Parents' Perspectives on the Lives of their Teenagers with Disabilities:

A Focus on Inclusion

A Thesis

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Dedication

This thesis is dedicated to my husband, Graeme
and my friend, Randy.
Their support and understanding during
these past two years has been invaluable.

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There are many people who I would like to thank for their hard work and support throughout these past two years.

My husband, Graeme Carr, was patient and understanding and who used all his alone time wisely by renovating the house.

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Abstract

The perspectives on inclusion of five parents of children with intellectual disabilities were explored in this qualitative study. Open-ended, semi-structured interviews were used to gain the parents' perspectives on their child's level of inclusion at home, in the community, and at school. Most parents in the study were content overall with how well their child was included in the school and community. However, all parents expressed a desire to have their children more active socially, in particular, making and sustaining friends. The parents felt that their child would benefit a great deal from closer friendships with their peers. All families indicated that they were the primary social group for their child as well as the key advocate. As a result of this work, a series of recommendations were developed to increase the level of inclusion in schools and communities. They included gaining a more holistic picture of inclusion by interviewing siblings and peers of children with disabilities, and educating the community about programs that include people with disabilities.

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Chapter One

Introduction

Inclusion is a term that has a broad definition and encompasses the diverse nature of our population. For the purposes of this thesis, inclusion is defined as a society "where adults and children with disabilities learn, play, and work in their community with their neighbours." (Timmons, 2005, p. 42). All people have a right to engage in the same activities, have the same opportunities, and enjoy independence. Including people with disabilities in our communities and schools fosters the development of positive attitudes towards disabilities (Bennett, Deluca, & Bruns, 1997). The goal of inclusion is a society that is tolerant of differences and appreciates the value of diversity (Dib, 2004).

Background

Historical Perspective

Inclusion is a term that is relatively new to society. In 1969 Bengt Nirje, the Director of Training with the Mental Retardation Services Branch of the Ontario Government, originated the principle of normalization (Wolfensberger, 1972). Nirje defined the principle of normalization as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 181). This quote highlights the need for involving individuals with disabilities in our community programs and services as opposed to developing programs and services that are exclusionary. People who are active members of society tend to have better physical health, have better social support networks, and have lower rates of depression (Evans, Barer, & Marmor, 1994). By contributing to society, individuals with disabilities enjoy a higher quality of life and increased self-confidence (Wolfensberger). The parents of teenagers with disabilities who participated in this research project reported that typically, the services that have been made accessible to them have been segregated with little or no contact with the regular society. Over the past 25 years, many services for people with disabilities have been created within the community (Minnes, Buell, Feldman, McColl, & McCreary, 2002). These services have created opportunities for the participants of the study but have not been effective in integrating their lives with society. Most of the participants in this study are employed in sheltered workshops where they do not interact with society. A sheltered workshop is a business such as a bakery that is built to provide employment for people with disabilities. In schools, many of the children in this study have been removed from the regular classroom and educated classrooms with other children who have disabilities.

Often modifying programs to include individuals with disabilities is successful during the younger ages (Kasari, Freeman, Bauminger, & Alkin, 1999). When children are included together, their differences are not as apparent as when adults are working together. As individuals with disabilities age, the divide between their abilities and those of the regular population tends to increase. In the past, involving people with disabilities in society has moved along a continuum from segregation to mainstreaming to integration to inclusion (Renzaglia, Karvonen, Drasgow, & Stoxen, 2003). This continuum reflected the attitude of society towards people with disabilities. In the early 1900's people with disabilities were often hidden in homes or sent to institutions. As the years progressed, human rights issues became prominent and the rights of people with disabilities were considered (Canadian Human Rights Act, 1976-77). The formation of special schools ensued and eventually those special schools and institutions were being shut down in favour of including people with disabilities in schools, communities, and society (Sobsey & Dreimanis, 1993).

In the past, building institutions to house and care for individuals with disabilities was seen as a solution to removing these people from society (Gostin, 2004). Segregation resulted in people with intellectual disabilities not being seen and, therefore, not part of society. According to Gostin, the inhuman conditions that institutions forced their patients to endure included; isolation, malnutrition, severe maltreatment, and lack of proper medicine. Until recently, people with disabilities were not seen as humans and were not afforded the same rights as the regular population (Scheerenberger, 1983). They were routinely dehumanized and marginalized. Scheerenberger discusses social controls such as restricting marriage and the sterilization of people with disabilities. In 1948, the United Nations passed *The Universal Declaration of Human Rights* (Canadian Human Rights Commission [CHRC], 2005). The declaration was accepted by nations across the world and stated, "everyone is entitled to fundamental rights without regard to distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status." (para. 3). Advocates for people with disabilities began questioning the treatment of individuals in institutions. Parents began keeping their children with disabilities in their homes instead of sending them to institutions that were often located hours from their home community (Meekosha

& Dowse, 1997). From the 1970's onward, provinces in Canada began recognizing the rights of individuals with disabilities in their Human Rights Acts and Charters of Human Rights and Freedom (CHRC, 2005). This increased awareness of individuals with disabilities precipitated the closure of institutions and the movement towards mainstreaming, integration, and inclusion.

Mainstreaming occurs when individuals with disabilities are segregated but are brought into the regular society for those tasks that they can perform satisfactorily (Renzaglia et al., 2003). Essentially, people with disabilities are taught tasks in a segregated environment. When their skill matches that of the general public, individuals with disabilities may then be included into the regular environment to perform that particular task. For example, the participants for this research project reported working for sheltered workshops where they were taught how to stuff letters into envelopes. Once they mastered this skill, local businesses often hired them once a month to perform a mail out of invoices and statements. This type of work is sporadic at best and does not give any opportunity for the individual to build other related skills. By only working once a month, it is difficult for a person to develop social relationships with other employees and, more importantly, feel a sense of belonging in a work environment (Renzaglia et al.).

In contrast to mainstreaming, according to Renzaglia et al. (2003) "integration implies bringing an individual back into a unified system; the physical act of bringing people back does not necessarily create an inclusive environment." (p. 140). With integration, individuals with disabilities can be working or learning beside their peers but on tasks that are completely unrelated to what their peers are working on. This discord between tasks makes it difficult to foster rapport between individuals with disabilities and their peers. For example, a child with a disability might be in a math class with his or her age level peers. Because of the child's disabilities he or she may be appointed a teacher assistant to support him or her. Typically, a teacher assistant will work on skills unrelated to math and often remove the student if the class is noisy or if the student's behaviour causes disruption (Frederickson, Dunsmuir, Lang, & Monsen, 2004). Integration focuses too much on the disparity between children, instead of working towards creating a program that allows children to learn together.

Timmons (2005) describes inclusion as all children being educated in the same classroom with their age appropriate peers. If children are in a math class, then all the children are working on math problems. Some children may require modified programs but the important factor is that "one population is being educated, not two: the disabled and the non-disabled" (Avramidis, Bayliss, & Burden, 2002; p. 144). For example, if a child with a disability is in a social studies class in school and that class has a test on Friday, the child with a disability should also have a test on Friday. The content may be modified but it is important that the child is studying along with his or her peers. A similar case can be made for individuals with disabilities working, living, and socializing in communities across the world.

Inclusion requires considerable resources and a dedication to training and building capacity within communities (Roeher Institute, 1999). In 1999, the Roeher Institute released a report entitled *Towards Inclusion: National Evaluation of Deinstitutionalization Initiatives*. This Canadian report advocated for the deinstitutionalization of people with disabilities and the creation of supports within the community to aid people in building their lives within their communities. Like Canada, most countries fall somewhere along the continuum between segregation and integration (United Nations Educational, Scientific & Cultural Organization [UNESCO], 1994). Each province in Canada is developing policies to ensure the rights of individuals with disabilities are being met (CHRC, 2005) and schools are attempting to provide for all the educational needs in the classrooms (Government of Prince Edward Island, 2001).

International Perspective

Including individuals with disabilities is on the international agenda as evidenced by the Salamanca Statement. In June of 1994, more than 300 participants worldwide attended a World Conference on Special Needs Education: Access and Quality in Salamanca, Spain. From this conference, the *Salamanca Statement and Framework for Action on Special Needs Education* was developed. The main thrust of this framework was the stated need for governments to develop "institutions which include everybody, celebrate differences, support learning, and respond to individual needs" (preface). The conference in Spain was precipitated by the 1990 World Conference on Education for All. After the 1990 conference, there was a marked increase of government and organizational involvement in the quest for inclusionary education (UNESCO, 1994; p. vii). As supported by the

Salamanca Statement, exclusion is no longer acceptable to many people. Over the last three decades "the trend in social policy...has been to promote integration and participation and to combat exclusion. Inclusion and participation are essential to human dignity and to the enjoyment and exercise of human rights" (UNESCO). The prevailing perspective is that inclusion is more than including people with differences; it is a matter of human rights.

According to Renzaglia et al. (2003), "Inclusion is a philosophy that must be incorporated into any activity from the onset." (p. 141). Renzaglia et al. state that programs for people with disabilities often have been adapted from existing programs, like an afterthought. Adapting programs can be effective for younger children whose abilities are similar (Freeman, 2000). As individuals with disabilities age, programs need to accommodate the differing levels of capabilities. For inclusion to be truly effective, these programs need to be developed for all people in a society (Avramidis et al., 2000). The *Salamanca Statement* calls for countries to focus on creating inclusive environments in their schools to create a shift in perspective starting with children (UNESCO, 1994). Not surprisingly, developing countries have much higher percentages of adults and children with disabilities who are uneducated (World Health Organization [WHO], 2005). Unfortunately, there are still many individuals with disabilities that are being marginalized and segregated in more prosperous countries such as Canada (WHO).

Canadian Perspective

In Canada, 12.4 % of people have a disability (Council of Canadians with Disabilities [CCD], 2001). All too often, society tends to marginalize people who are perceived to be different from the majority. People with intellectual disabilities have been subjected to institutionalization, sterilization, and forced dependence (Aunos & Feldman, 2002; Roeher Institute, 1999). For example, in 1928, Alberta passed the *Sexual Sterilization Act.* This act was passed in order to prevent "feeble-minded" people from reproducing (Alberta Heritage Alphabet, 2005, para. 4). Sterilization prevented these people from becoming possibly unfit parents and it also prevented the "transmission of defect" (Scheerenberger, 1983, p. 190). Other provinces of Canada followed in Alberta's footsteps and also implemented the mandatory sterilization of individuals with disabilities. The law was finally repealed in 1972 (CHRC, 2005). Sterilization is just one of the many examples of how society has dehumanized individuals with disabilities.

In the 1970's, the movement for closure of institutions for people with disabilities began in the United States (Partners in Policymaking, 2005). The U.S. government made funds available to support individuals with disabilities within the community. These funds facilitated the closure of institutions and a shift in attitude towards people with disabilities. Advocacy groups attempted to promote individuals with disabilities as active and contributing members of society (CCD, 2001). Canadians followed their neighbours to the south more slowly. In 1982, the Charter of Rights and Freedoms gave equal status to individuals with disabilities (Canadian Association for Community Living, 2005). Section 15 in the Canadian Charter of Rights and Freedom states, "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability." The Charter set the tone for the new millennium. From 1982 forward, Canada established itself as a world leader in human rights defined by partnerships between advocacy groups and the federal government (CHRC, 2005). In 1994, the federal and provincial government and the Canadian Association of Community Living formed a new partnership to further the trend of deinstitutionalization. In 1992, the government of Canada implemented the *National Strategy for the Integration of Persons with Disabilities* (Roeher Institute, 1999). This strategy was put forward in an effort to close down institutions that housed people with intellectual disabilities and reintegrate these people into the community (Roeher Institute). Many individuals with intellectual disabilities were able to return to their communities.

In Unison: A Canadian Approach to Disability, a document that promoted the integration of people with disabilities, was signed by the Government of Canada and provincial / territorial governments in 1997. This document addressed the needs and challenges of Canadians with disabilities. It states:

> Persons with disabilities participate as full citizens in all aspects of Canadian society. The full participation of persons with disabilities requires the commitment of all segments of society. The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that

> prevent their full participation. (Federal, Provincial, Territorial Ministers Responsible for Social Services, 1997)

In Unison calls for Canadians to advocate for the inclusion of all people regardless of differences. It argues that by maximizing people's potential, Canada's population will become stronger and less dependent on provincial and federal supports.

In Canada today, there has been much growth and understanding surrounding people with disabilities. The government has outlined significant social policies, which, if followed through, could promote profound changes for people with disabilities. In 2004, the Federal Budget committed to strengthening social programs. For persons with disabilities the budget focused on employment opportunities and training (Department of Finance Canada, 2004). In the throne speech made on February 2, 2004, it was stated, "We want a Canada in which citizens with disabilities have the opportunity to contribute to and benefit from Canada's prosperity as learners, workers, volunteers and family members." (Office of the Prime Minister, 2004). The budget allocated $30 million for employment supports and training needs of people with disabilities and study grants for students with disabilities. This substantial investment is seen as a hopeful start for advocacy groups across Canada (CCD, 2004).

In our classrooms, children with disabilities have more inclusionary opportunities than in the workforce. Strides have been made to make classrooms more inclusive but according to Porter (2004), "over 40% of Canadian children with intellectual disabilities are in special classes or segregated schools." (p.1). Fostering openness to diversity must begin early. Including all children in the classroom teaches children acceptance and openness to differences (Killoran, 2002). Although children with disabilities are being educated with their peers, most provinces in Canada are beginning to revisit their policies surrounding special education (CCD, 2004). As education is provincially legislated, the degree of segregation varies from province to province. For example, Alberta and Ontario still operate segregated schools. The Department of Education in Alberta defines a designated special education school as a "school that serves students with special needs including those who are diagnosed as having mild, moderate or severe disabilities." (Alberta Government, 2005). Provinces such as Prince Edward Island have made more significant gains with inclusion.

Prince Edward Island Perspective

There are approximately 1,100 people living with disabilities in Prince Edward Island (Government of Prince Edward Island, 2005). Provincially, there are three school boards; one French and two English that educate all children in PEI. There are no segregated schools. According to Timmons (2005), rural communities seem to be further ahead in offering inclusive services than the larger, urban centres of Canada. Often rural areas lack the resources and capacity to offer segregated and specialized services. This deficit of resources translates into all children being included in classes with their age appropriate peers. Urban centres are better able to divide children into classes based on their disability and then offer services specific to their needs (Timmons, 2005). This type of schooling endorses segregation. In 2004, Statistics Canada presented data on children with special needs in Canada to the Canadian Education Statistics Council. The information for Statistics Canada's presentation was gleaned from the *Participation and Activity Limitation Survey* (PALS). This national survey collected information from individuals with a disability including their employment status, their available supports, their income, and their participation in society (Statistics Canada, 2001). The survey compared literacy levels between disabled and non-disabled students. Results showed Prince Edward Island to have the smallest literacy gap between students with a disability and students without a disability, with Ontario and Newfoundland having the largest gap.

In PEI the entire elementary school system is inclusive. Children are taught in the regular classroom along with their peers. For those children that require additional assistance, the school board allocates funds for a teacher assistant or they may be removed from the classroom for short periods of time to work with a Resource Teacher. Many children with intellectual disabilities also have an Individualized Education Plan (IEP). IEP's are developed by a team of educators and sometimes the parent or guardian of the student. Academic and social goals are set that are in accordance with the regular classroom curriculum. All these supports enable children with disabilities to participate in the education system with their peers. The secondary and high schools still have segregated classrooms although efforts are being made to include children with intellectual disabilities in some regular classes.

In 1997, the Province of Prince Edward Island commissioned a review of special education in its schools. The Province needed guidance for the development of policies surrounding educating individuals with disabilities (Timmons, 2001). Mackey and

Associates conducted the review and emphasized the identification of students with special needs, programs for these students, resources available for these students, and special education policy (Prince Edward Island Department of Education, 1997). The report gave 43 recommendations that provided incentive for increased resources being allocated to student services for students with special needs (Timmons, 2001). Some recommendations included using a team approach to educating children with disabilities, to develop a partnership between the Department of Education and the Department of Health and Social Services, and to establish appropriate outcomes for students with special needs (Prince Edward Island Department of Education, 1997). The University of Prince Edward Island (UPEI) also works with the Prince Edward Island Department of Education in training teachers in inclusive education.

The Faculty of Education at UPEI offers a core course in inclusive education for the Bachelor of Education (B.Ed). All students in the B.Ed program are required to take this course. In addition, there is an elective course that offers information on individualized instruction for different disabilities. UPEI also has a Certificate in Inclusive Education designed for teachers who are already in the classroom. The Certificate program offers a wide range of courses that a teacher can tailor to their individual instructional needs (Timmons, 2001). The Master's of Education program at UPEI allows students to research a wide breadth of interests. There have been a number of students who have chosen researching children with special needs as their thesis topic. For example, Phyllis Horne (2001) wrote a thesis titled *Making it Work: Teacher's Perspectives on Inclusion* and Tara Deglan-Gallant (2004) wrote *Traumatic Brain Injury: Challenges and*

Considerations for the School. This study fits into a context where there has been significant work on inclusion.

This thesis will build on the research that has been conducted in Prince Edward Island by considering parents' perspectives of inclusion for their high school children. The focus of this study will be on teenagers as this age group experiences many life transitions within their school career and after their school career. Some of these challenges include the school to work transition, the broadening social and skills gap between children with disabilities and regular children, and the advent of the desire for independence. In this research study, parents were found to be the primary social support network for their children with disabilities. Given this important role in the life of individuals with disabilities, it was important to me to research the parents' perspectives of inclusion for their child.

Chapter Two

Literature Review

Introduction

Gaining parents' perspective on inclusion can give researchers, educators, and policymakers valuable insights into best practices on educating and including people with disabilities. Parents hold a wealth of knowledge about strategies that enhance their child's academic skills and can help create realistic social goals. Bennett et al. (1997) state that it is essential to include parents in the educational process as parents and their children are most affected by inclusionary practices (p. 128). According to Scheepstra, Nakken, and Pijl (1999) parents state that social integration opportunities for their children are the most important factor for inclusion. Parents believe that social relationships that are developed at school will enhance their child's social network in the community and society (Scheepstra et al. 1999). Kasari et al, (1999) also found that parents felt peer interaction was one of the most important outcomes for integrating their child into the regular classroom and community.

Education

Integrating students with special needs in the regular classroom poses a variety of challenges regarding academic programming and parental and school personnel attitudes. All too often parents are left out of their child's education planning (Frederickson et al, 2004). Research surrounding the parents' perspective of inclusive practices has not been as robust as that of the teachers' perspective (Avramidis et al., 2002; Miller & Strain, 1992). In the review of the literature regarding parents' perspectives on inclusive education for their children concerns regarding services, home/school relationships, and social opportunities were most prevalent (see Bennett et al., 1997; Frederickson et al.; Freeman, 2000; Scheepstra et al., 1999). The focus of inclusion for parents seems to be a social one whereas teachers have typically concentrated on the achievement of academic goals when instructing children with special needs.

Inclusion

Social integration, peer modeling, development of positive attitudes towards children with special needs, and increased social and academic achievement are all, from the parents' perspective, important aspects of an inclusive classroom (Frederickson et al., 2004; Freeman, 2000; Kasari et al., 1999; Leyser & Kirk, 2004; Palmer, Borthwick-Duffy, Widaman, & Best, 1998: Ryandak & Downing, 1996). Each aspect works as part of a whole to increase a student with a disability's social, academic, and overall enjoyment of their school experience.

Social integration. Including children with special needs in the regular classroom can have positive social outcomes for both children with and without a disability (Leyser & Kirk, 2004). According to the parents in a study done by Palmer et al. (1998), the potential for positive social interaction with peers outweighed academics. Parents felt that having their child with special needs learn and play with their nondisabled peers was more important than academic success (Palmer et al.). Scheepstra, Nakken, and Pijl (1999) suggest that building relationships with nondisabled peers can enhance contacts within the neighbourhood and community. These contacts can lead to a wider integration in society and lead to an individual's social success not only within the school but through the transition into adulthood (Scheepstra et al.). Including children with disabilities has shown to increase a child's social, academic, and developmental skills (Bennett et al., 1997). By learning alongside their peers, children with special needs often place higher expectations on themselves and they experience more academic improvements than those children with special needs that have been educated in a special education class (Freeman, 2000; Palmer, Fuller, Arora, & Nelson, 2001).

Peer modeling. Interacting and learning in an inclusive environment enables children with special needs to learn appropriate social behaviours from their peers (Bennett et al., 1997). The acquisition of appropriate social skills can help enable children with special needs to more easily build friendships (Freeman, 2000). Kasari et al. (1999) found that parents want their children to view their nondisabled peers as role models in hopes that inclusion would also promote friendships between their child with special needs and the children in the regular classroom.

Development of positive attitudes. Not only does having inclusive classrooms provide social and academic benefits for children with special needs, inclusion can also positively impact all children in the classroom. Freeman (2000) found that children in the regular classroom were not negatively impacted socially or academically by having children with special needs in the classroom. In fact, Leyser and Kirk (2004) discovered that inclusion had positive affects on classmates such as acceptance and sensitivity to individual differences (p. 281). Galant and Hanline (1993) state, “Parents believe that positive exposure to children with disabilities will promote acceptance and tolerance.” (p. 294). Miller and Strain (1992) reported similar findings stating that parents of typical children viewed inclusion positively. Ryandak and Downing (1996) found that “parents felt that if their child was to reach their desired goals, then their child had to be treated like, placed with, and expected to learn as their peers without disabilities, while having access to the same meaningful and valued educational activities and appropriate supports and adaptations.” (p. 12)

Parental Concerns and Involvement with the School

Social vs. academic. Improving social and academic skills are cited by parents as a priority for their children with special needs within their school experience (Frederickson et al., 2004; Freeman, 2000; Galant & Hanline, 1993; Leyser & Kirk, 2004; Miller & Strain, 1992; Palmer et al., 2001). Improving social skills is a major motivator for parents to want their child with special needs educated in the regular classroom (Scheepstra et al., 1999). Leyser and Kirk (2004) surveyed 437 parents of children with a disability. The researchers found that parents reported the main benefit of inclusion was the potential social opportunities for their child in a regular classroom. Palmer, Borthwick-Duffy, and Widaman (1998) surveyed 995 parents of children with disabilities and found that the attainment of social goals was of primary importance to parents. They suggested,

> Parents who place a higher value on the development of social skills may be willing to trade off 'special education' benefits such as: (a) a specialized curriculum, (b) easier access to ancillary services, and (c) more individualized instruction, for the social benefits that they consider to be more attainable in a general education setting. (p. 280)

Although the opportunity for social interaction was a desired outcome of inclusion, many parents were also concerned about bullying and possible negative reactions from the class towards their child (Galant & Hanline, 1993; Leyser & Kirk, 2004; Palmer et al., 2001). In a study done by Galant and Hanline, parents of children without a disability were interviewed and they reported that learning with children with special needs fostered tolerance and acceptance as opposed to negative reactions. Not only are children with special needs learning appropriate social behaviours from their nondisabled peers but those peers are learning about diversity in society.

Communication with the school. Effective communication between parents and the school is paramount to establishing good relationships and promoting effective instruction for a child with special needs (Bennett et al., 1997; Frederickson et al, 2004; Green & Shinn, 1994; Petr & Barney, 1993). Teacher attitude towards children with special needs was also cited as important by the parents (Bennett et al.; Miller and Strain, 1992; Petr & Barney).

Petr and Barney (1993) conducted focus groups with parents of children with special needs and found that parents felt teachers did not have positive attitudes towards their child's success. The participants of the research wanted educators to have higher expectations for their child, expectations that more closely mirrored their own. Bennett et al. (1997) suggested from their findings that parents wanted the teacher to create "an accepting environment in which the child is considered a valued member." (p. 128).

Parental involvement in school. A review of the literature shows that there seems to be a point where parental involvement with the school becomes a detriment to their advocacy efforts for their child with special needs (Bennett et al., 1997; Petr & Barney, 1993; Ryandak & Downing, 1996). Bennett et al. interviewed 15 parents. The questions focused on how involved the parent felt with their child's school and how the parent felt about their relationship with their child's teacher. The researchers reported that most of the parents felt quite involved with the school and were happy with their involvement. The parents felt that their relationship with the teacher was often strained and that they had to take on an adversarial role against the teacher to ensure inclusion for their child (Bennett et al.).

Support Networks

Support networks are an important part of any family functioning (Evans et al., 1994). Families who have an individual with a disability often require supports of a more varied nature (Petr & Barney, 1993). These supports can include: emotional, social, respite, financial, and instrumental (Marcenko & Meyers, 1991; White & Hastings, 2004). Of these supports, a review of the literature has revealed that family supports are often the most stable and supportive for families who have an individual with a disability (Dyson, 1993; Hastings, Allen, McDermott & Still, 2002; Marcenko & Meyers; Seltzer & Krauss, 2001).

Family

When reviewing literature on support networks for parents of children with disabilities there is considerable research being done on family support networks (Dyson, 1993; Grant & Whittell, 2000; Hastings et al., 2002; Marcenko & Meyers, 1991; McIntyre, Kraemer, Blacher, & Simmerman, 2004; Seltzer & Krauss, 2001; Trute, 2003; White & Hastings, 2004). Family support networks include support from a spouse/partner, parents, and siblings.

In a study by Hastings et al. (2002), the perception of support was vital to the stress levels of parents caring for a child with a disability. The researchers found that if the parents perceived that they had positive support systems within their family, their stress levels were not as high as those families who had negative perceptions about their familial support system. These informal, familial supports were used as coping strategies to reduce the "stresses and strains of caring for a child with an intellectual disability." (Hastings et al., p. 273). White and Hastings (2004) also found that increased social support improved the well being of families. The researchers surveyed 41 mothers of children with intellectual disabilities. They found that psychological impacts were the most important predictors of stress. The higher the perceived level of support, the more satisfied the mothers were with their life situation. An interesting finding was that the more caregiving their child required, the more personal growth and maturity the mother reported. The researchers postulate that caring for a child with a disability fosters increased maturity and feelings of efficacy.

Much of the research focuses on the mother's perspective of support (Hastings et al., 2002; McIntyre et al., 2004; Trute, 2003; White & Hastings, 2004). Trute interviewed 88 families and asked them to complete several standardized tests on stress, depression, self-esteem, and family assessment. He found that maternal grandmothers were considered the most positive and effective support system for mothers who have a child with a disability. In contrast, the relationships between the mother and paternal grandmother were often strained. Trute suggests that the tension could be from a feeling of guilt about bearing a child with a disability on the mother's side and feelings of blame from the paternal grandmother's side. Marcenko and Meyers (1991) interviewed 100 mothers of a child with a disability. Some mothers were single and others were married. The researchers analyzed the amount of support each group received and found that each group received similar amounts of support. The difference between the two groups was in the perception of support. The married women perceived much more support from their husband and husband's family than the single mothers (Marcenko & Meyers). In actual fact, the researchers found that the married women did not receive any more practical support such as housework and babysitting but their perceptions of support increased their psychological well being. Although psychological support is an important piece of overall support, practical help such as respite is also valued by families.

Respite is an opportunity for families to have some time away from their child with a disability to recuperate and reduce stress levels. Families who have a child with a disability often need to implement coping strategies to deal with the increased needs of their child (Grant & Whittell, 2000; Hastings et al., 2002; White & Hastings, 2004). Grant and Whittell interviewed 30 families about their coping strategies, relationships, experiences with support services, and caregiving history. The families' strategies including problem solving and cognitive coping; problem solving strategies included having a routine, building on personal experience, and having a trusting person to discuss issues with. Cognitive coping is somewhat more abstract and encompasses changing the way one views the situation. White and Hastings found that the two most frequent answers for cognitive coping were "realizing that there is always someone worse off than yourself (91%) and that the person you care for is not to blame (91%)" (p. 265). Women were found to have better developed coping strategies than men, and women had more self confidence and self belief in their abilities. Although women were better able to navigate difficult situations, believing that they were part of a team with their partner was integral to their well being. The researchers found that single parents had significantly higher stress and had difficulty negotiating all of their commitments.

Dyson (1993) researched two groups of families. One group had a child with a disability and the other group did not. She hypothesized that the families who had a child with a disability would experience higher stress and emotional difficulties than those families that did not have a child with a disability. Dyson found that there was no significant difference between the two groups of families. In fact, she found that the families who had a child with a disability reported greater strength of stability. This finding was corroborated by Seltzer and Krauss (2001) who found through a review of the relevant literature that families who have children with disabilities were characterized by close relationships and high emotional involvement. The researchers' interest was in the quality of life of individuals with disabilities. They found these individuals' social networks were primarily made up of family members highlighting the strength of family relationships and the importance of effective support networks for the family.

Petr and Barney (1993) found that families who had a child with a disability found support from other families in a similar situation helpful. The families in this study gained support from their own extended family but found the support inconsistent. According to the researchers the support from other families who have a child with a disability was more stable and reliable over time. The researchers reported, "these parents share a common bond that allows for understanding and support at the deepest levels." (p. 250).

As stated above, the research has shown that family supports are the most effective in reducing stress and empowering families to cope with having a child with a disability. Other forms of support are also considered essential such as respite and financial support.

Formal Supports

Formal supports such as respite and financial resources are typically reported by families as unreliable with inconsistent quality (Petr & Barney, 1993; Redmond & Richardson, 2003; Renzaglia et al., 2003; Udwin, Howlin, Davies, & Mannion, 1998). Respite services are highly valued by families although it is difficult for many families to hire qualified personnel (Redmond & Richardson; Udwin et al.).

Redmond and Richardson (2003) interviewed 17 mothers of children with disabilities and found that their most pressing complaint about outside services was the lack of available information. The mothers in the study found the information to be inconsistent and not easy to find. Some mothers reported asking many different people and organizations about the same service to gain the full picture of what the service being offered entailed. Petr and Barney (1993) were told by parents that they "stumbled on programs by chance…" (p. 250). The research suggests that there is a gap in the communication between support services and families.

Udwin et al. (1998) reported that families felt unsupported by government and organizations in their struggle to find appropriate respite services for their child. Again, the suitability of the respite service was called into question by the families. Udwin et al. found that often respite workers were not properly trained in providing service to people with special needs. Redmond & Richardson's (2003) participants discussed the oscillating quality of service provided. Their desire is for trained and skilled individuals who are available for home respite services. Because of the difficulty in finding skilled support workers, the families often take on the burden of care (Udwin et al.).

When families are the primary caregivers of their children with disabilities, the need for a variety of services increases (Petr & Barney, 1993). Having quality respite services can greatly increase the resilience of families as evidenced by a quote from one mother in Petr and Barney's study, "It's the break that people need – just to get away once in awhile. You can put up with a lot of garbage if you can get out to dinner." (p. 250).

Marcenko and Meyers (1991) detail the need for outside supports. Although familial support is considered essential by families, the make up of families and society is making it more difficult to draw on these resources (Marcenko & Meyers). The researchers suggest that families have fewer internal resources due to being more mobile with the extended family being too far away, having fewer children to help, and working longer hours.

One of the more abstract issues that arose in the literature surrounding formal support networks such as respite was the attitude of negativity from disability professionals and the community (Hastings et al., 2002; Petr & Barney, 1993). As illustrated above, the perception of support is critical to a mother's psychological well being. Hastings et al. found that mothers rated the level of emotional support from disability professionals poorly. The participants in Petr and Barney's study "pointed out the critical importance not only of services, but of the values, attitudes, and philosophies behind the way in which services are delivered" (p. 253).

Factors determining families' wellbeing. There are many factors that interrelate to increase the well being of families who have a child with a disability. Gaining a comprehensive view of such factors is beyond the scope of this project. Reviewing several of the factors sets the stage for some of the issues that the participants of this study struggle with. Support can be found in families and in government services. Enjoying established friendships is also a factor of overall wellbeing (Salisbury, Gallucci, Palombaro, & Peck, 1995).

Friendships

Friendships are an important aspect of a person's social network (Heiman, 2000). Social relationships are integral in developing age appropriate behaviours, cultural values and norms, and offering emotional support (Heiman; Knox & Hickson, 2001; Salisbury et al., 1995). Heiman describes friendships as "a connection between people which satisfies personal needs" (p.1). Knox and Hickson delve somewhat deeper into the meaning of friendships and state "it is axiomatic that close friendships enrich a person's life. Indeed, such relationships have consistently been seen as an essential aspect of an individual's quality of life." (p. 276). Without these important social relationships, people with disabilities can feel isolated and lonely (Jobling, Moni, & Nolan, 2000). Often people with disabilities have difficulty engaging and maintaining their peers in a friendship (Cuckle & Wilson, 2002). Lack of reciprocal friendships has been an issue for individuals with disabilities throughout their lifespan (Cuckle & Wilson; Heiman; Jobling et al.; Turnbull, Blue-Banning, & Pereira, 2000).

Heiman (2000) discusses the benefits of including people with disabilities. Socially, Heiman suggests that people with disabilities learn appropriate social and emotional behaviours from the general population. By increasing their appropriate social skills, the researcher found that people with disabilities experienced more independence and had more opportunities to experience social interaction. Although people with disabilities often have difficulty developing close friendships, the benefits of being part of society are obvious.

School Relationships

Children who are being educated in inclusive environments have the opportunity to interact with all of their peers and learn appropriate play behaviour (Salisbury et al., 1995). Heiman (2000) characterizes friendships between children as "based on affection, mutuality, the willingness to share their innermost thoughts and secrets, loyalty, openness, and intimacy." (p. 1).

People with intellectual disabilities define friendships differently than people without disabilities (Heiman, 2000). They define friendships in terms of the interactions they have with someone as opposed to the emotional aspect of a relationship. Heiman studied three groups of children consisting of a total of 575 students. Group 1 consisted of students with intellectual disabilities in a special education school; group 2 consisted of students with intellectual disabilities in an inclusive environment; group 3 consisted of students without a disability in a general education school. Heiman found that children who were in the special education classroom defined friendships using terms such as helpful, fun, and entertaining. In contrast, the group without disability focused on intimacy and described including their friends in their secrets and thoughts. The researcher found that the students with disabilities focused much less on the emotional aspect of the friendship.

Turnbull et al. (2000) found similar results when interviewing Hispanic children with disabilities. When asked to define a friendship, these students commented that it was someone who works with them. Jobling et al. (2000) found that people with disabilities often single out people who are paid to care for them as friends. Findings from the research suggest that the people who are closest to individuals with disabilities are those who are either family or paid to care for them.

There is debate surrounding the benefits of inclusion. Within the larger scope of the debate arises the issue of friendship. Some research has shown that children with disabilities develop longer lasting friendships with each other than they do with children who do not have a disability (Cuckle & Wilson, 2002; Knox & Hickson, 2001). Cuckle and Wilson stated that friendships developed among peer groups in special schools due to the children having similar interests and abilities. Knox and Hickson interviewed four people with a disability about their views and meanings of friendship. The researchers found that there was depth and richness in the relationships that the participants had developed with other individuals with disabilities. The participants found that their relationships with people without disabilities were characterized as superficial and transitional. Often the people without disabilities were service workers that were paid to care for the people with disabilities (Knox & Hickson). The participants spent the majority of the interview discussing their relationships with other people with disabilities as opposed to those people without disabilities. The authors suggest that the development of these long lasting relationships need to be considered by service workers and recognized as valuable.

Family Relationships

Family is by far the most important social and emotional support system for people with disabilities (Cuckle & Wilson, 2002; Heiman, 2000; Jobling et al., 2000; Knox & Hickson, 2001; Turnbull et al., 2000). Social activities are generally organized by the family within the community and include family friends (Cuckle & Wilson).

Jobling et al. (2000) ran a program for young adults with Down syndrome. This six session program was designed to help the participants understand friendships better. All of the participants lived at home and reported feeling lonely a lot of the time. The majority of their social activities were family centred or with people who were older than them. Cuckle and Wilson (2002) had a similar finding when they interviewed parents of teenagers with disabilities. The parents reported that most of their child's social activities were initiated from the home. For example, if their child was attending a sport program, the parent would always be the person to drive them to and from the program as opposed to the child getting a lift from friends. The friendships made at such programs did not extend outside of the program and into the home (Cuckle & Wilson). The researchers discovered a similar situation at school. The friendships children with disabilities made at school stayed at school.

The lives of people with disabilities can often be characterized by the lack of peer friendships. Without many friendships, people with disabilities often turn to more solitary activities with which to spend their time.

Leisure

Engaging in healthy, social, and interactive leisure activities is an important aspect of leading a holistic lifestyle (Duvdevany, 2002; Scheepstra et al., 1999). Recreational activities present the opportunity for community participation, developing healthy living habits, and learning new skills (Duvdevany; Mactavish & Schleien, 2004). Hodges and Henderson (1999) highlight the responsibility of the community for offering recreation and leisure programs that are available to all populations within a community. Recreation and leisure need to be fun as well as healthy in order for individuals to want to continue to participate (Hodges & Henderson). Unfortunately, there are many barriers to recreational participation for people with intellectual disabilities (Duvdevany; Hodges & Henderson; Mactavish & Schleien). Because of these barriers many people with disabilities experience isolation and reduced life quality (Bennett et al., 1997; Duvdevany; Mactavish & Schleien). From the research, the family emerged as the primary social outlet for recreational and leisure activities (Cuckle & Wilson, 2002;

Duvdevany; Heiman, 2000; Jobling et al., 2000; Knox & Hickson, 2001; Mactavish & Schleien; Turnbull et al., 2000). This finding has been a common thread throughout this paper.

Isolation

Many people with disabilities experience isolation and loneliness as part of their lives (Duvdevany, 2002; Jobling et al., 2000). This isolation is due to a variety of factors including lack of peer friendships (Knox & Hickson, 2001), barriers to participation in activities (Mactavish & Schleien, 2004), and lack of skills necessary to participate in recreational activities (Duvdevany). Isolation is a cycle that can be very difficult to break. If enough barriers exist that prevent someone with a disability from participating in an activity then they are unable to expand their social network to combat their isolation.

It is with removing barriers in mind that Duvdevany (2002) researched the social activities of 33 people with disabilities aged 14-60. Duvdevany suggests that people with disabilities often have their lives so tightly controlled that they are not given the opportunity to make their own choices about which activities they want to participate in. Social workers, teachers, staff, and parents tend to schedule much of a person with a disability's life so that they are not empowered with the ability to make their own choices. Duvdevany suggests creating leisure programs for people with disabilities that introduce these individuals to creative and interesting ways to spend their free time.

Having control over what activities they engage in, people with disabilities can increase their self-determination and self-esteem (Duvdevany).

The activities people with disabilities engage in during their free time are an indicator of their social lives. Jobling et al. (2000) found that watching television was a favourite past time for people with disabilities. Heiman's (2000) participants also reported watching television or nothing at all. Other answers included sleep, housework, and computer time. The answers such as sleep and housework would hardly be considered leisure activities by mainstream society. Heiman suggests the participants may have been grasping for an answer to the question of what they do in their free time in an effort to say something other than nothing.

Combating isolation and increasing activity can be challenging for people with disabilities and those who care for them. There are many barriers that impede participation.

Barriers

Some barriers that individuals with disabilities face when attempting to participate in leisure activities fall under three headings: personal barriers, familial barriers, and organizational/community barriers (Dattilo & Schleien, 1994; Duvdevany, 2002; Heiman, 2000; Mactavish & Schleien, 2004). Duvdevany states that one of the main barriers for individuals with disabilities is that the leisure programs that they are generally signed up for are segregated. Although segregated programs can increase skill and ability, individuals with disabilities should be given the opportunity to participate in activities with the community that they live in (Dattilo & Schleien).

Personal barriers. Many of the personal barriers that individuals with disabilities face are directly related to the available programming. For example a personal barrier could be the lack of skill or ability to participate in a particular activity (Mactavish & Schleien, 2004). A remedy would be for the community to offer an activity that accommodates a person's range of abilities. Other personal barriers include lack of companions for leisure activities, transportation to and from activities, and lack of awareness of available leisure and recreational activities in the community (Mactavish & Schleien). Lack of self esteem also plays a role in the level of participation a person with a disability engages in (Heiman, 2000). People with disabilities may be reluctant to participate in a program due to negative self-image, lack of initiative, and low self-esteem (Heiman; Mactavish & Schleien). Often the family plays an important role in alleviating the above barriers. Unfortunately, not all people with disabilities have a supportive family to advocate for them.

Familial barriers. The family is the safest and most accepting recreational environment for people with disabilities (Mactavish & Schleien, 2004). Mactavish and Schleien state that engaging in activities that are fun and rewarding for all members of the family can be a difficult task for the family. The levels of abilities and interest are different for all members. The researchers report that organization and decision making can often impede recreational activities. Families have obligations that sometimes need to take priority and scheduling activities can become cumbersome (Mactavish & Schleien). It is important for people with disabilities to experience independence in their leisure activities. This independence is easier to come by if the community has programs in place that can accommodate people with special needs.

Organizational/community barriers. Hodges and Henderson (1999) evaluated the Surgeon General's Report on parks and recreation. The researchers discuss how to promote the Surgeon General's physical activity recommendations for all members of the community. The areas of leisure and recreation that communities need to allocate resources to are: making facilities accessible, training staff to accommodate diverse needs, communicating what programs are available, and scheduling these programs so that people with transportation issues are able to secure transport (Hodges & Henderson).

Transitions

The research surrounding young people with disabilities transitioning from high school to work reveals large gaps in service and planning (Beresford, 2004; Blackorby & Wagner, 1996; Collet-Klingenberg 1998; Phelps & Hanley-Maxwell, 1997; Ward, Mallett, Heslop, & Simons, 2003). Transition planning helps people with disabilities prepare for the workforce or post secondary education. Services can include on the job training, job shadowing, social skills workshops, and financial planning (Collett-Klingenberger). Many of these services are not accessible to people with disabilities due to the nature of their content; not modified to a particular person's abilities or are being facilitated by a person who is not trained or skilled in teaching people with disabilities (Beresford).

Other barriers include lack of knowledge of available programs and few job opportunities (Blackorby & Wagner). In order to overcome these barriers research shows that there are key factors integral to a successful transition period for a young person with a disability.

Involvement of Family and Individual

The involvement of the family is one of the most important factors during transition periods. The family is the primary support for a person with a disability. Transition periods are more apt to be successful if the family is involved in the process and is available to support the person with the disability (Ward et al., 2003). Building partnerships with parents and gaining their perspectives can help make transition periods run more smoothly (Beresford, 2004). In addition to involving the family, Blackorby and Wagner (1996) suggest including the youth's goals, strengths, and needs into the transition plan. Incorporating the individual's perspective will increase the probability of the person with a disability finding a job or educational placement that is the right fit for him or her (Beresford).

Holistic Approach

When developing a transition plan, Collett-Klingenberger (1998) details the components that are needed for a successful plan. Including multiple agencies, skilled support people, early planning, and incorporating social skills are some of the components that Collett-Klingenberger discusses.

Including agencies in the transition planning can help to marry the needs of the agency with the needs of the individual with a disability (Collett-Klingenberger, 1998). Beresford (2004) calls for the need for agencies to be involved as well as providing services that are tailored to the needs of people with disabilities in education, training, and social skills.

Beginning transition planning early can help the young person with a disability prepare for the workforce or post secondary education (Collett-Klingenberger, 1998). Beginning planning early can also facilitate the involvement of the school and community. Ward et al. (2003) state the need for including living, personal, and social life in transition planning. Schools are an integral part of ensuring that social skills are worked on before the student leaves school (Collett-Klingenberger). Although there the components for success are readily apparent and known, transition programs are plagued by limitations and barriers for individuals with disabilities.

The relevancy of programs for individuals with disabilities is a recurring issue according to Collett-Klingenberger (1998). The researcher states that programs are often tailored to the regular population and not modified to make the program accessible to people with disabilities. Ward et al. (2003) discuss the continued involvement of the parents. Without the parents' involvement and advocacy, many children would not be able to navigate the myriad of programs available.

Chapter Three

Methodology

Based on the literature, the area of research chosen for this study was a qualitative design. Within this chapter I will discuss my theoretical framework, research method, site selection, participant selection, data collection, data management, data analysis, ethics, and trustworthiness features.

Theoretical Framework

When considering the theory that drives my research, it is clear that viewing life through the lens of the participant is paramount to my research. In order to examine the successes and challenges that individuals with disabilities face it is important to gain the perspective of the person living with the disability. In order to achieve a more holistic picture of these successes and challenges, interviewing the parent or guardian of a person with a disability is also important. In this section I will describe my theoretical position of social constructivism and rationalize how it best fits my research philosophy.

Guba and Lincoln (1981) describe two worlds that we live in: the social world and the natural world. The social world is constructed by humans through their own perceptions (Patton, 2002). Patton explains that these perceptions are "shaped by cultural and linguistic constructs" (p. 96). The natural world is the physical world in which we live. A person's worldview is made up of all of his or her learning experiences, the cultural context within which he or she lives, and the accumulation of prior knowledge (Patton).

All of these factors interact and form an individually constructed reality and knowledge about the world. This reality defining theory is known as constructivism. Crotty (2000) describes constructivism as "the meaning-making activity of the individual mind." (p. 58). In essence, not everyone views the world in the same way. For example, rain to the people living in the West Coast of Canada can be perceived as a precursor to floods and possible death. In contrast, people living in the Sahara desert can perceive rain as life giving. Both of these perceptions have been constructed by the acquisition of prior knowledge and life experience.

The theoretical position that guides my research is social constructivism. Social constructivism emphasizes the effect of community and culture in an individual's world view (Patton, 2002). When interviewing parents about their perspectives on inclusion, through their distinct lens, I asked them to tell me about their experiences on how well they think their child is included in society. Their lens has been shaped by the people surrounding them and their own experiences within society.

Constructivism grew out of postmodernism (Patton, 2002). Postmodernism rebukes the theory that knowledge can be generalized across space and time; instead postmodernism considers that "knowledge is viewed as relative to time and place..." (Patton, p. 100). The knowledge that this research project is attempting to gain is the parents' perspectives on inclusion. Their perspective is relative to Prince Edward Island, their community, and the school their child attends. A parent who lives in Alberta and has a child with a disability may have a completely different perspective on inclusion than a parent in

Prince Edward Island. All of these factors interrelate to provide context for the parents' perspective on inclusion. These perspectives are unique to each individual and cannot be generalized to families living in Europe or Asia. This postmodern perspective allows me to delve into the experiences of individuals and gives their understanding credence based on their interpretations of inclusion. Social constructivism theory holds the belief that there are many truths and not one truth can capture the experience of all parents who have children with disabilities (Saugstad, 2001).

As researchers, we can learn from the parents' perspectives to build our own knowledge base on inclusion and develop our own construction of the reality of inclusion. It is my hope that developing our realities about inclusion can allow us to better inform the participants, the public, and the policymakers to the salient issues surrounding successful inclusion. The important issues are those that are discovered by speaking to individuals living with disabilities and their support networks. Advocating for better policies about inclusion can influence how a policymaker constructs his or her knowledge about policies surrounding inclusion. It is my belief that many policymakers construct policy based on resources and the perceived importance of the topic to the public. The higher the public interest surrounding a particular topic, the more resources that topic is allocated. By shifting the focus of the policymaker from resources to the lived experience of people who have practical and lived knowledge about disabilities, the ensuing policies can be made or changed to better reflect the needs of these people.

Research Method: Interviews

This study used a qualitative research approach. Interviews were used as the primary data collection tool. According to Silverman (1998), using interviews in qualitative research can elicit rich information. I felt that interviews would best capture the experiences of parents of children with disabilities. I hoped that one-on-one discussions with parents about inclusion would give me an in-depth picture of their feelings. I asked the parents 20 open-ended interview questions. The questions were used as a framework to guide the interviews and many interviews contained well over 20 questions due to probing and the semi-structured nature of the interviews. Semi-structured interviews allow the participant to expand on his or her thoughts and feelings (Patton, 2002). In all of the interviews I helped participants elaborate a thought or feeling by probing. Probing is where the interviewer asks the participant to further clarify or discuss a particular topic that has arisen during the interview (Patton). Probing for more information is essential to obtaining "thick" data (Hiller & DiLuzio, 2004). Hiller and DiLuzio state that an interview becomes more rigorous with probing as probing elicits more in-depth data for analysis. Probing is also useful for increasing the accuracy of information. Literature on interviewing suggests asking for clarification of words or phrases as the interviewer and participant may not hold the same meanings for these words or phrases (see, Bodgen, 1998; Hiller & DiLuzio; Jack, 1999; Patton, 2002; Seidman, 1998). Ensuring that each individual understands the language of the other can open new avenues of understanding and identify linkages and motivations (Hiller & DiLuzio).

As there was no set time limit or agenda, just a loose framework of questions, I had the opportunity to explore, follow-up, and clarify at will. Although there may be no time limit for the interview, it can be advantageous for the both the interviewer and participant to establish a time guideline such as 30 minutes. A guideline gives the participant an indication of how much time will be needed from him or her. For the researcher, a time limit can be useful if the participant wants to converse for a lengthy period of time after the interview is over. Warren et al. (2003) discuss interviewers' experiences "after the interview". It can be uncomfortable for a researcher to end the meeting, especially when the participant has just discussed a possibly intimate topic and has volunteered his or her time. By identifying somewhat of a time structure to the interview, it allows the interviewer to end the meeting with prearranged expectations. When contacting a participant I always commented that the interviews typically were no shorter than 30 minutes but could range up to an hour or more depending on the detail the participant was comfortable in discussing. The interviews for this project ranged from 30 minutes to two hours with the average interview being 45 minutes.

Site Selection

The whole of Prince Edward Island was chosen as a site for this study. As indicated in the introduction to this thesis, according to Statistics Canada (2003), PEI leads the country in the literacy levels of individuals with disabilities. It is the intent of this study to gain the perspectives of the parents on the inclusive nature of the schools and communities on PEI.

Participant Selection

Participants were recruited for this study by word of mouth and by contacting a number of agencies and schools. Recruiting participants proved to be a more onerous task than originally anticipated. I thought that I would be able to recruit my participants mainly through the resource teachers at the high schools across PEI. In the end recruitment required face to face meetings with the resource teachers. The active recruitment of participants began in April 2004 and ended in February 2005. Five families were recruited that had a son or daughter between the ages of 13 and 17 with a diagnosed intellectual disability.

In April of 2004, a flyer was designed to aid in recruitment (see Appendix A). The flyer was brightly coloured and gave some general information about the research project as well as my contact name and number. Letters were written to the Superintendents of the Eastern and Western School Board asking for permission to contact the school principals (Appendix D). A copy of the flyer and an information letter (Appendix B) about the project were included with the permission letter to inform the Superintendents about the research. Once permission was granted from the school boards, a letter and flyers were sent to the 18 junior and senior high schools across PEI. It was the hope that the principals would distribute the flyers to their resource teachers, who would then distribute it to their students with an intellectual disability. The instructions were for the student to take the flyer and letter home to give to his or her parents. If the parents were interested in participating, my contact information was included in both the flyer and letter.

In addition to the schools, flyers were given to the Association of Community Living (ACL). A newsletter entitled "Open Doors" was mailed to all members of the ACL informing them of current issues and upcoming events in the field of disabilities. The flyer was included in their mail out.

Only one participant was recruited from the above efforts. Follow up phone calls were made to resource teachers and special needs teachers at each of the junior and senior high schools. I set up interviews with some of the resource teachers to further explain the project. I felt that meeting in person would foster better results than contacting the individuals by phone or email. Resource teachers at two different schools identified six students that fit the criteria but when the parents were contacted, they were not interested in participating in the study. Finally, four more families were recruited through extensive consultation with resource teachers. These four participants were recruited by phone and email discussions. The resource teacher would contact the family, explain the project, and then ask if they were interested in participating. If the family was interested, the resource teacher would ask for permission to forward their name and phone number to me for me to contact them. I then called the family and set up an interview time. When meeting for the interview, I explained the project in further detail and then gained consent for participation in the study. The consent form is attached as Appendix C.

Families of two female and three male teenagers between the ages of 13 and 17 with a diagnosed intellectual disability participated in the study. Only the mothers of the five families participated in the interview. In one case the father arrived once the interview had started and proceeded to listen but not participate in the rest of the interview. In another case, the father wanted to participate but it proved to be too difficult to coordinate the schedules of both parents and the mother agreed to be interviewed and speak on the behalf of both parents.

Data Collection

An interview protocol was developed for the parents that included questions about their child, the disability, and experiences at home, school, and in the community. The questions began quite broadly, for example, "Tell me about your child" and became more specific as the interview progressed. The interviews were recorded by both a tape recorder and digital recorder. It was found that the digital recorder was more reliable than the tape recorder in that there was no tape to erase or malfunction, one could make multiple copies of the digital recording, and the quality of sound was superior to that of the tape recorder. It was essential to record the interviews to ensure accuracy of information. Patton (2002) advocates for the use of a recording device to best capture what was spoken and to eliminate the need for extensive note taking during the interview. Patton vehemently states that recording an interview is by no means a substitute for note taking. I found note taking to be distracting to both myself and the interviewee and, therefore, only wrote bullet points of a topic I might want to further explore. It was important for me to maintain eye contact and give non verbal encouragement throughout the interview. Once the interview was over, I made extensive field notes. I noted such things as the environment the interview was being held in, the perceived mood and behaviour of the participant, any interruptions that occurred during the interview, and any personal thoughts and reflections about the interview or the participant.

The interviews were transcribed verbatim by a research assistant. I checked the transcription by listening to the tape and reading the transcript. The act of reviewing the transcripts allowed me to revisit the interviews, familiarize myself with the data, and verify the transcribing. The interviews were recorded using a digital recorder. Consent was given by the participants to record the interview. I found that recording the interview allowed me to listen more intently to the participant. Bodgen (1998) states the value of listening quite poetically, "Treat every word as having the potential to unlock the mystery of the subject's way of viewing the world" (p. 96).

Data Management

After each interview, I downloaded the recording to my computer and stored it in a password protected file. Because of the large size of the files, it was necessary to move the interview files from my computer to a number of CD's. These CD's are kept in a locked filing cabinet and will be kept for a period of three years following the acceptance of this thesis according to ethics requirements. The interview files were coded to protect the names of the participants. I worked from the CD's and did not create any hard copies of the interviews.

Data Analysis

The analysis of data is a complex process. There is the initial stage of immersion, followed by coding, and theme development. These processes each have their challenges and frustrations, in particular the coding. As I worked through the interview text, I was constantly reevaluating my coding structure and my reasoning for keeping or changing the structure.

I began the process of analysis by reading through all my interviews. I felt it was important to read all the data before beginning to code so that I could get a feel for the information available. The immersion of oneself in the data is well articulated by Holloway and Valentine (2001), "get to know your data through rigorous analysis before embarking upon structuring your argument." (p. 129). Ayers, Kavanaugh, and Knafl (2003) identify immersion as the "intensification and evocation...of the analysis" (p. 875). The goal of immersion is to preserve the individuality of the data while finding similarities across the interviews. For example, one of my interviewees lives on a farm. The farm is a major influence on the lives of this family and their experiences are quite different than those of the other families that I interviewed. That information could quickly become lost during analysis as farm living was not identified in any of the other interviews.

My intent was to use a computer based software program for analysis. Webb (1999) cautions researchers against becoming alienated from the data through the use of a software package. The researcher can become so involved with the process of coding that they lose the context of his or her data. It was important to me that I become familiar with the interviews so that the coding process would be as smooth as possible.

I chose to use N6 software to code my data. N6 is "[an] all-purpose qualitative data analysis system, which is designed to aid researchers in handling nonnumerical unstructured data by supporting processes of indexing, searching and theorizing." (http://www.utoronto.ca/ic/softdist/detail/nudist.htm). Morison and Moir (1998) suggest that using computer assisted qualitative data analysis increases the rigour and credibility of qualitative research.

I decided to start organizing the data by assembling the relevant text pieces into categories based on the structure of the questions. I began with codes for family, school, friends, and community. Palmer, Fuller, Arora, and Nelson (2001) initially coded their research project with two start lists. They later refined those categories to include subcategories (p. 472). I used a similar approach by refining the coding structure with subsequent readings. I essentially wanted to separate the data into broad "piles" with my first analysis. I added a 'miscellaneous' code to the text that did not fit into my other categories. My intent was to revisit that code after I was finished the initial coding in hopes that I could then find a "home" for that particular text. After, I went through all the interviews and coded them in my five broad categories, I scrolled through each category and read what I had coded. I made notes as I was reading the text in each category on what trends were emerging within the codes. I further refined my codes and established themes across the interviews.

Ethics

Ethics approval was granted by the University of Prince Edward Island's Research Ethics Board on March 2, 2004. All parents volunteered their time to participate in the study. When scheduling an interview, I ensured that the meeting was at a convenient time for the parent. I visited three of the five parents in their homes for the interview and met with the remaining parents at a local coffee shop and eating establishment. One parent chose to meet me at a restaurant so that her and her daughter could have supper during the interview. The other parent was quite firm in her refusal of me coming to her home and preferred to meet at a coffee shop. Before beginning the interview, I explained the research project to the parent and allowed them to review the questions I was going to ask. It was important for the parents that I interviewed at the coffee shop and restaurant to read over the questions so that they were aware of the topics we would be discussing in an environment where we might be overheard. Both parents indicated they were comfortable with the nature of the questions and agreed to proceed with the interview. I then gave each parent an information letter and had them sign the consent form, stressing that anything they said would be kept confidential.

Trustworthiness Features

Creating rigor within a research project is paramount to conducting valuable research that can inform other researchers, policy makers, and interested members of the public (Patton, 2002). Rigor and trustworthiness go hand in hand. Lincoln and Guba (1985) suggest the four components of trustworthiness are credibility, transferability, dependability, and confirmability. It can be difficult to demonstrate trustworthiness with research that follows the social constructivism paradigm (Denzin & Lincoln, 2003). Because the data is defined by the participant's reality, defining a cause and effect relationship can be problematic. Patton (2002) suggests extrapolation as a method of viewing the results. Extrapolation is "the applicability of findings to other situations under similar, but not identical, conditions... Extrapolations can be particularly useful when based on information-rich samples and designs..." (p. 584). Gaining the perspective of parents on inclusion can deliver valuable information for educators, policymakers, and other parents. The information from these interviews can be extrapolated to inform the above groups. In order to extrapolate my findings, I will discuss and demonstrate how my findings have credibility, transferability, dependability, and confirmability.

Patton (2002) discusses strategies for enhancing credibility including addressing bias, searching for alternate themes or explanations, and using triangulation. All people view the world through their own lens thus there is an inherent bias that is created from lived experience and a person's morals and values. Discussing bias is important to the credibility of the research because it informs the reader. Bowling (2003) describes interviewer bias as, "The interviewer can subconsciously, or even consciously, bias respondents to answer in a certain way: for example, by appearing to hold certain values which can lead to a social desirability bias, or by asking leading questions." (p. 154). When interviewing Bowling (2002) and McCracken (1988) caution the interviewer against leading the informant or reflecting their own biases onto the informant. This type of questioning can taint the validity of the interview. Studies show that informants generally like to accommodate the researcher (Bowling, 2003), and will respond with what they believe the researcher wants to hear, as opposed to how they actually feel about the question. When interviewing, it is imperative to find the balance between developing a rapport with the informant and becoming too friendly (McCracken, 1988). As my bias is in favour of inclusive practices, during interviewing I refrained from leading the participant in the direction I wanted the interview to go. Instead, I focused on reflecting back what the participant was saying and probing when I felt more information was needed. In order to reduce my bias during the interpretation of the data stage, I engaged in consultations with fellow researchers, my supervisor, other graduate students, and the co-investigators of the research project. These discussions centred on the emerging themes and alternate explanations for those themes.

All the interviews were recorded and transcribed verbatim. The transcriptions were checked and any errors were corrected. Bias was further reduced by ensuring the transcripts accurately reflected what was said during the interviews. The transcripts were coded by four researchers. Angela Irvine, a Ph.D. student at the University of Alberta, and I initially coded the interviews. This research study for my thesis is embedded in a larger research study entitled *Inclusion Across the Lifespan.* The larger study encompasses interviewing people with disabilities from three years old to the oldest age that we could recruit. In addition to interviewing individuals with disabilities we also interviewed their parents/guardians, employers, and teachers. In order to compare results across Canada, Angela Irvine was conducting the same research project in Alberta with matching methodology and questions.

When coding the data, Angela and I would sit across from each other and create the coding structure together. N6 was used to organize the data. Coding together was an excellent opportunity to discuss what text should be coded under how many different codes. After we were finished with the initial coding, we coded each other's interviews to test for reliability. Discussions were held about any discrepancies in the coding and were recoded by mutual agreement. Lastly Melissa MacIsaac, a Master's student at the University of Prince Edward Island, and Roslyn Jones, a Master's student at the University of Alberta, coded a random selection of interviews. Using multiple researchers to analyze findings is known as a facet of triangulation (Patton, 2002). Patton explains that triangulation is useful in "adding credibility by strengthening confidence in whatever conclusions are drawn." (p. 556).

During the interview process, each participant was ensured confidentiality and the purpose of the study was disclosed. Each participant was asked the same questions in the same order. These components further enhance the credibility of the research project.

Transferability is defined by Lincoln and Guba (1985) as the ability to replicate the research methodology and gain similar findings in a separate but similar population. Similar and divergent themes emerged between the two sites. Lincoln and Guba discuss the challenges of establishing transferability in qualitative research. Often qualitative researchers do not have controlled environments or laboratories to conduct their research, nor are such research environments applicable. Instead Lincoln and Guba suggest that the researcher “provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility” (p. 316).

I kept a journal of my day-to-day research activities. In the journal I noted any choices that I made or changes in approach that occurred. Keeping a journal of choices is a component of dependability. Schwandt (1997) describes dependability as a process that is “logical, traceable, and documented” (p.258). By documenting the interview and analysis process, I am also creating an audit trail for future research use (Lincoln & Guba, 1985).

The final component of trustworthiness is confirmability. Schwandt (1997) describes confirmability as “concerned with establishing the fact that the data and interpretations of an inquiry were not merely figments of the inquirer’s imagination.” (p. 259). As described above, keeping an audit trail is also a procedure useful for confirmability. In addition to a written journal, I engaged in lengthy discussions with my supervisor and colleagues about the data and the emerging themes. After the interview was transcribed I met with some of the participants so that they could read the transcription. Not all participants were interested in meeting with me to recount their interview. For the participants that were willing to meet, this meeting was to ensure that I had transcribed the information accurately and that the participant confirmed the content of the interview. Martella, Nelson, and Marchand-Martella (1999) discuss the importance of collaborating with participants to add credibility to the researcher’s conclusions. Showing the transcriptions to the participant is also an opportune time to discuss any parts of the interview where the meaning was unclear or the sound was muffled.

Chapter Four

Results

Introduction

In this chapter the themes that emerged from the interviews are presented. The themes are organized from the perspective of parents on educational issues, family relationships, and social relationships. Quotes have been used to illustrate the findings and to better develop the themes through personal stories. A brief introduction of the five participants is included as well as a description from the parent about their child with a disability.

Introduction to Participants

The following information is an introduction to the participants of this study. Names have been changed and some residential information has been omitted in order to protect the participant's identity.

Judy is approximately 35 years old and has a son with global developmental delay and epilepsy. Her family lives on a farm in rural PEI. Her husband and older son run the family farm and Judy runs her own landscaping business. Judy and her husband recently built a new house on their property. It is a two storey home with large windows, hardwood floors, and vaulted ceilings. The inside of the home has an open concept. The kitchen, dining room, and living room are all in one area. When I arrived to interview Judy, her 13 year old son, Tom, was playing with his tractors on the carpet in front of the couch. Although Tom is a teenager and based on his age should be in junior high school, Judy and her husband decided to hold him back two years in order to increase his skills. Judy and I sat at the kitchen table for the interview. During the interview Judy's husband and older son came home from working on the farm. The atmosphere of the home was relaxed and loving. The family was going out for dinner but refrained from telling me until after the interview was over so that I did not feel rushed.

Jane is 46 years old and has a daughter with Down syndrome. Her family lives in a rural area of PEI. She is married and her daughter, Susan, is their only child. Jane told me that Susan was the "most perfectly planned baby a parent could possibly ever have." Jane and her husband had decided early on in their marriage that they only wanted one child. I met with Jane and Susan at Wendy's restaurant. They had been at swimming practice for Special Olympics and wanted to meet over supper. Both Jane and Susan had hamburgers with a baked potato. Throughout the interview Susan kept on trying to steal the cheese and bacon out of her mother's hamburger. The interaction between mother and daughter was comfortable, amicable, and full of love. It was quickly apparent during the interview that the three of them, Jane, her husband, and Susan, are a close knit family who enjoy spending time together. Their privacy is quite important to them. When asked about outside supports Jane commented that they find strength from within and that they enjoy their large property where you could not see the neighbours.

Lisa is approximately 50 years old and has three sons with global developmental delays. Her family lives in a small town outside of the second largest city in PEI. Lisa's husband is a lobster and mussel fisherman. They have a beautiful heritage home that they recently renovated. The house has hardwood floors, large mouldings around the doors and windows, and a modern kitchen. The house felt cozy yet luxuriant and it had a distinct lived in feeling although the house was pristinely clean. All three of Lisa's sons have the same disability. The oldest son is 29. He fishes lobsters and mussels with her husband in the summer and fall and then draws on employment insurance for the rest of the year. When they renovated their house, Lisa and her husband built an apartment over their garage for their oldest son. Although he lives there, he still eats and drops his laundry off in the main house. Lisa feels that it is good for him to have his own space but thinks that it might be better if he was further away and had to do more on his own. Their middle son lives in the main house with the family. Lisa and her husband built a car wash in the town that they live in and the middle son runs that business. He also has a car detailing business on the side. The middle son is 27 years old. Their youngest son, John, is 17 and he is still in school. John has had some difficulty deciding which school he would like to attend so has bounced between two local high schools. When asked about her son's school experiences, Lisa sounds somewhat defeated. She has had to advocate for all three children with special needs and is tired. During the interview she says, "It's a nightmare like I'm going to be so happy when he's through of school if you want to know the truth, it's just a no win situation." Although Lisa's struggles with the school have left her tired, the family seems to bring her much joy. As we were interviewing, Lisa's husband and oldest son came home. They were very friendly and Lisa wanted to end the interview quickly so that she could spend lunchtime with them. Her husband talked her into finishing the interview with me so that I would not have to make the 40-minute drive back to their home. The final addition to the family is a Bassett hound that is only a year old and loves to chew. Lisa told me stories about the dog chewing and eating batteries and a razor and the expensive veterinarian bills that ensued. Before I left, the dog chewed my pen and digital recorder much to the embarrassment of Lisa.

Sarah is a single mom in her middle 40's. She has a daughter in her early 20's that still lives at home and a son, Troy, with Down syndrome. Sarah lives in a rural area. She has worked in a bank for the last 20 years. I met Sarah at her home during the evening. She owns an older home that looks like it may have been a farmhouse. It has two stories with very distinct, smaller rooms. When I arrived Troy was doing the supper dishes. Sarah and I settled in the living room. The living room seemed to be the hub of the house; it contained the television, computer, books, games, and movies. Sarah was very easy to talk to; she has an open and easygoing manner about her. Troy interrupted the interview a number of times to ask me questions about who I was and where I was from. Sarah seemed to really enjoy his inquisitive nature and spoke at length about Troy's outgoing manner. Sarah and her husband divorced a number of years ago and they both have found new partners. Troy seems excited about the possible marriage between his mom and her boyfriend. Sarah's boyfriend has a son and he and Troy have become good friends. Troy's dad is a fireman and Troy is obsessed with anything to do with fires, fire trucks, and firemen. His hope is to work at a fire hall cleaning and cooking for the firemen. I enjoyed interviewing Sarah, as she was very inviting and open.

Tina has two children, a son in his early 20's and a teenage daughter with global developmental delay. Tina lives in a large community and is married. I met Tina at Tim

Horton's as she was reluctant to meet at her home. Tina portrayed her daughter as bossy, rude, and difficult to have around. Denise struggles with some weight issues and Tina has difficulty teaching her healthy eating and exercise habits. Tina grew up in a larger family and experienced growing up with some family members who had an intellectual disability. I did not sense that the family was particularly close. They do not do many activities together and it was difficult to prompt Tina for more information.

Table 1

Participant Breakdown

Participant	Son/Daughter	Age	Disability	Description	Sibling/s	Urban/ Rural
Judy	Son – Tom	14	Epilepsy	Light brown hair, thin, likes to play with trucks	Older brother	Rural
Jane	Daughter – Susan	17	Down Syndrome	Dark hair, athletic but stocky, talkative and smiles a lot	None	Rural
Lisa	Son – John	16	Global Developmental Delay	Brown hair with blond tips, thin, quiet, likes movies.	2 older brothers	Rural
Tina	Daughter – Denise	17	Global developmental delay	Brown hair, heavyset, says what is on her mind.	Older brother	Urban
Sarah	Son – Troy	17	Down Syndrome	Brown hair, heavyset, inviting and open.	Older Sister	Urban

Description of Child

All parents in this study described their child as social. Sarah in particular was proud of how outgoing Troy is:

> …he's usually pretty happy. He mixes out well, like I can walk through school with him or whatever and almost everybody speaks to him by name. You know, even kids that aren't in his class or have nothing whatsoever to do with the

> classroom he's in, they all seem to know him, like they all talk to him and I have people come in to the bank and say like you know, 'My daughter thinks the world of Troy, he's just so cool and they have a great time with him at school.'

The descriptions varied widely from focusing on the child's disability, "…he was diagnosed with epilepsy when he was approximately two, so he had six years where he was extremely ill, with seizure activity…" to focusing on the child's strengths, "…she's pretty happy go lucky." Only Tina concentrated on the negative aspects of her child's personality. "…very aggressive. I have two sisters that are handicapped, they're special needs also. One is 40 and the other is 30 so Denise is like that. She's loud she's rude and she gets bored easily. It's a constant, constant. You don't get no rest when she's up."

Overall the parents gave me the general impression that they were proud of their children and received a lot of joy from them. Jane and Sarah both talked a lot about how much they enjoy hanging out with their children and became very animated when recounting an event. Judy discussed about how much strength her family has but also seemed worried about Tom's eventual transition into junior high school. Because Tom is not as high functioning as the other teenagers in this study, I could sense a lot more apprehension and nervousness about his upcoming school career. Lisa enjoys her children but I felt weariness from her. She has had three boys with significant disabilities and she is tired from advocating and is looking forward to her youngest child graduating from high school. Tina came across as somewhat complacent about Denise's education and future. Tina wants Denise to have a successful school career but I did not feel that she was prepared to advocate strongly for her. The parents' perspectives on education will be examined in more detail in the following paragraphs.

Education

All the parents interviewed generally felt that their child was included in school. Some were more positive in their answers than others but all parents said that an effort was being made to include their child. When I asked Judy if the school could do anything more to include Tom she said, "I don't think so, we have been thoroughly pleased." Jane said, "We had a bit of a struggle the first year she went in the [high school]. I think when Susan went to the [high school] they weren't expecting her to be as high functioning Down as she is." Lisa was happy with how the administration treated John, "Well, I think that for when you consider the fact that he just started in there last year that the principal has been outstanding." Most of the parents had to advocate quite strongly for their child for them to experience an inclusive environment or to acquire more supports. "…I got a note home that Susan wasn't cooperating today because she didn't want to leave the class when the TA wanted to take her out of the class. So my first question back to them was why are you taking her out?"

When asked what the school could do to better include their child, parents overwhelmingly responded that they would like to see more services offered to their child. Services in the form of one on one support, extracurricular activities, speech therapy, and a job coach for on the job training. Lisa is constantly trying to get the school to assign TA time to her son, "...they won't supply that [a TA] anymore, that's not going to be given we were more or less told, they told me to my face, that's not going to happen." Tina felt her daughter benefited from the extracurricular activities the elementary and junior high school offered. When Denise reached high school, those activities had been removed. "[They] used to go skating an hour in the afternoon on Wednesdays and then Fridays they used to go swimming and she used to love that, she enjoyed that and it got her away from the school, it gave her a break." Lisa summed the situation up as a poor attitude by the school towards children with special needs, "...when they [children with special needs] get to the higher grade levels its, well there's not much more we [teachers] can do with these kids, and I think that's translated down through the fact that they pull their supports from them."

Other issues that arose included communication between the parent and the school and segregated classes. Parents often felt that although they had frequent communication with the school, their wishes were not always considered. Repeated attempts to communicate their child's needs were not heeded. One parent explained that her child has been in a particular school for four years and after the first two years the school is finally putting her daughter in the classes that the parent wanted her to attend.

School Services

Parents spoke about the importance of educational services. Educational services include teacher assistant (TA) support, speech therapy, and social programs. When discussing services with the parents in this study, the difference in services that each child received was remarkable. It seemed the more strongly a parent advocates for his or her child, the more likely that his or her child will receive some or all of the support that is advocated for. The school also decides the level of support based on the child's needs. For example, Denise has some behavioural issues that require supervision. The school has assigned a TA to Denise in order to help her participate in the class. Parents in this study felt that the elementary schools their children attended allocated more resources than the high schools.

Judy's son is still in elementary school. Her experience with the amount of services has been very positive. "We have been thoroughly pleased. I was quite apprehensive to put him in the public school system...but the progress has been wonderful and the whole school has accepted him." Tom receives speech therapy and has been doing well with that support. "The last two years we have seen phenomenal growth in his ability. He sees [a speech therapist]...she's a speech therapist and every time she sees him she is bowled over with how well he is progressing."

Parents have learned to function within the scope of these resources and then are left frustrated and upset when their child transitions into junior high school and the supports are removed. One parent commented that her daughter was not involved in as many extracurricular programs at school due to the loss of TA support, "I guess its because they don't have a one on one, like when she was going through the younger grades she'd have a one on one from the morning til afternoon." Another parent enjoyed her son's time in elementary school and then became frustrated with the loss of services when he entered junior high school, "He got along terrific in elementary school, he had a teacher assistant with him the whole time there was one on one. …then in Grade 8 there was cutbacks…that was a disaster and then the resource teacher said to me that it was a disaster." I could sense definite frustration with the school system in some parents and anxiousness about the future in others.

Two of the schools offered job training programs for the students in order to develop skills for future use in a job. The parents who had children involved in a coop program were generally satisfied. A coop program places students with special needs in a work environment where they volunteer their services to gain experience for when they graduate high school. The students gain credit for their volunteer work and the program is usually part of a special needs class in the school. Sarah commented, "He's great, there's no problem in getting him to work, he knows what to do. He keeps telling the manager at a [local grocery store] that he's coming to work and he says okay." Tina felt that Denise had a good experience with the coop program, "She was working at the [local grocery store] doing a coop program…she got along pretty good."

When asked what the school could do to better include their child, most parents expressed a wish for more social programs that are accessible for their child. Lisa wanted non competitive sports to be offered. "When they get to high school or get in the higher grades the sports are so much more competitive like there's not really a place for them anymore in a lot of the structured activities…he'd love to play soccer with the high school team up here but he was never able to do that." Tina expressed the wish for more social activities for her daughter to become involved with a larger group of peers. "I know at [junior high school] she used to have girls and she was more involved with the students at [junior high school] than at the [high school]." Overall having access to social opportunities and being part of the school culture were important to the parents interviewed.

Communication with the School

A component of a child's successful inclusion in the school environment is positive and regular communication between the school and the parent (Neely, 2005). Parents were asked how well they felt that their child was included in the school and all parents discussed positive communication with the teacher and other school personnel as an important factor in their child's inclusion. Judy commented, "And I know the teacher there, she's really nice and you know they write notes back and forth everyday and they tell us like what's going on or you know how he's been…". Lisa discussed the positive support her son received from the school principal,

> Mr. Smith has gone out of his way and John really, really admires Mr. Smith, he will talk to John to see how he feels about things, to try to do what he can do to put things in place for him to make it more positive for him and Mrs. Rudy [the teacher] is the same way. They're both an exception.

Along with the positive comments about the school personnel some parents mentioned that they had productive discussions with teachers about their child's academic goals. One parent struggled to get the teachers to keep her child in class but was able to resolve the situation through effective communication with the school. "We got past that little hurdle and now she's doing whatever they're doing and I think a lot of their [her child's] inclusion has to do with, it has to be a team effort between the school and the parents..."

Some parents did find attempting to communicate with administration frustrating. A parent did not want her child in a special needs class when she transitioned into a new school but the administration enrolled her daughter in the class against the mother's wishes.

> I didn't want her in the class but they ended up putting her in the class anyways for one period to see, you know. I said, that's fine we will see what this is all about, let her have a period in that class and see what its all about...this is her third year and two years I never asked to have her in there.

Teamwork and communication with the school has left Lisa weary. She has had three children with special needs cycle through the school system and her struggles have left her frustrated and jaded:

> It's a nightmare, like I'm going to be so happy when he's through of school if you want to know the truth, it's just a no win situation. One person will send you to talk to somebody else and you're just talking until you're blue in the face and there doesn't seem to be anybody listening to you.

Most of the parents were able to express their wishes to school personnel with varying results. It is important for all parents to be involved with their child's school career, in the case of parents of children with special needs, advocating for their child and communicating with the school becomes a large part of their life while their child is in school.

Segregated Classes

The frustration that the parents felt stemmed from the loss of resources and the implementation of segregated classes. Four of the five parents experienced frustration and their child experienced behaviour issues when he/she transitioned into high school and were put either in a totally segregated environment or in segregated classes for part of the day. The remaining parent had asked for her son to repeat two grades so he stayed in elementary school and in an inclusive environment. She felt that her son was not ready for junior high school and wanted him to have more time developing his social and academic skills in elementary school.

One parents' frustration stemmed from her daughter being made to feel that she was different than her classmates by removing her from the class,

> When I first went to [high school] and I knew that there were special needs classes at the [high school], I knew that I absolutely wanted Jennifer to have no part of this. I didn't want her segregated in the class with the special needs. The first time she ever asked me what special needs was all about is when she started at the [high school]. She asked me one day what special meant because she was supposed to be special needs. I mean we've always told her she's special but not in that way. And she wanted to know what special was and what did they mean and what special needs was all about. That's at age 16.

Jane, Susan's mother, wanted her daughter to be learning with her peers and experiencing the same classroom environment:

> I more or less told them that I want her to be doing everything that they're doing. If they have a project due on some guy then she is to do the same project. If they are to do this test, then she is to have the test. You know maybe not the same test. But she has to know that she has been studying all week for a test she's having on Friday and the whole class is having a test on Friday. She's not getting out of doing reports and if they are studying a novel in English and have to do a report on it, so does she.

In contrast, the parent who had a son in elementary school was pleased that the TA removed her son from the classroom for one on one time. "He is pulled out of class and they have a separate little room which is wonderful." She felt he benefited more academically from being separated and given one on one time. Academics were also very important to Susan's mother, Jane, but she felt that keeping Susan in the regular class would motivate her to challenge herself and also provide her with a higher level of academics, "She is in math, she's in English and she's in social studies because I wanted to make a main core. I want all the basics." Jane mentioned that she wanted the teachers to have higher expectations for Susan: "I think they weren't expecting her to do as much as I wanted her to be doing." Convincing the school personnel was a frustrating venture for Jane but by advocating for Susan, she was able to keep Susan in the core courses, "...we got past that hurdle and now she's doing whatever they're doing..."

One of the students was put into a segregated class and his displeasure with the situation manifested itself into a behaviour issue where he was refusing to attend school. "...at Christmas time he was refusing to go to school. So I had him home for about a month, a little over a month and we were trying to do some home schooling...I was a nurse, not a teacher and I'm not a great teacher." Jane saw the segregated class as a rest period for her daughter, where she could relax. "I see that class as a time out for her. They play games, like money games, and they work on her vocabulary and they work on all that stuff, but still it's a relaxing class for her."

The parents in this study have mixed feelings about segregated classes. Lisa's two older sons were happier in the special needs class than they were in the regular classes. Their experience was what drove her to put John into the special needs class. Lisa did mention that she would have liked him to be able to participate in the regular classes but felt that the school did not offer enough support for him to succeed in that environment. In contrast, Jane was very upset when the school put Susan in a special needs class without her permission. Jane makes the comment that inclusion is what works best for the family, "What I've come to learn is...total inclusion depends on the individuals and the parents themselves."

Transitions

All families reported anxiety surrounding transitions. Some of the parents discussed their experiences with doctors and when they found out their child had a disability. They discussed the transition in expectations for the future of their child. Other transitions that were discussed included school and social transitions.

Emotional Transitions

Lisa and Jane were the most vocal about how they felt when they were told that their child had a disability. Jane had to change the way she thought about Susan's future.

> I remember when I came out of, I guess it was those crying spells you had and I was in my room crying, I guess it was just, [her husband] wasn't there yet or he had just left or something and I, you know, was just a bit emotional after the whole thing and everything hit me and I think I was bombarded with doctors that whole day, you know, doctors coming in for me, for the baby and all that stuff. A nurse came in and the thing she told me, she said, she says, you know I have a six year old niece that has Down's. And I said, really, and she said, yeah and she's starting Grade 1. And I was just like, she' going to school? And she said, yeah, she's in Grade 1. And it was like, wow, there was nothing there to even show me that that was a possibility six years down the road that she would go to school. She told me a little bit about what she was doing and I was just like, oh I never, you never thought that. You did but you didn't think about it because you were being bombarded too much about the medical prospects. You know, what's in her future. You had the other little information there, that definitely would have helped, emotionally wise.

Jane struggled to find information on Down syndrome and found the doctors to be negative in their discussions about Susan. “I find that most doctors are too hesitant to give you too much positives feedback on a lot of this because they don’t want you to be coming back and say, well you told me that she would walk and she never does, you know, like that type of thing, they are very restrained in what they tell you.”

Lisa had a very different experience. Both her sons were delayed and the doctors thought that there was a problem during their delivery. Lisa tells her story,

> He was born by caesarian section because they thought then the other two boys that have a problem, they thought that was a labour and delivery problem, not a genetic problem. So they booked a caesarian when I was pregnant with John. It wasn’t a planned pregnancy and I wasn’t totally thrilled about the fact that I was pregnant but I had a difficult enough time with the other two but anyway, they said, no we’ll do a section so you don’t have to worry about labour and delivery issues. And so anyway, John was born by section and he was a beautiful healthy baby until he was about six months. At six months to three years he went through the same pattern as the other two did, this failure to thrive and didn’t do well and didn’t meet any of his milestones.

The other parents spoke more about the disability their child had and not the emotional transitions that they faced when finding out about the disability. Jane summed up her experience quite well with the following quote, “I know the doctor when he told me she had Down syndrome, he basically, his next breath was that she is still a little girl that needs a Mom right now and probably it’s one of the best things he could have said or anybody could say because she was just a little girl at the time, just a baby who needed her Mom and needed her Dad…"

School Transitions

All parents discussed the transitions that they went through with their child either when they entered school or when their child transitioned into high school. The parents talk about these transitions with a lot of frustration and stress in their voices.

Four of the five parents had their child transition from elementary into high school. Three of the four parents found the transition time to be extremely stressful and had to advocate strongly for their children to have the services and resources that they felt their children needed. "I'd been going back and forth to the school all winter trying to get him some one to one help when he goes out to a job site. He wants to go on his own and work along and do his own thing and he's very perceptive of being seen to be handicapped…" Jane commented that to make inclusion and transitions smoother, the school and parent had to work together, "I think a lot of their inclusion has to do with, it has to be a team effort between the school and the parents…" Transitioning from one school to another and learning how to navigate through the new school can be a stressful time for any child. One student was getting in trouble for arriving to class late. The issue was that she was having difficulty finding the classrooms:

> They want you to be totally independent when you go to senior high, its not just Susan, every student that goes into senior high you all of a sudden have to be an adult. They want you to be totally responsible for getting to your classes, for

> making sure you have your books, being there on time, making decisions for what you want to do with your life when you are at age 18, you gotta make those choices before you go into senior high, right. And then you have to work towards those choices. Well you're 16 and well at 16 some can handle that. Can Susan handle that? No. So when she walked through the door at [high school], all I was getting was, she was late for class, well where was she? Well we found her somewhere else. We talked to her about how she has to be to class on time. Did you ever think that maybe she got lost in that school, it's a big school. And that's all we were hearing for the first three or four months, was late to class. To get to class on time, to make sure she has her books. I mean it is a great step towards being independent but I just found that the first year it was expecting a little bit too much because there is quite a change between junior high and senior high, anyway.

Not only was navigating the school a challenge for Susan, making important decisions about academics caused anxiety. Jane is very focused on Susan's academics. Of all five parents in this study, Jane is the most concerned that Susan takes all her academic core courses. She does not want to limit her daughter in what she can achieve. The other parents were more concerned about the social transitions that their children faced when moving from elementary school to high school.

Social Transitions

Creating lasting friendships was a topic that all parents had a lot to say about. Their desire for their child to experience the joy of love and acceptance through friendship was palpable. All of the parents spoke about a loss of friendships that their child has experienced.

All of the parents reported that their children had fairly good social networks at school. “I can walk through school with him or whatever and almost everybody speaks to him by name.”; He gets along really well at school.”; “She’s got a terrific bank of friends that seemed to just have followed her along in school because we’ve never kept her back any years…”. Unfortunately outside of school is a different situation. Parents commented that their child did not receive phone calls or get invited out at all.

The lack of supportive friendships is an issue that has caused these parents anxiety throughout their child’s lifetime. In almost all cases, a supportive and loving family environment is the primary social network for the children in this study.

Family

Four of the five parents interviewed said that they had a close knit family. The families found support from within and were the main outlet for social activities. There were a variety of relationships discussed within the family between siblings and parents but, in general, the families were close.

Support Networks

The Government of Prince Edward Island offers respite services for families that have a child with a diagnosed intellectual disability. In spite of these available resources only one of the five families used respite services. A child with special needs is considered to require more time resources than a regular child and, therefore, respite services offer the family time to replenish those resources without their child with special needs. Respite services can come in the form of a support worker who takes the child for an evening every other week or a respite home where the child goes to live for the weekend. Of the four families that were interviewed that did not make use of respite services a definite feeling of family cohesiveness was present in the interview. "Oh we're pretty close I guess we do spend a lot of family time together, a lot of quality time together. We just hang out together." Sarah discussed weekend trips to different areas in PEI to visit family. "He goes to his grandmother's in…once a month; his father takes him up there. He hangs out with his cousins and stuff up there." In sharp contrast, Tina, the mother who used respite was asked what her family did together and she answered, "Not a whole lot. She limits our activities and stuff; she's better off if she goes with somebody else and does things." In this family, the daughter goes to a respite home one weekend a month. She also has a one on one worker that takes her out in the evenings for four hours twice a month.

The family that lived on a farm in rural PEI had grandparents living down the road from them. The extended family was their support network. "They [the grandparents] have been excellent as an extended family and I often comment on how folks do it living in a city who don't have an extended family…" Not all families made use of available extended families, preferring to concentrate on their own strengths as a family: "I just found that we were independent people, you know self serving people, you know, whatever you want to call us but we reach within and find our own strength and have a hard time reaching outwards sometimes. But we learned how to do that." Another family has three boys with disabilities and the family has developed and built businesses for the boys. One of the five families was a single parent family. According to the mother, her relationship with her ex-husband was good and they shared custody of their son. "...we try to provide a stable environment for him, you know his father and I don't fight or argue or do anything like that, there's nothing pulling him one way or the other."

The trend for these families was to build support from within the family unit and not use outside resources for respite purposes. The sense was that each person was a part of their family and not the responsibility of anyone else. When reviewing my field notes after interviewing these families I often made notations of how close these families seemed to be. In one case I was interviewing one of the mothers and her husband came home. He took off his shoes and then stood behind her rubbing her back while she talked about her son.

Family Activities

Most of the families had very active lives that included a lot of sports and games. The families took advantage of the changing seasons on PEI and did snowshoeing, skating, and skiing in the winter and swimming, camping, and traveling around the Maritimes in the summer. In PEI a popular weekend past time is going for drives without a particular destination. Going for drives was the one activity that the family who used respite services engaged in. The other families listed a multitude of activities that they enjoyed with each other. “On the weekends we do a lot together, like we have a big property, large property so I mean we’re in the summer we have one of those big blow up pools, the big mushroom blue ones, you know, so we’re in that a lot.”

Another family travels quite extensively outside of Canada. “…we were down in Mexico this winter and he [her son] just loves to go, he’d never be ready for home until the rest of us are. He loves new experiences, he’d just love if you could just take and travel with him and show him new things and he’d love to go...” It was important to the parents to expose their children to different activities and experiences.

Judy’s family is quite involved in tractor pull racing in the summer. They travel around the Maritimes to attend the different functions. Judy became very animated when she discussed Tom’s love of going to the tractor pulls. It was an activity that every member of her family enjoyed thoroughly and Judy seemed to gain a lot of energy from her family. “We’re there [tractor pull] from 10 in the morning til maybe 1 o’clock in the morning on the following day.”

In all but one case, the families seemed to enjoy showing their children new experiences and using travel and activities to help them grow and learn. Sarah commented after the interview was over that she enjoyed taking Troy new places because she was able to experience it twice; once through her eyes and once through his eyes. She enjoys that Troy experiences life in a different way than she does. In most cases the siblings are significantly older than their brother or sister with a disability so their involvement was not as apparent as if they were closer in age.

Siblings

Four of the five families interviewed had more than one child. The four families that did have siblings, the siblings were all older than the child with a disability. The ages between siblings ranged from 14 months to 10 years. One family was an exception where all three children had the same disability. When asking the parent how the siblings got along two parents said quite well and two parents said that their children fought "like cats and dogs". One mother told me that her children fought so much that we could not meet at the local coffee shop as her son worked there and there would be too much tension if they were in the same area, "Well, her and her brother do not get along at all, they can't even look at each other." The other mother who said that her children fought portrayed it more as good natured teasing. "One can't walk by one without, you know, a little lip or saying something, you know." It is interesting to note that the two families where the siblings fight, the siblings are closer in age than the other two families.

The parents commented that no matter the age difference between their children, the older sibling was always concerned about the welfare of the child with a disability. The only exception was the family where there was a lot of tension between the two siblings. This caring was evidenced by the following quotes: "Mostly she looks out for him."; "...he's very receptive and loving to him which we've been very blessed with that."; "They've been really protective and John's a little bit spoiled on the account of the fact of having all the medical issues that he did and plus the fact that his two brothers are that much older so they would kind of give in to him…"

For these families the older siblings were portrayed in a more mothering role as opposed to a friendship or peer role. In two of the cases, the child with a disability was quite ill when they were younger and the sibling often had to help care for them. Without gaining the sibling perspective, the more intricate details of the sibling relationship is unknown.

Independence

When asked if her child "hangs out" with her friends after school one parent commented, "But as far as going with them [her friends] and doing things, she couldn't be trusted to go." The mother is concerned that her daughter will leave her friends and go on her own. For all of the parents, trusting their child was an issue. Parents were concerned about their child making the right choices to keep them safe in an environment that was not supervised. One parent commented that she was happy that her daughter was not interested in cars and boys and driving around town. Building independence and trust was very important to one mother who recently allowed her daughter to have a key to the house. Until recently the mother would leave work to pick her daughter up from school. Now that her daughter has a key she takes the bus home from school by herself and then is home alone for about an hour and a half until her parents arrive home from work. The same mother is teaching her daughter how to use a bank account and bank card in order to help her understand the cost of merchandise and how to manage an account. More often than not, it was apparent that the parents in this study tended to have much more structured time and activities for their children.

All of the parents commented that their child seemed to communicate and have more in common with younger children. "He tends to play with children that are younger than his age that are right handy type of thing."; "He has a little cousin who just turned four and they get along well so he plays with her."

Trust is an issue that can be difficult for parents of children with special needs. Jane commented that it was difficult for her to let Susan "spread her wings". Being a child with special needs requires more time and supervision; after the interview one mother commented that it was her plan to work outside of the home but when she had three children with special needs, she chose to work from home instead. Although parents know they need to give their child independence, the steps to get there can be difficult as evidenced by Jane in this quote, "...she is getting to the point that she wants to stay home by herself and have that independence and be grown up. If we do that, we don't go too far you know, she's always had a sitter up until this year. This is the first big step in being independent and being by herself. We don't go far you know."

Social Relationships

Parents seemed to be most passionate about building positive relationships for their children. When asked what the school could do to better include their child one mother wistfully said, "I'd love for there to be a way but I mean you can't make people hang out together. You can't pick friends for other people." Parents perceived that creating lasting friendships was integral to their child's happiness. "It'd be great I think if we had a circle of friends even close by here." Other parents commented that it was important for their child to be in inclusive classrooms so that they have the opportunity to make friendship connections. Some themes that became apparent throughout the interviews were the parents' desire for friendships for their children, the lack of similar interests between their children and regular children their age, and the value of the friendships that their children currently have.

Desire for Friendships

All parents interviewed stated their desire for their children to have lasting and fulfilling friendships. Four of the five parents reminisced about their child's elementary school career and discussed the acceptance that they felt their child had there. "...there seems to be an awful change in attitude from when they're in elementary, it seems that, or I felt with John that there was a warm feeling in the atmosphere, that they knew that the teachers knew when the other students sensed this was where he belonged to be." When their children transitioned into high school, four of the five mothers discussed the loss of friendships due to their child being pulled away from their peers into a segregated class. "So he lost his friends network whenever he got pulled into this other group [segregated class]."

One of the main reasons parents wanted their child in the regular classroom was to develop friendships. In two of the cases the parents felt that their child developed stronger friendships when they were placed in special needs classes. "...she's always talking about her friends that are in her special needs class."; "His best friend right now is Troy who has Down syndrome." A large part of the reason friendships seem to wane in the teenage years is due to the lack of common interests.

Common Interests

Another theme that emerged from the discussions with the parents about their child's friendships was the growing lack of common interests between their child and his or her peers. As their children have matured into teenagers it has become more apparent to the parents that their children have less and less in common with their friends. This lack of commonality and interest has resulted in the changing nature of some friendships into acquaintances.

All of the parents commented that their child's peers are starting to become interested in dating, going to the mall, and driving. When asked if her child gets asked to go with her friends the mother said:

> ...it's probably like any parent that's thinking it when you are 17 your girl is talking on the phone, the phone is ringing off the hook, let's go here, let's go there, let's do this and let's do that. The phone doesn't ring at home. You know what I mean, that type of thing cause once they leave school, they are doing their homework or they're out driving or they're into boyfriends or they've got their hockey and they are going in every direction but in school, in school they are her friends.

All the parents commented that their children mostly interacted with their friends at school. Their children were rarely invited over to other children's homes nor did other children visit their home. "Well, she doesn't have a lot of friends that come to the house…"; "He doesn't get invited out very much."; "Once, you know, they all start going out and they're doing things or they're going to the mall or whatever, you know, but they don't really come by to get him." When asked why they thought that their children were not being asked to join their peers outside of school, the parents commented about the lack of common interests.

Special Bonds

Two of the parents spoke about a particular friend that their child had made that had a significant impact on their lives. In one case the friend, Tony, was someone that John had grown up with at school. Their friendship has persisted through the years, through John being pulled into a segregated class, and even through going to different high schools. Throughout the interview Lisa repeatedly discussed John's relationship with Tony and how positive Tony's influence was for John. "Tony was always trying to very kindly and very gently help him to mature, like to think things through." Tony creates opportunities for John to meet other people and interact with his peers from other schools. Tony goes to a different high school than John but still attempts to include John in his life. "…he'll [Tony] sign John in for dances that they're having up here so like if John wants to go to a special dance or have him, Tony will call him and tell him, you know, it's at such and such a night and I signed you in if you'd like to come." Lisa really valued Tony's friendship with her son and discussed some qualities that Tony possessed that made him such an exceptional friend to John. "...like with Tony it was always like he was trying to help him learn something and Tony was very non judgmental. John when he was little if John had an accident or something Tony would just walk away until I could deal with the accident and never ever say anything cruel or be miserable to him or anything. So Tony was a driving influence in John's life..."

In the other case the friendship had been gained through a summer program. Troy attended a summer camp that was run by two Grade 12 students. Throughout the course of the program Troy became friends with the male counselor, Tim.

> He [Tim] was really good. He'd come on a Friday afternoon when the thing [program] didn't run on a Friday afternoon and he actually came a couple of times and picked Troy up and took him out to the Inn or, you know, hung out. He had really good initiative and, you know, he was going to make sure everything was okay when they were together. Even if he wasn't at work and it was an evening and they just went for a drive or walk on the beach.

The friendship was important to Sarah because she felt that a lot of children did not accept her son and Tim was important in building Troy's self esteem. "I shouldn't say this but some of the kids really don't like to be associated with someone with a handicap, you know. But these kids [the program counselors] have absolutely nothing like that."

In both cases the friendship has recently waned due to one friend going to university and the other making plans to go to university and spending his free time studying. "But

Tony is in Grade 11 now and he's a high achiever and he's got a job and he's trying to keep his average high so he doesn't have a whole lot of time to spend with John and he has other things too but he has been a real good friend to John and John was very fortunate to have a very good friend right up along although that friendship as he says now he lost his friend." Both parents commented that their children were sad at the loss of a friendship. "Well, he [John] was very very sad when he felt that he had lost Tony as his closest friend and that was really a sad time for him..."

The most lasting friendships seem to have been gained through the special needs class. Four of the five parents commented that their child's closest friend was from their special needs class. The class sizes are small and their children are often in the class over the lunch period and, therefore, have more opportunity to get to know the other children in the class,

> ...you gotta look at it the other way socially. She sits with all these kids at lunch time, she's in that class with them so she's always talking about her friends that are in her special need class. It's good because it's a smaller knit class and they are all working together or play together or doing a board game together so there's that benefit from it too.

Although another parent wants her son to have friends, she seems to wish that he would have a larger social network,

> ...I mean Troy is pretty social, I mean he walks right up to a group and starts talking, I think that's how come everybody knows him and the new fella here,

> John had started there he was very very shy and the teacher paired him up with Troy and the two of them get along exceptionally well now. But he said it was so good for John because he's quiet and shy and just wanted to hang back and didn't even want to look at anybody but Troy just took him with him and said let's go down to the cafeteria and let's go here and here...but I really, I don't know. It'd be great I think if we had a circle of friends...

Lisa feels that friends should challenge each other and open each other up to new experiences. Her son, John, found a friend like that in Tony but now that Tony has less time for John she is looking for those qualities in John's friend Troy,

> His best friend right now is Troy who has Down syndrome...and Troy, God love his heart, doesn't give him anything to aspire to, all they do is clown around. But he needs that. But it would be nice too if he had someone like Tony that would be trying to challenge him and bring him that much more along because there was so much that he helped him with.

Although the parents are aware of the divide between their children and their peers, one mother remains hopeful. "I keep saying that somewhere along the line, that's going to come back [her friendships]. They will come back, you see the closeness and then they pull away because of all these interests and I really believe that somewheres [sic] down the road they'll come back."

Leisure

The lack of friendships and activities with friends becomes apparent in the list of hobbies that the parents list and as well as their child's after school and weekend routines. All parents listed the TV, computer, and movies as major past time activities. Other hobbies included reading, crafts, playing, and some sports. The majority of after school activities centred around organized sports through Special Olympics and family outings.

Two of the five children are involved in Special Olympics and attended the Provincial Games that were held in Charlottetown in 2004. The Special Olympics is an excellent avenue for parents to let their children experience different places in a safe environment. Lisa talked about how exciting being away from home was for John.

> He was part of the provincial team for the curling so he got to take part in the national games there last winter in Charlottetown. That was a real thrill and experience for him. That's about the only time he's ever stayed away from home is with the Special Olympics sports. He's gone on weekend things with them and when he was in Charlottetown at the national games, that's pretty well the only time he's ever stayed with anyone other than us.

Jane and Susan enjoy traveling to the Special Olympics venues together. Jane is Susan's swimming coach and they work out three times a week in order for Susan to make the team. "We will be going over to the Nova Scotia games. And next year, the following year in 2006, the nationals of the games are in Brandon, Alberta." Jane detailed Susan's training schedule, "… she swims competitively for the Special Olympics on Tuesday nights and hopefully we have to get her into the pool for the provincial games that are coming up and she goes to those. Exercise would be our home equipment that we have at home, she's exercising on that two times a week, three times a week, getting that type of exercise." Although Jane and Susan are into competitive sports, Jane tries to create balance in their lives, "She's busy, yeah, she's busy. Special Olympics is great you know, she could even be busier if she wanted to be with them but she's still in school."

Denise had been part of the Special Olympics with bowling but decided that she was no longer interested in playing any sports. "...she was into bowling but she just, we used to go and she wasn't interested, she was more interested in the social aspect of it than anything." Troy and Tom are not involved in Special Olympics but are fairly active in other sports such as horseback riding, weight lifting, and running.

Sports are an integral part of almost the families' entire weekly schedule. The parents have attempted to balance their lives with school, play time, sports activities, and homework activities.

Conclusion

Throughout the interviews the importance of the family in the lives of the children with a disability was exceptional. The family acted as a support network, advocate, and enabler for their child. The next chapter will discuss the importance of family relating to education, social support, leisure, and friendships.

Chapter Five

Discussion

Overview

The purpose of this study was to explore the perspective of parents of teenagers with intellectual disabilities. I was interested in their perspective on their child's inclusion in school, home, leisure activities, and the community. The questions that guided my research were:

1. What are the attitudes, beliefs, and concerns of parents of children with intellectual disabilities regarding inclusion?
2. What programs and services do parents deem necessary to positively impact inclusion on Prince Edward Island?

Semi-structured interviews were used as the data source. Five parents of children with intellectual disabilities aged 13 to 17 were recruited to participate in this study. Questions asked ranged in topics from educational inclusion to community inclusion to social inclusion.

In this chapter the themes that emerged from the interviews will be discussed. Links to other studies and recommendations for further research will be made.

Education

The education system on Prince Edward Island is fully inclusive from grades 1 to 6. The junior and senior high schools vary in their level of inclusiveness for children with special needs. High schools can have separate classes, programs, or pull out programs. The children of the parents in this study ranged from being in a fully inclusive setting to being pulled out for a certain class to being in a completely separate program. The parents had varying levels of satisfaction with the school but all indicated there needed to be an increase in the number of services available to their children. Generally the parents had good communication with the school and felt part of their child's education planning.

Benefits of Inclusion

Frederickson et al. (2004) conducted telephone interviews with parents of students from a special school who were being included in a mainstream school for part of the school week. Parents in this study identified many benefits of inclusion including increased confidence and self-esteem as well as improvements in academic and social outcomes. All the parents in this study indicated the importance of peer relations and social opportunities that are created by including their children with disabilities in the regular classroom. One mother mentioned that her child is challenged academically by being in the general classroom with her peers. She is pleased with how well her child has risen to the challenge and has done well academically and socially.

In contrast, another parent wanted her son to be pulled out of the regular class for one on one attention. She felt that he learned better with such instruction and was happy with the amount of peer interaction her son received during recess and lunch time. Her son had significantly more cognitive delays than the previous child. In a study by Palmer, Borthwick-Duffy, Widaman, and Best (1998), the researchers found that parents of children with significant cognitive delays placed a higher value on specialized curriculum than on opportunities for social interaction. Palmer et al. postulate that parents may prefer such settings because the setting provides a sheltered environment and more individualized attention for their child. Only two parents in this study supported a segregated setting for their child. The other three advocated strongly to have their child in the regular classroom with their peers.

Overwhelmingly the parents in this study felt that the most important aspect of inclusion was the social benefits. In a study done by Leyser and Kirk (2004) which surveyed 437 parents of students with disabilities, results indicated that parents reported the main benefits of inclusion were the social outcomes for their children. Parents also discussed the benefits of inclusion for the regular children in the classroom. The researchers found that parents thought classmates were more likely be accepting of differences and become more sensitive to people with special needs. When I asked the parents in this study what the benefits of inclusion were they all indicated that their child's peers became more accepting of diversity. Miller and Strain (1992) found similar results. They surveyed 103 parents of children with a disability and 129 parents of children without a disability. The parents of children without a disability reported that being in a classroom with a child with a disability had positive effects on their child in the form of increased awareness of differences. The parents of children with disabilities were divided into two groups; those who had children in an inclusive setting, and those who had children in a segregated setting. The parents who had children in an inclusive setting reported a higher level of satisfaction with their child's placement than those parents who had children in a segregated setting. My research found parent satisfaction levels to be high for both settings. Those parents whose children were primarily in segregated classes were happy with the amount of individualized attention that their child was receiving. The parents whose children were in more inclusive environments were excited by the challenges and social opportunities presented to their child.

Peer modeling and positive social integration can help children with disabilities gain friendships and a supportive peer group. The families in this study reported that within their schools, their children knew a lot of the children in their grade level and considered many of them friends. Being exposed to peers is an excellent avenue for children with disabilities to learn appropriate social behaviours (Bennett et al., 1997). One mother in this study stated that her son's friends "won't let him get away with" certain inappropriate behaviours. She felt that it was more effective for his friends to tell him that what he was doing "wasn't cool" than having her or someone in the family correct his behaviour. Peers can have invaluable influence on each other (Freeman, 2000). In this study each parent commented on one or two peers in particular that had a tremendous positive influence on their child. This person accepted their child and exposed their child to challenges in a safe environment.

Communication with the School

Effective communication between the school and parents can often be challenging. Some of the parents in this study reported that their views about inclusion sometimes did not match the teacher's views of what was best for their child. One parent's requests were ignored by the school and another parent had to repeatedly advocate for her child to the point where she was extremely frustrated and now just wants her son's school experience to be over.

Bennett et al. (1997) surveyed 48 parents of children with disabilities and 84 teachers. The survey asked questions about their attitudes on inclusion, relationship to school and parents, and methods of communication. The researchers found that the stronger parents advocated for their child, the more their relationship with the teacher deteriorated. Bennett et al. suggest that this finding shows that parents see themselves in opposition with the teacher regarding their child's needs. I found a similar trend in my interviews with parents of teenage children with disabilities. Although all of them reported that they felt they had good communication with the school, their conversations with the school were frequently relayed in a confrontational manner. They were often contacting the school because their instructions were not carried out or they did not feel that their child was being given the best opportunity possible. Much of the unrest was found in the reduction of services from elementary to high school.

School Services

When the children in this study transitioned from elementary to high school many lost services viewed by the parents as essential. Their teacher assistant time was reduced or removed, speech therapy and occupational therapy were no longer provided, and it was more difficult for the parent to build a relationship with teachers because their child no longer had a single teacher. Some of the children were put in segregated classes and had little contact with the rest of the school population and other children were left to fend for themselves in a new and overwhelming environment. All parents reported a lot of stress during their child's transition into high school, for them and their child.

Petr and Barney (1993) conducted focus groups with 39 parents of children with disabilities. The researchers found that one of the major concerns the parents reported was quality of educational services being offered to their children. The parents wanted programs that matched their child's needs as opposed to their child being expected to fit into an existing program. A similar concern was raised by some of the parents in this study. One mother wanted less competitive recreational programs for her son. Her son was in a segregated class during school hours and she wanted the school to offer more recreational programs so that her son could interact with the general population of the school. Another parent wanted to the school to develop a peer buddy system to ease the stress of transitioning to a new school and hoped that a peer buddy would introduce her daughter to new social networks and help her navigate the school. Phelps et al. (1997) suggest that schools need to put programs in place to help prepare students with disabilities for the adult world. The parents in this study also felt that the school could offer more appropriate programming to reflect the diversity of the school's population.

Transitioning from elementary school to high school can be a stressful time for families but the transition from school to the workplace is a concern for all families in this study.

Transitions

All of the families were concerned about their child's eventual transition from high school to the adult world. Some families had a plan for their child whereas others were reluctant to discuss what was going to happen after their child finished school. This unease and possible fear is a testament to the fact that the programs at schools are not preparing children with disabilities for the workforce.

Ward et al. (2003) surveyed 272 families who have a child with a disability and found that a large percentage of the children were leaving school without a transition plan. Expectations of parents and the school can often vary widely. Ward et al. found that parents wanted the school to focus on leisure, social opportunities, and training. The school was more concerned with the student's academic achievement. This discrepancy in goals makes it difficult for a successful transition program to be installed. Ward et al. also suggest that parents, school personnel, employers, social workers, and colleges should all be part of the planning. Creating a structured plan with regular meetings can be a costly venture. It is no surprise that such programming has not become available to parents of children with disabilities. Some of the parents in this study were making their own work plans for their child. One family owns a car washing business that their son is beginning to work at on the weekends in order to get him prepared for when he graduates.

Collett-Klingenberger (1998) conducted a case study of six students with disabilities. The students were attending a school that was in the process of implementing programs to improve their transition services. The researchers found that using a multi-disciplinary approach was essential to successful transitions. The school involved parents, employers, and school personnel in planning the transition and following through after the student was in the workforce (Collett-Klingenberger). In contrast, the parents in this study did not know of any available transition planning being coordinated by the school or an outside agency. The only exception was one child who was taking part of a coop program. He was doing well with his work skills and had approached a local grocery store manager to ask for a job after he was done school. Another parent also had her son in the same coop program. Unfortunately her son required support to work and because he did not receive any, he did not attend his job placement.

Blackorby and Wagner (1996) suggest that early job experiences can be a good indicator of a student's success in the eventual labour market. The researchers found that jobs for people with disabilities are mostly available in the low paying sector as better jobs require higher educational attainment. The jobs that one of the schools in this study was preparing the students for were all in the service industry. One student had a placement at a grocery store and another was placed in the school cafeteria cleaning the tables and chairs after the students were finished lunch.

Because people with disabilities have difficulty finding work they are more likely to live at home longer (Collett-Klingenberger, 1998). All of the parents in this study were still supporting their children and were planning on doing so indefinitely. One family had three sons with disabilities ranging from 17 to 30. All three children were still living at home. The family had built an apartment above their garage for the eldest son but he was still heavily dependent on the family for all of his needs such as meals, laundry, and a vehicle.

A lot of research shows the need for effective transition programming for people with disabilities. Unfortunately many factors and supports have to be coordinated for a person with a disability to live independently. Many people with disabilities require support with meals, financial matters, and transportation. Without these supports, people with disabilities are often left dependent on family members for their daily needs as well as their social needs.

Importance of Family

Family is the primary support for people with disabilities. Most people with disabilities have family members to advocate for them, offer leisure and social opportunities, and financially support them for as long as is required. In this study it was found that without supportive family members, people with disabilities are often put in institutions or seniors residences.

Support Networks

There are a variety of support networks available to families who have children with disabilities including respite services, financial resources, and support groups.

Redmond and Richardson (2003) found that respite services were highly valued by families. Of the five families that were interviewed for this research project, only one family used the available respite service. The other four families did not feel that they needed time away from their child. Their support was gained from each other. One mother said, "…we reach within and find our own strength…". The parents valued respite and its availability but did not require it at this point in their lives.

Dyson (1993) researched families' stress levels. She compared families who had a child with a disability with those that did not. Her thesis was that the families who had a child with a disability would experience higher stress in comparison with the other families. Her results showed that there were no significant differences in the stress levels of the two families. When interviewing the families in this study, there was love and general happiness at being together as a family. Generally, stress was not an emotion that was brought out by the parents when discussing their child or their family. The exception was the family who had three sons with disabilities. The mother clearly indicated she was tired of advocating for her children and was looking forward to her youngest son being out of school. Dyson's results indicated that the families who had a child with a disability showed a greater strength of stability. Similarly the families in this study showed strong family ties and stability over time. Seltzer and Krauss (2001) reviewed the literature on families who have children with disabilities and found that the families were characterized by close relationships and high emotional involvement. Again, all but one family spent the majority of their time together engaging in activities that they enjoyed. They spent their vacations together and as one mother said, "we just enjoy hanging out a lot". The families are close knit and gain a lot of emotional support from one another.

Although only one of the five families used respite services, all five families took advantage of the financial support offered by the Prince Edward Island Government. When asked about the available financial supports, the families commented that it was difficult to find information on these supports and the information was often inconsistent. Petr and Barney (1993), Redmond and Richardson (2003), Renzaglia et al. (2003), and Udwin et al. (1998) all had similar results. They found that support services were reported by families as unreliable. Redmond and Richardson interviewed 17 mothers of children with disabilities and they found some success in asking different people and organizations about the same service in an effort to gain a complete picture of what the service entailed. In Petr and Barney's (1993) study one parent said that they "stumbled on programs by chance…" (p. 250). Similar findings were reported by parents in this study. They talked about receiving little to no information when their child was born on where to find resources and information on disabilities. Their child's early years were characterized by trips to different doctors with little information being given about how to raise a child with a disability or what resources are available. The focus seemed to be on the diagnosis as opposed to support.

Two of the parents in this study discussed support groups. They found the support groups to be more work and take more time than expected. The parents did not feel that they received much support and said the groups felt more like a comparison or competition between their children than giving and receiving support. One mother stated that she seemed to be the one everyone else called for advice and spent most of her time fielding phone calls. She distanced herself from the group as she felt it was taking away too much of her time from her family. Petr and Barney (1993) found contrasting results. The families in their study found the support from other families to be extremely helpful as the support from their extended family was often inconsistent. Marcenko and Meyers (1991) attributed the inconsistent support from extended family as a result of the make up of the modern family. Families today have fewer internal resources due to being more mobile and having extended family living further away. Other contributing factors were longer working hours and having fewer children to help (Marcenko & Meyers).

Although the situation of families being more transient is indicative of today's world, in Prince Edward Island families tend to be less transient and more rooted. Families tend to settle close to their extended families in Prince Edward Island and are less likely to move. The families in this study gained the majority of their support from their extended family and not on outside resources.

Leisure and Recreation

Most of the families in this study were very active and had their children involved in sports and leisure activities. Being involved in community activities increases the opportunities for people with disabilities to become further integrated within the community, develop healthy living habits, and learn new skills (Duvdevany, 2002; Scheepstra et al. 1999). Most of the recreational activities the families in this study engaged in were centred primarily around other family activities and not as much with the community. The research shows that the family is the primary outlet for leisure activities (Cuckle & Wilson, 2002; Duvdevany; Heman, 2000; Joblin et al., 2000).

Although Special Olympics is not an inclusive environment, it has provided the opportunity for the children with disabilities in this study to participate in sporting events without their parents. The children were involved in swimming, bowling, and floor hockey. One mother had to step in as coach of the swimming team when the other coach quit. A year has gone by and Special Olympics have been unable to find another coach. The mother continues to coach the team as she knows it would fold if she left. Her daughter is quite competitive in Special Olympics swimming and going to practices are a highlight of her week. Sports for people with disabilities just do not have the resources that are given to other community sports and parents often have to make up the shortfalls in order for the program to continue running. This parental participation is not unusual for children with disabilities.

Duvdevany (2002) found that parents schedule so much of their child's life that there often is not very much time left over for the child to make their own decisions about what to do in their spare time. Full scheduling was not the case in two of the five families' situations. One mother did not take a very active role in her daughter's leisure activities. Her daughter spent much of her free time watching TV or sleeping. She did get some activity when her respite worker would take her shopping or to the movies. Another mother wanted her son to have time just to play. She felt it was important for him to enjoy his trucks,

> ...he has his own little demo of tractor pulls on the couch and he recreates all the noises and will actually...he will pretend that is it he fella on the mic who is doing and he will mc his own little tractor pull with names of folks on tractors and how well they're doing going down the shaft."

The families in this study enjoyed doing activities with each other and most had a robust schedule of outings. Each season brings new activities for the families to enjoy. Most of the families traveled with their child and marveled at their child's zest for enjoying new experiences. Duvdevany (2002) and Jobling et al. (2000) found that many people with disabilities experience isolation and loneliness as part of their lives. Isolation and loneliness did not appear in any of the conversations I had with the families in this study. There was some mention of a desire for more friendships for their child but it did not translate into the fact that their child was lonely. It was more of a desire for their child to have friends to give them different experiences and fulfill needs that the family could not always fulfill. I believe the lack of loneliness and isolation could be due to the life stage the participants of this study and their children are in. All the children are in their teenage years and are, therefore, able to participate in many different activities that their parents enjoy as well. They are all still living at home and attending school so the children are in close proximity and are still dependent on their parents. I also believe that the nature of family in Prince Edward Island is characterized as close knit. Families choose to be each other's primary social group and it is no different for families who have children with disabilities. The sample size of this project is small with only five families participating, the families that did choose to participate could be characterized as close knit whereas the same family dynamic may not be apparent in other families with disabilities who did not choose to participate in this study.

Siblings

Siblings can be an important part in the life of their brother or sister with a disability. Siblings can offer increased exposure to social interactions and, more importantly, are another form of social and emotional support for a child with a disability. Four of the five families in this study had more than one child.

Research shows that siblings who have a brother or sister with a disability do now show any more behavioural issues than the general population (Cate & Loots, 2000; Dyson, 1999; Stainton & Besser; 1998; Stalker & Connors, 2004; Verte, Roeyers, & Buysse, 2003). Some of the qualities Cate and Loots found siblings of children with disabilities had were increased independence and self confidence.

Sibling relationships are an integral part of an individual with a disability's life. Further research and gaining the perspective of the sibling would enhance research on disabilities.

Friendships

Building a social network with peer friendships was a major concern for parents in this study. The parents wanted their children to experience the enjoyment of having a peer group and the ensuing confidence and social acceptance. Meaningful friendships can be difficult for people with disabilities to maintain (Cuckle & Wilson, 2002; Jobling et al., 2000; Turnbull et al., 2000).

Educating children in inclusive environments can help children with disabilities learn social norms and appropriate behaviours (Heiman, 2000; Knox & Hickson, 2001). One mother in this study commented that her son's peer group were not afraid to tell him if he did something that they felt was wrong. She thought it meant more to her son if his peer group told him what he was doing was unacceptable as opposed to her telling him. Peers hold each other accountable for their actions whereas adults are more likely to overlook social inappropriateness from a person with a disability.

All families in this study expressed the desire for their child with a disability to create a friendship with a child without a disability. As children with disabilities grow older, the gap between their interests and the interests of their peer group widens (Heiman, 2000).

This widening gap is well illustrated by parents in this study. Most of the parents fondly recalled their child's elementary school days when the parents felt that their children were well accepted by their peers. As their children matured and entered high school, many of their friends became acquaintances or were lost altogether. Cuckle and Wilson (2002) found that friendships developed among children with similar interests and abilities. Parents in this study commented that their children do not get called anymore to go places with other children. One mother said that in school her daughter has friends but after school when the teenagers are going to the mall or movies with their boyfriends, their phone does not ring. This study clearly indicated the increasing gap between children with and without disabilities as they age and become teenagers.

Some studies have shown that children with disabilities develop longer lasting friendships with each other than with children who do not have a disability (Cuckle & Wilson, 2002; Knox & Hickson, 2001). One parent in this study wanted her son to have friendships with someone who did not have a disability but commented that her son's best friend right now is a boy in his special needs class that has Down syndrome. Another mother commented that her daughter talked more about her friends in her special needs class than any of her other peers at the school. Knox and Hickson found when interviewing people with disabilities that they characterized their friendships with people who do not have a disability as superficial whereas they commented that they had deeper friendships with people who have a disability. A similar trend was found in this study.

As mentioned earlier, Heiman (2000) found that people with disabilities tended to name people that were helpful or worked with them as their friends. Turnbull et al. (2000) found similar results in their study. Their participants said that their friends were someone that they worked with. Similar results were found in this study. When parents discussed their child's closest friend, it was typically a school mate that helped their child with extracurricular activities outside of school or was part of a summer program. In two of the cases both friends have either moved on to university or are preparing to go to university and the friendship has faded over the last year.

Although some research shows that people with disabilities make longer lasting friendships with other people who have disabilities, it is by no means a strike against inclusion. People with disabilities have a right to be included in our schools, communities, workplaces, families, and social groups. Including people with disabilities fosters acceptance of diversity. People with disabilities give society a new way to look at and experience life. Not only is inclusion a human rights issue but it also allows people to be who they are.

Limitations

This study explored the perspective of parents regarding inclusion for their teenager living with an intellectual disability. The information gained from their perspective has given me a snapshot of the successes and challenges that families face on a daily, weekly, and yearly basis. The parents were very giving of information about their surprises, fears, and worries. There are limitations to engaging in qualitative research such as sample size, diversity of the sample, recruitment, and context.

The Size of the Sample

The sample size of this study was five parents of teenagers with intellectual disabilities. Although I received rich information from each of the parents, because of the small sample size it is difficult to generalize the results province wide.

Diversity of the Sample

The sample of participants was mostly made up of two parent families. Although there was diversity between urban and rural participants, all families seemed to be in the medium to high income bracket. The obligations of participating in this research may have been too high for single parents or low income families. I may have gained a different perspective if these groups were included in this study.

Recruitment

Recruitment was done through the schools and the Association for Community Living (ACL). Parents who are part of the ACL may be more aware of issues surrounding inclusion and be more willing to participate than parents of children with disabilities who are not part of the ACL.

Context

This study was done in Prince Edward Island. PEI is the smallest province in Canada and boasts a fully inclusive elementary school system. It would be difficult to generalize the results found in this research project to other provinces as their education systems could impact the perspective of the parents of children with disabilities. PEI is a small island that has a fairly homogenous population. The island has an aging population that has been stable over time. The rooted nature of the families in PEI could attribute to the valuable familial support systems that are discussed by the participants. Living in larger, urban centres could impact the availability of extended families and, in turn, impact the results.

Holistic Perspective

Gaining the parent perspective is integral to learning about the successes and challenges individuals with intellectual disabilities face. However, in order to gain a more holistic perspective it is important to interview the people with the disability as well as other important people in their lives. This research project is part of a much larger project that is gaining the perspective of parents and caregivers of individuals with disabilities across the lifespan. The individuals with the disability are being interviewed as well as their teachers and employers. The component of the holistic view that is missing is the perspective of siblings. Siblings can have very different experiences with their brother or sister with a disability and it is important to include them in this research.

The above limitations set the stage for further research. Gaining the parent perspective is the first step in many to fully understand what the schools, community, and society as a whole can do to better embrace diversity.

Recommendations

This study effectively answered both my research questions. As research often does, the results have brought on more questions and recommendations for schools and communities.

Recommendation 1

Recruit and interview siblings of people with intellectual disabilities to increase researcher's knowledge about the challenges families with children who have disabilities face. Siblings can give information on how living with a brother or sister impacts them and how they think they impact the life of their brother or sister.

Recommendation 2

Implement the same study in other provinces of Canada to achieve a national view of the challenges families with children with disabilities face.

Recommendation 3

Broaden the recruitment of families to include single parent and low income families. These families may face unique challenges not present in middle to high socioeconomic families.

Recommendation 4

Educate the community about programs that would benefit people with disabilities. Create programs that cater to different needs and have different goals than existing programs. Make information about these programs more readily available and seek out new routes of dissemination in order to contact all populations.

Recommendation 5

Communicate to the Department of Education on Prince Edward Island the parents' perspective of the support needs in the higher grades of children with disabilities. Advocate for the unique needs of individuals with disabilities and educate the department on best practices to meet these needs.

Recommendation 6

Implement transition programs to facilitate an individual with a disabilities move from school to the work place. These programs need to include work skills and job placement. It is also important to stress that transition programming needs to occur over a lengthy period of time such as three years and not a few months before the individual graduates.

It would also be helpful if these transition programs included people without disabilities to increase awareness and skills.

Recommendation 7

Create a resource pack for parents. This pack will contain information about services available to families who have a child with a disabilities as well as programs and websites for further information.

Theme Links to Inclusion

The following section discusses how the themes presented in this thesis link to inclusion for people with disabilities. The themes were generated from the parents' perspectives of how well they think their child is included in society.

Education

The parents in this study were mostly satisfied with their child's elementary school experience. Later frustrations typically stemmed from the less inclusive environment of junior and senior high school placements. For inclusion to be effective, parents felt that schools need to rework some of their systems to accommodate all children. Often changes made to better include children with disabilities, benefit all students in the classroom. A joint effort between the school, families, and support personnel needs to be realized for inclusion to be successful.

Transitions

Transitions were incredibly difficult for families to negotiate. Some transitions that parents discussed were the elementary school to junior high school transition and also their concern about future transitions. Although transitions are important and sometimes stressful events in all teenagers' lives, families of teenagers with disabilities face unique challenges dependent on their child's skill and social base. Again, parents felt that implementing a team approach to ready children and families for upcoming transitions can improve the success of the transition.

Family

Families are the primary support for people with disabilities. The family is the main advocate, social group, and leisure group for people with disabilities. The importance of including the family in a child's education, social, and transitional planning is paramount to the success of child. In this project the child's inclusion began and ended with their family and their advocacy.

Friendships

The development of positive social groups for their child was extremely important to parents in this research project. Most parents felt their child was included with their peer groups during school hours but wanted an increase of inclusion in extracurricular activities. Parents felt that the school would be a good venue to accommodate and run these extracurricular activities as the school is a safe environment. When asked about out of school activities, most parents were concerned about the possible influences peers would have on their child and were concerned their child would struggle to make appropriate choices. Although many parents wanted social inclusion for their children, they were aware that it could come at a price and were not prepared to take that risk and preferred monitored social activities.

Conclusion

All the parents wanted their child included in society but each parent had very distinct perceptions of how much support that they thought their child needed. Support included individualized instruction at school, segregated classes, chaperoning social events, and twenty-four hour supervision at home. Each parent advocated for different levels of support at school and implemented various levels of supervision at home. All parents commented that they were not comfortable with allowing their teenage children to engage in social activities with their peers without supervision. Their concerns in such situations included peer pressure and their child's safe decision making capabilities.

Concluding Comments

Throughout this research project I gained immense respect for the parents I interviewed. The participants let me into their homes, introduced me to their families, and discussed some difficult topics. I recently returned to one of the family's homes with a guest photographer to have some pictures taken of the family. I was talking to the mother while the photographer was taking pictures of the daughter. The daughter was posing and laughing and kept pulling her dog onto her lap so that he would be in the photos. The mother looked at me and said, "You know the greatest thing about Susan is that she taught us how to love." I am truly privileged to have these families give me a snapshot of their lives. I have learned so much from my experiences researching and writing this thesis. I have learned about my passion for qualitative research. How finding out the stories of people's lives is what makes the numbers meaningful. I learned about doing less talking and more listening during the interviews, that uncomfortable silences are only uncomfortable for me; they are giving the other person an opportunity to formulate an answer. I also learned to hold myself back. There were so many times that I wanted to probe into particular areas further but had to leave that interest in hopes it would generate a research proposal for another research project. Lastly I learned about why research is important for driving policy and practice. Finding out the needs of the people living with the disability or the needs of the support person is paramount to creating programs and policies that take their needs into account.

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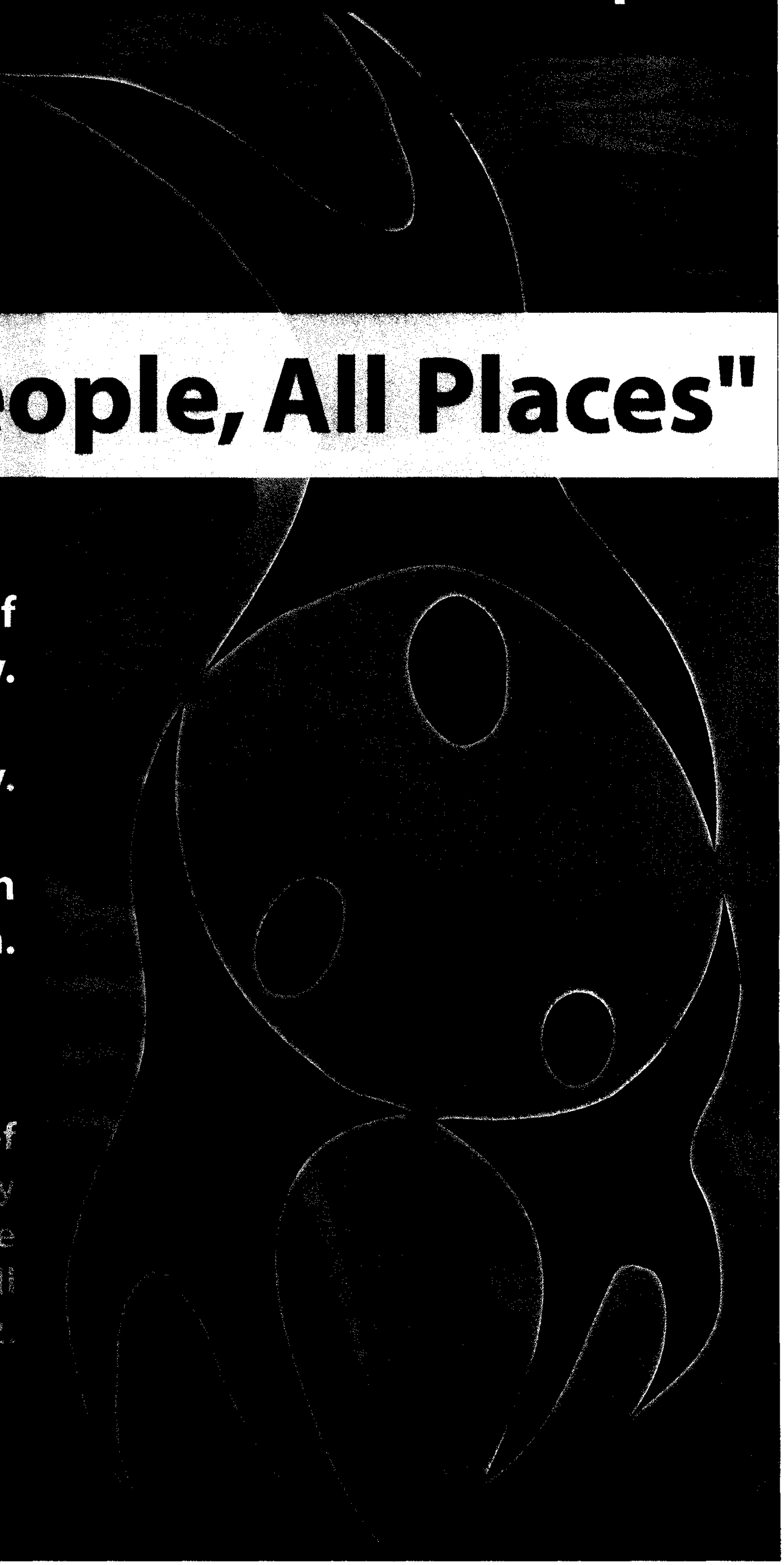
Appendix A

Recruitment Flyer

Inclusion Across the Lifespan



"All People, All Places"

Advocating for yourself and community.

Telling your life story.

Promoting research on inclusion.

If you want to be a part of this research sponsored by the University of Prince Edward Island, please call Bev at 894-2842.

Appendix B

Information Letter

To whom it may concern:

My Name is Dr. Vianne Timmons, I am the Vice-President Academic Development at the University of Prince Edward Island, conducting a research project along with my co-investigator, Dr. Judy Lupart (University of Alberta) and research assistants and graduate students. Our Prince Edward Island Research Team would like to invite you to participate in our study "Inclusion Across the Lifespan".

This letter is to provide information about our research project, so that you can make an informed decision regarding your participation. The purpose of this study is to investigate individuals with intellectual disabilities and their stories of inclusion at different life stages and analyze these stories to identify trends and patterns of inclusion that exist. It is hoped that the results from this study will be used to identify commonalities and variants considered as core in successful inclusive practices that can be recommended for future practice. Overall, there will be approximately 60 individuals as well as their families and employers/teachers participating in this part of the study.

If you agree to participate, you will be asked to partake in three interviews over the next year and a half with Beverly Gerg, a member of our PEI research team. Where appropriate your parents/guardians will also be requested to partake in several interviews regarding the inclusive experiences you have experienced. Each interview will be audio-taped to ensure accurate recording of your answers. As well as the interviews, the current policies regarding inclusion in PEI will be investigated through a document analysis to compare your experiences to what is required by these policies.

The results will be shared with the families through a one-day symposium at the end of the study in each site.

Participation in this study will involve no greater risks than those ordinarily experienced in daily life. You should be aware that even if you give your permission for participation, you are free to withdraw at any time for any reason without penalty. This includes your decision not to answer a question during the interviews. Results, which we will be reporting in published articles or graduate student theses, will ensure your complete anonymity, and no identifying data will be release to your teachers/employers. All information gathered from interviews and observations will be securely stored in a locked office and will only be accessible to those who are directly involved with this research project.

If you have any questions, please feel free to contact Beverly Gerg at (902) 894-2842.

Sincerely,

Vianne Timmons, Ph.D.

Appendix C

Consent Form

Parent/Guardian Consent Form

I, ______________________________ agree to participate in the Inclusion Across the Lifespan project. The Inclusion Across the Lifespan project has been explained to me. I understand that I will be asked some questions in an interview. The interview will take about 30 minutes. I also give my consent for the researchers to talk to my child(s) teacher/employer if applicable. They will not talk to the teacher without telling me first. These interviews will be recorded so the researcher can refer to them later. My name and my family's interview will be kept confidential. No one but the researchers will know what I say. I do not have to answer any questions if I don't want to. I can stop the interview any time I want. I will keep a copy of this consent. If I have any questions I can call 894-2842 for Bev. I understand that I can contact the UPEI Research Ethics Board at (902) 566-0637, or by email at lmacphee@upei.ca if I have any concerns about the ethical conduct of this study.

Signature: ______________________________

Date: ______________________________

Name: ______________________________

Address: ______________________________

____

____

Code No. ____________

Appendix D

Letters to the Superintendents of the School Boards

November 5, 2003

Alan Kennedy
Director of Instruction and Professional Development
Western School Board
272 MacEwen Road
Summerside, PE
C1N 2T7

Dear Mr. Kennedy,

The University of Prince Edward Island has received funding from the Social Sciences and Humanities Research Council for a research project titled Inclusion Across the Lifespan which represents a partnership with the University of Prince Edward Island and the University of Alberta. The research project is designed to analyze the trends and patterns of inclusion with children with intellectual disabilities. Our hope for this research is that, through dialogue with the children, parents, and teachers we can identify the trends that can influence policy and practice. Input from the students and teachers are a key component of this research project.

This study will be conducted over three years, following the inclusion experiences of ten children with intellectual disabilities between the ages of 7 and 17. Case study information on patterns and trends of inclusion will be gathered on each child through interviews with the child, parent, teacher, and (if applicable) employer. Observations of each child will be conducted in school settings.

Information on current educational practices will be gathered through interviews. An extensive literature review and contact with other jurisdictions in Canada will be conducted, in order to compile the most relevant and promising information on educational training and best practices for children with intellectual disabilities.

We would like to send a letter to all the school principals with this information requesting their support of this research project. We are also requesting that they distribute the enclosed flyer to families that they may feel are interested in participating in this research project. If you have any questions, please contact myself at 902-566-0405 or Beverly Gerg, Project Coordinator at the University of Prince Edward Island at 902-894-2842. Email messages may be sent to bgerg@upei.ca.

Sincerely,

Vianne Timmons, Ph.D.
Vice President Academic Development

November 5, 2003

Ken McAleer
Acting Superintendent of Education
Eastern School Board
PO Box 8600
Charlottetown, PE
C1A 8V7

Dear Mr. McAleer,

The University of Prince Edward Island has received funding from the Social Sciences and Humanities Research Council for a research project titled Inclusion Across the Lifespan which represents a partnership with the University of Prince Edward Island and the University of Alberta. The research project is designed to analyze the trends and patterns of inclusion with children with intellectual disabilities. Our hope for this research is that, through dialogue with the children, parents, and teachers we can identify the trends that can influence policy and practice. Input from the students and teachers are a key component of this research project.

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Sincerely,

Vianne Timmons, Ph.D.
Vice President Academic Development

Appendix E

Interview Protocol

Parent Protocol

1. What activities do you do with __________ in the summer months?

2. What holidays or vacations, if any does your family go on?

3. What is your definition of inclusion?

4. What strategies do you use to encourage ______ 's inclusion at home and in the community?

5. a) What settings has _____ lived in?

- Group home
- At home
- Institution

b) What was their experience in that setting?

6. a) Did _______ ever attend a segregated school? What was it like for him/her?

b) How much time did ____________ spend in regular education? In segregated education? When?

c) Did you notice any difference for _____________ in the regular schools? In the segregated schools (if applicable)?

d) What grade did _______________ complete in school (for adults)? Was that in the regular education system or a segregated school?

7. What types of physical activity does ___________ do? How much time does he/she spend in those activities?

8. a) How much time does ________ spend with his/her friends. How do you feel _________ benefits from his/her friendships?

b) How do you think _______'s friends benefit from his/her friendship?

9. a) How is _______'s brother/sister positively impacted by _____'s disability, if at all?

b) How is _______'s brother/sister negatively impacted by _____'s disability, if at all?

10. How does your extended family support you?

11. Do you use respite services? If so, which ones?

12. Tell me about any other forms of support that you have.

13. Some families named church or faith as a support system. Is this a support for you? If yes, how?

14. a) What are the positive impacts ___________'s disability has had on you and your partner, if any?

    b) What are the the negative impacts __________'s disability has had on you and your partner, if any?

15. a) What do you feel are the benefits of inclusion for _________ ?

    b) What do you feel the drawbacks of inclusion are for ________?

16. If you were approached by another parent and they asked about how to promote inclusion for his/her child what would you say?

17. Has there been a critical incident during your child's life that has impacted your view of inclusion?

18. What recommendations would you suggest for school and communities to improve the lives of other persons with disabilities?