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Exceptional Lives: Parents' Stories

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This phenomenological research study examined the perspectives of parents and caregivers of persons with low-incidence exceptionalities through the use of semi-structured interviews. The purpose of the study was to determine what, if any, barriers they face in providing the best life possible for their children. All of the adult children in question sustained a developmental disorder, were 20 years of age or older, had completed high school, and lived in Ontario, Canada. From the study emerged eight themes: school entry and leaving, assessment, placement, resources, teacher training, advocacy, independence, and friendship. All of the participants had faced numerous challenges in the rearing of their children, particularly in dealing with schools and community agencies. In general, the participants did not feel that they had an active and respectful role in their child's education or a satisfying relationship with their child's school. In addition, participants reported that community services were stretched thin and that the demands for meeting eligibility criteria were often confusing, frustrating, and exhausting.

In Canada, the Charter of Rights and Freedoms (1982) entrenches in the constitution the rights and freedoms of all persons. Section 15 of the charter guarantees equality rights, establishing that every individual is equal before and under the law and has the right to equal protection and benefit of the law without discrimination based on race, nationality or ethnic origin, religion, sex, age, or mental or physical disability. The duty to accommodate, as part of the Canadian Human Rights Act (1977, 1985) stresses accommodation in a manner most respectful of the dignity of the individual. Each person with a disability must be considered, assessed, and accommodated according to their individual needs.

The duty to accommodate requires organizations to provide the most appropriate accommodation without undue hardship. Schools and community and social service agencies are among the organizations with a duty to accommodate.

The Social Model of Disability

The social model of disability has as its focus societal and environmental barriers, rather than the impairment itself. The model distinguishes between impairment and disability. An impairment is the state of the body that is non-standard, such as blindness. Disability is viewed as a social construct: the attitudinal obstacles faced by persons with non-standard bodies. Negative attitudes can create further disability for the person with a disability, making it more difficult for them to possess a positive view about themselves, affecting self-esteem and independence. The social model views every person as equal, positing that it is society that restricts participation and opportunities.

The social model of disability has been important to the development of the Convention on the Rights of Persons with Disabilities (United Nations, 2006). In Canada, there has been little progress for persons with disabilities, Ontario and Nova Scotia being the only provinces with disability legislation. The Ontarians with Disabilities Act (2001) and related Accessibility for Ontarians with Disabilities Act (2005) laid out the standards for access to services by persons with disabilities and mandated that every municipality prepare annual accessibility plans. These plans must address barriers for persons with disabilities.

A result of the social model was that society was deemed at fault for barriers that people with disabilities experienced, rather than placing the blame on the individual (Crow, 1996). Much research points to the fact that children with disabilities and their families experience persistent discrimination and disadvantage (Emerson & Hatton, 2007; Office for National Statistics, 2010). While some of these experiences may be attributed to social barriers, it has come to light that disability is complex and multi-dimensional, spanning political, social, and cultural experiences. The social model offers a limited view of the lives of children with disabilities. Children who are disabled experience limitations that may have little to do with societal norms. Thomas (1999) stated that impairments can of themselves be limiting, making participation in a community or an activity impossible. It is through the lens of the social model that I consider the findings of the current research study, to explore the realities of disability through the perceptions of family members of persons who have disabilities, to understand the barriers that might exist as a result of the social model upon which the current climate of special education inclusion is commonly built.

The Educational Setting

In Canada, education falls under the jurisdiction of the provinces rather than the federal government. In consequence, the inclusion movement—the movement to include all students in regular classrooms regardless of ability—arrived at different times in provinces and territories throughout Canada. In Ontario, the mandate to include students with exceptionalities or special needs in regular schools was introduced with Bill 82, The Education Amendment Act (1980). This Ontario legislation laid out the

requirement that all school boards in the province would provide equal access to education for all children in the province, including children with exceptionalities. School boards were required to provide programs and services for children with exceptionalities and to assist each child in meeting their full potential. In practice this was to mean that no child was to be excluded from publicly funded education. In addition, an impartial and just appeal process was introduced whereby parents' voices could be heard and heeded.

Since passage of the Education Amendment Act (1980), parents have had access to the Identification, Placement, and Review Committee (IPRC), put into practice with Ontario Regulation 181/98 (1998; s. 10), amended by Ontario Regulation 137/01 (2001). The regulation, as it pertains to the involvement of parents, states that every school board must publish a detailed parents' guide (O. Reg. 181/98, s. 13), and that parents with or without a representative have the right to participate in all discussions concerning their child (O. Reg. 181/98, s. 5). The parents may not participate in any decision making. Their child is placed according to the IPRC decision, an Individual Education Plan (IEP) is developed and implemented, with the provision that the IEP be reviewed at least annually. The regulation also provides an appeal process should the parents disagree with the decision of the IPRC.

Rather than wait for the often lengthy IPRC process to unfold, many school boards have worked closely with parents to develop their child's program as soon as issues in the child's progress emerge, reducing the need for IPRCs (Ontario Ministry of Education, 2006). Regulatory requirements continue to exist, but the child's educational program is not necessarily dependent on IPRC decisions (Bennett, Dworet, & Weber, 2013). However, the appeal process is not available to parents unless decisions regarding the identification and placement of their child were made by an IPRC. Under these circumstances parents must request that an IPRC be convened to discuss their child's needs. In recent years, the use of mediation to resolve stalemates has proven to be less costly and time-consuming than formal appeals (Bennett et al., 2013).

Additionally, the Education Amendment Act (1980) required every school board in Ontario to establish a Special Education Advisory Committee (SEAC) to advise on special education programs and services and a special education plan that outlines programs and services necessary to meet the current needs of exceptional students. The law also required implementation of early and ongoing procedures for the identification of students' abilities and needs. The reissue of Ontario Regulation 464/97 (1997) governing SEACs was intended to strengthen parental roles. The provincial Ministry of Education instituted information and training programs for SEAC associates in 2003 (Ontario Ministry of Education, 2003).

The Ontario Ministry of Education appears to have been actively trying to respect and include the role of parents in the education of their children who have exceptionalities, as evidenced by these laws and regulations. It can be argued that this has occurred largely as a result of political activism by parents and other advocacy groups, who have a powerful effect on governments. Examples of strong and sophisticated lobbying efforts come from the Learning Disabilities Association of Ontario (LDAO), the Association for Bright Children (ABC Ontario), and the

Association for Community Living (ACL), to name a few. These and other organized groups have been effectively inducing educational authorities to improve the educational opportunities for students with exceptionalities. Without the advocacy of these groups, it may be argued, the legislation might not have been introduced or might have been introduced at a much later date. Parents play a pivotal role in the education of their children, particularly those students who have exceptional needs. Since the Education Amendment Act (1980) was adopted, parental participation in the development of educational programs for students with exceptionalities appears to have increased (El Nokali, Bachman, & Votruba-Drzal, 2010), for example, through organizations such as the Child Care Advocacy Association of Canada (CCAAC) and the Learning Disabilities Association of Canada (LDAC).

Community and Social Services

Before students enter the school system and again when they leave the system at age 21, social services is responsible for programs and delivery of services for people with low-incidence needs. The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2004) has defined a person with a developmental disability as a person who has the prescribed significant limitations in cognitive functioning and adaptive functioning. The limitations occur before the person reaches the age of 18, are lifelong by nature, and affect areas of life activity such as personal care, language skills, learning abilities, the capacity to live independently as an adult, or any other prescribed activity. The act was designed to improve services and ensure that people could access them in their own community. The services covered by the act include: residential services and supports, activities of daily living services and supports, community participation services and supports, caregiver respite services and supports, professional and specialized services, person-directed planning services and supports, and any other prescribed services and supports.

Funded services such as community participation supports through the Passport program were designed to help adults with developmental disabilities become more involved in their community (Developmental Services Ontario, 2014). Individuals can apply for Passport funding for community participation and for caregiver respite supports. Passport funding pays for activities that promote personal development, including transitions from school to community. The social workers are part of the school team in planning for transition from school into the community at age 21.

Special Services at Home (SSAH) is a program for children with developmental disabilities (Developmental Services Ontario, 2018). Under this program, beneficiaries' funding ends at age 18, at which point they must apply for Developmental Services Ontario (DSO) funding. The DSO funding is designed to pay for services such as speech and language therapy, occupational therapy and physiotherapy, and transitions from home to school. In any case, applications must be completed to receive these services and supports.

Number of Children and Families Affected

But how many children are we talking about? How many children are there in Ontario schools who demonstrate exceptional needs? In 1986, by the end of the first year of mandatory special education in Ontario, 6.5% of the school population was receiving special education services. In 2009, 7.02% of elementary and 13.67% of secondary students were identified by IPRCs and 6.09% of elementary and 4.54% of secondary students were not formally identified but receiving services (Ontario Ministry of Education, 2012). Of these identified students, 80–90% have high-incidence needs, including the categories of gifted, learning disability, mild and moderate intellectual and developmental, behaviour such as ADHD, social/emotional, and communication disabilities. The remaining 10–20% of identified students have low-incidence needs, consisting of the categories visual or hearing impairments, physical or health impairments, pervasive developmental disorders such as autism, traumatic brain injury, and moderate to severe intellectual and developmental disabilities (Ontario Ministry of Education, 2012). These students require specialized and individualized assistance and programs.

Education has changed in response to the needs of communities, largely due to the advocacy of parent groups and individual parents (e.g., Parents Advocacy in the School, n.d.). Upon reflection, it is apparent that the larger and more organized the group, the larger the voice, causing one to question the ability of parents of students who have a low-incidence exceptionality to have their voices heard. Students with low-incidence exceptionalities do not typically exceed 1% of the school population at any given time (Hutchinson, 2013). These low numbers present challenges for teachers and parents alike. Teachers have little exposure to these students and possess little knowledge on best pedagogical practices. In addition, they are unaware of how to access support services for the students from outside agencies. Consequently, the students can be difficult to serve in local public schools (Howell, 2005).

Students with low-incidence disabilities, as mentioned, are a much smaller group than the typical population of students and have unique specialized needs. Their parents consequently are a much smaller group with a small voice. Parents, similar to teachers, have had little previous exposure to low-incidence children, possess little knowledge on best parenting or teaching practices, and at the outset do not know how to access services from outside agencies (West, 2015; Weinhaus & Weinhaus, 1994). All of these things parents must learn on their own under the urgencies of time and demand. In addition, parents quickly learn that they must advocate for their children, tirelessly fight for services they require, and go through the bureaucratic lock steps of applications and of meeting imposed standards from government and agencies for everyday living (Drogan, & Perner, 2015; Weinhaus & Weinhaus, 1994). Increasing the burden is the fact that many parents of children with low-incidence exceptionalities have some kind of a developmental disability themselves (Ehlers-Flint, 2002).

How do these parents effectively advocate for the needs of their children? What are their stories? What, if any, barriers do they face in providing the best life possible for their children? This phenomenological research study attempted to give voice to this group of parents.

Method

With ethical approval from the university research ethics board a phenomenological study was undertaken to discover the experiences of parents and teachers of students who have low-incidence exceptionalities. To develop a better understanding of the challenges of raising a child who is disabled, it was imperative to gain an understanding of the meaning and essence of the experience as lived by the parents and caregivers who experienced the phenomena (Creswell, 2013; Moustakas, 1994). The phenomenological approach provided a way for the parents and caregivers to share their experience with the researcher as well as to explain how this experience affected their perceptions of their relationships with schools and community agencies. Questions were generated for a semi-structured interview to uncover the relationships parents had with their child's school and support agencies, with respect to input into programs and delivery of services. To what extent did parents believe that they had an active and respectful role in their child's education and community programs? This article reports on Part A of a larger study that describes parents' perceptions of their children's school and community experiences.

Six people were recruited to participate in Part A of the study, located in northern Ontario. The sample size reflects the occurrence rates of low-incidence exceptionalities in Canada, with 3.7% of the population aged 14 and under experiencing a disability and approximately 1% with a moderate to severe disability (Human Resources and Skills Development Canada, 2011). The participants were parents and caregivers of a person with a low-incidence exceptionality. The children that they were discussing were chronologically 20 years of age or older, were developmentally disabled, and had completed high school. Of this group of six participants, two were fathers, while the rest were mothers or family caregivers. All participants signed letters of informed consent, were eager to share their stories, and indicated that they were happy that someone showed an interest in their struggle to support their child.

Participants

Tom was a father who participated in the study. He was in his late 50s and presented as a quiet and gentle man. His partner, Julie, was a busy middle-aged woman who worked outside the home and was raising a total of six children. Abby, their daughter, was 20 years old with a developmental age of three, sometimes functioning at an equivalent of six years in special circumstances with lots of support. This means that regardless of her chronological age she possessed the mind of a three- or six-year-old. The family resided in northeastern Ontario.

Colleen was a retired teacher and principal from northwestern Ontario, and her son Martin was 32 years old with a diagnosis of Down syndrome from mild to moderate severity.

Susan was a young woman in her early 30s who is a caregiver for her sister, Emmie, aged 26. Susan's mother, Kathy, offered information and validation to the account. Emmie had a diagnosis of velocardiofacial syndrome, which is associated with a deletion in chromosome 22. This family also resided in northeastern Ontario.

Edith and Fred were octogenarians, aged 82 and 86 years respectively. Their daughter Betty was 40 years old and had Down syndrome with moderate severity. She was the second youngest of six children. They resided on a farm before moving to a nearby city in northwestern Ontario.

Findings of the Study

The overall findings of this study are that while all of the participants interviewed felt that they had an integral role to play in the education of their children with low-incidence special education needs, they reported that their voices were often ignored. Parents experience many barriers in their quest for a meaningful school and life career for their children, many caused by the very supports that were intended to relieve burden. In general, the participants did not feel that they had an active and respectful role in their child's education nor a satisfying relationship with their child's school. They further observed that community services were stretched thin and that the demands for meeting eligibility criteria were often confusing, frustrating, and exhausting. The following sections contain the results of the study as a series of eight themes that emerged from the study: school entry and leaving, assessment, placement, teacher training, resources, advocacy, independence and relationships.

School Entry and Leaving

In general, all of the participants indicated that the child in question started school at age five. In Ontario children enter the school system at age four into junior kindergarten (JK), indicating a one-year delay in school starting for these children. All of the children entered senior kindergarten (SK) in a regular classroom with no extra supports. One of the mothers, Colleen, said, "Martin started school at age five in SK. After three months he was moved to JK [junior kindergarten] with some support, an Educational Assistant [EA]. He had no support in SK."

Betty's story differs from the others' in that she was born in 1975, before the inclusion movement in Ontario, when legislation was introduced to facilitate equal opportunities for an education in the public school system. Edith remembered,

I sent Betty to school on the bus with her older brothers and sisters. By ten o'clock that morning the teacher called for me to pick up Betty from school. The teacher said Betty stole a pencil from another student, that she was bad and couldn't come to school.

When asked whether Edith and Fred had gone to the school board to protest, they insisted that there was no point.

There was no one to go to for help. The doctor had told us to put her in an institution when she was born. We just kept her at home after that. It was difficult because she was heartbroken that she couldn't go to school.

Compulsory school leaving is at age 21 in Ontario, and the participants in this study shared a concern regarding what happens after high school. There were a few community programs to provide activities, but not to the extent that there was at high school. The families had the added concern for their old age. "We worry about what will happen to our daughter once we are gone. Who will look after her?"

Assessment

The participants in this study all agreed that schools should accept parental input and see each child as an individual. “All children learn in a variety of ways and must be individually assessed,” Colleen stressed.

At the time Abby entered kindergarten, her social skills were normal for her age, speech was a little delayed, and playing seemed normal. She had limited short-term memory and no concept of time or day. Julie illustrated Abby’s difficulties by saying,

In kindergarten the teacher tried to teach her basic skills, trying to drill information. She couldn’t do it. She still doesn’t know the ABCs at 20 years old. We finally got a psychologist from Toronto to explain to the school that she had no concept of time. It simply gets her frustrated and feeling badly about herself.

This psychologist advocated for Abby and her family over a three-year period. The doctor helped them to get the services and program Abby needed. The psychologist advocated for functional programming for Abby, to which the school board finally agreed.

Assessment reveals strengths and weaknesses, and that information should be used for the development of an IEP. “But they don’t use it. When an IEP states that the teacher has to teach Abby how to make change for a dollar, that does not use the assessment information gathered from the tests,” said Julie, “because she clearly can’t do that.”

The issue of assessment is a hot topic for Emmie’s family. Emmie is 26 years old and functioning at about age 7 years. When Emmie was very young, her mother was told that she would not walk or talk due to heart issues. It was not until Emmie was 18 that she was diagnosed with velocardiofacial syndrome. This assessment was costly, as a blood sample had to be sent to a lab in Germany. The family had finally received funding for the assessment and her mother, Kathy, was currently attempting to gain funding for further government genetic testing with costs from \$10,000 to \$20,000.

In high school her assessment indicated that “she was too high functioning for special classes, when she wasn’t,” continues Kathy. “The school wouldn’t listen to me. I begged them to reconsider but they ‘knew best’ and wouldn’t budge. They just kept saying they couldn’t put her in a different class because she didn’t meet their criteria.”

Placement

Colleen, who was the mother of Martin with mild to moderate Down syndrome, stated that she felt that “students with fewer behavioural challenges” would be more successful in a regular classroom setting. “There is only so much time a teacher or EA can spend with individual students, and if behaviour is a constant, the learning time for other skills is reduced.”

With respect to placement, Julie shared that Abby had been in a special class every year after the initial year in kindergarten. A safe environment is important. Julie explained, “Otherwise your child gets sick, miserable, unhappy. I don’t understand why they have to go somewhere or do something that makes them feel that way.”

In contrast, Emmie had excellent school experiences in segregated classrooms until she reached high school, where the school did their own assessments and placed her in an

“IEP” class for Grades 9 to 12. The family disagreed with the decision. At age 16 most kids are partying, but Emmie’s mind was that of a 7-year-old. “Her friends in the class were partying, talking about sexual things that she knew nothing about. She started using words without knowing what they meant. They used her a lot and got her into a lot of trouble.” Susan continued, “They’d blame her for writing sexually explicit and vulgar notes until mom finally got called to the school board.”

Susan described Emmie as changing from an innocent girl to a girl who started to act “slutty—showing her breasts to guys.” Susan says Emmie is still following that path, striving for male attention, and the family blames Emmie’s high school experience for this problem.

The right environment was created for Emmie in elementary school by an excellent teacher, but she still had the disability. A good environment makes a difference for anyone! A different class at high school would also have helped her, but the school board would not listen. They always think they “know better.”

Susan added,

Emmie just stares at you if she doesn’t understand. She won’t ask for help. If the teacher were to call on her she would just stare. A regular classroom teacher wouldn’t understand that.

Edith and Fred recollected that in their small farming community there was no other place than the regular classroom for their daughter Betty. When the teacher refused to have Betty in her classroom, there was nowhere to turn. “There was no rule saying that the teacher had to let her go to school,” said Fred.

As mentioned, a parent guide for the IPRC process was to be made available to parents as a result of Ontario Regulation 181/98 (1998). Colleen, being a former teacher and principal was well versed in the IPRC process and had a copy of the parent guide. Edith and Fred had Betty in school before Regulation 181/98 came into effect. Upon questioning, the other parents did not recollect seeing a parent guide for the IPRC process that their child had undergone, even though it is required by the Ontario Ministry of Education and Training to be made available to parents. This is a disturbing fact, as it is incumbent upon the school to provide the guide to parents as a measure to facilitate their participation and safeguard their rights.

Teacher Training

A common theme from the interviews was teacher preparation. “A good teacher makes our lives so much easier.” Another comment was, “Kids are happy and do not act out when the program and teacher are right.”

The participants complained that regular classroom teachers do not have the specialized training that is necessary to understand the needs of these students and their families. “Teachers should be specialized and they need support,” agreed the participants, “and the senior administration doesn’t listen to teachers.”

Julie remembered that Abby’s first year with the special class with a specialized teacher was a happy one. “The teacher taught the kids how to respect people who are

different,” said Tom. “A teacher like that should have the authority to determine what is to be taught. She had training and understood these kids.”

At Abby’s school there was a set schedule every day. “Thursdays were swimming days so Abby didn’t like Thursdays.” She didn’t like swimming laps and the teacher was very stubborn and insisted that the curriculum required Abby to swim laps. Julie was at the school constantly to talk to the teacher because of the negative behaviours that Abby was demonstrating as a result of being coerced to swim laps.

For 2 years the parents had to deal with these behaviours of cursing, hitting, and swearing. “She was hitting me and beating me up until my father had to intervene. Dad would come to the house to try to calm her down.”

“If a child is assessed and there is no progress after a year in the recommended program, should we ignore the signs?” asked Abby’s father. He went on to say that it appears that in many cases the regular class teachers are not trained and therefore do not know how to respond. Julie concluded, “The reality is ignorance. People are so ignorant! Schools, government, and community agencies are all ignorant. How do you overcome ignorance?”

In Betty’s case, being sent to school before her right to a public education was mandated, the teacher simply got rid of her. “The teacher didn’t want to be bothered with her. Betty was sitting next to a little boy and she used his pencil. She didn’t steal it. She had her own,” explained her mother.

Resources

School supports. Starting school is a big event for every child and their family. Parents often note a change in their child, such as being tired or cranky. Julie shared that a week after starting school there was a change in Abby:

She refused to toilet. We had to potty train her all over again. We learned that even though there was to be an EA for Abby, no one was accompanying her to the washroom. It took 6 months of potty training after that happened to get her out of diapers and using the toilet again.

After this occurred, Julie said they did not send Abby to school, as she needed a special classroom and the school board insisted there was no money to provide one.

Abby’s mother went to the MPP for the area and demanded to know why there was no money for a special classroom for her daughter. Julie asked for financial disclosure from the school board and had to ask for the MPP’s help to secure it. “The document revealed that half of the budget for special needs was not being spent as it should have, such as on sports programs.” Mother brought this to the attention of the school board and “Two days later, after claiming they had no room for Abby, they had an opening at a school not too far from our home.” After starting in her new program, “she no longer went home after school every day and cried.”

EAs worked with Emmie in elementary school but not at high school. “There was no extra help and she needed help.” Susan explained that sometimes the older kids would

help out, but there was no consistency. "The system is overtaxed, with teachers and EAs trying to keep up to the demands."

Five of the six participants agreed that they felt "school doesn't want to listen to parents. Their attitude is like it or lump it." The participants in this study agreed that more flexibility on the part of the school and individual supports are needed.

Community supports. The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2004) was legislated to promote the inclusion of persons with developmental disabilities in their communities. In the communities in which the current study took place, there was general agreement that there are a number of supports, but parents have to "jump through the hoops" to get the services they need for their child. "Endless application forms to complete, meetings with the social workers, and house inspections to name a few," said Julie. "Parents have to figure out how to fight every time for services," agreed Abby's father.

In Betty's case, in the early 1970s, the parents noted that the YMCA in a nearby city was a welcoming organization and that they were willing to teach her swimming lessons along with the other kids. "They had a special instructor to assist Betty in the classes and she loved it. She became an excellent swimmer and loved going to the Y." Unfortunately, there were no other programs available to Betty until she became an adult.

Most of the participants indicated that their child had support from social services before entering the school system. Colleen said that "an infant development worker visited us regularly for at least a year. When Martin was 3, he took part in an inclusive daycare program with a specialist worker." In reference to social services, Susan and Kathy shared that "Emmie always had a worker and always got along with people."

When asked about where to turn for help, Abby's father said, "Talking to other parents is a bit helpful." Julie countered with,

But it often turns into a bitch session and sometimes jealousy of the help that others are receiving. Some people are better at dealing with the agencies and know how to get services. You sometimes compare your situation to others' and that may or may not be a good thing. Sometimes you feel fortunate and other times you don't.

Possessing a developmental disorder identifies persons with a low-incidence exceptionality as a vulnerable person requiring extra vigilance for their safety and well-being. A bitter pill to swallow for Abby's family was that their 24-year-old son had to have a police check to move back into his family home and was not allowed to be alone with or babysit his sister. "I think that is going too far," said Abby's parents. "That's his sister!"

Community programs. The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act of 2004 describes a person who has a developmental disability as possessing, "significant limitations in cognitive and adaptive functioning." Consequently, persons with a developmental disorder are not independent. Without supervision and intervention they would merely sit at home with nothing to do. The families in this study described the life of their children after completing high school.

Martin had a schedule of activities, including times at the gym, social times at an integrated facility for art pursuits, swimming with Special Olympics, visits to the library,

work placement for half a day per week, and church on Sundays. Colleen offered that Martin took care of his apartment daily, doing dishes and keeping up with his laundry and personal hygiene.

Abby also had a schedule of activities. On Mondays she worked with the Association for Community Living (ACL), Tuesdays and Thursdays with a local life skills group, and Friday with ACL again. In these programs they learned to cook simple meals, shop for groceries, do laundry, and manage everyday life skills. “Abby particularly likes karaoke, shopping, nails, and being a girl. But not swimming laps!”

Emmie also had a schedule for community involvement. On Mondays, Thursdays, and Fridays she volunteered at a daycare, and on Tuesdays she worked for pay at the same daycare from 10 a.m. until 1 p.m. playing with the kids. On Wednesdays she was involved with ACL in the mornings. Emmie was training with Special Olympics, as she was a good athlete, provincially and nationally.

Betty’s life on the farm was mostly uneventful. She went everywhere with her parents: to church, social activities, or shopping, but never alone or with anyone but her parents. When her parents were in their early 60s and Betty in her early 20s, they sold the farm and moved to the nearby city. Once settled into their new home, Edith and Fred decided they needed to start thinking about Betty’s future life without them. “She was totally dependent on us,” said Edith, “and we realized we weren’t always going to be here for her. We had to do something.”

Edith contacted a social worker on the advice of her granddaughter and found a sheltered workshop program that would accept Betty.

It was hard for us to send her off by herself, but the social worker was very kind and understanding. He made it easier for us by helping us with the application and other forms that we had to fill out.

Betty did well at the sheltered workshop and made friends with two girls immediately. Edith learned that these two girls were living with a married couple who received financial compensation from the government for looking after the girls. Edith says, “I immediately called the social worker and asked how I could get Betty into a sheltered living arrangement.” Fortunately, Betty was able to go to the same home as her new-found friends during the week and then go home for the weekends. Fred continued, “It was getting too much for us to get Betty up and ready every day and then drive her back and forth to the workshop. They tried to teach her to use the city bus, but she couldn’t do it.” It solved a lot of problems for the family. Betty was happy with her routine, friendships, and host family. Her parents were relieved to know that she was occupied and had community support.

Everything was fine until the workshop changed Betty’s program from making cellophane flowers for wedding cards to repairing, sanding, and staining wooden chairs. “All hell let loose,” chuckled Fred:

She came home on the weekend and said she was never going back. She cried and screamed and hollered.. It all got straightened out and Betty went back to making her wedding flowers and we have never seen her act like that again.

Advocacy

The need for advocacy is a very real part of life for these parents. People who work in schools and community agencies are the gatekeepers for services that their children require and to which they should be entitled. Often these gatekeepers become barriers to the programs and services the child needs.

As an example, Abby's teacher wouldn't budge about swimming laps. The Association for Community Living tried to help but "the teacher would change for 2 weeks and then go back to her old ways." When asked whether she went to the principal for help, Julie replied that she did not because she "didn't want to be treated like an idiot. Doors are always being slammed in your face. Their attitude is that the school knows best. Parents give up." Julie explained further that she had a bad temper and that "you cannot take back words.... My mother will fight for years but I don't have it in me. I have five other children and a husband, and I run out of energy. Dealing with agencies whose purpose is to help, is exhausting."

"To advocate you have to threaten, but once you do, the school board hates you," continued Julie. "Why can't we work together?" Julie insisted that she does not like to fight, but if put in a corner she will fight if she has to.

Abby has to show her face in this community, and it makes it difficult for all of us when we have to fight about everything to advocate for Abby. Parents get labelled as a problem, or go outside to another agency for help with one instance only, and then they are on their own again.

As noted by Julie, the Association for Community Living tried to intervene at times. They paid for Abby's cab fare to school. "Abby doesn't qualify for the Para Bus because she is able to physically walk.¹ She cannot go anywhere independently, as she is not capable, but because she can walk she doesn't qualify for para-transit." Julie continued by saying that this was her next battle. If Abby qualified for para-transit, she would not have to take a taxi, and that "would help another family out."

Julie explained why dealing with the agencies is exhausting:

The agencies have so many policies and procedures and rules. Parents have to have up-to-date CPR training and \$45 for police checks every year if you are involved with respite. Our home has to be re-approved every year for safety at costs of \$100 for a fire inspection, \$85 a year for CPR training updates, and \$1 million dollar liability insurance. Kitchens and bathrooms have to meet standards prescribed by the agency. Inside our freezer we have to keep a thermometer to ensure the temperature for safe food handling. I have to keep track of every penny that Abby spends from her monthly allowance of \$100 with receipts to account for the money. You have to have real receipts but the school doesn't give them real receipts at the canteen. The school canteen gave us a slip to indicate purchases but I got into trouble with social services because they wouldn't accept the slip as a receipt. At the end of the day you don't want to talk to the school principal or anyone else.

¹ Para Bus is a parallel-transit service, for people with disabilities operated by the Physically Handicapped Adults' Rehabilitation Association (PHARA), under agreement with the city. Individuals are eligible to ride the Para Bus if they cannot board a conventional bus or walk a distance of 175 meters due to a physical disability (Institute of Medicine, 2007).

Independence

The goal for people with low-incidence exceptionalities is to live as inclusive and independent a life as is possible. This level of independence varies depending on the capabilities of the individual. At age 32 Martin took possession of his own apartment, which he cleans himself; and he prepares simple meals. He relies on his family for transportation and for advice on buying groceries and meal planning. “He is still learning to cook a variety of dishes,” says his mother Colleen.

Susan described Emmie as being an independent spirit and that they have been thinking of future living on her own, but getting a spot with Assisted Living takes a long time, up to 10 years. At present she is living downstairs in a house that her mother bought, and her older sister lives upstairs and keeps an eye on her. Emmie is capable of routine, taking the bus, and cooking a limited number of things. She needs assistance with personal hygiene, and with cleaning and tidying her living space. Her mother does her housekeeping.

Susan noted that Emmie’s father, as well as a guidance counsellor, encouraged the mother to let Emmie have more independence and freedom. With that in mind, Emmie was allowed to meet a girl at a bus stop within a 2-minute walk from the house. As time passed Emmie’s mother became concerned and went looking for the girls. She found them at the bus terminal but the friend refused to go home with her. The friend’s father called at 11 p.m. because he could not find his daughter, and at 12 midnight the police questioned Emmie’s mother since she was the last person to have seen the girl. The final outcome was that Emmie’s friend had met someone on the internet and had gone to meet him, taking Emmie with her. This was upsetting to the family, as they recognized the potential danger that Emmie had been exposed to, but that Emmie did not understand. Balancing independence and safety is difficult for these families.

Relationships

Social inclusion means more than simply placing people within the same vicinity. A sense of belonging is nurtured through the development of valued relationships (Pockney, 2006). People with intellectual disabilities have very few meaningful relationships with people who do not have intellectual disabilities, are not relatives, and who are not paid to support them (Robertson et al., 2001). The participants in this study shared their stories of the struggle for friendships.

Abby’s parents described her as friendly but non-communicative with people she doesn’t know. “It takes her awhile to learn to trust someone,” father commented.

She loves young kids. She used to sit and wait for hours for the little girls next door to come home to play. She refused to come inside until the girls came home. Often it was too late to play outside when they returned, but as long as Abby saw them return she would agree to go inside.

Emmie made friends with her peers as well as with teachers at school. But at high school, “Emmie didn’t understand that she was being bullied,” said Susan. “The other kids in her class were higher functioning, and they used her as a guinea pig. And a guy kept telling her to kill herself.”

Betty, having grown up on a farm, had few opportunities to make friends outside of her family. She was the only one in her swim class who was disabled and she was taught alone with a swim instructor. She made a connection with the instructor, but each year the instructor would change and Betty would have no further contact with that person. A local youth group came to the family home to visit Betty as a “shut-in,” but the kids made fun of her when she tried to interact with them. “She didn’t know how to talk or behave with them, and they found her strange and awkward,” said Betty’s father.

“Betty’s first real friendships developed when she was in her early twenties, when we moved into town,” continued her mother:

She made friends with two girls at the sheltered workshop, and then she ended up living with the same host family. It’s one of the reasons she was so happy there. She was with people like herself who accepted her the way she was.

“And then there’s the issue of sex and pregnancy,” added a parent. “They don’t understand conception or contraception. It is very difficult to try to explain the morality or risks of promiscuity.” One of the parents added, “You can’t rely on them to take a pill every day, and they have to consent to a medical procedure they don’t understand and are afraid of.”

Abby’s mother gained power of attorney for her daughter and advocated for and got a physician to insert an intrauterine device (IUD) for contraception. “It took persistence and many hours of hard work, but it finally paid off.”

When Emmie was 18 years old, her mother arranged to have Emmie’s tubes tied. The doctor stressed that he could not perform the procedure unless Emmie agreed to it because it was against Abby’s human rights to do so (referring to the Charter of Rights and Freedoms, 1982). At the time Emmie was in a parenting class and did not like looking after the crying doll or having her freedom taken away, so she consented to the surgery. “Disabled adults getting pregnant means too often the girl’s parents end up with the baby. How is this fair to those parents?” asked Kathy. “What about the rights of parents who are the lifelong caregivers for these kids?”

Betty’s mother agreed with the grievance of puberty and sex for girls with a developmental disability. “I asked the doctor for help, if he could perform sterilization. She had the operation shortly after, but that was hard on her, too, because she didn’t understand any of it.” The Canadian Charter of Rights and Freedoms came into effect 17 years later.

Limitations of the Study

A limitation of the study is the long delay between some participants’ experiences with different agencies and activities and the timeframe of this research. The longer the time between experience and interview, the less accurate the recollections might be (Borgers, Leeuw, & Hox, 2000). Additionally, the participants were asked to provide information regarding their family member. Due to the nature of a developmental disability, the individuals themselves were deemed vulnerable and difficult to interview.

Recommendation for Future Research

It would be beneficial to replicate this study immediately after the experiences occurred, and with a larger group of individuals from different locations across the country, to determine commonalities and differences in peoples' stories and to determine whether location has an impact. Certainly, we learned from Betty's story that living in a rural community presented some barriers to social inclusion.

Conclusion

Considering the significant impact that the social model of disability has had on education with the inclusion of all learners in regular classrooms, the participants in this study were not convinced that the regular classroom is always the best placement option for their children. An appropriate environment and program often moderated the behaviours and learning of their children in a positive way, but the disability remained. As Shakespeare & Watson (2001) noted, the social model may be better suited to the political field as a means of radicalizing disability rather than as a basis for building an educational model for the delivery of services. Children who have a disability experience limitations that may have nothing to do with social structure.

This study has shown that when the assessment, placement, and programming at school or in the community is appropriate for the individual, life at home tends to run smoothly. When there is a problem with these, there is a problem at home. People with low-incidence exceptionalities, such as a developmental disability, express themselves through negative behaviours when they are unhappy due to their difficulty with language, particularly in the expression of feelings (Sundberg & Partington, 2013). It then becomes incumbent upon the parent to fix the problem, and therein lies the difficulty. When schools and other agencies do not agree and respond accordingly, the situation can become unbearable for the family.

Exploring the perceptions of parents of children with developmental disabilities has revealed some of the complex and challenging aspects of their lives. It is important for all professionals working with such families to have understanding and empathy in their approach to providing programs and supports.

While each person with a disability has unique challenges and needs, knowledge, understanding, compassion, and empathy can be built from their stories. From the voices of the participants it became clear that they were a small group that possessed a small voice. The needs of the group were complex, unique, and demanding; and they clearly needed advocacy support.

Individuals get frustrated and exhausted from fighting for their children on their own and overwhelmed by the paperwork, prohibitive costs, and standards they must meet in their everyday lives. The bureaucracy of services and supports is a barrage of demands and responsibilities in addition to the complex care of a child with a disability. It is a fight parents and caregivers cannot walk away from, but they do on occasion take a well deserved rest before they go back into the ring for another round of advocacy. They need empathy and, most of all, support and advocacy.

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