

Tell Me a Story About Your Child: A Narrative Exploration of Disability in Recreation

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be electronically available to the public.

Abstract

The purpose of this narrative inquiry was to explore how parents understand and experience their child's involvement and non-involvement in community leisure experiences. The study involved five parents with children between eight and twenty-one years of age, and asked them about the recreation experiences of their child who had a cognitive and/or physical disability. Narrative methodology enabled a holistic, comprehensive and personal approach to exploring their experiences. Each parent completed two narrative interviews, the first to produce a narrative account and the second to explore the meaning of his or her narrative. This study used a two step analysis process to explore the narratives. The descriptive analysis focused on establishing the context, and creating the narrative account using the interview transcripts and my interpretation of the stories. An interpretive analysis was completed in three phases to explore the purpose of the story, the order and sequence and presentation of self, and explored the cultural practices of the narratives. From the narratives I found many parents told their stories for other parents or recreation practitioners. The key message from the stories was the importance of recreation for social networking for both parent and child. Important spaces from the stories were identified: space to be social, space to succeed and space to be engaged or included. Other characters played critical roles in the recreation experiences. Internal conflict was often experienced by parents where the desire for the child to participate clashed with the parents' hesitation, concern, or schedule. The final phase of analysis revealed a difference between my understandings of key terms (segregation, integration and inclusion) and the parents' understandings of those terms. Many parents and children had experienced a level of exclusion both from and within recreation experiences. Inclusion was found to be an enabling and disabling practice. I found gains in political power developed through increases in social and psychological power. Levels of trust and the phases of empowerment were important to the parents' understandings of inclusion. The conclusions identified the parents as being responsible for negotiating recreation, and the children had an awareness of their disability. Finally, discrepancies about the meaning of segregation, integration and inclusion were identified.

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Chapter One: Introduction

The first time I realized just how smart Aiden¹ really was, and what kind of influence I had been on him was almost three years after our first meeting. Thinking back now, it took a long, long time for me to realize I was having an effect on someone. I had been working with Aiden as a personal care assistant, babysitter, life coach, companion and friend through my semesters at university and for one fun filled summer. I met Aiden because of his younger sister. Their family needed a regular babysitter who could manage a wheelchair bound teenager, and a toddler at the same time. Aiden and I had spent many afternoons and weekends together, hanging out in the same ways I did with my friends. We shared the same love for soccer, Tim Horton's and movies. The only difference was that Aiden used a wheelchair, and had been diagnosed early in life with a combination of developmental and physical disabilities; whatever, our time together was special.

Through the months and years I began to catch glimpses of his capabilities and began to dream about what he would be like if he were "normal." It might sound odd or offensive to some, but I can honestly admit I thought about it as I am sure others have too. What would it be like to have a real conversation with him where we both used words to articulate the deep and profound thoughts we were having like, what kind of jelly doughnut do I want today? I caught myself lost in a wishful thought one spring sunny afternoon while walking beside Aiden down Main Street to pick up the mail. Slowly sauntering down the grass lined sidewalk, lost in my own thoughts I felt a tug on my wrist. I looked down to Aiden and realized he was pulling at me to stop. I had come to the university driveway and Aiden was telling me to stop. We had been practicing stopping at crosswalks and major driveways for a few weeks. I had told myself that if he was ever to do this alone I would make sure he would be safe. What I realized when Aiden tugged on me was that he had not only recognized the need to stop himself, but took that thought further and caught me making a dangerous choice. He was watching out for me, and enforcing my own rules. I was blown away when I realized just how attentive and cheeky this young man was.

Filled with pride and determination, I set out on a mission to change Aiden's life and make him as independent as possible. I thought I could be the one to change his life but realized later he was the one to change mine. Armed with my new found egotism and supposed life changing skills I set out to change Aiden. Anything I used to do for him was now his with a few small exceptions like getting into and out of the pool or car. So began weeks of work with Aiden, teaching him and occasionally telling him to do things on his own. Having some minor personal experience in the art of teaching independence I picked activities and routine tasks for him to do. One of my greatest successes was getting Aiden to go down the ramp in front of his house, from the door to the driveway, alone. Aiden began to successfully complete sections of the ramp by himself with me waiting at each landing. He would have to wait until I was ready, and would have to go slowly and stop himself at the landing or else we would start again. He was never too impressed with starting again, but as I explained to him "if you don't want to do it again, then do it right the first time". Aiden would look at me, with a knowing grin and proceeded to laugh hysterically for several moments until the realization settled in that I was serious and yes, he would have to start again. As the summer weeks passed Aiden was descending the ramp while I got further and further away, eventually waiting at the bottom of the driveway for him. Then off we would go on another grand adventure, usually to get ice cream that would melt all over us in the summer heat.

One day while Aiden's parents were home, he and I started off for another adventurous walk through town. We said goodbye, and headed out the door. I checked with Aiden to make sure he was ready to do the ramp, and I hopped down the stairs to meet him at the bottom. As Aiden began down the ramp, I heard a shriek and saw his mother fly out the door sprint down the ramp and grab him just as he stopped himself at the first landing. "Oh goodness, he can't do this alone!" she exclaimed, "You have to be there with him." I looked up at Aiden's mom, smiled and asked her to join me at the bottom. After a few moments she took a

¹ All names used are pseudonyms.

tentative step towards me, remembering what great things Aiden had been doing all summer with me. I told her he would be fine, and asked her to come and see what Aiden could do. She cautiously left her son's side and came to stand with me. I threw my hands up in the air as if in defeat, looked up at Aiden, and said "Our secret's out! You're going to have to show your mom that you can do it on your own." And down he came, slow and safe, just like we had practiced. No tipping or crashing, just a smooth ride down the ramp coming to a controlled stop at his mother's feet. Aiden looked at me, I looked at his mom, and she stared mouth hanging open in complete shock at what her son had just done. She looked over at me, and with a grin I declared "he's been doing it for weeks! We've just been waiting for the right time to show you".

The Study

I believe that we live storied lives. We learn and live through stories² told by us and to us. The value of this study lies within the stories shared by these parents and myself. This study does not provide generalizations that apply to every parent, family, youth or person with a disability, because each experience and life is different. The personal stories from these parents have afforded us new insights into the experience of disability in a leisure context. The study offers insight into the parent's understandings of disability in the context of leisure. What we have gained from the insights of these parents is an understanding about the role the environment, activities, resources, policies, staff, volunteers, and other participants have played in shaping these stories and experiences. The group of parents selected for this study offer a unique perspective and have immensely broadened my own understanding of disability and recreation.

As I have reflected on my experiences with parents speaking about their "disabled children" I realized they often held a different understanding of their children and a unique perspective on disability. The parents shared in the journey of disability alongside their children, experiencing a range of emotions depending on the situation. These parents, like other parents, spend hours shuttling their children to and from various recreation activities and watching their children participate. I have learned that in many cases, parents of children with disabilities were often participating alongside their children and just as engaged in the

² As described by Glover (2003) the intent of narrative inquiry is to explore "first person accounts of experience" (p.163). Therefore, no distinction is made between narrative and story in this document, the terms will be used interchangeably (Glover, 2003).

programs and activities. From these (almost) shared leisure experiences these parents have developed their own ideas about disability and recreation.

The parents in the study were chosen because they have kept their children living at home, and they have actively sought recreation experiences for them. They never saw their children as being their disability, and embraced their children for just what they were, their sons and daughters. The children of parents in this study participated in a range of segregated, integrated and inclusive leisure programs, and in some instances experienced non-involvement. Throughout my undergraduate years I spent most weekends lifeguarding for the swimming portion of the Rainbow Recreation program in which Aiden had been a long-time participant. During one summer I participated at a local recreation society with Aiden and as a result had first hand exposure to the activities, staff and experiences this program offered. Both of these programs offered unique recreation opportunities for children and youth with disabilities. I consider both programs to be segregated.

The literature I had been introduced to in my undergraduate years identified limitations of and negative aspects of segregation and did not fit my experiences with this concept. Through graduate school I continued to reflect on issues such as choice, power, freedom, segregation, integration and the meaning of disability within the context of leisure. These concepts inspired the study, and my understanding of them has changed and evolved with increased exposure to them.

In recent decades there has been a movement away from the use of segregated programs towards the integration and inclusion of people with disabilities into community spaces and recreation programs (Hutchison & Lord, 1979; Lord & Hutchison, 2007; Schleien, Ray & Green, 1997). Despite this trend, there is a continued presence of segregated programs for people with disabilities. This presents a bit of a conundrum, if the Government of Canada has committed to “the full and active participation of all Canadians in our country’s social, cultural and economic life...and, to build communities in which everyone can be fully included” (Human Resources and Social Development Canada, 2005, p. 30), then what are segregated programs offering that integrated or inclusive programs are missing? Why are parents and families choosing

to participate in these programs when inclusive programs are supposed to meet their needs? What can we learn from the parents and families about their involvement in segregated, integrated and inclusive community recreation, and their non-involvement?

Many of the segregated programs offered today have been designed and implemented to meet the needs of a specific population, for example, persons with disabilities (Schleien et al., 1997). Hutchison and McGill (1992) identified one reason for the continuation of segregated programs, and the concern that is raised in response. According to these authors many segregated programs developed as a continuation of “the belief that people who have similar labels have the same needs, and that they can be best served together in congregated environments” (Hutchison & McGill, p. 18). However, they provide the counter argument, that often “segregation leads to further stigmatization and ostracizing of the person by accentuating differences” (Hutchison & McGill, p. 19). These two statements highlight one of the tensions standing between movement toward integration and inclusion and the continuation of segregated programs. The perspective parents hold about these terms can be drastically different than the descriptions provided in the literature. These parents’ narratives about their children’s experiences in community recreation give insight into their understanding of these terms and provide leisure researchers and practitioners with insight into how disability is experienced in recreation.

Purpose of the Study and Research Questions

To explore the experiences of parents a flexible and meaningful qualitative methodology was necessary. Qualitative research produces “descriptive data” or the words, descriptions, and explanations of the participants (Peter, 2000, p. 355). Narrative inquiry uses stories to collect and share experience and was well suited for this study as it retained a focus on participants’ stories of experience. Daly (2007) argues that:

[s]tories help us to comprehend our individual and cultural values (moral status), and they are a means by which we come to know our cultural practices (epistemic status). In this regard, narrative analysis goes beyond the lessons of the individual story: It is also a means to generate knowledge

that disrupts traditional explanations and allows us to see the complexities of human lives as they are shaped by changing cultural practices (p. 113).

The purpose of this narrative inquiry was to explore how parents understand and experience disability through their child's involvement in segregated, integrated, and inclusive leisure experiences and their non-involvement in recreation contexts. This collection of narratives deepened the knowledge and understanding we possess about recreation and disability. This exploratory study illuminated the role recreation (leisure) plays in the interpretation and experience of disability.

The research questions guiding this study included:

1. What are the stories of parents of children with disabilities?
2. How do these stories help us to understand the recreation experiences of children with disabilities?
3. How do these stories help us to understand disability in recreation practices?

Rationale for the Study

Studies involving parent perspective are gaining popularity in narrative, leisure and disability research (Brett 2002; Fisher & Goodley, 2007; Garcia, Mendez-Perez & Ortiz, 2000) but require further study. It was not the intention of this study to critique programs or practitioners (in segregated, integrated or inclusive environments). Parents provide insights about their children because they are often present for most of their children's experiences (Malone & Landers, 2001) outside of the school setting. Parents are experts in their own right, as they have shared and lived continual experiences of disability alongside their children. The wealth of knowledge and understanding from families including a child with a disability has only begun to be explored in leisure studies, education, sociology, and disability studies (Curtin & Clarke, 2005; Fennick & Royle, 2003; Smith & Sparkes, 2008).

The value of this study to leisure researchers and recreation practitioners is that it deepens awareness of the experiences, meanings and understandings of disability in different environments. These parents provided tremendous insights into their children's experiences in different recreation settings and levels of involvement.

Overview of the Thesis

This chapter has introduced the important concepts relating to this study including: disability, community recreation, inclusion, integration, segregation, parent perspective, and narrative inquiry. This chapter also presented the purpose statement and research questions. Chapter Two contains a detailed review of the literature including a description of: models of disability, involving people with disabilities in communities through integration, segregation and inclusion; studies on disability; and leisure and disability studies involving narrative inquiry. Chapter Three provides an overview of the methodological approach for this study, narrative inquiry. This chapter includes an introduction and explanation of narrative inquiry, details about the context and participants, and describes the methods used for data collection (narrative interviews) and describes the approach to narrative analysis. Also included are discussions of reflexivity, the significance of this study, and ethical considerations.

The findings for the study are presented in Chapter Four. This chapter contains the narratives of parents created through the descriptive analysis process and each is preceded by an introduction which establishes the context for the story and parent. These stories bring to light challenges and successes each parent and child has experienced through recreation. Finally, Chapter Five provides an interpretive analysis of the narratives from Chapter Four. In this chapter three phases of interpretive analysis were completed. Phase 1 explored the purpose of the story, who the audience was, and the emotional impact on the reader. Phase 2 explored important time and space frames, and explored who the protagonist was, the conflicts within the story, and how other characters were presented. Finally, Phase 3 utilized findings from Phases 1 and 2 to explore how the narratives produce an understanding of the cultural practices related to disability, recreation and levels of involvement. Chapter Five also includes a discussion of the implications of the study as well as conclusions.

Significance of Study

The knowledge produced from this study I believe is extremely valuable to other researchers in the fields of disability and leisure studies, to recreation and leisure practitioners, and to other communities including people with disabilities and families with children who have disabilities. This study did not attempt to produce generalized results or knowledge that can be applied to every parent or youth with disability. What this study has generated is an expanded understanding of disability in a recreation context by those people most directly affected by it. By having parents tell stories, this study provided an opportunity for the parents to share the meanings of those experiences. What these parents ultimately shared were their children's experiences as well as their own perceptions and understandings of these experiences through their own eyes. By seeking out stories of experience in different recreation settings (non-involvement, segregation, integration and inclusion) this study has begun to explore a range of experiences in recreation rather than focusing on one type.

This study is significant to the field of Recreation and Leisure Studies as it contributes to the use of narrative inquiry in leisure research, and provides further understanding of the recreation experiences for parents of children with disabilities. The parents' narratives produced from this study illuminated the numerous and pressing issues faced in life by these parents and their children. These issues require further exploration. By engaging parents, this study has supported the growing use of parents as sources of insight into the experiences of children.

Chapter Two: Review of Literature

Before I left Nova Scotia for grad school in Ontario I was asked by Aiden's parents to teach some of his new caregivers and babysitters about him. They told me "you have done such amazing things with him that we never thought were possible. You never accepted him for his disabilities and always pushed him to be and to do more." We all had tears in our eyes as we talked about my time with Aiden and all the things he had come to accomplish, trying to avoid the mention of it all coming to an end. The next day I met one of the new "buddies" for Aiden. His name was Mark, a massive football player from the university. I remember seeing him at the gym lifting ridiculously large weights with the other football players who also mysteriously lacked a neck like Mark. Well, I thought to myself, at least he'll be able to pick Aiden up. Heck, he could probably pick Aiden up in his wheelchair with one hand. I was already jealous of the time he would have with my Aiden. I shared Aiden with other caregivers and buddies but secretly knew I was one of his favourites.

Mark met us at the house, and so began my attempt to pass on all of my knowledge about Aiden in one shot. Naturally I had loaded Aiden up with as many balls as possible which I had instructed him to throw as fast as he could at this new guy. "Let's show him what you're made of!" I told Aiden in a hushed whisper, I was crouched beside the door watching Mark walk up the steps. "Mark!" I exclaimed, while opening the door, "we've been waiting for you! Aiden is so excited to have a new buddy, especially a sporty man like yourself!" I said with something of a devilish grin spread across my face. Mark took the ball assault surprisingly well. Although I was disappointed that he did not return fire on Aiden, or even pick up the balls until I started too.

We spent the next three hours, Mark, Aiden and I, doing and talking about everything I could think of. To be honest, I felt kind of bad overwhelming this new guy with all I knew, but I felt obliged to make sure everyone knew what Aiden was capable of, what they should and should not be doing for him, and every other tiny detail, whatever, I was ambitious and poor Mark was strapped in for the ride. He took it in stride and at the end of the day even seemed excited to spend tomorrow with us. After dinner that night I sat on the couch watching a World Cup soccer match with Aiden. I kept thinking about what I knew and had told Mark, trying to figure out what I had missed.

Here's what I knew about Aiden. When he wakes up in the morning the first person he wants is to see his mom, then he wants to know what's for breakfast. Aiden isn't picky about what he wears, as long as it has something sport related on it. Aiden likes cereal for breakfast and despises when I make him get it from the cupboard himself. Aiden adores his school bus driver and explodes with happiness whenever he sees a big yellow school bus, or any giant vehicle for that matter. Aiden has friends at school who eat lunch with him, and read with him, but outside of school rarely ever hangout with him. His favourite snacks are chocolate chip muffins, french-fries, and any type of neon coloured juice. If his parents would allow it, Aiden would eat hamburgers and chicken fingers every meal of each day with massive glasses of Coke to wash it down. Aiden hates honeydew melon but loves cantaloupe. In the summer his chin drips with strawberry juice from the fruit we pick together at the farm down the road. He will only eat chocolate ice cream, and only tries new things if I stare him down long enough until he gets past the humour in dropping the new food out of his mouth. He loves stop lights, and popcorn from the movie theatre. He is a daredevil and sweetheart. He can move himself around in his chair, but can't drive a car, walk down the street, or have a conversation the way I do with his parents. Aiden loves his family, and teasing his sister. He likes getting kisses from the family dog because it grosses his mom out. I know that Aiden is having the best life possible because his parents love him and have made incredible sacrifices to ensure his happiness and wellbeing. I don't know if Aiden misses me anymore, but I do know that I think about him, what we learned and what he taught me every day.

In total I worked with Aiden for three and half years while I completed my undergraduate degree in Nova Scotia. It was a combination of the length of time and the nature of my relationship with Aiden that

enabled me to learn, and remember so much about him. I spent time with Aiden in almost every context imaginable. From these reflections I realized I understood Aiden as a whole person. He was a classmate, a brother, a friend, a nephew, a neighbour, a son, a teammate, a student and a community member. Aiden has physical, emotional, spiritual, social and psychological aspects of his person like anyone else. To understand any person, a holistic approach is necessary. Similar to my comprehensive reflections on Aiden, it was important in this study to broadly examine the concepts of disability, leisure, and narrative inquiry. This chapter examines the two dominant models of disability, and then explores the concepts of non-involvement, segregation, integration and inclusion. Studies of disability are then reviewed, and the chapter concludes with an examination of narrative inquiry in disability studies and leisure studies.

Models of Disability

Where and how disability is situated, explored and understood shaped this research study, and my interpretations of disability. Defining the meaning of disability requires consideration of the many complex factors, perspectives, and historical and socio-political influences that shaped our collective understanding over time. To begin, a global definition of disability is provided and discussed. This first definition provides a basis to open the discussion of disability. This is followed by an exploration of disability in reference to the two main models that shaped our understanding of this concept: the medical model and the social model. These models are explored to determine the historical and social development of their perspectives, and their use in qualitative research.

The World Health Organization (WHO, 2009) produced a series of definitions which situate disability in relation to body function (and structure) and participation. The International Classification of Functioning, Disability and Health (ICF), provides the WHO guidelines for evaluating health and disability. The ICF uses three levels of classification in relation to disability: impairment, disability and handicap (WHO). The ICF recognizes that disability occurs in different domains: within the body (individual) and within society (social) (WHO). In addition the ICF recognizes that disability exists within a context, therefore environmental factors are considered in defining disability and function (WHO).

The Government of Canada (Federal/Provincial/Territorial Ministers Responsible for Social Service, 1998) used definitions provided by the WHO and ICF to describe the concept of impairment as disturbances at the level of the organ, and disability as:

[a]ny restriction or inability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being. Disability describes a functional limitation or activity restriction caused by an impairment. Disabilities are descriptions of disturbances in function at the level of the person. (Appendix A, para. 1)

These definitions of impairment and disability identify two important issues that are further discussed in reviewing the models of disability. The definition of impairment places the abnormality or loss of a physiological structure within the person; in other words, it is located within the individual (Federal/Provincial/Territorial Ministers Responsible for Social Service, 1998). The definition of disability recognizes the role of the impairment in restricting or limiting the individual from what would be considered the normal ability. In this definition the disability is attached to the individual, and an individual with a disability lies in contrast to non-disabled individuals with normal capacity or ability. The Federal/Provincial/Territorial Ministers Responsible for Social Service (1998) further note that a handicap is:

[a]ny disadvantage for a given individual resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual. The classification of handicap is a classification of circumstances that place the individual at a disadvantage relative to their peers when viewed from the norms of society. (Appendix A, para. 1)

A handicap results from relationships or interactions between the individual and his/her environment in comparison to non-disabled peers. This differentiation between impairment, disability and handicap has generated debate among scholars. Shogan (1998) supports the distinction made between impairment and disability, but disagrees with the further differentiation of handicap. This debate centres on the physical nature of impairment and disability, and the additional considerations of society and culture with the creation of a handicap (Shogan, 1998). Shogan argues that being disabled results from the context and relationship between the physical impairment and social places that produce a disability. For the purposes of this paper the terms impairment and disability will be used to describe the physical and social aspects respectively.

Medical Models of Disability

The medical model focuses on the individual and has been one of the most common approaches to understanding the meaning of disability. This model identifies people by their differences, and seeks to find solutions to their individual problems. Goering (2002) provides an overview of the medical model stating it, “holds that disability is internal, a problem with the person’s physical or mental self, and is a state that deserves medical attention and/or a curative treatment wherever possible” (p. 374). Devine and Sylvester (2005) provide a definition where disability within the medical model is viewed “as a negative variation from the physical norm that necessarily disadvantages the physically distinct subject’s life and life quality” (p. 87). Here the medical model of disability centres disability on the affected individual, and the physical impairments affecting that person. Oliver (1996) describes the focus of the medical or psychological aspects of disability as being internal to the person. As noted by Devin and Sylvester (2005), Oliver (1996), and Goering (2002), characteristics of the medical model include: an internal locus of disability, medicalization of the problem and its’ tragic nature, and an emphasis on fixing the problem. The individualization of disability is evident in medical and academic literature; each characteristic will be discussed below.

As Devine and Sylvester (2005) discussed, the medical model places disability within a person although it results from a physical (or structural) condition that limits the affected person’s ability to fully participate in society. As a result, the physical limitation (impairment) of the affected person becomes his or her defining characteristic. Salmon (1984) also describes the individuality of disability and locates it within the person’s body. Rather than being viewed as a human with a disability, the person is recognized by that physical limitation, or that difference becomes his/her defining trait. These physical differences deemed to be intrinsic to the person are identified, diagnosed and treated by professionals with expert knowledge (Brett, 2002). Oliver (1996) highlights two fundamental understandings of disability within the medical model. As previously noted, the medical model locates the “problem of disability within the individual”, and describes the cause of the problem as “stemming from the functional limitations of physiological losses which are assumed to arise from disability” (p. 32).

Several authors describe another characteristic of the medical model, that disability is viewed as a personal tragedy (Devine & Sylvester, 2005; Linton, 1988; Oliver, 1996). Within the medical model, disability is characterized by its inherently tragic nature and people with disabilities are viewed as suffering from differences which cause the person to suffer disadvantage, and a reduced quality of life (Devine & Sylvester, 2005). As Oliver (1996) states, referring to the personal tragedy of disability, “suggests that disability is some terrible chance of event which occurs at random to unfortunate individuals” (p. 32). The language used in describing disability reinforces the tragic nature of disability and its effect on the individual.

Medical professionals become the responsible actors who prescribe the actions required to adjust the individual to society as much as possible, to increase his/her ability to function normally (or to a standard) (Devine & Sylvester, 2005). Affected individuals are again defined by their differences in medical terms, and these differences must then be fixed or cured by professionals. Linton (1988) states the aim is to, “treat the condition and the person with the condition” instead of trying to remedy the social-environmental context. Goering (2002) also describes disability according to the medical model as requiring medical attention—the aim is to treat or cure the physical impairment. With a goal of treating or curing the physical impairment affecting a person, disability becomes medicalized, and the focus remains on changing the individual.

An example of medicalization and the individualistic nature of disability can be found in the fourth edition of the *Diagnostic Statistical Manual of Mental Disorders* (DSM-IV). The DSM-IV provides diagnostic information and medical descriptions of mental disorders. To illustrate some of the characteristics of the medical model, one disorder, mental retardation, will be explored. The two dominant diagnostic features of mental retardation are: general intellectual functioning (the intelligence quotient of an individual) and adaptive functioning (American Psychiatric Association, 2000). Mental retardation is defined as a “disorder characterized by significantly sub-average intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning” (American Psychiatric Association, 2000, p. 39). The adaptive function of a person “refers to how effectively individuals

cope with common life demands and how well they meet the standards of personal independence expected for someone in their particular age group, socio-cultural background, and community setting” (American Psychiatric Association, p. 42). The areas of adaptive functioning used to medically diagnose mental retardation include, “communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety” (American Psychiatric Association, p. 40). The DSM-IV identifies four degrees of mental retardation based on the level of intellectual impairment affecting the individual. This definition illustrates the medicalized and individual approach to understanding and diagnosing disability through the use of medical terminology which emphasizes the functional limits of the individual.

The medical model of disability has been highly criticized for placing the ‘problem’ within the individual and emphasizing his/her need to adapt to society. The medical model does not consider the role of the environment in creating or identifying disability. What the medical model does provide, however, is the often necessary support and treatment of the physical (or structural) impairments of the individuals experiencing them. As Shogan (1998) states “there is after all, a physicality to disability, which often includes discomfort and pain” (p. 269). Many advances in knowledge, technology and support of people with disabilities have been generated from this medical model.

Social Model of Disability

In response to the medical model and in conjunction with the disability rights movements of the 1960s and 1970s the social model has been growing in recognition (Berger, 2008). The social model of disability emphasizes the social construction of disability providing an alternative understanding of people with disabilities. Jones (1996) describes the social construction perspective of disability stating that it “...offers promise of such new understandings because it defines disability not solely as an individual experience or medical condition but as a socially constructed phenomenon that incorporates the experience of those living with disability in interaction with their environments” (p. 348).

According to Oliver (1996):

The social model does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization. (p. 32)

Shogan (1998) furthers the discussion of the production of disability stating that “when some are at a disadvantage by the way that a social context is organized; it can be argued that disability is an effect of the social context. In other words, disability is socially constructed” (p. 274). Jenks (2005) elaborates on this description stating that “disability is socially constructed by those who are not considered different” (p. 153). The common characteristics of the social model, identified by this collection of definitions include: social construction of disability, the external or social location of disability, and on changing society. As Oliver (1996) describes, within the social model there is a distinction made between an impairment and disability:

we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (p. 22)

Social constructionism underpins the social model and emphasizes the process of creating understanding and meaning in our society. Devine (2004) elaborates on social construction describing it as a theory that looks to find explanations of how information is produced and accepted as truth. Social constructionism maintains that “if people construct meaning through social interactions, then their behaviours, objects and language will reflect that meaning” (Devine, 2004, p. 143). Devine and Sylvester (2005) identify social constructionism as having “a critical stance towards taken for granted knowledge, historical and cultural specificity, that knowledge is sustained by social processes, that reality can be created in many ways and that each creation of reality provokes a different reaction” (pp. 85-86). This has meant that people in society have produced, accepted and reproduced a negative meaning of disability through their words, action and environment (context) (Devine, 2004). In the social model, a perspective rooted in social constructionism identifies the interconnected roles of people, history, culture, language, environment, and context in forming the meaning and understanding of concepts such as disability.

From the foundation of social constructionism, disability is located in the external environment, rather than internal to the individual. As Siebers (2006) describes, in the social model disability is a response to an environment that is hostile to some bodies and not to others. In the social model it is the components of the external environment (physical, social, structural, etceteras) that identify and emphasize disabilities (Shakespeare & Watson, 1997; Siebers). Since society has not created, or made adaptations for differences in ability, disability exists within society and is external to the individual who has an impairment.

Shakespeare and Watson (1997) define disability as, “the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (p. 198). These barriers to participation have been created and maintained by society. As Brett (2002) describes, environmental and social barriers exist to exclude people from full participation in society. These barriers include for example, physical, economic, or material structures (environmental), as well as attitudes, behaviours, and language (Connors & Stalker, 2007). Consequently, several authors identify a need to address issues and barriers found in society rather than those of the individual (Brett, 2002; Connors & Stalker, 2007; Shakespeare & Watson, 1997; Siebers, 2006). In contrast to the medical model, the social model emphasizes “changing the environment to fit the person” (Jenks, 2005, p. 152).

The social model has received criticism for its role in shaping research into politics, and for its lack of recognition of the biological aspects of disability (Coles, 2001). Some researchers contend that the social model shifts the focus of research from the collection and production of knowledge about disability, to emphasizing the need to challenge and change existing socio-political contexts (Berger, 2008; Coles, 2001). Jenks (2005) discusses the positioning of disability between the medical and social models, highlighting that disability is neither one nor the other; rather, it “is simultaneously physically embodied and socially constructed” (p. 146). In keeping with this idea, Brittain (2004) notes that environmental changes do not equal changes in experience for people with disabilities. Brittain identifies the importance of changing underlying attitudes and understandings of disability if lived experiences of disability for disabled people are

to change. Both Jenks and Brittain identify that environmental and social changes must take place to change the understanding and meaning of disability. An emphasis on the intersection of the individual and social models is common, and people affected by disability (family in particular) produce their own understandings and interpretations of the meaning of disability through their exposure to both models (Skinner & Weisner, 2007).

Involving People with Disabilities in Community

Along with our changing understanding of disability, our knowledge about involving people with disabilities in community has also changed. Within the integration and the inclusion movements change can be traced alongside the human rights movements that unfolded as people in society began to recognize all types of limitations based on different characteristics. Hutchison and Lord (1979) traced the development of the integration of people with disabilities from the 1950s through the 1970s. Prior to the 1950s, persons with disabilities often experienced non-involvement, or segregation in their communities and society in general (Schleien et al., 1997). As a result, parents of youth with disabilities began to form associations to provide services and programs lacking in schools and community recreation programs (Hutchison & Lord, 1979).

The integration movement began in the 1950s as a response to the needs of people with disabilities, particularly in education and recreation settings (Lord & Hutchison, 2007). In the 1960s, groups of parents, and concerned citizens began to lobby for the rights of people with disabilities for programs and services similar to those offered to non-disabled people (Hutchison & Lord, 1979). There has been more rapid expansion of professional and community supports since the 1960s (Lord & Hutchison, 2007). In the 1980s the concept of inclusion began to grow and develop as a reaction to the divide between 'us' and 'them' in society (Lord & Hutchison, 2007). Inclusionary practices developed with the recognition that persons with disabilities are valuable people who have the same right to participate in the same programs as their peers (Schleien et al., 1997). Following these lobbyists, coalitions and advocacy groups formed to champion for people with disabilities and their families to support the "belief that all citizens have a right to live, work and play in the community with dignity" (Hutchison & Lord, 1979, p. 31). As a result of the disability rights

movement and an identified need for the inclusion of people with disabilities in all aspects of life (beyond education and recreation), governments and organizations began to adopt inclusive policies. As a result of these social and historical changes in the disability movement, concepts of integration and inclusion developed to challenge the non-involvement and segregation of people with disabilities. These concepts are discussed in the following sections.

The Non-Involvement and Segregation of People with Disabilities

Non-involvement is the base level where no participation occurs (Schleien et al., 1997). Non-involvement has often continued when parents, who have a unique understanding of the needs of their children, have not been enabled to advocate for the needs and rights of their children.

For the purposes of this thesis, segregation was then defined by the qualities of both physical and social isolation and separation from other groups or participants. In some situations parents have responded privately to the needs of their children with disabilities. Schelein et al. describe that segregated programs are often initiated or developed by the parents of children or youth with disabilities as a response to a lack of programs from service providers and facilities. In the past, it was often the case that parents of “normal” children and youth opposed integration as they believed their child would catch the disability of the integrated youth, or that their child would have a less valuable or meaningful experience in an inclusive or integrated program (Schleien et al.). In contrast, parents of youth with disabilities were concerned about the quality of inclusive or integrated programs and activities being offered, the safety of their youth, and as a result, often questioned the benefits being gained from participation (Schleien et al.).

Schleien et al. (1997) also noted that social attitudes and behaviours of parents of youth without disabilities affect their decision to keep their child in a program. Parents of youth with disabilities are often concerned that their children will be harmed or might feel isolated in an integrated or inclusive program. In other cases, Schleien et al. discussed parents' previous experience in integrated programs where service providers were unwilling or unprepared to accommodate and support youth with disabilities. In some cases segregated programs continued because these programs and activities have been accepted by the

community as the norm for serving persons with disabilities (Schleien et al.). It is often the combination of past experiences in which needs were not met, support was not provided, or full participation was not achieved that led to parents seeking segregated programs.

Segregation has been defined by Datillo (1994) as, "the separation or isolation of a group or an individual in a restricted area by discriminatory means that results in the members of the group, or an individual, receiving treatment that is different from other people" (p. 341). Segregation occurs when a person or a group of people are separated or isolated from the rest of the group or other participants (Datillo, 1994; Schleien et al., 1997). This could include using a separate facility or a designated space in a facility for a specific group.

Segregated programs can provide recreation opportunities for persons with disabilities. In segregated programs, the groups are homogeneous (all participants have a disability), the emphasis of the activity is on skill development, and this level of program is seen as a steppingstone to integration and inclusion (Schleien et al., 1997). According to Hutchison and McGill (1992) segregation of persons with disabilities occurs because practitioners believe group members have similar needs which can be successfully met in a congregated environment. One issue stemming from segregation is that it leads to further stigmatization and ostracizing of persons with disabilities because they are identified and defined by their differences by other members of society (Hutchison & McGill, 1992).

Segregation also has social characteristics that define it. Participants in segregated programs or activities receive treatment that differs from normal standards (Datillo, 1994). Schleien et al. (1997) describe segregated programs as having special staff, services, equipment, and environments assigned to participants with disabilities. Staff are often trained and have some level of knowledge and understanding of the skills, abilities and behaviours common to persons with disabilities (Schleien et al.). Further, four commonalities define segregated programs: (1) a low skill level of participants, (2) programs that target low skill levels, (3) large groupings of persons with disabilities, and (4) the outcomes of large groups of persons with disabilities (Schleien et al., p. 15). Perceptions of lower skill level often results from the lowered

expectations of program or activity providers, a lack of staff support for the participants, and a lack of challenge for participants (Schleien et al.). As a result of the lowered skill level of participants with disabilities, staff in segregated programs often identify and work at the lowest skill level because it is common to all participants (Schleien et al.).

Segregated programs often have a larger number of participants than integrated or inclusive programs (Schleien et al., 1997). As a result of this large grouping of persons with disabilities, interactions with the surrounding community and people without disabilities are discouraged (Schleien et al.). If there is a (large) segregated group of persons with disabilities then other people in the facility are not likely to interact with or engage the group (Schleien et al.). Similarly, Hutchison and McGill (1992) noted that groups of people with disabilities appear deviant by society's standards which make outsiders uncomfortable and reluctant to approach or interact with group members.

Schleien et al. (1997) identify that if segregated programs are appropriate to the age and functional capacity of participants, the benefits of segregated programs include participation in safe, structured and secure leisure experiences that participants might not have in integrated programs (Schleien et al.). However, segregated programs for persons with disabilities are seen to be controversial. Hutchison and McGill (1992) discussed the perceptions that arise among community members about people with disabilities who are congregated together in segregated programs or spaces. In segregated programs participants are perceived as a group, not as individuals, which enables outsiders to generalize or stereotype all group members (Hutchison & McGill). When persons with disabilities are in a group context, outsiders may generalize and assume all group members have the same physical and development disabilities (Hutchison, & McGill).

Hutchison and Lord (1979) described the purpose of segregated programs as steppingstones for people with disabilities into integrated or inclusive programs. Despite the positive intention, integration or inclusion is not always the end result. In the specialized setting of a segregated program, people with disabilities can receive specific skill development which will enable their successful transition and

participation in an integrated environment. Hutchison and Lord discuss the pitfalls and problems which often occur in segregated environments including: a lack of age appropriate activities, staff do not always use appropriate language, and parental permission is required for people to participate (Hutchison & Lord). Often in segregated environments there are few chances for participants to take risks, staff are over protective and have lowered expectations of participants (Hutchison & Lord). Finally, despite effort to enhance the skills of participants with disabilities to a level where they could participate in integrated programs with others, it is not always the case that other activities are available or programs have the capacity to successfully integrate people with disabilities in a meaningful way (Hutchison & Lord).

Integration for Persons with Disabilities

Integration has been defined by Datillo (1994) as “making use of the activities, community resources and facilities available to all people, including those with disabilities” (p. 337). Integrated programs include participants of mixed abilities. The focus of integrated programs is on the individual, and integration strategies are used to engage people with disabilities and ultimately provide opportunities for participation (Schleien et al., 1997). Including a person with disability into a basketball game would require them to have learned the specific skills (e.g., dribbling, passing, shooting, offense/defence, rules, etceteras) to successfully participate in the game. Inclusion has not occurred if the participant lacks in some skills and is included in the game but unable to fully participate; instead of inclusion the person has simply been integrated into the activity.

There is a distinction made between physical and social integration (Hutchison & Lord, 1979; Hutchison & McGill, 1992). Physical integration “refers to the physical presence of people who have been devalued in ordinary settings, activities and contexts where ordinary community members are also present. Physical integration is a prerequisite for social integration but it does not ensure interaction between participants” (Hutchison & McGill, 1992, p. 102). Where physical integration is simply the presence of people with disabilities in a program, social integration involves “the participation of people with disabilities, in social interactions and relationships with non-devalued citizens, in ordinary settings and contexts” (Hutchison &

McGill, p. 102). Many community members and recreation practitioners have previously misunderstood physical integration as being the same as social integration; however, physical integration is simply a precursor to social integration and inclusion. As Hutchison and McGill (1992) noted, having people with disabilities physically present does not mean they are integrated into the group if social interactions with other group members do not occur. An important and unique component of integration identified by Hutchison and McGill (1992) is friendship. Social relationships between people with and without disabilities can result in the development of friendships which ultimately enable people with disabilities to gain social roles valued by society (Hutchison & McGill). In addition to the social roles, Hutchison and McGill identify the benefits of friendships between persons with and without disabilities because they help people focus on each other's positive qualities and commonalities, rather than emphasizing the differences that exist between them.

In addition, Schleien et al. (1997) identified *passive* and *active* integration as two different types. Passive integration refers to a situation whereby a person with a disability engages in an activity that was chosen, planned, or implemented by another person (e.g., a parents, community recreation practitioners, etceteras). In comparison, active integration occurs when the person with a disability chooses which environment, activity or program to participate in (Schleien et al.).

Normalization and Social Role Valorization: Aspects of Integration

The development of concepts of normalization and social role valorization were connected to the development of integration. Normalization initially developed in the 1980s as a response to (and in conjunction with) changes being made in institutions for people with disabilities. Researchers and professionals began to shift away from institutions housing large numbers of people with disabilities, to deinstitutionalization and the integration of individuals into communities and society. Nirje (1999) and Wolfensberger (1999) were key actors in the development of the concept of normalization and its related elements. Normalization has been defined by Hutchison and McGill (1992) as the "use of culturally normative means to offer person life conditions at least as good as that of average citizens and to as much

as possible enhance or support their behaviour, appearances, experiences, status and reputation” (p. 55). For Yates (1999), culturally normative meant “a range of what’s broadly accepted, a range of what is expectable and ordinary, where people would not raise their eyebrows to encounter” (p. 118). Schleien et al. (1997) described normalization as an attempt to set a standard against which services and treatment of people with disabilities is measured. The services for people with disabilities should be provided in keeping with a cultural norm (Schleien et al.).

Social role valorization expanded the meaning of normalization and encompassed two key ideas: social role and value. Thomas and Wolfensberger (1999) defined a social role as “a combination of behaviours, privileges, duties, and responsibilities that is socially defined, is widely understood and recognized within a society, and is characteristic or expected of a person occupying a particular position within a social system” (p. 125). Thomas and Wolfensberger discussed the existence of valued and devalued social roles in communities, and societies. Being valued or devalued results from positive or negative perceptions and judgements from other people and can be attributed to individuals or groups (Thomas and Wolfensberger). Examples of valued social roles include “president, scholar and champion athlete” while devalued roles include criminal, prostitute and garbage picker (Thomas and Wolfensberger, p.128). Schleien et al. (1997) defined social role valorization as “the creation, support and defence of valued social roles for people who are at risk of social devaluation” (p. 10). Social role valorization recognizes that while people with disabilities can be devalued or perceived negatively by other people they can also acquire valued social roles. Social role valorization marks the shift from segregation and physical integration to social integration. When people with disabilities have been devalued they have been placed according to their role, meaning they were grouped in segregated environments with others holding the same diminished social role. Social role valorization is enmeshed with social integration when a person with a disability is physically moved into an environment with people with valued social roles. Through interactions able bodied people begin to reassign value to people with disabilities and accord them valued social roles (for example, from water boy to teammate on a sports team).

Accomplishing Integration

Integrating people with disabilities in recreation programs occurs when there is participation alongside persons without disabilities (Schleien et al., 1997). In some integrated programs specialized staff may support participants with disabilities, but additional support (staff or resources) may not have been assembled prior to the start of the program due to a lack of awareness of the participant's needs (Schleien et al.). Successful integration requires adequate and appropriate support for people with disabilities.

Hutchison and Lord (1979) describe physical integration into a community recreation facility as part of the integration process, leading to interactions between people with and without disabilities (social integration). Integration is a continual process requiring community members and recreation practitioners to become aware of the purpose of integration and support people with disabilities in an appropriate manner.

According to Hutchison and Lord (1979) integration includes the following assumptions:

- It is a process whereby individuals participate and enjoy experiences similar to their non-disabled peers.
- It is a means of providing people with opportunities to upgrade skills and confidence.
- It provides supports and changing services where necessary, not simply using services already in place.
- It means community support for changes in attitudes and policies towards people with disabilities and their rights.

(p. 32)

For Hutchison and Lord (1979) integration is a process not a result. This represents a major change although the person with a disability has adapted himself/herself to be able to participate. Similarly, Frattura and Capper (2006) discussed the requirements for successful integration (in an educational setting) of students with disabilities identifying the importance of core principles, location of services, curriculum and instruction, and funding and policy. These issues must be addressed in recreation settings to support the successful integration of students.

Inclusion and People with Disabilities

For Schleien et al. (1997) inclusion occurs when regular and friendly exchanges take place between people with and without disabilities. Further, "inclusion means becoming a full participant in community life"

(Schleien et al., p. 15). Datillo (1994) described the importance of providing opportunities for choice, supporting the growth and development of connections, and feeling valued in developing an inclusive program or environment. Inclusive programs provide multiple opportunities and choices for participants; there are appropriate levels of independence, and participation results in leisure satisfaction (Schleien et al.). To facilitate the inclusion of persons with disabilities, practitioners must develop an awareness and understanding of needs, and supports must then be put in place for a person or group to be fully incorporated into the program or activity. According to Schleien et al., key components to the successful inclusion of persons with disabilities include:

- Transportation to and from the facility.
- Access to and mobility with the facility.
- Trained personnel/staff.
- Positive attitude towards persons with disabilities and their integration into the programs of personnel/staff/other participants. (p. 14)

Datillo (1994) discussed the required knowledge and understanding a practitioner should have about specific types of support needed from staff, the physical environment and other participants. Datillo identified the importance of knowing the skill level of participants, and understanding the skills or skill level necessary for safe, effective and meaningful participation. According to Schleien et al. (1997), inclusion includes several key components which can be used to measure success. The components include: outsider's perceptions, shared environment, and social interaction (Schleien et al.). Perceptions of persons with disabilities by persons without disabilities is used to determine the extent of which persons without disabilities recognize, focus, and define persons with disabilities by their disability characteristics (e.g., use of a wheelchair or other apparatus, syndrome or diagnosis, etceteras) (Schleien et al.). Shared environment refers to the sharing of space and the physical proximity of persons with disabilities to those without. Similarly, social interactions are based on participation in different types of interactions with persons without disabilities (Schleien et al.). In addition to these components, Schleien et al. discussed the importance of individualized instruction instead of group instruction for the inclusion of persons with disabilities.

For Schleien et al. (1997), inclusive programs benefit people with disabilities providing opportunities for, “learning and socializing with peers, providing stimulation and motivation, social interaction with persons without disabilities, and learning social norms from leaders and peers” (Schleien, p. 22). Additionally Schleien et al. identified two benefits to inclusive programs for the participants without disabilities, including “the development of positive attitudes and accurate conceptions of people with disabilities, and that there was no detrimental effect to the non-disabled participants from inclusion” (p. 22). In contrast, inhibitors to the successful inclusion of persons with disabilities have been identified and include:

- communication problems with participants,
- short attention span of participants,
- a lack of social acceptance as equals by other participants/personnel/staff,
- feeding and toileting needs of participants,
- meeting the transportation needs of participants.

(Schleien et al., 1997, p. 14)

The differences between non-involvement, segregation, integration and inclusion were important to this study because the aim of this study was to explore community recreation experiences of youth with disabilities. As the findings reveal, aspects of each type of participation were present in the parents’ narratives. In addition parents’ understandings of their children’s experiences provided different ways of understanding these concepts of non-involvement, segregation, integration and inclusion.

Studies on Disability

Qualitative studies reviewed presented a range of insight into the varied experiences of disability in different contexts. Included in this section is a discussion of: the changes in how disability is understood by people with disabilities and those connected to them, the shared experience of disability for parents, the importance of parent perspective, and the role of context and culture in understanding disability.

Understandings of Disability

Research found that people with disabilities (or those connected to them) experience disability through the actions and opinions of those without disabilities, and perceptions and understanding of disability change over time and through experience (Berger, 2008; Brittain, 2004; Connors & Stalker, 2007;

Fisher & Goodley, 2007). Studies highlighted the importance of exploring changing understandings of disability. For example, Fisher and Goodley (2007) conducted an ethnographic study to explore the definitions and meaning of disability for mothers of infants or young children with disabilities and found that meanings and understanding of disability evolved but their first experiences were medicalized. Initially, the mothers learned about disability from a professional who provided expertise, but they then negotiated the meaning of disability over time (Fisher & Goodley). Connors and Stalker (2007) examined the experiences of children living with disabilities and how they negotiated and perceived their experiences. This study used an adaptation of the social model as a framework for analysis. This framework by Thomas (1999) defined disability in relation to a person's lived experience, and identified unequal social relationships as an important component. This study found that children experiences disability in four ways: impairments, difference, other people's behaviour, and material barriers. This study highlighted understandings of disability for children experiencing it, and highlighted their awareness and perceptions of disability in response to their physical and social environment.

Brittain (2004) used the social model to explore the perceptions of disability in the lives of Paralympics athletes. Brittain sought to understand barriers facing athletes with disabilities. This study identified negative perceptions of disability on: social interaction, self-confidence, self-image, dependency on others, self-perception in sports, and lack of awareness of the effects of others perceptions. In addition, the role of the media was explored and found that depictions of disability in sport typically reinforced common societal perceptions of athletes with disabilities (Brittain). Berger (2008) conducted a study examining the experiences of "supercrip" athletes to understand wheelchair basketball programs. Berger explores the meaning of the "supercrip," an athlete whose inspiring story defies the odds of disability and accomplishes something exceptional. Berger determined that the concept of the "supercrip" athlete is concerning—it supports the idea that people with disabilities can achieve, if they try hard enough. These studies highlight the perceptions of others as important to understanding disability.

Parent's Experiences of Disability

Studies focused on parents' and family members' experiences of disability explored external pressures to meet a standard and found that parents share in the experience of disability with their child (Brett, 2002; Fleischmann, 2004; Huws, 2001). These studies identified the importance of exploring parent experiences of their child's disability. Parents of children with disabilities often experience external pressure from society to meet a standard of normal as parents, and for their families (Brett, 2002). Brett recognized that parent perspectives are essential to exploring experiences of disability. Brett found that parents shared the experiences of physical, societal, social, professional, and environmental barriers associated with disability. Perceptions were that parents of children with disabilities were also labelled and constrained by barriers (social and environmental), and felt pressure to be a good parent while feeling stigmatized, patronized, powerless, vulnerable, and they experienced pressure from others, were not taken seriously, and felt constantly judged (Brett, p. 836).

Fleischmann (2004) examined the online narratives of parents with autistic children. The study explored how parents of autistic children coped with and understood the diagnostic process. It was determined that parents used the internet for three major reasons: to find information following diagnosis, to assist other parents, and to make their feelings and experiences accessible to others facing similar circumstances (raising an autistic child). Fleischmann used grounded theory to classify the attitudes, feelings and perspectives of the participants. Huws et al. (2001) conducted an internet based study of parents with autistic children, using participants and data from an online email group. It was determined that formal online networks helped parents of children with autism to find information and feel supported through their experiences. One important distinction made in this study was that parents often felt socially isolated as a result of their child's disability. Both authors called for further investigation into the social isolation and effects of raising a child with disabilities, emphasizing the need to explore parents' coping strategies (Fleischmann, 2004; Huws, 2001).

The Value of the Parent Perspective in Research

It was determined that parents are important and often unused sources of knowledge about the leisure experiences of their children with disabilities (Goodwin et al., 2006; Malone & Landers, 2001). Malone and Landers (2001) identified the knowledge and perspective held by mothers of their preschoolers with intellectual disabilities. Their study focused on mothers' views about play and leisure. Malone and Landers highlighted that parents (mothers in particular) observe their children in the home and other settings, and that parents have valuable information about behaviours and abilities of their children. Goodwin et al. (2006) examined parents' perspectives about their children's participation in Special Olympics. The study used interviews, artefacts (meaningful images, objects or documents), and field notes to understand reasons behind the parent's decision to enrol their children in the Special Olympics program (Goodwin et al.). This study found that parents chose to have their child participate in a segregated program for four reasons: opportunities for success, trained and supportive staff, expectations of participants, and the social environment (Goodwin et al., 2006). These studies identified parents as important sources of knowledge of children's leisure experiences, and called for further research.

Understanding Disability: Role of Context and Culture

The context, location and culture play an important role in how disability is understood (Baker & Donnelly, 2001; Devine, 2004; Garcia et al., 2007). These studies identified the importance of exploring different environments and contexts to expand understandings of disability. Devine (2004) conducted a study using a social constructionist approach to explore the perceptions of people with disabilities, social acceptance and inclusive leisure settings. Devine (2004) identified that leisure settings or contexts are important because they "may provide a window for understanding social structures, and much about society's norms, attitudes, beliefs and values" (p. 138). Devine suggested inclusive leisure contexts could enable participants to make social connections with others, emphasize differences between participants, or act as a neutralizer producing neither acceptance nor distance between participants. Devine identified a need for further studies to understand leisure situations as reflections of society and as places of social

change. Baker and Donnelly (2001) explored the role of environment in social experiences of children with disabilities, including integrated and segregated learning environments. They found that negative perceptions of disability held by others impacted children involved, and created barriers. This study identified the important role of family, parents in particular, in defining children's valued social identities and social experiences (Baker & Donnelly, 2001). Garcia et al. (2000) described the role different cultures play in shaping the understanding and meaning of disability. In their study of Mexican American families including children with disabilities, Garcia et al. stated that parents' beliefs about disability had an effect on their responses and interactions with their children.

In summary, these studies identified parents as sharing in the experience of disability with their child, and called for further research on parents of people with disabilities in different contexts, including leisure settings. In addition these studies identified parents as valuable sources of knowledge about disability. My study provided a new perspective by exploring disability in different community recreation settings from the perspective of parents.

Narrative Inquiry in Leisure and Disability Studies

Few studies engaged a narrative methodology to examine disability in the context of leisure. The studies reviewed below highlight the important understandings, experiences and perspectives that narratives from parents of children with disabilities can provide to academics and practitioners. The literature described the use of narrative as an appropriate methodology for studying disability and leisure and that it is infrequently used (Davis & Salkin, 2005; Grace, Llewellyn, Wedgwood, Fenech & McConnell, 2008; Jenks, 2005; and Kluth et al., 2007).

Kluth et al. (2007) examined the stories of parents who chose to move their family to find inclusive educational opportunities for their child with a disability. This study found that parents have unique experiences that are different from, but similar to, those of their children in negotiating disability in an able-bodied world (Kluth et al.). As the authors described, "the stories reported here have the potential to help both practitioners and researchers understand not only the concerns of families of children with disabilities

but also the state of inclusive practice in the United States” (p. 55). Grace et al. (2008) used narrative interviews to explore expectations of mothers and early childhood educators and their experiences with inclusive programs for young children. The study determined that parents sought experiences where their children would fit in, and where there was open communication between parents and staff.

Davis and Salkin (2005) conducted a narrative analysis of the experiences of being a sibling of a person with a disability, and their role as a caregiver. These authors explored experiences of both the individual with a disability and his/her siblings and found that siblings without disabilities often had less attention and more autonomy than the sibling with disabilities (Davis & Salkin). In addition, they found families of children with disabilities experienced societal expectations to achieve the image of a normal family (Davis & Salkin, 2005).

In an ethnographic study, Jenks (2005) used her personal stories and stories of parents of visually impaired children to discuss the meaning and interpretation of disability. Emphasizing the social construction of disability while simultaneously engaging the medical model, Jenks demonstrated that “disability is located in the interplay between individual’s physical bodies and society’s constructed meanings of difference” (pp. 145-146). The study demonstrated that parents of children with disabilities provide unique and personal insight about their child’s disability.

These studies identified the importance of narrative inquiry and the collection of stories in disability studies. The infrequent use of narrative as an identified methodology in leisure and disability research demonstrated the need for use of this methodology. This study adds to the literature on disability and leisure literature as it used narrative inquiry to explore experiences in different community recreation settings of children with disabilities from the parent perspective.

Additional Topics for this Study

Following the analysis of data, several additional topics and concepts were found to be important for this study. Empowerment, exclusion and disabling practices, and levels of trust were found to be emerging within the narrative analysis. Discussion of these concepts was added to the review of literature.

The concept of empowerment was found to be valuable in enriching the understanding and meaning of the narratives of this study. According to Arai (1996) empowerment is a multidimensional process which involves five phases: experiencing powerlessness, awareness, connecting and learning, mobilization, and contribution (p. 37). Powerlessness is experienced first, and is followed by the establishment of awareness when a person was presented with new information, developed an emotional response to a stimulus or responded to a concern or issue (Arai). Connecting and learning is then a process of making social connections which enables people to gather resources and as a result broaden their choices (Arai). Next, mobilization occurs when a person or group of people put their relationships, resources and choices into action, and can develop social and political skills (Arai). Finally, contribution occurs when the people or groups incorporate their skills, relationships, resources and information into their everyday lives (Arai).

Power is a key component of empowerment and was identified as an important concept in the narratives. Lord and Hutchison (2007) described three types power: power over, power from within, and power with. Lord and Hutchison stated that “exploring the concept of power is important because lack of power and control is so pervasive among citizens” (p.75). Power over is most common and is often continued, sometimes unknowingly, by a group in society who have control over another (Lord and Hutchison). For example, professionals often have power over participants. The description of ‘power from within’ paralleled the ideas of empowerment previously described where “everyone has power inside themselves that can be nurtured” and when an awareness of this internal power develops it can be utilized (p.76). As Arai (1996) described, empowerment involves a change, increased ability to use power or control; it is multidimensional and includes psychological, social, economic and political changes. Arai described psychological power as involving increases in “self-conception, self-efficacy, and locus of control” (p.29). Social power was described as gains in “increased access to information, knowledge and skills, participation in social organizations, and financial resources” (Arai, p. 29). Finally, political power was described as concerning “not only the right to vote, but the access of the individual to the process by which decisions are made” and also includes “the power of voice and collective action” (Arai, p. 29).

Changes in power and phases of empowerment may occur at the individual, group or community level and requires a holistic framework to recognize the interactions within the process of empowerment. Further, empowerment cannot be given to an individual, group or community, nor does it only come solely from within an individual (p. 28). The process of empowerment was evident in narratives of the parents and explored in the Discussion to further explore the cultural practice of disability.

Exclusion as a Disabling Practice

Exclusion became an important concept for this study as many of the stories told by the parents included an experience of exclusion. Lord and Hutchison (2007) stated that “people are excluded in our culture for many reasons” (p. 19). They described ways a person could be excluded including: exclusion because of a condition or impairment, physical and emotional exclusion, social conditions or dependency on formal services (Lord and Hutchison). Lord and Hutchison described exclusion as “being left out” (p.19). According to Labonte (2004) exclusion and inclusion are twinned concepts that must be discussed in conjunction and people with disabilities are among those who are excluded and require inclusion. Labonte described social exclusion noting that it “defines disadvantage as an outcome of social process, rather than as a group trait” (p.117). As a result, people are “no longer at fault for their disadvantage. But their disadvantage is seen to lie in their exclusion, rather than in excluding structures” (Labonte, p.117). One issue with the concept of inclusion is that it is often superficial and focuses on the individual rather than the structures and policies which caused the exclusion (Labonte). The solution is not to “include” someone by bringing the individual into a space or community but rather to create “inclusion” by challenging and changing the structures, attitudes and policies that kept them out.

In the context of this study exclusion is applicable to both the parents and the children with disabilities. For both groups, exclusion can occur when people are left out of decision making practices. Lord and Hutchison (2007) described how in many instances practitioners would make decisions, set parameters and ultimately create a situation where compliance was expected. Practitioners are able to maintain the compliance by limiting participation in decisions making, retaining control which can leave the

parents and children feeling or being 'powerless' (Lord and Hutchison). Exclusion is a disabling practice when it is used to limit participation or involvement. Similarly, as described by Labonte (2004) inclusion can be a disabling practice when it involves the superficial involvement of a person rather than challenging the structures which left them out. Being included in a group does not mean you are a part of a group.

Levels of Trust

Levels of trust became an important concept relating to the study because it related to the relationships and social networks of the parents and children. Levels of trust also became important because of the ideas of individualism and community that developed through the narrative analysis. Arai and Pedlar (2003) identified three levels of trust found within communities: thick trust, thin trust and abstract trust. Thick trust was described as developing "by intensive daily contact between people", where there is "distrust of the wider society" and is found in "small groups or institutions" (p.193). Thin trust is characterized by "looser forms of relationships" which "produces weak ties" and result from broader social networking (p.193). Finally, abstract trust "is the foundation of imaginary, empathic or reflexive communities", can be created through "national social movement organizations, mass media and education" which teach "cooperation, citizenship, trust, fairness and equality" (p.193). These levels of trust and their connections to the narratives are further explored in the Discussion and narrative analysis.

Chapter Summary

Chapter Two provided a review of the literature on disability and leisure. The chapter began with an examination of the two models of disability (the medical model and the social model) and concepts of non-involvement, segregation, integration and inclusion were explored. A review of studies focused on disability, and specifically, narrative studies focusing on disability and leisure using parent perspectives were explored. This review of literature provided a foundation for this study. In the following chapter, Chapter Three, the narrative methodology used for the study is described. Chapter Three includes an introduction and explanation of narrative inquiry and the construction of narratives, and describes the context and participants for this study. Chapter Three also describes the data collection approach (narrative interviews)

and the analysis process used. The chapter concludes with a description of the role of the researcher, significance of the study, and ethical considerations.

Chapter Three: Methodology

It's a hot summer day in July, and Aiden and I are on our way to the beach. I shift gears as we race down the dusty back roads, the music blaring and even though Aiden's hearing aids are out I still think he can feel the beat. I look over at Aiden, and catch a glimpse of myself in the mirror. Sun kissed nose and the relaxed face of a university graduate. This will be my last summer with Aiden before I move home for grad school, my last few weeks with him. I wonder if he'll miss me. I look at Aiden, stick out my tongue and make an obnoxious fart noise, he laughs, and then I laugh. Aiden looks at me, leans forward and then falls back with laughter. I have his favourite sun glasses on today, the best for our road trip, mirrored aviators. You could dress a super model in the reflection of these glasses. Aiden loves them, because when he gets close the mirrored lenses warp his face. I love them because they make Aiden happy.

We pull up to the beach and into our accustomed parking space with a big white wheel-chair man half covered by sand. I have to admit, sometimes I think of myself as a super hero for what it takes to get Aiden and I, and all of our stuff, from the truck to the beach. I struggle over to our usual spot, heave our bags, swim gear, floaties, snack pack, and chairs to the ground. Aiden watches my near collapse under the weight of it all, turns and points to the lake. He wants to swim. I get Aiden ready for some quality beach time: sun, sand, and swimming. The beach is unusually quiet for a hot day like this, but neither of us is bothered. As we sit on the beach, flipping through our magazines and chattering away to each other, a Frisbee lands right by Aiden's feet. A young girl in a polka dot swimsuit with matching hat and sunglasses follows after it. She stops when she arrives at his feet, and looks at me cautiously and asks "is it ok if I pick it up?" "Oh yah!" I tell the girl. I look at Aiden, "This girl's come to get her Frisbee back, could you please pass it to her?" Aiden continues to chatter away, stretches forward to retrieve the disc. He reaches out the Frisbee to her. Timidly she accepts it with a quiet "thanks." I resume my magazine flipping momentarily until I realize she is still standing in front of us. "What's up sweetheart?" I ask her. "Is he talking? Is that what that noise he's making is?" she asks, unashamed of her curiosity. "Yes," I reply "Aiden and I chat all the time. He tells me about his day, or what he's reading or what he wants for dinner, you know the usual stuff." "But how do you understand what he's saying? He isn't using words like normal people do, so how do you know what those sounds mean?" I settle in for a long explanation about how Aiden communicates in other forms than "normal people" words using gestures, pictures and sounds, and how we've spent years together so I've learned what it all means. I collect my thoughts, look up at her inquisitive eyes and say "I know what he's saying because I listen to him with my eyes, with feelings, and with my heart." Apparently heart is the code word to send any child running back to the safety of her parent's arms.

I look at Aiden who's been oblivious to my recent conversation with the polka dot princess, he's holding up his magazine. He points to a picture and says, "Mmm. Bah. Bah. Mmm." He's telling me he wants chicken for dinner with his family: Dad, mom and sister. He adds a final "Kah" before returning to the glossy pages of this month's Bon Appétit. Kah! That means I'm staying for chicken too.

Introduction

As identified in Chapter Two, narrative inquiry was seldom used in disability and leisure studies (Davis & Salkin, 2005; Grace, Llewelly, Wedgwood, Fenech & McConnell, 2008; Jenks, 2005; Kluth et al., 2007). Parents have also been identified as a valuable resource for knowledge about their children's experiences (Brett, 2002; Fisher & Goodley, 2007; Fleischmann, 2004; Garcia et al., 2000; Goodwin, et al., 2006). The purpose of this narrative inquiry was to explore how parents understand and experience

disability through their child's involvement in segregated, integrated and inclusive leisure experiences and their non-involvement in recreation contexts. The research questions guiding this study included:

1. What are the stories of parents of children with disabilities?
2. How do these stories help us to understand the recreation experiences of children with disabilities?
3. How do these stories help us understand disability in recreation practices?

Stories shared by participants display the significance that events have for one another (Polkinghorne, 1988); in this study, participants shared personal stories on the topic (disability) in a specific context (recreation). This study focused on parents' stories of their children's recreation experiences (including experiences of non-involvement, segregation, integration and inclusion). By enabling participants the freedom to choose which stories to tell, we gain an understanding of events and experiences that have been significant and meaningful (Polkinghorne, 1988). Rather than impart our own interpretations, narratives provide participants with the power to make those decisions, reversing the flow of knowledge and understanding. Glover (2003) argued that narrative research "has much to teach us about leisure experiences because it is a distinctly human expression of how individuals construct their own lived experiences and imbue them with meaning" (p. 149). Narrative inquiry openly seeks meaning and interpretation of experience from the participants in their own words. Smith and Sparkes (2008) argued that for disability studies the stories of participants in narrative inquiry "are useful as they impart information about theirs or others internalized world, thereby allowing researchers to explore lived experiences and preserve a sense of the individual person" (p. 18).

Selecting a methodology appropriate to the research questions and purpose of this study took time, reflection, and exploration. The following pages describe the methodology used for this study—narrative inquiry—and how narratives were collected and analyzed. This chapter describes the history, development and explanation of narrative as a methodology and justification for the use narrative inquiry in this study. Also included is a description of the participants and context of the study. The chapter concludes with a discussion of the role of the researcher, significance of the study, and ethical considerations.

Narrative Inquiry

We are a storytelling species. Storytelling is in our blood. According to Atkinson (2007) we think in story form, speak in story form, and bring meaning to our lives through story. Our life stories connect us to our roots, give us direction, validate our own experience, and restore value to our lives (Atkinson).

Narrative research has been gaining in popularity and use as a methodological approach to data collection and analysis in the social sciences (Booth & Booth, 1996). Narrative inquiry is a collaborative approach to developing an understanding of how meaning is generated and understood for various social groups. Polkinghorne (1988) discussed narrative inquiry stating that “the aim of narrative study is to make explicit the operations that produce its particular kind of meaning, and to draw out the implications this meaning has for understanding human experience” (p. 6). Curtin and Clarke (2005) elaborate on the role of narrative in opening our understanding of different perspectives of experiences as this methodology enables the researcher to focus on life experiences. Through the use of narrative inquiry and focus on experiences, participants are able to tell stories in their own words, and attach personal meaning to them (Curtin & Clarke, 2005). Clandinin & Connelly (2000) summarized the discussion of what narrative inquiry is stating that “it is a way of understanding experience. It is a collaboration between researcher and participants...narrative inquiry is stories lived and told” (p. 20). Stories enhance our understanding of the meaning of events, actions and experiences for the people who have lived them. Stories also demonstrate the complexity of life and experience.

Narrative inquiry has been categorized in relation to either the protagonist (Polkinghorne, 1988) or the purpose of the story (Clandinin & Connelly, 2000; Glover, 2003). The descriptions and categories of narratives will be explored to determine the elements that typify narrative inquiry. Polkinghorne described three types of narratives that differ depending on the experience and outcome for the protagonist. A stability narrative is one where the protagonist remains unchanged with respect to the goal of the story (Polkinghorne). A progressive narrative is one where the protagonist makes advances towards to goal

(Polkinghorne). Finally, a regressive narrative is one where the protagonist actually ends up further away from the goal (Polkinghorne).

Building on Polkinghorne's narrative types, Clandinin and Connelly (2000) and Glover (2003) categorized narratives as descriptive or explanatory. Descriptive narratives "produce an accurate description of the interpretive narrative accounts individuals or groups use to make sequences of events in their lives or organizations meaningful" (Clandinin & Connelly, p. 17). In contrast, explanatory narratives, "account for the connection between events in a casual sense and to provide the necessary narrative accounts that supply the connections" (Clandinin & Connelly, p. 16).

For this study, I used Glover's (2003) approach to generate descriptive narratives to explore the experience of the participants, and provide an account of the meaning found with them. Rather than conducting an explanatory narrative inquiry to understand why something happened, the descriptive narrative inquiry has enabled me to "represent the stories individuals or groups use to understand the temporal connections between the events they have experienced and account for their own and other's motives, reasons, expectations, and memories" (Glover, p.152). For this study I asked parents to share stories about their children in recreation contexts. This produced descriptive narratives which broaden knowledge about the role of recreation and leisure in the context of disability.

Structure and Organization of Narratives

Glover (2003) identified two types of data produced from narrative inquiry: personal experience stories and personal histories. Whereas experience stories focus on "a significant episode, event or personal experience" the personal histories (sometimes referred to as life stories) are a "more encompassing and involved account, which reconstructs an individual's life story" (p.154). This study has resulted in a combination of personal experience stories and personal stories. Using interviews, I had intended to collect personal experience stories with a focus on specific experiences of parents in recreation; however, what resulted were personal stories (of specific events) that spanned the life of each parent and child. The components and sequence of the story were then identified.

Narratives have thematic organization and an internal structure (Daly, 2007; Glover, 2003; Polkinghorne, 1988). According to Daly there are five characteristics of the thematic organization of narratives: constructions of reality, sequentiality, temporality, actor-focus, and function. *Reality* refers to the idea that narratives “are provisional constructions that constitute reality” (Daly, p. 110). It was assumed for this narrative study that stories collected from parents are not be exact replicas of past experiences; rather the stories present their interpretations of events, actions, people and results of those experiences. In this respect, narratives are not characterized by the validity of the story, but rather by creation and narration of the story. This study did not intend to produce generalizable results; therefore pattern or theme checking (for reliability) did not occur. Instead, validity requires a belief that stories of participants are required, participants are trustworthy, and the stories they tell are authentic interpretations (Creswell, 2003).

Sequentiality refers to the order of actions, experiences, and people in the story which connect to create a plot (Daly, 2007, p. 110). Narrative researchers are interested in the order in which the story is told by the narrator. Considering the way the story is told is as important as the sequence found within the story. What narrative researchers must account for is the role and effect of the present on the narrative. *Actor focus* in narrative inquiry explores how the protagonist (typically the narrator) is presented to the audience and the effect on the interpretation and meaning of the narrative (Daly). Narratives serve many *functions* in social life (Daly). Narrative researchers shift focus away from validity of the story, emphasizing instead the impact of the story on the audience, society, and narrator (Daly). Narratives are also *temporal* and typically enable the narrator “to make meaning of the past” (Daly, p. 111). From this temporal order the internal structure which “arranges the sequence of events in temporal order” (Glover, 2003, p. 147) can be identified.

According to Glover (2003), common elements of stories (e.g., internal structure, ordered transformation) enable the audience to share in understanding the significance of an event or experience. The typical sequence found within a story includes: an abstract, orientation, complication, evaluation, result

and conclusion (Fleischmann, 2004; Glover, 2003). Following both Fleischmann and Glover, Table 1 describes the components of an internal structure.

The elements of narrative identified by Daly (2007), Fleischmann (2004), and Glover (2003) provided a useful framework for analyzing the narratives. These elements shaped the analysis, focusing on what was found within the story and to whom and how the story was presented, and by whom. Narrative inquiry examines how these elements are put together by the storyteller (Daly). By identifying these elements, narrative researchers interpret meaning within these stories.

Table 1

Internal Structure of a Narrative

Internal Structure	Description of component
Abstract	Explains the essence of the story (what the narrative is about). An opening, sometimes separate, from the narrative that follows.
Orientation	Explains where the events take place, who the protagonist and characters of the story are, and the subject of the narrative.
Complication	Explains in a chronological order what happened and identifies critical activity that changed the course of the study.
Evaluation	Explains what meaning the storyteller assigns to the event.
Result	Explains the outcome (or what happened).
Conclusion	Explains the ending of the story.

Stories or narratives are a powerful form of expression for people. The ability of narrative to provide a meaningful venue for parents of children with disabilities to share their experiences was significant. Experiences hold meaning for the actors involved; however, this meaning is not frozen by time or place. Meaning is restless, flowing, and ever-changing; the meaning of specific experiences or events for one person is not identical to that of another person (Polkinghorne, 1988). The meaning or understanding of a story told today will be different than the same story told years ago because the parent will have had many experiences and interactions that will have changed their current interpretations of past events.

Narrative differs from other research strategies and methodologies. It is not intended to create formalistic outcomes, contribute to a developing theory, to replicate a theory, to produce knowledge claims or be analyzed by a rigid theory structure (Clandinin & Connelly, 2000). Instead, narrative inquiry contributes to the literature and academia by creating “a new sense of meaning and significance with respect to the research topic” (Clandinin & Connelly, p. 42). Narrative inquiry has been criticized for not being theoretical enough (Clandinin & Connelly). Instead of contributing to an existing framework or theory, narrative inquiry can generate new meanings and understandings of a topic which deepen our pool of knowledge about disability and leisure. Narrative inquiry is emic in nature, rather than etic (Daly, 2007). An emic perspective (used for this study) seeks to understand the inside accounts of people who experienced the phenomenon. This contrasts with an etic perspective in which the researcher examines experience using pre-existing theory and empirical findings (Daly).

One prominent criticism of narrative inquiry is the notion of embellishment, and the role of memory in the telling stories. The validity of the stories in narrative inquiry is often questioned by objectivists and post-positivists concerned with the truth (Daly, 2007). Rather than focusing on the truth or falseness of stories, Daly explained that “the power of narrative is not measured by the degree of correspondence between plot and events, but rather by the unique way the story has been constructed and told” (p. 110). Narrative researchers are typically subjectivists who, as Daly (2007) described, are “fundamentally indifferent to extralinguistic reality” (p. 110). Narrative researchers focus on the construction and interpretation of stories rather than the validity found within them. Daly described the issue of validity in the text by identifying a need to make sense of the reality the participant has experienced rather than copying it.

Context for Study

Participants for this study were drawn from two organizations in Nova Scotia which provide recreation experiences for children and youth with disabilities. These organizations were selected for several reasons. First, I wanted to engage parents whose children participated in community recreation programs. Second, I wanted to engage parents whose children had a range of experiences (integration,

segregation, inclusion). Third, I wanted to engage parents whose children were living at home. Although I intended to draw my sample from only one organization, it became necessary to use two organizations to involve the number of parents required for this study. Both organizations had similar characteristics and types of participants; often the children or youth with disabilities had participated in programs from both organizations.

Initially both organizations were identified as providing segregated recreation experiences for children and youth with disabilities. Drawing on the description of segregated programs from Schleien et al. (1997) the following describes the segregated programs. Both organizations provided specific programming to a target group of children and youth with disabilities in the area (a homogenous group of participants). In addition both organizations utilized trained staff and volunteers from the surrounding communities (specialized staff who some possessed knowledge and training). These volunteers acted as a buddy, partner or assistant at a one to one ratio with the participants. The activities offered within the programs included elements of skill development, and specialized equipment. Both programs were run in spaces used by other community members, which in combination with the previous characteristics resulted in “segregated programs which provide a safe, structured leisure experience” (Schleien et al., 1997, p.25).

To gain access to the families who had been participants in one of the two community recreation programs in Nova Scotia, I contacted directors of both organizations, and provided them with a detailed outline of this study, the requirements for participants, and description of benefits to their organizations (see Appendix A and B). After initial discussions by email, I met separately with each program. After gaining consent from both organizations for assistance in participant recruitment, I provided a detailed description of the criteria for participant selection for this study.

Participant Sampling and Recruitment

Purposive sampling, an approach to non-probability sampling, was used for this study. It was not my intention to study large numbers of parents, but rather to produce a deeper understanding from a small number of participants (Neuman, 2007a). Purposive sampling enabled me to identify and select specific

cases for an in-depth investigation (Neuman, 2007a). Purposive sampling was appropriate in this situation as this was an exploratory study.

For this study I planned to interview 4-6 parents (both mothers and fathers) of children (male and female) ages 12-18 years with developmental/cognitive disabilities. After initial challenges in recruiting participants I changed the criteria for the selection of parents to include:

- Child is living at home.
- Child has participated in at least one segregated program.
- Child has participated in at least one integrated community recreation program.

Once permission from the organizations was granted I provided the organizations with informational flyers to distribute to families currently or formerly engaged with their organization (see Appendix C). These flyers were to be distributed by email or in hardcopy. The flyer included contact information for myself and my advisor, interested parents were asked to contact me so that I could describe the study in more detail and request participation.

What unfolded was that the staff from these organizations used the flyers, study description and participant selection criteria to contact parents themselves. The organizations thought this would be the most effective way to generate participants for the study. The staff of both organizations contacted (phone, email or in person) a number of parents whom they thought would be interested in participating. During this initial contact (by the organizations) a description of this study was provided to each parent, and the connection between myself and the organization established. Then permission was sought from each parent for me to contact him/her to determine interest in participating in the study.

As a result, 12 parents contacted by the organizations consented to have me contact them by phone to discuss the study and answer questions. I made follow up phone calls with each parent to outline the study and answer any questions using a call guide (see Appendix F). During these phone calls, basic information was gathered about the parent and child based on the selection criteria. At that time, the first interview was scheduled with each participant who agreed to participate in the study. Of the 12 parents initially contacted to participate in the study 8 consented to be interviewed, and five were included in this

study. The interview from one parent was removed from the study due to poor sound quality on the audio recording. What resulted was a group of 7 parents (6 mothers, 1 father). I had planned to interview each parent separately; however, there was one couple (mother and father) who preferred to be interviewed together. This interview was also removed.

As previously noted there were difficulties in finding parents who qualified for this study, and restrictions on who was able to be contacted. Although I had hoped to engage fathers and more parents of female children, the final group represents 4 male children and 1 female child, and 5 mothers. Table 2 provides a description of the parent participants. As it was my intention to interview parents not specifically mothers I refer to the group participants as “parents.”

Table 2

Participant Description

Parent (Pseudonym)	Child (Pseudonym), age
Carolyn	Keith, 20 years old
Leslie	Steven, 14 years old
Johanna	Brandon, 8 years old
Anne	Daniel, 17 years old
Rebecca	Clara, 8 years old

Each parent contributes a unique understanding and interpretation of their experiences of disability. It has been my goal to maintain the individuality of the parents in the study and the integrity of each parent’s story. Additional information about informed consent and details about the interviews are provided later in this section.

Participant Agreement and Ethical Considerations

The main ethical considerations involved in this research study included free and informed consent, participant wellbeing, and confidentiality. These considerations are described below, each followed by a discussion of how each were addressed in accordance with research policies of the University of Waterloo.

Throughout this process I provide all participants with clear, detailed and appropriate information about the study in which they were participating. Elliott (2005) states that:

As far as possible participation in sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on behalf of the researcher to explain in appropriate detail and in terms meaningful to participants, what the research is about. (p.141)

It was necessary to provide potential participants with information needed to make a clear, informed and free choice of whether they wish to participate in this study. To begin, participants were contacted and invited to participate in the study by the two recreation organizations. This included phone contact by the organizations to gain initial consent for me to contact the parents. In addition, the recruitment flyers were distributed by the organizations at their discretion (see Appendix C). By inviting potential participants to participate each person was able to determine interest for himself/herself. Initial contact by the organizations was followed up with a phone call by me where further detailed information about the study was provided, in addition I answered all questions and arranged the first interview with the participants. During my phone conversations with each participant, I outlined the requirements for participating in this study (2 interviews approximately 1 hour in length each), and provided a general description of the topic of conversation for the interview (the recreation stories and experiences of his/her child with disabilities). In addition, I informed each parent that prior to beginning the first interview I would provide written copies of information for the study and be seeking his/her informed consent to participate.

Upon meeting each parent for the first interview (before any questions were asked) each parent was presented with an information package which included a description of the study, and a consent form as well as contact information for myself, my supervisor, and the Office of Ethics Research at the University of Waterloo (see Appendix D). I described the purpose of the study, outlined the information available in the letter and informed the participants of their rights, and discussed the benefits of participating. I explained the interview process (audio recording) and discussed anonymity and confidentiality. Next participants were asked to read over informed consent forms (see Appendix E) and sign if they wished to proceed in the study. Every participant signed a consent form for participation in the study, and agreed to have the interview audio recorded.

The Canadian Institutes of Health Research (2005) defines free and informed consent as “the dialogue, information sharing and general process through which prospective subject choose to participate in research involving themselves” (p. 2.1). All participants were over the age of 18, and able to provide informed consent. In addition, both recreation organizations (represented by the program directors) were also asked to sign a form indicating their willingness to support the research. The organization had the right to decide whether they (the directors) wished their organizations to be identified directly in the study (see Appendix A and B). The directors and organizations were provided with information letters describing the study which contained contact information for me, my supervisor and the Office of Research Ethics at the University of Waterloo.

Consideration for the wellbeing of the participants was important to this study. It was the intent that this study would not cause any distress or discomfort, emotionally, psychologically, physically, or spiritually than is experienced in the context of daily life. While I could not guarantee participants would not be affected by their participation in this study, narrative offers people the opportunity for “re-authoring of stories...as means of arriving at new meanings of past events” (Daly, 2007, p.112). I made every effort possible to ensure the wellbeing of parents involved in this study. During interviews I was sensitive to any discomfort, and acknowledged immediately any desire to stop an interview or cease participation in the study. In addition I ensured confidentiality for each participant.

The issues of privacy and confidentiality are paramount to this study. As the identity of participants was known to me, their anonymity cannot be guaranteed, however I have guaranteed the confidentiality of their personal information. The Canadian Institutes of Health Research (2005) describes privacy and confidentiality, and the process of protecting participants:

Information that is disclosed in the context of a professional or research relationships must be held confidential. Thus, when a research subject confides personal information to a researchers, the researcher has a duty not to share the information with others without the subject’s free and informed consent...Confidentiality applies to information obtained directly from subjects or from other researchers or organization that have a legal obligation to maintain personal records confidential.(p. 3.1)

Information disclosed during the interviews was kept confidential, and was not used or shared unless the participant has signed the informed consent form which outlines the intended use of his/her information. Confidentiality was guaranteed using three strategies. First, the use of pseudonyms for all participants ensured no participant will be connected to any specific material in the study. Second, any identifiers within the text or quotations have been stripped to further protect the identity of participants. Third, no specific descriptions of individual participants are provided, only general descriptions are included in the study.

Narrative Interviews

Interviews are the most common method of generating narrative data, and narrative interviews are approached as conversations (Clandinin & Connelly, 2000; Glover, 2003; Polkinghorne, 1988). Creswell (2003) described interviews as being conducted face to face where the researcher asks pre-determined questions to collect opinions and experiences of participants. The *narrative interview* is intended to have a conversational tone where the researcher enables the storyteller to speak (relatively) uninterrupted, and typically produces an organized story (Clandinin & Connelly; Glover; Polkinghorne). Glover contrasts the narrative interview with traditional qualitative interviews which provide rigid or standardized questions and often results in the storyteller being cut off. Narrative researchers prefer less structure in interviews which provides the storyteller with more control and the opportunity to tell the complete story (Glover).

Although narrative interviews have less structure and the storyteller may struggle to present the story, conducting an active interview addresses this issue. Glover described the process of active interviewing in narrative research whereby the researcher and storyteller are “actively engaged in a process of trying to understand important aspects of an event” (p. 155). By actively participating in the interview, the research process is shared between researcher and participant, and what results is a collaborative understanding of the story (Glover, 2003). Interview guides for this study were developed in accordance with the active narrative interview. In addition to simple story seeking questions about the recreation experiences of the child, a series of follow up questions enabled myself to help the participant tell the story, and to

produce a collaborative understanding. These follow up steps were critical to ensuring I clearly understood what the participant was telling me.

Piloting the Interview Guide

Prior to conducting interviews with participants, one pilot interview was conducted with a volunteer. The pilot interview followed the same format as the interview guide for this study using Interview Guide A. This pilot interview was not recorded, and no information resulting from the interview appears in this document. After testing the interview format and questions, I made minor modifications to Interview Guide A to clarify questions and to maintain the openness of the intended discussion. I found some of my original questions were rigid, academic, and vague in their wording. The questions were modified slightly to increase the comprehension and responsiveness of participants. A second interview was used to further explore experiences, illuminate meaning, and clarify misunderstandings from the first interview. For this second interview, Interview Guide B, was developed after the first round of interviews and focused on specific sections of the preliminary narrative.

Interview 1

During the first interview I had parents tell me first about their child and our conversation branched into stories about the child's recreation experiences. I used Interview Guide A (see Appendix G) to help elicit these stories. The first interviews lasted on average 45 minutes and were conducted in a place of comfort, convenience and privacy for the participants. Four of the interviews were conducted at the parent's workplace, and one interview was conducted in the home of the participant. I was flexible in the time of the interviews. The interviews were conducted at a range of times during the day--ranging from early in the morning, over the lunch hour, after work, and the evening.

As previously outlined, upon meeting each parent I presented the information letter, explained the study and their rights as a participant, and had each parent sign the consent form. I confirmed the participants' agreement to have the interview recorded, turned the device on and began the interview. I began each interview with the set preamble of Interview Guide A (see Appendix G). While having the parent

share their experiences with me, I actively worked to interpret and make meaning of their stories with them using the follow up questions to produce as much detail as possible for each story. At the end of each interview I thanked the parent for participating and scheduled our second interview. Following each interview, I completed a full transcription of each interview as soon as possible, and began preliminary descriptive analysis.

Interview 2

Whereas the purpose of the first interview was to have the parent tell a story about his/her child's recreation experiences, the second interview was an opportunity to explore and interpret that story. Interview Guide B (see Appendix H) was developed and adapted for the second interview based on the descriptive analysis from the first interview. Prior to the second interview I sent each participant a copy of his/her story from the first interview. Before the second interview started I read the preamble for Interview 2, and asked each parent to read his/her story. I then asked each parent to comment if it was reflective and true to what he/she had said, and if there was anything the parent wanted to change, add, or remove from the story.

During the rest of the second interview I sought clarification about specific experiences and statements made by the parent using Interview Guide B to aid in interpreting the stories. I would identify a section or statement from the story, explain my thoughts on it and ask the parent for further information or description. There was approximately two weeks between the interviews with each parent. The second interviews were conducted in the same locations for each participant: work places and homes.

Data Management and Securing the Data

Full transcription of the recordings began as soon as possible after each interview, and was typically completed within 72 hours of the interview. The interviews were transcribed verbatim. Each parent and child was assigned a pseudonym to protect his/her identity. Upon the transcription of each interview, a copy was stored on a password protected flash drive. My personal reflections were also stored on a password

protected flash drive. When I returned to the University of Waterloo I continued my reflections to ensure that I was conscious of my role and interpretation of the stories.

All of the data generated for this study were kept locked in my desk at my residence while I was in Nova Scotia, and then locked in my office while at the University of Waterloo. Only myself and my supervisor have had access to the raw data. Each interview was recorded on a password protected flash drive and the assigned pseudonyms were used to identify the participants. All names mentioned during the interview (people, places and organizations) were changed. Parents and children have only been described by gender and/or age, and a description or identification of the children's disabilities does not appear in this thesis document. Field notes and reflections were kept locked and stored on a password protected flash drive and on my password locked computer. Data will be destroyed within three years of the study in accordance with the ethics protocol of the University of Waterloo.

Narrative Analysis and Procedure

There were two phases to the narrative collection and analysis process: descriptive and interpretative (Daly, 2007). Although these are separate steps of analysis (descriptive and interpretative) they blended together to enable co-creation and interpretation of the narrative by both myself and the parent (storyteller). Figure 1, provides an overview of the process and elements found with each phase of the collection and analysis process.

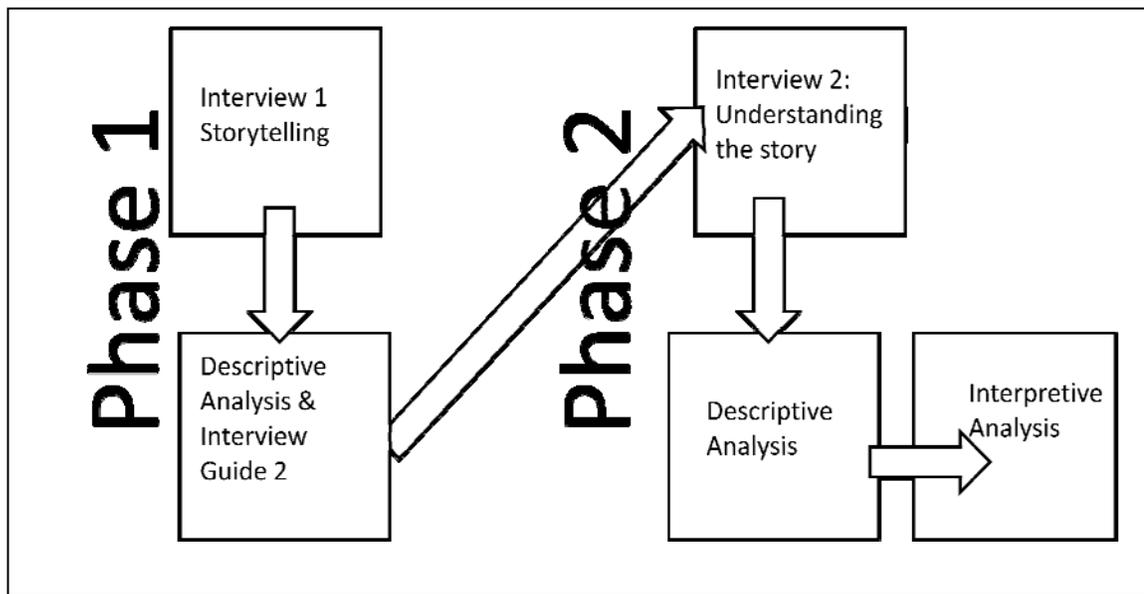


Figure 1 . Interview and descriptive analysis procedure.

During the first interview, parents told a story (or stories) about their child in a recreation context with support from questions posed in Interview Guide A (see Appendix G). Interviews were transcribed and the preliminary descriptive analysis conducted to produce the narrative account for each parent. At the end of this phase, I had refined each interview into a rough-draft of each narrative. Each parent was provided with a copy of this narrative draft for review. Parents were asked if they wished any changes, additions or parts removed from the account.

The second interview focused on interpretation of the narrative accounts from the first interview. The second interview used Interview Guide B which focused on co-interpretation and exploration of the narrative account, and the telling of other stories (see I). The second interview was transcribed, and narratives were revised based on changes requested by parents. Descriptive analysis was then completed on each narrative and interpretive analysis began.

Narrative Analysis

After each interview was transcribed I began the process of narrative analysis, descriptive first then interpretive. This process is referred to as narrative analysis rather than analysis of narrative. Glover (2003)

describes the narrative analysis process which “involves taking the elements of a story, possibly from a variety of sources, and reconstructing it into a coherent sequence of events that retains the essence of the story teller’s account(s)” (p.156). The process of deconstruction and analysis is referred to as the analysis of narrative where the focus is on the individual pieces found within the story, rather than focusing on the story as a whole (Glover; Polkinghorne, 1995). The narrative analysis approach contrasts with other qualitative methodologies which “deconstruct narrative into common themes and explain the interconnections between them” (Glover, p.156).

In the analysis process it has been important to maintain the structure and integrity of the story rather than breaking it into pieces for examination. According to Daly (2007) “the primary goal of narrative is to understand how individuals construct their experience within the context of their life” (p. 113). It was of the utmost importance that while I conducted the narrative analysis that I maintained the parent’s authorship and interpretations of the stories, while acknowledging my collaboration in the process.

Analysis began first with an organization of the narrative accounts. This included writing the context, and identifying the internal structure (or plot) using Glover’s (2003) narrative structure (as identified in Table 1). Next, an interpretive analysis was conducted using the narrative account of each parent. This interpretive analysis was developed from Daly’s (2007) interpretive narrative framework.

Descriptive Analysis: Creating Stories

To begin the analysis I wrote the context for each story and parent. Glover (2003) identifies establishing context as an important step because it is “helpful to introduce the storytellers and their personal and general circumstances” (p. 157). The context will include characteristics of the story as well as the interview including:

- The context in which the story took place.
- The protagonist, his/her choices and actions.
- Other significant characters.
- The context of the interview situation.

(Glover, 2003, p. 157)

The context for each parent is presented at the beginning of each narrative account in Chapter Four. I then carefully reviewed each interview transcript, listening to the audio-recording to identify plots and internal structure (following Table 1). I did not analyze components of these structures, but rather identified them from the text and joined them to make a full story using (verbatim) accounts from each parent. I slowly processed each interview transcript to identify the flow of the story within the conversation. I added notes in brackets to help the reader transition from topic to topic. This process was completed for each interview, and for (multiple) stories within the interview transcripts. Once the descriptive analysis was complete, interpretive analysis began.

Interpretive Analysis of Narrative Accounts

This process was guided by Daly's (2007) interpretive analysis for narratives and was completed for each narrative account. As described by Daly interpreting the narratives uncovers the understanding I have of the meaning of each story and the narrator's intention (our collaboration). For Daly (2007) "narrative interpretation is a hermeneutic process that involves the correlation of participant and researcher meanings" (p. 224). When interpreting stories generated from the descriptive analysis I considered: why the story was told the way it was, how it was located in relation to other events, and how it was located in the storyteller's life (Daly). Table 3 presents analysis questions which guided interpretation of the narrative accounts.

Interpretive analysis questions from Daly (2007) (see column 1 in Table 3), were adapted and a series of questions created for this study (column 2 in Table 3). These questions were used to guide the interpretation in each of the three phases. The interpretive analysis for Phases one, two and three appear in Chapter Five.

Table 3

Interpretive Analysis Questions

Interpretive Analysis Questions (Daly, 2007, p. 117)	Adapted Questions
<i>Narrative Analysis (Phase 1)</i>	
Why was the story told in the way it was?	What was the purpose of telling the story?
Who was the audience the storyteller had in mind? How is the story positioned in relation to the audience?	Who is the intended audience for the message?
What purpose is served by the narrative? What is accomplished?	What is the outcome of this story being told? What has happened as a result of the telling of this story? What is the (emotional) impact on the reader? What is the importance of the message? Where does power lie within the story? Who is it connected to? How? Why?
<i>Narrative Analysis (Phase 2)</i>	
What is the order and sequence of the story?	What time (when) and space (where) frames emerge that are important to the organization of the story?
How is the self presented in the story?	Who is the protagonist in the story? How are others represented in the story? What internal and interpersonal conflicts are experienced by the protagonist, or other characters?
<i>Narrative Analysis (Phase Three)</i>	
How does the story help us to understand cultural practice?	How does the story help us to understand disability (for youth)? How does the story help us to understand non-involved, segregated, integrated or inclusive leisure experiences for youth with disabilities? What language (words, phrases, jargon, slang) was used by parents? How are these concepts understood by parents? What kinds of values and morals are included in the story? Whose are they? How does the story compare to models of disability?
Where do I fit into this process?	How is the story positioned in relation to me (as a researcher)? How did I (as a researcher) influence the telling of the story? What assumptions are made by the parents, or by me? What did we take for granted?

As the analysis unfolded, it became clear that I needed more clarity around some of the elements in Daly's interpretative analysis (Phase Two); mainly the idea of self and protagonist. Polkinghorne (1988) discusses three constructions of self within narratives: material self, social self and spiritual self. According to Polkinghorne (1988) the material self is "derived from an awareness of one's body including clothing, family, home and property" (p. 149). The social self includes "perceptions or images of one's person that one assumes are held by other, personally significant individuals or groups of individuals, and on the other

hand, the social values and norms shared by the person with others” (Polkinghorne, p. 149). The spiritual self is the “awareness of one’s own frailties, dispositions, and self-understandings and judgement” (Polkinghorne, p.149). Since there were more than one protagonist in each narrative and the stories were not works of fiction I chose a definition of narrative which was broad and encompassing. *Oxford University Press* (2008) dictionary: “one who takes the leading part in a drama; the chief character of a novel or story in or around whom the action centres; the spokesman or leader for a cause, the principal mover; an active participant, the supporter of an idea or action” (para. 1) The broader range of characterizations of who and what a protagonist is and his/her role in the story accommodates the complex roles of both parent and child in these narratives.

Questions from Phase Three of the interpretive analysis which address my role as a researcher and where (and how) I fit into this process are addressed in the following section and in the conclusions to Chapter Five. This final reflective piece provides a re-examination of my role, position, and understandings of this research, the narratives, and the concept of disability.

Role of the Researcher

It is important in this approach to research that I have been upfront and clear about my role and participation in this study. One distinctive element of narrative research is that as a researcher I was engaged as a co-participant or collaborator in the production of these narratives. As Daly (2007) describes, “[w]hile the story essentially belongs to the participants, the researcher plays an important role through gestures, prompts and questions in shaping the form and structure of the narrative” (p. 114). This is an important distinction; in my role in this narrative inquiry I have actively participated in co-construction of stories in the interviews to generate detail rich stories.

Narrative inquiry entails a study *with* participants instead of *on* participants. Narrative requires the development of relationships with the participants, and requires me to acknowledge my contributions to this study (Clandinin & Connelly, 2000). My past experiences, understandings and knowledge of leisure and disability have influenced my interpretations of the narratives. However, an awareness of my own

understandings has helped me recognize when they have emerged and their impact on the study. What I hoped to produce from this study are stories of how leisure has been experienced by children with disabilities from their parent's perspective. As Glover (2003) states, "researchers must value interpreting these stories with the people who have lived them" (p. 159). Throughout the process I actively sought interpretations from parents of the meanings of their stories rather than simply imparting my own interpretation on them. In addition, to clarify my role in the research and any potential influence I brought to this study, I believe it was necessary for (myself) the researcher to begin by identifying my own understandings, meaning and knowledge of disability.

Reflexivity

Reflexivity is essential to the success of this narrative study. As previously noted by Glover (2003) and Clandinin and Connelly (2000), the researcher must acknowledge her role in the study, and acknowledge the influence of her interpretations on the study. Citing Mertens, Creswell (2003) describes reflexivity stating "this introspection and acknowledgement of biases, values, and interests (or reflexivity) typifies qualitative research today. The personal-self becomes inseparable from the researcher-self. Reflexivity also represents honesty and openness to research, acknowledging that all inquiry is laden with values" (p. 182). In qualitative research, reflexivity is the crossroads at which the researcher, stories, and the world meet, are identified and critically examined (Macbeth, 2001). For this study it has been crucial that I recognize, acknowledge, embrace and present my own thoughts, biases and understandings of this topic, and related concepts. Rather than trying to separate myself or my knowledge from this study, I asked myself the following questions:

1. What are my own experiences and understandings of disability?
2. What do I think about my understandings?
3. Where did my understanding come from?

Reflexivity appears in the form of personal written reflections throughout the process of this study. The reflection process has been guided by a series of questions that have been developed to challenge what I have heard, how I understand and interpret the stories, and important concepts as they arise. I have

written reflections about my own past experiences and present experiences as this study progressed using the following questions to guide my reflections:

- What concepts or ideas were discussed today?
- What do I think about each of those concepts?
- Where did I learn about them?
- What do they mean to me?
- What did I think about the interview?
- What stood out?
- Did anything surprise me?
- Was non-involvement/segregation/integration/inclusion discussed today?
- What was the context?
- Has what I think about those concepts changed?
- Did anything today remind me of a past experience?
- Describe that story.
- Where did my knowledge, their stories and the world meet?

These reflections were written and kept on my computer. They are important because they aid in my recognition of my own assumptions and understandings about this topic. These questions enabled me to recognize when and where my understandings and experiences affected the interpretation of the story. By reflectively writing I have been able to identify what I have brought to the study as a researcher and recognized myself in the process of analysis. Throughout the course of this study I regularly wrote down my thoughts, feelings and experiences focusing on ideas and concepts related to this study. The following sections contain my reflections before, during and after the interviews.

Researcher Reflections Before the Interviews

My exposure to, and interaction with, youth with disabilities was limited until my undergraduate university experience in Nova Scotia. During my first year I was exposed to a range of programs and groups for people with disabilities from my work as a part-time lifeguard at the campus pool. I observed power dynamics that existed within these groups, and how others treated or approached people with disabilities. In the fall of my second year, I began working as a babysitter for a family including a boy with range of disabilities, Aiden. My experiences with Aiden did not fully develop until the spring months of that school year. I began to spend one afternoon a week with him. In my early experiences with Aiden I was hesitant to challenge him. What I did not realize at this time was that Aiden, like other youth, was challenging me. I overlooked his awareness and understanding of the world because of his disabilities. I was a pushover for the first few months. I was afraid of testing his capabilities because I assumed that he was incapable and because I liked doing things for him. It made me feel productive and useful. Everything I learned growing up about disability played out in those first few months. I had been raised to be sensitive and considerate of others, and I never thought my actions or words did more harm than good. I thought that people with disabilities often required help but I rarely thought to ask if it was necessary.

As time progressed, I became frustrated with Aiden and started making him doing things on his own. I began to realize that I enabled him, as were most of his other caregivers. Our responses to his behaviour told him that it was okay to do these things (card throwing), because we would always be there to make it right (cleaning up the mess). The months passed. I spent a semester studying abroad and returned to Aiden the following winter. What progressed over the next two years was my continual challenging of Aiden to develop in him some level of autonomy, self-reliance and capability. Through those years Aiden participated in several leisure programs and activities. Most were labelled inclusive and three were, as I identified them, segregated. When I took him to these different activities, I became aware of how he was treated by others. Some people would talk down to him, use baby language and engage him in extremely simplistic activities or roles. Sometimes he sat on the sidelines for the entire program. In other instances, people recognized his disabilities but still engaged him and encouraged his full participation.

When I left Aiden and Nova Scotia, I had no intention of studying disability at university but early in the first year of my Master's degree I realized that something about those experiences with Aiden stood out. I took a graduate course on recreation and leisure for people with disabilities, and had my understanding and knowledge about the meaning of disability challenged. I developed a strong connection to the social model and social construction of disability which postulates that what we understand and believe about disability is derived from interactions between people and their environments (Jones, 1996). In social constructionism, disability is not a direct attribute of an individual, but instead disability is created when people interact with their environment (social, physical, etceteras) and others (Jones, 1996). Practices in society create barriers which in turn create disability. As Jenks (2005) eloquently stated "of course there are all sorts of differences between people. But only some differences matter" (p. 143).

Throughout this study, rather than presenting myself as a researcher who is studying a specific phenomenon, which could create a power divide between myself and the participants, I presented myself as a student interested in learning from the experiences of participants. By building relationships with parents, collaborating and actively seeking their interpretations, I sought to reduce the power divide that could exist between us. The participants held the meaning I sought to understand.

Researcher Reflections During and After the Interviews

The following provides a summary of my reflections from my time in Nova Scotia. These reflections began prior to the first interviews and continued through to the end of data collection.

I feel like I do not know anything at all. After speaking with one of the program directors I found out that they do not want to be labelled segregated. This makes no sense to me because this program fits all of the characteristics of a segregated program. Why is segregation such a bad word? And why do they think they are not segregated? They run a program for kids with disabilities by people without disabilities in a space that is away from people without disabilities! I feel confused because this is an amazing program and I have seen it do amazing things for these kids, but I just do not get why it is not "segregated"?

Apparently segregation is a dirty word. Obviously I do not think that segregation is such a bad thing but that is because I have seen these "segregated" programs provide some really incredible experiences for kids with disabilities. I have also seen some inclusive and integrated programs provide some really terrible and demeaning experiences. I know that at the root of segregation is the idea of separating people based on a specific characteristic. I do understand why segregation has a negative connotation and that it has been used in negative and harmful ways through time but when the purpose of it is intended to benefit a group of people, what is so wrong with that? We make segregation out to be a bad thing based on any kind of discriminatory reference to a person's characteristics but we totally neglect the fact that all we really do in our world is segregate people. I think that we have tagged segregation as a bad word but continue the action of it under a new guise of separation. We like our groups and we like being with groups of people who are like ourselves. There is comfort and consistency in the presence of similarity. We separate older adults from society and collectively stick them in nicely contained retirement homes. We take kids out of regular classrooms for being extra smart and put them in special classrooms with the other really smart kids so they can all be smart together. Even in my readings I felt that there was a debate on segregation, sometimes people think it's a good thing if its purpose is to help people with characteristics in group A learn to function with normal and expected characteristic in group B. If it's a "steppingstone" or a place to bring skills up to par with the rest of us, then it isn't so bad but if that element of moving up and being able to fake a more "normal" performance in the world is missing then its discrimination and it's horrible. Is it ok to group people by similarities and not by differences? The positive spin of 'similarity' is a wonderful ploy.

When I started this I kept finding that integration, segregation and inclusion were neatly tucked into defined boxes with an assigned checklist of contents. That never felt right to me. It seemed too easy to stand back from a program or a facility or a group and say definitively this program meets these criteria therefore it is segregated/integrated/inclusive. However, when you are in that program or that facility and you are living it, it is totally different.

Wow. I am totally overwhelmed by the last few days. Each parent I spoke to has been through such a roller coaster ride with their child, it's hard to fathom how they are all still standing. After each interview I had more and more questions about the terms we use in relation to disability. I also became progressively more frustrated and angry with what these parents have had to deal with. I cannot imagine having to live with indifference and reluctance at such a high level.

What talking to these parents has done is really make me think about what I am studying. Why I am studying disability, and more importantly what will happen as a result of this project. Parents really do have a wealth of information with regards to their children. I do not think we have a thorough understanding of what integration, segregation and inclusion mean in the world today.

Chapter Summary

This chapter outlined methodological procedures guiding this narrative inquiry including: an introduction to narrative inquiry and the components of narratives, context for the study, ethical considerations, and participant sampling and recruitment. Also described was the approach to data collection, narrative interviews, and the descriptive and interpretive narrative analysis strategy. The chapter concluded with a discussion of the role of the researcher and reflexivity. Chapter Four contains the descriptive analysis of narratives. Chapter Five continues the interpretive analysis and discussion of the narratives in relation to the disability and leisure studies literature.

Chapter Four: Descriptive Analysis

This chapter contains the findings from the descriptive analysis and provides us with insight into parents' words and descriptions of their children's recreation experiences. Even though I refined the stories, what remains is the essence of each story told in the parents' own words. Each story begins with a brief description of the internal structure of the narrative and establishes the context for the story. The storyteller and some of the main characters and important events or recreation experiences are introduced. Context is established through a description of time and place. Background information about the storyteller is provided so that the reader may understand who the parent is, and why each story is being told. I also include an excerpt from my reflexive notes to provide the voice of the researcher in constructing the narratives. Finally, following the analysis strategy of Daly (2007), the question of why was this story told in the way it was will be addressed at the end of each narrative. Enjoy!

Anne's Narrative about Daniel

Anne told me the story of Daniel's recreation and focused mostly on his current or recent experiences. Anne emphasized the importance of several programs for Daniel including Special Olympics and Rainbow Recreation. She explained how they became involved in these programs and what they had meant to their lives. Most of Daniel's recreation experiences have been places where he has met and maintained friendships with other youth both with and without disabilities. His friend Tiffany had become a regular part of his recreation experiences and is spoken of often through the story. She is, as Anne calls her, a special friend of Daniel's. Anne mentioned that Daniel had friends from school and in recreation programs but there was limited description about them or discussion of their significance in his life. Daniel sees his friends at school or at programs but not with any frequency outside of these places. For our second interview Anne arrived with a scrap-book album of photos and memories of Daniel's life. Anne shared more of Daniel's life with me through these pictures and mementos. When Anne showed me these pictures, I saw a mother's passion, commitment, and love for her son. Each picture, or note from an old teacher, put a sparkle in her eye, and I could feel the joy these memories brought her. These were the good moments and

the good people who had made her son's life better. What I remember from talking to Anne was that although she seemed happy with the experiences her son had, there was always the reminder that he really did not have all that much with regards to recreation experiences. He had tried just about everything possible but it really was not enough. Anne and Daniel's story is set in the communities surrounding a small town in Nova Scotia. Anne and her husband have exerted significant effort to provide a life for their son in a world that is at times reluctant to embrace him. Their story highlighted challenges in school and community, and the difficulty of finding year round activities that were both meaningful and willing to engage Daniel. The following is my reflection following interviews with Anne:

Anne's interviews were so completely different. Do not ask me why but for some reason I expected everyone to be super conversational and opinionated, that people would jump right into the stories and chatter on for the entire hour. I truly enjoyed talking with Anne because she brought such a different element to the interview. It was in Anne's interview that I really learned about the shared and collaborative element of narrative, her interviews were really more like conversations. Anne came prepared with notes about what her son had done because she did not want to forget anything. I think she was a little shocked when I began the interview by having her tell me about Daniel. There is a light that glows from a parent when they are telling you about their child. This was even more evident in our second chat when she showed me a scrapbook of Daniel, although I had not asked for it I was delighted to learn more about him and the scrapbook really helped Anne bring Daniel to life and share his experiences. It's amazing what pictures and mementos will do.

About Daniel: Growth and Change

Anne told me about what Daniel was like when he was growing up. She described how he used to communicate by writing with a Magnadoodle and how he started talking one day. Anne described Daniel's development:

(When he was little) he didn't know how to talk. He was learning sign language and, before he was in school he was in child development and he had speech therapy. He was doing lots of stuff before school. Well, once you go to school you don't have any of that stuff right? So we went into the school system and he couldn't speak so they started teaching him, sign language. He had a Magnadoodle. Well, he went through four of those, wore them out because he used to write down everything. So in about grade one, he started to talk. He came home one day, and he'd never ever said 'mum' before. He used to always call me 'dija'. Wherever he got that I don't know, but he threw away the Magnadoodle and started talking. Then he lost the writing. He used to write so much, and could do everything but now he doesn't write as well. But he speaks in broken sentences. Speech therapy would be good, if you can afford it, and the school doesn't have it.

As Anne described, in his early years Daniel responded at times with fear. For example in his experience with dogs, Daniel grew from being petrified and running away from them, to his love and

adoration of Henry the family dog. As Anne described, Daniel will “*lay with (Henry) before he goes to school and pet him and tell him he's beautiful*”. In other situations Daniel would respond by crying. This was the case in his early experiences with Rainbow Recreation. As Anne describes, “*we used to drop him off and of course he'd cry and (then) we'd have to go around the corner and watch him you know and it's like ok he's fine*”.

Anne described Daniel's growth and that he is becoming “*such a normal teenager in some respects*” and still having some characteristics of a child. According to Anne, Daniel is:

...a happy guy, (who) never gets mad...he loves to dance, he loves music. He likes Shrek and he has an mp3 player. He just started using one probably about a year ago. He never used to before, and it's funny he's just like a normal teenager! We'll be driving in the car and he'll have it in his ears and listen and of course, he's singing out loud! (Laughs). Yeah he's a pretty bad singer too. (Laughs) Oh my god. Just like a normal teenager. He's pretty independent. He comes home from school at quarter to four and he gets in the house by himself and stays there, I mean he's watching TV or whatever until I come home. My husband and I are gone to work before he goes to school and he's been doing it probably the last three years and only one time he missed the bus. He's very independent, and if I'm late it's like, 'mum, you're late!' He goes and gets my knapsack and gets my lunch and it's like he's getting me out because he wants to go watch TV a little while before he goes to school. He's like, being the mother. (Laughs) 'Here's your stuff, you're late!' (Laughs).

Anne's description of her son highlighted his independence and “*normal teenage*” behaviour when he sang along to his music in the car. Anne seemed proud of her son's ability to get himself to and from school for the past few years.

Experiencing the Divide: Friends and Peers

Many unnamed characters stood out in Anne and Daniel's story as having made significant contributions to their lives. These people have supported Daniel, challenged him and enabled him to grow as any young man would. Other important characters in this story include: Glen (Anne's husband/Daniel's father), Tiffany (a girl from school), Emily (the Special Olympics coach), and Daniel's friends from recreation programs.

Anne noted that challenges related to Daniel's social life outside of the school environment are becoming apparent. As Anne says “*at school he has all kinds of friends but when he goes home there's nobody*” and there is a lack of friends in their neighbourhood. Anne and her husband have made efforts to

support Daniel's social life outside of school by encouraging him. But as Anne describes, now *"it's harder, there's a couple of girls that are younger than him that he likes to invite over every now and then but he doesn't really have a guy friend"*.

Anne continued to describe how Daniel is becoming a *"normal teenager"* using a trip to the movies as an example. Daniel insisted on sitting with his friend Tiffany alone, forcing Anne to sit by herself at the back of the theatre.

Tiffany is in grade eight, and Daniel's supposed to be in grade eleven and he'll ask her. I took them a few times and (once when we) went to the movie theatre I'm going to sit down with them and he says 'No, mom! I wasn't allowed to sit with them! (Laughs) That was the first time I've ever been to the movies by myself! I was sitting in the back row. (Laughs). I see them turn around to see where I was, like he couldn't see me where I was but I could see him. Yep, I sat by myself and he sat with Tiffany! (Laughs) You know, he's mature now! He's seventeen and thinks he's old enough to do that.

Anne then said, *"I don't know where he got that from because it was you know, two weeks before that he and I went and it was fine ... maybe it was because it was Tiffany and she was a girl"*. Despite her surprise of having to sit alone at the movies, Anne said *"I think it's great, that he would even think to do that. You know, it's normal for him, for a teenager to do that. It's great for him"*.

Support from People through Participation in Programs

Throughout the story Anne identified a number of people who supported Daniel in his life and in recreation. Specifically, Anne spoke about Daniel's leaders at Rainbow Recreation and Emily the Special Olympics swim coach.

Anne described Nick, one of Daniel's Rainbow Recreation leaders, who was very funny. Daniel and Nick were buddies in the program for about three years. Nick was a great support for Daniel, able to engage him in activities Daniel would not usually do. As Anne described:

Daniel really didn't participate in a lot of stuff, but Nick was such a happy-go-lucky guy and he would get Daniel involved in everything just because of the way he acted, and stuff like that. Daniel (would be) like, 'no no no no thank you,' he says. He (says he) doesn't want to participate and stuff, but he did with Nick.

After Nick, Daniel was partnered with a cousin for about four years. The program enabled Daniel to spend more time with his cousin than he usually would. As Anne described, Daniel would have seen him

"maybe twice a year so it was great that, they got to know each other that way". After his cousin has completed his degree and moved on, Daniel was partnered again with a different cousin who is now at the university.

An important support in Daniel's story has been Emily, the coach of the Special Olympics swim program. Anne became involved with the Special Olympics through a connection with another parent, and then with the swim program when Emily joined. "Emily came to one of our meetings and she said that she wanted to start up the swim meet for the Special Olympics. That was right up our alley! I mean that's what Daniel liked the best!" Anne then identified the recent challenge with the swim program - the practice time has been moved from the afternoon to the early morning, a change made to suit Emily's schedule.

It's not a good time! I never take him now, my husband takes him. It's eight o'clock in the morning because Emily, she does so much and she's burnt out. She belongs to the Masters (swim program) and she thought that she could combine the two of them because she's there anyway.

Anne highlighted the significance of the program and her hope of Emily staying with the program. "I mean, she's all we have right? I don't know whether she'll do it next year or not. I hope it keeps going, for Daniel too. I understand Emily though, she's burnt out."

Swimming, Movies and Youth Groups: Anne's Desire for Daniel's Active Life

Anne shared the stories of Daniel's leisure experiences including: recreation through his school, his love of swimming, his time with the youth group, his experiences at the movie theatre, and his summertime experiences. I asked Anne to tell me about Daniel's leisure experiences:

We got him a trampoline, he loves the trampoline. I mean it's hard to find stuff for Daniel. I mean he had Rainbow Recreation, he had the youth group, and he had the swimming on Sunday morning, and he also joined Special Olympics bowling this year so that was every second Thursday night. So there was a few things there for him.

Anne further described Daniel's recreation activities and her desire for more activities, "he's involved in quite a few things now which is good but it's always good to have a little bit more stuff too." I asked Anne if there was any recreation for Daniel connected to his schooling. Anne proceeded to tell me more about Daniel's experiences in school and about the activities in the coming weeks as school wraps up for the year.

...well, actually they're going fishing tomorrow. They have a fishing derby through school. Then, Monday they have off and then Tuesday, Wednesday, Thursday they go to a camp the next town over. He's in the learning centre, he goes to classes but he has a social skills or whatever in the learning centre, so they're taking all those kids to camp for a couple of nights. They did that last year too. Off to the woods probably, you know, camp stuff and bon fires.

Daniel seemed to have a number of different activities through school. I asked Anne to tell me more about the things he had done there, she commented that Daniel's E.A. had been an important figure in his exposure to new activities.

...When he was at primary school every year the E.A. would make a point of making him learn something. Like, try the skating, and he did the swimming lessons and he did the rollerblading. This one E.A. was so determined that he was going to learn and he did. They took a film of it and sent it to me. So I think it was the school. They did so much with him, at high school not so much. I think probably in high school it's more academic than play. Although he does play a bit I suppose, but I guess now they concentrate more on the sports.

Anne also talked about activities Daniel tried through school including a few that were not successful.

Anne described how Daniel has tried skating, rollerblading, and skiing through his school but that few of these activities have stuck. She commented that she did not have the space or resources to keep most of them going.

He tried to learn how to skate through school. They did that for like three years and then, actually he probably went for the five years but he didn't like skating. He didn't learn. He learned how to rollerblade. He used to rollerblade in the gym, but he doesn't rollerblade now I mean we don't have a gym for him to.

Anne further described the skiing experience:

That was awful. I remember going to the school that day to pick him up from school and, 'Oh hi Daniel,' you know, 'did you have a great time?' He just said it was 'ok' and he sat in the car and he just balled his eyes out. No I think he was just overwhelmed. It was a change of routine; it was just too much for him. He didn't enjoy it, I mean we talked about going to skate today and he will not. 'No, no, no'. He will have nothing to do with it. He doesn't like to be cold. I mean every night, every morning even when it's hot in the house he'll go and he'll sit by, we have a blower heater and he'll sit by there. He does not like to be cold. So maybe that's why he doesn't like skating and, skiing and stuff like that.

When I asked Anne if Daniel attended any of the school dances or events, she noted that when Daniel was younger he would attend the school dances but now in high school he has "no interest" in attending. Although he did not attend the school dances, Daniel did go to the dances put on by the Special Olympics.

I asked if Daniel had ever been involved in art, music, or drama programs. Anne quickly responded that Daniel was not particularly artistic. I asked has Daniel had ever done any sport activities. Anne responded:

No, he's never done any sports. There's no sports for him to do. I mean really in school because usually the sports teams at school are competitive against other schools. I mean during gym class he would play basketball, or soccer, or stuff like that. He loves basketball, so that would have been one that he would have enjoyed but we don't have basketball, that would be just at school and that again would just be competitions against others. I know when he goes to gym apparently he does a lot in the weight room by himself. They do try to get him involved with the other kids and encourage him to play whatever they're playing you know, basketball or soccer.

The competitive aspect of sports seemed to be an issue for Anne and Daniel. Anne commented that Daniel seemed to enjoy sports but he separated himself during gym class even though his classmates tried to involve him. I asked Anne to tell me more about the issue of competition in sports:

Right now he could probably do soccer, and know which way to shoot the ball but when it was his age group. I mean he's 17 but if he could go back to age 12 the way he is right now he'd do fine. But when he was 12 years old he'd probably go the other way with the soccer ball, you know he didn't know any better. But where you're 17 and playing with other 17 year olds, he's never been able to do it. So there really wasn't anything.

Anne paused to think about Daniel's other recreation experiences. She quickly identified swimming as one of the most significant programs and environments for her son.

That's what he's most passionate about is his swimming. He did (swimming lessons) and he could swim like a fish. When he was at school, I think it was grade four and grade five they would take them and he got a couple of badges. Then he never went back. We didn't think that he would listen because he already knew how to swim.

Anne told me that Daniel's early experiences with swimming lead to his joining the Special Olympics swim program. Daniel practiced with the swim team every weekend for at least five years. Through the Special Olympics program Daniel has been able to compete against other swimmers at an annual swim meet in the city. This event provided a new experience for Daniel, "that was the first time he's ever been away from home. The first year he didn't want to do it, but he did and now he loves to go away. Just that one time a year and he looks forward to it."

Anne described the changes in Daniel through his swimming career.

He loved the water and at first he had the life jacket on, but I mean after a year he was swimming! Then people would say, like, 'can he swim?' because he was so little! Daniel was small for his age, and I mean he would jump in the lake and he would be gone to the other end and, it was just amazing how he could swim! Now when he swims for Special Olympics it's like (laughs) very slow, very relaxed, he's not very competitive. It's like he's out for a stroll. He used to swim a lot better when he was younger but when he goes to Special Olympics and he's competing he will try to win the race. And he's laughing and he's smiling at the next person in the next lane like, 'I'm going to get you,' right, like, 'I'm going to win'!

Anne described one of Daniel's other passions, the movies. Daniel's love of movies has helped him grow into what Anne calls a "normal teenager".

He loves watching movies. When he used to take movies to school, the teacher would say that they would love watching Daniel, not the TV because Daniel doesn't sit down when the movie's on. He recites them and he's acting it out. (Laughs). He is so funny to watch. I think that's why he's so skinny because he never sits down he's always going, acting out different skits and stuff like that.

Despite Daniel's evident love for movies, Anne went on to say she thought he "watches them too much." She further described her hesitation and the importance of the movie theatre for Daniel:

I mean we watch movies too so we can't not let him watch movies, right? You've got to when we're sitting there watching a movie we like. We go to the movie theatre (a lot). As soon as one comes out he knows and he'll call up the line because we have it on speed dial, and he'll write down this movie's at this time. Now he likes to ask his little friend Tiffany to go.

As Anne described earlier, it is at the movies that Daniel shows signs of being a "normal teenager."

This also came about when he refused to use an Easter Seals card to receive a discount. As Anne described:

He has the little card for Easter Seals thing for free and he does not like me to use that. He's like, 'No, put that away.' I think he thinks, he's not special, maybe, I don't know. But, he is.

I asked Anne to tell me more about the Youth Group that Daniel joined. Anne shared the story of how they became involved and Daniel's upcoming camping trip with the group.

He joined youth group the last couple of months. It's at a church in the area and some of his friends from school go to it. Tiffany goes there and her mom had suggested that Daniel join that because Daniel hangs around with her at school. I called the pastor up and, he wasn't sure at first though, he was surprised. Then he said he had to talk it over with the other people. I'm surprised he would, instead of just saying oh yah sure we'll take him. There was no problem he just felt he that he needed to (check it over). He probably didn't realize how good Daniel was, and maybe he thought he could get violent or you know could be hard to handle but Daniel wasn't. Maybe it was just that, and there was a lady there that knew Daniel so when he went he would have known who she was, and maybe that helped too. So they said they would love to have him.

Anne seemed to be pleased with Daniel's experiences with the youth group despite the initial hesitation by the pastor. I asked her to tell me more about the youth group and I learned that Daniel would be attending an upcoming camping trip with the group:

I don't know what they do, they have some guitars and music, and they do crafts, and this Friday night is their closing, and one of the ladies has a cottage out on the lake. They're going to the lake for the night but it says camping. I called the pastor last night and left a message on his phone to ask them, 'does this mean tent?' So if it does, we're going to let him go and if he doesn't go in the tent we'll just go get him. I mean it's only twenty minutes from where we live so it's no big deal. We kind of had to encourage him to go there because he really didn't want to go. I mean he's excited about the (summer) camp but going to this one for the night, I don't know whether or not he's enjoying the youth group. The first night he went to youth group, he came home and I asked him how he enjoyed it, he said it's good and I said 'you go back the next week?' He says, 'no no, just one time, just one time.' Then the following week I asked him, I said 'Daniel, do you want to go to youth group again?' 'Oh yeah! Ok!' And then, it's been every Monday like he's never said no after, it was just that one time.

During our second interview I asked Anne how the Youth Group camping trip went. She told me about her conversation with one of the leaders since she could not get much detail out of Daniel:

I went and talked to the leader when they got back. She said there was no problem at all, he joined in when he wanted to, and if he didn't want to he just wandered around. They played games she said, and they had a bonfire, and sing songs. They were going to take their swimming trunks but it was too cold. He had a great time she said, and you can't get much out of Daniel, he doesn't like to elaborate on what he does.

Anne told me about some of the other activities Daniel has tried like riding bikes in the neighbourhood, something they used to do as a family. This led to Anne describing her hopes for Daniel to have an active life:

I wish he was more active and, at least he's got his swimming, and I mean he's gone to youth group this year and the bowling, he loves the bowling. When he used to go at first he had to have Bill (on his team), Bill swims with Daniel. Now Bill is doing speech therapy now and so he doesn't go to bowling, but now it doesn't matter to Daniel whose team he goes on. Now, you know, he goes and he bowls with whoever is there.

Anne seemed happy with the activities Daniel had but commented that she wished they had retained some of the activities:

...I wish he would've kept some of it up though. He can run, and he was in track and field there a couple of weeks ago. From school, they did the track and field. He only went in one race. He usually doesn't do track and field. He came in third! 'So-and-so beat me!' (Laughs) 'Ok, Daniel!' Maybe that's why he didn't go in more races. I can just see him now, 'No thank-you! I'm not going in.'

The Challenge of Finding Summer Activities without Repeat, Rejection or Boredom

I asked Anne about Daniel's recreation in the summer. Anne told me about a program run by two university students that Daniel participated in when he was younger. Daniel went to the camp with his older brother. They did things like going to the beach and walking trails. Anne described that Daniel really liked the program and had a great time. Anne described that summer is a difficult time for any parent, but noted that she and her husband had been fortunate to discover a few camps and activities that made the months more fulfilling and enjoyable.

Anne told me about a camp near their family cottage that Daniel participated in during the previous summer. Daniel had a great time and Anne had hoped to enrol him again this year but found out the camp "was for parents on disability." As a result, Anne had to find another camp for Daniel. She told me that she found a camp through another parent. Anne said Daniel was "excited" for camp and I asked her what he was excited about:

I thought like since he had a disability that no camp would take him. I just found out a couple of weeks ago that, this one out there will because there's a couple of kids on his swim team for Special Olympics that go there too. They've been going for years, so we're going to send him there. And, I mean he can't wait! He's excited! He probably just likes hanging out, and other kids, because he doesn't care for fire. He's got this thing about fire. You know, like if I light a candle he keeps asking, 'when are you putting the candle out?' He doesn't like it. It's probably the swimming part and just being around other kids I would think. He doesn't like sleeping in a tent, has to be the cabin, so as long as it's not a tent he's fine. He (probably won't have) put any bug spray on though, or sunscreen, I imagine he'll come home with tons of bug bites.

Anne described this new camp, and the difficulty they have had finding a summer camp for Daniel:

We went to an open house last week or two weeks ago to see the camp and talked to the counsellors. She said that when Daniel goes there will be about 5 children with disabilities who will go. They've always have taken kids with disabilities but it's not well known, it almost sounded like they have a child with a disability. This camp, it's not a one-on-one it might be a two-on-one or three-on-one. Someone was saying there's lots of staff, so no worries. They will have a program for other kids, and at the same time have a program for disability children. They will include them with the other kids.

Anne noted that there "was no other camp in the province that offers to take children with disabilities" and shared her concerns with sending Daniel to camp for "normal people":

I mean they do have camps for normal people, but I've never sent him. Like they get on a bus and they go to the lake or (pause) but, you know you're not sure if they would watch him good enough,

you know? I almost think someone should be looking after him. I mean, he wouldn't run away or anything, but I don't know. I wasn't sure that he would be safe to send him.

Anne described the challenge of finding activities for Daniel in the summer. Though Anne has her summers off, she says “*there's nothing. I mean we have the pool and we go to the zoo. But he's already been to the zoo with the school you know, I mean I could take him again.*” Anne commented that at Daniel's age it is difficult to find anything for him because a lot of kids who are 17 are working in the summer. When Anne and her husband do find activities for Daniel, Anne said:

He always comes first no matter what. Like if I had something planned or if my husband had something planned. His would definitely come before anything we had planned. It's him. We're second, he's first so. You know there's so little out there for him that you just grab the chance to take him and do whatever there is at that time.

I asked Anne what Daniel did in the summer when he was younger. Anne told me that she used to hire someone to look after him during the day. In her search for summer activities, Anne told me about programs in the city that were available every day. Anne said the cost of the program would not matter to her, but to drive him there and pick him up each day (an hour's drive each way) “*would be too much*”.

The Uncertainty of Daniel's Future and the Possibility of Work after School

Anne opened up and described her hopes and fears of Daniel's future. She described that she was overjoyed to find out his school staff were beginning work training with Daniel so that he will have something once high school is over.

They looked at me, and said he'll be working. He'll be working? Oh yah, she said next year he'll be going out maybe an hour a week to start his training for work, and the next year he'll do more and by the time he graduates he'll have a job. He loves videos as you know, so now he's working at the library and putting the books in alphabetical order. They're looking at a small video store or something like that, or if not they figured he'd be able to stock shelves. They figure if he can stay on the task for 45 minutes straight, they figure when he graduates that he'll have a job. They have a lot of support for kids with disabilities while the kids at school, but they don't have that in every community. She thinks around here, the community supports those kids. That's why when he graduates he's going to have a job.

Anne described her surprise and joy when she found out from Daniel's school staff that he would have something when school ended. She commented that although she “sees him every day” she does not

know what happens at school. When she asks Daniel how was school, she gets a “normal” response, it was “fine.”

Carolyn's Narrative about Keith

Carolyn intentionally sought out and created recreation opportunities for Keith. Carolyn is a passionate and determined mother who found and fought for her son's involvement in the community, school and in recreation. Keith has grown up in a small community with loving parents and older sisters. Keith is a social, friendly and intuitive young man who has a desire to please those around him. He has a passion for sports and people. His many recreation experiences included: basketball, the Special Olympics programs, Rainbow Recreation, and community theatre. Keith and Carolyn faced the same challenges as many other parents-over commitment and involvement makes it impossible to continue with every activity. They had to choose which activities to remain a part of. Keith has excelled in these different environments because of his mother's support and many other significant characters that include: his basketball coaches and teammates, and his speech therapist. Each of these people have encouraged Keith's participation and provided the resources necessary for his involvement, and have demonstrated to others that he is valuable and can make a contribution. Throughout his life Keith has been his own advocate at times, demanding from the people around that he have the same as everyone else. In telling Keith's story, Carolyn interwove her own lifetime of experiences with disability. She offered insightful reflections and comments on Keith's experiences and her own because of her own connections and understanding of disability. Here is my reflection following interviews with Carolyn:

After Carolyn's interview I was so enthralled with how and what she has been able to do for her son. She was there for everything, and only now how many years later is she finally stepping back a little. Can you imagine being present for everything your child has done? Dropping her son off was not an option for her even though her family had met some really incredible leaders. I was completely shocked in the interview when Carolyn turned a question on me, asking what I think integration and inclusion are. I was not prepared for that but I think I handled it well, I told her what I think those terms mean: that integration is when people are in a space together and, that inclusion is when those people create some sort of meaningful relationship with each other. The awkward gawking, whispers and mildly pleasant smiles become a jovial wave and smile, and sincere comment about the game or event. I found Carolyn fascinating because of her involvement in the disability community in the area. She was opinionated because of her life and because of the life she desired for her son.

About Keith: His Intuition and Desire to Be the Same

Carolyn and her husband Doug adopted Keith just before he reached the age of one year. Carolyn told me she spent the next four years with Keith in and out of the hospital dealing with Keith's health issues. Keith has two older sisters with whom he is very close. He has lived in the same community all of his life. Carolyn described Keith as having very strong social skills, and "*so is very well liked by people and he plays that for all its worth*". Carolyn further described Keith's social-side:

Keith is extremely good at remembering your name, and who you are, and what you do. So people love that of course because he can usually say hi to you when he sees you. He's pretty easy to get along with, so I mean whatever's going he'll usually kind of go along with it. Unless it involves a lot of walking and then he may get a little cranky but other than that. He is very loving. He's you know, you'll see him and he'll say I love you.

In addition to being very loving, Carolyn described Keith's intuitive side and said that he is "*very quick to pick up on things*". He uses his intuition in many cases to keep a group cohesive and dispel any tension.

As Carolyn described:

He's a riot because he can assess any tension that's in the group or anything like that. He's very good at keeping a group cohesive, so if he's part of it he's very sensitive to where everybody's at. He will ensure that everybody's getting along and if people aren't talking or whatever he'll kind of keep that together.

According to Carolyn, Keith will mimic the people or children he is around, "*so if he's with people with behavioural issues and stuff he mimics those, and if he's with normal children he mimics those*". This behaviour has appeared in other environments including at school where Keith:

Wants to do what other people do. When they were in class when he was in elementary school his book had to look like their book so they had to make his book look like even though when you opened it up it wasn't the same. He had to be sitting at the desk, the same desk that they were even though he was doing something completely different. He demanded that, he wouldn't cooperate with them unless they did it. So it was kind of cool, I didn't have to do much to make that happen. He made it happen.

Keith's Passion for Basketball, Rainbow Recreation, and Making a Contribution

Keith is a "*sports fanatic*" who developed an immense passion for basketball. Carolyn spoke of Keith's early basketball experiences around the age of six years when he participated in a community program that took place in the evenings at the local school gym. Carolyn said the experience was great

because it was based on the idea that “*everybody gets involved, everybody plays.*” Carolyn described

Keith’s experiences in this program throughout elementary school:

Keith at that point certainly was not as quick as the other kids but he was, he for some reason he managed to get the skills quite quickly and so even though he wouldn’t move as fast as everybody else he had the basic skills. It was quite an amazing experience for Doug and I, because we had wanted Keith to be integrated, so when he would go on the floor the whole game would slow down and the other team would agree to it, and Keith was able to participate fully. That was a really a really positive experience.

When Keith was in middle school Carolyn attempted to get him involved in the basketball program but found “*no openness to him coming involved so we sort of backed off and let it be.*” Once Keith moved to high school he became re-involved in basketball. Carolyn told the story of how Keith became the manager of the high school boys basketball team “*that’s the longest winning team, that’s won two provincial titles*”:

When we first started high school they wanted Keith as sort of his extracircular was that he was going to work on garbage detail and work at the recycling and stuff. They were doing it for niceness, I mean this is a way of they earned a little money, they could go bowling and stuff. I fought the school on that one. I finally had to go to the vice principal over it, and put my foot down and trust me; they got a few words from me, oh yes. It’s just so sad. That’s normalization too, and that whole deviancy thing. I just said that you just don’t put somebody who already has issues with a deviant position. It was just so, it’s so important and so subtle that you know people don’t get it... It’s a huge status support that he’s the manager of that team, it’s quite amazing. To take him from garbage detail to that was big and so for us that was very critical that what he was doing had dignity.

Carolyn told me about the significance of the relationships and friendships that developed between Keith and the basketball players. She described what an important fixture Keith has been for the team and how “*if Keith misses a time or whatever they’re all beside themselves. They’re like we need Keith.*” Keith maintains his friendships with many of the past players over Facebook, and will reconnect with them when they are in town.

The school basketball team has become the focus of Keith and Carolyn’s lives, and other leisure activities must be fit around that schedule, as Carolyn describes:

I mean I have to say when you’re in basketball you’re not in anything else, and all the rest of the kids are the same, that’s your whole life so. So unfortunately or fortunately for Keith there was just no way to really take on much else. Even Rainbow Recreation becomes difficult because it was like as I say, you can’t miss a practice and you can’t miss a game so it’s like, it takes number one.

Carolyn briefly touched on some other activities Keith tried, though none stuck like basketball. Carolyn commented “*basketball that has just taken over our life*”. Keith tried swimming lessons when he was young, and participated in track and field both through his school and with the Special Olympics program. Keith became involved in track and field at high school because of a teacher in the school resource department. Carolyn commented that he “*loves it*”. Keith participated in the Special Olympics program for one year and enjoyed it but it was “*another big commitment...we just couldn't take on*”.

Keith has also been involved in the Rainbow Recreation program since he was 3 years old. Carolyn described the program as being critical to his recreation, and also that it provided an opportunity for her and Doug to have a break. Carolyn said she had been surprised at Keith's success in the program and attributes the positive experiences to the leaders and the attitude of the program saying,

I think there's a real attitude that you know no we don't jack around here we're here for a reason and we're gettin' on with what we have to do and expectations are fairly high. Somebody got that right early on because I have never seen (otherwise), and as I say, it is segregated.

Rainbow Recreation provided Keith with a chance to be in the water which he loves despite never learning to swim. Recently Keith and Carolyn had difficulty attending the program because of Keith's commitment to basketball:

He was having a hard time getting to all the Rainbow programs and I know how important it is to the students that they show up. So I said 'look I think it's time for Keith to leave the program' and they phoned and said 'NOOOOO! (Laughs) He is the program' and I said 'ok ok! We just have an arrangement now where if Keith can go then I just write ahead and say 'ok we're here this day but we're not here this day'. Anyway, so he has stayed involved a little bit over the last couple of years but not as much as he used to.

Carolyn commented about the value of the Rainbow Recreation program for the leaders, and what Keith has been able to share with them:

The amazing thing about that program is that it exposes young people to this, which is just critical as they move forward in the world... Someone like Keith teaches you tolerance and patience and to see, the positive in the person. I think that just kind of to be open to what might be, and I can pretty much guarantee that I've never had a person who hasn't said that they got a lot more out of Keith than Keith got out of them.

...Every parent that I've ever had anything to do with, thanks me for bringing Keith and for what their child has learned. I don't know whether I've just been lucky I guess. The parents that I've seen would

want their children to be exposed to this, and want their children to bring out that humanistic side of their child. I think that it's amazing really, I didn't expect that.

Carolyn also described that Keith was also valued for his contributions on the basketball team. Here she described the humanity that he brings to their interactions:

On the basketball team I kind of thought, because it's highly competitive that these kids who get university scholarships I mean they're not jacking around, it's work you know. I was worried that Keith might take away from that, but what Keith actually brought to the team, I mean I get cards from the parents every year just thanking me for having Keith involved and for what he's given to their child. Again Keith brings the human side, there is attention to basketball and they do have to work very, very, hard and there is a lot of underground stuff that I probably don't know about or understand. But Keith releases the tension, he keeps them together as a team like they're his boys and you, if there's any tension in the team it ends. I mean he creates an atmosphere that they've never seen before and they just love it. It's been amazing. He's valued for what he does. So I haven't had, well I mean there probably have been I just haven't heard of, but I've never heard anybody not think that Keith was an asset to be there.

The Challenges of Unstructured Leisure

By this point in the interview, Carolyn had told me about Keith's recreation activities but I realized that they all sounded highly organized and structured. Carolyn commented that non-organized recreation is "more of a challenge":

The non (recreation), like you know if there's a dance in town or you know if there's a bowling thing, I find that much more challenging to figure out how to participate in. He will bring home things from the programs that there's something going on and he'll want to do it and it's just not (happening).

Carolyn went on to comment that the lack of participation can be attributed to "parents being pooped" and because of her lack of comfort in sending Keith to an activity if she doesn't know the people. "Keith is still I would say fairly vulnerable and so how's he going to handle that situation, and I don't really know and so it would mean a lot of work on my part to sort of figure it all out."

Summertime and Summer Camps: Providing an Extra Counselor

Carolyn told me about Keith's activities in the summer months including his experiences at the local summer day camp. Keith attended the camp for many years and was able to "participate in everything" but ultimately outgrew the camp. Carolyn provided an aide for Keith herself, a student who acted more like "an extra counsellor" for rather than "hovering over" Keith. Carolyn said the role of the aide for Keith was to

engage and support all of the other kids but to also deal with any toileting accident that Keith had. The only challenge facing the camp was that Keith did not like to walk far, and *“so that was always the biggest issue at day camp, was they'd have to start out 15 minutes ahead of time from everybody else.”*

Keith the Intuitive Actor: The Rough Middle School Years

During the *“rough middle school year, from grades 7 to 9”* when Keith did not participate in basketball he became involved in the school band and in drama. Keith was *“a full member of the band and he did percussion. He has incredible rhythm and so he was able to fully participate in the percussion part.”* In middle school Keith was also involved with drama. Keith knew many of the other youth from their church, and Carolyn commented that they were *“very good”* with him and *“if Keith was going in the wrong direction they'd just kind of grab him by his hand and off they'd go.”* Carolyn also spoke of how Keith had to dance with a girl as part of a play, and *“this girl, she is very special there's no question about it she just took Keith under her wing. Again you know they weren't perfect in their dancing but didn't bother her; she was all about Keith.”*

More recently Keith became involved with a community production where he began to develop some *“separation”* from Carolyn. Initially Carolyn said she was resistant to Keith's participation because of the level of professionalism associated with it:

I mean it does involve children so of course it's a bit not perfect but still they've got pretty high standards. I was a little concerned about whether he would be able to meet those standards I just kept saying to them 'you know even just for him to be involved at the rehearsals is fine, if he doesn't do the plays like that's ok'. I didn't want them to feel like (obligated), 'cause I didn't want him to bring down the production which didn't end up happening he ended up being the star of the show.

Keith considers himself an actor, and identifies with other actors because *“he's so intuitive was that the play actually becomes quite real...so he really acts appropriately.”* Though Keith does not memorize the words, his participation in the chorus has benefited him. Carolyn commented:

What's neat about it is its very repetitive because you're repeating the same thing over and over and over again. For Keith it was great for speech because it was repeating things over and over and over again so he would get to learn the basics of the song and get to know the choruses and that kind of stuff.

What Keith brought to the production was enthusiasm and cohesion. Carolyn told me that Keith was able to help the group remain intact and eliminate any of the melodrama usually found with this group:

Everybody said it was the best play as far as the atmosphere went. When he came into the situation, I mean he wouldn't tolerate it, just wouldn't, and it was amazing. I think they did it for him, so it was kind of cool that he contributed to this overall atmosphere.

Acceptance and Challenge from Supportive People in Keith's Life

The leaders in Keith's recreation experiences stand out as playing a critical role in his story. On several occasions Carolyn noted the impact of leaders who were not supportive or engaging of Keith, and told me about the impact that these experiences had.

Carolyn described the lack of leadership when Keith moved to middle school and she pursued basketball for him. She commented that there was “*no openness*” to his participation. After having a successful experience with the middle school band, there was no leader in high school music who “*took him under their wing*”. Through the summer months Carolyn and Doug had tried hiring students to be with Keith but were unsatisfied with treatment he received. Carolyn said:

For us Keith is expected to do what everybody else is expected to do we don't tolerate any kind of you know 'because you're handicapped you can't do it'. We would find students would want to get into babying him and you know doing it for him and that kind of stuff, and not giving him the shove in the rear end that he needs. We would be challenged by that sometimes.

The leaders who did have had a positive impact on Keith's recreation include: his basketball coaches and teammates, his speech therapist, as well as his parents Carolyn in particular. Leaders have been very important in Keith's recreation experiences. Carolyn commented that “*we hit people that were the right people. I mean I think we've just lucked, you know I think that I think they were people that were clued in anyway.*”

Keith has encountered two very positive leaders in his basketball experience. Carolyn said that Keith gained a solid foundation of basketball from the coach who expected the same from Keith as all the other participants. “*She wouldn't let him away with anything he had to do what everybody else did and he had to do it the way everybody else did.*” Carolyn commented that she felt incredible support from this coach.

Keith has been the Manager of the high school basketball team for four years and travels with the team on all the trips. The coach, Marc, is described by Carolyn as being “*very clued into the world of disability*”. Similarly to Keith’s first coach, Marc:

Expected out of Keith what he expected out of the players...He said 'Keith has to be at every practice and he has to fully participate or otherwise no he can't be part of it'. We agreed to that, and said yes we had the same feeling that either he did or he didn't do it.

Carolyn credits the coach for developing an atmosphere of value and appreciation for what Keith contributes to the team. If Keith misses a practice Carolyn told me that the boys are “*beside themselves. They're like we need Keith!*” Being with the basketball team has also developed some separation between Keith and Carolyn. Despite being present at the games, Carolyn said:

It's really cool because they all go in the locker room and nobody is allowed to know what goes on in the locker room. I have no idea what happens in the locker room and I'll never know. It's like this whole world and I think it's so cool that Keith has a world that I know nothing about and I love it. I think it's so cool.

The team helped create a social network for Keith with current and former teammates. Carolyn said that former teammates still communicate with Keith over Facebook and “*when they come back to town they want to see Keith*”. Carolyn continued:

It brings tears to my eyes sometimes they're just so phenomenal with him and have become very close friends. Of course Facebook helps, so they're all on together. It's been a great because the social side is really tough in high school for kids with special needs it's really hard to figure that out, and so having this basketball is a huge, huge help.

Carolyn discussed how Keith’s social experiences changed since becoming a part of the basketball team. She commented that with school activities including the athletic banquet she felt comfortable sending Keith with the boys, but she wished that social activities would continue beyond the boundaries of the school and basketball team. Carolyn then told me about a new group of teammates who have begun including Keith in their activities:

There's a new group of basketball crew last year and when we used to go on the basketball trips, we would kind of go to our room and the boys would be doing stuff. Keith knew they were doing stuff but I didn't feel comfortable to say, "take him" sort of, so I would just leave it. Last year every time we went away this new little group, and they would invite him. They'd say we're going swimming do you want to come? And he'd go off, or they're going for supper and he'd, so he'd go with them for supper instead of me. Which was kind of cool, that was sort of neat. And so I expect that to continue this

year because they are still involved. That was the first time I started to see a little bit of social stuff, but sometimes you wish that they would phone up and say you know we're going to the movies can Keith come, but how do you impose that?

The first teacher who engaged Keith in drama was described by Carolyn as “*not being intimidated by his needs at all*”. Carolyn commented that she “*took Keith under her wing*” and was the reason his experience was successful. More recently it was his speech therapist who got Keith involved in the community production. Carolyn went on to tell me about how Keith became involved in the production for which his speech therapist was the choreographer:

Here's this really complicated dance number, she was determined he was going to be in it. And I said, "he can't do it", and she said, "yes he can". I think it was like 2 days before the dress rehearsal and it was just a disaster and I said, "he can't do it and you're going to have to, you know, and that's fine he doesn't need to be part of this". She just said, "Carolyn, he's going to be able to do it," and so I just backed away you know and let it be. And sure enough at the dress rehearsal (laughing) he was perfect. OK (laughing)! He was the star of the show, he stole the show. (Laughing.) You know and she was right, she knew that situation better than I did. And so I thought that's pretty cool because she knew how important it was to him and obviously she had the commitment to make that successful.

Role of Parents: Setting Up and Monitoring the Recreation

From Keith's story it was apparent his parents played a critical role in his recreation exposure and experiences. Carolyn commented that she and Doug typically initiated most of Keith's recreation activities. Carolyn told me about how she and Doug try to set up activities so that the experience would be successful:

All along Doug and I have been very firm with leaders that you are to expect of Keith what you expect of the other children, and Keith is not special he's you know just like any of the other kids. I think with those expectations Keith responds better, and when he's let away with stuff he can get into some not good behaviour. For me as a parent it isn't about control.

Carolyn and Doug spent a great deal of time reminding people about the need to treat Keith as they would any other child. As Carolyn described, their purpose is to set up and monitor the situation:

I saw my job as the parent to set up the situation. With Keith what I tend to do is monitor and set up the situation. I know who's going to be there. I know what that person can do with Keith. I know what support they need, I know what the physical set up is. I know what he knows. For me it's more of, so once I have that set up then I'm usually quite free to go. I would say that's only been in the last 2 years where I feel like he has the ability to advocate for himself. That's a big thing too, and he isn't there yet. You send him out into the big bad world and if he's not able to advocate for himself then he's pretty vulnerable.

Aside from the strong leaders Keith has encountered, he has always had one of his parents with him.

Carolyn described that as a parent she felt pressure to be really involved, or with Keith, at all times.

Even though people kind of say no you don't have to be, well you do have to be and during the elementary years Keith was still having accidents. There would have been issues that yes on a good day wouldn't have been a problem, but on a bad day, I wouldn't want to have anybody to have to deal with that. So we couldn't really leave. There wasn't a lot of support for us as parents around involving him, if you involved him in something that's integrated then you're pretty much with him.

Carolyn spoke about Keith's experiences in school where he has always been "integrated." She told me how from the beginning in Kindergarten (or Primary) she advocated for Keith's right to be in the class with his peers, and reminded his teachers that he was just another student.

Within the school system, I mean, he was always integrated in the classroom but when he got a little older they had a resource class and that kind of stuff. What they liked to do is the group activity where one teacher takes out three people and off they go, and we just said from the very beginning, "no." He's not allowed to do that, that he has a fulltime aide and there's absolutely no need to do that. I understand that you'd like to use his aid for other people but for us it is very important that he's going out with his friend. And they bought it. They never (laughing) argued with us. There's been the odd instance where we've bent a little bit but mostly they have been very respectful of that.

Carolyn told me about the changes she has noticed in the school system through Keith's years. I

asked her to tell me more about these changes:

I don't find there's the fear. When I first went to the primary school and we, you know, we had Keith there because I wanted him completely fully integrated and I wouldn't listen to anything else. The teachers kept saying but we don't know what to do with somebody with special needs, and I'm like, "he's a kid just treat him like a kid. If you're a teacher, if you can teach you can teach anybody. So don't give me that bullshit just be confident in your teaching ability." Well I mean at the end of every year I'd have the teacher come to me and say "Oh well, you know, it wasn't that big a deal and it wasn't that hard to integrate Keith, you know it was a little bit of creativity he was a part of the class." It was like, yah it's not that difficult, you know, so I think that's the same everywhere.

Keith's Experience of Community in a Small Town

On several instances Carolyn referred to the importance of community for Keith. Carolyn referred to the importance of community and consequent relationships in helping Keith get through the middle years.

Carolyn highlighted the importance of community for social reasons:

I was out with him yesterday, and it was like every second person he knows who they are and says hello to them. They sincerely want to see him, and they always have a few minutes to talk to him and it's really kind of cool. If we had kept him in a situation where he had a limited number of people who were around him he wouldn't have the richness in his life that he has today.

Within the town, community has been important in Keith and Carolyn's lives because it provides a secure and safe environment where Keith can exert some independence. Carolyn described community as an opportunity or means by which to integrate Keith and keep him integrated. Carolyn commented that although she and Doug do not attend as many events and festivals as they did with their older daughters, they do attend them with Keith:

I think it's important for Keith to be involved in the community... I think Keith knows everybody and so usually at those things he can be quite independent because as long as we kind of know generally where he is, he can wander off and do his thing. That's the joy of being part of small town isn't it? I mean it's a real big advantage, having been in big cities it's just a different situation. I mean here, honestly I would never worry about Keith. He would be known by somebody and they would get him back to where he belonged. It's a very secure town and it's great for the community stuff, so it helps.

The Future: Life Outside of the Family?

Carolyn told me about a work place program that Keith is involved in where “*the goal is that that he'll have something after school ends, which will be the end of next year.*” When I asked Carolyn about Keith's future she said:

I think that for Doug and I there's a reality check that's going to come (laughing). It is coming in the next few years. He's not going to be able to live independently, he is going to have to live with other people with special needs so we're aware of that. He will in his older years become integrated (in disability groups) but hopefully with the community we have created for him because of the younger years he'll have (those relationships).

I asked Carolyn to tell me about her thoughts on terms such as integration, segregation and inclusion, comparing her feelings now to when she would have been in her twenties:

I would have been extremely judgemental and I would have said it all had to be integrated and I didn't believe in segregation at all, period. I have certainly come around to, thinking that for some people maybe segregation works. But I think in my heart I don't believe it does. You know I really don't believe in segregation. Partly because, I just think of the relationships that Keith has with people and the lives that he has touched in his life is phenomenal. So we're robbing society of that too and this isn't just about Keith it's about society. Rainbow Recreation to me is sort of the epitome of that. I mean you know from your experience, the relationships are incredible, and I have no doubt that those students that work with our kids are changed people when they leave. I have no question about it.

Carolyn commented that recreation programs should be open to including people with disabilities, and that if they considered involving one person and asking “*what could their contribution be?*” then “*it wouldn't feel so overwhelming.*” She further commented that:

I think the same things with other things that people could realize that. And again, I'm not saying it's for everybody, I'm not that naive. I would say for many, many people with special needs, you know, there is a place for them in recreational programs. I think if parents knew there was an openness because that's the thing is for parents, is that it's frightening to approach these people because you feel like you're asking them to take on this burden. Yet it's so critical, and what I think is so important is that Keith has a little bit of a life outside of the family. I mean, you know, you look at yourself and you imagine if you, if you had no life outside of your family I mean it would just be terrible. All the learning that you did in those social settings, I mean they're critical to your learning, and kids with special needs don't get to benefit from that you know.

Carolyn also noted that recreation will play an important part in Keith's life, particularly for the physical and social health benefits. As she notes in the following quote, both continue to be a struggle for Keith:

(What does recreation mean for Keith's life?) Certainly for his health, I mean he needs to be active so that's going to be important for him because he's fairly sedentary otherwise so he, when he's out with other people and there's activity going on he's quite happy to be moving. Certainly the social side is critical for him and that's like I've said, I've never really been able to develop into the point where his friend would phone and they would go out and do something. I've not been able to get it to that stage, so it becomes more critical for him because those are his social outlets that get him away from us, and having that is very important.

In addition, the future, and Keith's movement toward more independence will require, as Carolyn describes, more trust:

I think for me, you know it's trusting him. I mean even today when he came to work with me and he wants to do something. (So I said) ok, well why don't you put these in the boxes, well I wasn't sure he could do it but I just thought well I'll see if he can do it. No problem, so we worked all morning. He put them in the boxes and I sorted them and it was great. He said 'good mom? Are you proud of me mom'? And yah, it was really cool. The other day we were in here and we were cleaning up and he wanted to clean and he did. He cleaned the whole counter. So it's kind of cool.

Johanna's Narrative About Brandon

After Brandon went to bed and before she went to work for the night shift, Johanna told me about Brandon, his passion for sports and other recreation experiences. This was the only time in the day Johanna could spare to share her son with me. Johanna, her husband and Brandon live outside of the small community where Brandon has plenty of room to play and explore. Johanna told me about the importance of sports for Brandon, and the other recreation programs and activities including: Rainbow Recreation, sledge hockey, and the local Beavers program. Brandon has struggled with many of the activities he wants to participate in and Johanna has struggled equally to find replacement activities that he will enjoy and

succeed in. Brandon is very social and enjoys attention which seemed to perplex his mother as neither she nor her husband share that characteristic with their son. Through the stories, Johanna highlighted the importance of strong and thoughtful leadership, and described several leaders who have made an impact in their lives. The story of Johanna and Brandon is set in the community surrounding a small town in Nova Scotia. Johanna has worked tirelessly to provide recreation opportunities for Brandon where he can be successful. Their story exemplifies the range in recreational experiences and the challenges faced at school, in the community and at home. The following is my reflection after speaking with Johanna:

Johanna was undoubtedly my most emotional interview. It was moments after meeting her, a sweet and very welcoming woman that I learned of her struggle to have Brandon included on his school trip later that week. Needless to say by the end of the evening I was ready to knock some people around for her and at the same time in total awe of how well she handled the situation. She was determined, unrelenting, eloquent, persistent, courteous and respectful through the entire situation in spite of the treatment she and her son were receiving. When I left her house I could not decide whether to break down and cry or beat someone up. What struck me at the end was how well Johanna understood what it was like to live in a world with the words of integration, segregation and inclusion. She had to watch her son live in a world that used these words and twisted their meaning to set up barricades preventing Brandon from fully participating in anything. Despite all of these challenges Johanna still found and raved about programs and activities that did work for her son. Parents know what works for their children, and similar to the other moms Johanna was more than willing to bend over backwards to make participation happen for Brandon. From all this I really began to think deeply about inclusion, and I realized that I do not relate to inclusion because I do not know what it is. I cannot say that I have ever experienced inclusion in the ways that it is traditionally defined. I think many people make great efforts to be inclusive in a way that works for their program.

Brandon: A Fearless and Social Boy

Johanna described Brandon as being “*totally social, outgoing, and funny.*” She spoke at length about Brandon being a “social ham” and jokingly questioned how he could be related to her or her husband. “*He is incredibly social and he will talk your ear off and he will be right in the center of things, he’s not shy. He has no problem being right in the center of things.*”

Johanna told me about Brandon’s success in school and his skill with reading and math. She went on to say while laughing “*he’s not shy to do anything, he’ll just go barge ahead. Actually he was in grade one we got a note because he was trying to answers the questions too much. He never holds back.*”

Brandon recently requested to give a presentation at a school assembly about karate, and is described as being fearless in social situations.

Brandon's Love of Sports: Swimming, Skating, Bowling and Sledge Hockey

Most of Brandon's recreation activities seemed to focus on sports and being with other people. These activities happened in many different places including his school and community sports centre. Johanna told me about his involvement in swimming, skating with his school, bowling and sledge hockey through the Rainbow Recreation program. Johanna also told me about Brandon's immense love for sports which has been at times a point of frustration for both of them:

Loves sports. Every sport you can image, basketball he will play for hours in the driveway, and he'll watch any sporting event on TV, any sporting event. His father golfs so he wants to go golfing, he hasn't got there yet. Any sport (laughs) any sport, to watch or to play. Having said that he can't, so that's frustrating, 'cause he has the desire. He wants to play baseball, he wants to play soccer, he wants to play basketball, but it's just not happening. He has more desire there than most little boys do. He just wants to play everything.

Johanna told me about the range of new sports and recreation activities Brandon tried recently, some of which have not been successful. Brandon tried karate but he was unable to block balls as part of an activity, and so they "lost that after one night". Johanna told me about when Brandon tried soccer but because of the size of the field she felt that he was being "set up for failure." Brandon has talked about trying baseball but Johanna told me about her concerns with it because "he's not liking things thrown, but he wouldn't be able to get on base" which again would be setting him up for failure.

Swimming is one activity Johanna and her husband hope will work out for Brandon. Johanna described the issue with swimming as a combination of fear and that they had not found a flotation device which would support Brandon in the water. Brandon does swim with the Rainbow Recreation program, and Johanna has been taking him swimming herself:

(Rainbow Recreation) is the only time he will swim but he won't let go of them, so I can't put him in swimming lessons. My ultimate goal for this summer is to get him swimming. I actually took him out to a pool a month and a half, two months ago, thinking if I did it every week by the time summer came and summer birthday parties he might go in (pauses), maybe not independently but at least not be petrified. He screamed for an hour and latched on to me so bad he kept pulling my bathing suit down. Now his father can swim really, really, good and it was one of the things we thought would be a good activity as an individual.

Johanna hopes Brandon will be a swimmer like his father. They tried swimming lessons but Brandon would hang on to the leader instead of trying the skills on his own.

Brandon has also learned how to skate. Johanna told me that this past year was the first time that Brandon had been able to skate independently. She said *“it was a tough three years to get to that point, and the smiles from him once he was able to do it.”* Johanna went on to say that they would probably continue skating for the enjoyment and social aspect, but not for the sport.

Johanna also told me that Brandon recently learned to bowl and that *“he loves it”*. She told me that she hopes it could be an activity he continues when he gets older because:

that's something that can be kind of individual but yet kind of a team, and it's numbers, so it's automatically, he gets the pins and marks the numbers and will tally it up. That's another thing we'd love to look into but (pause) he is at a disadvantage even with that.

Johanna hinted at the challenges Brandon faced because of his disability. As he was physically unable to perform or participate in an activity in the way an able bodied child would, he was at a disadvantage and could not participate fully. There were always adaptations to be made for him, and that was the challenge.

A new activity, sledge hockey, had become a part of Brandon's recreation activities. Sledge Hockey was run in a nearby town, and Johanna told me she found out about it through another parent:

they mentioned that their daughters were playing. I was like, “whoa, whoa, whoa, like what did you say your daughters were playing?” They're like, “They are playing hockey.” I was like, “What?” One of their girls is in a wheelchair, so I was, “ok you have to tell me what is it.” And we went the very next Sunday and he's played ever since, (pause) but I didn't know anything about it. If I had of known ahead of time he probably would have played for the whole season.

Johanna commented that sledge hockey has had its *“up and downs”* but that *“overall the experience has been good.”* She told me about how she tried to sit in Brandon's sled, because she wanted to *“experience it”* and ended up stuck. Johanna told me that Brandon had struggled with the sport because *“he doesn't have the upper body strength. So he couldn't get going”*. She told me that they hope with another year of growing he will be strong enough to move more easily. Johanna commented that the sledge hockey was Brandon's first team experience and that *“he was on it with other people who understood that he couldn't get going.”*

Johanna told me about Brandon's experiences with this sport, and her own experience watching from the side:

He did like sledge hockey but he got frustrated. Oh he could throw a temper out there. But they were good I had to leave the arena a couple times, because I would look and he'd get really mad. He would tip over and can't get back over. I don't think I could get back over. He'd snap while the others kept going but we did try different sticks with him, I would like to know when we do it with him again if there is any way to modify the equipment just a little bit to make it, to give him a little bit of an advantage. We really want to keep him in that if we can, 'cause that seems positive.

Johanna went on to tell me about the challenge of being on the sidelines, how it has provided both her and Brandon with some space. With his mom on the sideline, Brandon has had to learn to deal with his own frustrations and Johanna has been able to meet and network with other families.

A big component from a parent's perspective because all of the kids in that activity have challenges is that the parents aren't on the ice. It's one of the activities where the parents aren't involved. They are observers, except for the getting in and out of the sled. It gave us the opportunity to get closer to another family. We were able to talk about similar experiences and specialists, and that was kind of neat so now we have that resource that we can pull on. That was good, that was super positive. That will probably indirectly involve Brandon. I think a lot of it is just picking and choosing what fits your family the best. Then you don't get in to many frustrating situations. I do think parents can help other parents.

Introducing New Activities after Success in Others: Sledding and Geo-caching

Brandon's participation in Beavers has been successful. Johanna raved about the program and leaders throughout the interview. Johanna told me she and her husband had planned to enrol Brandon in Beavers, and then "one of his close friends was in it so we thought it would be a good way to transition him into it, put him in it because there was someone else there." Johanna described being shocked by the number of new activities that Brandon has tried through Beavers:

We went sledding, never thought he'd go sledding, never in my wildest dreams. He didn't like the motions. Justin basically had him going up and down that hill and he was like a little bullet going down the hill. I was amazed so if he only got one thing out of Beavers this year the fact that he went sledding was well worth the whole experience. I never ever would have dreamt that but the sledding, wow. The little red torpedo, just wow.

Since the success of sledding with Beavers, Johanna commented that it has "opened up other opportunities" and said that he wanted to go sledding "all the time after that." Johanna and her husband took Brandon sledding on a hill near their house but he got stuck going down because of the snow conditions.

Brandon enjoyed sledding so much he even tried on the snow drifts outside their house “*but just couldn't get the speed up that he wanted for all the work it takes to climb up there.*”

Another activity that developed from Beavers was geo-caching which Johanna said they planned to get him involved in but were concerned about the amount of hiking involved. She described Brandon as “*our little GPS system. When we are in the car he tells me where I'm going and if I'm taking the wrong exit or wherever. We thought geo-caching would be an obvious hit.*”

According to Johanna, Brandon has been involved in the Rainbow Recreation program for four years:

We were going to put him in it the first year but we couldn't because he was still on oxygen, so once we got him off the oxygen so he was probably four so it's probably been four years. He loves it! When each session ends, like the session, he's mad. He wants to go, he'd go all summer. He goes through school during the week and that's all he talks about, he gets to go swimming. He goes on the weekend too and loves it. There's nothing about it he doesn't like.

Johanna described her joy with the program because she and her family are able to watch Brandon participate in the activities since there are not many other activities where they can watch him.

Importance of Supports from Peers and People Who Go Above and Beyond

Many characters stand out in Johanna and Brandon's story, and have made significant contributions to Brandon's recreation experiences. These characters include: other children in the activities, Deb the Beavers leader, his Rainbow Recreation leaders, and Johanna.

On several occasions Johanna commented that other children and Brandon's friends had provided great support for him in an activity. She described that some of the other sledge hockey participants as “*really good*”. She commented that other players and their siblings “*were very positive and very encouraging to the kids that helped made a big difference. The older kids were able to just offer that encouragement that another child is more able to do.*” Similarly when Brandon was learning to skate, Johanna said that his friends were “*incredibly encouraging*”. In addition to his friends, Brandon also received support in learning to skate from a former principal who volunteered his time to teach Brandon. Johanna described him being “*invaluable.*”

Johanna raved about Deb, the Beavers leader on several occasions. She said that Deb is what makes the experience so great for Brandon because she is able “*to modify things without making it obvious*”. Deb “*includes*” Brandon in everything because she plans the activities so he can fully participate. Johanna described how Deb would bring her son Justin to the activities including geo-caching and sledding so that he would be a buddy and support Brandon without making it “*obvious because it's just another kid*”. Johanna also told me about a recent bike rodeo where Deb went “*above and beyond*”:

Well for instance the week before the bike rodeo she brought her kids here to encourage him to go on the bike so that when it came time to for the bike rodeo with the police officers he would do it. That's where she went above and beyond, that definitely helped. In planning the geo-caching, I know she could have probably planned a much longer more intensive hunt but she kept it very simple as far as walking. Same as going on a hike, she's very accommodating with all the kids. I didn't [go] on the scavenger hunt with them but I had the sense that it was the same idea. For those excursions in particular she'd bring an older student to be a shadow. It made a big difference. The older student being able to help but blending in so well that you didn't realize there was an older student there.

Johanna told me that she was also “*always impressed*” with Brandon’s Rainbow Recreation leaders. She commented that there were always a lot of leaders around and that they made the experience a lot of fun for Brandon. She told me about a specific leader who became his soccer coach outside of the program:

she had him for two years, his first two years, and for three summers she took him, she'd take him for a day here, a day there, evening here, and even coached a soccer team the year that he played soccer. We were scrambling because we didn't have a coach and they stepped in they were like, “yah, we'll do it.” It was nice because he was able to see her outside of the program environment, and she is what made soccer successful for him that year because she had already worked with him. She was able to just fall right into that role and there was two of them so she would always be the one running with him at the back of the field or she would be encouraging another child to come. She was able to have the inclusion in that team where, not only Brandon but other kids were able to get the most out of that season. She's wonderful it must be the training, must be.

Social Brandon’s Summers and Sleepovers

Johanna told me that Brandon spends time with a close group of friends outside of school. Brandon has friends over regularly and they “*went to the park and they played, just threw the basketball around, played on the play ground just kind of walked around and explored.*” Johanna told me about a sleepover Brandon had been to:

when he went to bed she [the child's mother] said, “Do you want me to tuck you in?” and “Do you want?” and he said, “No, but you can sit in the chair across the room ‘til I fall asleep.” She said, “Well no, I can lay down with you?” and he said, “No please don't” Because he's very independent. She

said, "Are you alright?" and he's goes, "Well I do miss my mom, but I'm going to go to sleep now. Good night." (Laughs)

Johanna commented that she had been waiting for a call to come and pick her son up but the night went well. She also told me about a family outing recently where Brandon had wanted to sleepover with a friend:

we were out at a bonfire and they all brought their campers, and his best friend, who's a girl, was going to bed. He was adamant that he was going to bed too. So he went to the mother and asked, "Can I stay for a sleep over?" And she said, "Oh, we have a busy day tomorrow." I said, "You know what, Brandon we're not going to." "But I really, really want to," and she said, "Alright." I said, "you can go to sleep in there and I'll wake you up and take you home." The only way either of them would do it was if they could sleep in the same bed, under the blankets and those two giggled and giggled, and the mother was willing to let him stay until I told her how loudly he snores. She said, "yah know, you can make sure he's out there by 11:30." At the end of the evening she said, "he can come for a sleepover at our place anytime he wants, we'll wear ear plugs that night." But she said she's never seen a kid who, when you say it's bed time just goes. He just goes, and that's it. So hopefully that'll help him out for sleep over, as long as I send ear plugs because it is very loud. They could hear him three sites over. When he gets out of the tent in the morning they're expecting like a big man and when he walks out, and we've had other campers who go "no" and they're like, "but we're three sites over. How can that be?"

Johanna described the summer months as "downtime" for Brandon when he will typically participate in a summer camp because of his parents' work schedules. During the summer, Brandon also keeps in touch with his friends from school "he made a list of friends he will be able to exchange phone numbers with. I like in the summer for him to keep in touch with kids."

She described the summer as being the "only time he's not in anything because I don't know what I could put him in." I asked Johanna about Brandon's summer camp experiences, she said:

He goes to the day camp in the summer and he loves that. I don't really know what they do, what I normally do when I go to pick him up I'll sneak in to observe but when I get there it's the end of the day and they are all kind of tired and it's a free for all on the play ground. They went on trips for that they went to the beaches and the one beach, that was a challenge for him. All the stairs. I've take him there a couple times in summer, the stairs are a lot, a lot of stairs and (pause) the day camp instructors are good. They don't always look ahead and plan so what they found out is it took long time to get down and long time to get up and they didn't count for that time. (Pause) Now that's one area where Deb (Beaver leader) always kind of looks ahead and she can (plan and adapt) in spite of those things and that's helpful. Any of the organizations where they don't have the foresight to look ahead, oh walking, yup that's going to be too much.

I asked if Brandon has ever attended a sleep-away camp, Johanna said no but that he “*would love a sleep over camp*”. She then told me about a summer sleep-away camp she had heard about but said she was confused by conflicting information about whether Brandon would be eligible to participate or not.

Brandon’s Experiences of Challenging Supports and Exclusion

Although there are many great people who support Brandon’s recreation, summer camp leaders and his occupational therapist have not been particularly supportive. Johanna commented that summer camp leaders “*don’t understand*” Brandon and they do not think the activities through. Johanna told me about her frustration with the enrolment forms because “*they are generic and they don’t portray the whole child*”. She told me she usually calls the camp or program leader ahead of time to chat and help them understand Brandon and how to involve him successfully.

Johanna also told me that their occupational therapist has not provided the support she was looking for. She spoke about her frustration while searching for a swim device to keep Brandon floating while not standing out. The OT recommended a regular swimming vest but Johanna said “*that doesn’t really help me out, because I mean any parent can do that. That’s not really what I needed.*”

Johanna described another frustrating situation to me and the challenge she was facing with Brandon’s school. In this situation he was not being “*included*” in the transportation to and from a school field trip:

most time because of where they are going, the class trip for them is the bus ride. That’s what the kids are looking forward to. They’re not looking forward to going through a museum and looking at pictures and that’s not what they are looking for they are looking forward to the time on the bus. Brandon doesn’t get that.

Johanna told me there had been a sudden change in the school’s decision to take Brandon on a bus. Whereas on previous trips he had been allowed, on this trip, he was not.

I was so mad and that’s what I [was] speaking with the teacher about, “You cannot tell me that in grade 1 that he’s allowed to go on the bus for a class trip and then in grade 2 he’s not allowed.” When I questioned about them about skating, they said, “someone obviously made a mistake.” I said, “yah you forgot to get my consent to take him on that bus, you’re the one that tells me he’s not allowed on the bus you took him on the bus 6 times this year without my consent and now you’re saying it’s a mistake. No.” Anyways as far as their attempt at the inclusion they said they will allow him on the bus in a four point harness system (pause). It’s designed for kids with a different disability.

Safety regulations! They didn't change from last year to this year. I said to them, "I take vacation days for his class trip, so that I can be involved and I will accept the liability. I will take him, I will go on the bus, he will be allowed to go on the bus, I will be there."

Johanna was controlled in her description but obviously upset with the situation and the impact it would have on Brandon:

This is what I've been dealing with. Last Fall I had many phone calls in with the school board transportation. I discussed it with the school board, "we are not putting him in a harness, it's a race car harness. He is at a higher risk of being bullied than most, and you are telling me you are going to strap him into a bus. None of the other kids are strapped in, and you're going to strap him in and he's defenceless." Not only that, this is the kicker, you'll love this part, his fine motor skills are delayed, he can't buckle the thing. That's ok, they are going to get whoever sits with him to be responsible to buckle him in and ensuring he is safe. I said, "would you like to tell me what set of parents are going to agree to let their 7 year old to be responsible for my 8 year olds' safety on the bus, on the bus every day, twice."

Future activities: The Pursuit of New Activities and Teams

I remembered that Johanna had mentioned she found out about Sledge Hockey from another parent, and I asked her where she found out about programs and activities for Brandon.

School and just other parents really (pause). I don't know it just seems like if there are more opportunities out there how do you find out about them. and she gives like little reports when OT sends me an email I think it's every week now from York, I don't know, I do know I get those emails and I just have seen a few things on there that seemed interesting but again everything for that is in York but not here.

Johanna told me about other activities she and her husband hope will be a part of Brandon's future recreation and the challenges they will face:

We want to eventually get him in 4H but again I don't know what obstacles will be there. Depending on what area you go into you might grow a garden and report on that or you might raise bunnies and report on how you've raised, or grow a big pumpkin or something. I've never been involved. My husband hasn't either but he, you know, he knows what it is. I think with that he can kind of pick and choose. So, we can kind of steer him in a direction that might not be as challenging but then if there is an area that he really wants to do, that's kind of sad too, you know, if we don't think he can do it.

Johanna told me that although any future recreation activity may "present challenges" Brandon will have the experience and support needed to adapt and change. She commented that she would love Brandon to have more sports but shared her concerns about treatment from other children:

His all time favourite thing is basketball, and I just don't see that as being an option. As kids get older, they also form very strong opinions. So we have the net here, and it works. I'm already finding they're not as accepting that it's down low. They want it up high, and that's all there is to it. They're

not mature yet but they know that if they have the net down lower they can include him but it's the single-mindedness. They know that they can do it high, so they want to do it high.

Johanna told me she hopes for individual activities to build his confidence and group activities for the team. Johanna went on to tell me about her desire for Brandon to have a team:

I would love him to have a team, to be part of a team, which sledge hockey provides, but at this point all of the kids are still learning so much that there is a lot of one on one. As far as having it feel like a team, they're all there but they just get on the ice and the practice and the drills and then play. The way it's run the kids kind of have to have more one on one, you don't get that bond, the team bond. I think it would be wonderful. Anyone who's played sports knows there's such a bond on your team and with your team, and that bond carries you through to other avenues in life.

Johanna's Support: Separation and Stepping In

Throughout the story of Brandon's recreation, Johanna stood out as a source of tremendous support for her son's experiences. Johanna attended birthday parties with Brandon, although she made an important distinction that she removes herself as the parent, and reminds him he is on someone else's turf:

I go as the parent's friend, and she knows that she has full control like if I wasn't there. I just think, well I can step in if he's being really, really, bad but I'm not going there to be a mother I'm going to visit my friend, and that's how I separate it. It has worked well because then he knows he has to listen to other authority figures, and he knows that I have friends. I'll say, 'cause a few times he'll say, "you need to go now, it's time for you to go home." I say, "no no, I'm going to visit too. Well no but this is my visit, no this is my visit too."

I asked Johanna to tell me more about staying at events and supporting Brandon:

If it's a parent or a family we don't know it's not knowing how acceptance or tolerance will be. That's getting better, the core group of friends is getting stronger. But if it's outside of that core group then it becomes more of a challenge. As far as recreation, right now we're not leaving anything. Beavers he goes, he stays, because Deb's able to do that, but I go to a lot of the events. Rainbow Recreation he goes and stays but then we watch the swimming, and sledge hockey. We go because we have to, we have to be the voice of reason that yes he does have to stay on the ice.

Johanna also told me about an organization that provided support for Brandon and the family. As she described, they "modify and adapt everything for people with disabilities." She told me that they have done four projects for Brandon:

It's all volunteers. It's no cost to the person. When Brandon was a baby they did a crib so the sides came down for my husband, a stroller so my husband could push it so it wasn't up so high, a tricycle for Brandon, and a bathroom stool for him they are invaluable.

Johanna and her family have found resources in the form of people, programs and organizations that enabled Brandon to have so many recreation experiences. The experiences Johanna has had serve as a learning opportunity for others.

Leslie's Narrative About Steven

Leslie was an active and engaged parent who sought and created recreation opportunities for Steven and his family. Steven was the oldest boy in his family with two younger brothers and an older sister. Steven and his family lived outside of a small town in Nova Scotia which made participating in recreation activities a challenge. Both of Steven's parents had been highly involved in his recreation experiences most often to ensure he had opportunities for recreational experience. Steven's siblings were very active and his family does a number of recreation activities together including: skiing, playing at home, and attending local festivals and events. The recreation experiences Steven had outside of his family ranged from successful to disastrous. Leslie described a number of the recreation programs and activities which Steven tried outside of the family. These activities included: the Rainbow Recreation program, Special Olympics opportunities for swimming and track and field, and summer day camps. Leslie spoke with great passion about the programs and activities her son has tried. Above all she is a mother who wants her son to succeed and have the same opportunities as other children in the area. The following is my reflection from these interviews with Leslie:

Talking to Leslie made me think three things. First, this mom has literally created many of the programs her son participates in. Second, other people are jerks. And third, what happens to these kids after (high) school is over? When programs and activities are reluctant to even attempt to engage a child with a disability, what do you do? Leslie commented a number of times that part of the reason why she and her family have been able to provide constant recreation for Steven is because of their connections to the university. Having access to people in the field makes a huge difference. Some of the other mothers do not have access to those kinds of resources which can make it extremely difficult to find anything in the area. I was amazed to hear Leslie describe the programs she started with other community members including a branch of the Special Olympics. In a program like the Special Olympics, the participants not only get to engage in some real physical activity but they also get a new, or another, social network. That means more people in their lives to care about them, to help them grow, to teach them, to challenge them and to expect something of them. I find that people with disabilities are often expected to do nothing, be nothing and contribute nothing. How do you make someone a valuable part of the world and of your community if you do not believe that they can make a contribution?

About other people being jerks. I think it's true, and I think a lot of people should be smacked upside the head. I found it painful to learn that not only Leslie but the other mothers describe the treatment

they and their children have received (the looks and stares and comments) from other parents. As an adult shouldn't you know better than to make someone else feel like an imposition or a waste of time? For me this goes back to the group thing. People like to be in groups where everyone is like them in most ways. The other kids in the programs were not the issue. It was the adults. How does that happen? How do children go from being care free and accepting of difference to discriminating and judging others?

As Leslie was my last interview in both the first and the second round, I found myself connecting things I had heard or talked about from other interviews with what she was saying. One of the big flashing lights for me was the conversation about what happens after school is done? What is life like for people with disability once school is over for good? For some of the parents these thoughts are still a few years off but for the others like Leslie this problem is like a train in the distance barreling down on you. You know it is coming but you don't know what you can do stop it. And when it hits you? When your child no longer has a daily activity or place to be, then what? Do you put them in a home, or find a day program for them? Can they work? Would anyone be willing to hire them to work? Do we believe they can contribute anything to our communities or to society after school, or do they simply use resources and take up space? This is a truly terrifying thought for many of these parents. They are not going to be young forever, the kids will grow up and what will happen after the parents pass away or if they are not able to take care of their children anymore. The life after school thought never crossed my mind before I started this study, but I am glad it came up.

Steven's Diagnosis Does Not Preclude His Humour

At the time of the interview Steven was thirteen, and was diagnosed at the age of three. Leslie said that since the diagnosis the family has been very involved. Steven has a large and active family. He *"is the oldest boy of four children in the family. We have a very inclusive family. Just because he has a diagnosis, that doesn't mean he can just sit around and do nothing. We are very active."*

Leslie told me about Steven's great sense of humour which, she said, some people find surprising. She commented that the teachers and schools use textbook definitions about disability and presume that Steven will fit those characteristics. She described how shocked they are when they find out how funny he is. Leslie went on to tell me that Steven is very punctual and has even been *"keeping his teachers on track"* and he checks his schedule regularly.

"Inclusion" and Social Experiences Through Rainbow Recreation and Special Olympics

Leslie told me that she and her husband keep Steven involved in recreation to keep him from being lost in his own world and to develop social experiences. As she described:

I think the goal is wanting to keep him stimulated, to not get lost in his own little world, or the computer world. It's a constant effort to work on a social skill because to a certain point we need

social skills. I think through recreation you also learn how to interpret emotion, body language and all that stuff. Which, you can try to teach him by a book; this is what you do when this happens but you have to experience. Actually life experiences, I think, is what we try most in the hopes that he gets a friend out of it.

Leslie described her hope that Steven would gain a friend or companion through recreation. Leslie kept Steven involved in a number of recreation activities including: the Rainbow Recreation program, Special Olympics programs, and summer day camps. Steven has also been exposed to other recreation activities through his family and through school.

Steven has been participating in the Rainbow Recreation program since his diagnosis at the “age of three” and has continued in the program throughout his life moving from the child program to the teen program. Leslie commented that Rainbow Recreation has been “one of the most important things in his life.” Leslie described that Steven was one of the first preschoolers to join the program, and that early on he was labelled “the horrible kid because he was very tantrum-y and didn’t want to be there but yet I dragged him in.” She went on to say that “his first year was hell. I think he chased away about six instructors, so we didn’t have the routine or consistency.”

Leslie described how she with a group of parents developed the Special Olympics program for youth in the area:

we started the youth program that was for children with special needs, in a sports setting. Now we had two programs back then, it was a gym setting which we used, a school gym, and we did kind of like the athletic type of things like the run, jump, skip, throw. That type of stuff. Then we had the aquatics setting where we had use the pool in a youth centre. We basically had an adapted learn-to-swim program because these kids obviously couldn’t handle, or whatever, a regular swim program.

Leslie told me that the gym program had stopped for a while but is now rebuilding, and the swim program has remained intact through the years. Leslie described the swim program:

It’s an inclusive setting so that the siblings, my kids also swam in this program, so that it was a social time for people with special needs. It was really neat to see my then ten year old daughter splashing around and playing just like she would any other ten year old girls, but they just happened to have Down Syndrome. It was just like they simply forgot about the disability, and, well the ability I guess is what they noticed.

The swim program was run by a volunteer who had a niece with a disability. Leslie described that the volunteer was “*aware of everything.*” Leslie told me that the swim program developed as a response to the children’s interest in swimming and their lack of fear towards the water. She said that she thought “*all children should be able to swim, and enjoy swimming*” while noting that as a parent she did not want to be scared by her son’s fearlessness in the water:

it started with an adapted learn to swim. We took the Red Cross levels, and we looked at what you had to do for Level 1 and we sort of adapted it and we did a swim lesson. It might have taken twenty weeks but that was ok! We were going to put our face in the water, we were going to blow bubbles, we were going to do all that. Then we just moved it up.

From the initial program, Leslie said the intention moved to teaching the children and youth to swim properly. She told me how she had seen some competitors in the Special Olympics program who did not know proper strokes, and thought “*they’re capable of doing it properly if taught right.*” Leslie then described Steven’s swimming:

He does about twenty lengths a week of various strokes, like breaststroke. He’s got what they call a natural whip-kick. Which is apparently the hardest kick but that’s how he kicks and so does his brother. So we’re working on that, with hopes that he will compete.

Leslie also discussed the gym program which was intended to focus on exercise but also created opportunities for social connections between the children:

We were just doing the basic stretching, walk, run around the gym. Then we’d set up stations which would be like, throw a ball in a basketball, or skip or walk on a low balance beam just some of those activities. Then we’d always end with a group parachute game. A lot of it was inclusive. The siblings were invited to be in it so it became that social bond. You’d see the girls doing the walk and run together. You’d see the boys, you know doing things together. Again to give them something social too, and it would be neat to see Kevin with Steven, and they had a common interest so they would walk and talk, sort of- to each other or Kevin would grab Steven to hurry up because Steven was lagging, you know?

Leslie also commented that the gym program had stopped for a while because the parents who had been running it “*were just tired.*”

Leslie told me about Steven’s participation in the track and field program of the Special Olympics. She commented that Steven was oriented towards individual rather than team sports, and participated in a number of track and field events including “*the 100 meter, he’s done relays, he’s done standing long jump,*

running long jump and shot put and has won a number of medals. Leslie also described Steven's level of commitment to track and field:

He hasn't gone to Special Olympics, the actual Provincial games the past couple of years because he wasn't really committed to it and I didn't want him to take a spot that another athlete could take. But he still went out on the track and participated and stuff. It was like if he's not one hundred percent committed and that individual over there is more committed I don't want a space taken.

Leslie told me that Steven is “*not a lover of track*” because he does not like bugs which always seem to be around at practice, and how he has not competed in provincial events yet:

I think he ran fast simply to get away from the bugs. [Laughs] To be honest with you, I think that was an incentive. At one point in time he was kind of walking because he didn't want to run in this particular race and, you know sometimes there is bribery with all children! He really likes a chocolate bar, so it was like, “You finish this race and you can have your chocolate bar.” [Laughs] That's why he ran!

From the discussion about Special Olympics, Leslie shared her thoughts about the program:

Special Olympics there's a certain criteria, right? But it was developed because the big world wouldn't include them. They couldn't compete in track, or they couldn't compete in swimming or whatever because of their differences, if you want to use that word. So they had to make a segregated program per criteria, you know, you have to have a cognitive disability in order to get [into] it. Just because you're in a wheelchair doesn't make you in Special Olympics, you're in the Paralympics. There's all kinds of segregated programs.

Importance of Open Communication and Instant Bonds with Program Staff

Leslie described that when Steven attended summer day camp the staff were “*great and very helpful.*” For several years, a municipal grant enabled Steven to be partnered with an inclusion worker at the day camp. Leslie told me that the inclusion staff were really keen and often had experience with the Rainbow Recreation program. She commented that “*they always met with me before the camp started so that I could inform them about Steven's likes, dislikes, triggers, behavioural issues, anything like that so they had a profile of Steven before it started.*” This openness to finding out about Steven was a partly the reason the experience was successful. Leslie described the summer day camp experiences and the reciprocity received from the staff:

The fact that it was like, you know, contact me anytime if you have any questions, don't hesitate to contact me. The big thing was warning [me] if something was coming up, like if there's a field trip coming up on Friday, let's start talking about it on Monday, you know? He needs to know that he's going on a bus, so you know prepare him ahead of time. Don't spring something on him, and that

was great. They would tell me how best to do it, and they would always fill me in at the end of the day too. He had a good day, bad day, he didn't like this game so we just sat over here, and I'd say, "well let's try and include him as much as possible. He'll try to manipulate you not to do stuff so just, well five minutes of playing the game and then five minutes and we'll read a book." So it was really helpful. Yeah, and this town is the only one that I ever knew about that had an inclusion worker.

Though Steven struggled in the Rainbow Recreation program at first, when he was partnered up with a male leader Leslie said that "*it made everything*" for him. Leslie said that Steven had an "*incredible and instant bond*" with his leader Luke and the following leader Jon. Leslie told me about how Luke was able to get Steven swimming:

I mean we went with Luke where Steven wouldn't dip his toe in the pool to by the end of the second year he was swimming in the deep end. You saw growth and stuff like that. I think it's the bond in partners you've got to be a special person to work with someone with special needs. If you're someone there just putting in time and want something on a resume, it won't work.

Soccer and Beavers: Difference and the Challenges of Inclusion

Leslie told me about unsuccessful attempts to engage Steven in local soccer and Beavers. She told me how it was the "*norm*" that everyone in their family played soccer. Leslie commented that Steven would run around on the field with his siblings but was not included in anything organized or that "*the coaches didn't even want to try to include him.*" She told me later that there had been talk of starting a soccer team for kids with disabilities but that it was "*all lip service*" and never materialized.

Steven has also tried the Beavers program when he was young. Leslie described that experience as "*nightmarish*" and "*awful.*" She commented that the leaders of the program were great but she felt uncomfortable leaving Steven, and "*always felt the need to stay.*" Leslie described the challenges that leaders and other parents had around Steven's participation:

the leaders were great, although they never sort of told the other parents involved that there was a child. I had no problems with them saying that there's a child who has this diagnosis, so that there would be some understanding. It was awful because they were just sort of staring at, like look at this awful kid, his behaviours and stuff like that. That's still hard.

From the experience, Leslie commented that she thought Steven was seen as a nuisance rather than being accepted when she tried to engage him in activities.

Lack of Social Support from Other Parents: Being Visible or Being “Written Off”

Within the story there were many people who did not provide support for Steven or his engagement in activities and programs. The most dominant group that was not supportive of Steven included the parents of other children. Leslie said that she, “*always had that impression that, other parents are saying, like, ‘Oh look at that child he’s so disruptive’ or ‘If I was that kid’s mother I’d take him home.’*” Leslie told me she often left in tears and decided that it was easier to not go through that, nor was it worth it.

In some instances Leslie would endure the lack of support from other parents. Leslie told me that Steven attended events at his school including his recent middle school graduation and prom. In our first interview Leslie told me about the upcoming prom and graduations:

His graduation dance is at the end of the month so I said, “you are going to that,” like, “you ARE going to that.” And he sighs, but we, will make him go. He’s fine in there, like he’ll pace around but, I think he should go. I want him to be included in that. Same with his graduation ceremony, he will go to that.

During our second interview, after the event, she told me about her surprise and struggle:

The night I took him to the prom and I dropped him off, parents who have known me his whole life were turning around and saying, “oh why are you here?” And it was like, “well Steven is in grade eight.” And they went, “oh yeah.” It was like he didn’t exist to them. I had three or four parents who I know really well say, “why are you here? Heather is in grade nine and Tommy’s only in grade five.” And I go, “No, Steven, remember him?” I was a little put off by it. I mean he’s out there, he’s doing stuff but people just don’t notice him? I don’t know if they don’t notice him, or they just write him off.

In-School Support from School Classmates

Leslie described Steven’s classmates at school as being very supportive of him. Even when Steven was much younger at daycare, his classmates seemed to accept him and his behaviour without any difficulty. She described Steven’s classmates who have supported him:

The kids in Steven’s class have been fantastic! He’s got a good class, god forbid, he has never been bullied. They’ve looked after him when, when like a new kid is coming to school and maybe tried something they’re like, “you don’t touch Steven,” like, “you don’t sit in Steven’s chair, that’s Steven’s chair! That’s Steven’s spot! That’s Steven’s...” you know. Others have stood up for him in that sense, but maybe it’s natural because that’s when inclusion has worked. Yet there’s still segregation, and it’s a complicated. Like I said they have, no one has every truly put their money into it. The first programs that seem to get cut are, you know, we’re always fighting for E.A. [educational assistant] time, we’re always fighting for this and that.

Although Steven's classmates were supportive, Leslie also spoke about Steven's lack of a social network outside of school time. Leslie refers to Steven's classmates who will say hi to him as acquaintances rather than as friends.

the hardest thing with having a child with special needs is the lack of social things for him. You don't really notice it and it kind of hit home, maybe last year when my now ten year old said, "Well you know Heather," who's the oldest in the family, "she's always sleeping over at her friends' house, she's always going to birthday parties." You know, and, "I'm always going to birthday parties, but Steven never goes to birthdays, how come Steven doesn't go to birthday parties?" He doesn't have that 'friend' group and that's the saddest part, is that, we all know how important friends are and that whole social network and when I find individuals with special needs don't necessarily have that.

School Experiences: Fitting Steven to Expectations or Adapting Expectations to Steven?

Throughout the story, Leslie spoke on several occasions about the expectations that are set for children and her frustration with them both in school and in recreation. Leslie told me about the challenge she has faced while raising Steven. When Steven was young professionals told her Steven would need a "schedule and pictures" and she said "Oh my Lord, like, that's just too much for me' I know what I'm capable of and that just seems so overwhelming." Instead the family created supports that worked for them, and Steven adapted to them. She said that she knows Steven "can be a productive member of society" but the challenge is finding things he wants to do, and fostering that interest. Leslie commented about the expectations people have about the type of recreation children should participate in, including Beavers, soccer and team sports. As Leslie described, none of these have been successful for Steven.

Similarly, school imposed expectations that do not work toward a positive experience for Steven.

Leslie described:

If you put the effort in, and if we find the subjects that he has an interest in, let's foster that interest and he can be very successful. Why does he need to know French? If French, if another language is something that is so difficult for him, why do we have these curriculums that are so boxed? You know, he can't do that, so let him do something else that is going to be for him and put the time into it. In math, in science, like, you know, let's put the time into it and he can do it.

Leslie told me about Steven's experiences in school where he was the first child at his school to have a "true diagnosis":

He entered the school with a diagnosis in grade primary so he's kind of been the groundbreaker. Now since he's been in the school, there's certainly others in behind him. We've always looked at

whatever we've done has sort of been setting the ground for the kids coming up behind him, and he has changed some of the perceptions. Like, Tech Ed for example where they're working with the machinery. It was like, "oh Steven will never be able to handle the noise," or this and that. And we're like, "don't say no, let him try. There's ear protectors, maybe he wears the ear protector, the sound protectors all the time in that class, instead of just when he's working on a machine". You know what, he built the best shelf going, and he got one hundred on his shelf that he built because he's so precise! It was perfect and that surprised them.

Leslie spoke further about Steven's capabilities and her thoughts about the education system and the term inclusion:

I've always pondered what true inclusion was. I do, I ponder it, and I, when I look at the education setting, (Pause) Steven isn't a dummy. He's probably smarter than you and I put together in some areas. Yes he has deficits, but he's got a lot going for him and I know in my heart of hearts that he can be an extremely productive member of society. He could support himself and he could do all this but there's, I find it frustrating. They say there's inclusion in school, but yet why are the graduation for high school criteria so rigid? So, you know if he doesn't fit in that square box, he can't graduate or he can't go on and do this or that or the other. You're going like, but he could be the best damn mechanic out there. I would want to take my car to him because it's going to work perfectly because he's not going to stop working on it or whatever.

Leslie continued discussing her thoughts on the concept of inclusion. She shared her frustrations with inclusion. While she supported the need for inclusion she recognized that "inclusion" has not been successfully implemented or provided the necessary supports for Steven.

So ok then let's not be so inclusive, let's take him out and put him in a room with a teacher or an aid or whatever to work on this thing. If that's going to make tick and make him successful, then DO it! I want him in the classroom too but I mean, it's kind of like AH! Do I think people need to be included? Absolutely! But so many attitudes need to be changed. One of the most frustrating things that I find is that the school boards, the department of education, the province, whatever, may say and I'm harping on education here but, is that it's inclusive but they've never put the money into it. So they do it, in my mind, half-assed. So let's do something good, and if it means pulling a kid out of the classroom and giving him an education that is, you know, geared to him and is going to make THAT kid successful, or this group of individuals successful then, you do it.

Connecting With the World through Family Activities

Steven has participated in a number of recreation activities because of his family including skiing and the local festival. Leslie told me that the whole family skis, and that she was able to find a reduced rate ski pass for Steven which she said was "helpful". From his skiing with his family, Steven also became involved in a school ski club which he attends every Friday with his father who is a chaperone:

He's joined that every year since grade five and he's going into grade nine next year. His dad was a ski instructor, so he always went up as a volunteer and got Steven started. He's just sort of gone

from doing, you know, twenty runs on the bunny hill to his father grabbing him and saying, "ok we're going up the chairlift." You know, it might have taken them forty-five minutes to come down from the top, but he came down. Again it's that whole individual thing where he can do it on his own. He's quite funny I guess going up the chairlift because like it could be a complete stranger who's going up on the chairlift with but he's very chatty. I don't [know] if it's his nerves coming out, but he becomes quite chatty and he talks, (laughs) talks your ear off. That's something we've done like the past, about three years where we've gone up on our own and we've done it. He, like I said, he goes up with his dad or he'll just make his way down and he just gets back in line.

Leslie described that Steven's ability to ski has shocked teachers at his school. She said "*the teachers are often blown away, and will say, 'wow he's got better balance than I do.'*"

The family also attends the local spring festival each year to watch the parade. Leslie commented that their outings can be "*hairy*" with four kids, and now that Steven is a teenager he is more reluctant to go. She told me how they have used the event as an opportunity to teach Steven about the world, and how to cope with it:

It used to be more trying when Steven was younger and trying to deal with all his issues like fire truck sirens and loud noises and crowds and everything else. We always had the philosophy of "life isn't fair, you've got to deal with this and we'll try to help you through it. But you've got to understand that if there's a parade and there's a fire truck and the fire truck sees a little, the fire truck driver sees a little kid he's going to blow the sirens." That's life, right? It was like, "plug your ears if you see a fire truck, put your fingers in your ears! Then they're there in advance in case he blows it."

Leslie told me that Steven will watch his sister's sports games and concerts which he finds boring and will sit with "*his ears plugged*". She went on to tell me how her mother lives with the family, and the debate around leaving Steven at home because he would hate the event anyway and "*trying to make him do as many things as possible.*"

Slow Summers and Family Camping Trips

I asked Leslie to tell me about what Steven does in the summer. She replied that "*summer[s] are a hard time, a hard time for any youth.*" When Steven was younger he attended summer day camps in town where Leslie works. Once he had turned the age of twelve years, he was no longer able to attend. Leslie questioned why participation had to end at that age. Leslie told me about Steven's experiences at day camp:

We always brought him to the local day camp, and they always had an inclusion worker because it was the only camp at the time that had that. Steven had a great time. Camp was great. They'd do

your typical games and crafts, and they always had a theme whether it be an environmental theme or whatever the theme was of the week. They'd go on field trips and walking trips around town and I mean he knows the back way to the town gardens and forest better than anybody because he's been there so much. But he enjoyed it, like you dragged him to it every day but you had to drag him to anything. Once he was there he was fine.

Once Steven became too old to attend summer day camp, he was then at home with his father.

Leslie described that “*it is difficult to find him an activity*” and Steven often ends up accidentally watching TV or playing on his computer.

Leslie described that the family has also been camping in the summers. It was on these trips that Steven learned to ride a bike:

that's what Steven tends to do when we go to a campground is, just go around on his bike. I mean it took us a long time to teach him how to balance actually being on a bike. So he'll do that, but he won't do it at home, like the other kids will go out and ride up and down the driveway, no that's not where he bikes. He bikes when we're camping, he'll do his little laps or whatever around the campsite.

Family Supports for Steven: Pushing the Boundaries of Steven and the World

Steven has very active siblings who inspired and motivated Leslie to find and create active recreation opportunities for him. Leslie commented that the involvement of Steven's siblings meant that he automatically joined in whatever the activity was. She went on to “*highly recommend a big family*” because the children are able to learn from all of their experiences with each other. She described the importance of siblings:

I always said he's quite lucky to have siblings. So many families that I know with an individual or son or daughter with a disability kind of like, stop, and we're not smart enough to stop. I don't know, we never planned any of them! His siblings have been so fantastic because they're relentless, right? They accept him for who he is, or don't accept him for who he is.

His brother Tommy, I mean I credit Tommy for everything. Heather's older so Heather was the mother. So we had to sort of tell her you have to step away and let Steven do it, you don't have to do it for Steven. Tommy was the relentless little brother, pain in the butt. Steven would be yelling and screaming he didn't want to play. Well that wasn't good enough for Tommy because “you are my big brother and you're playing with me.” So he would grab him and go, so then Steven would relent and play with him for five minutes and that would shut up him. So Steven's learned that ok, it's easier just to do and then he'll leave me alone.

I find it funny. I have a five year old, Bob's five so Steven's thirteen. He's been very protective of his little brother. Like, just, “where's Bob?” When Bob was toddling and learning how to walk, Steven would be behind him! It was just neat to see. Now he didn't do that with Tommy but it was just, he

was that much older, the age difference was that much greater that he felt that he had to be there. That's neat to see because he, like they tell you, with his disability the child doesn't care about anything else. Well, guess what, he cared that his little brother was going to fall. So it was like, "Steven, stop following him around! He's going to be fine! If he falls he learns not to do that." It's just funny.

Steven's parents have also been important characters in the story of his recreation. On several occasions, Leslie commented "it just seemed that if we wanted something for Steven, we had to do it." She described the lack of programs and activities available, or how when they approached someone about involving Steven they were "scared off." Leslie described her feeling of needing to stay with Steven for his behaviour and to protect him:

I guess it's that feeling of just being there in case something goes wrong, or that you know how to deal with his behaviours if something should happen. You can't really let go like other children you can drop off and, and come back later. It's always that nagging, "should I go or should I stay? What if he does this? What will happen?" And I think a sense of protection, too. We have that sense of protection. Just recently we made Steven go to his school prom, and I didn't stay. I walked him in and I let him go and his grandmothers were quite surprised that I didn't chaperone the dance or anything. It was a therapy for me to try to just drive away, and it was hard! It was really hard to drive away, but I did! I came back maybe fifteen minutes earlier, but I did come back and he was fine. It was hard to do that and I think it was that sense of just making sure he's ok.

I asked Leslie to tell me more about the challenge of finding recreation opportunities for Steve, and she described her struggle further:

I mean I don't live [in] town. I work here so I, maybe that's the difference, you know? We live up out of town, the recreation department out there folded years ago, so there's nothing. I mean there's lots of stuff for kids, right? But, well there's nothing inclusive. They don't understand. I guess if you're a parent organizing it or a group organizing it and it doesn't affect you, you don't do it. But those that are affected usually are too busy to necessarily sit on every committee, right?

I asked Leslie about Steven and inclusion, she told me that she does not differentiate between integration and inclusion. She described her understanding of the terms which included not only differences but parents who supported the engagement of all abilities:

I guess so that you have one program where all abilities are involved. All abilities are able to participate in the activity. Some individuals may need some assistance depending on whatever, but still they are all able to participate, and the participants understand each other's needs, understand and accept each other's needs. So that they don't stand out or that it's not like "oh I don't want him on my team because..." It's like, "oh yeah, sure, he can be on our team." Like more those attitudes.

I asked Leslie if Steven had any segregated experiences. She told me that segregation was part of the reason that she and her husband have remained so highly involved in Steven's life, "to protect him from that." Leslie further described this fear:

That was the fear in the back of our minds. So you stay in the front, parents stay there so we can watch, make sure that doesn't happen. The day camp here in town was ten times ahead of other rec departments, certainly in that area. I hear from other parents through the Special Olympics program in smaller communities who, you know have put their children in day camp and then after half a day have been called and said, "can you please come get him, we can't handle him!" and that breaks my heart.

I asked Leslie to tell me more about finding activities for Steven, she summarized the experience as "frustrating" and described that it was not only the lack of activities but the constant struggle to motivate Steven to attend:

Frustrating not just on because of lack of programs or trying to get him into programs. It's frustrating as a parent dealing with the individual with a disability. He doesn't want to do something. Everything's a fight, and you have to say in your mind, like, "this is the best for him, I've got to do this fight, I've got to make him go, I've got to make him do these things." Although, some days it would be really easy to say, "Fine just do what you want to do." So I think there's two-fold. One, there's the lack of the programs, but it's just plain being tired sometimes of just, of being a parent. I think, you know, that may sound bad but ...

During our second interview Leslie spoke further about keeping Steven engaged in recreation:

I think the big thing is the fact that we never put him in a closet or never let him just sit and home and, and waste away I guess, in lack of a better word. We wanted him to be involved so maybe [this] rocked his world a little bit by forcing, and force is not a good word but, you know, making him do things even when he said he didn't want to. But really when he got there he wanted to. You know, we were always the ones pushing him a little bit out of his comfort zone. That is hard to do as a parent because, of course, you know, you get the stares when your kid's upset or not being very good in the eyes of others "why are they doing that?" But we knew it was best for him. I guess that was a big thing, is that we pushed, we got involved, we made him do things to get him out because I didn't want him to just to sit in a room for his entire life and waste away.

Leslie spoke about her and Steven's future and commented on the ongoing support that Steven will need:

...we joke around with some of our, you know, friends and they say like, "oh!" you know, "ten more years and the kids are all out of the house!" We sort of sit there going, yeah. Me? I don't think so. You know, what has the future got, are we going to have an adult child live with us all the time? So it's that whole exhaustion of, "oh my lord!" You know? I think the lack of the programming, the lack of things out there.

Rebecca's Narrative About Clara

Clara lived with her mother Rebecca and her older brother and father in home outside of a small town in Nova Scotia. Rebecca's mother had been important in Clara's life and acted as her caregiver during the day while Rebecca and her husband ran a successful business in the local town. Despite having a very busy work schedule, Rebecca has engaged Clara in a number of recreation activities some of which had been fantastic and others had been disappointments. Rebecca shared her thoughts about Clara's recreation experiences with me, including Clara's years with the Rainbow Recreation program, their community church and her school. In both of these programs, Clara received a tremendous amount of support and developed relationships with a number of people which has made a great experience better in Rebecca's eyes. Rebecca also shared details about challenges she experienced in the summer months finding recreation experiences that she was comfortable with for Clara. Clara was the youngest participant in the study (age eight years) and so Rebecca's story covered all of the experiences she has had in her life to date. Clara has had other recreation experiences including: horseback riding, swimming, soccer, events and activities through her school, and spending time with the family pets. The following is my reflexive note after speaking with Rebecca:

My time with Rebecca was a genuine experience of sharing. There is nothing like being invited to watch the child of your study participant in her debut acting role. That was what was so great again about these interviews and doing narrative is that I can really be a part of it all, that I can share myself with these people and make them feel comfortable about sharing their children with me. Rebecca was articulate throughout the interviews, and reminded me constantly that having a child with a disability is an all encompassing lifelong challenge. Rebecca embraced it and loved it, and again has done everything possible to provide Clara with recreational experiences. She also reminded me that family plays a critical role in life, and that the disability of a child touches everyone she knows. Rebecca was well read in the area of disability and held a very unique perspective about the topic because of her own personal life, as well as her professional training.

Rebecca raised a few interesting points. The first being that I totally forgot how living anywhere outside of a town or city centre can be one the largest challenges in having any child participate in an activity. That is a lot of driving at the end of a long day. Second, she brought to light the idea around including Clara or any kid with a disability is great but not at the expense of another child. Rebecca was the first person to really describe what must be an intense internal struggle. You want your child to be included in the classroom but you also know that there are other kids in that classroom who require attention and support. I get both sides of the argument. It also reminds me of why I think there is a kind of standstill in the inclusion movement. There have been great improvements in the way people with disabilities are treated and engaged by the rest of society but it kind of feels like we

are at a "is this good enough" roadblock. Is it good enough? Could it go further? Have we done enough to integrate or include people and how much room for improvement is there? If programs and people won't make the idea of inclusion work then what? Then do we go back to segregation? Do we accept how we and others around us live?

Clara's Love of Books, Movies, Singing and Games

Rebecca told me about Clara who loves books and movies. Rebecca described that Clara has a great memory, and after someone has read Clara a story a few times she will re-read the story to herself for hours. Clara also loves movies but only happy ones:

like the Disney-Pixar movies she likes. Monsters Inc., or a Bugs Life, or Lion King is probably her favourite. As far as other movies, she likes the bible story movies only because she's heard them a lot and she likes that repetition and common themes. She doesn't like anything where really bad things happen, you know it's hard to find movies that don't have bad guys in them. She doesn't like it when it gets too emotional. She doesn't like Shrek, she thinks it's scary, won't watch it. Scares her to death. But she likes Charlotte's Web the cartoon version is ok, the real version is a little more dramatic and she's like, mm no I don't want to watch that one.

Rebecca told me that Clara does not like crowds or loud noises saying that "*she gets very overwhelmed and intimidated and, her defence mechanism against all of that would be to just go and hide somewhere you know or to or go to sleep.*" Clara loves animals and adores their family pets including a dog, cat and very old and large goldfish.

Rebecca showed me pictures of Clara and her brother Josh from a family album. In the photos Clara was playing dress up with her mom's clothes and doing funny things to get a laugh. The next photo was of Clara singing karaoke, Rebecca told me that Clara will "*sing and sing and sing as long as she has a microphone*". The last photo was of Clara and her brother with "Oreo cookie faces" showing their love for chocolate.

Rebecca told me how Clara has been playing board games and understands taking turns:

loves games. She's got lots. We have one whole table in the living room that is stacked with games. Well one of her new favourites is Mouse Trap because it's very physical. She'd have to test it every time you put a new piece on 'let's test it!' She'd want to test the ball so, we'd roll it and then let's test it! (Laughing)

Rebecca commented how Clara has always liked games including cards. She also told me about Clara's bead collection which she spends time sorting and resorting, adding that she likes the repetition of it and likes to make things consistent:

she has a collection of beads. There are different colours but every stand has to be uniform in colour, uniform in size and they have to either have no clasps they have to be all perfect. Then she'll just play with them, and she'll make these very intricate designs with the beads like artwork, she'll spin them around and make different colours or she'll pile them in different ways. Or she'll throw them against the window and see how they kind of reflect back, and then she'll throw them again and let them reflect back. It's almost like she's singing and talking to them at the same time so they become almost like these characters in her little world.

Rainbow Recreation Experiences: Exposure for Clara

Rebecca told me that Clara has been in the Rainbow Recreation program since she was three years old. She told me the program has been good for Clara because it exposed her to "kids and chaos and noise" which has helped her develop tolerance. During the first three years of the program Clara had the same leader with whom she became very close. Rebecca commented that the program has worked for Clara because it combines group and individual activities. Rebecca told me about what Clara does at the program:

puppets, lots of puppets because she likes that type of play and books. They did the balance beams and that kind of gym activity. Arts and crafts and stuff. If it was getting your hands in the paint Clara would love to do the painting; the more messy the better and less structure the better. If you say paint me this, she would say no (laughs). She has her own ideas of what she wants to do, and don't tell her what colour she's going to use, 'cause she's going to make it all blue and that's just her mood today, and this is what it is. She may just go like that, and there my picture done. She likes that kind of medium as well.

Rebecca told me that Clara "loves swimming" and is able to swim independently:

...She's always loved water, and when she was a baby, again Josh would have been about 2 and she was just an infant. I got a pool pass and we'd just take her in the water. She's always loved the water so she has very little to no fear so just jumping in even though realizing that she can't touch after a while. It's been good it's a really good medium for her. The only thing that would bother her is the other kids around when it became too crowded, and it really bothered her because she really needs her personal space.

Clara has done swimming through the Rainbow Recreation program. Rebecca told me how Clara likes to be in the "middle of the deep-end where there wasn't anybody." I asked Rebecca if she had ever tried swimming lessons, she told me she had enrolled her in a lesson but since Clara swims with the Rainbow Recreation program she "hasn't bothered with lessons."

Rebecca told me that she will typically stay and watch Clara participate but occasionally has to leave so she is not distracted. She commented that she tries to stay close by in case she needs to get involved:

If I don't have to [stay] that's fine, but I'm in the background somewhere. She was in the pool one day and didn't want to get out one day and she wasn't getting out. She stayed in when every other kid was out, and I could see her instructor kind of go, "Ok Clara let's go let's go." Then other people started coming around trying to say how are we going to get this kid out of the pool and I was like, "I'M COMIN'!" And I'm like. "there's one [counting]; you're going to lose this. Get out of the pool. Here's two, you're getting that much closer." Sometimes by the time I get to three its, ok, you just have to physically, and I don't expect anyone else has to physically but for me to actually physically pick her up and drag her right now. I can do it (laughing). I'll do that.

Family Church and Musical Experiences

The family church has provided a number of recreation experiences for Clara including the Sunday school program and the musical productions put on each year. Rebecca told me that one of the reasons the family became involved with the church was to introduce Clara to social environments and groups of people. She describes the church as being very "family oriented with lots of kids" which has meant the congregation has been very accepting of the kids dancing and moving around to the songs. The church also provided Clara with exposure to music which she loves:

Music is really key for her when we go to church because there's certain children's songs and if it's high energy dance stuff then she'll get up and dance in the aisles. If she likes it. If she doesn't she's nu-huh (shakes head no), you know. A lot of people are just waiting to see, is this the song, is this one she's going to go up and dance. She'll go up and down the aisles and dance, and sometimes other kids will join her. We play VBS songs so the kids are up there, and they're dancing and they've got their shakers you know, and they're getting the congregation to sort of dance, and move a little bit.

At the church Clara has been involved in the Sunday school program since she was about five years old. Rebecca told me that when they started Clara she was with a younger age group which was more compatible for her but she has since moved to an older classroom and is now separate from her mom:

(the younger program was) more tell a story, do something like a little, colour a picture or do a little craft that was related to the story and it was very casual and it was only two or three other kids usually so it wasn't really intimidating. Again she didn't really like it, but she eventually kind of got used to it so it's evolved to the point where now there's her own classroom. I pretty much have been with her most of the time. The classroom I teach now is her brother's class, and there's another class that she's in. There's a certain amount of flexibility, like she can go and sit and participate in the other class but yet if she really doesn't want to be there she, doesn't want to stay then sometimes she'll come in and she'll join in on our class, but she's getting better with you know getting used to the other kids and talking more and participating more where before she wouldn't say anything at all.

Rebecca told me about the musicals she directed at the church. She described that Clara has been involved in the musicals including the upcoming production of the Lion King. Clara will play baby Simba. Rebecca told me about the previous productions where Clara became reluctant to be a part of the final play though she had learned all the actions and songs. When I asked Rebecca how Clara went from reluctance to a lead role she told me how it happened:

I kind of just waited to see what she wanted to do because I've kind of just been working on the play and she loves the movie and she loves everything about Lion King all of the things the auxiliary movies and stuff. I've been working with the choir and she would kind of say "they're not singing it right" because you know, the choir director would get them to back up and start at different parts of it. She was getting like "they're not singing it right" and I'm like, "I know, it's alright." Then I said "Clara why don't you get up and sing it with them?" and I said "we'll just go from front to back" and, and so as soon as she had the mic in her hand and she sang the whole song right straight through I was like "ok, well why don't you be baby Simba and go up sing?" She's like "yah!" So it was more like she developed her own role, and I didn't really pick. She just kind of evolved into it.

I thought it was interesting that Clara knew the movie so well and that she vocalized her issues with them "*not singing it right.*" As Rebecca described, this led to the development of an individual role of Clara rather than being part of a chorus group. Clara seemed to have had enough with being a part of a group and was happy to take on her own role. From what Rebecca described, Clara was aware of her previous roles and desired the attention and separation from the group. Clara wanted to be a part of the play not just in the background with everyone else. Rebecca went on:

I'm hoping that giving her a microphone and saying you're singing, and it's all about her (laugh). I think that she's gonna be ok this time because she's a character, she isn't a person. Not like well everybody's doing it, they don't really need me.

Clara's Involvement in Sports and Individual Pursuits

At different times through the interview, Rebecca told me about a number of other activities Clara has tried. Clara and her brother did riding classes through the local university which they both loved. She commented that she thought the riding was successful because it was "*more individual than team based so Clara was able to work on her own skills and watch other people*". Clara has also tried playing T-Ball with her family at home, and Rebecca said she thinks Clara might participate in the Special Olympics in the future where she would be able to do individual events.

Rebecca told me about the experience of having Clara in a local soccer league which she hoped would be “*non-competitive and fun.*” I asked how Rebecca became involved and she told me that she had contacted the program leader who said having Clara “*wouldn't be a problem.*” She told me that soccer was not very successful because Clara “*couldn't keep up with the other kids*”, she went on:

she's not an aggressive person so she's not going to run after the ball and, there really isn't at that age you know passing and you know politeness and all that. It just ended up being very frustrating, and they'd have to stop the game and give her the ball so she could at least kick it once or twice during the game. She'd get a kick in but it wasn't that she was trying to score a goal or anything like that either. After awhile I think she didn't like it because it wasn't really 'the game'.

Then it started to be like, ok well she's being treated differently but it's, you know I understand why they did that because otherwise she wouldn't have had a chance to play. There was definitely a difference, and we decided not to continue with that because it wasn't working for anybody.

Rebecca told me how she felt she was an “active participant” in comparison to the other parents who would just “*plant themselves and watching their kids run.*” She described how she was “*out there, trying to get her, move her off or she's angry, or she'd run off someplace and I'd have to go get her.*”

Clara's Integrated and Segregated Experiences At School

Rebecca told me about a recent school fundraiser she attended with Clara and Josh. She commented that the other children are very supportive of Clara and said “*hi*” to her “*every five minutes.*”

Rebecca told me how Josh and Clara took turns choosing activities and about the night:

First, she wanted to put her brother in jail. There was a mock jail so she paid to have him thrown in jail and she really enjoyed that, (laughs) because once you were in the mock jail, they had people standing around the jail and they were squirting them with squirt guns for 2 minutes they just got soaked and then they were out. Then it was ok well, Clara will pick something and then Josh will pick something so she wanted to go to something it was called the frog pond and they had just these bottles set up with a lily pad on and you throw the ball and if you knock the lily pad off you get the prize that's inside. . . Then her brother went off and did something like, it was sort of like musical chairs and if you happened to be on the right number at the right time when they pulled it you won a prize. There was, you could shoot some hoops and if you got so many baskets you get certain prizes, and you know then we got hot dogs.

Then there was a jumping the air jumping thing (bouncy castle) and Clara loves that too. So she got her few minutes in there and no injuries, cause I'm like ah, and you know they fly into each other so easily. Stuff like that and the cotton candy but it was all kinds of things like they had finger nail painting and you know the fake tattoos and photographs, and just you know everything. They had the book fair, and of course that's what she wanted to do was go to the book fair. Except I'm like, “I didn't bring any money Clara; I brought enough for you guys to do you know your thing.” Two or three

times a year they have a book fair and she always wants to get books, like she would buy the whole entire place out if she had her way.

Rebecca told me about Clara's recreation at school where she has regular gym class and a specialized program which focuses on fine and gross motor development. Rebecca contrasted the specialized program where Clara received a personalized program to support her growth and development, with the mainstream program in which Clara goes along with whatever her class is doing:

I think it's once a week that she goes, and then they have a certain theme and they work on all kinds of things. It's a smaller group I think there might be between 5 to 10 kids that they draw from all other classrooms and I think that works well because I think she gets a lot of attention that way on specific goals, where when she's in the gym class with all of her classmates again it's just you know whatever she can do and, you know go along with the class as much as possible and she has her E.A. there as well.

Clara Care's for the Family Pets

I asked Rebecca to tell me more about the family pets that Clara loves. She told me that Clara was the reason they have family pets. They began with a cat who has been "good with the kids and is fairly low maintenance." Next the family got goldfish which Clara is "intrigued by making sure that they get fed, and that the goldfish get their medicine." Rebecca told me of her surprise with the longevity of the goldfish which have lived for a number of years and grown very large. Then Rebecca told me that they had been given a puppy a year ago. Rebecca described that Lucky the dog is:

best friends with everybody and a really good dog for the kids 'cause you can do no wrong with her. You can do you anything you want and she'd still be, just give me more. Lucky has one chair, and she knows if you sit in that chair it's the wrestling chair. If you're anywhere else but if you sit in that seat then you better beware because she's going to be everywhere, all over you.

Rebecca told me that it is Josh's responsibility to feed the pets, and that Clara "tries to help out or wants to help out but she really loves if you say we'll, let's pat dog." Rebecca also told me how Clara likes to "tattle on them, like, "the cats bad" or ah, "he's frisky he's not being very nice" 'cause the cat and the dog together, they have their little spats and stuff.

Flexible Supports and Openness in Leisure Spaces

Through the story of Clara's recreation experiences there a number of people who have provided support to her. Rebecca spoke about support provided to Clara by their church congregation, her first Rainbow Recreation leader, and friends of the family. Though Rebecca did not go into much detail she did comment that Josh, Clara's older brother has been very supportive of his sister. The commonality between these supports is that they provided flexibility and consideration of Clara's needs, and an open environment in which Clara could move.

Rebecca described the positive experiences Clara had at their family church and commented the congregation has been very supportive of her:

A lot of them have seen her right from young all the way through and there's, there's one other girl who's probably, she might be 16, 17 years old and she has the same disability as Clara. She's been there probably from when she was a very young girl, and so because I think the congregation that has been there the longest has also seen her come through, that with Clara, they're all just kind of waiting for her to do something.

Clara's first Rainbow Recreation leader was "great" and developed a real connection with Clara over their three years together.

she would then pick up on her cues and if she knew that there were kids that were yelling or screaming or doing too much commotion around her then she would take her off in the middle of the pool and they would do something, and then they were still in their own space and working on different skills. She got to know what she liked and then could work on different skills with her in the mediums that she liked to play with, yet always still trying to get her exposed to the things that she really didn't care for.

Rebecca commented that since her first leader, Clara has not developed a strong bond with any of the new leaders since they change every few months. Rebecca attributed Clara's enjoyment and success with the program to the relationship she had with that first leader and how she was able to pick up on Clara's cues if she was overwhelmed by a situation. She told me how that first leader will still call and email with the family, and described their relationship in the program.

I asked Rebecca about a recent spring festival in town, and she told me how friends of the family had taken Clara and Josh. Rebecca credited her friend's previous work with children with behavioural problems to the success of the experience:

she was able to take the kids to the parade because of knowing how to structure herself around children who have some issues. She said that's fine cause her and her husband could take the kids, and then if Clara decided that she had enough or that she wasn't going to go, then she was going to come back to the house and her husband was going to stay with the other kids to watch the parade. Before I've tried taking her to the parade but she doesn't like the loud noises and again he crowds and the whole thing, so you kind of just have to see how it goes. She made it halfway through and then said this is enough, and so they went back and she wanted to kind of do some independent play and just do her own thing.

Rebecca told me about Clara's experiences in the summer with different day camp programs. She commented that their experience with their churches Vacation Bible Study camp was positive because Clara was partnered with a teenage buddy:

it would be structured that she had a buddy who would go around with her. Again, it depended on Clara because sometimes she would stay with the group and sometimes she just really didn't want to do that. So her buddy could move about with her, but sometimes it just ended up that you know, at least someone was watching her and if they had to get an adult of whatever they could get an adult. Most times it ended up being if she would just sit and play on her own so it was hard to kind of get her to participate and encourage her to do that kind of stuff. That was fine because that teenager buddy, really enjoyed that part of it because that gave her a role. She was too old to be involved in VBS [Vacation Bible Study], but yet she didn't want to be a leader in a whole group.

Rebecca contrasted this experience with her son Josh's experiences at the town day camp. From Josh's experiences with the camp she questioned whether she could send Clara and if she would have the supervision and support she needed.

Josh went to the summer camp and there were a lot of young teens, and young meaning probably fifteen, sixteen year olds, who didn't mind putting their time in to babysit people, but really had no control, authority or interest in it whatsoever in what was going on, here's the project and so on. Although my son tolerated it, and he's very good to not get himself into trouble and he's a good kid so I didn't really worry about it. I knew he wasn't real happy so I would never even think about putting her into it because it was chaos and he hated it (laughs) so obviously I'm not going to do this.

Rebecca told me about her own debate around involving Clara in a program like the summer camp because:

she needs to have that 100% supervision, even if it's just sitting away. If I could take her or something like that its fine then but right now you have to have that extra body and I really don't want to put that on an organization or a group to say, you need to.

Rebecca explained her concerns with enrolling Clara and leaving her in a program with someone she did not know since she does not respond well in those situations. She described struggling with expecting an organization to provide one-on-one support for Clara:

I know when you're designing a program and you're trying to figure out costs, you need so many people for so many children on average and this and this. To budget in adding an extra person, and have Clara pay the same rate as all the other kids, isn't fair you know? And I don't expect that. So if I were sending her to something like that, I either would organize someone to go with her whether it's me or whether it's someone else that I would pay as a babysitter who knew her well enough and could work with her or I'd really have to see how that would be set up to include Clara.

Rebecca's Thoughts on Inclusion in the Context of Family, School and Community

When Rebecca told me about Clara's recreation experiences she told me she hopes the programs keep her active and moving, and keeps Clara as a part of the community. Rebecca commented about the difficulty in finding out about recreation experiences available in the area, and her struggle to balance Clara's structure and freedom in recreation. She told me that since their home is out of town, she finds it difficult and tiring to coordinate bringing Clara back into town for an activity or program:

She loves to dance but I haven't put her in any kind of organized dance. I'd like to but part of it's our work schedule too because we work well over 40 hours a week, my husband and I. It makes it difficult because we're not getting home until 6 o'clock, and getting them organized, and then they don't like to be too overwhelmed 'cause when we have that one thing during the week it just sometimes throws everything off. It's better the more routine we have and then they get their own time.

Rebecca also told me trying balance the attention between Josh and Clara. She described how she tries to ensure that she has time for Josh to do his activities, or time together with him while Clara is at her activities:

it always seemed like there's a lot of focus on Clara but I really want him to make sure that, if she's doing this then he's doing that, when we go we all go together to the gym. Although he may have a half hour lesson then he's taking things that he really wants to do whether it's a book he's reading or whether he wants to play his D.S. or he's got something like that we still have our time together. So him and I share that time together while she's doing things so that's worked out well to just trying to keep it very family oriented.

Throughout the interview Rebecca placed an emphasis on equality among people, whether or not they have a disability. Rebecca told me about a recent conference she had been to where she was able to connect to some resources that provide necessary supports so that people with disabilities can be an "equal member in society." She then told me about some of what she had learned at the conference and her thoughts on equality in public services:

some of it was disability specific and some of it was more people who have disabilities. It's not equal among people who have disabilities as you know because number one there are certain government funding that specially is diagnosis specific, it's not need specific which is very frustrating and again. One example would be there's a lot of emphasis on kids with autism and, so there's a lot of money being pushed that way and they get bumped to the front of the line for all services. And other kids who have exactly the same needs but have a different diagnosis are expected to wait on their waiting lists. So you know if we're making it equal, then it should be any person regardless of who they are, whether they have a special need or don't have a special need. If it's equal its equal, if it's public money. Now if someone's paying for it, if you're paying for the service whatever you want to do, but if its public money I think there should be equality.

I asked Rebecca about her thoughts on integration and inclusion. Rebecca seemed to use the words interchangeably, although she recognized that there was a difference between them. She spoke of integration as being a physical presence in space:

Those are kind of the two biggie words. I should probably say inclusion. That she's allowed to be included in everything, and given an opportunity to be included in everything. Integration is more that, you know the presence is there and that if we go back to the seventies when they integrated children with, again, special needs into the school. So they now are a presence in the school because they are part of the school, but there's not necessarily that inclusion, they're just now there.

Rebecca also commented on several occasions about a balance between integration or inclusion, and the limits of inclusion. I was surprised when she went on to say she “*used the wrong terms*” to describe her desired involvement for Clara. Rebecca commented that although she wanted Clara involved she did not want people “*to go way out of their way for one individual*” and that she would rather be the one to make an activity or experience work rather than expecting someone else to. I asked Rebecca to tell me more:

I probably used the wrong terms, but it should be more inclusion is what I'm looking for. That people are given the opportunity, but also that there's enough, tolerance to say that ok, this is either working, this is not working. I really don't want people to go way, way, way out of their way for one individual, regardless of who it is, you know. Things can be in place and, and it's just like if I went somewhere and I knew that I wouldn't cope well with something, I have to take that on myself to try to figure out how to make it work. I don't expect someone else to do it.

Rebecca shared her philosophy about Clara's involvement in the classroom. Her insights go beyond the impact of having Clara in a class. Rebecca also considered the impact Clara (and her behaviour) can have on her classmates.

My philosophy as far as school goes is that number one if Clara is acting out and its inhibiting someone else from learning I'd rather her not be there, and have to expect that child to just to learn tolerance. When Clara's not getting anything out of it, if she's in that state, they might as well just find a place where she can learn. You know not giving into the behaviour but also making sure that it's

productive for everybody and that it works for everybody because just making a kid, you know be upset and, well I don't think it works.

I asked Rebecca about segregation and if Clara had a segregated experience. Rebecca commented that the only example she could think of relating to segregation was in regards to the diagnosis of a specific disability and the support or lack thereof that came with it.

I guess the only other issue that I have is just medically is, and I had mentioned it is the way that the government places priority on certain diagnoses. That may be the only true example of being segregated because she has a certain diagnosis that she's on this list as far as health care and this group because they have this diagnosis is on this list, and they get priority on health care.

Rebecca went on that she did not think Clara had had a definitively segregated experience. She spoke about how people and programs will often try to make Clara fit and that there are times when she does not fit:

I don't know that if things were specifically set up to segregate her because she, because of her disability that she was like, "you need to be here and all the other kids are here." I don't think that there's anything that pops out of my mind because I think that people are really more trying to make Clara fit. She doesn't always fit, (Laughs) and I think it's more frustrating for them because they failed to get her to be part of the group. I think it's just that she has the opportunity to be part of it.

Summary of Chapter Four

Chapter Four provided the narrative accounts and descriptive analysis of each parent. Each story highlighted the challenges and successes of the parents and children in recreation. The narratives identified important characters and explained their roles in the recreation experiences. Blended into each narrative account were some of my thoughts and reflections. Chapter Five contains the interpretive analysis of each narrative account. Phases One and Two of the narrative analysis process have been combined to produce a comprehensive exploration of each parent's story. Then, Phase Three explores the cultural practices of disability, recreation and levels of involvement reflected in each narrative. In Phase Three the five narrative accounts were explored as a collective. Next, the implications of this study for other parents, recreation practitioners, theory and methodology are described. I have also included final reflections on my role as researcher. The Chapter ends with a discussion of the limitations of the study, suggestions for future research, and a final thought on the impact of this study.

Chapter Five: Interpretive Analysis

The purpose of this narrative inquiry was to explore how parents understand and experience disability through their child's involvement in leisure experiences in a recreation context. The study examined non-involvement and involvement in segregated, integrated, and inclusive leisure contexts. Three main research questions guided this study. The first question asked: What are the stories of parents of children with disabilities? The stories of five parents (Anne, Carolyn, Johanna, Leslie and Rebecca) about their children's experiences with recreation (Daniel, Keith, Brandon, Steven and Clara) were provided in Chapter Four.

In Chapter Five we then turn to an interpretive analysis of these stories using Daly's (2007) questions as introduced in Chapter Three (see Narrative Analysis Phase One, Two and Three in Table 3). Phases One and Two were completed independently but have been combined to provide a comprehensive exploration and understanding of each narrative. Phase One of narrative analysis responds to the second research question: How do these stories help us to understand the recreation experiences of children with disabilities? In response to this question the main messages contained in each parent's narrative provide insight into recreation experiences. This question was addressed using the following analysis questions adapted from Daly (2007): why the story was told, who the audience was, and how the story is then positioned in relation to that audience. Phase Two continued the narrative analysis, using questions adapted from Daly (2007), which examines the time, space and presentation of self in the story, the protagonist and other characters within the context of each story.

The third research question—How do these stories help us to understand disability in recreation practices?—is then addressed in Phase Three which broadens the scope of analysis and considers how the narratives help to understand cultural practices around disability and recreation. In the section titled *Narrative Analysis Phase Three: Cultural Practices of Disability and Recreation and the Researcher as Audience*, the questions of: how do the stories help us to understand the cultural practices of disability, and

where do I fit into this process, adapted from Daly's (2007) interpretive analysis strategy are addressed.

This discussion is found after the Interpretive Analysis of all five narratives.

Interpretive Analysis of Anne's Narrative

The following sections contain an analysis of Anne's narrative including: important spaces and presentation of self, the messages from the story, an exploration of the protagonist and conflict, the role of psychological, social and political power, and finally a discussion of my reflections and the intended audience. Anne identified recreation as providing important spaces to be successful, to be social and to be normal for Daniel. Connected to these recreation spaces was the development and presentation of Daniel's material, social and spiritual self. The main messages from Anne's narrative highlighted the lack of recreation opportunities available for children with disabilities, her fear of Daniel being isolated at home, and the importance of social supports from other parents. The discussion of protagonist and conflict shows both Anne and Daniel as protagonists, and the internal and interpersonal conflicts experienced between Daniel, Anne, and other characters. This section also explores Anne's material self and social self since they are connected to, and demonstrated through, her role as a protagonist. Next, a discussion of power explores the psychological, social and political power of Daniel, Anne and other characters. I found that Anne and Daniel gained social power but experienced limited political power. I found that other characters held power over them. Finally, my reflections on her narrative are presented in combination with a discussion of Anne's intended audience including other parents and recreation practitioners.

Presentation of Self and Spaces to Succeed, to be Social and to be Normal

Recreation provided important spaces for Daniel to succeed, be with friends and peers, be independent and social, and to be "*normal*." In these spaces Daniel's material self and social self were able to emerge; however, I did not find a connection to his spiritual self.

Swimming provided Daniel with *space to succeed* including a space to demonstrate his skills and abilities and experience feelings of accomplishment. Anne described swimming as the activity Daniel was "*most passionate about*" and would astonish people at his ability. Swimming provided continuity for his

recreation experiences beginning at a young age. He then participated in swimming lessons through school and earned swimming level badges, and joined the Special Olympics where he has been training and competing in an annual swim meet for over 5 years. Anne described the swim competition as an event which Daniel “*loves*” and “*looks forward to*” and where he will try to win his events. Daniel developed an understanding of his material self through physical activities and his family. Daniel is a skilled and successful swimmer, and it was through swimming he developed and an awareness of his body. Daniel's understanding of his material self was also established through his family.

In several instances recreation space provided Daniel with important *social space* for being with friends and a space for independence. The Special Olympics swimming and bowling programs were spaces to be with friends/peers and where Daniel had a level of separation from his parents. In the story Anne commented that in school Daniel has “*all kinds of friends*” but contrasts it with their home neighbourhood where there is “*nobody*”. The movies, particularly Daniel's attendance with Tiffany, provided another space where Daniel was able to spend time with friends and experience independence from his mother. Similarly, summer camps provided a social space. Anne said that she thought Daniel enjoyed “*being around other kids*” as one of the reasons for liking summer camps. Having space to be social with friends and peers is important for Daniel because as Anne pointed out at home there is “*nobody*”.

Daniel's *social and independent self* was displayed in many recreation spaces. They also demonstrated his role as protagonist in the narrative. The experience at the movie theatre showed Daniel's understanding of his social self which often contrasted with Anne's understanding of her son. As described in the previous paragraph Daniel wanted to sit alone with his friend, and Anne seemed shocked and amused by Daniel's independence. Anne commented that “*I wasn't allowed to sit with them*” while laughing. She went on how Daniel “*thinks he's old enough to do that*” which hints at a discrepancy between them over what Daniel can do. Daniel had to contend with his mother's attempt to sit with him and was ultimately able to establish independence and overcome her challenge. Another example of Daniel's social self was evident in the conflict which arose between Anne and Daniel regarding the use of the “*Easter Seals*” card at the

movie theatre. In this experience he demonstrated an awareness of the card as a marker of disability or difference, and expressed concern for what other people would think or assume if he used it. Anne commented “*he thinks he’s not special, maybe. I don’t know. But he is*”. The development of Daniel’s social self and independent self were also present in space to be normal. The connection between self and space will be further discussed below.

Having space to be independent was connected to the idea of having space to be normal and was a significant theme throughout Daniel’s story. The space to be normal also provides insight about Daniel’s social self. On several occasions Anne commented that Daniel was ‘normal’ in many ways, or that he was a ‘normal teenager’ at times. When Anne described experiences at the movie theatre with Daniel’s friend Tiffany she commented that it was “*great, that he would even think to do that. You know it’s normal for him, for a teenager to do that*”. She also referred to Daniel as a “*normal teenager*” when describing his singing in the car with his music player. Although Anne did not say that the annual swim meet was ‘normal’, Daniel would travel to an annual swim meet with his team and spend one night out of town away from his parents. I felt this was another example of being ‘normal’ because Daniel had space and time away from his parents like other teenagers competing in sports.

I felt that there was an absence of a spiritual self in Anne’s narrative. Anne seemed to accept Daniel and his disability without contest. While reflecting on her narrative I focused on her final section when she spoke about Daniel having something (work) once he finished high school. It seemed to me that in Anne’s story of Daniel there was no identification of him having a greater purpose in life.

Anne’s Message: the Importance of Daniel Being Active and Engaged, Now and Forever

The discussion of space and self presented above enabled me to consider the message within Anne’s narrative. The important spaces previously identified provided insight into the importance of recreation for Daniel and about the important elements found within a space. Similarly, the discussion of self provided further insights into the role of recreation into the development of Daniel’s material, social and independent self. It was through the combination of space and self that I identified the important messages

in Anne's narrative. Three main ideas stood out about Daniel's experiences: Anne identified a lack of recreation opportunities for her son and other people with disabilities, she described her concern for Daniel being isolated at home, and finally, she identified recreation programs as important sources of social support and information.

First, I believe that Anne told her story to show the lack of recreation opportunities for children with disabilities. I found it significant the number of times she commented about the great activities that Daniel had, but always added that she wished he had more. When Anne spoke about the summer time she commented there was really nothing available. She listed the activities he was involved in and said there were "*a few things for him.*" These few things can be counted on one hand, and most of his recreation experiences were connected to each other. I remember noting through the interview with Anne that it seemed that although Daniel enjoyed his activities there were not many experiences to draw from.

Second, I thought that Anne's concerns about Daniel's recreation experiences were paralleled in her concerns about other aspects of his life. Mainly, Anne was concerned Daniel would be isolated at home. Anne commented she did not want him "*sitting at home doing nothing*" once school was done, and seemed elated when she found out he would be working after school. Anne's concerns with Daniel having limited or nothing to do were echoed throughout the story. Anne was left with questions like: What do you do outside of a structured environment like school? What happens when school is over for the week, the year or for life?

Third, this narrative also indicated that through recreation programs Anne gained important social supports from other parents. Through connections with other parents, information about leisure programs and opportunities were shared. Daniel became involved with new programs after Anne learned of them from another parent.

I identified these three messages from the discussion of space and self, and through reflection on Anne's narrative. It was also through this reflection that I explored both Anne and Daniel's role in the story.

The following section explores the role of both Anne and Daniel as protagonists. This discussion is combined with an exploration of the internal and interpersonal conflicts found in the narrative.

The Shared Role of Protagonist, Experiences of Conflict and Presentation of Anne's Self

Anne's narrative centred on Daniel, yet Anne herself became a protagonist too. Daniel's role as a protagonist, since he was the focus of the stories, was previously explored in the Presentation of Self and Space. This section will focus on Anne's role as a protagonist in the narrative through which her presentation of self was developed. This also includes an exploration of the shared role of protagonist in the story between Anne and Daniel. I often found other characters acted as antagonists challenging Anne and Daniel, such as Emily the swim coach and the pastor of the youth group. In other cases the other characters provided social support for them including his E.A. at school and his Rainbow Recreation leaders. Relationships and interactions with other characters showed the shifting role of protagonist and the development of Anne's self. Three examples demonstrated both Anne's role as protagonist, her social self, and her shared role with and Daniel in this narrative. These examples include: summer camps, the Special Olympics swim program, and the youth group.

The experiences of finding summer camps for Daniel showed Anne's role in facilitating recreation for Daniel. Anne's understanding of Daniel and her social self were also found in the experience of having him involved in summer camp. Anne commented she found it difficult to find activities in the summer for Daniel. She spoke about her attempts to find a summer camp for him saying, "*I thought like since he had a disability that no camp would take him.*" This statement revealed her assumption that her son would be excluded from camp by others because of disability. Perceptions assumed to be held by others was a key element of the social self. This experience revealed Anne's significant role in finding and facilitating recreation opportunities for Daniel.

When Anne described Daniel's participation in the Special Olympics swim program she highlighted the impact other characters (people) have had on recreation experiences. In this example, Anne was the protagonist because the experience was focused on her reaction and because she was in conflict with the

swim coach. Anne had to contend with the time change desired and instituted by the swim coach. Anne experienced internal conflict with this change in time and she accepted the change without question and kept her opinion of the move private. In the narrative Anne did not comment on whether the time change affected Daniel, instead she spoke about the impact on her. This experience demonstrated the shared role of protagonist between Anne and Daniel, although the story was about Daniel's involvement in the swim program, Anne shifted to focus the experience and impact on herself.

The experience of having Daniel involved in the youth group demonstrated Anne's role in facilitating recreation, the shared role of protagonist, and interpersonal conflict. In this experience, Anne initiated Daniel's involvement in the youth group at the suggestion of another parent. Anne experienced conflict when the pastor was initially hesitant to involve Daniel. Anne questioned why he would need to think about involving Daniel. She was "*surprised*" Daniel was not immediately accepted since she thought they would just "*take him*." Anne seemed to understand his desire to discuss Daniel's involvement with the other leaders, and wondered if the pastor's hesitation was because he was concerned about Daniel's behaviour. This example parallels Anne's presumptions from the summer camp experience although in this case she assumed Daniel would be involved since there was another child with a disability in the group. In this experience Anne was the protagonist and the pastor acted as the antagonist challenging her. Similar to the Special Olympics example above, the story was about Daniel's involvement in the youth group (Daniel as protagonist) but it was Anne who facilitated the recreation experience, and it was she who experienced the conflict. This experience also developed Anne's social self through her reaction to the pastor's hesitation of Daniel's involvement.

The examples of summer camps, the Special Olympics swim program and the youth group demonstrated the shared role of protagonist between Anne and Daniel. These experiences also highlighted the role of other characters in Daniel's recreation experiences, and their roles as antagonists mainly through conflict with Anne. It was also through these experiences that Anne's social self was developed. Through

these experiences, the conflict and impact of other characters, we can explore the role of power in the narrative.

The Power of Daniel, Anne and Other Characters

From Anne's narrative I found that power shifted between Daniel, Anne and other characters through conflict. Within the narrative Daniel held power in specific contexts in relation to his mother and others. Anne was often in a position of power over Daniel. I also found that in the context of recreation the practitioners or leaders ultimately held power over Anne and Daniel's involvement. Each of these elements of power will be further explored considering the psychological, social and political power relevant to each case.

I found that Daniel experienced gains in psychological and social power through his experiences including the movie theatre, school and the various programs he participated in. I felt Daniel gained psychological and social power in his recreation experiences at the movie theatre. Daniel had psychological power over Anne when he refused to let Anne sit with him and his friend at the movie theatre. I felt Daniel used his skills and knowledge (social power) to gain access to information about the movie times independently. Anne had described how Daniel would call the movie theatre to get show times if there was a movie he wanted to see. His psychological power was also demonstrated when Anne described how Daniel would get himself to and from school on the bus. In this example, Daniel showed his self-efficacy in his ability to get himself to the bus and school on time, and when he came home. I thought the movies also provided an example of when Daniel may have initiated the recreation opportunity on his own this is an example of Daniel's social power. Daniel's social power was also developed through his participation in a number of programs including the Special Olympics, Rainbow Recreation and the youth group. Another example of Daniel's growing social power was through his work training at school. Anne had explained how Daniel was learning the skills to work once he finished high school. When I consider Daniel's political power, I thought about his role in decision making practices. From the narrative I found that Anne was often responsible for initiating or facilitating Daniel's recreation experiences and that he seemed to have little input into his participation. In his case I thought that other people made decisions in his life (e.g., his mother, the

E.A. or teachers at school, program leaders, etceteras) and Daniel had limited involvement in decision making processes.

Anne's social power was evident throughout the narrative. I thought Anne's social power was stronger or had become stronger whereas her psychological and political powers were relatively low. I found Anne's social power developed and grew through the story. Anne gained knowledge about programs or resources available for her son through social organizations including his school, Rainbow Recreation, and the other parents she met or connected with through these organizations. For example, Anne connected with another parent through Rainbow Recreation who suggested the Special Olympics swim program for Daniel. I thought Anne's psychological power seemed to shift through the story and was often connected to her political power. At times I thought she had experienced loss or low psychological power because Daniel's recreation participation was so often controlled by others. Anne had commented she found it difficult to find recreation opportunities for Daniel, and had described how the program leaders were in control of his participation. I thought that Anne had low self-efficacy with regards to Daniel's involvement and this was connected to her limited political power.

In the narrative Anne had political power over Daniel but limited political power with regards to his involvement. Anne often found and chose the recreation activities that Daniel participated in yet she was aware of the limited recreation opportunities for her son. For example, Anne initiated Daniel's involvement in the Rainbow Recreation program and insisted on his involvement. Anne had also found and registered Daniel for the summer camp programs he had attended. I did not find that Anne had access or influence over decisions regarding her son's involvement in a program. Nor was she involved in any collective action to change her political power. Anne enrolled Daniel in the Special Olympics swim program but Emily (the coach) chose the practice times. In this case, Emily held the power of deciding when the recreation program would occur, and Anne had no involvement in the decision making process. Similarly, in the experience of the youth group the decision to involve Daniel was held by the pastor and other leaders. Anne seemed to accept that other people would make the decision of involvement and I thought she felt she could not

change the process. Anne's narrative highlighted the challenge of involvement in recreation, and identified other characters as having power over her and Daniel.

The Impact of Anne's Narrative and Her Audience: Parents and Recreation Professionals

As Anne told me her story of Daniel I felt a number of emotions including appreciation, frustration and joy. I felt appreciative of the people who had been positive and supportive in Daniel's life. Throughout the narrative Anne never spoke poorly of a person even if she was frustrated or challenged by them, she was critical of experiences but not people. Anne clearly appreciated the efforts made by the recreation leaders Daniel experienced and I shared that feeling with her. Anne's story made me feel frustrated by the lack of opportunities for Daniel and simultaneously inspired by Anne's sacrifices to ensure he *had* experiences. Anne commented there were few opportunities for her son and that she engaged him in everything possible to ensure that he had activities and experiences. I was inspired by her dedication when Anne said "*he always comes first no matter what.*" Anne was committed to ensuring her son had experiences even if it meant sacrificing her own. Finally, I felt joy and relief when Anne told me that Daniel would be working once high school was done. When she told me she knew people whose children (with disabilities) were at "*home doing nothing*" I was terrified to think that once school ended Daniel would have nothing to do. Anne said that she was "*overwhelmed*" when Daniel's teacher told her he would be working after school. Learning he was having work training for a job felt like a weight lifted from Anne's shoulders.

I think there were two possible audiences Anne intended for her narrative: parents (and mothers) of children with disabilities, and professionals in the field of recreation. The first audience, other parents/mothers, was evident in a few key areas of her narrative. Anne often described how she found other programs and resources for Daniel through other parents. It seems to me that Anne is inadvertently suggesting that parents should talk to other parents. As Anne described it was often difficult to find programs or activities for Daniel and thus any source of information or connection to activities and programs would benefit other families. I also think Anne wanted other parents to know and recognize the future challenges of having a child with a disability. Anne described her concern for Daniel's well-being and the

isolation he experienced. When she told me teachers at his school were preparing him to work once school was over she was surprised and elated because her fear had been that he would have nothing. I think Anne wanted other parents to think about their children's future and to know that there is a possibility of life after school.

I think Anne also shared her story of Daniel to reach recreation professionals for many of the same reasons as described above. Anne wanted people in the recreation profession to know it is challenging finding programs for her son. Programs and activities Daniel had participated in were of benefit and kept him involved in community rather than isolated at home. Finally, her story was also told for recreational professionals to highlight the many times in a person's life when recreation is lacking including the summer months for students, the teenage years, and for adults after school ends.

Interpretive Analysis of Carolyn's Narrative

The following sections contain the analysis of Carolyn's narrative including: important spaces and presentation of self, messages from the story, an exploration of the protagonist and conflict, psychological, social and political power, and finally a discussion of my reflections and the intended audience. The important spaces in Carolyn's narrative were space to be away from family, space to develop skills, and space to make a valued contribution. Connected to these spaces was the development and presentation of Keith's material, social and spiritual self. The main messages from Carolyn's narrative highlighted the importance of recreation for people with disabilities, the significant and beneficial impact Keith had on others, and the value of community or social networks for people with disabilities. The discussion of protagonist and conflict shows both Carolyn and Keith as protagonists, and the internal and interpersonal conflicts experienced between Keith, Carolyn and other characters. This section also explores Carolyn's material self and social self since they were connected to and demonstrated through her role as a protagonist. Next, a discussion of power explores the psychological, social and political power of Keith, Carolyn and other characters. Keith developed psychological and social power through the support of his mother and experienced some political power. I found that Carolyn gained political power through her social

and psychological power but experienced limited political power. I also thought that other characters had limited power over Keith's involvement, and often they supported his engagement rather than denying it. Finally, my reflections on her narrative are presented in combination with a discussion of Carolyn's intended audience including other parents, recreation practitioners and people.

Presentation of Self and Important Spaces for Keith

The significant spaces in Carolyn's narrative of Keith and his recreation experiences were: space to be away from his parents, space to achieve success, space to contribute something of value, and space to be social and have a community. Keith's material self and social self were described throughout the narrative by Carolyn and developed in the important spaces identified. Keith's material self developed through his interactions with his family and recreation activities such as basketball. His social self was further developed through recreation and the social relationships that resulted from his participation. I found little description or development of Keith's spiritual self.

Throughout the story of Keith's recreation experiences it was evident that Carolyn was with him most of the time. Carolyn recognized that she was with Keith for nearly all of his recreation experiences. She commented it was important for Keith to have space and experience away from his family and his parents. An example of space away from parents was found with the high school basketball team. Carolyn described that when Keith goes into the locker room with the boys she has "*no idea what happens in the locker room and I'll never know. It's like this whole world and I think it's so cool that Keith has a world that I know nothing about and I love it.*" Another space where Keith was separate from his parents was the Rainbow Recreation program. Carolyn commented that Rainbow Recreation provided an opportunity for her and her husband Doug to be away from Keith. She said they were able to run errands or get a cup of coffee knowing that he was in a safe environment and having fun. Finally, the recent community theatre play offered a space where Keith was able to be separate from his mother. Carolyn commented that through his involvement with the play she felt Keith developed separation from her.

Keith's social self was developed through some of the recreation experiences described above. These opportunities enabled him to interact with people and develop social relationships. Carolyn described a number of recreation experiences including basketball and community theatre where Keith developed social relationships with a range of people. The basketball team was a key example of Keith's social self in the narrative. Carolyn said Keith had become "*very close friends*" with the boys on the team which was significant in his life because social life can be "*tough in high school for kids with special needs.*" His role on the basketball team also provided Keith with social status in the school where he was known as the "*manager of the basketball team.*" Carolyn also commented that the boys on the team would be "*beside themselves*" if Keith missed a practice. The basketball team was also a shared passion between Keith, the players and the coaches. The development of Keith's social self through community theatre will be discussed later.

Having space to develop skill and achieve success was important to Keith's story because it highlighted his capabilities through recreation. Carolyn spoke of how the early community basketball program was where Keith learned the same basic basketball skills as the other child participants. She commented it was the coach of the team who developed a good foundation in the sport which enabled him to participate in the games. Carolyn described her amazement at Keith's engagement in the game "*when (Keith) would go on the floor the whole game would slow down and the other team would agree to it, and (he) was able to participate fully.*" His teammates, the other players and coaches were accepting of Keith and supported his involvement in the space. The coach of the team played a significant role in encouraging Keith and the other youth, as Carolyn described "*he had to do what everybody else did and he had to do it the way everybody else did.*" The expectations set for Keith enabled and encouraged him to achieve the same skills as the other players.

Basketball was also important in the development of Keith's material self. For example, he developed an awareness of his body and physical capabilities while playing community basketball in his primary years. Carolyn commented that Keith was able to "*get the skills quickly.*" Keith's material self also

developed through the description Carolyn provided of Keith at the beginning of the story including his family. Keith was the youngest child in his family, he had two older sisters and was adopted as a baby. Through Keith's material self he became the protagonist in the story, he was the focus of the action and experiences described by his mother.

Another space where Keith was able to achieve success was in the community play previously mentioned. With the support of his speech therapist Keith learned the dance routine and chorus for the play. Although Carolyn was concerned about his ability to perform the skills and routines, however Keith "*ended up being the star of the show.*" In both examples Keith had a space where he was encouraged and supported to learn new skills, and was provided with an opportunity to demonstrate his success and achievements. As previously mentioned, the community play was also important in the development of Keith's social self. Through the community play Keith was able to develop his social network and connect with other people who loved performing as he did. With the support of his speech therapist, Keith challenged his mother's assumption that he could not perform to the expected standard. Keith had been able to gain valued social roles through several of his recreation experiences including the community play and basketball. In the case of the community play, Keith experienced a positive response to his involvement in the play from the other actors and the audience. The valued social role gained through basketball will be discussed below.

Space to contribute something of value was significant in Keith's story. At both the community play and his high school basketball team, Carolyn spoke of the contribution Keith made to each group and the recognition and value of that contribution by the group members. As Carolyn described Keith is very intuitive and will "*assess any tension in a group*" and is "*very good at keeping a group cohesive.*" Carolyn attributed the recognition and value of what Keith contributed to the basketball team to the team's coach. She said that on the team the coach expected the same from Keith as he did all of the players, and that he brought "*an attitude that Keith is valued for what Keith can give.*" In the community play Keith was credited with helping to create and maintain the "*best atmosphere*" the group had ever experienced.

Finally, a space to be social and have community was significant because of the friendships and social networks Keith developed through his recreational experiences. Carolyn used Keith's experience in the middle school band to explain the importance of community for Keith, "*the relationships that stemmed out of that were critical to him kind of getting through those middle years.*" She described Keith's experiences in the town where he knew everyone and he was able to say hi and talk with the people around him. The basketball team also provided Keith with a community where he developed close and supportive relationships with the players. In this space Keith developed relationships with his peers. Carolyn commented how Keith stays in touch with old teammates through Facebook and they reconnect when they are in town together.

The significant spaces for Keith provided him with opportunities to be successful, to be away from his parents, to gain valued social roles, and to be social. In addition, through these spaces Keith's material and social self were developed. I did not think that Keith's spiritual self was developed through the narrative.

Carolyn's Message: Recreation Benefits Everyone

The discussion of space and self presented above enabled me to consider the message within Carolyn's narrative. The important spaces previously identified provided insight into the importance of recreation for Keith and the important elements found within a space. Similarly, the discussion of self provided further insights into the role of recreation in the development of Keith's material self and social self. It was through the combination of space and self that I identified the important messages in Carolyn's narrative. Three main ideas about Keith stood out in Carolyn's narrative: the importance of recreation for people with disabilities, the significant and beneficial impact Keith had on others and the value of community or social networks for people with disabilities.

I thought Carolyn shared her story of Keith to emphasize the importance of recreation for people with disabilities. Programs and activities Keith participated in provided him with physical activity and social interaction, benefiting his health and his life. Carolyn commented that recreation activities and programs had provided Keith with an opportunity to get away from his family and be with other people in a social setting.

She reiterated several times the importance of social experiences for people with disabilities which can be provided in recreation activities and programs.

Carolyn had described the significant and beneficial impact Keith had on others. Carolyn witnessed and received recognition from other people for the impact Keith had on people in his recreation experiences. In her narrative, Carolyn commented that parents of boys on Keith's basketball team expressed their appreciation for Keith's involvement. She noted that the parents spoke about what Keith has given their children. She said that Keith brings the "*human side*" to a very competitive and intense atmosphere. As Carolyn said "*we live in a diverse world*" and it is especially important for young people to be exposed to difference, and to understand the value of difference and not fear it. She used the basketball team as an example of a context in which people learn to recognize and value the contributions of someone with a disability. Carolyn wanted others to understand that people with disabilities enrich our lives and our communities. She identified the importance of recognizing the value and contribution that a person with a disability can make. She explained that Keith could not fill the water bottles for the basketball team but instead was able to identify and diffuse any tension on the team. She also described his ability to develop cohesion in groups. Carolyn commented that she had no doubt that people who come into contact with Keith (e.g., Rainbow leaders, basketball players) were changed for the better.

Finally, Carolyn also spoke about the value of community or a social network to a person with a disability and the need to involve people with disabilities in recreation experiences. She reflected on the reluctance of the middle school basketball team to involve Keith, and commented some organizations and people feel "*overwhelmed*" about involving people with disabilities. Carolyn stated she thought involving Keith in the basketball team was enough for that team but suggested that if other school teams and groups could involve one person with a disability they would not feel "*so overwhelmed*." Rather than involving a large number of people with disabilities in one activity, if one or two people with disabilities were involved in each activity then there could be less pressure on parents to set up, monitor, and attend all recreation

experiences. From Carolyn's story we have gained an understanding of the value of recreation for everyone's lives as it creates spaces for people to engage, contribute and succeed.

I identified these three messages from the discussion of space and self, and through reflection on Carolyn's narrative. It was also through this reflection that I explored both Carolyn and Keith's roles as protagonists. A discussion of protagonists present in the narrative and an exploration of the internal and interpersonal conflicts found in the narrative follows.

The Shared Role of Protagonist, Experiences of Conflict and Presentation of Carolyn's Self

Carolyn's narrative focused on Keith's experiences in recreation, yet Carolyn herself also became a protagonist. Keith's role as a protagonist and development of self was previously explored in the Presentation of Self and Space. This section will focus on Carolyn's role as a protagonist in the narrative through which her material, social and spiritual selves developed. This will also include an exploration of the shared role of protagonist in the story between Carolyn and Keith. I often found other characters acted as antagonists challenging Carolyn and Keith, such as the high school administration, and his elementary school teachers. Other characters provided social support for them including Keith's Rainbow Recreation leaders, his speech therapist, and basketball coaches. The relationships and interactions with other characters show the shifting role of protagonist and the development of Carolyn's self. Three examples from the narrative describe Carolyn's social self including: the community play, extracurricular activities for Keith in high school, and the students who worked with Keith. These three examples also highlight some of the conflicts experienced by Keith and Carolyn.

Carolyn had been concerned with Keith's participation in the community play. She commented she was worried because the show was professional and people paid money to see it. She said "*they've got pretty high standards. I was a little concerned about whether he would be able to meet those standards.*" Her comment demonstrated her perceived idea that people would be uncomfortable or unsupportive of Keith in the play. There was conflict between Carolyn and Keith's speech therapist. Keith's speech therapist pushed for Keith's full engagement in the community play and she challenged Carolyn about limiting Keith's

involvement. This conflict demonstrated Carolyn's concern for her son's abilities, and also the type of support and encouragement Keith received outside of his family. This situation also presented internal conflict for Carolyn when she debated Keith's full participation in a theatre production and shared her worries about his skills and performance.

Carolyn was responsible for facilitating many of Keith's recreation experiences, and she had negotiated a place for Keith on the high school basketball team. When the school suggested that Keith be on "*garbage duty*" as his extracurricular activity Carolyn challenged the school administration, rejected the activity for Keith and demanded an activity with "*dignity*." Carolyn recognized the assumptions others would have if her son was involved in "*garbage duty*." She demanded a valued role for Keith and was able to get him on the basketball team as a manager. Carolyn experienced conflict with the principal (and other administrators) at Keith's high school. Finding Keith an extracurricular activity created conflict between Carolyn and the school administrators.

Carolyn described the challenge of students who would "*baby*" Keith instead of "*giving him the shove in the rear end that he needs*." Carolyn recognized that the students assumed Keith was incapable or required help. She said "*for us Keith is expected to do what everybody else is expected to do we don't tolerate any kind of you know 'because you're handicapped you can't do it'*." Carolyn recognized her son had a disability but was reluctant to let it define him or limit what he was capable of doing.

Carolyn's material self and spiritual self were developed in the narrative. Carolyn was as a mother of three, a business owner, and an activist. She and her husband had been involved in the disability movement long before they adopted Keith. In Carolyn's narrative I found some development of her spiritual self which was presented through her recognition of Keith's impact on others including his Rainbow Recreation leaders and the basketball players. Carolyn said that she has "*no doubt*" that the people in Keith's life had been changed by him. She went on to describe how parents of the basketball players had "*thanked*" her for Keith's involvement and "*what he's given to their child*." Another example of Carolyn's spiritual self was present when she demanded an extracurricular activity with "*dignity*" for her son. In this

case she was demanding an activity that would provide him with a purpose and recognition in school. Carolyn's spiritual self was developed through her recognition of Keith's impact on others, and her expectation that his experiences serve a purpose in his life.

Conflict was evident between Keith and Carolyn with regards to his activity participation. Carolyn described her reluctance to let him participate in activities and events because she was uncomfortable with new or unknown activities. "*He will bring home things from the programs that there's something going on and he'll want to do it and it's just not (happening).*" This also represented Carolyn's internal conflict because she believed Keith still had a level of "*vulnerability.*" She commented that participation in a new activity would "*mean a lot of work on my part to sort of figure it all out.*" Carolyn described how she discouraged Keith's participation because she was tired.

The examples of the community play, extracurricular activities for Keith in high school, and the students who worked with Keith highlighted Carolyn's shared role as a protagonist in the narrative. These experiences also highlighted the role of other characters in Keith's recreation experiences, and their roles as antagonists mainly through conflict with Carolyn. Carolyn's material, social and spiritual selves were developed through these experiences. From the examples of conflict and impact of other characters we can explore the role of power in the narrative.

The Power of Keith, Carolyn and Other Characters

I found that through conflict, power often shifted between Keith, Carolyn, and other characters. Within the narrative Keith held power in specific contexts in relation to his mother and others including his E.A.s at school. Anne was often in a position of power over Daniel and experienced a lot of conflict with other characters. I thought in Carolyn's case she was often able to retain power because of her awareness, social connections, and activism. There were however, several examples where the practitioners or leaders held power over Carolyn and Keith's involvement.

Keith experienced gains in his psychological, social and political power through the support of his mother and other characters. Keith's psychological power grew through positive experiences including

basketball, his classroom experiences, and working with his mother. When Keith was first introduced to basketball in elementary school he developed “*a really good foundation of basketball*” and was supported by a coach who expected Keith to “*do what everybody else did.*” When Keith was the manager of the high school basketball team he was recognized as making a “*valuable contribution*” by the coach and players. His experiences in basketball supported the development of Keith’s self concept as being capable and valuable. Keith demonstrated self-efficacy in his classroom where he “*demande*” from his teachers and support staff that his school experience including his workbooks and desk be the same as other students. Carolyn went on to say that “*he made it happen.*” Keith’s was able to independently exert a level of control of his school experience. Keith’s psychological power was also developed through work with Carolyn. She described how Keith worked in her office sorting boxes and cleaning, and when he finished he asked “*good mom? Are you proud of me mom?*” Keith’s ability to successfully complete tasks enabled Keith’s psychological power to grow.

Keith’s social power developed through his participation in several social groups including the high school basketball team and community play. As previously described, Keith was the manager of the basketball team and was valued for his contribution to the team. Carolyn commented that his being manager of the team was a “*huge status support*” in high school and that was the role for which he was known. Keith developed a strong social network with the players and was involved in other activities with them because of the relationship. Carolyn described that the players included Keith in dinners and swimming when away on trips and that he occasionally went to the movies or school events with them. Carolyn described Keith’s involvement in “*musicals at school*” where he gained the skills to participate in the community play. Through the community play Keith further developed his skills as an actor and learned the choreography for a “*complicated dance number.*” The development of Keith’s psychological and social power enabled Keith’s to develop a degree of political power. Keith was able to access and influence some of the decisions being made regarding his life and recreation. Carolyn commented how recently Keith was able to “*advocate for himself*” and exert some influence on decision making practices. As previously

described, Keith “*demanded*” his education appear the same as his peers in the classroom. I thought Keith had limited access to decision making practices regarding his involvement in recreation and most often it was Carolyn who made or influenced decisions regarding his involvement.

Carolyn gained political power through the development of her psychological and in particular her social power. Her psychological power was evident throughout the narrative. I thought Carolyn recognized her own abilities to get Keith involved in recreation, or to demand a level of involvement at his school. Carolyn’s social power was evident through her description of her activism and involvement in the disability movement. She has been a professional in the field of disability for “*15 years.*” Carolyn described her work in “*institutions*” and her role in having them closed in her community. She has a wealth of knowledge, experience and skills and access to a number of social organizations in the community. I thought that Carolyn had political power over Keith’s recreation experiences, and sometimes over recreation programs and leaders. Carolyn gained access to the decision making practices regarding Keith’s involvement through her participation in social organizations, and her self-efficacy. An example of Carolyn’s political power was demonstrated when the school had offered Keith “*garbage duty*” for his extracurricular activity. Carolyn rejected the idea and demanded an activity that would allow her son to have “*dignity.*” Carolyn also demonstrated her political power in Keith’s (elementary) school when she said she wanted Keith to be “*completely fully integrated*” and “*wouldn’t listen to anything else.*” Carolyn’s political power was challenged in the narrative when the middle school had “*no openness to him coming involved.*” I thought this was the only example of other characters controlling or impacting Keith’s involvement. Other characters challenged Carolyn’s power but in most cases she was able to have Keith’s involved.

I found that other characters provided support and enabled Keith’s involvement in recreation rather than challenging or denying it. Basketball coaches, the band leader, and the speech therapist were examples of people who supported Keith’s involvement. I had asked Carolyn about the role of leaders in Keith’s recreation and she said “*I think that we hit people that, that were the right people*” and often referred to them as being “*very clued in.*” The elementary and high school basketball coaches were described as

having the same expectations for Keith as for all other participants. Carolyn said the middle school band leader “took Keith under her wing” and “did great stuff with him.” In the case of the community play, the speech therapist challenged Carolyn about Keith’s level of involvement. Carolyn had described her concern with Keith’s ability to perform but the speech therapist was “determined he was going to be in it” and went on “she was right, she knew the situation better than I did, and so I thought that was pretty cool because she knew how important it was to him and obviously she had the commitment to make that successful.”

Carolyn’s narrative highlights the important role other characters had for Keith’s involvement. Keith was often able to be involved because of support provided by other characters.

The psychological, social and political power of both Keith and Carolyn were evident throughout the narrative. Keith was able to develop social and political power through his strong psychological power and awareness, and with the support of his mother and other characters. Carolyn developed strong political power through her years of experience, skills, and knowledge of disability. What follows is my reflection on Carolyn’s power in the story and the power of her story.

The Impact of Carolyn’s Narrative and Her Audience: Parents, Professionals and People

Carolyn’s story evoked frustration and amazement in me. I felt frustration when she described how in a few instances, programs or people had refused to engage Keith. I also felt frustration when Carolyn told me how some students who worked with Keith would try to baby him. She had said sometimes they would get into “because you’re handicapped you can’t do it” or they lacked expectations regarding Keith’s ability to do things. I was frustrated because I often felt the same way with Aiden when other people would do things for him or assume he could not do something. I also felt amazement throughout the story with regards to Carolyn’s commitment and dedication to Keith’s recreation experiences. She found, created and fought for his participation in recreation. I was amazed to think that with his high school basketball team she attended every practice and game with Keith. I was enthralled with what Carolyn had accomplished for her son. She was there for everything, and only now, years later she was finally stepping back a little. Can you imagine being present for everything your child has done? Dropping her son off was not an option for her even

though her family had met some really incredible leaders. I found Carolyn fascinating because of her involvement in the disability community in the area. She was opinionated because of her life and because of the life she desired for her son. She and her husband had worked for years promoting the rights of people with disabilities. Her story demonstrated to me that a person can impact his or her community. Carolyn was a warrior in her son's life, and Keith had obviously grown and benefited from her fight.

I think she told her story for other parents, for professionals and for people in general. At different times through Carolyn's narrative I felt she was telling pieces of her story for different groups. When she spoke about her involvement in Keith's recreation experiences, I felt she was sharing with other parents her experiences with finding, developing and advocating for her son's involvement in recreation. In the story of how Keith became involved on the high school basketball team, Carolyn demonstrated for other parents the results of advocating for your child and not accepting opportunities presented by someone else. Carolyn also told this story for professionals, including professionals in the fields of recreation and education to highlight the importance of involving people with disabilities and to demonstrate how involvement can be accomplished. Carolyn recognized that involving someone with a disability can be scary or intimidating but that it can be accomplished. Finally, I felt that Carolyn told her story for everyone (people connected to disability in some capacity and those who are not) to share her experiences in her struggles to have Keith involved, and how she negotiated and supported his involvement. She told her story so that other people could learn from her experiences, and realize that disability is not scary and that involvement can be accomplished.

Interpretive Analysis of Johanna's Narrative

The following sections contain the analysis of Johanna's narrative including: important spaces and presentation of self, messages from the story, an exploration of the protagonist and conflict, the role of psychological, social and political power, and finally a discussion of my reflections and the intended audience. Johanna identified space to experience success, to be social, and to be included as important for Brandon. Connected to these spaces was the development and presentation of Brandon's material, social

and spiritual self. The main messages from Johanna's narrative identified the many ways exclusion was used to prevent involvement, and the importance of planning for the involvement of people with disabilities. Discussion of protagonist and conflict shows both Johanna and Brandon as protagonists, and the internal and interpersonal conflicts experienced between Brandon, Johanna, and other characters. This section also explores Johanna's material self and social self since they are connected to, and demonstrated through, her role as a protagonist. Next, a discussion of power explores the psychological, social and political power of Brandon, Johanna and other characters. I found that Johanna and Brandon gained psychological power and social power but experienced limited political power. I found other characters held power over Brandon's involvement in recreation. Finally, my reflections on Johanna's narrative are presented in combination with a discussion of recreation practitioners and leaders her intended audience.

Presentation of Self and Important Spaces for Brandon

Significant spaces in Johanna's narrative of Brandon and his recreation experiences included space to experience success, to be social, and to be included. Brandon's material self and social self were described through Johanna's descriptions in the narrative. The development of Brandon's material and social self often occurred in the important spaces identified. His material self developed through his interactions with his family and recreation activities including sports and Beavers. His social self was further developed through recreation and the social relationships that resulted from his participation. I found little description or development of Brandon's spiritual self.

The space to experience success was important for Brandon to achieve new skills and feel accomplishment. The Beavers program and a soccer experience demonstrated the importance of the space to succeed for Brandon and Johanna. Beavers provided Brandon with an opportunity to be successful because of the design and planning of the program and activities, and the supports and resources available for him. Johanna described that Beavers enabled Brandon to try new activities alongside his peers. She described how Brandon went sledding for the first time with the support of the Beaver leader's son. The success of that experience "*opened up other opportunities.*" Johanna commented that the leader planned

ahead and was able “*modify things without making it obvious.*” When exploring future recreation opportunities for Brandon, Johanna and her husband considered the odds of him succeeding at them. Soccer highlighted Johanna’s desire for Brandon to experience success. She commented that regular participation on a full sized soccer field was “*setting him up for failure.*” Soccer and other sports were important in the development of Brandon’s material self. He developed an awareness of his body from his family who have supported his recreation experiences. Brandon was an only child, and his parents adapted their family home for his needs. Johanna described an organization which provided adapted home amenities for their family including a crib and stroller. Brandon’s intense desire to play sports was another example where his material self developed since he was unable to compete physically with his peers.

Space to be social was significant in the narratives because as Johanna described, Brandon was “*social social social.*” Brandon enjoyed having attention and being “*in the centre of things.*” Johanna described how he requested to do a presentation at an assembly in front of his school. When you consider the range of activities Brandon had been involved in, they all involve groups of people (Beavers, Rainbow Recreation, Sledge Hockey, etceteras). They are all social activities where Brandon was able to be with friends and peers. Johanna commented that the summertime was difficult for Brandon and she and her husband made efforts to maintain contact between Brandon and his friends from school. Brandon obviously enjoyed being around people, and would “*talk your ear off.*”

Finally, having space to be included was important for Brandon’s story. As previously mentioned the Beavers program had been successful for Brandon because it was a space where he was included in the program and activities as a result of the planning and preparation of the leaders. The school field trip was an example of where Brandon was being excluded from the trip. Johanna recognized the significance of Brandon being excluded and challenged the administration for his inclusion. Johanna commented that the bus ride to and from the museum was the real experience for the children, and that since Brandon was being left out of he was not being included in the trip.

Brandon's social self was developed through his interactions and relationships with others. As Johanna described, Brandon was a social person and enjoyed being around people. I did not find many examples where Brandon was acutely aware of the assumptions of others. I think he may have been aware of his disability but it was not outwardly identified or described by Johanna. Let me explain with an example. When she and Brandon are with friends Johanna said "*they are up there and Brandon and I are at the back*" and continued "*it's disheartening for him, he wants to be out there but, he just can't.*" Another example was basketball where his peers wanted the net "*way up high*" which affects Brandon's ability to participate. From this description Johanna hinted at Brandon's awareness of himself in relation to others and the impact it may have had on him.

From the descriptions it was evident that Brandon was a protagonist in the narrative since the story focused on him and was about his experiences. I felt Johanna's social self was more clearly developed through the narrative. Her material and social self will be further explored later in the section Protagonist and Conflict.

Johanna's Message: Think it Through and be Consistent

The discussion of space and self presented above enabled me to consider the message within Johanna's narrative. The important spaces previously identified provided insight into the importance of recreation for Brandon and the important elements found within a space. Similarly, the discussion of self provided further insights into the role of recreation in the development of Brandon's material and social self. It was through the combination of space and self that I identified the important messages in Johanna's narrative. Two main ideas stood out about Brandon's experiences: Johanna wanted people to understand that exclusion comes in many forms, and to understand the importance and significance of planning for the involvement of a person with a disability.

I think Johanna wanted people to understand exclusion comes in many forms and policy was often used by decision-makers as an excuse for the practice of exclusion. While Johanna noted that children with disabilities need to be, and should be included in programs and activities, she also shared her

experiences in which Brandon was included and times when he was not. To highlight the constant challenge she encountered, Johanna shared her experience of Brandon's exclusion from riding the bus on the school field trip. She described her anger toward the treatment Brandon received. In that situation there was no real reason why he was not going to be allowed on the bus. The school administrators hid behind policy documents, and displayed a lack of concern for Brandon and his experience. Johanna understood that adaptations are required for Brandon's participation but she also stated adaptations are not an excuse to leave someone out. She said that to her inclusion means "*not being left out. Not standing out in the crowd more than you usual. Being able to participate and not having it really obvious that you're doing it different.*" Johanna stated that leaders need to realize that what might not seem like a big deal to them (not riding the school bus with your friends) was a big deal to a person with a disability (sharing that time and experience with your friends).

Second, I thought Johanna also told her story to emphasize the importance and significance of planning for the involvement of people with disabilities. Johanna used the Beavers program as an example. Taking into consideration Brandon's abilities and skills in the planning of activities enabled him to participate and enjoy the activities. Johanna provided other examples where program staff had not planned for Brandon which prevented him from enjoying and fully participating in an activity or experience. She used the summer camp out-trip to the beach to highlight the impact of a lack of planning (there were many stairs down to the beach, and it took Brandon extra time to get down which meant he did not get to have the same full experience as the other youth).

I identified these messages from the discussion of space and self, and through reflection on Johanna's narrative. It was also through this reflection that I explored both Johanna and Brandon's roles as protagonists. A discussion of protagonist and an exploration of the internal and interpersonal conflicts found in the narrative will follow.

The Shared Role of Protagonist, Experiences of Conflict and the Presentation of Johanna's Self

Johanna's narrative centred on Brandon, yet Johanna herself became a protagonist too. Brandon's role as a protagonist, since he was the focus of the stories, was previously explored. This section focuses on Johanna's role as a protagonist in the narrative through which her presentation of self was developed. This also includes an exploration of the shared role of protagonist in the story between Johanna and Brandon. I often found other characters acted as antagonists challenging Johanna and Brandon, such as day camp instructors, and most distinctively the school administration. In other cases the other characters provided social support for them including Deb the Beavers leaders, and his Rainbow Recreation leaders. The relationships, interactions and conflict with other characters show the shifting role of protagonist and the development of Johanna's self. Three examples demonstrate both Johanna's role as protagonist, her social self, and the shared role between her and Brandon in this narrative. These examples include her proactive work with program leaders, the Beavers program, family friends, and the school field trip.

Johanna's material self and social self developed through the narrative and often in situations of conflict. Johanna described how she would contact organizations and leaders before Brandon became a participant. She presumed that program leaders would not understand him and his challenges. Johanna was proactive in trying to ensure a positive and adapted experience for her son to enable his inclusion in the activity or program. Johanna explained that she tried to ensure practitioners understood that "*the desire is there, the ability it just might be a little slower coming.*" She went on "*keeping up is a big thing, he just can't keep up, but it's not that he doesn't want to he just can't.*" Johanna recognized the potential limitations others might perceive about Brandon. Conflict with program leaders developed when Johanna "*couldn't seem to get through to them*" about modifications necessary for Brandon. She also described that she tried to be present with Brandon for his recreation and school activities as an "*extra set of hands*" so she can see what needs to be "*modified.*" I thought Johanna's efforts to support her son's involvement were also an

attempt to eliminate or prevent any preconceived ideas people would have about Brandon and his abilities. Her active role in his recreation also demonstrates Johanna's role as a protagonist in the narrative.

The Beavers program further developed Johanna's social self through which her own assumptions about Brandon were challenged. Johanna described her amazement when Brandon went sledding, an activity she never thought he would do because of his disability. I thought elements of Johanna's social self were developed through her description of the family's social network. She commented that when Brandon goes to visit his friends, his parents know and are friends with those families. She said "*typically he goes over to friend's houses that are friends of ours because there is no grey area there, they know him well enough that there's no issues.*" Johanna and her husband developed a close knit social network with people who shared their values. She went on to describe how their friends are "*figuring it out*" and that the other families are learning the adaptations Brandon requires. The experience of the school field trip highlighted Johanna's role as a protagonist in the narrative. In this case her description of the event was focused on her perspective and the conflict she experienced. This experience was a clear example of the power struggles faced by Johanna and Brandon, and will be explored in the discussion of power.

I thought Johanna experienced internal conflict when she described her hopes for Brandon's future recreation experiences. Johanna described that she and her husband would try to engage Brandon in activities in which he would succeed. Johanna commented, "*we can kind of steer him a direction that might be as challenging.*" She went on to say that it was "*sad...when we don't think he can do it.*" This also identifies the conflict between Brandon and Johanna where his desire to engage in an activity conflicted with Johanna's understanding of her son's abilities. Johanna commented Brandon had the "*desire*" to play sports but his disability prevented his successful engagement. Many of the characters provided support for Brandon and enabled him to have successful experiences.

Examples of her proactive work with program leaders, Beavers, family friends, and the school field trip demonstrated the shared role of protagonist between Johanna and Brandon. These experiences also highlighted the significance of other characters in Brandon's recreation experiences. Through these

experiences Johanna's social self was also developed. It is through these experiences and the conflict and impact of other characters, we can explore the role of power in the narrative.

The Power of Brandon, Johanna and Other Characters

From Johanna's narrative I found power shifted between Brandon, Johanna and other characters through conflict. Within the narrative Brandon had limited power in specific contexts in relation to his mother and others. Johanna was often in a position of power over Brandon and his recreation experiences. I also found that in the context of recreation Johanna had a stronger impact on Brandon's involvement than the program leaders. The psychological, social and political power of Brandon, Johanna and other characters will be explored.

Brandon's psychological, social and political power experienced limited development through the narrative. I thought that Brandon had a strong sense of himself as a social person, and that he gained some self-efficacy through school. For example, when the school had an assembly Brandon "*requested*" to do a presentation. Johanna said he did the presentation "*up on stage so he's not afraid of that.*" I thought that Brandon's self-concept grew through his experiences with the Beavers program because he was set up for success. Johanna commented that he tried new activities including sledding, geo-caching and a bike rodeo with the group which has "*opened up other opportunities*" for him. I thought that Brandon's social power grew through the narrative as he became involved in more recreation experiences though his mother had involved him in them. As the number of social organizations grew, Brandon was able to connect with more people and develop his social network. It was also through these experiences he developed skills. Brandon was involved with the Rainbow Recreation program, Beavers, and Sledge Hockey. He was also enabled to gain new skills through school. For example, Brandon learned to skate with the support of his principal. Brandon's experienced very limited political power in the narrative because he was not often involved in making decisions about his life. I thought Johanna had power over Brandon and would choose what activities he would be involved in. Another example where Brandon was not involved in decision making

practices was with his adapted school curriculum. Johanna described how she met with the school support team to establish "*priorities*" but made no mention of involving Brandon in this process.

Johanna's psychological, social and political power developed through the narrative. I thought Johanna's social power was connected to her psychological power and these two dimensions developed together. Johanna seemed to be very much in control of the recreation experiences in Brandon's life. Throughout her narrative she often commented about Brandon's desire to participate in an activity and would describe how or why she would limit his involvement. For example, Johanna said she and her husband "*planned*" to involve Brandon in the "*4H Club*" where she would be able to "*steer him in a direction that might not be as challenging.*" Her social power grew as she connected with social organizations and other parents. Through these connections Johanna found new recreation opportunities for Brandon. Rainbow Recreation was an example of a social organization Johanna connected with and gained information about other recreation opportunities for Brandon including Sledge Hockey. I thought that Johanna gained political power through her psychological and social power. She had power over Brandon both in his recreation and school experiences. In the case of Brandon's school, Johanna had access to the decision making process regarding his involvement. As previously mentioned, she was a member of his school support team who set goals and learning objectives. Johanna also had access to the decision making process regarding Brandon's involvement with his class trip. In this instance Johanna used her skills, knowledge and access to the decision makers (school administrators), to challenge their attempt to exclude Brandon from riding on the bus.

The Impact of Johanna's Narrative and Her Audience: Professionals

Johanna's narrative evoked an emotional response in me that I was not prepared for. Her story made me feel angry, frustrated and inspired. I was angry at the people who barred Brandon from participating in an activity, frustrated at how hard it was for her to find activities or supports for him, and inspired by her dedication and commitment to her son. By the end of her story I was ready to knock some people around for her and at the same time in total awe of how well she handled the situation. She was determined,

unrelenting, eloquent, persistent, courteous and respectful through the entire situation in spite of the treatment she and her son received.

What struck me at the end was how well Johanna understood what it was like to live in a world with the words of integration, segregation and inclusion. She had to watch her son live in a world that used these words and twisted their meaning to set up barricades preventing Brandon from fully participating in anything. Despite all of these challenges Johanna still found and raved about programs and activities that did work for her son. Parents know what works for their children, and similar to the other moms Johanna was more than willing to bend over backwards to make participation happen for Brandon. Her story impacted the way I have thought about inclusion, its meaning and the experience of it.

I think Johanna told her story intending to reach recreation professionals (program coordinators and staff, etceteras). Throughout her story, I identified two messages directed towards professionals or coordinators. First, Johanna identified herself and other parents as having valuable and useful information about their children. Johanna's knowledge of Brandon, his skills and abilities, meant she could identify potential challenges or barriers to his involvement and suggest ways to overcome them. Johanna commented that speaking with a parent "one on one" will provide more information about a child than any registration form could. Second, Johanna shared her story of Brandon's experiences so that professionals can learn to plan for the involvement of children with disabilities. This related to her suggestions about speaking to parents so that a coordinator or professional had the necessary information to support a child's involvement. Johanna told her story to help professionals learn to identify sources of information which can support the involvement of people with disabilities.

Interpretive Analysis of Leslie's Narrative

The following sections contain the analysis of Leslie's narrative including: important spaces and presentation of self, messages from the story, an exploration of the protagonist and conflict, psychological, social and political power, and finally a discussion of my reflections and the intended audience. For Steven, Leslie identified important spaces to be included or engaged, social and active, and successful or

demonstrate ability were important for Steven. Connected to these spaces was the development and presentation of Steven's material, social and spiritual self. Main messages from Leslie's narrative highlighted the involvement of parents in their child's recreation experiences, and the importance of recreation experiences for people with disabilities in providing opportunities for social networking and relationships, and the significance of family for a person with a disability. Discussion of the protagonist and conflict shows both Leslie and Steven, as protagonists, and the internal and interpersonal conflicts experienced between Leslie, Steven, and other characters. This section also explores Leslie's material self and social self as demonstrated through her role as a protagonist. Next, a discussion of power explores the psychological, social and political power of Steven, Leslie and other characters. I found Steven developed social power in the story but his psychological and political powers were limited. I thought Leslie had gained political power through the development of her social and psychological powers. Other characters exerted limited power over Steven and Leslie. Finally, my reflections on Leslie's narrative are presented in combination with a discussion of her intended audience including other parents and recreation practitioners.

Presentation of Self and Important Spaces for Steven

Significant spaces in Steven's story were space to be included or involved, space to be active and social, and space to be successful and demonstrate capability. Steven's material and social self were connected to these spaces. I did not identify Steven's spiritual self in the narrative. Steven's role as a protagonist was evident in the discussion since he was the focus of Leslie's stories.

Having space to be included or engaged was important in Steven's story and significant for Leslie. The local summer day camp was an example of a space where Steven was included in part due to the support an "*inclusion worker*" and Leslie's efforts to make the experience successful. At the day camp Steven participated in the activities with his peers. The Special Olympics swim and gym programs were important spaces where Steven was able to be included. Leslie described the program as being "*inclusive*" to everyone, and the siblings were also able to participate. These experiences contrasted with spaces

where Steven was not included. Leslie described the challenge of having Steven involved in soccer. The other coaches “*didn’t even want to try to include*” and were reluctant to engage him in their programs.

Steven’s social self was developed through the narrative. Two examples of his social self were found in his participation in the Special Olympics swim and gym programs and through his siblings. Leslie described how in the Special Olympics gym program the youth would often buddy up with each other while engaging in activities. She said the experience provided an opportunity to be “*social*” and often the youth would walk and talk with each other. Steven’s social self was also presented through his interactions with his siblings who has Leslie said “*they accept him for who he is or don’t accept him for who he is.*” She described his siblings as relentless and how they often forced Steven to do activities with them. His siblings enabled Steven to understand and perceive himself as a brother. His older sister commented to Leslie about the other siblings would go and play with friends but Steven did not. Leslie seemed more concerned about the lack of social experiences for Steven then he was. I did not think Steven was concerned with the perceptions of others and understood himself through his abilities and family.

The space to be social and active was significant because these were Leslie’s desires for her son, and were an intentional part of the opportunities and experiences he had. Leslie commented that she hoped recreation opportunities would help Steven develop his social skills and keep him from “*getting lost in his own world.*” As previously described, Leslie commented that the Special Olympics gym program was a place where Steven had some exercise and was able to socialize with other children. Rainbow Recreation provided another opportunity for Steven had been active and social. At the program Steven developed relationships with his leaders, and was swimming each week. Finally, skiing was a place where Steven could be active and have some social interaction. Steven’s father would take him up and down the mountain no matter how long each run took. She described how Steven would chat with whoever was beside him on the chairlift. Leslie highlighted the significance of providing space for Steve to be active and social with the hopes of him gaining a friend or companion from his involvement.

Steven's material self developed through his physical recreation experiences and his family. As previously described, Steven's father taught him to ski and skiing became a successful activity. His family was responsible for many of his activities including skiing through which developed an awareness of his own body. As Leslie said *"just because he has a diagnosis, that doesn't mean he can just sit around and do nothing. We are very active."* Steven's family were significant in the development of his material self. Steven's two younger brothers were important characters in his life. Leslie described that one brother would not relent until Steven would play with him. When the youngest brother was born Steven took on a very protective and nurturing role.

Finally, having space to be successful and demonstrate ability was important in Steven's story because it showed his skills and abilities, and provided recognition for his accomplishments. Skiing provided Steven with a space to participate alongside his peers from school and he could astonish his teachers with his abilities. Leslie commented teachers were *"blown away"* and *"shocked"* to see how good he was at skiing. Skiing was a space where Steven has been able to gain skills, and successfully demonstrate his capabilities to others. The Special Olympics track and field program has been another place where Steven experienced success. Leslie said Steven had won numerous medals in *"the 100 meter, he's done relays, he's done standing long jump, running long jump and shot put"* through competitions.

Leslie's Message: Keep Your Child Engaged Even if You Have to Do It Yourself.

The discussion of space and self presented above enabled me to consider the message within Leslie's narrative. Important spaces previously identified provided insight into the importance of recreation for Steven and about the important elements found within a space. Similarly, the discussion of self provided further insights into the role of recreation in the development of Steven's social self and material self. It was through the combination of space and self that I identified the important messages in Leslie's narrative. Three main ideas stood out about Daniel's experiences. First, parents are often required to be heavily involved and committed in their child's recreation experiences. Second, recreation experiences are

important for people with disabilities as they provide opportunities for social networking and relationships.

Third, Leslie described the significance of family for a person with a disability.

First, it was apparent that Leslie and her husband have been heavily involved in Steven's recreation experiences. They have been responsible for finding, facilitating, and even running many of the programs in which Steven has participated. I thought Leslie told her story to show people how much time and energy she and a small group of others put into creating recreation opportunities for children with disabilities. I thought she wanted to bring awareness to the needs of children with disabilities and their families, and the need for recreation opportunities to be provided by other people. Leslie described the exhaustion of being the one person doing everything.

Second, recreation experiences provide social opportunities for youth with disabilities. As Leslie commented, the social side of life can be difficult for people with disabilities. She commented that Steven had a lack of friends, social networks or groups in comparison to his siblings and she found his loneliness the "*hardest part*." Leslie said recreation experiences provided opportunities for Steven to socialize with his peers and develop a social network.

Third, the importance and significance of family was a distinct message in Leslie's story. She commented on several instances how the family (parents and siblings) share all sorts of recreation experiences including skiing, sports and community events. Steven's family was very active and engaged in a range of activities, and this meant Steven participated in many of these same activities. Steven's siblings were important because they provided Leslie and her husband with a degree of comparison. Their other children were involved in a range of activities. This prompted them to ask "*well why can't Steven?*" As a result Steven was involved in a range of recreation experiences he might not have otherwise experienced.

I developed three messages from the discussion of space and self, and through reflection on Leslie's narrative. Through this reflection I explored both Leslie and Steven's roles as protagonists. A discussion of protagonist and an exploration of the internal and interpersonal conflicts found in the narrative follows.

The Shared Role of Protagonist, Experiences of Conflict and the Presentation of Leslie's Self

Leslie's narrative centred on Steven, yet Leslie herself also became a protagonist. Steven's role as a protagonist, since he was the focus of the stories, was previously explored. This section focuses on Leslie's role as a protagonist in the narrative through which her presentation of self was developed. This also includes an exploration of the shared role of protagonist in the story between Leslie and Steven. I often found other characters acted as antagonists challenging Leslie and Steven, such as other parents and the soccer coaches. In other cases the other characters provided social support for them including his Rainbow Recreation leaders and his family. Relationships and interactions with other characters show the shifting role of protagonist and the development of Leslie's self. Three examples demonstrate Anne's role as protagonist, her social self, and the shared role between her and Daniel in this narrative. These examples include soccer, Steven's school, Rainbow Recreation and the Special Olympics programs.

Steven shared the role as protagonist with his mother throughout the narrative. I felt the story was as much about Leslie's experiences as it was about Steven's. This is not a criticism but rather a recognition and acknowledgement of the level of Leslie's engagement in Steven's life and recreation experiences. Leslie was present for nearly all of Steven's experiences and often seemed more affected by the experiences than her son. It also was the case that Leslie or her husband created a number of the programs in which Steven participated. Throughout the narrative Leslie wove her feelings and described her experiences in parallel with Steven's. Leslie's material self was developed through her awareness of her role as a mother. She frequently made reference to being a mother, her other children, and the family. Leslie said "*we're involved with all the children's lives*" she went on to describe her feeling of needing to stay with Steven while with the "*other children you can drop (them) off and come back later.*" Leslie was very involved in Steven's recreation, and through this involvement her social self was developed.

Leslie's social self was woven throughout the narrative and was heavily intertwined with Steven's experiences. Her social self developed through her interactions with other characters including other parents

and coaches, and school staff. Leslie described her experiences with other parents and coaches. The soccer coaches refused to engage Steven, and Leslie said other parents would often comment on Steven's "disruptive" behaviour. She went on to describe how she had an "impression" from other parents that they thought Steven should not be a participant. Leslie spoke again of her "feeling" from other parents in the Beavers program. While leaders were supportive of Steven's involvement, other parents disagreed with Steven's presence. Leslie clearly understood the feelings from other parents and perceived their rejection of her son's participation. Leslie's social self was also developed in interactions with Steven's school staff. She commented that since Steven was the first in his school with his disability he has "changed some of the perceptions." She found teachers would assume Steven could not be successful in certain classes (for example, Technical Education), however, he would end up succeeding because of his determination and work ethic (building a perfect shelf).

Interactions with coaches and other parents demonstrated interpersonal conflict between Leslie and other characters, and internal conflict experienced by Leslie. As previously mentioned the soccer coaches were reluctant to engage Steven in the program, and what resulted was Steven's father coaching the team. Leslie said she "stopped asking" if Steven could participate because "there just seemed to be nothing out there...and then when you approached somebody they were like scared off." Leslie said "everything is a fight" to have him involved and she was "exhausted" and "frustrated" with the lack of programs and opportunities. Leslie often experienced conflict with other parents who passively challenged or disagreed with Steven's participation. In the case of soccer Leslie said, "I always had that impression that, other parents are saying, like, 'Oh look at that child he's so disruptive'. You had that peer pressure surround you. I was leaving there in tears so it was easier just to not go through that." Another example of conflict between Leslie and other parents was identified when Steven attended his middle school prom. Leslie said other parents were asking her why she was there because her other children were older or younger. She had to remind them that Steven was graduating, she said "it was as if he didn't exist to them." Despite challenge

and conflict with other parents and coaches, Leslie and Steven did experience support from other characters.

Rainbow Recreation and the Special Olympic programs were two other examples of Leslie's role as a protagonist in the story. When Leslie described Steven's involvement in the Rainbow Recreation program she also commented that she used to be a leader in the program years before. I thought that Leslie shifted the focus of her narrative from Steven to herself when she described the Special Olympics programs. Throughout her description of the Special Olympics programs Leslie wove her story of developing the programs with Steven's experiences in them. She described the activities of the gym and swim programs, their development and the rationale for developing them, and then moved on to describe Steven's experiences in the program. The Rainbow Recreation and Special Olympics programs also identified some of the supportive characters in Leslie's narrative. In the Rainbow Recreation program Steven was eventually partnered with a male leader with whom he developed "*an instant bond.*" The Rainbow leader was able to engage Steven in activities he would otherwise not have done including swimming. In the Special Olympic programs there were program leaders and other participants who supported Steven's involvement. Leslie described the volunteer swim instructor as being "*aware of everything*" and enabled all the children to participate.

The examples of soccer, Steven's school, Rainbow Recreation, and the Special Olympics programs demonstrated the shared role of protagonist between Leslie and Steven, and the development of Leslie's social and material selves. I did not find much development or reference to Leslie's spiritual self. These experiences also highlighted the role of other characters in Steven's recreation experiences but as supporters and as antagonists. It is through these experiences, the conflict and impact of other characters we can explore the role of power in the narrative.

The Power of Steven, Leslie and Other Characters

In Leslie's narrative I found that power shifted between Steven, Leslie and other characters most often through conflict. Within the narrative Steven held power in specific contexts. Leslie was often in a

position of power over Steven but was often overpowered by other characters. I also found that in the context of recreation the practitioners or leaders often held power over Leslie and Steven's involvement but Leslie reclaimed power by developing recreation opportunities for Steven. The psychological, social and political power of Steve, Leslie and other characters will be explored.

Steven experienced gains in psychological power and some social power through the narrative. I thought he experienced low political power since he had limited access to decision making practices. He gained psychological power through his success in the Special Olympics track program where he "*won about eight medals.*" Leslie said they taught Steven to "*work through*" or "*deal*" with the challenges in life. For example, when they took Steven to the spring parade, Steven learned to "*plug his ears*" whenever a fire truck went past. His parents enabled him to cope with or manage situations and experiences he did not like. Steven gained some social power through participation in the Rainbow Recreation program where he developed new skills with the support of his leader. Steven became a part of a social organization at school, the ski club. The ski club enabled him to develop skills and expand his social network. I thought Steven had little control over his participation in events, and that Leslie chose what he participated in even if "*he doesn't want to do something.*" She went on to explain, "*we wanted him to be involved so we, we maybe rocked his world a little bit by forcing, and force is not a good word, you know, making him do things even when he said he didn't want to.*" I found Leslie often made decisions regarding Steven's involvement and that the two experienced conflict throughout the narrative. For example, Leslie said they "*will make him go*" to his middle school prom despite Steven's lack of interest in the event. Leslie commented that they had to "*drag*" Steven to events or program but "*once he was there he was fine.*" Since he had little control regarding his involvement and limited access to decision making practices Steven had low psychological power and political power in particular.

Leslie's psychological, social, and political powers were strong in comparison to Steven's and developed through the narrative. Leslie's psychological power was developed through her strong self concept as a mother, and her capability of finding or creating recreation opportunities for Steven. I thought

Leslie recognized the power of others to limit Steven's involvement but this did not restrict her. Consider the soccer experience as an example. As previously described, the soccer coaches did not involve Steven on their teams. Instead of accepting their power to control his participation, Leslie's husband created and coached a team that included Steven. Two examples demonstrated Leslie's social power: access to information and funding for an inclusion worker at summer day camp, and her connections to social organizations. She was able to access funding through a "grant" for an "inclusion worker" to support Steven at summer day camp. Leslie accessed the grant information through the town recreation department. I thought Leslie had access to, or was involved, in a number of social organizations including: Rainbow Recreation, and the Special Olympics programs. In the Special Olympics program Leslie used and gained skills and information to create an "active" and "social" recreation experience for Steven and other children with disabilities. She described how the program developed because she had been a volunteer for the Special Olympics with "adults", and along with "a group of parents" decided to develop a "youth program." Leslie's political power developed because of her psychological and social power. I thought that she had power over Steven's involvement in recreation and said they sometimes "made" him participate because "we thought it was best for him." I also found that other characters had power over Leslie and Steven's involvement in recreation. Leslie commented that there were limited recreation opportunities for children with disabilities in their area. She said "there's lots of stuff for kids...right? but there's nothing...well there's nothing inclusive." She described the challenge of other characters including coaches and recreation leaders because "they just don't understand." Leslie reclaimed power when she created recreation opportunities for Steven.

I found in Leslie's narrative other characters held some power but I thought that she and her husband worked very hard to retain power to shape Steven's recreation experiences. Other characters who held power in the narrative included other parents, coaches, and teachers at Steven's school. Experiences with other parents and the soccer coach were previously described. Other parents gave Leslie the "impression" that Steven was "disruptive" or the "perception" that Steven should not be there. She went on

to describe how she would “*leave in tears*” and said that “*it’s not worth it.*” The soccer coaches had power to refuse Steven’s involvement on their teams and how they “*didn’t even want to try to include him.*” I thought Leslie recognized the power held by others but refused to be limited by it. I thought Leslie had a similar experience with Steven’s school where the school staff controlled Steven’s involvement in certain classes but Leslie was able to effectively challenge their power. She had described the teachers’ concerns with Steven in “*Tech Ed*” because they thought “*oh Steven will never be able to handle the noise, or this or that*” and she went on to challenge them saying “*don’t say no, let him try.*”

In the narrative I found that power was most often held by Leslie. She gained psychological, social and political power through her capabilities, control, and access to funding and social groups. I thought that Steven gained social power through his involvement in the ski club but his political power was limited because he was not involved in decision making practices. Other characters exerted some power over Leslie but I thought she refused to accept it.

The Impact of Leslie’s Narrative and Her Audience: Parents and Recreation Professionals

Leslie’s story made me feel in awe of her commitment to her son and his experiences. I also felt frustration and anger toward parents and leaders who rejected Steven, and I reflected on Leslie’s internal conflict with the idea of inclusion. Leslie created many of the programs her son participated in as a response to the lack of programs, or to Steven’s exclusion from existing programs. Leslie and her husband were dedicated to providing Steven with recreation experiences. I was also amazed to hear Leslie describe her resourcefulness in finding Steven opportunities and her ability to gain funding (often through grants) to support his involvement. I felt frustration toward many of the people described in her story who challenged Steven’s right to be at an activity or event. I was angry when she told me she used to leave in tears because of the comments and responses to Steven from other parents. I was angrier when she told me how some program leaders would not even consider involving Steven. These experiences in her story made me feel disappointment. I became contemplative when I thought about the experience of inclusion in her story. Leslie described her internal conflict over whether to support the idea of inclusion or not. She recognized

and articulated challenges to inclusion. Ultimately she wanted her son to have the best opportunities, support and education possible and she realized this might not happen in a 'regular' school program. Leslie's story impacted the way I think about inclusion and what is necessary to make it work.

I think Leslie told this story for other parents and for recreation professionals. I think Leslie told her story for all parents regardless of whether their child has a disability. She commented that other parents were a source of frustration for her and she often left leisure and community spaces upset by the comments and actions of other parents. I think Leslie wanted parents to know and recognize the impact they can have on the people around them. In Leslie's story we can see she and her husband made a significant commitment to her son's recreation experiences. The high level of commitment by Leslie—creating programs, attending activities to support Steven or advocating for his right to participate—has clearly taken a toll on her. By telling her story of Steven, Leslie described for recreation professionals a lack of opportunities and openness for her son. This story can help professionals recognize the need for more opportunities in their programs and activities.

Interpretive Analysis of Rebecca's Narrative

The following sections contain the interpretive analysis of Rebecca's narrative including: important spaces and presentation of self, messages from the story, an exploration of the protagonist and conflict, the role of psychological, social and political power, and finally a discussion of my reflections and the intended audience. For Clara Rebecca identified important spaces to be social, engaged and challenged, and perform or express as important for Clara. Connected to these spaces was the development and presentation of Clara's material, social and spiritual self. Main messages from Rebecca's narrative were that inclusion does not work when people try to make someone fit, and each person with a disability should be afforded the same treatment. Discussion of the protagonist and conflict shows both Rebecca and Clara as protagonists, and the internal and interpersonal conflicts experienced between Clara, Rebecca, and other characters. This section also explores Rebecca's material self and social self since they demonstrated through her role as a protagonist. Next, a discussion of power explores the psychological, social and

political power of Clara, Rebecca and other characters. I found that Clara experienced some psychological and social power but had limited political power, whereas Rebecca had strong psychological, social and political power. I did not find that other characters took power from Rebecca and Clara, rather they provided support for their involvement. Finally, my reflections on her narrative are presented in combination with a discussion of Rebecca's intended audience including other parents and recreation practitioners.

Presentation of Self and Important Spaces for Clara

In Rebecca's narrative there were three important spaces for Clara: space to be social and develop relationships, space to engaged and challenged, and space to perform or express. Clara's material and social selves developed through these spaces. I did not find development of Clara's spiritual self in the narrative.

Clara's material self was developed through her family, and home experiences. As Rebecca described Clara loved movies but had her own opinions about which to watch. Clara does not like scary or emotional movies so she does not watch them. Clara seemed to enjoy being in small groups or on her own, Rebecca said she would rather "*withdraw from society and do her own thing.*" Rebecca described a number of activities the family does at home including karaoke, dress-up and T-ball. When Clara participated in a recreation activity outside of the home she was typically with her mother and often other family members. The narrative focused on Clara's experiences in recreation. Rebecca described important spaces and experiences as they related to Clara making her a protagonist.

Space to be social and to develop relationships was important in Rebecca's story of Clara. Being social and developing relationships was important because her recreation experiences were more positive when she knew her leaders, developed a connection with them, and when the leaders understood her. Rainbow Recreation was an example of a place where Clara was able to develop a close relationship with her leader which enabled her to have a successful and positive experience. Rebecca said it was because the leader understood Clara and was attuned to her emotions and "*picked up on her cues.*" The leader was able to keep her engaged in activities and find places where she would continue to participate. It was also

important for Clara to have spaces to be social and build relationships because of the support she gained through those relationships. Another space where Clara was able to experience social interaction with a number of people is at the community church her family attends. Rebecca commented how in the church Clara is known by the entire congregation and said they have been “*really supportive of her.*” Exposure to social environments enabled Clara to develop relationships.

Having space to be engaged and challenged was important for Clara’s growth and development. Rebecca described the importance of Rainbow Recreation for Clara because it exposed her to “*kids and chaos and noise.*” Participation in the program enabled Clara to learn to deal with these challenges with the support of her leader. The flexibility of the programs also provided Clara with the space to move between activities and groups depending on her mood. In the program Clara engaged in individual or group activities, and worked on skill development. The church youth programs were another space where Clara experienced some levels of engagement and challenge, though not to the same degree as with the Rainbow program.

Finally, having space to perform and express was significant because as Rebecca said, Clara will do anything “*if she thinks she can get a laugh*”. Rebecca described on several occasions Clara’s performances including karaoke at home and in the church play. Clara will “*sing and sing and sing as long as she has a microphone*” at home with the family karaoke machine. Rebecca described how Clara acquired a role in the church play of the Lion King where she would be singing with a microphone in front of the whole congregation. She described Clara’s reluctance to participate in previous plays but found giving her an actual role and a microphone made Clara very happy. It seemed to me Clara enjoyed the attention and spotlight of her individual role rather than being a part of the chorus group. The church has also enabled Clara to “*express*” herself through music and when she likes a song she will dance in the aisles.

Clara’s social self developed through her understanding of her surroundings. The spaces identified above were often where Clara learned about herself. Clara recognized when she was being treated differently. As Rebecca described in the soccer example, Clara “*didn’t like it because it wasn’t really ‘the game’.* She’d get a kick in but it wasn’t that she was trying to score a goal or anything like that either.” The

soccer experience was “*frustrating*” for Clara because she recognized how her participation was different than the other children. Clara seemed to know she was being treated differently. Rebecca described a similar experience with the church play where Clara did not want to be involved until she had her own role. When Clara had been in the chorus she was “*like well everybody’s doing it, they don’t really need me.*” Clara’s social self developed through her interactions with others, and an awareness of how others were treating her. I did not find Clara’s spiritual self to be developed in the narrative.

Rebecca’s Message: I Appreciate Your Effort But She Will Not Always “Fit”

The discussion of space and self presented above enabled me to consider the message within Rebecca’s narrative. The important spaces previously identified provided insight into the importance of recreation for Clara and about the important elements found within a space. Similarly, discussion of self provided further insights into the role of recreation into the development of Clara’s material, social, and independent self. It was through the combination of space and self I identified the important messages in Rebecca’s narrative. I found two messages in Rebecca’s narrative that inclusion does not work when people try to make someone fit, and each person with a disability should be afforded the same treatment. The messages will be further discussed below

First, inclusion does not work when people try to make someone with a disability fit. Rebecca’s narrative demonstrated how people with a disability should have opportunities to be included there are times when it is reasonable to say inclusion or involvement is not working. Though many people do make great efforts to include children, there are instances when inclusion does not work because not every child will fit with every activity and environment. As Rebecca described, at times it seemed like people were trying to make Clara “*fit*” and there were times and places where Clara simply did not. Rebecca commented that often practitioners in those situations were frustrated when they could not make it work, but Rebecca did not think this was a failure or was negative. She recognized the efforts made to engage Clara but acknowledged that it was not always be possible.

I thought Rebecca wanted people to know each person with a disability should be afforded the same treatment. I believe Rebecca told this story to highlight how each person with a disability should be afforded the same treatment and support no matter their diagnosis. Rebecca described her concern with the range in levels of support for different disabilities. She described how if you had disability A you seemed to be fast tracked and provided with more resources, but if you had disability B or C you were put on a waiting list and provided with substantially less support. I think Rebecca identified this unbalanced approach to disability to highlight the discrepancies found within what she thought should be fair systems and policies.

I identified these messages from the discussion of space and self, and through reflection on Rebecca's narrative. Through reflection I explored both Rebecca and Clara's roles as protagonists. A discussion of Rebecca as protagonist and an exploration of the internal and interpersonal conflicts found in the narrative follows.

The Shared Role of Protagonist, Experiences of Conflict and the Presentation of Rebecca's Self

Rebecca's narrative focused on Clara, yet Rebecca herself also became a protagonist. Clara's role as a protagonist, since he was the focus of the stories, was previously explored. This section focuses on Rebecca's role as a protagonist in the narrative through which her presentation of self was developed. This will also include an exploration of the shared role of protagonist in the story between Rebecca and Clara. I often found other characters provided more support than challenge for Rebecca and Clara including Rainbow Recreation leaders, and the church community. The relationships and interactions with other characters show the shifting role of protagonist and the development of Rebecca's self. Three examples demonstrate both Rebecca's role as protagonist, her social self, and the shared role between her and Clara in this narrative including soccer, the community church, and other recreation activities.

Rebecca's material self and social self were developed through her interactions with other parents and characters in the narrative. Rebecca acknowledged her role as a mother and was aware of her impact on children's recreation experiences. Rebecca contrasted herself with the other parents when she described

Clara's soccer experience. While other parents sat and watched their children play soccer, Rebecca was "*an active participant*" trying to keep Clara "*in check*." I did not think Rebecca's spiritual self was developed in the narrative. Rebecca was heavily intertwined with Clara's narrative since she attended most activities with her and even described herself on one occasion (soccer) as a "*participant*" alongside her daughter.

When Rebecca described the church play she was directing, she became a protagonist as the description and focus of the experience was hers. After she described her role in the production and how she got "*the whole Sunday school organized*", she then moved to describe Clara's experience. I thought her description of the play demonstrated the shift between of protagonist between Clara and Rebecca when she said "*well it's the third one that I've done, and she's been a part of.*" Rebecca experienced mild conflict with Clara during the church play. From her roles in the previous plays, it seemed that Clara wanted her own role and not to be a part of the group. Clara developed her own role when she kept telling Rebecca how the choir "*was not singing it right.*" After several reminders from Clara, Rebecca handed her a microphone and said "*why don't you get up and sing it with them.*" Beyond the scope of the play, the church was "*really supportive*" of Clara and provided Rebecca with a group with whom she shared similar value of family.

From other recreation experiences in the narrative, Rebecca's social self and role as a protagonist were further developed. Consider the examples of summer camps and the activities Clara did not participate in. In the summer camp programs, Rebecca experienced a combination of internal conflict, and interpersonal conflict with leaders. In this case Rebecca based her description on her son's experience at the camp and her perception of them. Rebecca said she was hesitant to "*trust*" in the training and competencies of the young day camp leaders. As Rebecca described through her son's experiences in the summer camp, she was not impressed with their lack of "*control, authority or interest.*" The program leaders in this instance did not demonstrate the capability to support Clara and engage her in the programs. She went on to identify her potential concerns with Clara's participation knowing that her daughter would require "*100% supervision.*" She said it was not "*fair*" for Clara to pay the same rate as other children when she required extra support. Rebecca also experienced internal conflict with regards to the family schedule

conflict and participation in recreation activities. She described the difficulties in arranging weekday recreation experiences when she and her husband arrived home late and would then have to drive a distance back to town for a program when they were “*tired*.” She went on to say “*it’s not that I wouldn’t like her to, it’s just that, it’s just kind of not fitting in the whole*.” Rebecca experienced internal conflict regarding Clara’s involvement in other recreation experiences.

The examples of soccer, community church, and other recreation activities demonstrated the shared role of protagonist between Clara and Rebecca. These experiences also highlighted the role of other characters in Clara’s recreation experiences, and the support they provided her and Rebecca. Rebecca’s social self was developed through these experiences. It was through these experiences, the conflict and impact of other characters we can explore the role of power in the narrative.

The Power of Clara, Rebecca and Other Characters

In Rebecca’s narrative I found that power shifted between her and other characters but she was most often in power. Within the narrative Clara experienced limited development of her psychological, social and political power. Rebecca was often in a position of power over Clara and other characters, and her three types of power were well developed through the narrative. I found in the context of recreation the practitioners or leaders had little power over Rebecca.

In the narrative I found Clara’s psychological, social and political power increased or developed through her experiences. Clara did not have control over her participation in many activities, it was her mother who decided what recreation experiences she would have. Rebecca had described Clara’s preference for being on her own where she would not “*have to deal with anybody*.” Rebecca commented how the Rainbow Recreation program provided Clara with “*exposure to other kids and chaos*” which has enabled her to develop some “*tolerance*.” I thought this demonstrate Rebecca’s power over Clara where she insisted on her involvement. Clara’s social power increased through her participation in the Rainbow Recreation program because it enabled her to gain and develop skills. Clara’s leader was very “*sensitive*” to her and helped her “*work on different skills in the mediums that she liked*.” I thought the community church

provided Clara with an opportunity to develop her psychological and social power. Rebecca described Clara's role in the church play as *"good for confidence."* Clara's psychological power grew when she *"developed"* her own role in the play. Clara gained some control since she experienced a level of *"flexibility"* in the church where she was free to move between Sunday school classes and up to the congregation. Clara also seemed to have a level of control regarding her participation in other events including the spring parade. Rebecca had created a situation with the support of a friend where *"if Clara decided that she had enough"* she could leave. In this case Clara gained some political power because she was able to be a part of the decision making process whether to stay with the parade. However, with regards to other recreation experiences Clara seemed to have little impact on the decisions of participation.

In the narrative I found Rebecca had power in nearly every situation. She was a very involved and in Clara's recreation experiences and facilitated her participation in them. Rebecca's psychological power was evident in her description of Clara's recreation experiences. She described her involvement driving Clara to and from many most of her activities. Rebecca's psychological power was also highlighted in her control and facilitation of the recreation experiences including staff support. Rebecca also described how she will test programs with her son to determine if Clara could participate. For example, when Rebecca spoke about local summer camp for Clara she commented that she *"could not trust"* putting Clara in the program after her son's experiences. She commented how she would consider the *"structure"* and *"staff"* when considering an activity for Clara. Rebecca controlled the recreation experiences of Clara (and her bother) in part due to where the location of the family home and her work schedule. Rebecca commented described her desire for Clara to participate in other activities but often she and her husband are *"too tired"* to drive back to town. Rebecca was connected with many social organizations including a child support centre through which she connected with many recreation opportunities for Clara. Rebecca's work in the health field also provided her with access to *"resources."* Rebecca had access to information through social organizations including her attendance at a conference on disability.

Through her psychological power and social power Rebecca's political power increased. I thought Rebecca had access and was able to influence decision making practices regarding Clara. She typically initiated Clara's involvement and would try to arrange for Clara's support in the activity by either providing a support person, herself or her mother. Rebecca did not experience much challenge from other characters rather she received support for Clara's involvement. I thought she experienced some challenge from recreation leaders who would "*try to make Clara fit, and she doesn't always fit.*" She went on, "*I think it's more frustrating for them because they failed to get her to be a part of the group.*" In this case, Rebecca was challenging the program leaders desire to involve Clara. Other characters provided support for Clara and Rebecca rather than challenging their involvement in a recreation experience.

The Impact of Rebecca's Narrative and Her Audience: Recreation Professionals and People Connected to Disability

Rebecca's story made me feel excited, surprised and reflective. Rebecca reminded me that having a child with a disability is an all encompassing lifelong challenge. Rebecca embraced her role as Clara's mother and was determined to provide her daughter with positive recreation experiences. Her story excited me because of all the fun, positive recreation experiences Clara had. Rebecca was enthusiastic about sharing Clara's experiences and that in turn made me excited about them. Rebecca's story surprised me because she raised interesting points regarding the involvement of Clara in recreation. Being from an urban area I was surprised to be reminded about the impact of living anywhere outside of a town or city centre can be one the largest challenges for participation. Rebecca also raised interesting ideas about how including Clara is great but not at the expense of another child. I was surprised. Rebecca was the first person to articulate this internal conflict. Rebecca's story made me reflect on the involvement of people with disabilities in mainstream or "*normal*" programs.

I think the intended audience was professionals in recreation or people who have a connection to a person with a disability. As mentioned above, Rebecca noticed differences in the treatment of people with disabilities. I think she wanted professionals to recognize there are different levels of treatment and support

depending on the diagnosis. For professionals connected to disability this story helps to develop an awareness of the supports in place for varying disabilities, and making efforts to balance them. For recreation professionals the same idea applies. I also think from Rebecca's story, recreation professionals can take away the message that although inclusion is the goal, it is not always possible and that it is alright if someone with a disability, like Clara, is not able to participate in every activity or program.

Discussion of Narrative Analysis in Phases One and Two

The following section reviews: the important spaces and presentation of self, messages from each story, the role of protagonist, conflicts, and the impact and audience of each narrative. The discussion of power (psychological, social and political) will be woven through. I found that power is connected to experiences or elements described in each section, and thus will be discussed as relevant. Each section will review the important experiences from each narrative, and will explore them in relation to the relevant literature.

The Important Spaces and Presentation of Self

In each parent's narrative, important *spaces* were identified for their contribution to the recreation experiences of the child. I understand the concept of space not by a physical definition which would entail a physical place but rather space as a feeling created by people, programs and experiences. The important elements of space and time from each story were: (Anne and Daniel) space to succeed, to be social, and to be "normal"; (Carolyn and Keith) space to be away from parents, to develop skills and accomplish success, to contribute something of value, and to be social and active; (Johanna and Brandon) space to experience success, to be social, and to be included; (Leslie and Steven) space to be included or engaged, to be social and active, and to be successful or demonstrate capability; and (Rebecca and Clara) space to be social and have relationships, to be engaged or challenged, and to perform or express. It is interesting to note that there were common elements of space found in many of the narratives though this is not generalizable outside of this study. Space to be social was important in all five of the narratives. All of the parents

commented on the challenges and importance of socializing their children. Other common elements included having the space to succeed, and the space to be engaged or included.

Space to be social is important because social relationships between people with and without disabilities can result in the development of friendships which ultimately enable people with disabilities to gain social roles valued by society (Hutchison & McGill, 1992). This connects with Carolyn's identification of the need for her son to have space to contribute something of value. Consider Keith's experiences in high school where he went from "*garbage duty*" a devalued social role to manager of the basketball team, a valued social role (Thomas & Wolfensberger, 1999). Through social relationships people with disabilities are enabled to develop valued social roles.

Time frames helped to place the story and experiences in context. In the narratives the parents spoke of both past timeframes for their children, described current experiences, and occasionally commented about the short and long term future. Since I had asked the parents to tell me about their children's experiences, most parents started at the beginning of each child's life and proceeded, often chronologically, through the child's recreation experiences. I felt there was often a shift in time through the stories. For example, when parents were describing specific recreation experiences of their children (basketball, summer camp, etceteras) they spoke in past tense. When I asked for more information or an evaluation of that experience, the parent would shift to the present. I also found that the future (or reference to the future) was most often used towards the end of the narratives. When parents commented on the future it was often with concern and uncertainty for what it would bring. Several of the parents questioned what their child would have or do once high school ended. The parents also spoke about time in reference to the age of the child. They would describe events or experiences that had happened when the child was 'x' years old.

The material *self*, *social self* and *spiritual self* were portrayed in relation to recreation and leisure spaces. In my analysis I realized that there were two representations of self and explored the shared role of protagonist between parent and child. The shared role of protagonist developed because each of the

parents was responsible for facilitating or negotiating recreation opportunities for the child. I found the parents described their own experiences while describing the child's experience. Since there were two protagonists, I explored the presentation of self for both parent and child. The protagonist was defined as "one who takes the leading part in a drama; the chief character of a novel or story in or around whom the action centres; the spokesman or leader for a cause, the principal mover; an active participant, the supporter of an idea or action" (Oxford University Press, 2008, para. 1). This definition of protagonist provided a broader understanding of both who and what a protagonist is and his/her role in the story. This definition accommodated the complex roles of both parent and child in these narratives. I found the child was the focus of the action and central to the story. The parent often became central to the action of the story as well and was an active participant in the experience, or as defined above was the spokesman, leader, and supporter of the child (Oxford University Press).

Parent's Messages

The messages from each parent's story were identified and examined. Anne identified a lack of recreation opportunities, concern for her son's social isolation and described recreation programs as sources of social networking and support. Carolyn described the importance of recreation for children with disabilities, the impact her son had had on others, and importance of community or a social network for people with disabilities. Johanna identified practices of exclusion and policies being used against children with disabilities, and described the important of planning for the involvement of children with disabilities. Leslie identified the involvement and commitment in recreation of parents, the development of a social network through recreation, and the significance of family for children with disabilities. Rebecca described practices of inclusion are not always successful, and highlighted the differences in support and resources depending on the diagnosis of a disability.

Several of the messages from the parent's stories connect to the literature previously explored in Chapter Two. Three of the parents spoke about the development of a social network through recreation for their children and for themselves. Hutchinson and McGill (1992) had identified friendship as a unique

component of integration which can help people focus on each other's positive qualities and commonalities rather than emphasizing the differences that exist between them. Friendships can lead to the development of valued social roles for people with disabilities (Hutchinson & McGill). This was evident in Carolyn's narrative where Keith became valued for his contributions to the basketball team through the friendships he developed with the players. Huws et al. (2001) described the feelings of isolation parents of children with disabilities often experience. Both Anne and Johanna had commented that (their children's) recreation provided an opportunity for them to develop or broaden their social network and supports since they would meet and connect with other parents at or through the activities/programs. Social relationships were also a component of Carolyn's description of the impact her son had had on others. This could be connected to Devine's (2004) description of recreation as being a place where social change could happen through social interaction. Carolyn commented that she thought others were changed because of their interactions and relationships with her son. Finally, the importance of family for children with disabilities was described by Baker and Donnelly (2001) and was highlighted in Leslie's story. I found that the immediate family, parents in particular were important in every narrative. Leslie described the significant role her son's family had had on his life. These close social bonds demonstrate thick trust in the families which developed through their daily contact (Arai & Pedlar, 2003).

The development of social networks parallels a method through which a person gains or increases social power. Arai (1996) had described how a person can increase social power through "participation in social organizations" (p. 29). In the case of the parents, their child's participation in an organization such as Rainbow Recreation enabled them to connect with other parents and expand their social network. When the parents were a part of a social organization they often gained knowledge, skills and in one case access to financial resources which all contributed to the growth of their social power. With regards to the children, they developed social power through participation in social organizations. Each of the parents had involved her child in recreation experiences involving other children including: sports teams, the Special Olympics, Rainbow Recreation, and the Beavers program. In these programs the children were able to interact and

develop relationships with their peers. The recreation programs described demonstrate a level of thin trust where the parents and children developed loose relationships which enabled social integration (Arai & Pedlar, 2003)

Through increases in social power and the development of thin trust noted above, the parents and two of the children experienced gains in political power. Arai (1996) described political power as “access to the process by which decisions are made” (p. 29). I found the children typically experienced limited amounts of political power. In the case of the children, I considered there to be an increase in political power if the child had gained access to decision making practices about their own lives. I found Daniel and Keith experienced political power since they were able to influence and impact decisions about their own lives and recreation experiences. Whereas Carolyn, Johanna, Leslie and Rebecca increased and expressed their political power I did not find an increase in Anne’s political power. I thought Anne seemed to accept the decisions made by both people regarding her son’s recreation and life opportunities. From her narrative I thought she did not have access to the decision making processes regarding her son’s involvement. I found Carolyn and Johanna had gained political power through their psychological and social power. Both of these women were involved in the decisions regarding their children’s involvement in recreation. Leslie and Rebecca also had political power but I did not find that they used it to same degree as Carolyn and Johanna. I thought Leslie and Rebecca had strong psychological and social power as did Carolyn and Johanna.

Other messages included: the lack of recreation opportunities available, the importance of recreation for people with disabilities, the influence people with disabilities have on others, the impact of exclusionist practices and policies, the importance of planning and preparation for the involvement of people with disabilities, the limitations of inclusion, and the need for equitable supports no matter the diagnosis. These messages are connected to the literature on inclusion and exclusion.

The lack of recreation opportunities available for children with disabilities was evident in many of the narratives. This lack of opportunities is an example of the practice of exclusion, and demonstrates how

recreation can be a space for disabling practices. As some parents described, there were few opportunities available or they were denied participation. The power of professionals (other characters) was described by Lord and Hutchison (2007) where the professional is in control of decision making practices what often results is exclusion. The importance of recreation for people with disabilities can be found both in its ability to enable social networking and consequently the creation of valued social roles (Devine, 2004; Hutchison & McGill, 1992). Devine (2004) had identified recreation as an important space through which people with disabilities were able to socialize and gain friendships. Hutchison and McGill (1992) described how through social relationships people can gain valued social roles. When people with disabilities are left out of recreation spaces they experience exclusion. Through this exclusion, recreation becomes a disabling space.

The other messages from the parents' narratives are connected to the literature on inclusion and exclusion. The influence people with disabilities have on others was explored by Devine (2004) and Schleien et al, (1997). Schleien et al, described how through social interactions the perceptions of others regarding disability can be changed. When people with disabilities are included what can results are positive attitudes and accurate perceptions towards people with disabilities (Schleien, et al.). Carolyn's description of the impact Keith had had on others demonstrates this point. Through relationships people with disabilities can experience inclusion in recreation. The relationships are an example of an enabling practice through which inclusion can occur.

In the narratives exclusionist practices and policies were often used by practitioners or professionals to prevent the participation of a child with a disability. It was also evident in the narratives that there were limitations to inclusion where the attempt at inclusion became a disabling practice. As Labonte (2004) described, exclusion and inclusion are twinned concepts and require a shared discussion. Lord and Hutchison (2007) stated that people were often excluded because of an impairment. This type of exclusion was evident in many of the narratives, and demonstrates how recreation can be a disabling practice. Leslie and Steven experienced exclusion from soccer. Carolyn and Keith were excluded from middle school basketball. Brandon was excluded from riding the bus for a class field trip, and Johanna was excluded from

the decisions regarding his participation. Through Rebecca's narrative we learned of exclusionist practices regarding the support of specific children with disabilities. As Rebecca had described, certain disabilities received more support than others. The limitations of inclusion were demonstrated in Rebecca's narrative where recreation leaders tried to make Clara fit the program but it did not work. This is where inclusion can become a disabling practice. Johanna had described the importance of planning and preparation for the involvement of a child with disabilities. Inclusion is a process which can be facilitated through the planning and preparation for the involvement of a child with a disability (Schleien, et al., 1997). If a child with disabilities is included in a recreation experience which has not prepared the necessary accommodations, the recreation space becomes disabling for the child. The impairments and limitations of the child are highlighted because the recreation space has not provided the necessary adaptations to support the successful and full involvement of the child. These narratives have highlighted the practice of excluding children with disabilities.

The Role of Protagonist, Conflict and Other Characters in the Narrative

Other characters and conflicts must be taken into consideration as they contribute to the presentation of the self by the storyteller. How other characters are presented in the story provides insight into the experiences of the parents and children. The question of *conflict* both between characters and within themselves highlights the necessity of dual protagonists in these narratives since both parents and children were challenged by antagonists. Through the conflicts experienced by and between the children parents and other characters deepen our understanding of the experiences of recreation and disability. From the interpretive analysis conflict was evident between parent and child, parent and other characters, and internal conflict for the parents.

In the narratives, other characters provided support to the child and family or challenged the child's experience. Important characters were often (adult) leaders who had the power to involve a child in a program, activity or experience and thus could include or exclude a child from a recreation experience. Thomas (1999) had described how children experience disability in four ways: impairments, difference,

other people's behaviour, and material barriers. Thomas highlighted awareness children with disabilities have about the perceptions of disability through their physical and social environment. Other people's behaviour and social interactions have an impact on how children with disabilities experience and understand 'disability' (Thomas). From the narratives of the parents and their descriptions of other characters we learned how other characters have impacted the child's understanding of disability. In some cases the children were enabled and supported by other characters to be full involved in an activity, were able to be successful or make a valued contribution. For example, Keith's basketball coach and Brandon's Beavers leader.

Conflicts experienced by the parents were both internal and interpersonal. Internal conflict was experienced by most of the parents in the study. Internal conflict was often related to a desire for the child's involvement in a recreation experience but hesitation or concern about the activity, leaders and staff, other children, and supports and resources. Parents often experienced feelings of internal conflict again between the desire for the child to participate and the mother's own schedule and energy levels. Interpersonal conflict was experienced between the mothers and other groups of people including program leaders and other parents. The parents experienced interpersonal conflict with other characters in each narrative. These conflicts will be further explored in the following discussion of power.

The Intended Audience and Impact of the Narratives

I found each of the narratives had an impact on me. They evoked an emotional response which I was not prepared for. I think that these narratives have the power to evoke an emotional response from other readers. When I considered who the intended audience was, I found recreation professionals to be an important audience group in all of the narratives. In four narratives, I thought the stories were told for other parents, and in two I thought the stories were told for people. The implications of this study for other parents and recreation practitioners is further explored in the section on Implications of the Study.

Summary of Narrative Analysis Phases One and Two

The preceding section explored: the important spaces, presentation of self, messages, role of protagonist and experiences of conflict, development and use of power, and the intended audience for each narrative. From the narratives we learned about the importance of recreation for children with disabilities, the value and importance of social networks, and the impact other people have on experience. In the following section, Phase Three of the Interpretive Analysis is discussed. This next section uses the five narratives as a collective to explore the cultural practice of disability through recreation.

Narrative Analysis Phase Three: Cultural Practices of Disability and Recreation

Phase Three of the interpretive analysis further explores the meaning the narratives, specifically cultural practices of disability. In this section, the narratives are examined as a collective rather than as individual stories. This enabled a more comprehensive understanding of exclusion, segregation, integration, inclusion, and disability in the context of recreation. Reflecting on, and analyzing the group of stories produced an understanding of the cultural practices of disability.

To enhance our understanding of the cultural practice of disability a series of questions were used to explore important concepts and language used by the parents, and how they explained their child's levels of involvement. The narratives were considered for the language, jargon, or terminology used by the parents. Next, the parents' experiences and understandings of disability were contrasted with the literature on disability and recreation. Following this, I completed an analysis of the "researcher as audience" to explore my position in relation to the stories.

The Use and Significance of Language By Parents

I found there was often a difference between the language I used with regards to disability and the language used by parents. Whereas I used person first language (child with disability, etceteras), the terms used by the parents included: special, special needs, disabled, and disability. I found parents would change or adapt their language after hearing me use the person first language but would often revert back to the language and terms they were more comfortable with.

In Chapter Two, disability was defined within the medical model and the social model. Within the medical model, Devine and Sylvester (2005) note that disability is defined “as a negative variation from the physical norm that necessarily disadvantages the physically distinct subject’s life and life quality” (p. 87). In contrast, the social model separates impairment and disability. Within the social model, Oliver (1996) notes that impairment means “lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body” (p.22) and disability is “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (p. 22).

Many of the stories from each parent began with disability in a medical context. The parents spoke about when their children were “diagnosed” with a specific disability and what that meant for the child. As the parents moved away from the initial diagnosis, there continued to be instances where a child’s disability was medicalized. For example, Brandon’s disability was continually medicalized as the focus was always on him, and adapting him to his environment or activity. There were also instances where his disability was understood within the social model. When viewed within the social model, Brandon’s experience with riding the bus for a school field trip provides an example of externally imposed barriers that shape the experience of disability. In addition, several parents spoke about trying soccer with their children, and this shows us disability through the social model where the soccer program or staff took no account of the children with disabilities and excluded them from participating. From this study and the parents’ narratives, it is evident that disability does not exist in either the medical or social model of disability, rather it exists in between. In the narratives, disability was both an impairment and social experience.

Insights into Exclusion

Most parents and children had experienced exclusion when the child had been intentionally or unintentionally left out of an activity, program or recreation experience. In these stories exclusion was often produced when there was “*no openness*” to bringing a child with a disability into a program; for example, Carolyn (middle school basketball for Keith), Leslie (soccer for Steven), and Johanna (school field trip for

Brandon). In these narratives Carolyn, Leslie and Johanna spoke about their attempts to involve Keith, Steven and Brandon in the recreation activity. They described the reluctance and refusal they experienced from program leaders. In Johanna's narrative, Brandon experienced exclusion on his class field trip. In this example, school administration used a school policy and cited "*safety regulations*" to exclude him from participating in the trip in the same capacity as his peers. Anne and Daniel experienced exclusion in the lack of recreation experiences available. Exclusion was also found in Anne's perception that Daniel would not be involved because of his disability. In Rebecca's case, Clara was not involved in more recreation experiences because of Rebecca's work schedule and the driving required for participation.

Exclusion was present in some capacity in each of the narratives. In two of the examples, exclusion happened because people or leaders refused to involve a child with a disability. In one example, policy was used to exclude the child. In these cases recreation became a space where disabling practices occurred through limited participation and power of practitioners. As described by Lord and Hutchison (2007) exclusion is a disabling practice when it is used to limit the participation or involvement of a person. Exclusion can result from being left out of decision making practices and is often perpetrated by practitioners (Lord & Hutchison). In many instances, practitioners make decisions, set parameters, and expect compliance (Lord & Hutchison). In this study exclusion was perpetrated by people in positions of power, coaches in Carolyn and Leslie's narratives and school administration in Johanna's. In these three narratives, the parent had an awareness of exclusion but was unable to change or force the involvement of their children. The parents' awareness of the exclusion of their children was both a realization of powerlessness and often the catalyst from which parents' empowerment developed.

Insights About Segregation

Building on the social construction of segregation and the empowerment of the parents, I was able to explore how disability was socially constructed in the narratives. A concept is given meaning through the social interactions of people. Devine (2004) describes social constructionism as requiring the consideration of the interconnected roles of people, history, culture, language, environment, and context all play in forming

the meaning and understanding of a concept. In this study, the concept of disability and its meaning developed through the social interactions of the parents and children with others including recreation practitioners, professionals and community members.

In this study, the definition of segregation provided in the literature differs from the meaning of that term to the parents. Within a lens of social construction, the meaning of segregation in this study can be explored. Devine (2004) described social construction as a theory that looks to find explanations of how information is produced and accepted as truth. Daly (2007) describes social constructionism as an interactive (social) process through which meaning is produced and reproduced by groups. In this section, the different meanings and understandings of segregation are explored to demonstrate how segregation is a socially constructed for different groups. I begin by exploring the meanings of segregation provided in the literature, including definitions and characteristics. Next I explore the meaning of segregation held by parents. Finally, a discussion of the social construction of segregation highlights how redefining segregation contributed to the empowerment of parents.

Segregation was previously defined in this study as “the separation or isolation of a group or an individuals in a restricted area by discriminatory means that results in the members of the group, or an individual, receiving treatment that is different from other people” (Datillo, 1994, p. 341). In the literature, segregated programs were described as providing recreation opportunities for homogeneous groups where the emphasis is on skill development and there are large groupings of persons with disabilities (Schleien et al., 1997). In the narratives, the Rainbow Recreation program or the Special Olympic programs were two examples of recreation experiences specifically for children with disabilities where the participants learn and develop skills. It is important to note that in the Special Olympic program described by Leslie, program participants included siblings (without disabilities) but the swim program described by Anne did not. The literature also described segregation as characterized by special staff, services, equipment, and environments assigned to participants with disabilities (Schleien et al.). Again, in the narratives, the Rainbow Recreation program and Special Olympic programs both utilized trained leaders, equipment and resources

to support the participation of children with disabilities. Another characteristic of segregated programs described in the literature is that participants receive treatment considered different from the “norm” (Schleien et al.). Despite these programs fitting the criteria of segregated programs, many parents commented their children did not have ‘segregated’ experiences.

All of the parents and children described “segregation” at some point in the narrative but many did not identify their children’s experiences as segregated. Each parent had a different perspective and understanding of the meaning of segregation. It is through these individual understandings of segregation we see the social construction of segregation. Johanna described segregation as a lack of “*acceptance*” or a *lack of “willingness to include.”* As I understood, Carolyn described segregation as the separation of people with disabilities from the rest of a group, or as the opposite of integration. Rebecca described segregation as “*because of your disability...you need to be here and all the other kids are [over] here.*” Leslie said that “*there is certain criteria*” and that segregated programs developed when the “*world wouldn’t include them [children with disabilities].*” Anne did not comment on or describe segregation in her narrative. It is evident from the stories that these parents understand segregation as involving a separation of people (or children) with disabilities from the “*rest of society or a group.*” Four of the parents demonstrate an awareness of segregation but some did not associate “segregation” with the programs their children were participating in, even though the programs involved only youth with disabilities.

The parents expressed differing opinions about segregation which prompted an exploration about whether segregation is a disabling practice or an enabling practice. Anne did not comment directly on segregation in her narrative; however, it seemed to me she wanted Daniel involved in recreation and the type of involvement did not matter as long as he had an activity. I found Carolyn and Johanna’s opinions of segregation contrasted with Leslie and Rebecca’s. Carolyn and Johanna were more supportive of integration and inclusion. In comparison, Leslie and Rebecca were more supportive of segregation. Carolyn commented that when she was younger she thought that everything had to be “*integrated*” and she did not “*believe in segregation at all*” but she has realized that “*for some people maybe segregation works.*” She

went on to say that "*I really don't believe in segregation.*" I think Carolyn views segregation as a disabling practice because it separates people with disabilities from the rest of society. Although Johanna did not comment directly on segregation, I thought her opinion was similar to Carolyn's. Johanna commented that she wanted Brandon to be involved or included in everything possible.

These opinions contrast with Leslie and Rebecca who seemed to support the idea of segregation in specific contexts. Leslie's opinion of segregation seemed to be if inclusion was not working for the child then segregation was alright if it enabled success. In Leslie's narrative, her description of Steven's school and rigid curriculum demonstrate inclusion as a disabling practice, and identify where segregation could enable a child to succeed. Leslie commented that people should be "*included*" but when the resources, funding and attitudes are not in place to support inclusion it does not work. She seemed to support segregation if it enabled a child to succeed and if the support for inclusion was not in place. I found Leslie and Steven's experiences demonstrated Labonte's (2004) description of how inclusion could be a disabling practice. As Leslie described the curriculum was rigid and did not enable her son to succeed. His inclusion in education was superficial, and efforts should be directed to changing the curriculum and structures in education which would enable his inclusion. Rebecca shared a similar opinion in support of segregation and commented that "*I don't think that everybody has to be integrated all the time.*" This opinion seemed to stem from Clara's experiences where people would try to "*make her fit*" but sometimes it did not work. Rebecca also commented how it was alright to segregate in the school setting if Clara was "*inhibiting someone else from learning.*" Differences of opinion about segregation highlight the debate surrounding segregation and how the understanding of the concept is fluid. Whereas Carolyn and Johanna seemed to view segregation as a disabling practice in which a person with a disability is separated from others and loses out on experiences, Leslie and Rebecca seemed to describe that segregation enables people with disabilities to succeed.

The previous discussions demonstrated how segregation was socially constructed first by professionals and researchers, and then how it has been redefined by parents. From the literature it was evident that segregation had a negative association and was often an excluding practice where the

involvement of children with disabilities was limited or restricted. In this case, segregation had been defined by a practitioner or expert, and was then used to control the child's recreation opportunities and experiences. This contrasts with the meaning of segregation for the parents whereby segregated recreation practices often enabled the child to gain skills, develop relationships and ultimately have a successful experience. In the case of the parents, the meaning of segregation developed through social interactions with recreation practitioners, professionals, other parents and other children. Through these social interactions parents experienced the meaning of segregation for others, and redefined its meaning for themselves and their children.

By challenging the meaning of segregation, parents also experienced empowerment. In the narratives, parents understanding of segregation often developed through social interaction with recreation professionals and practitioners. In these interactions parents explored their power and developed awareness. Through recreation experiences of their children, parents were able to make social connections and expand recreation opportunities for their children. These social connections and the expansion of recreation choices demonstrated the connecting and learning phase of empowerment described by Arai (1996). In this study, the development of social networks often occurred at what would be considered segregated recreation spaces including Rainbow Recreation. Using their social connections, knowledge and skills the parents were able to advocate or create recreation opportunities for their children and ultimately redefine the meaning of those recreation experiences. Mobilization, as described by Arai, was also evident when parents developed skills and gained knowledge, and were able to change recreation experiences for their children. An example of the mobilization of the knowledge and skills was found in Leslie's narrative where she used her social connections, information and abilities to develop a "segregated" recreation experience for her son (Special Olympics programs). Contribution involves the integration of skills and knowledge into everyday life (Arai). In this study, contribution was found as parents wove new meanings and experiences of segregation into their daily lives. Through the process of empowerment, parents were

able to explore the meaning of segregation and redefine the concept based on their children's recreation experiences.

Insights About Integration and Inclusion

Parents seemed to use the terms "integration" and "inclusion" interchangeably. Integration was previously explored as involving both physical and social aspects (Lord & Hutchison, 1979; Hutchison & McGill, 1992). Datillo (1994) described integration as the process through which people with disabilities are enabled to use the resources, support, facilities and programs of a community. Schleien et al. (1997) described inclusion as, "becoming a full participant in community life" (p. 15). While inclusion often seemed to be the goal for people with disabilities, Labonte (2004) highlighted the limitations of inclusion when it was superficial. Labonte noted that one of the key components of inclusion is participation in decision making. In the study I found parents created their own meaning of integration and inclusion that developed through the recreation experiences of the children, and through social interactions with other community members, professionals, and recreation practitioners. During the interview Rebecca said "*I probably used the wrong terms, but it should be more inclusion is what I'm looking for*" when describing her hopes for Clara's recreation experiences. Carolyn said that inclusion "*isn't about making handicapped people normal.*" She commented that inclusion was critical but then used the term integration. Johanna said that inclusion means "*not being left out. Not standing out in the crowd more than usual. Being able to participate and not, (pause) having it really obvious that you're doing it different.*" Anne's description of being included focused around having people in the same space and participating in the same activity. It is critical to consider the impact of the interchangeable nature of the terms for the parents and differences in their understandings of this term.

Most of the parents in this study described "inclusion" as experiences in which the child was able to be included. In some cases, what the parent described as "inclusion" would have been recognized as integration based on the definitions in the literature. Beavers provided an example of an experience where Brandon was enabled to be included because the resources and supports necessary for his full engagement and participation were planned and prepared in advance. Leslie described Steven's participation in the

summer day camps where he experienced inclusion because of the financial support, resources and staff in combination with Leslie's efforts. The church was an inclusive experience for Clara where she was enabled to be included through the support and acceptance of the congregation and through Rebecca's support. Daniel seemed to have been enabled by many people into a number of experiences including his youth group. I also thought that Daniel was being enabled by his school staff to be included in the workforce once he finishes school. These enabling practices contrast with the disabling practices previously discussed.

Understanding Disability Through Lenses of Power, Empowerment and Trust

The social construction of disability involves social interactions between parents, children, and their community. The meaning of disability, and how that meaning was produced may be explored using the lens of empowerment; specifically, looking at the development of psychological, social and political power. In the following discussion the development of these types of power by the parents is explored including the development and role of the empowerment process and levels of trust. Arai (1996) described empowerment as a process which involved four steps: awareness, connecting and learning, mobilization, and contribution. I found examples of the process of empowerment throughout the narratives.

Awareness was described as recognition and response to new information (Arai). I thought Johanna and Carolyn developed awareness when their children were left out of recreation experiences. Psychological power was described as including self concept, self efficacy, and locus of control (Arai, 1996). In this study psychological power was often demonstrated through the parent or child's ability to define himself or herself rather than being defined by others. The presentation of material, social and spiritual self previously described in the interpretive analysis of each parent's narrative explored how each aspect of self was developed and expressed.

Connecting and learning occurred when social networks developed through which people gained access to resources (Arai). The development of thin trust is a component of connecting and learning. I found parents made connections with other parents through their children's recreation experiences. The expansion and connection with other social networks often provided the opportunity for integration or inclusion of the

children in other recreation experiences. The development of psychological power often coincided with parents gaining knowledge and developing skills and with the connecting and learning phase of empowerment (Arai). An important component of connecting and learning is the ability to act on new choices (Arai). Once parents developed social networks with other parents, they were often able to use their knowledge and skills to facilitate or develop more recreation opportunities for their children. For example, Leslie used her skills and social connections to develop a Special Olympics programs for her son, and in another situation her husband developed a soccer team for their son. Through the Rainbow Recreation program where she met other parents, Johanna was able to find other recreation opportunities including sledge hockey. Similarly, Anne used her social network of other parents through the Special Olympics program to enrol her son in summer camp. In each of these examples the parents' psychological power increased through the connecting and learning phase of empowerment.

Social power was described as increasing through gains in skills and knowledge, access to resources, and involvement in social organizations (Arai, 1996). An important aspect of the development of social power was the types of trust which existed between the parent and other community members. Thick trust was evident in these narratives and in the lives of the characters. Arai and Pedlar (2003) described that thick trust is developed in small social groups and produced through daily contact. In most cases, parent and child have a very small and tight knit social community. Thick trust exists where there is intense daily contact between people (Arai & Pedlar). Examples of thick trust can be found between Keith, Clara, Daniel, Brandon, Steven, and their families. Many parents described an intense social cohesion within their family or immediate social network but a lack of openness to bringing others in, or extending out, beyond their group. Although thick trust was important, the development of thin trust was critical to the involvement of people with disabilities in recreation spaces.

Thin trust was also evident in the narratives, although not to the same degree as thick trust. Thin trust was described as existing within social networks and in "looser forms of relationship" (Arai & Pedlar, 2003, p. 193). Arai and Pedlar described the development of thin trust as resulting from the overlapping of

social networks through which “weak ties” between community members develop (p. 193). Although many parents described close knit social groups including family, there was often a lack of thin trust between the parent and child, and the rest of the community. The expansion of social networks and thin trust is critical to the development of communities that are open and inclusive (Arai & Pedlar). A lack of thin trust was evident in the narratives. As in the case of Keith’s basketball team, he spent time each day with his teammates but their relationships do not extend beyond the borders of that group. The basketball team provided an opportunity for thin trust to develop as Keith had an opportunity to form loose relationships. However, thin trust did not develop as the relationships did not result in an opportunity for expanded involvement in the community. Thin trust was developed to a degree through the Rainbow Recreation program which enabled families and parents to share information and expand their social networks. The program enabled the parents to develop weak social ties with other parents in the disability community, however, it did not provide an opportunity to expand their social networks beyond those borders. It was evident in the narratives that parents had limited opportunities to expand their social networks and establish relationships with other community social networks.

The levels of trust emphasize challenges faced by people with disabilities and their families; that is, they often experience thick trust but limited thin trust. While they have a tight knit and small social group, there is little outward connection with other groups or the formation of a broad social network. The development of social power is critical the development of thin trust.

Mobilization occurs when people use their skills, knowledge and social networks to develop organizational skills, join groups and expand participation in decision making processes (Arai). Leslie mobilized her skills, knowledge and social connections to create a recreation program for her son, and to gained access to funding supports for an inclusion worker. Carolyn used her skills, knowledge and social connections to confront the school administration regarding her son’s extracurricular activities. Political power, then, is described as access to and involvement in decision making processes, the power of voice, and the influence of groups (Arai, 1996). Political power was often demonstrated or developed through the

parents' ability to define self and disability and its associated concepts such as segregation, integration and inclusion. The parents often experienced conflict of power with other parents and recreation practitioners in particular. Through these social interactions political power to define self was often negotiated. For example, when Johanna was in conflict with the school administrators she was negotiating the meaning of disability and how it defined her son. The school administrators had power over Johanna and Brandon to control his experience on the school trip. Another example was when Carolyn was in conflict with the school administrators about Keith's extracurricular activities. In both of these examples, professionals attempted to exert power over the parent and define the child by his disability while the parent challenged the power of the school administrators. The development of political power was contingent upon the previous development of psychological and social power (Arai). The parents were able to vocalize their concerns and challenge the meaning of disability by using their skills, knowledge, and social networks.

The narratives of these parents demonstrated the continual changes of the meaning of disability. The parents were able to redefine disability and associated concepts through their social interactions with others, development of their psychological, social and political powers, and the development thick and thin trust. It was also through these gains the parents were able to experience empowerment which enabled them to assign their own meaning to disability. What these narratives demonstrate is how disability is socially constructed through social interaction with other children, parents, recreation practitioners, professionals and community members. As part of the empowerment process, contribution, is described as the integration of a person's skills and knowledge into everyday life (Arai). I found many of the parents were beginning to experience this level of empowerment.

Researcher as Audience

This section explores my role as researcher and my impact on the study. The following questions are explored: How did I influence the telling of the story? What are my understandings and reflections on the concepts of this study? How is the story positioned in relation to me as the researcher? My role as the audience for the initial telling of the stories is significant to explore since it enhances understandings of the

storytelling process. It was also important that I return to my reflections and consider my impact on this entire process and the impact of this process on me. I have been changed by the stories the parents shared with me and this required exploration.

How did I (as a researcher) influence the telling of the story? I found it interesting to note through my reflections and reviews of the transcripts the changes within the first round of interviews and between the first and second interviews. Typically the first interview began with a very clear delineation between me as “the researcher” and the parent as my “participant.” I made numerous efforts in those first few moments to cover the necessary ethical information and quickly break from the rigid and academic feeling to a feeling of comfort, support and understanding. I accomplished this by telling the parent about myself, my background and experiences with Aiden, and why I was doing this study. It was interesting to note a shift early on in the interviews from a exchange of “question and answer” to a playful, sincere, and meaningful banter back and forth. A clear example of this was in my first interview with Rebecca. She shared her experiences at the community church and I, in return, shared mine with her. The transcript moved from short questions and prompts from myself with long responses by Rebecca, to short banter back and forth between us that was full of laughter.

The difference between the first and second interviews felt like the difference between meeting a new friend versus an old friend for coffee. In the second interviews, a relationship and connection already existed, and the first few minutes were spent catching up on the happenings of the past few weeks. For example, when I met Anne for our second interview she spent some time telling me about a trip she had taken in the weeks between our interviews. The interaction became very conversational in tone and truly a shared experience between me and the participants.

What are my opinions of the important concepts from this study? When I began this study I had strong opinions and ideas about disability, segregation, integration, inclusion and exclusion. At the end of this study I do not feel as strong a conviction to my understandings. I feel as though I recognize the value in both the parent’s understandings of the terms and the information in the available literature. After a hint from

my supervisor I came to realize that I was considering these terms using theory and looking at the big picture, the parents understood these terms as they related directly to their children. The parents were concerned with the experiences their children had and not with the associated label. While the parents said they wanted or were looking for “inclusion” their focus was on providing their child with a positive, successful and meaningful experience.

Reflecting on the messages in the stories and meanings of concepts I returned to my original narratives of Aiden. The narratives at the beginning of Chapters One, Two and Three were written before the interviews with the parents, and before I had thoroughly researched the meanings of the central concepts in this study (disability, integration, segregation, exclusion, inclusion). As I reviewed my stories of Aiden I asked myself whether I would change them. The answer was simply no. Although I have been exposed to more knowledge and experiences through this study, I would not change my stories of Aiden or how they were written because it is important to be able to recognize and reflect on my own understandings.

Through my reflections on my narratives I was amazed to find so many moments where my story shared similarities with the stories of the parents. I had the same thoughts as they did. For example I, like Carolyn, did not like when other people treated Aiden (in her case Keith) as incompetent or when people would do things for him or baby him. Another place where I felt a change was in my descriptions of Aiden. I had described him as a “wheelchair bound teenager” which I found interesting because I had stated that he was in a wheelchair. In another place I mentioned that he had hearing aids. I found myself wondering if there was a more diplomatic or correct way of describing him. Would it have been better to simply say that he had a disability or why was it important to me that I share his mobility or hearing impairment with the reader? What is the impact of describing him with reference to a wheelchair or as having hearing aids? I think I used to be focused on making people get *what* Aiden was rather than *who* he was. I do not think I would change the way I describe Aiden because being in a wheelchair and having hearing aids is part of who he is, and it helps people understand and relate to him.

Upon further reflection I realized that what this study has demonstrated is how disability is socially constructed. There are many people who impact and influence the understanding of this term. There are people who live disability as parents or as children, and there are people who live outside of disability. Both groups define, understand, and assign meaning to disability in different ways. The meaning of disability, who defines it, and who that definition serves are important questions in exploring this concept.

Conclusions

This study explored recreation experiences of children with disabilities through stories told by their parents. These stories raised important questions, challenged existing understandings of disability, segregation, integration and inclusion. These narratives also demonstrated how these concepts are socially constructed through social interactions and were shared through the parents' descriptions of everyday life, their experiences, and perceptions (Daly, 2007). Lord and Hutchison (2007) stated that critical thinking enables us "to look beyond the surface of a program or service and examine the concepts and values that maintain the program" (p. 26). This study provided myself, and the parents, with an opportunity to do just that.

The meaning of disability was previously determined experts, researchers, and professionals. This study demonstrated that parents negotiated the meaning of disability through their social interactions, power, and negotiation of leisure spaces. When the parents and children interacted with other community members, recreation practitioners and professionals, they encountered the boundaries of disability as set by others. This study demonstrates the power of recreation as a space where the meaning of disability is negotiated. While parents were nearly always responsible for finding and facilitating recreation opportunities, recreation practitioners controlled the child's experience. These narratives also revealed the awareness children have about their disability and its meaning. Through recreation experiences of the children, they developed an understanding of how disability was perceived and understood by others children, parents, community members and recreation practitioners. Through the recreation, the meaning of segregation, integration, and inclusion were experienced by the parents.

Implications

Implications for Other Parents

It is the messages and experiences of these stories that hold value for other parents. The stories from this study can be used as resources for other parents of children with disabilities. Parents in this study demonstrated the importance of recreation. Through recreation, the children gained skills, developed an understanding of self, and were able to expand their social networks. Recreation was also a space where children could develop personal empowerment. Through recreation, children with disabilities are able to challenge perceptions about themselves, including their own and those held by others. Recreation provides a space where children with disabilities and children without disabilities are able to define and redefine the meaning of disability. Remember Carolyn's description of Keith's impact on others? She said people were changed because of their relationships with her son. Recreation was also an important space for parents to use their skills, expand their social networks, and define themselves. As many parents mentioned, their children's' recreation experiences also provided them with an opportunity to network with other parents and organizations. Through recreation, parents were able to redefine and assign meaning to disability in ways that challenged what they previously thought about, or knew of, disability.

Implications for Recreation Practitioners

Recreation practitioners play a critical role in the recreation experiences of children with disabilities. Recreation practitioners have the power to create positive, successful, and inclusive recreation opportunities where children with disabilities are able to socialize and successfully participate in a program or activity. Similarly, recreation practitioners have the power to exclude children with disabilities. They also may create a space where children with disabilities develop friendships, be recognized for abilities, and gain valued social roles. We saw in the narratives, that recreation provided a space where children with disabilities could succeed. Recreation practitioners may use this study as a learning opportunity; to help them recognize and reflect upon experiences children with disabilities have in their programs and facilities. From this study it was evident that appropriate and thorough training for staff is necessary to support the involvement of children

with disabilities. Since the staff work directly with the children, they must have both the necessary training and a positive attitude towards children with disabilities. Recreation practitioners and staff are able to get results that parents are often unable to achieve themselves with their children.

The parents stories highlighted the emotional impact recreation may have on children and parents. The impact of other parents was also evident. Recreation practitioners need to develop an awareness of how all participants in recreation space are responding to someone with a disability. Remember how Leslie said she would leave in tears because of the things she felt from other parents? It is important for recreation practitioners to develop an awareness of the parents, other adults or other participants, and what their effect is on participants and their families.

Parents commented that their choice to involve their children in a program was often determined by their level of comfort and trust in the organizers. It is important in recreation practice when involving people with disabilities that programs and activities are carefully planned in advance, with consideration given to the various challenges that may result. This study demonstrated the importance of communicating with parent(s) of children with disabilities as they are an invaluable resource of information about the child. Parents in this study identified themselves as important resources, full of knowledge and insight about their children. Speaking to parents prior to the beginning of a program can help ensure the successful involvement of that child, and can help to establish a level of trust and comfort between the parent, practitioner.

Implications for Theory

This study contributed to our knowledge about the social construction of disability in recreation spaces. As parents recounted their child's recreation experiences, they described how they have come to understand and define disability. Recreation provides an important space where the meaning of concepts can be explored. In recreation values, attitudes, and beliefs of people and their communities are played out in everyday life and through interactions with others.

The narratives highlighted how the meaning of disability and other terms (segregation, integration and inclusion) have come to be defined and understood by parents through interaction with their children, recreation practitioners, and community members. From the narratives we saw how the parents redefined many of the identified terms through experiences in recreation. The narratives identified a need to explore the intertwining of inclusion and integration. From this study it was evident that parents used the terms interchangeably, which raises questions about the usefulness of them. Are these terms still relevant? Do they serve a purpose? Do descriptions of integration, inclusion, and segregation provided in the literature reflect their meaning in life? This study can be used as a catalyst to evaluate the meaning of these terms in our society. When we consider enabling and disabling practices these key terms begin to shift. These terms (integration, inclusion, and segregation) are not concrete, rather they are fluid and change as our world changes. When inclusion is superficial it becomes a disabling practice and the term inclusion is no longer valid. The implications of this study for theory are the importance of evaluating and challenging the definitions we have come to accept. This study also connected explorations of power and empowerment with the social construction of disability and disabling and enabling practices of inclusion and exclusion.

This study highlights the value and challenges of labelling practices. Labelling can be both an enabling and disabling practice. It is both beneficial and detrimental to the labelled person, their family, and community. I recognize the importance of being diagnosed. Diagnosis results in increased access to resources and supports people might not have otherwise had; however, I also recognize the longevity and impact of being defined by a single term. A term provides a place to begin understanding; however, it does not, and should not, define a person. Remember how Leslie described her son Steven and commented that many of his personality traits contradict the information and definition of his disability?

Implications for Research

This study has implications for research on disability. These stories demonstrated the critical role these parents had in finding, facilitating and negotiating recreation spaces for their children. This study supports the use of parents as expert sources about their children's experiences (Brett, 2002; Fleischmann,

2004; Goodwin, et al., 2006; Huws, 2001; Malone & Landers, 2001). Through these stories we gained rich and powerful insights into the recreation experiences of children with disabilities.

This study supports the use of narrative as a methodology for the study of disability and leisure, and contributes a process through which narrative can be used. As previously identified, there has been limited use of narrative as a methodology in disability and leisure research (Davis & Salkin, 2005; Grace, Llewelly, Wedgwood, Fenech & McConnell, 2008; Jenks, 2005; and Kluth et al., 2007).

Limitations of the Study and Suggestions for Future Research

A limitation of this study was the partner organizations who contacted participants (using my requirements as a guide) they deemed acceptable and likely to participate rather than inviting all participants of the program to participate. Another limitation of the study was the time restrictions on gathering participants. In future research if every member of an organization is to be invited to participate contact should be made at minimum 6 weeks prior. The use of only mothers as participants is another limitation of the study. Similarly, the study only engaged one female child and four male children. I had intended to interview both mothers and fathers and had hoped for a balance of male and female children but was unable to because of the limited participant group.

This study demonstrated a clear need for other research in the context of disability and recreation. Future research should focus in one of the following areas which will be further discussed: participants, location, type of disability, the spiritual experience of disability, methodology and methods.

More research is needed to comprehensively understand the experience of recreation for people with disabilities. This study used a range of participants, from ages 8 to 21 years. I suggest that in future research the age groups of the children be kept within ranges of 2-4 years or by school level, if parallels are to be drawn between participants. Future research should expand on the number of participants included to generate more understanding of parent's knowledge and experience. This study could be repeated with a larger group of participants with a smaller range in ages. For example, 8-12 (parent) participants of children ages 8 to 12 or 14 to 18 years, or children in elementary school/middle school/high school. I also think the

children should or could be engaged as participants. From the narratives I found many examples where the children demonstrated an understanding and awareness of their disability and its impact on their recreation experiences.

I believe that the location of the study may have impacted the outcomes of this study and future research should be conducted in other provinces and communities across Canada. This study could be repeated in a larger urban area or in another small rural town, or a study could be completed comparing the experiences of families living in an urban area versus a rural area.

Further exploration into the recreation experiences of children or youth with other types of disabilities could be completed. This would provide an opportunity for narrative research to collect personal recreation histories of people with disabilities. This study could be repeated using parents of children who have a specific type of disability (ADHD, Down Syndrome, Autism, etceteras)

Another area for further research was identified in the narrative analysis. It was found that the parents provided limited or no description of their “spiritual” self in the narratives. This could be completed through the addition of interview questions directed at the spiritual self of parents, or through a separate study on the presentation of self by parents of children with disabilities.

The use of a different methodology could enhance our knowledge and understanding of recreation experiences for children and youth with disabilities. The use of a mixed methodology to collect demographic information about families in combination with a qualitative methodology (narrative or other) could enhance our understanding of how families are impacted by disability. Future research could be conducted using an alternative qualitative methodology, for example, phenomenology could be used to further explore the experience of being a parent raising a child with a disability or an ethnography could be conducted which would allow for a researcher to gain firsthand exposure to recreation for people with disabilities. In addition, the use or inclusion of artefacts (pictures, objects, mementos etceteras), using focus groups or a survey would enhance our understanding of the experience depending on the level and depth of information being sought.

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Appendix A: Letter of Consent for organizations



Date

Dear ____ :

This letter is an invitation to participate in a study I am conducting as part of my Masters degree in the Department of Recreation and Leisure Studies at the University of Waterloo, Ontario, under the supervision of Dr. Susan Arai. The title of my research project is "Tell me a story about your child: A narrative exploration disability in community recreation". I would like to provide you with more information about this project that explores the knowledge and understanding of disability using parent's stories.

First, I would like to thank you for your interest and consideration of support for including [organization] in this study. The purpose of this study is to collect stories of community recreation experiences from parents of youth with disabilities to provide insights about the role that leisure experiences have in the meaning of disability for parents. Knowledge and information generated from this study may help other researchers, leisure programmers, and community members in understanding disability.

It is my hope to connect with families who are engaged in the programs of the [organization] to invite them to participate in this research project. I believe that the participants and families of your program have unique understandings and stories relating to leisure experiences and disability. During the course of this study, I will be conducting interviews with parents to gather their stories of leisure experiences. At the end of this study the publication of this thesis will share the knowledge from this study with other leisure researchers, leisure programmers, and community members.

To respect the privacy and rights of the [organization] and its participants, I will not be contacting the families or parents directly. What I intend to do, is provide the [organization] with information flyers to be distributed by the [organization] at their discretion. Contact information for me and my advisor will be contained on the flyers or packages. If a parent is interested in participating they will be invited to contact me, Kate Pearce, to discuss participation in this study in further detail.

Participation of any parent is completely voluntary. Each parent will make their own independent decision as to whether or not they would like to be involved. All participants will be informed and reminded of their rights to participate or withdraw before any interview, or at any time in the study. Parents will receive an information letter including detailed information about this study, as well as informed consent forms.

Each participant may decide to withdraw from this study at anytime without any negative consequences by advising me. To support the findings of this study, quotations and excerpts from the stories will be used labelled with pseudonyms to protect the identity of the participants. Names of participants will not appear in the thesis or reports resulting from this study. Participants will not be identifiable, and only described by gender and as parent/child.

If the [organization] wishes the identity of the organization to remain confidential, a pseudonym will be given to the organization. All paper field (paper) notes collected will be retained locked in my residence while I am in Nova Scotia, and then in a secure cabinet in the Recreation and Leisure Studies Department at the University of Waterloo. All paper notes will be confidentially destroyed after three years. Further, all electronic data will be stored indefinitely on a CD with no personal identifiers. Finally, only I and my advisor

(Dr. Susan Arai in the Department of Recreation and Leisure Studies at the University of Waterloo) will have access to these materials. There are no known or anticipated risks to participants in this study.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics, University of Waterloo (file: 15609). However, the final decision about participation belongs to the [organization], and the parents. If you have any comments or concerns resulting from your participation in this study, please feel free to contact Dr. Susan Sykes, Director, Office of Research Ethics at (519)888-4567 ext. 36005 or by email ssykes@uwaterloo.ca

If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please contact me at (902-300-0642) or by email (kpearce@uwaterloo.ca). You may also contact my supervisor, Dr. Susan Arai at (519-888-4567 ext. 33758) or by email (sarai@uwaterloo.ca).

I hope that the results of my study will be beneficial to the [organization], to your families, and to the communities of families including youth with a disability across Canada, as well as the broader research community. I very much look forward to speaking with you and your child, and thank you in advance for your assistance with this project.

Yours sincerely,

Kate Pearce
Masters Candidate
Department of Recreation and Leisure Studies
University of Waterloo

Dr. Susan Arai
Associate Professor
Department of Recreation and Leisure Studies
University of Waterloo

Appendix B: Organization Consent Form



Organization Consent Form

We have read the information presented in the information letter about a study being conducted by Kate Pearce of the Department of Recreation and Leisure Studies at the University of Waterloo, Ontario, under the supervision of Dr. Susan Arai at the University of Waterloo. We have had the opportunity to ask any questions related to this study, to receive satisfactory answers to our questions, and any additional details we wanted.

We are also aware that excerpts from the interviews conducted with parents may be included in the thesis and/or publications to come from this research, with the understanding that the participants in the study will be identified using pseudonyms only. We are aware that the name of our organization will only be used in the thesis or any publications that comes from the research with our permission.

We were informed that participants and this organization may withdraw my consent at any time without penalty by advising the researcher.

We have been informed this project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo (file: 15609) and that questions we have about the study may be directed to Kate Pearce at 902-300-0642 or by email (kpearce@uwaterloo.ca) and Dr. Susan Arai at 519-888-4567 ext. 33758 or by email (sarai@uwaterloo.ca).

We were informed that if we have any comments or concerns resulting from my participation in this study, we may also contact the Dr. Susan Sykes, Director, Office of Research Ethics at (519) 888-4567 ext. 36005 or ssykes@uwaterloo.ca

Kate Pearce
Masters Candidate
Department of Recreation and Leisure Studies
University of Waterloo

Dr. Susan Arai
Associate Professor
Department of Recreation and Leisure Studies
University of Waterloo

With full knowledge of all foregoing, we agree, of our own free will, to participate in this study.
 YES NO

We agree, of our own free will, to help Kate recruit participants for this study from among the families who are users of the program and services of the [organization].
 YES NO

We agree to the use of the name of the [organization] in any thesis or publication that comes of this research.
 YES NO

If NO, a pseudonym will be used to protect the identity of the organization.

Director Name: _____ (Please print)

Director Signature: _____

Board of Directors Representative Name: _____ (Please print)

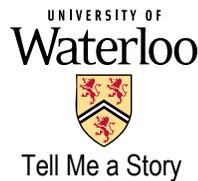
Board of Directors Representative Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

Appendix C: Parent Flyer



The [organization] and Kate Pearce from the Department of Recreation and Leisure Studies at the University of Waterloo, Ontario, would like to invite you to...

Share your Experiences, Tell your Stories, and Create Knowledge about Disability

I (KATE) am conducting a research project in [town], NS for my Master's thesis. The [organization] and I have partnered to help me speak to parents of children and youth with disabilities about their children's experiences in community recreation.

I think stories are one of the best ways we can share our experiences with each other, and with the world. I want to use stories to help other researchers, leisure programmers and communities understand disability. I will be interviewing about 6 different parents (of male or female child under 18 currently living at home). What does this really mean...?

Here's what it means for you:

- You will be interviewed individually twice, whenever it works for you (each interview will last about 1 hour).
- You will be asked to share stories about your child's community recreation experiences.

Here's what it means for me:

- I get to reconnect with people and an organization I admire and respect.
- I get to hear stories about your child's community recreation experiences, and then...
- I get to share these stories with other academic, recreation practitioners and community members.

And here's what it means to our communities:

- We all get a better understanding of people's experiences around disability in community recreation.
- We all get a better understanding of how we can make community recreation experiences the best possible for everyone involved.

If you are interested in participating or would like more information to aid you in making a decision about participation, please contact me, Kate Pearce at 902-300-0642 or by email at kpearce@uwaterloo.ca

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Waterloo, Ontario. If you have questions or concerns about this study you may also contact my advisor Dr. Susan Arai at 519-888-4567 ext. 33758 or (sarai@uwaterloo.ca).

Kate Pearce, Masters Candidate
Department of Recreation and Leisure Studies
University of Waterloo

Dr. Susan Arai, Associate Professor
Department of Recreation and Leisure Studies
University of Waterloo

Appendix D: Letter of consent for parents



Date

Dear _____:

This letter is an invitation to participate in a study I am conducting as part of my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo, Ontario, under the supervision of Dr. Susan Arai. The title of my research project is "Tell me a story: A narrative exploration disability in community recreation".

First, I would like to thank you for your interest and consideration of participating in this study. The purpose of this narrative study is to gather stories of community recreation experience from parents of youth with disabilities. You have been asked to participate in the study based on your child's previous involvement with the [organization] of [organization 2] in [town], Nova Scotia. Your stories will provide insights for other researchers, leisure programmers, and community members about leisure experiences in community recreation. Upon completion of this study a summary of the study results (or entire thesis) will be shared with all participants, and the [organization] and [organization 2].

To be considered for participation in this study you must be: over 18 years old, and a parent to a child with disabilities. Your child must be under 18 years old and currently living at home. In addition, parents of both male and female children are being intentionally sought to provide a range of experiences and stories.

Participating in this study would involve participation in two interviews approximately 1 to 2 weeks apart. Each interview will last approximately 1 hour. These interviews will take place in a setting of your choosing, and at a time that is convenient for you. This setting is intended to be a place of comfort for you. You may decline to answer any of the interview questions, or decline to share any story or experience, if you wish. With your permission the interviews will be audio-recorded to facilitate the collection of stories, and interviews will be later transcribed for analysis. As a participant you may choose to withdraw from the study at any time without repercussion; your rights will be respected and you would be removed from the study totally and immediately.

All information collected is considered completely confidential. To support the findings of this study, verbatim quotations and excerpts from your stories will be used however your name, your child's name, and other names (people or organizations) mentioned will not appear in any thesis or reports resulting from this study. You will be assigned a pseudonym to protect your identity as will anyone mentioned in your interview. You and your child will only be identified in the study by gender, and as parent or child. No description of your child's disabilities will appear in the thesis or any relating publications.

All paper field notes collected will be retained in my locked residence while in Nova Scotia, and then in a secure cabinet in the Department of Recreation and Leisure Studies at the University of Waterloo, Ontario. All paper notes will be confidentially destroyed at the end of the study. Further, all electronic data will be stored securely on a password protected storage device, and will be confidentially destroyed after 3 years. Finally, only my advisor (Dr. Susan Arai) will have access to these materials. There are no known or anticipated risks to participants in this study.

If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please contact me at 902-300-0642 or by email (kpearce@uwaterloo.ca). You may also contact my supervisor, Dr. Susan Arai at (519-888-4567 ext. 33758) or by email (sarai@uwaterloo.ca).

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics, University of Waterloo (file: 15609). However, the final decision about participation belongs to you. If you have any comments or concerns resulting from your participation in this study, please feel free to contact Dr. Susan Sykes, Director, Office of Research Ethics at (519)888-4567 ext. 36005 or by email ssykes@uwaterloo.ca

I hope that the results of my study will be beneficial to the [organization] and [organization 2], to you and your family, and to families including youth with a disability across Canada, as well as the broader research community. I very much look forward to speaking with you and your child, and thank you in advance for your assistance in this project.

Yours sincerely,

Kate Pearce
Masters Candidate
Department of Recreation and Leisure Studies
University of Waterloo

Dr. Susan Arai
Associate Professor
Department of Recreation and Leisure Studies
University of Waterloo

Appendix E: Participant Consent Form



Participant Consent Form

I have read the information presented in the information letter about the study "Tell me a story: A narrative exploration disability in community recreation" being conducted by Kate Pearce of the Department of Recreation and Leisure Studies at the University of Waterloo, under the supervision of Dr. Susan Arai. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that verbatim quotations may be used; however pseudonyms will be used in place of my name and my child's name. As well pseudonyms will be assigned in place of all other names (people or organizations).

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact Kate Pearce at 902-300-0642 or kpearce@uwaterloo.ca, or Dr. Susan Arai at (519-888-4567 ext. 33758). I also understand that this project has been reviewed, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo (file: 15609) and questions about the study may also be directed to Dr. Susan Sykes, Director, Office of Research Ethics at (519) 888-4567 ext. 36005 or ssykes@uwaterloo.ca

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES NO

I agree to have my interview audio recorded.

YES NO

I agree to the use of verbatim quotations (with the use of a pseudonym) in any thesis or publication that comes of this research.

YES NO

I would like to receive a summary of the research results.

YES NO

By email _____

Or by mail (please write address)

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

Withdrawal From Study (Verbal or Written)

_____ wishes to withdraw from participating in the
study by Kate Pearce from the University of Waterloo, Ontario.

Participant Name: _____

Participant Signature (optional): _____

Researcher Name: _____

Researcher Signature: _____

Date: _____

Appendix F: Call guide for parent participants

Hi, this is Kate Pearce calling from the University of Waterloo. I'm calling in response to your interest in my thesis project in connection to the [organization]. I would like to thank you for expressing interest in this study and would be happy to answer any questions you have. Is there anything you would like to know about the study? What questions do you have?

For this study I am hoping to collect a range of experiences from parents. I would like to ask you a few questions about your child to determine if you qualify for this study. Can I ask you about child? How would you describe (child's name)? Does (child) currently live at home? Has your child participated in both integrated and segregated community recreation programs? Do you have any questions?

I will be contacting you within a week to let you know if you have been selected for this study. As this is a very small study I will only be interviewing 4-6 parents I will contact you to explain the reasoning for my selection. If you are selected, I would like to set up our first interview at that time. Also at our first interview I will provide you with a package outlining the study and ask you for your informed consent? Please let me know if you have any questions or concerns, I would be more than happy to answer them.

Thanks again for your interest. Bye!

Appendix G: Interview guide 1

Preamble/Opening Statement:

Thank you for agreeing to participate in this study. As mentioned I am hoping to learn about experiences in community recreation settings for children with disabilities from their parent's perspectives and I'm excited to hear your stories.

I would like to remind you that you are not obligated to participate in the study or respond to any questions in the interview you do not wish to. You may choose to end the interview and/or your participation in this study at any time without repercussions. Would it be alright if I turned the audio recorder on now?

What I would like to do in this interview is have you tell me stories about your child. I would like you to think of experiences your child has had in different community recreation settings. These may include experiences with the [organization] or [organization 2] but also other community recreation experiences.

Questions

To begin, can you tell me about [insert child's name]? Can you tell me the story about [insert child's name]'s involvement in community recreation in [town]?

Ask about details for question 1

- Who was involved
- What happened?
- Where was it?
- When was that?

Are there other parts of the story about [child]'s experiences with community recreation?

You didn't mention (other types of involvement) experiences?

[Interviewer will cycle through questions 1-3 several times as need in conversational interview]

What sorts of other experiences has [child] had with (integrated/segregated/inclusion)?

[Interviewer will repeat question2 for other experiences]

Are there any activities that [child] would like to be involved in but hasn't?

What has prevented [child]'s involvement?

Closing Statement

I would like to thank you very much for your time tonight (today/this morning). I really appreciate your participation in this study, and enjoyed hearing your stories. I believe that the stories I am collecting will have a positive impact on our communities, and recreation programs. If you have any questions, comments or concerns please do not hesitate to contact me or my advisor by phone or email. When would you like to have our next interview? Where will we meet?

Appendix H: Interview guide 2

Preamble/Opening Statement:

It is good to see you again! In this interview I am hoping to explore the story (stories) you told me last time. Again, I would like to thank you for choosing to participate in this study, your understanding and experiences are valuable, and I'm excited to explore your stories and hear more.

I would like to remind you that you are not obligated to participate in the study or respond to any questions in the interview you do not wish to. You may choose to end the interview and/or your participation in this study at any time without repercussions. Would it be ok to turn the audio recorder on now?

What I would like to do in this interview is talk about the story (stories) you told me last time. I want to make sure that my interpretations of the story are the same as yours. Let's begin, here's the story I understood from our first conversation...

Interview Guide 2

These first questions focus on the narrative as a whole.

Did I capture the story of [child]'s involvement in community recreation?

Tell me what you think about the story you told me?

What does it mean to you?

What was important to you about this story?

I want to explore specific parts of the narrative with you. [Interviewer, Kate, identifies each part and asks the following questions about each.

Here's what I understood from the story...

What did you want to share about [child] when you told this story?

Is that what you meant? Can you clarify that for me?

What can we learn from your child's experiences?

For each question above the following questions will be used to further the conversation:

And then what happened?

Can you say more about what that was like?

Can you tell me the story about it?

How/Why did you feel that way?

What did you like about that?

What didn't you like about that?

What did it mean to you?

What did you think about that?

Can you describe what you were doing?

Closing Statement

I would like to thank you very much for your time tonight (today/this morning). I really appreciate your participation in this study. I've truly enjoyed hearing your stories, and our shared understanding of them. The stories you have told me can provide new ideas and experiences for researchers to think about and explore. If you have any questions, comments or concerns please do not hesitate to contact me or my advisor by phone or email. I would also like to present you with a letter of thanks. My advisor and I are both interested in learning about your thoughts of this interview and research process, and would be happy to receive any feedback you have about this experience.

Appendix I: Letter of thanks to parents



Date

Dear *(Insert Name of Participant)*,

I would like to thank you for your participation in this study "Tell me a story: A narrative exploration of disability in community recreation". As a reminder, the purpose of this study was to collect stories of community recreation experiences from parents of children and youth with disabilities. Your stories will contribute to a better understanding of disability for other researchers, community recreation practitioners and community members. I would like to remind you that all information collected during this study is considered and will be kept confidential.

Once all the stories are collected and analyzed for this project, I plan on sharing this understanding through my final thesis. Upon completion of this study a summary of results will be shared with you and the [organization]. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me, Kate Pearce at 902-300-0642 or by email kpearce@uwaterloo.ca, or my supervisor Dr. Susan Arai at (519-888-4567 ext. 33758).

As with all University of Waterloo projects, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo, Ontario. Should you have any comments or concerns resulting from your participation in this study, you may also contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567, ext. 36005 or ssykes@uwaterloo.ca

Thank you again for your participation. If you indicated that you wished a summary of the findings for this study they will be sent to you around November 2009.

Kate Pearce
Masters Candidate
Department of Recreation and Leisure Studies
University of Waterloo

Dr. Susan Arai
Associate Professor
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University of Waterloo

Appendix J: Letter of thank you for organizations



Date

Dear [organization],

I would like to thank you for your participation and cooperation of your organization in this study "Tell me a story: A narrative exploration of disability in community". As a reminder, the purpose of this study was to collect stories of community recreation experiences from parents of children and youth with disabilities.

The stories collected during interviews will contribute to a better understanding of disability for other researchers, community recreation practitioners and community members. All information collected during the interviews is considered and will be kept confidential.

Once all the stories are collected and analyzed for this project, I plan on sharing this understanding through my final thesis. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me Kate Pearce at 902-300-0642 or by email kpearce@uwaterloo.ca, or my advisor Dr. Susan Arai at (519-888-4567 ext. 33758). If you would like a summary of the study, please feel free to contact me. The study is expected to be completed by November 2009.

As with all University of Waterloo projects, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo, Ontario. Should you have any comments or concerns resulting from your participation in this study, you may also contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567, ext. 36005 or ssykes@uwaterloo.ca

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