'regular classroom.' Moving Emma into what essentially was a segregated placement meant her parents needed to revisit their commitments. They needed to find ways to support Emma within the constraints of the education system.

Similarly Jared's mother found that some of her expectations had to change in order to focus on what mattered most to Jared.

I see the quality of Jared's life in the social aspects that he has from it right now. The academics aren't that important…But if he goes out on a work site and he has friends that he can be with and he enjoys that, and he's not mad every time he goes, that's a good thing. And that's the social part for him. And I think that's what I hope for him – that he's happy and that his quality of life is enhanced by the people that are around him, not by being on his own. So I have to lower my expectation for some of the things that I'm not happy about, but I can't keep up with all of them either.

Flexibility appeared to characterize adult support for both disabled and nondisabled youth. Jared's EPA argued that flexibility lies at the very heart of what it means to be inclusive. When environment, routines, communication approaches and activities are all flexible disabled youth are more likely to experience a sense of belonging (Gordon, Feldman, & Chiriboga, 2005; Meyer, 2001; Priestley & Rabiee, 2002).

Sometimes, no matter how well adults orchestrated an encounter, how ideal the activity and the setting were, how similar the interests and abilities might be, some people simply do not connect. One parent put it succinctly, *"We couldn't make their friendship work for them."* It wasn't until years after first meeting each other that Brandon and Jay demonstrated a mutual liking, described by Jay's mother in the following interview excerpt.

They were both signed up for Special Olympics swimming. And I think that was really – because they saw each other every week and got a chance to just kind of fool around and, you know in a, in a supervised, but loosely supervised setting. Where there was lots of chance for them to share jokes and so on. And I think we were taking them together too. We were sharing the transportation, so they were traveling back and forth together. And that's really when things started to come together for them. And they reached a comfort level where you know they could, well they discovered they had a lot in common…And things took off.

An adult taking the responses of disabled teens seriously was part of all of these examples. Carefully attending to how disabled teens connect (or don't) mattered. Just because the indicators were all present that a friendship could happen did not guarantee success; however, Brandon and Jay's story also indicated that revisiting potential friendships at different points in time can be worthwhile.

b)   Being Proactive

Adult support was characterized by the ability to anticipate what demands the next stage of life will bring. One mother described it this way,

I'm always seeing three years ahead. The high school thing is already done. Yeah transition. So where is she going to be, you know housing, education, employment, transportation, recreation. Like what are we going to do? So my planning's not done, but I'm working – these next three years I will be working on that.

How social policies shaped the transition from high school for disabled youth garnered much attention from the parents of disabled youth. They recognized that working within or contesting these policies required months if not years of delicate negotiations with people from multiple systems (e.g. Department of Education, Department of Health, Department of Community Services). Incorporating strategies for initiating or sustaining friendships was raised as an important dimension of the transition plan. The friendships of all the disabled teens involved in this study depended to a large extent on government policies and available resources. The parents of Jared and Gavin lobbied the government to establish a group home for them in the community. This would have allowed Jared and Gavin to move away from home, while maintaining stable friendships. Emma and Lauren were also concerned that their friendship would decline after graduation. The labels assigned to these girls meant that one could go to community college, while the other had to go on a long waiting list for a supported work program. Their destinations after high school would completely separate them. Although this

happens for many teens as they transition out of high school, there is a substantial difference. Nondisabled teens choose from a range of options; whereas disabled youth, particularly intellectually disabled youth, often have no choice at all. If friendship became a more prominent element in the transition planning process, parents hoped that the friendships of disabled youth could be more sustainable.

c)   Collaborating

Adult support was collaborative. Friendships seemed to be more likely when all of the adults involved in supporting a disabled teen shared the same vision and worked together with the teen to make it happen. This approach seemed to reduce the experience of burn out in parents, gave educational staff a sense of accomplishment, and the friendships of disabled teens became well-established. This was exemplified in the friendship between Jay and Brandon. A few years ago, when deciding which high school Brandon would attend, his mother relied on the research done by Jay's mom. They opted to choose the same high school for these friends, both to encourage their academic development and to maintain the relationship. This decision was described by Brandon's mother.

> *We were deciding between [two different high schools], which school should he go to?... [Jay's mother] went and visited both schools. And she had interviews, talked to the teachers and all that. And I remember saying on the phone, and she said, 'where's Brandon going to go?' And I said, ' you're doing all the research. Wherever Jay goes Brandon will go.' And it was just like this great big responsibility was taken off my shoulders because the friendship I felt they should go to the same school…she did all the research. She has good judgment. I could go with that.*

This kind of intensive cooperation was also evident in some the relationships between parents and EPAs involved in the study. The two friendships where this form of collaboration was most obvious involved disabled teens who could become distressed in unfamiliar situations. Perhaps this dimension of impairment required adults to engage with one another more intimately. The trust between Jesse's mother and his EPA was apparent during the participant observation sessions. They planned these community outings together, based on destinations the friends identified. The adults demonstrated much mutual respect and liking. They talked and laughed easily while Jesse and his friends engaged in a highly competitive round of glow-in-the-dark mini-golf. They reflected on how far Jesse and his friends have come over the past few years in a

relationship that started with briefly playing controlled computer games in a quiet room at school. This dramatic evolution in this friendship was in no small part due to home and school equally supporting these teens.

d)	*Demonstrating Respect*

Respect is a hallmark of adult support for the friendships of disabled teens. Jared's mother noted that both his EPA and resource teacher approached all students with respect.

> *[The resource teacher is] very respectful of all kids. But she again knows how to deal with kids, especially kids at risk or kids that have problems. She treats them all the same. They're all on equal ground. They all have the same degree of respect. They're not treated any differently… I think that she has provided a framework for kids to all come to the learning centre and be able to engage there even though they don't 'belong' in the learning centre necessarily. They are allowed to come there and congregate. Which is good and bad. It takes away from the kids who really need the learning centre and the resource centre from a learning or academic profile, but it's built that relationship for the kids who need friends.*

Making the learning centre a space where everyone is welcome reduced the stigma of this environment while it simultaneously enhanced the friendship opportunities for disabled and nondisabled students.

Respect was also about acknowledging that disabled youth were in the process of becoming adults. Jay's mother demonstrated incredible respect for the ability of disabled youth to engage in decision making and to take on the responsibility and excitement of dating and sexuality.

> *I mean one of the things that he has had the hardest, the most trouble coming to grips with is he's not going to have a relationship with somebody who does not have an intellectual disability. It's just not going to happen. Yet often that's who he's attracted to. And again he thinks he does have a rapport with them. And again, you talk about not being able to have a friendship with someone who's not intellectually disabled, well he's certainly not going to have a romantic relationship. Like that is like the last frontier. Nobody's going to cross that one. They aren't. It's not going to happen. And it's very hard to get that across to him. And I feel cruel [laughing] every time I do, you know. I just feel cruel, you know to say, "Oh yeah Jay you're great. You can do lots of things. You're just like everybody else. But you're never going to have a romantic relationship with a girl who doesn't have an intellectual disability. So don't even look there."*

Parents often had difficult conversations with disabled teens about how norms and stigma shape their friendships and romantic relationships. Jay's mother did not stop him from pursuing connections with nondisabled women. With gentle guidance she tried to help him understand why his interest, both friendly and romantic, was not reciprocated by nondisabled women. This kind of respectful guidance was demonstrated by all of the adults in this study. They empathized with disabled youth and understood the ways stigma interfered with the friendships of these teens.

Making sure disabled teens had choices available to them was another way of demonstrating respect for their evolving autonomy. This could be as simple as decisions about hair color, clothing, music, or recreational preferences. Participants in the current study often negotiated these decisions both with adults and with friends. For example, after much debate about which hair color would make them more attractive, Jay dyed his hair black and Brandon dyed his red. Respecting Jared's choice to wear sweats and a t-shirt every day helped him stay calm and relaxed, thus available to interact with his friends. Encouraging disabled teens to stretch their limits in terms of expanding recreational choices gave friends plenty to talk about later on MSN or Facebook – especially after trying something completely new like adapted paddling. Like findings reported by Rabiee, Sloper, and Beresford (2005), supporting the choices of disabled youth created opportunities to build confidence and strengthen friendships.

5.6   Chapter Summary

In this study support refers to the activities adults engaged in to promote the friendships of disabled teens, while respecting the emerging autonomy of the youth. Turnbull, Pereira and Blue-Banning (1999) found that parents of nondisabled children provide a range of supports that included organizing recreational activities, coordinating social opportunities and supervising relationships with peers. Adults in the current study engaged in similar activities to promote the friendships of disabled youth. Support for the friendships of disabled teens took many forms ranging from instrumental or practical support, to advocacy and mentorship. Adult support offered in the early days of a friendship tended to continue on in order to maintain these friendships over time. According to LaGreca (1990, 1992) the support offered by parents and friends differs, with family providing more of the practical support and friends offering higher degrees of companionship. In contrast, Antle, Montgomery, and Stapleford (2009) found that

parents, mothers in particular, were the most important providers of all types of support in the lives of the disabled young people in their study. Instrumental support from adults was recognized as crucial by disabled youth as they worked on developing friendships with new people both in terms of developing a strong set of social skills and in terms of having opportunities to meet potential friends, disabled and nondisabled (Middleton, 1999). Findings from the current study are closely aligned with those of Turnbull, Pereira, and Blue-Banning (1999) and Antle and her colleagues in terms of mothers' support being crucial. Without these women, the disabled teens in the study would not have had the social clubs, the summer camps, or the weekend trips to visit friends. Additionally, the support provided by EPAs was key to identifying potential friends and then creating environments that allowed the friendships to flourish across multiple environments.

The protective instincts of parents were often rooted in experiences of discrimination against disabled teens, a finding that was consistent with Baker and Donelly (2001). This history made it particularly challenging for parents to remain supportive without becoming over-protective. Surveillance was reflected in situations where adults crossed into the realm of control with respect to the friendships of disabled youth; where over-protectiveness limited the autonomy of teens. The tension between support and surveillance that adults and teens need to negotiate was not identified by Antle and her colleagues (2009); however, it was strongly present in the current study. Disabled teens, not unlike their nondisabled counterparts, had a wide range of strategies to draw upon in order to demonstrate resistance to adult surveillance. Participants in this study effectively used humor to point out moments when adults were interfering with their friendships. Although some opted for subtle approaches like avoiding situations, others did not hesitate to explicitly state their opposition. Subverting authority by leaving out details was common. Many stories highlighted the need for adults to see disabled teens as having the ability to make their own decisions as autonomous young people. The teens clearly knew who they preferred to spend time with and what activities they enjoyed doing with their friends. Although they appreciated the chauffeur services of the adults in their lives, disabled teens wanted to be able to have time where they were not monitored, time where they could just hang out with their friends. Adults interviewed continually questioned their roles and how their involvement affected the friendships of disabled teens. Adults involved in this study were receptive to these messages and

demonstrated the flexibility needed to shift out of surveillance mode and back into providing the support needed for the friendships of disabled teens to succeed.

One mother made a sobering comment about the surveillance of intellectually disabled youth.

> *That's the sad thing about their lives that somebody else, whether it's their own family or an institution is probably always going to control a lot of their lives. It's a really sad thing. But again, it's going to be to keep them safe. I mean I really want to minimize the control and still provide enough safety that nothing horrible happens. But you know I heard another phrase, because I was talking to [a woman] about all this. And she used the phrase, 'the dignity of risk.'*

The phrase "dignity of risk and the right to failure" was penned by author Deegan (1993). It was her frustrated response to paternalistic treatment she experienced after being labeled with mental illness. This phrase captures the belief that disabled people have the right to make mistakes rather than living under the burden of constant surveillance argued to be for their own good, for their protection. In a society where risk management is constantly fore-grounded, Mitchell (1994) argues that without the counter balance of risk enhancement we are paradoxically exposed to substantial harm, the harm of having no sense of control over our own lives. "Older people have taught me that making mistakes is life's way of teaching. I have been reminded that art, invention, freedom, friendship, love, triumph, and discovery are the fruits of failure and risk" (Mitchell, 1994, p.10). Almack, Clegg, and Murphy (2009) describe the similar processes of negotiation between parents and disabled youth in their study. Parents struggled with providing just the right amount of support and protection as disabled youth moved into adulthood, took more risks and demanded greater personal autonomy. Findings from the current study suggest that exposure to risk is a fundamental aspect of making friends.

The dignity of risk does not preclude the need for ongoing support from key adults in the lives of disabled youth. A participant from Middleton's (1999) study offered this comment, "There was one teacher, she was very supporting of me trying things. She said, 'give it a go. It doesn't matter if it doesn't work out. At least you'll have tried.' It took the pressure off somehow" (p. 17). The dignity of risk moves adults toward respecting the emerging autonomy of disabled youth and was raised as a crucial dimension of adult support by participants in Middleton's study. Respecting privacy, recognizing individuality, focusing on abilities, and including disabled youth in all decisions that affect

their lives were listed by participants as key ways that adults could demonstrate this respect (Middleton).

The right level of adult involvement supports the friendships of disabled youth. But the stories of these friendships do not hinge solely upon the adults surrounding participants. The disabled teens themselves were actively engaged in disrupting oppression through a variety of mechanisms in order to create lasting friendships. These are presented in Chapter 6.

CHAPTER 6   DISRUPTING OPPRESSION

6.1   Introduction

I can't say what a difference in quality of life it has made for him to have a best friend. And other parents who have seen their relationship have come up to me and said, 'oh those boys are so lucky to have found each other.' And most of their kids – this is more of the exception than the rule (parent).

Friendship enriches our lives in countless ways, but can we simply attribute the friendships of disabled youth to luck? If so, then there would be no need for this study, for what could a detailed accounting of the friendships of disabled teens do to change fate? Did the disabled teens who participated just happen to be in the right place at the right time in order to make friends? There is no question they were the exception rather than the rule in terms of having good friends. However, as demonstrated in Chapter 4, all participants experienced discrimination deeply rooted in the stigmatizing processes of labeling, stereotyping, separation, and status loss. These friends found each other despite, or perhaps because of, their experience of stigma. Their success can be understood, in part, by the support offered by the adults in their lives as described in Chapter 5. But there are many disabled youth who continue to struggle to make and keep friends despite having incredibly supportive parents. If most disabled teens encounter comparable forces of oppression (read ableism) and many have supportive adults in their lives, how is it that only some disabled teens are able to create lasting friendships? This chapter discusses the range of approaches used by participants to respond to the power of stigma in their friendships.

6.2   Negotiating Friendship Under Oppression

Negotiating friendships is a complex process for all of us – sorting out who we connect with, how much personal information to share at what point in the relationship, how often we are in touch, what things we do together, and what to do when conflict inevitably surfaces. Lasting friendships are challenging at the best of times. When oppression is factored in as a significant force in the lives of disabled youth, making and keeping friends is even more complicated. Any attempt to explain how participants and their families negotiated friendships under oppression requires an oversimplification of these processes as they are re-presented in text. With that caveat, participants predominantly

engaged in constructive forms of resistance that disrupted stigma; however, nearly everyone in the study told stories that involved adhering to norms in ways that may have harmed participants or other disabled teens. It is this cluster of strategies that will be addressed first. The transformative strategies will be discussed in section 6.3.

6.2.1   Reproducing Normative Expectations: Horizontal Hostility

Horizontal hostility is a concept that emerged within feminist discourse in the 1970s to describe the conflicts disrupting the women's movement (White & Langer, 1999). This relational concept has been used to understand acts of aggression among social groups such as nurses (Craig, 2008), immigrants (White & Langer, 1999), and female teenagers (Brown, 2005). Horizontal hostility appears to be a mechanism through which the dominant system of oppression is reproduced either within or between marginalized groups since it is not acceptable, and often not possible, for people from marginalized groups to direct anger toward the dominant group (Diversity Dictionary, 2009). It should not be surprising then that horizontal hostility surfaced in this study as a strategy for trying to manage the experience of stigmatization. This phenomenon was evident in most of the friendship stories included in this study. Raising this issue could potentially harm individuals, thus pseudonyms are purposely avoided to add a further layer of protection for participants.

Horizontal hostility, the diminishing of those in one's own social group, in order to at least temporarily elevate one's own status, was illustrated by a parent who compared her own disabled child with the child's best friend, in terms of their abilities. She indicated concern that the best friend's lower ability status could compromise her child's education.

> *Parent: But see I'm caught between a rock and a hard place because even though [my child] is disabled, he's not [like his best friend].*
>
> *Interviewer: The kind of supports they'd need would be very, very different?*
>
> *Parent: Totally different, so there's no way that [my child] could be in class with [his best friend]. Absolutely no way. I don't see how [the best friend] can be in any class. Because as the parent of one special needs and one quote normal I'd have a fit if [my other, nondisabled child] couldn't learn because of a special needs kid. I really would. I think that's no different. Because a child's special needs doesn't mean it should affect my child negatively.*

For this mother, inclusion was conditional. The more impaired teens can be in shared spaces as long as no 'disruption' to the normative routine happens. Only disabled teens that fit with normative standards should then be eligible for inclusion. This quote reflects a hierarchical construction of disability referred to in chapter 4, where physically disabled teens are assigned a higher social status than intellectually disabled youth. Both of the teens referred to in the quote experienced stigma, yet in this situation the parent further stigmatizes the best friend. She distanced her child from the best friend who was labeled as more impaired, aligning her child with 'more normal.' One was believed to be closer to normal than the other and therefore seen as having higher status. This parent then felt justified in her stance; a position that discriminated against the 'less normal' best friend. As established in Chapter 5, parent support is a crucial ingredient for sustainable friendships. If left unchecked, the horizontal hostility embedded in the above comment could inadvertently terminate the friendship between these two disabled teens.

This notion of more/less disabled surfaced time and again. In describing a situation where her son was dramatically segregated by peers, the difference between physical and intellectual disability was raised: *"[My child] had two girls sitting with him. This Sue kid who wouldn't know the difference, [she was an intellectually disabled] kid."* This statement reflected the pain of witnessing her son rejected by nondisabled peers, while simultaneously distancing him from another disabled classmate, Sue. She argued that her child was closer to normal, so he should not have been rejected; that unlike the intellectually disabled girl, her child knew the difference between rejection and belonging. This comment explicitly stated that the intellectually disabled girl *'wouldn't know the difference,'* yet many of the intellectually disabled participants in this study clearly described feeling the sting of rejection and social isolation. This mother wanted to support her son's friendships with peers viewed as his intellectual equals, thus the intellectually disabled classmate was not considered a potential friendship partner. This was not a conscious act of discrimination. No harm was intended, yet the consequences were real for her child and for the disabled classmate in that it limited friendship opportunities for both.

This imposition of ideas about who is more or less disabled was apparent even in disability-only venues. Rather than experiencing acceptance and belonging in the exclusive group, many disabled teens were faced with further marginalization. One parent spoke about a cooking club designed with disabled teens in mind. She felt that

this club was not a good fit for her child since teens she perceived as more disabled were involved.

> *I don't necessarily want [my child] in the disability [cooking club]. The last one that they had I mean, and it's no offence to anyone, [my child] couldn't learn with [the best friend] there. [Another disabled child] was there. Alan was not high functioning at all. You know, so there's no way that [my child] could have learned if they were teaching at that level.*

If this ability levels approach were applied systematically then these two friends would be separated in all of their extracurricular activities, just as they were separated at school. Without being able to spend any time together, how could this friendship possibly endure? There were many instances of this type of hierarchical belief about who is more or less disabled, and who holds whom back. Systems are often organized around designated levels of ability. This seems to come from the belief that grouping people according to perceptions of ability will somehow create greater efficiencies in the system. For example, if everyone who benefits from step-by-step instruction is introduced to a cooking activity together this will mean that budding chefs won't have to learn at this same slow pace. This kind of reasoning is used to justify the continued existence of segregation in the era of inclusion (Allan, 2006; Fitch, 2003). There are many other ways to approach an activity that enables participants to engage at a pace that works for them. Few parents or disabled teens have ever had this type of experience, so it may be difficult to imagine something so far outside of one's personal experience.

The above examples focused on parents engaging in horizontal hostility. Although adults expressed horizontal hostility more frequently than did disabled youth, a few teens in the study also described situations where they assigned stigma to others. For example, one participant noted that people who go to Special Olympics are quite different from him.

> *Teen: But mostly everyone at swimming are kind of different from me.*

> *Interviewer: How?*

> *Teen: I don't mean by the way I look. I mean the way they talk.*

> *Interviewer: Like what?*

> *Teen: Like right now I talk like I normally talk. But people like– I think you can have a disability that, some kind of disability that makes your voice sound weird.*

> *Interviewer: Oh yeah. Like how?*

Teen: I don't know. I just know that when I was at that [a centre] there was a little girl I know… who always sounds like a donkey when talking.

Interviewer: Sounds like a what?

Teen: You know like an animal, the donkey. Kind of like that. [imitates the sound the girl makes when talking, kind of high pitched and nasally]. I'm like, "that is really annoying. I'm trying to eat."

Interviewer: So her voice sounds different?

Teen: Yeah. I think she has a disability that makes her talk differently. And that is something that I do NOT have. I know THAT for a fact.

Here the participant distances himself from those he identifies as disabled. Both this teen and the young woman he referred to were stigmatized by broader society. They attended the same recreational venues and participated in a similar vocation training program. Yet this disabled teen clearly viewed the young woman as being very different from him. She was disabled because she 'sounds weird.' By naming the young woman as the one who was *really* disabled, this participant identified himself as more normal than her. This participant assigned himself a higher social status – "*that is something that I do NOT have. I know THAT for a fact.*" There appeared to be an inference that people with communication impairments are the most disabled. Her approach to communication literally sickened him – he could not eat when she talks. This participant's beliefs about who shared his social status ruled the young woman out as a viable friend.

This belief that standard verbal communication is required for sustainable friendships (comparable ability levels) was also raised by adults. This apparent imbalance in communication strategies was present in nearly all of the sets of friends involved in the study. Some parents struggled to understand the connection between the friends, particularly when one teen talked and their friend used alternative communication strategies as was the case with 3 pairs of friends. Parents readily identified aspects of the friendships that signified care giving and care receiving; however, it was difficult for parents to recognize other ways of thinking about balance in friendships.

Interviewer: So are there other dimensions to their friendship beyond this caregiving, care receiving part of it? 'Cause I've seen that part of it for sure in a bunch of different ways.

Parent: Honestly, I don't know. I really don't. 'Cause I have a lot of friends who I gab with. Who I'll sit down and have a drink with. Who I will – whatever. And there's none of that with [my child] and [his friend]. [My child] adores [his friend] and [his friend] adores [him]. [My child] 95% of the time loves to be with [his friend]. It's certainly no imposition, but I certainly don't know the dynamics there. I mean [my child] and [his friend] have very little in common when you think about it.

This parent was unable to identify what her child and the best friend had in common. From her perspective their differences were obvious and interfered with making a connection. This parent readily engaged with her own friends through conversation. She found it difficult to imagine what the boys had in common given that she identified her child as being much less disabled than the best friend. For this mother there was a fundamental imbalance in the relationship, where her son contributed more to the friendship than he received from it. In this situation both sets of parents were incredibly supportive of the friendship even though they may not have understood the bonds between the disabled friends. This is not typically the case. When a disabled youth or a parent believes that another teen's disability is somehow more pronounced, friendship often seems to be untenable (Middleton, 1999; Davis & Watson, 2001). This violates one of the basic rules of friendship – that friendship only occurs among equals (Allan, 1998; Bukowski & Sippola, 1996). When a relationship does not pass this litmus test, it seemed difficult for disabled youth to have the adult support needed to maintain the friendship over time.

One might imagine that horizontal hostility would vanish in a disability-only venue. All participants at some point opted to engage in exclusive recreation where disabled teens chose to hang out only with other disabled teens. During many of the participant observation sessions it was noted that an exclusive venue alone did not solve the problems of discrimination. Some disabled teens were identified as being 'more disabled' than others and were set aside by the 'less disabled' teens or parents. Horizontal hostility made its way into exclusive recreational venues like the Special Olympics. For example, one mother noted that because Special Olympics is based on the normative model of competition, it re-created segregation for her daughter. This disabled teen was an excellent swimmer, but swimming the whole length of the pool was not appealing. She preferred swimming in circles around her best friend. Because she would not swim to the end of the pool, this girl was never selected to go to the larger competitions. This mom felt that constantly passing over her daughter contradicted the

Special Olympics commitment to being inclusive. In effect, leaving her out of competitions further marginalized this disabled teen within an exclusive group.

In every exclusive group observed during this study there was a cluster of disabled teens who remained on the periphery. If this was the space where they were most comfortable, then it was not considered segregation; however, if they were on the periphery because the activity did not encourage their participation or if other group members actively distanced themselves from these disabled youth, then segregation was re-enacted. Unless we are willing to acknowledge stigma, it seems it will inevitably be reproduced in exclusive venues via acts of horizontal hostility. This reduced the number of potential friendship partners for the 'less' disabled teens and made it virtually impossible for the 'more' disabled teens to connect with anyone.

Disabled people rejecting others who share the label of disability is not uncommon. Davis and Watson (2002) described situations where one disabled youth oppressed another disabled teen in acts of horizontal hostility. In another publication these same authors discussed how participants in their study engaged in labeling each other as they emulated adult discourses around disability. Participants described others as not as academically able as they were, as demonstrating bad behavior, as being 'stupid' – thus establishing social distance (Davis & Watson, 2001).These acts of oppression were often based on hierarchies around impairment; for example, where someone with a visual impairment engaged in acts of aggression against someone who was blind. Priestley (1998) argued that disabled teens are more likely to be bullied than nondisabled peers, but also are more likely than nondisabled peers to bully others. Low's (1996) research involving how disabled university students manage stigma is particularly salient. She found that many disabled students distanced themselves from other students they believed were more disabled arguing that the others were too dependent, too self-involved, complained too much, or used disability as an excuse for not achieving, thus reinforcing societal stereotypes. Low suggested that students at that time did not want to connect with disabled peers since it would further distance them from nondisabled university students – or that it would not be a pleasant experience.

6.2.2   Passing as Nondisabled

As described in Chapter 4, being able to identify as "normal" generally means that one has managed to avoid being stigmatized. Sean may have been the only participant in

the study who could fully pass as "normal." His disability was invisible. Sean described his efforts to hide his disability whenever he meets new people. Sean started consciously passing as "normal" in elementary school because of constant conflict with nondisabled peers.

> *I try to hide [my disability]. If I didn't tell somebody, they would never know. 'Cause I hide it very well… I hide it because I'm able to hide it. I know it will hold me back. I know it is something I'll always have to live with. And I know things are really different for me than for somebody who doesn't have a disability. But I don't show it to everybody right off the bat. I gain their confidence and then I tell them… At school, I try to act more like a high school student. When I'm home I'm nice and relaxed I can just be who I want to be. There's really no expectations. I can just relax.*

Sean performed as a nondisabled high school student every day at school. He believed that if others knew about his disability "*it will hold [him] back.*" He recognized that passing as nondisabled protected him from adverse events like social distancing and losing his social status. He could only let his guard down at home. In addition to protecting Sean, passing as nondisabled gave him access to a wider range of potential friendship partners than someone identified as disabled.

Passing as nondisabled was accomplished in a variety of ways – sometimes consciously as Sean indicated, but at other times it was imposed. Many teens and adults in the study commented on feeling pressured to fit into normative expectations. Sometimes this happened through specific behavioral training to modify how a disabled teen interacted with others. In other situations disabled teens were given prescription medications to help them manage their behaviors. One EPA described the following scenario.

> *EPA: People probably just said, "yes, here's your medicine. Calm down." You don't need to medicate kids so much. It's not doing them any good. There's no pill for [this particular diagnosis]… Like [this disabled teen] has been heavily medicated since he was five!*
>
> *Interviewer: Really?*
>
> *EPA: Like uppers and downers at the same time. He'd go to school and he'd have Ritalin. He'd come home he'd have something to bring him up and then he'd have a Ritalin to bring him down.*

This is not to say that using prescription medication is inherently negative. There are many situations when medication is an excellent choice, particularly when the medication eases distress and makes it possible to create or maintain meaningful

relationships with others. If the medication is used only to fabricate a "normal" façade then its use needs to be called into question (Morgan, 2001). In the above scenario, the EPA believed that medication was used to address concerns about stigmatizing behaviors, locating disability in the body of the disabled youth. If this disabled teen's neurochemical and physiological processes were altered, then he could more closely approximate "normal" behavior. Perhaps his parents hoped that this disabled teen would be able to participate more in academic and social activities where friendships were more likely to form than if he were completely marginalized due to his non-normative behaviors.

The previous quote focuses on adjusting behaviors to fit better within social expectations. For other participants, different aspects of their disabilities were the focal point of passing as "normal." For example, Rachel chose to use a walker over a wheelchair because she wanted to maintain her ability to walk. Her mother explained,

> *People don't really quite know what to expect from her. She's in a walker. She can't keep up and do all the things that they do. And maybe if she had've had a wheelchair, she could have gone there. She definitely could have been faster. But that was the decision that we made not to put her in a wheelchair. And she didn't want to be in a wheelchair. And we just felt that if she was in a wheelchair she would lose all that mobility that she has. And she was quite content to be in a walker.*

Would Rachel have lost her ability to walk by using a wheelchair for going longer distances? What was the subtext here? Is walking always better than wheeling, as ableism contends (Hehir, 2002)? Norms in society set up walking as the standard for how we move through the world. People who use walkers are often considered less disabled than people who use wheelchairs for mobility. In Low's (1996) study involving disabled students at McMaster University she reported that numerous participants did not bring along the technologies that supported their learning (e.g. Braille writers, cane) in an effort to be less conspicuous, to appear more "normal." Similarly, Doubt and McColl (2003) found that a number of participants attempted to mask their disabilities by minimizing the presence of mobility devices. For example, one participant in that study described transferring out of his wheelchair to sit in a regular chair at lunch to appear more "normal." Understandably, if given the choice, most people would opt for the least intrusive mobility device to better fit with the normative expectation. When faced with this choice, Rachel may have believed that using a wheelchair would have created further

stigma and social isolation. Ironically, this choice may have literally created distance between Rachel and her nondisabled peers. Wheeling is often much faster than walking and can save a great deal of effort and energy. Both Rachel and her parents wondered if choosing to use a walker limited the opportunities she had to spend time with friends outside of school. Rather than supporting her friendships and participation, choosing to walk with a walker over wheeling made it impossible to keep up with friends at the mall as they hurried from one sale to the next. Additionally, wheelchairs are much better suited than walkers for handling the rough terrain that often accompanies weekend bonfire parties. These experiences were not accessible to Rachel, thus limiting her participation in the shared activities that can sustain friendships over the long term.

Passing as nondisabled seems to exist along a continuum. Sean had an invisible disability, so he could decide when to talk to new people in his life about his disability. Many disabled teens in this study put extraordinary effort into identifying with their nondisabled peers even though they were readily marked as having impairments. Jay offered a provocative example of a disabled teen working to identify with the nondisabled.

> *Like I'm more into like rap. I listen to a lot of rap and rock. I do like rock, but mostly rap. I like to talk rap slang, like to be cool. I like to be a player, like breaking the school rules. That's why I break the rules and say bad stuff. I kind of live the life of being a bad boy and stuff.*

In this quote Jay established himself as a "*player,*" offering examples to support his claim. He worked this identity across a range of situations. For example, on a bus trip home from a participant observation session Jay struck up a conversation about rap music with an African Nova Scotian guy sitting nearby. Upon exiting the bus Jay did an impromptu hip hop performance – presumably for the benefit of the guy he had just spent the past 10 minutes talking with. He wore the clothes to match the nondisabled identity he wanted to align himself with – the low slung jeans, hooded sweatshirts, dark sunglasses. Jay noted, *"I like to be down. I like to be hip."* Jay invested heavily in shifting his Master status and its stigma into the background so that he could identify with nondisabled.

Like Jay, Rachel had a visible disability, yet she talked about situations that could be interpreted as an effort to pass as nondisabled in particular ways. Recall that Rachel turned down many invitations for sleepovers at friends' homes when she was younger

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because she was concerned about how nondisabled Others would react to her personal care routines. By turning down the invitations Rachel was able to pass as nondisabled in this regard. This choice protected her from the potential loss of social status had her nondisabled friends not accepted the difference connected to the care routine as described in Chapter 4. Yet what was the price for passing? Her mother wondered whether Rachel's friendships would be different today had she come out as disabled to her friends.

> *As hard as it is, sometimes I think if you actually just 'fess up and tell your friends what your medical issues are, maybe they are mature enough to understand it. And we didn't encourage Rachel to be open about that because we thought that these were kids and they'd be cruel. And they wouldn't understand why she had to use the bathroom the way she did. But I guess that's a personal preference, but I think that maybe I didn't give her friends, and her one good friend, enough credit for maturity. Maybe she could have accepted it. I think if that had've been a little more open she would have stayed in touch with that group instead of getting pushed to the side.*

In a world where stigma is deeply entrenched, passing is for many the only safe way to get through difficult situations. This quote highlights the perception of risk involved in coming out as disabled – a common concern expressed by disabled teens (Doubt & McColl, 2003; Fitch, 2003; Kennedy, 2009; Low, 1996; Middleton, 1999). Although we often think about disability as being quite visible or evident, many aspects of disability are private, not obvious to the normative gaze. Although Rachel used a walker to get around, there were many other aspects of her medical diagnosis to which stigma would be ascribed had they been revealed to others. Rachel believed (probably rightly) that telling people about how her body worked exposed her to the risk of complete isolation, rather than the marginalization she was accustomed to. It could have made her disappear completely from the social scene at school.

> *Rachel: At one point I was afraid to tell– maybe I could have told them more about me. But I just felt like they wouldn't understand so I didn't bother.*
>
> *Interviewer: And when you're saying 'told them more about you' is it things about your body? How your body works?*
>
> *Rachel: And like about my disability and stuff. So maybe I could have told them about that. But maybe– I just didn't.*
>
> *Interviewer: But that would feel like really taking big risks, huh?*

Rachel: Yeah. And I didn't, I think, like I'm not really friends with these people. I'm friends with them, but I'm not like great friends with them. So they do like, they say hi to me. And I was afraid if maybe I told them too much, they'd stay away.

Rachel's story is reminiscent of that told by Sean. Both disabled teens indicated well-founded fears that they would be rejected by their nondisabled peers if their disability was more fully known. They were both cautious, unsure about who to trust. As children get older trust becomes a stronger feature in their friendships (Berndt & Perry, 1986; Cotterell, 1996). If disabled teens struggle to trust others because of long histories of stigma and oppression, then they may find the increasing demands for trust and intimacy present in teen friendships daunting.

Swain and Cameron (1999) acknowledged that disabled people are under intense pressure to pass as normal. Davis and Watson (2002) commented, "the children were constantly reminded [by adults] that they were essentially different from their nondisabled peers, but they were also compelled to conform to specific ways of speaking, ways of walking, table manners and so on" (p.674). Many disabled teens in the current study worked incredibly hard to force their disability status into the background so that they could be recognized first as a teenager, as a girl or guy, as a musician, an actor, an artist, a fashionista or a sledge hockey player. Being able to pass as "normal" does not necessarily mean that a medical diagnosis is invisible. For example, although the standard symbol for disability is the line drawing of a generic person sitting in a wheelchair, many people who use wheelchairs for mobility do not identify as disabled (Watson, 2002). Indeed, if they have not experienced reduced chances for meaningful quality of life, have access to home, work, social and recreational spaces then wheelchair users may not be disabled at all. Yet there are many disabled people who seem to believe that in order to fully participate in society they need to align themselves with the majority, the nondisabled, in order to be accepted. Consider the story of Christopher Reeves following his spinal cord injury. For the rest of his life he advocated for medical research into enabling people with spinal cord injuries to walk again (McRuer, 2003). Despite the incredible social pressure to pass as nondisabled, most disabled teens in the current study resisted this pressure and found ways to create enduring friendships.

6.2.3   Making a Distinction: Offering Support vs Requiring Disabled Teens to 'Pass'

Almost all therapies and educational programming for disabled youth are directed toward passing as normal or nondisabled (Hehir, 2002; Middleton, 1999). Think of how many children and youth identified as having autism spectrum disorders are engaged in a range of approaches to modify their behaviors so that they will be able to communicate with others and be able to engage in normative society. I am not discounting these approaches, particularly those that improve quality of life for both the teen and their family. Yet, this creates a tension between being accepted for who you are and being required to pass as abled. For example, Josh supported Gavin as he learned how to introduce himself to people so that new acquaintances would be receptive to Gavin's approach. In this scenario Gavin enjoyed meeting people, hence Josh offered him the support he needed to engage with others in a way that improved Gavin's quality of life. This was not considered imposing a nondisabled status on Gavin.

Like Josh, the mother of another participant offered him guidance about how to approach others, especially women, in ways that created positive relationships. This participant, a huge fan of hyper-masculine movies like the James Bond series, often made sexist remarks. He needed feedback about how to read the body language of others, so that he could adjust his approach to the situation. On several occasions his inability to recognize boundaries resulted in broken friendships. When reflecting on one situation he explained,

> *We used to like each other up until I [made a] threat… Just out of the blue for no reason and now she's afraid of me. So I guess I just have really broken that relationship…I just wasn't thinking. It's just one of those things that you say out of the blue without knowing what you're saying.*

This example demonstrates the clear difference between offering disabled teens timely support and demanding that they pass as nondisabled. This guy lost a good friend because of this inappropriate exchange. His mother was not forcing him to enact behavior that is nondisabled; rather, she encouraged him to understand how his behavior affected other people. The message was that we need to be concerned about the well-being of others if we want to make and keep friends. The focus was not on passing as nondisabled. It was about learning how to respectfully engage with friends and acquaintances.

There were numerous examples in the study of nondisabled peers offering spontaneous feedback to disabled teens about what was acceptable in a given situation. One mother described this well.

> *Some kids can be very– I don't think it's cruel. But they're just so honest… [They are] out there with it, like you know. "It's not cool." Only they say it in a [more blunt way]. And I think that it helps to bring that whole appropriateness along… [giving him clues] about what the topic of conversation is, what you talk about. You know, what shows people are talking about. What movies they might be talking about. You know, what the cool stuff is…And those things help to have you, they give you something to talk about. They give you something in common with the broader community.*

These exchanges were not demanding that disabled youth suppress their disability status. We all learn social norms by observing others, by having more experienced people give us the lay of the land, through discourse (Priestley, Corker, & Watson, 1999). If we use the latter strategy we often face the repercussions of violating norms. Passing as nondisabled involves deliberately altering how the self is presented to align with a safer way of being in the world. Learning the subtleties of communication and "being cool" seemed to be about managing stigma in order to connect better with potential friends.

Many teens involved in the study were not part of the social scene at school; however, the adults in their lives argued that being educated along with nondisabled peers, particularly in elementary school years, was crucial to them learning how to understand the nuances of social behaviors. An EPA explained,

> *[Jesse] needed to be with some peers in order to even begin to understand what they did and how they did it. If he was never exposed to them it would have been even more difficult for him to make friendships with Sean or Alexandra.*

Without the early social foundation provided by being in classes with nondisabled peers, Jesse would have missed the experience of carefully watching how nondisabled kids related to one another. Opportunities to understand how social life works were not about changing who Jesse was. Jesse was not forced to interact in ways that masked his disability; rather, this exposure helped him understand the value of communication. His EPA described what a major breakthrough it was for Jesse when he realized that in addition to making him more comfortable and relaxed, communicating with others could also make it easier to maintain good friendships.

Concern arises when the range of what is acceptable is so narrow that the difference of disability is discriminated against. Many attempts by participants to pass as nondisabled were thwarted by the Master status of disability. Consider the following comment about clothing and fashion,

> *Mother: But say for Amanda, clothes. If you're going to make clothes an issue about whether or not someone's going to be your friend. She has a specific clothing requirement. She can't wear the shrink wrapped cropped t-shirt.*
>
> *Interviewer: You get her some LuLu Lemon and she's got it going on.*
>
> *Mother: Well hey, if that's what it takes! What's a few bucks! [laughing]… You know what, this is going to be sad. This is going to be sad, but if she showed up with it, it would turn it off for the others.*
>
> *Interviewer: Why do you think that would be?*
>
> *Mother: I think in this particular age group of kids it's that bad. Maybe not, I'm saying there are certain things that I bet would be a turn off if she was fitting in with something – or tried to fit in because she has the same t-shirt or whatever thing was in. I'm thinking that it might make Amanda feel like she was fitting in, but I think other kids would think – that stigma of not wanting to be associated with that group [disabled]. Because there's a stigma associated with that group, right?*

In this scenario, if Amanda attempted to fit in with her nondisabled peers by imitating the fashion trends, this attempt to shift her Master status would inevitably result in further censure. Wearing trendy clothes would not create more social connections for Amanda. This comment contrasts beliefs of parents in the studies of Llewellyn (2000) and Rabiee, Sloper and Beresford (2005) who hoped that fashionable clothes would help their disabled teens blend in with nondisabled peers. Amanda's mother speculated that this approach could instead create a backlash of social isolation since the trend setters might then go out and buy new clothes that clearly distance them (popular, nondisabled) from Amanda. From this mother's perspective the stigma of disability was so strong that if a disabled teen adopts a popular trend, it may well lose popularity.

What do I wear? Who can I trust? How much do I tell people about my disability? To what extent am I allowed to present another version of myself (outside of disability) without creating a backlash? Disabled teens have to navigate through a myriad of impossible dilemmas as they negotiate around stigma to create sustainable friendships. Perhaps the move toward disrupting oppression witnessed during the course of this study is grounded in disabled teens facing these challenges on a daily basis. They

recognized the stigma and concomitant discrimination that permeated their lives and continually found ways to contest their marginalized locations.

6.3 Disrupting Oppression to Create Sustainable Friendships

Disabled youth do not passively accept the stigmatizing discourses of dependency and vulnerability imposed on them (Davis & Watson, 2001). Disrupting oppression can take many forms from subtle to dramatic, pre-meditated to impulsive, singular to organized, immediate to long term, local to global. Disabled teens demonstrated multi-layered strategies for disrupting ableism that ranged from naming discrimination, to verbal aggression, to overt disruptions via verbal or behavioral resistance to oppressive adult actions. This section describes how participants in the current study responded to oppression by contesting normative expectations around friendship, coming out as disabled, connecting through the experience of stigma, choosing self-exclusion and engaging in disability activism.

6.3.1 Disrupting Normative Expectations of Friendship

Expectations about who friends are and what they do to demonstrate their commitment to each other during the teen years are well-established (refer to the literature review Section 2.3). The friendships of disabled youth are comparable to those of nondisabled teens in many respects. All of the friends in this study spent time together on a regular basis. They enjoyed participating in shared recreational pursuits like watching movies, going to dances, shopping, playing videogames, swimming, paddling, talking on the phone, chatting on MSN, and playing basketball. Each friend offered companionship and practical help to the other. Trust was a crucial part of each of these friendships. For some, trust was demonstrated by being comfortable with letting the friend into their personal space. For others trust involved sharing secrets and knowing that the friend would understand and respect the confidence. These friendships were full of jokes and good-natured teasing. There were also many moments of conflict and tension that the friends had to work through. All of these qualities of friendship are comparable to those of nondisabled youth.

While the friendships of disabled youth had many parallels to those of nondisabled youth, one substantial difference surfaced: participants had to resist prevailing norms about friendship. Equality and balance in friendship are two standard expectations that

had to be redefined by participants. The question of balance or reciprocity arose in three particular sets of friends where one disabled teen was articulate and participated in many activities with nondisabled peers. The other friend used alternative communication (e.g. sign language, gestures, picture exchange system) and was identified as having an intellectual disability. In functional terms these friends were considered by adults to be very different. Many adults interviewed believed these friendships were about caregiving and helping on the part of the 'less disabled' teen. Adults were unsure what the 'less disabled' teen got out of the relationship, yet one of these friendships was longstanding, having lasted at least 4 years. Few people would engage in a relationship for such an extended time unless they were benefiting in some way. Was it only about giving and receiving help as many parents and teachers believed? Absolutely not. The reciprocity in these friendships, though not traditional, was vibrant and meaningful.

Jared's mother was surprised to find out that Jared initiated a friendship with Timothy, a nondisabled peer. When asked what he got out of his friendship with Jared, Timothy did not hesitate to say that it allowed him to learn new things and to break down stereotypes he had about disabled people. Jared was very particular about who he was willing to be friends with. Being singled out by Jared as a friend was incredibly affirming for Timothy. Given that Timothy had also experienced marginalization, having so much positive attention from both Jared and the adults surrounding Jared was especially meaningful for him. The EPA connected to these two friends noted that because of his friendship with Jared, Timothy was able to experience

> *companionship, leadership, and positive reinforcement…He's also been noticed within the school board. He's also been noticed within the [disability] realm. He's also been noticed with these families and friends. And he's not only been a leader to them, but he's a leader with all the other friends with the compassion that he has.*

Timothy, a nondisabled student at risk of dropping out of high school, took on a leadership role. The connection with Jared extended Timothy's own network of support both academically and socially. It quickly became evident that Timothy was, at the very least, getting back what he offered to the friendship.

Lauren and Emma provide another example of a friendship that was uniquely balanced. Their friendship was rooted in deep affection for one another. Lauren offered Emma some physical help and guidance. Emma loved being in the spotlight while Lauren

tended to be shy and reserved. At large gatherings Emma happily introduced Lauren to everyone. Emma was also physically active and encouraged Lauren to get involved in many more recreational events than she participated in before they became friends. Additionally Emma completely adored Lauren. Lauren described what she gets from the friendship this way,

> *It's just like I'm a hero or something. I'm a superstar. Like I'm a big fan of somebody else and Emma's a big fan of me…Sometimes it's frustrating but other times it feels really, really good. 'Cause you have a friend that's like you that it doesn't really matter how strong you are or how difficult you have [it], like if you can't talk…She's just always happy. She's a wonderful person.*

Because of our perceptions about who is more or less disabled, adults often base judgments about the balance between giving and receiving (reciprocity) in a friendship on who is providing physical assistance. The default position is to assume that the person receiving physical assistance is not able to give back equally. Indeed, it is clear that Emma did not give Lauren any physical assistance. But did this necessarily mean that Emma offered nothing back to her friend? Lauren didn't need any physical assistance, so it wouldn't make sense for Emma to respond 'in kind.' Instead Emma offered Lauren something she needed, affirmation and a sense of belonging.

In both of the above examples, one friend did not use the typical mode of verbal communication. It seems that normative society has forgotten to attend to the many ways that we all share information every moment we are engaged in a social situation. Those non-verbal modes of communication made it possible for many of these friendships to flourish. For example, Jesse was a man of few words, yet Sean and Alexandra were completely tuned into his body language. They were able to respond to the subtle cues Jesse offered to indicate that something about the situation needed to change for him to stay involved. They did this without hesitating; the interaction was seamless, flowing more smoothly than most conversations, understanding each other outside the limitations of language. By disrupting normative expectations about how friends communicate, these teens were able to establish strong connections with one another.

Jared and Timothy had a similar nonverbal way of relating, of reminding each other of the experiences they shared in the past. These guys told the stories of their friendship

through body language, reminiscing about the past by physically connecting in the present. A fieldnote excerpt reads,

> *Timothy went over and sat on the mat with Jared to keep the two other campers away from him. Although Jared looks like he is asleep he is typically attending to what is happening around him. Once Timothy settled in on the mat Jared started poking him in the belly and the back. Timothy poked him back each time. This appears to be one of the ways they interact on a regular basis. On the surface it appears to be an immature activity, but after observing for a while there seems to be a strong element of trust connected with this activity. Jared will only poke people he really likes – especially since he wants the poke to be reciprocated. It is a familiar and comfortable way of interacting. Later on Timothy said that it was one of the first ways he and Jared interacted as their friendship started to form. This mode of interacting has remained constant for several years now. So poking each other may be comparable to other people reminding each other of things they have done together that connect them. It is a shared memory that they bring into the present each time Jared pokes Timothy.*

Here Jared and Timothy demonstrated an unconventional way of knowing one another. This can be understood as a form of resistance against normative expectations about how friends communicate with one another. A mother in the study by Rabiee, Sloper and Beresford (2005) defined friendship outside the bounds of language in a similar way. She stated that friendship for her son, a disabled child who used an alternative communication approach, meant

> being in the same room with certain people because he actually likes those people. He likes they way they talk. He likes the way they giggle. He likes the fun that they have and he can join in their fun. For me that is [him] having a friend" (p.483).

Enjoying the company of friends does not require a verbal exchange. As indicated in these examples it is possible to have fun, share jokes, and laugh with friends – all actions that contribute to lasting friendship.

Friends in this study also disrupted norms by engaging in activities that were unexpected and incredibly fun. The following is an excerpt from a fieldnote written after hanging out with the guys in a playground, watching with amazement at how joyful and uninhibited the disabled and nondisabled guys were as they chased each other and climbed on the structures.

> *As I watched Timothy pursue Jared through the maze of the playground structures I wondered why we stop playing as adults. We get so caught up in what is acceptable that maybe we forget to have fun and to run just for the*

pleasure of the chase…There seem to be so many social rules that constrain me/us from participating in pleasurable activities. Jared doesn't appear to experience these same constraints.

The norms surrounding which spaces are designed for whom are raised by this observation. While the guys ran through tunnels, barreled across bridges and hurtled down slides they also seemed to dismantle the invisible structures identifying who was allowed to play and have a good time in this recreational space. Going to the playground with disabled teens gave the nondisabled workers and friends permission to act differently, to break the norms by joining in on the fun. Participating in non-normative activities that both enjoyed strengthened their friendship.

6.3.2   Coming Out as Disabled: "Never Having to be Somebody You're Not"

"Coming out" is a process or event that is often associated with sexual orientation, where someone identifies as being outside the normative heterosexual domain. This term has also been used to describe the process of identifying as belonging to another group that is discriminated against, the disabled (Swain & Cameron, 1999; Corker, 1996). Coming out occurs along a continuum since it is not always a choice, nor is it always chosen (Brenda Beagan, personal communication, July 29, 2009). Swain and Cameron (1999) stated, "coming out, then, for disabled people, is a process of redefinition of one's personal identity through rejecting the tyranny of the normate, positive recognition of impairment and embracing disability as a valid social identity" (p.76). The act of rejecting the norms of ability and claiming a disabled identity is understood as a political act by many disability scholars (Swain & Cameron, 1999; Linton, 1998). For many participants coming out as disabled was a conscious and calculated decision, but did not necessarily involve a claim to a political identity. Sean described it as follows,

Sean: Really what I look for when I meet somebody, I don't tell them right away.

Interviewer: About your disability?

Sean: Yeah. 'Cause I found in the past if I tell them right away they kind of [shy] away. So I get to know them, then I tell them.

Interviewer: Ok. That is so interesting Sean because it has come up so many times in the study, this whole thing about when you don't have kind of a visible disability, when is the right time to kind of put it out there with somebody? So when is the right time for you? What do you think about that?

Sean: [sigh] I try to have at least a couple of months before I say anything.

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Interviewer: So what makes you think, you know this is probably a good time to let them know. What is it about that person that lets you know you can trust them?

Sean: How they act around me. Like if they're friends with me everyday and they talk with me. I'm able to talk to them. And then I decide, ok that's going to be a good friend of mine. I think I can tell them.

Sean carefully thought this through. He reflected on his early life experiences with rejection and made calculated decisions about when and how he would come out as disabled. Sean waited until he established a baseline of trust. He believed that once people knew him as an interesting, entertaining guy then disability would not disrupt his friendships. By working to control the information flow about his disability, Sean felt more comfortable initiating connections with new people both at school and in his many recreational pursuits. When he felt safe to come out as disabled, Sean disrupted what his friends believed about people with disabilities. It could be argued that Sean's approach (though fraught with risk) meant that nondisabled others had the opportunity to know him as a person first. In one sense this is in keeping with the People First movement – where activists argue against the Master status of disability (Shapiro, 1994).

Other participants were not reluctant to come out as disabled. Amanda was incredibly courageous when she addressed an ongoing conflict with her nondisabled peers about accessing an alternative curriculum through the learning centre in her junior high school. As discussed earlier, to address constant accusations of cheating Amanda decided to do a presentation to the class about what it meant to be on an individual program plan (IPP). Her mother told the story.

At the end of that power point a lot of the kids got up and said, 'I'm on an IPP for math, or I'm on an IPP.' And it was so many kids, it was like you know… people were able to stand up and say, 'Well I have trouble with math.' And it was an opening to allow the other kids to say – 'cause the teachers aren't allowed to say, 'Well you know Julie, she's on an IPP.' You can't say that right? Where these kids got up of their own accord…And then she could see, 'cause she couldn't see before that other people had IPPs for certain things…So it helped her to understand that not just she needed help.

Although Amanda was identified as a disabled student by her peers, very few people knew alternative measures were in place to assess her learning. Rather than timidly accepting the accusations of her peers, Amanda let her peers know what an IPP was

and why she needed to have one. This act created a safe space for others to come out as disabled, in effect reducing the stigma assigned to students who get support from resource teachers. Doubt and McColl (2003) identified educating peers as one of the ways that disabled students in their study negotiated inclusion. Amanda's choice to address stigma at this broader level served to mitigate the status loss experienced when she was accused of cheating by her peers. Regaining her previous social status with her classmates meant Amanda was able to maintain her friendships with a few of her nondisabled peers at school.

In addition to identifying as disabled at school, Amanda also claimed disability on a broader scale. Recall that she was featured in a newsletter about home modifications. Being so public about her disability status enabled Amanda and Rachel to initiate their friendship. Amanda's choice to self-identify as disabled created the safety that Rachel needed to also come out as disabled. This was the beginning of a friendship characterized by social activism. Unlike Amanda, there were many participants who had no choice but to be out as disabled. Something about their bodies or behaviors meant that disability was the Master status that was always already present. For these participants the choice was not about whether to come out as disabled, rather, it was about how much information to share with others. The parents of disabled teens for whom social situations were very challenging did not hesitate to explain unusual behaviors to new acquaintances. This made the disabled teens' ways of being in the world more comprehensible to new people, making long term friendship a viable possibility. In contrast recall that Rachel's cautious approach to disclosing personal information seemed to lead to social isolation.

The mother of another young man with unconventional behavior argued that it was better to offer as much information as possible about Jared and what helps him stay relaxed.

> *I made it very clear that it was ok to ask people questions. And I would tell them, all the teachers, 'if anyone has a question about Jared, please answer it. Don't tell them you can't tell them. Because to me that's just excluding him more. That's making it an unknown and then people get anxious and nervous. You know, Jared's not going to hurt their kids…And I go and I talk to teachers about that and say, 'Here's what you need to know. Please ask me any questions. It's not embarrassing. It might not be very comfortable and it might not be very pleasant. But I'd rather you asked a question than sit around and not know or do nothing with him at all, or create this stigma around him.*

Like other participants with unconventional behavior or communication strategies, Jared was constantly "outed" as disabled without anyone ever saying a word. Not talking about what was going on only created more stigma around Jared according to his mother. When Jared was calm and comfortable he was available to connect with his peers. Sharing information about what stressed Jared and how to communicate with him made shared experience a viable option. Minimizing the stressors in Jared's life reduced the social distance created by his unconventional behavior. Given that Jared and the other participants in this study who used alternative communication strategies all had long term friendships, it is possible that openly discussing how these disabled teens understand the world contributed to sustainable friendships.

6.3.3 Connecting Through Experience of Stigma

For many disabled teens, connecting to one another meant they didn't have to explicitly come out as disabled to potentially hostile Others. Their friend already knew what it meant to be disabled, so the painful and awkward process of explaining behaviors or bodies wasn't necessary. Establishing friendship with someone who shared the disability experience meant these teens did not have to gather the courage needed to come out as disabled in situations where they might be rejected. The friend also faced similar stigmatization and fear around the "tyranny of the norm" (Davis, 1995/2002, p.6). Amanda and Rachel shared a tacit understanding of what it meant to be disabled, both in terms of how bodies work and in the shared experience of stigma. Rachel compared her experience of connecting with Amanda to the challenges she had relating to nondisabled peers in her community.

> *Rachel: I can talk to Amanda more.*
>
> *Interviewer: Why is that?*
>
> *Rachel: I think because we can relate. We go through some of the same stuff – or most of the same stuff. So I can tell her different things that go on. So I just find it easier to talk to her I guess.*
>
> *Interviewer: How much of that has to do with you both having the same kind of medical concerns?*
>
> *Rachel: Yeah. I think that helps… I don't tell them [other friends] as much – I try not to. 'Cause well I can't because they don't understand. Amanda understands.*

Rachel's mother also described what she believed connected the two girls during a separate interview.

> *I think [friendship between Amanda and Rachel] is easy because there's nothing fake. There's no pretending. They both have the same kind of issues… they have so much in common, so many similarities that there's so much to talk about. With her other friends there were so many things about her body that she didn't want to tell…Amanda has all those same issues. They go through all the same stuff and they have so much – I guess it's common ground is what it is.*

Having the "common ground" of a similar medical diagnosis meant that they didn't have to pass as abled. They didn't have to "pretend." Although stigma created social isolation for each of these girls in certain places, rather than silencing the girls, it inspired many conversations around disability rights issues. Both of these teens were highly politicized and articulate around their rights as disabled people.

Although most disabled teens involved in the study engaged in activities that disrupted oppression, the commitment to disability activism appeared to be one of the strongest links in the friendship between Rachel and Amanda. For example, they completely rejected the discourse of difference, bracketing it out with air quotes during their joint interview.

> *Rachel: Yeah. It's not just me, like it's any kind of different, difference [using air quotes]*
>
> *Amanda: Different [using air quotes]*
>
> *Interviewer: You're saying different with your little quotations. Tell me what you mean by that.*
>
> *Amanda: Well we're technically –*
>
> *Rachel: We're not different. We're all the same.*
>
> *Amanda: Yeah, technically, but they think like different themselves. Like we're not saying we're different, it's because they think it not because we think it.*
>
> *Interviewer: Ok, so it's who's deciding what different is?*
>
> *Amanda: Yeah.*

With support from their families these girls engaged in fund raising activities in support of breast cancer research. Amanda was taking training sessions for public speaking and was very aware of accessibility issues for disabled people. In their joint interview it

seemed that they planned to take Disability Awareness Week by storm. Besides a shared interest in music, facebook and MSN chat, these friends had a strong interest in political action based on the shared experience of discrimination. Linton (1998) argued that it is through oppression that a disability community is forged. "We have found one another and found a voice to express not despair at our fate, but outrage at our social positioning" (p.4). Amanda and Rachel expressed their "outrage" at being discriminated against. These two girls, with the support of their parents, were already making forays into the realm of disability activism. Having a friend who shared this same commitment to disability rights seemed to fuel their interest in self-advocacy.

Knowing each other well as disabled friends allowed teens to relax and be themselves. Talking about her friendship with Emma, Lauren noted, "*We get to have fun together and we don't have to worry about our disability. We don't have to worry about [a shared medical problem] or having something wrong with us. We just stick together.*" Not having to come out as disabled offered a sense of freedom that many participants rarely experienced in their lives – the freedom from the normative gaze, from stigma. For Lauren spending time with a friend who had a similar medical problem meant she didn't need to feel self-conscious or explain herself. Not having to worry about how bodies work freed up the time and attention to get to know each other, to go shopping, to get involved in a wide range of sports events, to be good friends.

Many disabled teens in the study were convinced that the person they initiated a friendship with (also disabled) would never be cruel to them. They immediately felt a sense of kinship or trust based on their mutual experience of stigmatization. Sean explained,

> *Sean: Jesse I found was more accepting right away…There wasn't a lot of working for it.*
>
> *Interviewer: So why do you think it is that other kids don't accept you in that way?*
>
> *Sean: Because they don't understand what it [my impairment] is exactly.*
>
> *Interviewer: And so what makes Jesse different do you think?*
>
> *Sean: I think it's the fact like he has a disability and I have a disability. We're able to relate to each other a little more.*

Stigma attached to disability was a deep, strong point of contact for many of the disabled teens involved in this study. While stigma acts to socially isolate and oppress, when teens can connect through it they start from a very strong basis of unity. Participants successfully disrupted oppression to create enduring friendships by rejecting the normative discourses that narrowly define inclusive friendship as a relationship between disabled and nondisabled youth only (Meyer, 2001; Turnbull, Blue-Banning, Pereira, 2000). Research about friendships between disabled youth is rare (Webster & Carter, 2007); however, the friendships of teens who connect through the experience of disability were highlighted in a few recent studies (Curtin & Clarke, 2005; Matheson, Olsen, & Weisner, 2007).

6.3.4   Disrupting Segregation by Choosing Self-exclusion

Every one of the disabled teens involved in this study experienced segregation at some point in their lives. For some it happened as early as grade three when they were identified as different, as not meeting normative expectations about how to move through the world, how to learn, how to behave, or how to communicate. This experience of segregation left them with a clear choice – to remain in social isolation or to choose to focus on disabled teens (or other marginalized teens) as potential friends. All of the participants chose the latter. For some this meant interacting only with other disabled teens at school, excluding nondisabled peers from friendship. Lauren noted that all of her friends were disabled. This was the case for most of the participants. After much debate, Emma's parents moved her into a segregated classroom in junior high, where she had contact exclusively with other disabled teens. Once Emma established friendships there her parents noticed that she relaxed and slept better at night.

For others choosing exclusion – exclusive networks of disabled teens – meant checking out disability-specific recreational venues. As noted earlier, one mother created a summer camp designed specifically around the needs of teens who shared Jared's diagnosis. She stated,

> *It became an exclusionary camp I guess primarily because there are just so many kids that needed a place to go and there wasn't any other place that understood them. So that's kind of what happened with it. And I guess, say for the adolescent camp, they seem to interact fairly well to some degree. So they do kind of have each other, plus they have the staff who seem to engage fairly nicely with all of them. So that has worked out well.*

Going somewhere that people understand you, where you feel accepted, where you are the norm, is welcomed with relief by adults and disabled teens alike. Although the exclusion, the restriction of interactions to similar others, may at first glance look the same as segregation the crucial difference is that it is chosen. Being segregated by others, pushed off to the side, is painfully discriminatory. Choosing to hang out with others with whom you feel safe was a self-affirming choice, albeit within the context of oppression against disability.

Storey (2004) echoed the concerns I had about disability-specific recreation before I completed the current project. He argued that venues like the Special Olympics are segregated, age inappropriate, and perpetuate stereotypes of intellectually disabled people as vulnerable and incompetent. I remain concerned about these issues; however, many of the friends in this study connected through exclusive recreation. Storey concluded that disabled people would select "typical recreational settings" under a person-centred model of practice. Perhaps they would, if such venues existed in all communities. Until that time comes, it is not surprising that disabled teens and their parents both attend and establish disability-only venues. Storey's approach would disrupt every friendship in the current study and could very likely return every one of the participants to social isolation. Implementing person-centred planning and supporting self-determination as he suggests, does nothing to address the oppression of disabled youth.

A number of participants described scenarios where, after experiencing intense discrimination by nondisabled peers, they in turn rebuffed those acquaintances later on. Disabled teens refused to acknowledge the nondisabled teens who treated them badly in the past. An excerpt from Alexandra's interview is a typical example.

> *Alexandra: Well I stopped talking to her and I ended up deleting her off my MSN list. And then all of the sudden at some point in grade 9 she decided to add me back on 'cause she obviously felt bad for what she did.*
>
> *Interviewer: So what did you do then with that? When she kind of tried to put you back on her friend list, what did you do?*
>
> *Alexandra: Well, I talk to her, but I only talk to her every once in a while.*
>
> *Interviewer: So you feel – how would you say you feel about your relationship with her?*

> *Alexandra: I'd say on a scale of 1 to 10, it would be about a 2.*

The memory of rejection appeared to be intense and not easily assuaged. Similarly, Emma's mother noted,

> *In grade 7 she was very hurt. And then she started to ignore them. And now if we see them she doesn't even acknowledge them. It's them trying to talk to her a little bit and she doesn't even acknowledge them now…She just realized, I can do that too you know. But I don't know. But we were out grocery shopping the other day and happened upon a couple of people that [left her out in junior high]. She didn't even acknowledge them. Which we kind of said 'great! Finally! Good! It is payback time!'*

Rejecting nondisabled peers as friends can be interpreted as a mechanism for disrupting norms. Both Emma and Alexandra were stigmatized, by their nondisabled peers when they were younger. They were confident in their existing relationships with disabled friends and did not appear to aspire to reconnect with those nondisabled Others.

For many teens involved in the study, parents came to the decision to pursue exclusive disability venues to support the development of friendship. Parents created exclusive summer camps, social clubs, and creative expression groups. One mother described her reasons for supporting her son's participation in exclusive venues.

> *I think there has to be a time for the big wide world, integration, the classroom. But there also has to be a time when they're just all in the same room doing stuff. And whether it's through Special Olympics whether it's through something else. You don't find out who your friends are unless you go out and actually hang out there. And if you're doing something that you enjoy and there's other people there, then you've got one thing in common…You know, they all like the movies, watching the movies and the dance videos…I guess the only thing I can say is that they do seem to genuinely be peers as opposed to an integrated school or recreation setting where clearly our kids are included out of kindness, but not out of genuine you know peer rapport.*

Exclusive disability groups created a space where disability was the norm, where disabled teens connected around interests and created shared memories, where their disability was simply part of who they are. Participating meant they already identified as sharing the disability experience. Because disability was both expected and welcomed, disabled teens shifted their attention to initiating and sustaining *"genuine"* friendships. This concern was reflected by parents interviewed by Overton and Rausch (2002) as well. In the current study the terms "true, "real" and "genuine" were predominantly used by adults to name the quality of friendships they hoped their disabled children would

develop. Although disabled teens did not use the concise language of adults, they clearly valued mutual, reciprocal friendships. As demonstrated throughout the findings chapters, participants enjoyed spending time with people who laughed at their jokes, shared their interests, and treated them like superstars. These were "genuine" friends.

Spending time in places that felt safe and comfortable for disabled teens in this study was a key element of all the friendships. After years of rejection by nondisabled peers, feeling safe was important to participants. They needed to be able to trust that their friends would accept them. An EPA described the sense of safety surrounding the friendship of Alexandra, Jesse and Sean.

> *Well I guess just somebody who's willing to be there and listen and not judge. All three of them, they don't judge each other. They treat each other like people. Yeah. So Sean has somebody that he can go to. And he knows that when he comes there it doesn't matter if he's a little active that day. They'll ask him to be quiet, but it's almost like a little safety net for them. Some place where they feel like nobody in this room's judging me.*

Freedom from the normative judgments about behavior, conversation, and interaction offered these disabled teens the chance to be accepted and appreciated in ways that had previously eluded them.

Feeling safe and accepted surfaced time and again in the stories of friendship shared by participants. Several disabled teens who felt stressed in unpredictable social situations, were able to make and keep close friends in part because of spending time together in safe spaces. These venues afforded them the control they needed to stay calm enough to get to know new people and ease into the friendship at their own pace. A fieldnote excerpt from a session with Gavin and Jared demonstrates this.

> *Today I didn't see too much direct interaction between Gavin and Jared. For the most part they were relaxed and comfortable sitting beside each other in a variety of situations and environments…Once in a while Gavin would put his hand on Jared's shoulder for a moment, but otherwise they just sat together calmly. This act of respectfully sharing space to me looks very significant for someone who, like Jared, is very particular about who is near him, and certainly who he allows to touch him. Gavin and Jared seem to have some kind of understanding.*

Attending to what is not happening is often as important as focusing on the action. For these boys the absence of anxiety or stress was remarkable. Two guys who had unpredictable behaviors were completely at ease with one another. They seemed to

have an unspoken trust, confident that the other would not be intrusive or demanding. This minimalist approach seemed to be what both guys valued. It formed the basis of their friendship, outside the boundaries of verbal language. Engaging with others in safe spaces promoted the friendships of disabled teens in this study, transforming stigma and segregation into a sense of belonging as teens finally felt included in shared experiences with other disabled teens. Once disabled teens became involved in venues where they felt safe – whether at home, school, or in community recreation – they were able to disrupt normative expectations about disability and create lasting friendships.

There are several points of contact between the experiences of disabled youth in the current study and participants involved in Kennedy's (2009) research with Maritime teens she identified as deaf or hard of hearing. Her qualitative analysis lead to her description of three key relational processes that disabled teens used to "mitigate marginalization" in order to fit in with their nondisabled peers at school – struggling, striving, and thriving. The first process, struggling, was characterized by attempting to reduce feelings of vulnerability by avoiding situations that felt risky, masking their impairment, making excuses, acting out, feigning disinterest, engaging in self-harm or substance abuse. This stage of struggling connects with the somewhat negative strategies employed by disabled teens in the current study to manage stigma – attempting to pass as nondisabled and enacting horizontal hostility.

Within the second process identified by Kennedy (2009), striving, disabled teens no longer tried to mask the presence of disability, instead they identified their needs, worked to have those needs met, and concentrated on building relationships. Similarly Low (1996) found that disabled college students enacted resistance to stereotypes of disability by voicing their concerns, engaging in constructive dialogue with nondisabled people, finding humor in situations, and consciously avoiding conflict. In the current study disabled teens also used a range of strategies to disrupt stigma in order to initiate and sustain friendships – disrupting normative expectations about friendship, coming out as disabled, connected through the experience of stigma, and choosing self-exclusion. It was through these intensive efforts that disabled teens in the current study were able to make and keep good friends. This appears to be reminiscent of Kennedy's third process – thriving – where teens demonstrated a sense of empowerment, planning for the future, and setting goals. Many participants in the current study were engaged in planning for what life would hold after graduating high school, felt confident in their relationships and

were developing political savvy about disability rights. Although for some participants faced much uncertainty about future what resources would be available to support their friendships after high school, their friendships were indeed thriving.

6.4   Chapter Summary

This chapter outlined the complexity of the connection between friendship and stigma. Despite struggles, enduring friendships were realized. In some instances friendship was forged through the experience of stigma. Coming out as disabled made it possible for some participants to connect with one another. In other situations the simple act of two disabled teens becoming friends disrupted normative expectations about who makes acceptable friendship partners. Rather than remaining in social isolation, these disabled teens chose to establish friendships with other marginalized peers. The shared experience of oppression appeared to be a key point of connection in these friendships.

Like participants in research completed by Davis and Watson (2002), disabled teens in the current study demonstrated that they "are not passive, vulnerable or incompetent. They are neither solely the victims of impairment, nor are they always silent victims of society that is structured so as to exclude them" (p. 172). Disabled teens navigated around stigma to create sustainable friendships. The challenges they faced were rarely attributed to their experiences of impairment; rather, discrimination in the form of ableism appeared to be one of the core barriers to engaging in meaningful friendship.

The findings in Chapter 4 demonstrated that disabled youth negotiated around stigma to create lasting friendships. Adult support was crucial in this process. Chapter 5 described the challenges parents and Education Program Assistants faced when balancing support against the impulse to overprotect disabled youth. This exposure to both failure and risk served to promote the autonomy of disabled teens as they gained both confidence and skill in establishing and maintaining good friendships. The final theme chapter discussed how disabled youth made their friendships work in a stigmatizing society. In the conclusion the usefulness of these findings is considered.

CHAPTER 7   CONCLUSION

7.1   Introduction

The excited smile on a friend's face, the laughter over a shared memory, the familiar teasing, the reassurance of acceptance, the connections beyond language – friendship meant all of this and more to participants in this study. Three friends described what friendship meant to them succinctly in Chapter 4.

> *Alexandra: Oh! Friends are people who stick together no matter what.*

> *Sean: Friends are people who help you cheer up when you are down… Jesse?*

> *Interviewer: Jesse what would you put on Wikipedia?*

> *Jesse: Fun.*

Disabled teens involved in this study were generous and forthcoming about their experiences of friendship. In the preceding chapters we saw how this small group of teens established and maintained close friendships in the face of pervasive social stigma against disability. The ways that adults supported and hindered the development of these relationships was considered. We explored how disabled youth both conformed with and challenged oppression and ableism to create lasting friendships. I turn now to examining what we have learned about the central research question: *how is friendship understood and experienced by disabled youth*? Attention is then focused on the potential contribution(s) of this study to the larger body of research around the friendships of disabled teens. What do the findings suggest in terms of practical application? How much confidence can the reader have in the findings presented?

7.2   Synthesis of Findings

Each of the sets of friends involved in this study had a unique story, yet there were some experiences that everyone shared. All participants went through a period in their lives where segregation was imposed on them. This separation was sometimes overt, taking the form of mandatory segregation based on educational policy or how that policy was put into practice. Several participants talked about spending at least part of the day in a

learning centre or quiet work area away from nondisabled peers. Given that consistent contact and proximity are two key factors in friendship formation, this separation interfered with initiating friendships with nondisabled peers but facilitated friendships with disabled teens. Another direct form of segregation was outright rejection by nondisabled peers that took the form of ignoring, verbal aggression, or acts of physical violence. Yet these direct approaches to segregation were not the only ones at play. Subtle forms of discrimination also interfered with disabled teens engaging in friendship. Participants explained that friendships from earlier years gradually dissipated due to changing interests. Good friends became acquaintances who said "hi" when they passed in the hallway at school. This shift was attributed to disabled youth, particularly intellectually disabled teens, not maturing at the same rate as their nondisabled peers. In other studies, when teens were asked about this 'drift' form of segregation, nondisabled youth argued that it was more the imposed segregation of disabled teens that created the distance; that there was not enough consistent contact for relationships to be maintained or to form and evolve into friendships (Bunch & Valeo, 2004; Fisher, 1999; Hendrickson, Shokoohi-Yekta, Hamre-Nietupski, Gable, 1996).

Among participants in this study, there were multiple interpretations about the sources of segregation, yet one element surfaced continually: policies promoting inclusion played a complex role in the lives of these teens. Inclusion as a liberal social and educational policy expects that people are equal and thus will automatically have access to physical spaces and relationships once barriers to participation are removed. This underlying assumption of equality offers no way of dealing with the social reality that people are *not* equal and that removing barriers is not enough to ensure comparable experiences.

Participants were not uniformly in favor of how inclusion was enacted in their lives at school and in the community. Rather, many participants (teens and adults) talked about the struggle to fit in and find a place to belong amid a climate of ableism. As demonstrated in Chapter 4, ableism as a form of discrimination based on disability status is the culmination of multiple elements including labeling, stereotyping, separation, and status loss for disabled youth. It was clear that all participants experienced stigmatization based on the presence of disability. Ableism was embedded within multiple dimensions of power that shaped the friendship opportunities of these disabled youth. In addition to the power of social policy, there was also the power that adults hold over children. Adults decide what school disabled teens will attend, how they will get to school, how much of

the day will be spent where, who disabled youth are in contact with during the day both at school and in recreational venues. There were also many examples of the power groups have over individuals. A group of teens had the ability to choose to include or exclude individuals based on the fit with the group's identity and values. Peer pressure meant nondisabled teens were often cautious about contact with disabled youth since they risked their own social status in their peer group, if they were 'hanging out' with disabled youth. Every participant in the current study had been rejected by their peer group, experiencing segregation and social isolation. This is not to portray disabled teens as being without power or agency. They clearly demonstrated their ability to negotiate social contexts in order to create lasting friendships in the face of stigma.

The experience of social isolation was only the beginning of the stories of friendship in this study. Isolation by nondisabled peers was the point at which disabled teens finally connected with good friends. These friendships developed against a backdrop of adult support. Providing transportation, money, coordinating schedules, and finding (or creating) recreational venues were just some of the acts of practical support demonstrated by parents and paid support staff at school and in the community. Emotional support was also crucial as adults gently provided feedback about disabled teens' interaction styles and explained social rules. With one notable exception, all of the adults involved in supporting the friendships of disabled teens in this study were women. They promoted friendships based on the mutual interests of disabled teens and on shared or similar experiences of stigma and/or marginalization.

These shared interests and experiences were typically expressed through engagement in leisure activities. Whether they met at school or in community locations, six sets of friends connected when engaging in activities they enjoyed such as playing computer games, swimming, making puzzles or listening to music. All of the friendships were sustained by participating in recreational activities together that transcended the place where they first met. Leisure activities included in-person experiences at home (e.g. meals, sleep-overs, listening to music, watching movies, playing video games) or in the community. The latter incorporated both unstructured activities (e.g., movies, pizza) and organized activities such as Special Olympics or general recreation (e.g., dance class). Many teens also engaged in recreation via distance technologies. When existing recreation options were inadequate, parents often created new venues that appealed to their children and to other disabled teens (e.g. social club, summer camp).

Adult support was characterized by flexibility – mothers in particular demonstrated the ability to adjust their schedules to accommodate the needs of the friends. They also found ways to negotiate through differences in parenting approaches in order to support the friendships of their children. This involved understanding and respecting the rules, values and expectations of the friend's parents. Adult support also focused on setting the stage for meaningful participation. This was accomplished by creating opportunities for disabled teens to connect with one another in relaxed atmospheres. Interestingly, at a time when parents of nondisabled teens typically back away (or are pushed away) from involvement in the recreational lives of their children, the parents of these disabled youth, especially the intellectually disabled youth, seemed to be ramping up their efforts to promote engagement in recreational activities outside the home. An important part of setting the stage was anticipating what needed to be in place for friendships to form such as inviting a critical mass of potential friendship partners and sharing enough information with potential friends so that they would understand how particular disabled teens experience the social world. Once all the background work was done, the adults who successfully supported enduring friendships faded, seeming to know when and how to get out of the way of the developing friendship.

Adult support for these friendships was remarkable, yet both adults and disabled teens expressed concern over how easily support can shift into surveillance, disrupting friendship. Surveillance can be thought of as over-protection. It sometimes blocked connections by accident, sometimes in the form of missed opportunities because the adult was in the way or did not notice a gesture of interest by another teen. Adult protection was found to sometimes have the paradoxical effect of further isolating the disabled teens. Defining the border between surveillance and support is a difficult task given how flexible the boundary line is. One clear mechanism for identifying when an adult strayed over into surveillance involved attending to the reaction of the teen – when they push back. In the study this was noted to happen in both direct and subtle ways. Direct strategies employed by teens were in response to rules that they felt were intrusive or that limited/restricted their autonomy. Teens also used humor to gently nudge adults into reflecting on their own behavior. More subtle forms of resistance to surveillance included withholding information or avoiding people or situations altogether.

This constant negotiation between surveillance and support happened in part because the boundary is unique to each person, and may shift over time. Strategies to balance

this power dynamic between surveillance and support included involving disabled teens in making decisions about who they wanted to spend time with, what activities they wanted to experience together, and what rules they needed to abide by. Openly talking about social rules was challenging; however, it was an important process in supporting the autonomy of disabled teens. Another strategy that effectively kept adult surveillance in check was simply recognizing that a friendship can not be hurried along from meeting to becoming best friends. Allowing friendships to proceed at their own pace and staying out of the way when conflict erupts were both important supports offered by adults. Maintaining enough distance to be available if needed, but to ensure disabled teens have enough privacy to work problems out on their own made a significant contribution to the friendships of teens in this study. When siblings were readily available they were often quick to monitor the behavior of adults, pointing out over-protective behaviors.

The combination of the agency of disabled teens and adult supports available to them enabled participants to negotiate around stigma to create lasting friendships as presented in Chapter 6. Disabled teens (and their parents) engaged in many strategies to manage stigma. Some of these approaches had potentially deleterious consequences: horizontal hostility and passing as nondisabled. Horizontal hostility involved perpetuating discrimination or contributing to the stigmatization of other disabled youth while simultaneously discounting this person as a potential friend. In effect participants enacted the harmful process of stigmatizing other marginalized teens. Many teens in the study also engaged in passing as nondisabled, where they made efforts to mask the effects of impairment. But these two approaches to stigma management were not the whole story. Participants also found constructive ways to disrupt the oppression of ableism. They created uniquely balanced friendships where the traditional conceptions of reciprocity did not apply. Numerous participants did not hesitate to stretch the boundaries around social norms about the meaning of age-appropriate activities by chasing one another through playgrounds and wrestling in bouncing castles. They actively chose self-exclusion by engaging in friendships with other disabled teens or participated in disability-only recreational venues. Many reflected on the relief they felt when they were finally able to just be themselves with other disabled friends. They felt safe and accepted in these exclusive venues and friendships.

An interesting contrast in the findings suggests that differing strategies concerning ableism may have very different consequences. The parents of both Jared and Jesse

shared a great deal of information about their impairments with potential friends. Given that Jared and Jesse both have long term friendships with numerous peers, openly discussing how these young men experience the world appears to have contributed to sustainable friendships. In contrast, Rachel shared very little about her disability with potential friends, which seemed to contribute to growing social isolation. She – with good reason – feared that disclosure would prevent connection with peers. At the same time, she may have been acting out of an internalized ableism, a deep sense that disabled bodies are abnormal and unacceptable. 'Passing' as nondisabled, or hiding aspects of disability, may then contribute not only to horizontal hostility against other disabled people, but also against the self. Though speculative, given the study design, the contrast between the friendship experiences of Jesse and Jared and those of Rachel hints that there may be an important role in helping teens think through where fears of social ostracism are well-founded and where they may reflect internalized ableism. Helping teens develop strategies to figure out when and how to push past their own comfort zones to risk engagement with potential friends warrants further investigation.

Beyond stigma management and the supports provided by adults, what made these friendships last? Mutual liking and moving beyond the point of origin were early indicators that a casual friendship could become a close friendship. Consistently spending time together while engaging in shared interests were crucial to making friendships last. These experiences became the stories that friends constantly referred back to with amusement. Shared history, both verbal and experiential, made an important contribution to lasting friendship. These stories were sometimes quite entertaining, making everyone laugh when recalling them. But these friendships were not just about acceptance and shared values. They, like most teen friendships, were also riddled with conflict. The friendships endured because the disabled teens, with the support of adults in their lives, were willing to work through these disagreements effectively.

7.3   Evaluating the Project

A set of questions was presented in Chapter 3 to guide the reader in terms of evaluating the merit of this study. The concept of accountability is used to frame the evaluation – including but moving beyond the traditional strengths and limitations approach. The question that underpins accountability is: How did the researcher demonstrate ethical

commitments in the research process? The sub questions raised in section 3.10 are each addressed in turn.

7.3.1   Substantive Contribution

Preliminary findings were presented to another group of parents and disabled teens to see if the analysis connected with their experiences. Many of those who attended this session were the parents of younger children who were in the transition between feeling included (early elementary) and beginning to feel the effects of stigmatization. They were not surprised by the findings that stigma interfered with friendships, but were encouraged by the strategies used by participants to mitigate the effects of stigma as they developed friendships. This suggests the research results resonate with disabled teens and their families who were not involved in the study. While the study is small, and the methodology does not intend generalization, it nonetheless suggests valuable avenues for education and social policy. These are explored in section 7.5. Thus it seems this study has some utility.

7.3.2   Structure

One aspect of accountability concerns whether any part of the findings raise alarm, particularly whether they might bring about negative consequences for disabled youth, or harm them. Certainly, the findings about self-exclusion could be misconstrued as an argument in favor of continued segregation of disabled youth at school and in the community. This is not my position. Disabled youth chose self-exclusion because they were rejected by nondisabled peers. In a stigmatizing society, these disabled teens had few options. In this scenario, self-exclusion makes sense. This choice led to meaningful friendships for all the participants.

The examples of horizontal hostility included in Chapter 6 could be troubling to participants who read this work, particularly if they recognize their own words in the text. There is always risk in naming how oppression becomes internalized, yet it is important to do so. It is valuable to see how negative social perceptions that predominate in a society are picked up by everyone. Being a member of a marginalized group does not make you immune to these messages. This demonstrates the need to take on the much bigger challenge of countering stigma against disability that circulates in social

discourses, rather than suggesting segregation is the only option. Self-exclusion in the face of ableism means confronting ableism, not condoning segregation.

Other structural factors to consider are the depth and breadth of the account offered within the text. Detailed coding was completed in Atlas.ti followed by a cross-case analysis of the friendships. This lead to the development of the concept map where the relationship among the themes was constructed. The query tool in Atlas.ti was then used to gather quotes together that helped explain the three main research themes. The narrative is deeply connected to the participants' voices. Thus, there is a substantial pool of experiences from participants to support the claims made in this text. Additionally, this dissertation provides a broad account of how disabled youth negotiate around stigma to create lasting friendships. The quotes provide a glimpse into the individual experiences; however, the depth of each friendship is not strongly represented in the text. In a text as detailed as a dissertation care must be taken not to provide so much detail about friendships that individuals would become identifiable. In upcoming publications I may choose to depict individual friendships as in-depth case studies that more fully flesh out the relationships.

7.3.3   Engagement of Reader

As the author of this text it is difficult for me to assess the response of the reader. I worked to represent these stories of friendship in a way that held the attention of the reader by incorporating many quotes from participants. Listening to the experiences of participants was at times joyful, distressing, uncomfortable, infuriating, and hilarious. I included a wide range of accounts that evoked these emotions in me. Whether they create a similar response in the reader is uncertain given how much is lost in the translation of experience to text. Representing the friendships of disabled teens was a complex ethical process given the loss of confidentiality involved in telling too much of participants' lives. I could have ensured reader engagement by incorporating in-depth descriptions of the experiences of participants – full of rich story lines and intense emotions. Even though several participants expressed a willingness to be identifiable in the text, the disclosure of the identity of one participant would have essentially named all those involved in that friendship set. The potential cost to participants was too great. Thus, the stories told in this document may not fully satisfy the reader in terms of more fully accessing the lives of participants.

Reader engagement can also be assessed by considering whether the text inspired ideas for future research directions. As I re-read the research findings numerous follow-up questions arose. The teen years involve many transitions. It would be interesting to do a more in-depth analysis of the various 'rites of passage' as teens move into adulthood. Do some of these friendships become roommate situations? Many of the participants expressed their interest in and frustration around dating. Another avenue to pursue in future work could focus on how dating affects the friendships of disabled teens. Given that all of the friends in the study were either in the process of leaving high school or soon would be, a better understanding of what happens when friends are structurally separated after high school is worthwhile. Many women, particularly mothers and female EPAs, strongly shaped the friendship opportunities of participants. It was fascinating to see the different approaches used by the men involved in this study as they supported the friendships of disabled youth. Thus another key area for research involves developing a better understanding about how fathers and male support workers facilitate the friendships of disabled youth.

7.3.4   Representation

Efforts to understand how power functioned in the research process and actions taken to mitigate the negative effects of power are crucial aspects of accountability. I had substantial power in this study, as an adult, as someone who is currently nondisabled, as someone with a health professional background, as someone with many years of education. These markers of status required thoughtful consideration as I prepared for and engaged in the research project. The three years of reading and thinking within the field of disability studies challenged many of my assumptions about what it meant to be nondisabled and to think about the many layers of oppression that shape the experiences of disabled teens. My ongoing caregiving experiences involving my mother also placed me on the receiving end of healthcare services, making me acutely aware of the power imbalance and caused me to think critically about my own history of working with disabled youth and their families. It was from this location that I developed the research proposal with the support of my doctoral committee, all of whom have particular commitments to the rights of disabled people. They guided the development of the research proposal. That document was then approved by the Social Sciences Research Ethics Board at Dalhousie University.

One of the earliest moments for reflection on power occurred during recruitment of participants. After a few months of relatively slow recruitment, the research project was reviewed with my supervisor to identify potential barriers to participation. The original proposal placed a heavy burden on participants in terms of time commitment, both for the teens and for their parents (chauffeurs), thus we opted to reduce the number of interactions participants would have with me. The study was amended and recruitment gradually picked up. In a sense, this means that by 'voting with their feet' potential participants changed the research design.

As part of the research proposal I developed a series of questions to guide the interviews. Participants were asked to bring along photos of fun things they have done together. These images were used as the focal point of the interview. In the end participants answered all of the questions I had developed, but they did it in ways that felt comfortable to them. They set the tone and pace of the interview. This enabled participants to highlight what was most important to them about their friendships. Interviewing the teens together altered the power dynamics. This strategy appeared to be particularly effective as the first interaction between the researcher and participants. It meant they could rely on each other to respond to questions. This also gave participants someone with whom to joke with and tease, thus reducing the stress of the interview situation and enabling them to evade uncomfortable questions.

Many teens prefer not to have an adult around when they are hanging out with their friends, posing a unique challenge around participant observation sessions. To address this concern, participants were all give the option of taking a video camera along to record what they wanted to about their friendship. In the end all participants invited me to join them in their various recreational pursuits. These were all teens who always had adults nearby, so my joining them did not seem to be an unusual experience. All of the contacts with participants (interviews and participant observation) happened at locations and times selected by participants, demonstrating my appreciation of the fact that they were the ones taking the time to include me in their lives, taking the time to tell me about their friendships.

Participants were given the opportunity to read through the findings from the research. Recognizing that the findings chapters are lengthy and that many disabled teens involved in the study are not inclined to read (or listen while someone else reads) the

document, a brief summary of the findings was sent to participants via email. I offered to meet with participants individually to discuss the findings and review the preliminary implications of the study.

Careful consideration of whose knowledge was privileged in this dissertation is part of an evaluation of the accountability of the researcher. Throughout the analytical process the question of whose voices were most prominent was returned to time and again. At times I considered whose interviews I was drawing more quotations from, adults or youth. It became apparent that my attention was drawn to the concise adult comments. I then returned to Atlas.ti and selected only documents from youth to review in order to put adults' stories into the background. For example, the many meanings of friendship presented in Chapter 4 was compiled only from interviews with disabled youth. Feedback from disabled youth both refined and contested aspects of the research findings. For example, at the outset of this project I felt conflicted about the role of Special Olympics. I viewed this organization as segregating disabled youth from nondisabled peers. Yet this and other disability-specific recreation venues were the locations where disabled youth were finally able to establish lasting friendships. Their experiences of acceptance and friendship in these spaces contested my perspective, moving my early beliefs into the background.

A commitment was made to incorporating a range of partial perspectives in this text. Although the stories of disabled youth remained central, interview excerpts were also drawn from parents, education program assistants and my fieldnotes. I did not attempt to have one parent represent the experiences of all parents. Disabled teens, even those who shared a similar medical diagnosis, had vastly different life experiences around disability and impairment. The EPAs interviewed both supported and interfered with the friendships of disabled teens. We are all complex, thus I did not seek out singular perspectives even within individual accounts. Many participants made statements that could be interpreted as contradictory within their own narratives. For example, someone might be a highly supportive parent, but also slide into surveillance. Both accounts are not only possible, they are important to understand. Likewise, teens are multidimensional. They are both victims of discrimination and oppression, and agents making clear choices for their social lives. Some of those choices challenge ableism, while other choices reinforce it. There was room in this account for those multiple truths to co-exist.

7.3.5 Reflexivity

Reflexivity was an ever-present process from the preliminary planning of the research study through to the presentation of the findings. For example, although an ethnographic approach was clearly aligned with the research question, it was apparent that immersion in the culture of disabled youth was not supportable. There are many disability organizations in Nova Scotia; however, there does not appear to be a cohesive disability culture *per se* to become immersed in. Additionally, spending months on end shadowing one or more disabled teens would have placed an incredible burden on them and their families. The primary concern was with friendship, thus, I spent time with disabled teens and their friends in ways that were minimally intrusive to their routines.

Employing a reflexive approach to data collection strengthened the study. Methods were frequently adjusted during the study based on a critical analysis of each participant's unique situation. Some participants enjoyed teasing and making jokes, while others eased into conversations only after several social chats. One participant asked that he be provided with questions in advance and that I follow the order of the questions during our interview. This enabled him to discuss his friendships at length. Some research sessions were divided up into brief interactions over a period of several months, while others requested their involvement take place over an intensive 3 day period. Still other participants could not be interviewed directly. Interviews were replaced by extended participant observation sessions. After these sessions I talked to people who knew these participants well to see if my interpretations of those friendships made sense. My background of working closely with disabled youth who use alternative communication strategies enabled me to comfortably engage with these teens. This experience also seemed to heighten my awareness of unique forms of reciprocity in friendship that are not currently represented in the literature.

The ongoing analysis was discussed with my supervisor at regular intervals. Getting to know participants was a key element of reflexive research practice as described by Davis (1998). The research question and design of my project precluded using the traditional ethnographic method of immersion in the field; however, spending a full year engaging in interviews and participant observation sessions with research participants offered a depth of experience that built upon the breadth of my 16 years of professional practice with disabled youth in Canada and the United States. Spreading the interactions with participants out over time was an opportunity to critically consider the dynamics of

each session and adjust my approach to better fit with participants' preferences and communication styles.

A concept map was designed using an iterative process, beginning with discussions of the preliminary analysis with my supervisor. The map focused the key findings after all interview transcripts and fieldnotes were coded in Atlas.ti. This was not treated as a firm model, instead as the analysis deepened the map shifted in response. This then directed me toward new readings and further data analysis in Atlas.ti that continually modified the map.

Near the end of study I touched base with participants to see if my preliminary impressions fit with their experiences of friendship. This was not done to see if I 'got it right', rather, to see if participants felt comfortable with how their stories were represented in the findings. To accomplish this I developed a 'voice thread movie' using the Website http://voicethread.com. I uploaded the pdf of a power point presentation and layered my voice onto the set of slides creating a 30 minute voice thread. I then sent out the url (http://voicethread.com/share/634049/) to all participants in the study via individual emails. Responses from participants are expected to come in over the next week. Their comments will shape the final version of the voice thread and will inform the implications section of this paper.

An accounting of the personal and professional background that informed this project is provided in Chapter 1. Although that position statement offered general guideposts, it does not fully explain the dialectical interaction that took place between me and participants throughout the course of this study. My experiences as an occupational therapist uniquely prepared me to engage with disabled teens and their families in terms of understanding a range of communication approaches. Unexpected behaviors have been a consistent part of my personal and professional life for many years. I understand them as ways of expressing one's inner world. I was also able to bring stories from my professional experience to the interviews – both to support what participants contributed and to provide counter examples for them to respond to. Although I carried those skills forward into the project, I did not hold to medicalized understandings of disability, nor did I presume what someone's abilities, disabilities, or priorities would be. I engaged with participants as teenagers, as people with interesting lives and important perspectives. They brought forward their understandings of what disability meant in their friendship

stories. Having witnessed the gradual social isolation experienced by my mother as she became a disabled woman heightened my awareness of the painful processes involved in the stigmatization experienced by disabled youth and their parents.

This analysis was intimately informed by my ethical commitment to centralize the voices of disabled teens, my experiences as a caregiver, my clinical experiences as an occupational therapist and by a feminist, critical disability perspective. This unique combination of lenses guided me throughout the research process. The research question itself finds its roots in those years of working closely with disabled teens and their families in communities across Canada and the United State. These experiences enabled me to readily connect strongly with parents, primarily mothers. It was through these women that I was able to access the friendship stories of disabled teens. The flexible approach to data collection was only possible because of my background as a community-based occupational therapist. My reluctance to commit any of these research findings to print is directly linked to my acute awareness of how harmful text can be in the lives of disabled people.

7.4   Limitations

Overall, this study accomplished what it set out to do. It provides a multi-voiced account of the friendships of a group of disabled teens. As part of my commitment to offering a balanced account of the project, I will review some of the limitations encountered in the process of this study. Interviewing teens comes with particular challenges as described by Bassett and colleagues (2008). Teens are generally not at a developmental stage at which they think abstractly or reflectively about their life stories and relationships. This made it particularly challenging to find ways to prompt participants to offer greater detail and depth about why their friendships worked so well. This is not to say that teens do not have important insights, clearly they do.

Although there is a balance of male and female participants, with only one exception, all disabled teens involved in this study were white. This does not reflect the diversity in the population, particularly in Halifax. That said, cultural diversity was not the focus of this project. It was advertised through a range of listservs and community groups throughout two regions of the province; therefore, information about the project was available to a wide range of potential participants. Recruitment focused on teens who identified as

being treated differently from their peers based on the presence of disability. Another aspect of recruitment proved particularly challenging. It was nearly impossible to approach disabled youth directly about the study. Adults such as parents, teachers, health professionals, and community workers acted as gatekeepers. This made recruitment particularly challenging since I could not personally interact with potential participants to introduce myself and the project.

At the outset of this paper I highlighted some the challenges of being an outsider. I was, and continue at this moment to be nondisabled. There is much of the experience of disability that I cannot begin to understand. Although I have experienced discrimination, it was not based on my ability status. For several years of my life I was a teenager, but I have not claimed that label for two decades. There were many times during interviews where I felt like I could not quite figure out how to tap into the experiences of participants. This was not about teens not being able to respond to queries, rather it seemed to be more of a reflection of my difficulty in reframing questions that connected with participants' ways of understanding the social world.

In a qualitative study the researcher must make decisions, based on the research question and theoretical orientation, about how to focus the analysis. Attending to particular dimensions of the data automatically moved other valuable aspects of participants' experiences into the background. For example, at present there is no comment about any differences noted between the girls and boys in the study. Given the number of participants (7 girls, 7 boys) there is not enough data to confidently make claims about gender differences in these friendships, nor is comparative analysis usually the intent of qualitative research. Another area that was not fully analyzed was the importance of technology in the social lives of disabled teens. Offering an in-depth account about how technology contributed to the friendships of disabled teens could be valuable. The role of conflict in the friendships of disabled youth is also worthy of further analysis. Additionally, conflict involving friends, parents, teachers, recreation program staff, and policy makers appeared to be an integral part of the friendships of disabled teens. Closer consideration of conflict within these friendships has merit.

7.5   Preliminary Implications of Findings

On the basis of a single study, with this particular study design, I have some reluctance about identifying potential implications. They should be considered a starting point for discussion in academic and non-academic forums. How might these findings inform disabled teens, nondisabled teens, parents, EPAs, educators, school board members, policy makers and researchers as we all work together to support the friendships of disabled teens? Ableism forms the backdrop for this entire study. Eradicating or reducing it would change everything in these findings. The study suggests implications at three complementary social levels: individual, education system, and community.

7.5.1   Individual Implications

Findings from this study offer some guidance about where to focus our efforts at the individual level. This includes suggestions about what disabled teens might do to promote change themselves, what parents and other adult allies can do to support the friendships of disabled youth. First, consider some of the actions disabled youth took to establish and maintain their friendship. Recall that all participants experienced painful social isolation, sometimes beginning as early as grade 3. They recognized the personal risk involved when initiating friendships, but they went ahead and tried to initiate new friendships anyway. Friendship takes courage, and for participants in the study the risk appeared to be worthwhile.

Expressing an interest in a potential friend was the starting point in all of the friendships in the study. One participant in the study directly asked for help from adults to facilitate their friendship. Recall that Rachel and Amanda first connected because of that newsletter. Rachel expressed an interest in meeting the girl in the story with whom she seemed to have much in common. This request made their friendship possible. Indicating one's preference for a potential friend did not always require words. Jared specifically sought out a friendship with Timothy by sitting with him on the school bus. Emma treated Lauren like a superstar every time their paths crossed at school. Turning to another set of friends in the study, Jay and Brandon, we learn that it is possible to connect with someone who may be an acquaintance from years gone by. These guys seemed to have little interest in one another when they were young, but as teenagers they became best friends. Many teens in the study also let adults know when they needed more privacy. Sometimes this was done verbally such as Brandon telling his

mom to move to a different chair so she would not have a full view of the dance floor. At other times teens were more subtle, simply going to another room in the house to hang out away from parents.

Taking the initiative in friendship also meant that disabled teens in this study put themselves into social situations. Some went to disability-specific social clubs, others participated in disability sport. The friendships of most teens in the study developed over a period of months or years. They were all willing to invest the time in gradually getting to know one another. Doing this in the context of a social gathering or sporting event seemed to make the teens feel more comfortable with one another. They didn't have to interact directly and could gradually get to know one another. A key factor for all of the friends was that they extended their friendships beyond the original point of contact. For example, if they met at school, like Sabrina and Cassidy, they then exchanged phone numbers, and chatted with each other from home. All of these friends spent time together across a range of settings that for many included home, school, community locations, and virtual spaces such as Facebook and MSN.

One participant in the study confronted discrimination directly in an effort to dispel stereotypes about disabilities. This was done in part to reduce the conflict she was experiencing with nondisabled peers. Until this tension was addressed it was difficult for her to make and keep friends at school. She opted to develop a presentation to explain particular aspects of her impairment. She described the experience of sharing this personal information both daunting and exhilarating. There was no guarantee that sharing this information (essentially coming out as disabled) would counter the effects of stigma, but Amanda took the risk. She felt this action lead to greater understanding from her nondisabled peers and, more importantly, was an incredible boost to her confidence in expressing her views and advocating for her rights as a disabled teen.

Disabled youth involved in this study offered numerous suggestions both through their words and actions about how other disabled teens might pursue meaningful friendships, but the implications of their stories do not end there. Adults can learn much about dismantling ableism from these friendships as well. At the very least adults involved in the lives of disabled teens can reflexively ask themselves, "at this moment am I engaging in support or surveillance?" Other suggestions raised by supportive adults in the study included working on social skills with disabled teens in real life situations. They

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emphasized the importance of gently guiding disabled youth as they learn about the complicated web of social rules that form the foundation for solid friendship.

Countering ableism is not the sole responsibility of those who experience it. Adults need to learn about stigma and explore our own values and beliefs around disability. Together disabled teens, their friends, and adult allies need to openly discuss what ableism is and how it affects their lives, including horizontal hostility. It is the responsibility of adults (disabled and nondisabled) to help teens develop skills for challenging ableism. Just as parents from racialized groups spend an inordinate amount of time teaching their children how to handle racism in ways that do not reduce their future life chances, so parents of disabled youth have to teach stigma management.

A key implication is that adults need to figure out how to stay in the background. We are in supportive roles, but are not the significant players in friendship. Disabled teens need to have the space and privacy for their friendships to develop – and for those same friendships to potentially fail. We all deserve the dignity of taking these risks. As adults we can take the time to talk about our own friendships – including the ones that did not last. We all need to move beyond traditional ideas about what it means to have a balanced friendship and instead consider some of the unique ways friends can demonstrate reciprocity and mutual liking.

As an adult my voice tends to have greater influence than the voices of the participants in this study. With my position of relative power and privilege comes the responsibility of countering ableism through my daily actions, in my research practice, in my writings and presentations. I need to partner more with disabled youth in deciding what kinds of research questions to ask, how to go about responding to those questions, and how to represent the findings.

7.5.2 Classroom Implications

Although this study did not focus on friendships within the school system, nearly all of the disabled teens involved in the study spent time together at school. During their interviews benefits and drawbacks of educational policy often surfaced. Adults made these references to policy directly. Disabled youth were not necessarily aware of how policy shaped their friendship opportunities; however, they described many situations that connected to how educational policy was interpreted within their schools.

Administrators and educators need to carefully examine what version of inclusion they are enacting within the education system. Are they setting inclusion up as shared space that leads to social isolation or as shared experience that leads to a sense of belonging and friendship? Building diversity into the curriculum, and specifically naming ableism, would raise awareness of this dimension of discrimination. In this study the earliest accounts of stigmatization were reported in grade three. Children learn ableism. It can be unlearned. It would also be useful for school administration to clearly differentiate between equality and equity in the classroom and around the school campus. Disabled youth and their peers need to see that everyone has equitable (not equal) consequences and expectations.

There is a large volume of research available regarding how to effectively implement inclusive educational policy. It is beyond the scope of the current study to provide broad classroom recommendations; however, participants had specific suggestions for promoting friendships at school. For example, they advocated for setting up cooperative learning activities in junior high and high school to encourage disabled teens and their disabled and nondisabled peers to interact in a structured activity so that they can gradually get to know one another. Additionally, given that the friendships of disabled youth face unique challenges, ensuring that these friends can spend time together during the school day could help sustain the relationship. Administrators need to think carefully about the implications of particular policies, such as the practice of separating friends in the elementary school years. This policy appears to be designed to encourage children to connect to a wider range of potential friends; however, it may inadvertently disrupt meaningful friendships. We need to recognize that friendships between disabled youth are at least as valuable as the friendships disabled youth establish with nondisabled peers.

EPAs in the current study were skilled at recognizing mutual liking between potential friends. Nearly every friendship in this study started with an EPA letting parents know who seemed to be genuinely interested in becoming friends. If a disabled teen is struggling to make friends, adults may want to focus on supporting connections between disabled teens and other students who understand what it is like to experience stigma. At the same time it is crucial that adults avoid turning budding friendships into helping relationships since this seems to lead to the demise of the relationship. Given the important role EPAs play in supporting the friendships of disabled youth, school

administrators need to ensure that EPAs are skilled at negotiating the complex boundary between surveillance and support. EPAs need to have opportunities to talk amongst themselves and learn from one another during professional development days.

7.5.3   Community Implications

Ableism is a pervasive social problem. There is much work to be done to dismantle this damaging set of assumptions, beliefs and practices. I do not pretend to know how this is to be accomplished; however, participants in the study had some ideas of where we might begin. We need to focus on similarities between children – they already know what their differences are. In order for disabled teens to engage in enduring friendships, their partners (disabled or nondisabled) need to appreciate the diversity they bring to the social world. Friendship is about acceptance, both at an individual level and at a broader social level. Since most friendships involve some element of community-based recreation (e.g., going out to a movie, restaurant, mall, bowling alley, swimming pool) these venues need to be more than just physically accessible – they need to actively resist the stigmatization of disabled youth.

Finally, outing oneself as disabled is a complex personal and political act. It moves far beyond the individual realm. Perhaps there are lessons to be learned from the social movements such as the Lesbian, Gay, Bisexual, and Transgendered (LGBT) movement. At present it seems that disabled youth are separated by diagnostic labels. In some important ways this diminishes the political power of disabled people. If disabled people and their allies were able to connect over the experience of disability more broadly, perhaps a more cohesive political community would emerge – a community that could then connect with other anti-oppressive movements. The disabled youth in the current study have already begun. They connected with one another despite the many social structures that function to separate them. We need to build on their example and forge a wider community that has the power to dismantle ableism.

7.6   Future Directions

Preparing this dissertation is the early stage of knowledge translation. It will serve as the foundation for a series of presentations and publications in the next 2 years. The first key activity will involve developing a parallel text of the research findings that is accessible to everyone who participated in the study, including those who do not read. The voice

thread movie is a work in progress that could evolve into a parallel text of sorts. Other formats for parallel text will rely heavily on visual imagery in printed material or video/audio files on my research website. Presenting the research analysis on an accessible website for youth could keep the analysis open to new readings continuing the recursive cycle of reflexive methodology. I will also develop research papers for publication based on findings in this dissertation. The conceptual framework is already accepted for publication in *Disability and Society* (Salmon & Bassett, 2009). An article based on Chapter 5, focused on adult support/surveillance could be targeted to an education journal. I may prepare Chapters 4 and 6 for publication in a journal around the sociology of youth. It would be informative to further analyze data in Atlas.ti in order to more fully develop an article focused on the role recreation plays in developing and sustaining friendships. As I entertain these and other possibilities, research participants will be invited to collaborate in preparing and presenting the research results at local, national and international disability, social policy and rehabilitation conferences.

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APPENDIX A: MAP OF RESEARCH THEMES
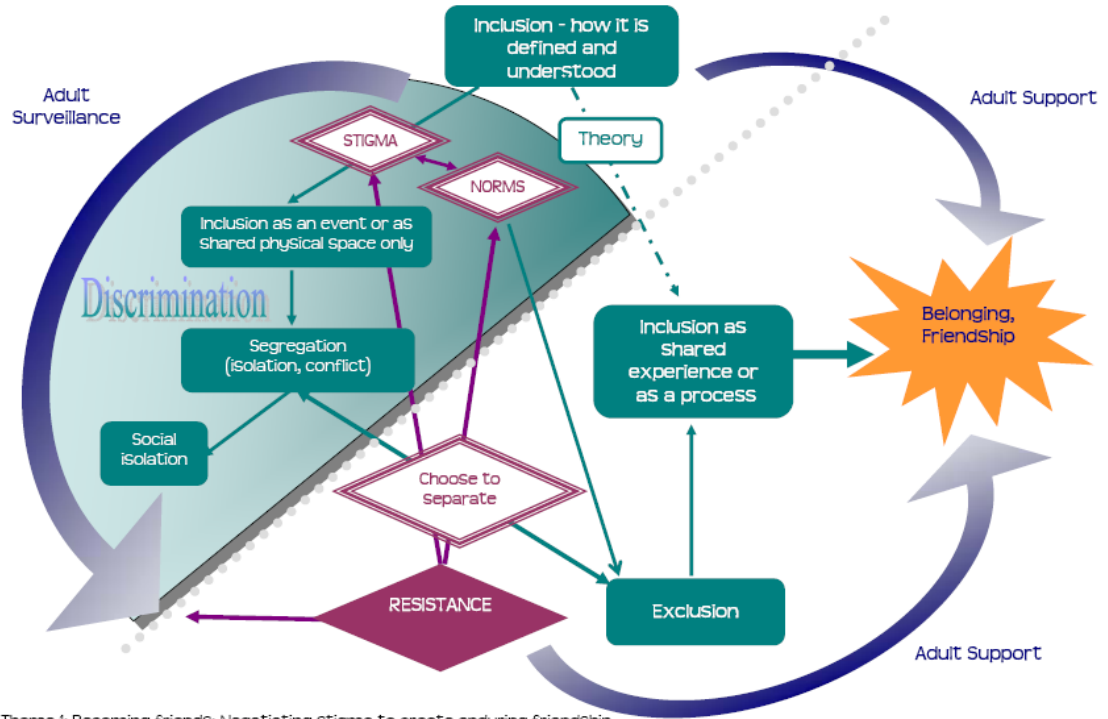
Theme 1: Becoming friends: Negotiating stigma to create enduring friendship
Themes 2: Finding a balance: Adult support and surveillance in friendship
Theme 3: Transforming oppression through friendship

APPENDIX B: RESEARCH MAP

Master's Research (1998)
Paving rough roads: Transition experiences of students with disabilities and their families

Doctoral Research Question (2004)
How is friendship understood and experienced by disabled youth?

Methodology: Ethnographic Case Studies
(January 2008 – October 2008)
14 teens (13 disabled; 1 nondisabled)
7 girls, 7 boys ages 15-20

Fieldnotes
1. Descriptive Notes
2. Analytic Memos
3. Personal Response Journal
4. Theoretical Notes

Interviews (31 total)
1. Friendship dyads (8)
2. Individual interviews with friends (14)
3. Parent or support staff (10)

Observations (14 total)
Observe friendship partners engaged in preferred activities

Preliminary Ethnographic Analysis
(May 2008 - June 2009)

Present Preliminary Findings
June 2009 Preliminary findings presented at Atlantic Provinces Special Education Authority (APSEA) family conference as keynote address

Reflexive Interpretation (June- July 2009)

Final Analysis and Preparation of Dissertation Defense (August-September 2009)
Ongoing Knowledge Translation

APPENDIX D: INTRODUCTORY LETTER

Date:

I am so pleased about your interest in "A place to belong." The purpose of this study is to learn about the friendships of teens with disabilities. This research project is part of my PhD studies at Dalhousie University. I worked for many years as an occupational therapist both in Canada and in the United States. Many teenagers with disabilities talked to me about how hard it was to make friends. Lots of people have written about why it is hard for teens with disabilities to make good friends. Few people have tried to understand why some friendships do work! This study will give us some ideas about how to support the friendships of youth with disabilities.

This study will involve 10 teens with disabilities. The project has several parts. These are included in the attached chart:
1. An interview with you and your friend together at the beginning and at the end of the study.
2. Two individual interviews with you.
3. One individual interview with your friend.
4. Discussing two video recordings you and your friend make of activities you enjoy doing together.
5. One interview with an adult who has been around to see your friendship develop over time.

Here are the details about each activity. First I will interview you and your friend together at the beginning of the study, then again about 6 months later. It is important that you have been friends for at least 6 months and you contact each other outside of school. For our first interview you can bring along photographs of you and your friend doing things together. We will talk about how you became friends, what you enjoy doing, and what makes your friendship work. Near the end of the study I will interview you and your friend together again. This time you can create something that describes your friendship and bring it to our interview. You could do many things including making be a video, a set of music clips, a photo collage, writing a story or a poem. In this interview I will ask you to tell me about your friendship project.

These interviews will last about one hour and will be digitally recorded if you agree. This recording will later be typed up so that I can read it carefully. This will help me think about how your experiences connect to the experiences of other people in the study. Real names will not be used when I talk about my research.

Second, I would like to talk with you on your own about friendship two times. This will give you a chance to add any ideas that you thought about after our first interview with your friend. Each interview will be about one hour long. I will meet you at a place where you feel comfortable to talk. These interviews will be audiotaped if you agree. It will be typed out to make it easier for me to remember.

Third, I will interview your friend on his/her own once. This interview will last about an hour. It will be audiotaped and typed out later.

Fourth, I will watch you and your friend two times during the study while you do an activity you enjoy together. This might be playing video games, going to the mall, watching a movie, or going for a swim. It is whatever you usually do together away from school where it feels ok to have me around. I will hang out with you for about 2 hours. I'll write down what I noticed about your friendship. If this feels uncomfortable, then you can make a video about your favorite activities. I will show you how to use the recorder and where, who, when, and what is ok to record. Once you make a recording about your activities, we will get together so you can play the recording for me and tell me about it. This interview will last about an hour and will be audiotaped if you agree. It will be typed out to make it easier for me to remember everything you talk about.

Fifth, I will interview your parent, or another adult who has been around to watch your friendship develop. This interview will last about 45–60 minutes. It will also be audiotaped and typed up.

At the beginning of each interview or meeting I will ask you if you are willing to participate in the study and if you agree to audiotaping. If at any time you feel uncomfortable or want to stop the interview or observation that's fine. For example, you can stop talking, ask me to turn off the digital recorder, or say that it is time to go home.

Any time you, your friend, or your parent(s) drive to meet me, you will get a $15 voucher to cover the cost of gas. You and your friend will each get a $20 gift certificate half way through the study to thank you for your time. You will get another gift certificate at the end of the project. These will be from a sports store, music store, or on-line business.

All information will be kept safe in a locked cabinet in my university office. The digital files of all photographs, audio and video recordings will be encrypted and password protected to make sure no one can access them. No digital file will be transmitted over the web. The written notes and electronic files will be stored at Dalhousie University for five years after the study ends.

The information from this study will be used in many ways. I will write up a large report as my thesis or the story of the research. Parts of the study will be presented at conferences. People with disabilities, teachers, and health care workers will learn more about how to support friendships. Posters, brochures, newspaper articles, radio interviews, podcasts, and web pages might also be created so that many people can learn from your experiences.

Please contact me with any questions or to set up a time to meet in person. My office phone number is (902) 494–8804 and my email is nsalmon@dal.ca . You can also visit the research website for more information: <insert website when complete>

Thanks so much for your time,

Nancy Salmon, M.Sc.O.T. (c)
Doctoral Candidate

APPENDIX E: NEWSPAPER ARTICLE

Study looks at teen friendships

Relationships often more difficult for those with disabilities

By LISA BROWN
lbrown@southshorenow.ca

COUNTY — It's hard to imagine teenagers without close friends, but it happens, especially with teens who have disabilities.

That's why a PhD student at Dalhousie University is researching the successful friendships of teens with disabilities in an effort to grasp what makes those relationships work.

"I want to understand what they're doing that the rest of us have somehow missed," Nancy Salmon explains.

Ms Salmon worked for nearly 20 years as an occupational therapist, including a stint at South Shore Regional Hospital. During that time, many teens with disabilities spoke to her about how hard it was to make friends.

While lots of research has looked at those difficulties, Ms Salmon decided to study friendships from the other side. By learning what makes friendships work, how teens negotiate long-lasting friendships despite the existing barriers, she hopes to help other teens.

"A lot of times adults don't quite get it, including me," she says. "We try to impose ideas on kids, whether it's some kind of social skills program or a social networking scheme, we try to impose something that we think will work to try to help kids make friends. Ultimately, most of them fail and you have these kids that are even more devastated."

Ms Salmon currently has six sets of friends from the Halifax and South Shore areas participating in her research project. She's looking for four more sets of friends from this area willing to take part.

The teens must be between the ages of 15 and 19. They must identify themselves as having a disability — any type of disability — and have a friend they spend time with outside of school. The friend can be any age.

"Friendships are one of the strongest protective factors for kids and for adults, in terms of our health, our well-being, our social adjustment. In high school, if you think in terms of the social pressures and bullying that often happen to kids that are identified as different in some way, friendship is an enormous protector against those negative social interactions that can happen," Ms Salmon says.

Anyone interested in participating can contact Nancy Salmon at 494-2330 or nsalmon@dal.ca or through her web site at www.placetobelong.ca.

July 29, 2008   Bridgewater Bulletin   A20

APPENDIX F: CONSENT FORM FOR FRIENDS

A place to belong: Friendship as experienced by youth with disabilities

Introduction:
You are invited to be part of a research project about the friendships of teens with disabilities in Nova Scotia between the ages of 15 and 19. Nancy Salmon, a graduate student at Dalhousie University, is doing this study as part of her PhD work. Your participation in this study is voluntary and you may withdraw from the study at any time. If you choose not to stay involved in the study, it will have no impact on your access to services. The study is described below. This description tells you about the risks, inconvenience, or discomfort which you might experience. Participating in the study might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about this study with Nancy. The whole project will take about 18–19 hours of your time over 6 months. That includes the time it takes to get ready to meet me and the time we spend together.

Contact Information:

Address:	Nancy Salmon, M.Sc.O.T.
	Interdisciplinary Ph.D. Programme
	School of Occupational Therapy
	Dalhousie University
	Halifax, NS
	B3H 3J5
Phone:	(902) 494–8804
Email:	nsalmon@dal.ca
Fax:	(902) 494–1229
	Supervisor: Brenda Beagan (494–6555)

Purpose of the Study
The purpose of this study is to learn about the friendships of teens with disabilities. Detailed stories about good friends will be created.

Study Design
Ten teenagers with disabilities and their friends will be part of this study. This study is made up of four parts: (1) interviews with teens and friends, (2) interviews with someone who knows about how your friendship started, (3) observations, and (4) looking at papers that help me understand the bigger picture about friendship and disability (e.g. newspaper stories, individual program plans, medical reports, and school policies).

Who can Participate in the Study
Teenagers with disabilities who are between the ages of 15 and 19 are invited to be part of this study. A close friend of each teen with a disability needs to also agree to be part of the study. A close friend is someone you have known for more than 6 months and is a person you spend time with outside of school.

Who will be Conducting the Research
Nancy Salmon will be doing this study with the help of her supervisor, Dr. Brenda Beagan and two other advisors, Dr. Joyce Magill-Evans and Dr. Judy MacDonald. These people are able to look at all of the information you offer Nancy. This includes recordings of interviews and any photos or videos you make as part of the study.

What you will be asked to do
Interviews: You will be asked to do a set of interviews, on your own and with your friend, where you can talk about your friendship, the things you do together, and what makes your friendship work. These interviews will be audiotaped and later written out to help me remember what you say. You and your friend will be asked not tell other people what is talked about; but one of you may still decide to tell other people about the interview you do together. When the study is done, you will also be asked if quotes from your interview can be used when Nancy tells other people about this study. No one will be told the words are from your interview.

Observations: The things you and your friend like to do together are also good to know about. There are two ways you can show your favorite activities. First, Nancy can join you and your friend as long as it wouldn't feel strange to have an adult around. Second, Nancy can loan you a camera so that you can make a video about some of the things you and your friend like to do. If you would like to make a video, then Nancy will go over a few things with you, like how to use the camera and when it is ok to include people other than you and your friend.

Confidentiality and Anonymity
Anonymity**:** You will be asked to pick a fake name that will replace your real name in the study. A paper that has both your real name and your fake name will be kept in a locked drawer in Nancy's office at the university. Your name will not be used in anything that is written or presented about this research. Because you know your friend and the adult you invite to be part of the study, it is possible that you will recognize quotes from each other. You should be aware that this limits the anonymity that can be provided to you in the study. If you make any videos or create any other artwork as part of this study, these items will only be used when I tell other people about the study if you agree. At the end of the study I will show you what items (e.g. photos, video clips, and artwork) I would like to use in presentations and papers I write. You can tell me if it is ok to use them at that time.

Confidentiality: The recordings of your interviews and any other digital files, like video clips and photographs, will be stored on Nancy's computer. They will be in a hidden file in the computer and will be password protected. All information from the study will be securely stored at Dalhousie University for five years after the study ends. Nancy will keep everything you say private unless you talk about child abuse or abuse by a partner. Nancy has to report this kind of information to the local Family and Children's Service agency

Your Rights: You can say that you don't want to answer any question that is asked. You can stop the interview at any time. Nancy will not be upset and will stop right away. You can listen to the tape of your interview or read the typed copy. Nancy can give you a copy of the summary she writes about your meetings. It will not affect Nancy's schoolwork if you decide you want to stop being in this study. You can ask Nancy any questions you want to about the study or you can talk to her supervisor, Dr. Brenda Beagan at Dalhousie University.

Possible Risks and Discomforts
Sometimes things come up in an interview that can make you feel upset. Talking about your friendship might feel uncomfortable. You don't have to talk about anything you don't want to. When you are interviewed with your friend, one of you might say something that hurts the other person's feelings. You can tell Nancy you want to stop at any time. If you stay upset after the interview, you can be referred to a counselor to help sort out your feelings.

Possible Benefits
The study will not help you, but it could give us ideas that will help younger kids with disabilities to make good friends when they become teenagers. Sometimes talking about friendships makes you feel closer to your friend. This study gives you the chance to think about what makes friendships work for you. This may help you to make more close friends.

Compensation/Reimbursement
If you, your friend, or your parent needs to drive anywhere to meet me, then you will be provided with a voucher for $15 to cover the cost of gas for each visit. You and your friend will each get a $20 gift certificate half way through the study to thank you for your time. You will get another gift certificate at the end of the project. These will be from a sports store, music store, or on-line business.

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Patricia Lindley, Director of Dalhousie University's Office of Human Research Ethics Administration, for assistance at (902) 494-1462.

Consent Form for Friends
A place to belong: Friendship as experienced by youth with disabilities

I have read/heard the letter about this study. I have read/heard the consent form. All my questions have been answered at this time and I agree to be part of this study. I know that I am free to stop being part of this study at any time. I can ask for copies of my interviews. I have been given a copy of the letter and this signed consent form.

_____   I consent to having interviews audiotaped

_____   I consent to Nancy including quotations from my interviews when she tells
                        other   people about this study. I know that I can change my mind
                        about this until Nancy has written up the first full draft of her final report
                        about this study.

_____   I consent to being videotaped. At the end of the study Nancy will show me
                        any video clips she would like to use when she writes about or tells other
                        people about this study. At that time I will tell her if she can use them.

_____   I consent to Nancy having copies of any photos I provide to her. At the
                        end of the study Nancy will show me any photos she would like to use
                        when she writes about or tells other people about this study. At that time I
                        will tell her if she can use them.

_____   _____
Participant's Signature or Signature of Proxy   Date

_____   _____
Researcher's Signature   Date

Consent to use images or original work of participant
<to be obtained at end of study>

_____   I consent to Nancy including the _____ (insert number) photographs,
                        the _____ (insert number) videoclips and _____ (e.g.
                        artwork, poem, story, music) in her dissertation and any papers she writes
                        or presentations she gives about this study.

_____   _____
Participant's Signature or Signature of Proxy   Date

_____   _____
Researcher's Signature   Date

APPENDIX G: PARENT ASSENT FORM

A place to belong: Friendship as experienced by youth with disabilities.

Your son/daughter has agreed to be part of a study called "A place to belong: Friendship as experienced by youth with disabilities." Learning about the friendships of teens with disabilities is the focus of this study. This study includes youth in Nova Scotia between the ages of 15 and 19. Nancy Salmon, a graduate student in the Interdisciplinary PhD Programme at Dalhousie University, is doing this study as part of her PhD work.

Your son/daughter will be asked to be part of a series of up to 4 interviews and 2 observations where s/he can talk about his/her friendship. I would also like to learn about the things s/he does with his/her friends and what makes their friendship work. The talks I have with your son/daughter are private and will not be shared with you directly. He/She is allowed to refuse to answer any question that is asked. She/He can stop the interview at any time. Your child's name will not be used in anything that is written or presented about this research.

●——●

I have read/heard the information letter about "A place to belong: Friendship as experienced by youth with disabilities." All my questions have been answered at this time and I know my child is part of this study. I was given with a copy of the information letter and the signed assent form.

_____   _____
Participant's Signature   Date

_____   _____
Researcher's Signature   Date

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Patricia Lindley, Director of Dalhousie University's Office of Human Research Ethics Administration, for assistance at (902) 494-1462.

APPENDIX H: CONSENT FOR TERTIARY PARTICIPANTS

A place to belong: Friendship as experienced by youth with disabilities

Introduction:
You are invited to be part of a research project about the friendships of teens with disabilities in Nova Scotia between the ages of 15 and 19. Nancy Salmon, a graduate student at Dalhousie University, is doing this study as part of her PhD programme. Your participation in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconvenience, or discomfort which you might experience. Participating in the study might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about this study with Nancy. The whole project will take about 4 hours of your time. That includes getting ready for our meeting and the time we spend together.

Contact Information:

Address:	Nancy Salmon, M.Sc.O.T.
	Interdisciplinary Ph.D. Programme
	School of Occupational Therapy
	Dalhousie University
	Halifax, NS
	B3H 3J5

Phone:	(902) 494–8804
Email:	nsalmon@dal.ca
Fax:	(902) 494–1229

Supervisor: Brenda Beagan (494–6555)

Purpose of the Study
The purpose of this study is to learn about the friendships of teens with disabilities. Detailed stories about good friends will be created.

Study Design
Ten teenagers with disabilities and their friends will be part of this study. This study is made up of four parts: (1) interviews with teens and friends, (2) interviews with someone who knows about how the friendship started, (3) observations, and (4) looking at papers that help me understand the bigger picture about friendship and disability (e.g. newspaper stories, individual program plans, medical reports, and school policies).

Who can Participate in the Study
Only people identified by the student with a disability can be included in this part of the study. You were identified by that person as someone who knows about his/her friendship.

Who will be Conducting the Research
Nancy Salmon will be doing this study with the help of her supervisor, Dr. Brenda Beagan and two other advisors, Dr. Joyce Magill-Evans and Dr. Judy MacDonald. These people are able to look at all of the information you offer Nancy. This includes recordings of interviews and any photos or videos you make as part of the study.

What you will be asked to do
Interviews: You will be asked to do on interview where you can talk to Nancy about your observations of the friendship between the youth with a disability and his/her friend and what makes their friendship work. This interview will be audiotaped and later written out to help me remember what you say. When the study is done, you will also be asked if quotes you make during an interview can be used when Nancy tells other people about this study. No one will know the words are from your interview.

Confidentiality and Anonymity
Anonymity**:** You will be asked to pick a fake name that will replace your real name in the study. A paper that has both your real name and your fake name will be kept in a locked drawer in Nancy's office at the university. Your name will not be used in anything that is written or presented about this research. Because you know the two main research participants well (youth with a disability and his/her friend), it is possible that you will recognize quotes from each other. You should be aware that this limits the anonymity that can be provided to you in the study.

Confidentiality: The digital recordings of your interviews will be stored on Nancy's computer. They will be in a hidden file in the computer and will be password protected. All data collected during this study will be securely stored at Dalhousie University for five years after the study ends. Nancy will keep everything you say private unless you talk about child abuse or abuse by a partner. Nancy has to report this kind of information to the local Family and Children's Service agency

Your Rights: You can say that you don't want to answer any question that is asked. You can stop the interview at any time. Nancy will not be upset and will stop right away. You can listen to the tape of your interview or read the typed copy. Nancy can give you a copy of the summary she writes about your meetings. It will not affect Nancy's schoolwork if you decide you want to stop being in this study. You can ask Nancy any questions you want to about the study or you can talk to her supervisor, Dr. Brenda Beagan at Dalhousie University.

Possible Risks and Discomforts
Sometimes things come up in an interview that can make you feel upset. You don't have to talk about anything you don't want to. You can tell Nancy you want to stop at any time. If you stay upset after the interview, Nancy can refer you to a counselor to help sort out your feelings.

Possible Benefits
The study will not help you, but it could give us ideas that will help kids with disabilities to make good friends when they become teenagers.

Compensation/Reimbursement
If you need to drive anywhere to meet me, then you will be given a voucher for $15 to cover the cost of gas.

> **If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Patricia Lindley, Director of Dalhousie University's Office of Human Research Ethics Administration, for assistance at (902) 494-1462.**

I have read/heard the letter about this study. I have read/heard the consent form. All my questions have been answered at this time and I agree to be part of this study. I know that I am free to stop being part of this study at any time. I have been given a copy of the letter and this signed consent form.

_____   I consent to having interviews audiotaped

_____   I consent to Nancy including quotations from my interviews when she tells other people about this study. Nancy will contact me to ask my permission to include my quotes in her work. I know that I can change my mind about this until Nancy has written up the first full draft of her final report about this study.

_____   _____
Participant's Signature or Signature of Proxy   Date

_____   _____
Researcher's Signature   Date

APPENDIX I: SUMMARY OF RESEARCH ACTIVITIES

Month	Activity	Estimated Time	Travel Money
1	Meet to go over information letter and consent form	45–60 minutes	$15 if you or your friend needs to drive to get to our meeting.
	First interview with you and your friend together	45 – 60 minutes	$15 if you or your friend needs to drive to get to our meeting.
2	First individual interview with you	45 – 60 minutes	$15 if you need to drive to get to our meeting.
	Individual interview with your friend	45 – 60 minutes	$15 if your friend needs to drive to get to our meeting.
3	Observation or video of you and your friend doing activity you enjoy outside of school	2–3 hours	None. I will travel to the place you and your friend meet.
4	Interview with an adult in your life	45–60 minutes	$15 if this person needs to drive to get to our meeting.
	Observation or video of you and your friend doing activity you enjoy outside of school	2–3 hours	None. I will travel to the place you and your friend meet.
5	Interview with you and your friend together	1–2 hours	$15 if you or your friend needs to drive to get to our meeting.
6	Second individual interview with you	45 – 60 minutes	$15 if you need to drive to get to our meeting.

Primary Participants: **19 hours total** including preparation and travel time as follows:
- 9–11 hours direct contact with researcher
- 2–3 hours travel time
- 2–3 hours preparation for interviews (collecting photos, creating representation of friendship)

Secondary Participants: 18 hours total including preparation and travel time as follows:
- 8–10 hours direct contact with researcher
- 2–3 hours travel time
- 2–3 hours preparation for interviews (collecting photos, creating representation of friendship)

Tertiary Participants: 4 hours total including
- 2 hours direct contact with researcher
- 1 hour travel time
- 1 hour checking in after interview

APPENDIX J: INITIAL INTERVIEW WITH FRIENDS TOGETHER

1. Opening Comment: I am happy that you are able to talk with me today about your friendship. You do not have to answer any questions that make you feel uncomfortable. Remember that either of you can stop the interview at any time. If I notice that you seem uncomfortable I will ask you if you would like to stop the interview.

Question: I see you were able to collect a few photos. Tell me about them.

Probes: a. Looking at pictures is a great way to remember fun times. Tell me the story that   goes along with these photos.
*   b. How did you two meet?*
*   c. How did you get to be good friends?*

2. Comment: There are many different kinds of friends. For example, I like chatting on the phone with some of my friends. Other friends are great to go hiking or cycling with. I also have a few friends that I study with.

Question: What do you enjoy doing together?
Probes: a. How do you get together after school?
*   b. What are some of your favorite places to go? (Use community map as a prompt).*

3. Comment: Some friendships last a few weeks. Others last for years. You two have been friends for _____ months/years.

Question: What helps you stay friends?
Probes: a. You mentioned _____ (frequent contact, living nearby, both enjoy videogames) earlier in our talk. Does that help?

APPENDIX K: SECOND JOINT INTERVIEW WITH FRIENDS

1. Opening Comment: This is our last interview together for this study. We have learned a lot about your friendship over the past few months. Last time we met I asked you to come up with some way to describe your friendship. This could be a poem, a song, a painting, a video, a set of photos – anything that works for you.

    Question: What did you come up with?

    Probes: a. Describe what these images (this music etc) mean to you.
        b. What parts of your friendship are they about?
        c. Are these the most important things in your friendship? If not, what are the things that matter to you most about being friends?
        d. Are there parts of your friendship that you left out? If so, what are they?

2. Comment: Friendships often change over time. Sometimes friendships get stronger, sometimes new friends enter our lives, sometimes friends grow apart or move away.

    Question: Are there any changes you notice in your friendship when you think of it now compared to six months ago?

    Question: When you picture your life in another year where do you think you will be? What will that mean to your friendship?

APPENDIX L: FIRST INDIVIDUAL INTERVIEW

1. Opening Comment: I'd like to learn more about your friendship in our conversation today.

Questions: *What things are important to you in a friendship that you see in your friendship with _____? What things are missing, if any, that you would like to have?*

Probes: *a. What are some things about you that your friend likes?*
           b. What do you get from this friendship?
           c. What do you like most about your friend? Why?
           d. What do you like least? Why?
           e. What does your friend get from this friendship?
           f. Is there anything you would like to change about your friendship if you could? What would that be? Why?
           g. Why do you think your friendship with ____ works so well?
           h. What things make it easier or harder for you and ____ to stay good friends?

2. Comment: People around us often watch what happens in our lives.

Question: **How do you think other people see your friendship with _____? Why? What are the ways that this affects you and _____?**

3. Comment: Some people like friendships where they can give a lot to the other person. Others want more equal friendships.

*Question*: **Where does your friendship with ____ fit in?**

4. Comment: Some people say when you have a disability that the disability is what everyone notices first.

Question: Do you think that is true? Where does your (or your friend's) disability fit in your friendship? In what ways does it matter to your friend has/does not have a disability?

APPENDIX M: FRIENDSHIP MAP

This diagram may be used in the second individual interview as a place to start the conversation.

Comment: Place the names of everyone you know and like in the green circle. Then think about which of these people you feel closer to than others. Move their names into the yellow circle. Finally, think about your very favorite people. Move their names into the blue circle in the middle. Where does your friendship with _____ fit?

People I really like

My favorite people

People I know and like
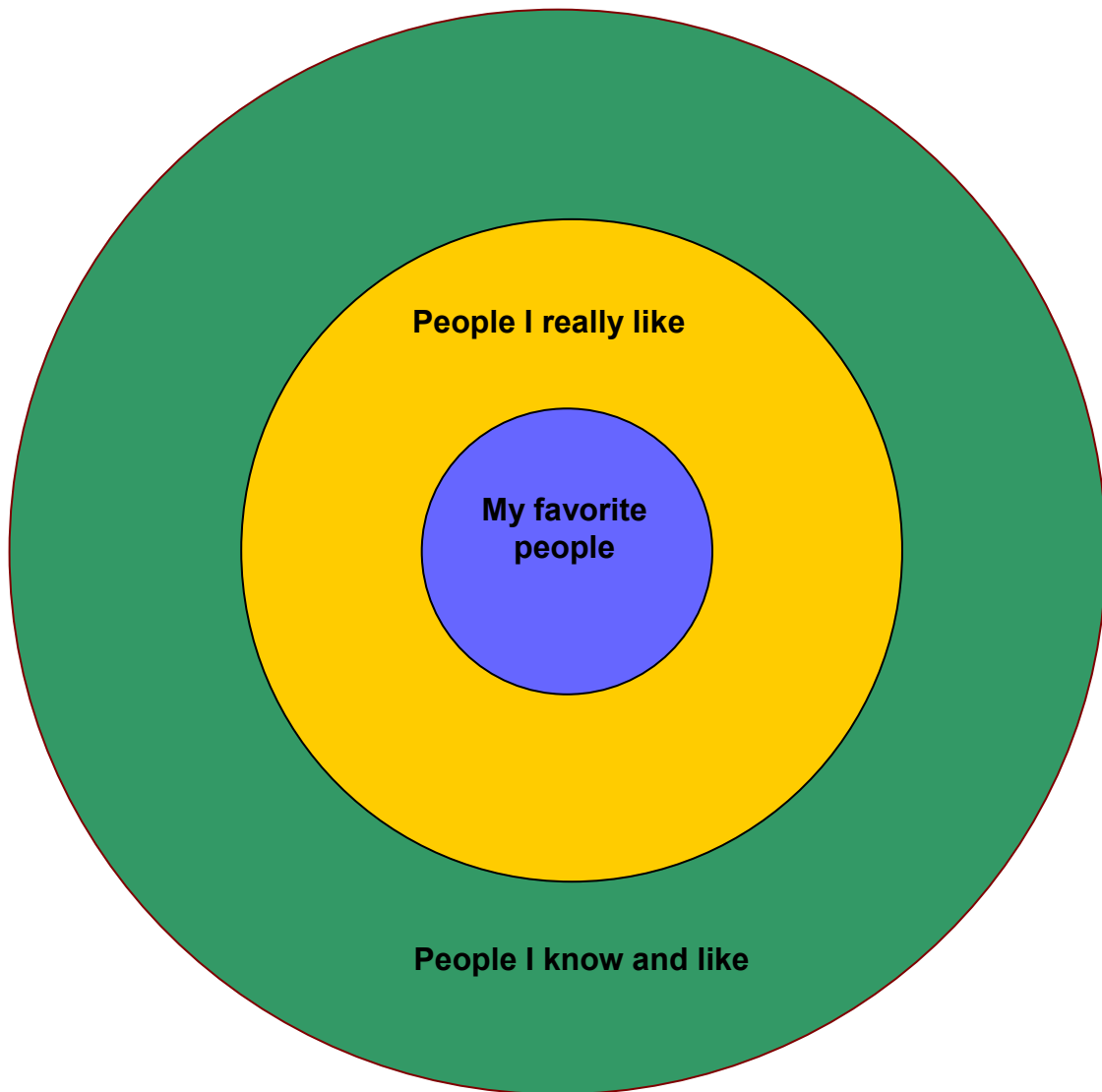
APPENDIX N: SECOND INDIVIDUAL INTERVIEW WITH FRIENDS

1. Opening Comment: I'd like to work on this friendship map with you. Where would you like to start? You can just name people and show me where you would put them in the picture or you can have some time on your own to figure out where you want to put names.

Question: Tell me about your relationships with some of these people.

Probes:
> *a. What makes the difference between the group of people in the green circle and the people you included in the yellow ring?*

> *b. What is different about the people in the blue circle? Why are they your favorite people? Tell me about some of these friendships.*

2. Comment: I'd like to know about your observations of other kids with disabilities and their friends.

Question: What have you noticed about the friendships of other kids with disabilities?

Probes:
> *a. What do you think would make it easier for other kids with disabilities to make friends?*

> *b. What do you think would make it easier for kids with disabilities to keep friends?*

APPENDIX O: INTERVIEW GUIDE FOR ADULT WITNESSES

1. Opening Comment: As you know, I have been working closely with _____ (primary participant) over the last few months trying to understand what contributes to positive friendship experiences for teens with disabilities. I'm interested in hearing your perspective.

Question: Tell me how this friendship developed over time.

> *Probes:*
> *a. What do you think holds the friendship together?*
> *b. What kinds of supports have the kids needed in order to be successful?*
> *c. Where do you see this friendship going from here?*
> *d. Tell me about _____'s other friendships? Previous friendships?*
> *e. How do you feel about this one?*

2. **Comment**: Some people believe that disability makes a difference in how people are treated. I'd like to know what you think about that statement in terms of friendship opportunities.

Question: How do you think disability influences this friendship?

3. Comment: I'd like to hear about your observations of other kids with disabilities and their friends.

Question: What have you noticed about the friendships of other kids with disabilities?

> *Probes:*
> *a. What do you think would make it easier for other kids with disabilities to make friends?*
> *b. What do you think would make it easier for kids with disabilities to keep friends?*