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Towards a good life: One family's experiences with individualized supports

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TOWARDS A GOOD LIFE:
ONE FAMILY'S EXPERIENCES WITH INDIVIDUALIZED SUPPORTS

BY

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THESIS

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Abstract

Individualized funding and supports for people with a disability have emerged in Canada as an alternative to traditional supports such as group homes and day programs. In this thesis, I examine one family's experiences with individualized disability-related supports. From the perspective of an individual with an intellectual disability and her family members, friends, support workers and service providers, the benefits and challenges of individualized supports are profiled. Furthermore, how individualized supports impact upon relationships and community inclusion for this individual is explored along with the experiences of parents, siblings and support workers. As a qualitative study, information was gathered from participants through in-depth interviews, observations, and photographs. In addition, I discuss individualized funding and supports in relation to the concepts of self determination and quality of life for people with an intellectual disability and their families. Lastly, recommendations for resolving the shortcomings of the individualized approach are shared.

Acknowledgements

Thank you so much to Hope, Judy, Allan and their support network of family, friends, workers and service providers for helping me to establish the focus of my thesis work and sharing your experiences, thoughts and perspectives with me. I am very grateful to you for your patience and understanding throughout this whole process. I am also hopeful this work captures your story and contributes to your efforts to build a good life for Hope.

Thanks also to my advisor, Dr. Juanne Clarke, for connecting me with the family and for your support of my work and accommodation of my circumstances. Thanks to Dr. Richard Walsh-Bowers and Dr. Peter Dunn for agreeing to be on my committee and for your constructive criticism of my work.

Thank you to my loved ones – Erik, mum and dad – this would not be possible without your love and support. For my daughter, Talia Reet, whose incredible spirit inspired me to continue.

If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each diverse human gift will find a fitting place.

Margaret Mead

Table of Contents

List of Tables

Table Page

CHAPTER ONE

Introduction

It seems that people who take on the challenge of doing research in the community, for the benefit of the community, are often drawn to working with people and issues that in someway have touched their lives. As I embarked on my thesis journey, I too felt strongly about using this opportunity to illuminate the experiences of people who have had a profound impact on my life. I had been working with people with an intellectual disability[1] for over ten years when I decided to apply for graduate school. I still remember the interview for my first job in my chosen field when I graduated from university. The interview was coming to a close when the interviewer leaned closer to me and asked "what do you think is the most important thing that you will need to bring to this position and to the families we work with?" It felt more like a challenge than a question. "Well", I hesitated, "I hope that my education will be of benefit to me in my work with the families." She nodded and replied, "We hope that whoever we hire for this position will be open to learning from the people with a disability and their families."

There goes another botched interview, I thought as I headed out of the office. Much to my surprise they called me back. Her advice has stayed with me as I realized how much I still had to learn and how much the people I worked with had to teach me. I feel honored that people have trusted me enough to share the joys and challenges of their lives; of living with a disability in a world that excludes and

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[1] The term intellectual disability is used in this paper in place of the label mental retardation for which it is a synonym. This term is in keeping with the preferences of the self-advocacy movement in Canada.

devalues people with a disability, and of caring for and supporting family members with a disability to have happy and secure futures. Over the years, there have been many reasons to celebrate with others and I have experienced a sense of satisfaction and community in my work. It has not always been positive, however as I have felt a great deal of frustration being caught between the needs of families and individuals, and a service system that is unresponsive and lacks adequate resources. I have also, at times, felt overwhelmed by the hardships that people with a disability experience and feelings of powerlessness to make a difference in their lives.

The family who agreed to work with me on my thesis project had a strong influence on its focus. Over the last year and a half, they have shared with me their experiences of having a daughter with a disability and their struggle to ensure that she has the best life possible, now and in the future. After some discussion, we decided that I would examine the importance of individualized disability-related supports in the life of their daughter. After experiencing more traditional support arrangements for people with an intellectual disability such as a group home and day program, this woman and her family have found success with individualized supports. From the perspective of her family members, friends, support workers and service providers, I will discuss the benefits and shortcomings of individualized supports and how they have impacted on this woman's quality of life as well as that of her family. By focusing on the unique circumstances of this individual and her family, I feel my research has captured a more detailed and nuanced understanding of the complexities of individualized disability supports. Finally, I have strived to ensure that the work I have done is relevant to this family and others in similar situations.

In order to gain a more holistic perspective of the issues in my study, I will examine the current state of disability-related supports in Canada as well as current literature in the area of individualized supports and funding, relationships, and caregivers' experiences. This review will be followed by a discussion of my motives for conducting research in this area, the methodological assumptions that underlie the research, along with a discussion of sampling, research methods, and ethical issues.

CHAPTER TWO

Context of the Research

People with an intellectual disability in Western societies have traditionally been viewed from the perspective of a medical model that sees disability as lying within the individual. The person who is "impaired" was deemed less than perfect and unable to take on meaningful social roles and contribute to society. These negative perceptions of people with a disability as being a burden on others influenced how social policies for people with an intellectual disability were developed (Barnes & Mercer, 2003). In the past, people with an intellectual disability were routinely placed in large, segregated institutions so that society, apart from their paid caregivers, would be protected from their differences and they would no longer be a burden to others. This dominant paradigm also led to the sterilization of many individuals with an intellectual disability, without their consent, in an effort to rid society of differences (Crichton & Jongbloed, 1998). Although it is not as common today for individuals to be placed in large facilities or sterilized against their will, the medical model is still reflected in the many supports and services available today which are meant to rehabilitate individuals. These services often take the form of group homes, sheltered workshops, skill development programs, and segregated classroom settings where the focus is on improving individual functioning rather than changing environments to accommodate disability (Rioux & Bach, 1994).

In response to the medical model, a social model of disability has arisen which "acknowledges the structural and personal barriers created by society" (Johnstone, 2001, p. 20). This critical theory of disability sees the cause of disability not within the individual but within the society that surrounds them. The social model acknowledges that people with an intellectual disability have very little power, resources, and opportunities to participate equally in society due to the exclusion and oppression that they face on a daily basis. This model of disability was developed by people with a disability in order to bring attention to their social and political context, a context that the medical model largely ignores. This perspective has given rise to the disability movement in keeping with other social movements such as the women's, civil rights, and consumer/survivor movements (Johnstone, 2001).

The emergence of the social model of disability and a rights-based paradigm shift has had a major impact on the way disability-related supports and services for people with an intellectual disability are provided in Canada (Roeher Institute, 1999; Crichton & Jongbloed, 1998). In the 1960's, parents of children with an intellectual disability, along with self-advocacy groups, protested against living conditions in large institutions and began to advocate for more community-based living arrangements where people could be closer to family and friends and be a part of their communities (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999). These efforts, along with the legislation guaranteeing equal rights for people with disabilities in the Charter of Rights and Freedoms and the Human Rights Code in the early 1980's spurred a wave of deinstitutionalization initiatives across Canada (Stainton, 1994). Six large facilities were closed and downsized. In response, community services were established to meet the needs of the increasing numbers of people living in the community (Crichton & Jongbloed, 1998; Roeher Institute, 1999). Government funding was now provided to agencies in the form of transfer payments to support people in group homes, day programs, and sheltered workshops.

Certain beliefs and assumptions regarding people with an intellectual disability and social welfare underlie the use of transfer payments to respond to the basic and disability-related needs of individuals with a disability and their families. The redistribution concept of social welfare is

> based on the assumption that there are inherent inequalities in the present Western industrial society. Inequalities in the distribution of power, income, goods and services have created a disadvantaged social class within North America (Yelaja, 1978, p. 14).

Individuals with an intellectual disability are seen as vulnerable members of the capitalist system as they are faced with barriers to employment, decision-making, and everyday life experiences. Without opportunities to support themselves financially, the majority of people with a disability are reliant on Canada's social safety net (Dunn, 2003). When government funding is provided to agencies or directly to individuals and families, the government is recognizing that the state is responsible for intervening, providing opportunities, and protecting the rights of people with a disability. This measure represents a more liberal ideology as it recognizes "society's responsibility to provide for those unable to care for themselves in a capitalist society" (Macht & Quam, 1986, p. 29).

Although these new community settings were an improvement on the living conditions of large institutions, it was not long before they came under heavy criticism for replicating the restrictive environments of institutions and consequently preventing individuals from exercising self-determination and participating fully in the community (Pedlar et al., 1999). While people are now living in homes that are located within the community, they remain segregated from community life as "many of the principles of this (traditional community service) model are the same as those in institutional services" (Dunn, 1999, p. 233). As a result, community services are "institutionalizing people in the community" (Dunn, 2003, p. 203).

Furthermore, not all individuals have been served well by these programs, as strict eligibility criteria, such as mandatory participation in day activities when living in group homes, make it difficult for many individuals to conform to the expectations of the service. It is rare that such programs are designed around the needs and interests of individuals (Roeher Institute, 1990). Despite the shortcomings of these segregated living and day supports, they remain the most prevalent options for community living for people with an intellectual disability (Pedlar et al., 1999).

In addition to having to contend with a rigid and unresponsive service system, people with an intellectual disability and their families have also been challenged over the last decade by government cost-cutting (Pedlar & Hutchison, 2000). Disability-related supports and services, like many other publicly funded services, have had to provide service to growing numbers of people with minimal amounts of new funding from provincial and federal governments. As a result of the lack of formal supports, individuals have limited opportunities to experience community living and self-actualization. This shortage of supports and services is most relevant for people who have no family or other informal support as they often live in poverty and experience isolation, loneliness and boredom.

Moreover, the withdrawal of government responsibility for supporting people with an intellectual disability has placed greater expectations on families and communities to support individuals (Pedlar et al., 1999; Roeher Institute, 2002). In a study conducted by the Roeher Institute (2002), a number of parents reported feeling overburdened with responsibilities related to caregiving and employment demands. At the same time that governments recognize the importance of furthering equal rights for people with a disability, the lack of adequate funding for supports has made it difficult for people to realize this equality.

In addition to advocating for additional funding for disability supports, disability groups also support changes in service delivery that are more rights-based. These changes involve more individualized approaches to disability supports that promote person-centered planning and supports as well as a system of individualized funding where funds are transferred directly to individuals and families rather than agencies. Advocates of individualized supports and funding argue that this approach has distinct advantages for individuals and families over traditional services such as choice and control by individuals and families over the supports provided; the facilitation of relationships and community inclusion and the use of natural as well as paid supports (Roeher Institute, 2002).

CHAPTER THREE

Review of the Current Literature

Research in the area of intellectual disability has shifted its focus on biomedical concerns to a more critical approach to disability. This approach amplifies the voices of people with an intellectual disability and their families, understands their experiences, and recognizes how social, economic, and political factors impact upon these experiences (Rioux & Bach, 1994).

The following is a review of the literature that addresses three main areas: individualized supports and funding, factors affecting establishing relationships and the experiences of caregivers. Although not as prevalent as traditional supports, there are some individuals and families who have access to individualized supports and funding. In the following section, I review the current literature that examines people's experiences with this approach.

Definition of Terms

The terms person-centred planning, individualized supports and individualized funding are used throughout this case study. I will define each term in order to clarify and demonstrate the relationship between these approaches to supporting people with an intellectual disability and administering funding for these supports.

Person-centred Planning. The process of developing a life plan with people with an intellectual disability that focuses on their strengths, needs and interests. The planning process is based upon the principles of community inclusion, quality of life and a social model of disability (Circles Network, 2005). It is owned by the individual and involves people of their choosing such as family, friends, workers and service providers. The outcome of the planning process is a document called a Life Plan that describes the individual and their current life and outlines his or her goals for the future and the supports needed to achieve these goals.

Individualized Disability Related Supports. Individualized supports that are tailored to the specific strengths, needs, interests of individuals and are established to assist the person to meet the goals identified in the Life Plan. For example, a person receiving individualized supports would have access to support workers who would assist them in various aspects of their life such as personal or medical care, shopping or cooking, employment or volunteer responsibilities, developing and maintaining friendships and accessing transportation and leisure pursuits. Dunn (2003) states that "there are no common agreed upon definitions of personal supports" (p. 210) for people with a disability. Within an individualized support arrangement, the worker provides support to only one person at a time. This is in contrast to a group home or a day program which provides support to groups of people.

Individualized Funding. Money from government sources that is provided directly to individuals with a disability and/or their families to purchase the disability related supports they need. Individualized funding may or may not result in individualized supports and community inclusion as funding can be used to purchase a space in a day program or group home from traditional service providers. However, if the values and principles of community inclusion and self-determination are upheld by individuals and families, individualized supports are more likely to be purchased.

Individualized Supports and Funding

In Canada, access to individualized funding, where funding is transferred directly to individuals and families to purchase the disability-related supports and services they require, remains limited (Pedlar, Hutchison, Arai, & Dunn, 2000). Individualized supports, however, are more readily available, as many traditional service providers have taken steps to overcome the limitations of providing supports in congregate settings. Individualized supports are being implemented through person-centred plans in an effort to help individuals identify and realize personal goals that may not be achieved in a group setting (Mount, 1994). Despite the wide spread use of person-centred planning among service providers that focuses on the strengths of individuals with an intellectual disability and gives them a voice, there are often challenges to implementing plans. The organizational change that leads to person-centred supports does not always accompany the development of plans (Mount, 1994). In a British study of person-centred planning, Mansell and Beadle-Brown (2004) point to several areas of change which are needed to make traditional services more individualized. The authors' recommendations include establishing policy measures that place person-centred planning and supports as a top priority, training staff to facilitate community involvement for individuals, and focusing on evaluating outcomes for individuals. Furthermore, there is a need for direct individualized funding to individuals and families so that plans can be implemented and goals can be achieved (Emerson & Stancliffe, 2004; Mansell & Beadle-Brown, 2004).

Several studies with people with a disability and consumer/survivors in Britain and Canada demonstrate the advantages and disadvantages of receiving direct individualized funding to purchase supports and services. Individuals interviewed shared how direct payments increased the amount of choice and control over many aspects of their lives and the support they received (Ridley & Jones, 2003; Williams, Simons, Gramlich, McBride, Snelham, & Myers, 2003; Carmichael & Brown, 2002). Being able to employ their own support workers allowed them to choose who would provide them with supports as well as how the support would be provided (Carmichael & Brown, 2002). Furthermore, having supports that were separate from their housing gave them the opportunity to have more choice about where and with whom they could live. Support that was more responsive to their individual needs allowed them to work towards goals they had set for themselves and participate more in their communities (Pedlar et al., 1999).

Families of individuals with a disability spoke of how direct funding and individualized supports benefited the entire family as relatives were able to gain independence while family members were able to give up some caregiving responsibilities (Williams et al., 2003). Families also felt more control over the supports and services their family members were receiving whereas with more traditional supports the power lay more with service providers. Family members who were interviewed reported keeping the best interests of their family member at heart when assisting them to hire staff. Fears of family members having more power and input into decision making than the individual were balanced by the presence of a circle of friends who would ensure the focus individual had a voice. A circle of friends or circle of support is a group of people who come together regularly to help someone with a disability to realize their personal goals. "The circle acts as a community around that person (the focus person) who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help" (Circles Network, 2005). A circle may involve family, friends, service providers and community members who work together to plan with and support the person with a disability. Overall, participants who received individualized funding reported an improved quality of life both for the individual as well as the family members (Williams et al., 2003).

A commonly cited disadvantage of individualized funding among research participants of various studies was the amount of work involved in administering and managing the funds and being an employer (Roeher Institute, 1993; Ridley & Jones, 2003; Carmichael & Brown, 2002; Williams et al., 2003). Families indicated that in a strong economy, recruiting and retaining workers who are skilled and reliable can present a challenge, as funding for workers' wages is often inadequate (Lord & Hutchison, 2003; Carmichael & Brown, 2002). Managing support arrangements was further complicated when support workers quit or became sick as individuals and families often found themselves without supports and no alternatives for back-up (Roeher Institute, 1993). Furthermore, families and individuals indicated that continual reassessments and justification of the need for funding was a great source of stress (Carmichael & Brown, 2002). Despite these disadvantages, many individuals and families reported that the advantages of having individualized funding far outweighed the challenges (Carmichael & Brown, 2002).

The Canadian Experience

While many agencies that provide services to people with an intellectual disability in Canada are adopting more individualized planning approaches to meeting the needs of the people they serve, the opportunity for people to secure individualized funding is not widespread. Pedlar et al. (2000) found that program funding where funds were directed towards agencies and programs remains the most prevalent form of funding in Canada. Historically, individualized funding first appeared in Canada in the early 1980's in British Columbia as a response to the closure of the Woodlands Institution. The province of Alberta adopted individualized funding whole-heartedly as it was established as the primary funding approach for the province in 1990. In the early 1990's in British Columbia, microboards - non-profit organizations comprised of five to eight non-paid members - were established as legal entities to which government funding could be directed to purchase supports for an individual (Dunn, 1999). Hutchison, Lord and Salisbury (2006) discuss current and emerging North American approaches to planning and individualized funding that have proven to be successful in their most recent work

In Ontario, individualized funding is available to people with an intellectual disability through the Special Services at Home program funded by the Ministry of Community and Social Services and several pilot projects located in Windsor, Thunder Bay, Mississauga, and Toronto. For people with a physical disability who are able to direct their own supports, the Ontario Direct Funding Project started as a pilot project in 1993. It is now a permanent program funded by the Ministry of Health and Long Term Care and coordinated by the Centre for Independent Living in

Toronto (Ontario Federation for Cerebral Palsy, 2003, Dunn, 1999). Evaluations of these projects revealed favourable feedback from participants such as increased relationships, control over services, self-determination and community capacity. In the final evaluation report of the Individualized Quality of Life Project in Toronto completed by the Roeher Institute (2000), participants spoke of an increase in self-determination through the ability to exercise more control over their supports, establish a vision for the future, live independently from family members, and enhance relationships with others. Other benefits highlighted by people involved in the project were an increase in community participation and the ability to secure supports. Participants also spoke of the challenges they faced with individualized funding and supports such as the uncertainty of continued funding, recruiting, training and retaining support workers, as well as the additional responsibility of managing the individualized funds. Despite the success of the Special Services at Home Program and various pilot projects, individualized funding in Ontario is limited, as there is no policy that supports this approach (Ontario Federation for Cerebral Palsy, 2000). In fact, for people with a disability in Canada, even accessing basic personal supports has become increasingly challenging (Dunn, 1999).

Relationships

Relationships are an important aspect of the lives of people with an intellectual disability that is often overlooked. While it is widely acknowledged that relationships with others contribute to well-being, it is often not recognized that people with an intellectual disability have the same needs for intimacy and acceptance that non-disabled people do. This lack of recognition stems from misconceptions that people with an intellectual disability do not know how to reciprocate in a relationship (Roeher Institute, 1990).

A considerable amount of research has focused on relationships between people with and without disabilities. A study done by Roeher Institute (1990) identified that people with an intellectual disability have a desire to meet people and develop relationships outside of their immediate family, service providers and other individuals who have a disability, but they often faced barriers to realizing this goal. Being segregated in their living arrangements, day activities, and recreational pursuits often limits the opportunities people have to meet people who do not have a disability. In addition, lack of supports to facilitate and nurture friendships as well as the attitudes of community members towards people with an intellectual disability can inhibit relationships from forming (Luftiyya, 1997; Roeher Institute, 1990). Luftiyya (1997) argues that by recognizing the importance of friendship in the lives of people with a disability, providing the supports needed to promote relationships, and establishing integrated education and recreational opportunities from an early age, barriers to friendships with people without a disability can be overcome.

Critics of research on relationships between people with and without a disability state that an overemphasis on exploring these relationships shows a "lack of regard of the significance and worth of friendships between people with a disability" (Knox & Hickson, 2001, p. 287). In a participatory action study with people with an intellectual disability, Knox and Hickson (2001) discovered what participants considered to be important aspects of their friendships with other people with an intellectual disability. Friendships with others who also have a disability provided participants with security as they had known each other for many years and provided each other with mutual support. In addition, participants emphasized that they shared common interests with their friends who have a disability. The authors state it is important to listen to the voices of individuals to understand, from their perspective, who the important people are in their lives. When others decide with whom individuals with a disability should form relationships, their ability to exercise self determination is stifled (Knox & Hickson, 2001; Pedlar et. al, 1999).

Relationships between people with an intellectual disability and paid supporters have also been examined. Although strong relationships do develop between individuals and their supporters, there are concerns about power differences in paid relationships where the individual with a disability has more invested in the friendship than the supporter. Pedlar et al. (1999) discovered that genuine relationships are more likely to develop between individuals and supporters in more individualized support arrangements as individuals, family and friends have more choice and control over who is hired to provide support and the way support is provided. Furthermore, because supporters are only working with one individual at a time, closer relationships can develop.

How services are provided can also facilitate or inhibit relationships for people with an intellectual disability. The rigid policies and procedures of more traditional services can stifle relationships. Lack of privacy in group living arrangements along with little choice and control over daily routines leaves little opportunity to spend time with friends or family (Knox & Hickson, 2001). In addition, "the power that service workers have to support, enable or actively destroy individuals' relationships cannot be ignored" (Knox & Hickson, 2001, p. 289). Support workers who recognize the need for people with an intellectual disability to form friendships can be more effective in facilitating friendships rather than limiting their interactions to the person whom they are supporting (Pedlar et al., 1999). Families can also have an impact on the ability of individuals to make friends. Whether friendships are developed between people with or without a disability, family members are in a position to create opportunities for friendships to develop and nurture these relationships (Luftiyya, 1997).

Caregiving Experiences

Literature on the experiences of parents of children with an intellectual disability has often focused on the stress that parents experience as a result of caregiving. Kelly and Kropf (1995) refer to older caregivers as "perpetual and stigmatized parents" who as a result of many years of caregiving experience physical problems and emotional worries. Financial concerns as a result of additional costs associated with their child's disability are often a great source of stress. In addition, greater demands on their time as a result of caregiving as well as concerns about the child's future when they will no longer be able to care for them can contribute to the stress that parents experience (Roberto, 1993). Moreover, parents often have to contend with a service system that is lacking in resources and not responsive to their needs. Ongoing navigation of the service system and battles to secure much needed services are also cited as a source of stress in the lives of parents with a child with a disability (Kelly & Kropf, 1995).

Grant and Ramcharan (2001) responded to these findings by suggesting that families have been "pathologized" by research that solely focuses on problems and deficits. All too often, caregivers are seen as “victims trapped in their roles or obligated to support dependent relatives with little or no material and psychological support” (Grant & Ramcharan, 2001, p. 367). In studies completed by Mullins (1987) and Behr and Murphy (1993), a different side of parents’ experiences is revealed. Parents identified how the presence of a child with a disability contributed to their family life by improving family relationships, expanding support networks as well as strengthening their faith and tolerance. Overall, parents felt their lives had been enriched by having a child with special needs. Furthermore, the coping abilities of families are also ignored in research that emphasizes problems within the family. In his work with older caregivers, Tobin (1996) discovered how older caregivers tend to possess more knowledge and sense of control in their role as caregivers than younger parents.

From a social model of disability, Dowling and Dolan (2001) examined how social inequality impacts the entire family, not just the family member with a disability. From this perspective, it is not caring for a child with a disability that causes hardship for families, but the attitudes of society towards the family, inadequate supports and services, and barriers that limit opportunities. Parents interviewed in this study cited various barriers that contribute to the amount of stress they experience. In relation to formal supports and services, parents report a great deal of frustration when having to contend with long waiting lists and complex application requirements, which require continual re-application for funding and services. In addition, the ways in which services are provided do not always recognize the needs of family. Having a child with a disability often means that families must attend numerous appointments with health care providers and social workers, creating demanding schedules where the family is required to travel long distances. More often than not, services are provided in ways that meet the needs of providers rather than families as families are required to go to the service provider rather than having the service provider coming to families' homes (Dowling & Dolan, 2001).

Furthermore, primary caregivers, usually mothers, are often placed in a position where they must give up employment to meet the additional responsibilities they face in having a child with a disability. For example, in a study completed by Clarke, Fletcher, and Schneider (2005) with mothers caring for children with cancer, mothers reported the work of caring for their child both at home and in the hospital left no time for employment despite the need for this additional income. Not only do families have to live on smaller incomes, but also they are faced with meeting the additional costs associated with having a child with a disability (Kelly & Kropf, 1995).

In the late 1990's, a large number of Ontario families were overwhelmed with the stress of caring for their child with a disability at home and meeting associated costs with little or no government support. As a result, they turned to Children's Aid Societies for help. As a condition of providing supports, child welfare authorities insisted these parents falsely claim they were unfit to care for their children and turn over custody of their children to the state. Outraged by this condition, over two thousand families launched a class action law suit against the provincial government, suing them for millions of dollars (Philp, 2001; Greenberg, 2005). As a result of this lawsuit and an investigation by the Ontario Ombudsman, these agreements were reversed and custody was returned to the parents.

Dowling and Dolan (2001) recommend that policy measures should be taken to ensure that caregivers are provided with a wage to alleviate the financial stress that they experience. Overall, the authors point to the importance of how social, economic, and political factors need to be considered when looking at the experiences of caregivers and that the social model of disability should be taken into consideration when developing policy related to people with a disability and their families.

CHAPTER FOUR

Researcher Standpoint

As a researcher, my identity, standpoint and approach has primarily been influenced by feminism and my experiences working with people who have very little power in society. In my work and personal life, I live by feminist principles, as I struggle not only against sexism, but many other types of discrimination such as racism, heterosexism, classism, ageism, and ableism. Furthermore, I have always been conscious of my social position in relation to the people that I work with and this awareness influences how I approach my working relationships. In my role as practitioner, I recognized the power that I possess and I will continue to acknowledge issues of power in my work. I cannot change this power imbalance, but I can acknowledge its existence and use it in a way that benefits people who are marginalized rather than further oppressing them.

Central to my work was developing partnerships with people whose experiences and perspectives have been excluded from traditional research. By facilitating the involvement of the family in every aspect of the research process from the design to the communication of the results, I hoped to safeguard against the further oppression of people by sharing control and ownership over the process and results with those participating. In working with people who have a disability, I strived to conduct research that brings the voices of all citizens to the forefront and advocates for social change and equality.

My interest in and work with people with an intellectual disability has been long standing. It is my relationships with people with an intellectual disability and how they have shaped my life along with my belief in their right to social and economic inclusion that motivated me to use my thesis work to explore the experiences of a person with an intellectual disability, her family and friends. As a practitioner, I strived to support people with an intellectual disability to identify and pursue goals that relate to all aspects of life.

In my work, it was essential that I stepped back and listened to the stories and experiences of people with a disability and their families and not impose my own biases through my interpretation of what they shared with me. It was also important to explore with the focus participant and her parents what the focus of the research should be so that my work would be relevant to them. I presented my thoughts and ideas, but the final decision was made by the participants.

I also identify strongly with the critical paradigm in my beliefs about knowledge. I believe that knowledge is generated through the interactions of the researcher and participants. In order for the knowledge I gained about people with a disability to be valid, it was important to conduct a naturalistic inquiry into the experiences of the focus participant and her family. Given that people's realities are shaped by a historical context, it was important for me as a researcher to take into consideration the social, political, and economic factors that impact upon people with a disability and their families. I also feel there are limits to what I can truly know about the experiences of the individual and her family because I do not have a disability or a family member with a disability. It is my hope that my interpretation of the research findings is truly reflective of the experiences of the people I am working with. By pursuing research from a critical stance with people with a disability, I hope to raise awareness of the rights of people with an intellectual disability to equal opportunities and citizenship. I would also like to generate support for an intervention that promotes justice and inclusion.

CHAPTER FIVE

Methodology

Theoretical Perspectives and Values Underlying My Research Approach

As a Community Psychologist, certain values and principles such as holism, self determination, participation, accountability to oppressed groups, diversity, social justice, inclusion, ecology and empowerment guide my thesis work. Consequently, I felt it was critical to use qualitative research methodologies to explore the experiences of this individual and her family in accessing and maintaining appropriate supports to participate in the community. Qualitative methods are consistent with Community Psychology values as they represent a departure from traditional, positivist epistemologies and a shift towards social constructionism. This paradigm acknowledges the subjectivity and value base of research; recognizes the impact that social, political, economic and historical context has on the lives of people with an intellectual disability; as well as promotes collaboration between the researcher and participants (Banyard & Miller, 1998). Furthermore, qualitative methods, such as in-depth interviews and observation, allow the researcher to get a clearer understanding of the perspectives and experiences of participants as they "give to the research participant the power of self-determination and story-telling" (Clarke et al., 2005, p. 3).

More specifically, in considering a methodology that was most effective in understanding the experiences of the family I collaborated with on this research project, my primary focus was on case study research.

Case Study Research

The case study approach to research allows the researcher to gather in-depth information about an individual or small group that emphasizes the specific context in which that person or group exists (Yin, 2003). Stake (1995) describes this method as follows:

> A case study is expected to catch the complexity of a single case…We study a case when itself is of very special interest. We look for the detail of interaction with its contexts. Case study is the study of particularity and complexity of a single case, coming to understand its activity within important circumstances (p. xi).

In addition to allowing researchers to explore people and events in natural settings, case study research captures more accurately the actual lived experience of the participants as well as a more holistic understanding of people and how larger social, economic and political circumstances influence the actions of individuals (Orum et al., 1991).

Case studies have been criticized, as more traditional researchers see them as not generalizable (Yin, 2003). However, the main reason for conducting case studies is not to understand how different or similar it is to other cases, but to have a deeper understanding of the uniqueness of a particular individual or group (Stake, 1995). Stake (1994) argued that "damage occurs when commitment to generalize or create theory runs so strong that the researcher's attention is drawn away from features important for understanding the case itself" (p. 238). Yin (2003) furthered this discussion by stating the goal of case study research is not to generalize to populations, but to analyze and generalize to theories. The theoretical generalization that results from case study research gives it an advantage over quantitative research as quantitative research is primarily concerned with statistical generalization (Orum, Feagin, & Sjoberg, 1991).

Since I focused my research on a single individual, case study research was an appropriate method as it typically involves a small number of participants. In addition, conducting a case study has allowed me to provide a richer description of the participant in all aspects of her life, her experiences, and the experiences of her family with individualized community living supports and community inclusion. Furthermore,

> the growing interest in 'emancipatory research' and the development of qualitative case study research...has shifted investigations of disability towards an exploration of the lived experiences of disabled people within the developing policies and practices of inclusive communities (Johnstone, 2001, p. 122).

Overall, the goal of my thesis work was to advocate for social change for people with an intellectual disability. As a result, the findings of my research will be used by a local organization to support their discussions with decision-makers regarding the needs of individuals with a disability and their families and the merits of individualized supports. I hope that this awareness will encourage decision-makers to develop creative solutions to the problem of disempowering community living supports for people with a disability.

Sampling of Participants

With the knowledge that I wanted my thesis work to benefit people with an intellectual disability, the connection to the family who worked with me came through a faculty member who also has an interest in people with a disability and the issues they face. It was important in approaching potential participants that they would be open to sharing their stories and experiences and that somehow the research would be of benefit to them. After getting to know the family, it was clear that they felt comfortable with working with me and that their unique experiences, circumstances, and knowledge of important issues would further knowledge in this area. In addition, the family saw how the research could also be of benefit to them and perhaps others who are in a similar position. Patton (2002) identifies this type of sampling as intensity sampling which he defines as "information-rich cases that manifest the phenomenon intensely, but not extremely" (p. 243). Stake (1995) emphasized that cases should be selected on the basis that they broaden what can be learned. It was clear to me upon meeting this family that they met these criteria.

CHAPTER SIX

Gathering and Analyzing Information

Methods for Gathering Information

Upon first meeting the family, I spent time with them both in Hope's (the focus participant) home and their family home where I learned more about the journey that had led them to their current situation. The time I spent with the family listening to their story was critical, as it helped me to understand what they saw as their most pressing concerns and goals. Based on this information, I was able to provide the family with a small list of suggested topics which my thesis work could focus on and could also result in social action. The family felt that it would be important to examine their experiences with individualized supports with the eventual goal of submitting a proposal on their daughter's behalf for individualized funding.

Once the focus of my thesis was established and additional participants were identified by the family, I primarily relied on in-depth interviews with the focus participant's family members, support workers, employer, and service providers. In total, seven interviews were conducted involving three siblings, two service providers, one support worker and one employer. Each interview was conducted in person on an individual basis. I used an interview guide (see Appendix A) to give the interview a focus, but also allowed for the discussion to be spontaneous and conversational. The interview questions were developed to meet the objectives of the study and with the purpose of the study in mind. All of the questions were open-ended, went from general to more specific and were intended to gather historical as well as current information that answer the research questions (Wellesley Central

Health Corporation, 2004). During the interviews, the information that participants provided helped me to develop additional questions in response to specific perspectives or ideas that they raised.

Interviews were audio-taped with the permission of the participants. Minimal notes were taken during the interview and I set aside time after the interview to record in further detail the key thoughts, ideas, and meanings of the person interviewed and interpret the information provided.

In addition, I was able to spend time with Hope in a variety of settings in the community. Overall, I spent a total of nine hours over a period of two days with the Hope and her support worker. I accompanied them to a community garden club, the nursing home where the focus participant volunteers, her co-op home, and on her Meals on Wheels delivery route. These experiences allowed me to be more familiar with the people and places outside of her family that are central to her life.

Lastly, with the help of her support worker, Hope took a number of photographs to create a personal portfolio of favourite people, places, and things in her life. With the family's permission, I used these photographs as a way of including Hope's voice in the thesis document. I chose to use this method of gathering information rather than conducting an interview to avoid placing pressure on Hope to respond to questions which may have caused her unnecessary stress.

Analysis of the Information Gathered

Once I completed the tape-recorded interviews, I transcribed each conversation. Before the analysis of the information, each person received a copy of the transcript from his or her interview so that I could obtain feedback on the accuracy of the script. Since the research was inductive, I gathered information through open-ended questioning that allowed themes to emerge naturally (Patton, 2002). The analysis involved reviewing all the transcripts and identifying points that were mentioned frequently. Based on these reoccurring points, I developed categories or codes and organized the points according to each category. I also included the notes from the observation days into these categories. From those categories, I identified larger themes that grouped the categories together. My original research questions guided my work during the analysis phase, as my original theoretical proposition "helped to focus attention on certain data and ignore other data" (Yin, 2003, p. 27). In order to ensure credibility of the data analysis, I sought feedback from Hope and her family on the themes that I had developed. During the analysis of the photographs, I made descriptive notes and reflections on each photograph which provided the basis of my findings in this area.

Verifying the Trustworthiness of Information Gathered

In order to verify the trustworthiness of the data, I adopted four approaches: triangulation, member checks, thick description, and an audit trail. Triangulation is the process of collecting data from a variety of sources and through more than one method (Patton, 2002). I achieved triangulation by spending time with and interviewing Hope and her parents as well as siblings, friends, support workers and service providers. I also used a variety of methods of gathering information to achieve triangulation. The methods used were interviews, observation, and examining photographs.

The trustworthiness of the data was also verified through member checks. Member checks involved requesting feedback from the participants during the research process including the development of the proposal and reviewing of transcripts as well as rough drafts of the actual thesis paper. Furthermore, by obtaining a thick description of the experiences of the participants, the audience can determine the ability to transfer the results to other situations and contexts. Lastly, I maintained a record of the research process in order to be more prepared to answer questions about how I arrived at certain conclusions. A record of the research process was achieved through journaling and maintaining a clear coding scheme during the analysis of the data (Wellesley Central Health Corporation, 2004).

CHAPTER SEVEN

Ethical Issues in this Research

As a researcher, it was critical that I ensured there were very few risks involved for the participants. A collaborative approach made the research process more transparent to the family as they were partners in the research process. Feedback and approval was sought from the family once partial and full drafts of the thesis paper had been developed. Decisions about how to best communicate the findings of the research will be made jointly with the participant and the family. In addition to providing each participant with a copy of the thesis document, I will also invite him or her to a debriefing meeting where I will share the results and answer questions.

Furthermore, prior to beginning any interviews or observations I ensured that each person involved was fully aware that they were being researched, the nature and the purpose of the research and that all data collected would be shared with the participant and her family. I asked participants to sign a consent form, which informed them that they were not required to respond to questions with which they felt uncomfortable and that they could withdraw from the research process at any time. Consent to speak to third parties was also requested from Hope. To reduce the risk to participants of being exposed to negative comments from other participants, I discussed my concerns with the family regarding the possibility of this occurrence prior to conducting the interviews.

I protected anonymity and confidentiality through a variety of measures. I changed names within the thesis document to ensure that participants remained anonymous. Furthermore, any information that was shared with me by participants was not shared with others. Tapes and transcripts were locked in a secure drawer. In addition, I assured participants that I would be the only person to hear the tapes and the family and I would be the only people to read transcripts. I also erased interview tapes once they were transcribed.

Lastly, from my perspective, working with one individual and her family rather than a large number of participants allowed me to establish closer relationships. Rather than being a detached observer or consultant, I feel it was my role as a researcher to work in partnership with the family and become an active and contributing member of an already knowledgeable and committed support team. As a member of a team working on behalf of Hope to ensure she has a more secure and positive future, I saw myself more as a concerned community member and fellow citizen rather than a service provider or professional. In circles of support, Mount, Beeman, and Ducharme (1988) refer to what is called interdependence among people, rather than dependence or independence, where it is important to nurture people and relationships so that everyone is engaged in mutual support. In addition to supporting the focus person to realize her goals, a circle also provides support and a sense of community to all of its members.

CHAPTER EIGHT

Findings

Table 1

Findings from Case Study of Individualized Supports

Themes	**Sub-themes**
Looking to the Past to Understand the Present and Guide the Future: Hope's Life History	
A Profile of Hope's Individualized Supports	***Flexible Support Means Choice and Control*** ***Belonging to a Community*** ***Focus on Support Workers*** *Relationships with workers* *Recruitment, training and retention of workers* *Roles of workers* ***Parent Experiences*** ***Sibling Experiences*** ***Challenges of Individualized Supports*** ***Hope's Photo Voice***

In order to provide some insight into Hope and her family's current situation, I will begin the findings section with a history of important life experiences that have influenced their decision to pursue individualized supports. This history will be followed by a profile of Hope's individualized supports as well as the benefits and challenges that individualized supports present to Hope and her family.

Looking to the Past to Understand the Present and Guide the Future: Hope's Life History

Hope was born in a small city in Ontario in 1969, the second oldest child of Judy and Allan. Judy and Allan were busy in those days caring for Hope and her older sister and trying to establish themselves as a young family. When Hope was around six months of age, Judy noticed that she was not developing as quickly as other infants her age. After determining that Hope had an intellectual disability, Judy and Allan sought professional help to develop a therapeutic program that would give her the best start possible. As a preschooler, Hope attended a segregated day program for children with developmental challenges. At the age of six, Hope went to live in a large institution for people with intellectual disabilities which was outside of her home community. When Hope turned ten years old, her parents advocated for her to move to a group home in a nearby community so she could be closer to her family. At the age of thirteen, Judy and Allan made the decision that Hope should come home to live and, once again, advocated for her return to their family home.

During this time, Judy and Allan became very active in the community-living movement for people with a disability and were members of local, provincial and national associations for community living. In addition, they were among a group of parents who founded Organization B, a grassroots community organization committed to developing friendships and community connections for people with a disability. With a desire to have Hope attend her local school, they joined together with other parents to advocate for the integration of students with special needs into the school system. Their efforts in this area were successful and Hope began attending a regular high school at the age of seventeen after being at a segregated school for many years.

Hope was close to graduating from high school when she began to experience challenging behaviours, so much so that the school indicated that she could no longer return. Judy and Allan felt strongly that Hope should remain in school until she was twenty-one and negotiated successfully with the school to provide funding for a part-time support worker so she could continue to attend. The family was able to secure the services of Organization B to administer the funding for the support worker contract.

As Hope was about to leave the school system and make the transition into adulthood, Judy and Allan started to envision a life for Hope where she could live more independently from her family. They began to work alongside other parents in an effort to establish group homes based on a family-style model that would provide independent living opportunities for their adult children. Their efforts proved successful as Hope had the opportunity to move into a newly established group home several years later while continuing to receive individualized support during the day time.

Unfortunately, Hope found it very difficult living with other individuals with a disability who needed a great deal of support. She experienced a lot of anxiety in this situation which contributed to her having many outbursts. It was not long before the support workers felt they could not manage to support Hope along with the other individuals living in the home.

In order to find an alternative living arrangement for Hope, Judy and Allan worked closely with Organization B. She soon moved into her own place in a co-op housing community with a live-in support worker. This living arrangement, along with the individualized daytime supports, met Hope's needs effectively. Hope developed a good relationship with her live-in support worker and became an active member of the co-op community. After years of living with Hope, the worker left his position to pursue other opportunities. Despite efforts to secure a replacement worker, no one was found and Hope returned home to live with her parents.

During this period, Judy and Allan faced additional challenges, as they were informed by the government that Hope had to attend a segregated day program, as the funding she was receiving for her support worker was being withdrawn. Hope started attending a local day program which gave her very little opportunity to continue with her volunteer work and community activities, as she was expected to take part in the activities of the day program. The staff did not have the flexibility to support Hope to pursue her interests, as they were supporting so many other individuals.

Hope began having difficulties managing in this setting as it was difficult for her to adjust to being with so many people in such close quarters. Not all of the individuals respected Hope's need for personal space. This created a lot of anxiety for

Hope which led to physical outbursts. Staff at the day program found it difficult to support Hope during these times. As a result, Judy and Hope's support worker Colleen would often have to come to the program to assist. Eventually, those involved recognized that this setting was not meeting Hope's needs and interests and the program staff was not able to manage when Hope acted on her anxiety and frustrations.

Two years later, another live-in worker was found and Hope returned to her home to live. After a few months of living in her own place, Hope began to experience severe anxiety and behavioural difficulties which led to a mental health crisis. During this time, Hope could not continue with her regular routine. Getting out of bed and dressing was difficult as she needed more sleep. She often found it challenging to leave her home, even to be with some of the support workers she had known for many years. Hope increasingly looked to her mother for comfort and security and became quite attached to her. As a result, Judy moved in with Hope to provide her with support during this challenging time. Hope began seeing a psychiatrist in her community, but Judy continued to search for a psychiatrist who would better understand Hope's needs. Through another family connected with Organization B, Judy heard about a psychiatrist who specialized in working with people with a dual diagnosis of an intellectual disability and mental illness. This proved to be a good resource for Hope and her family, as he was able to help her manage her anxiety and depression through medication and consequently lessen her outbursts. Hope ended up going back to her parents' home to live. It has been two years since Hope moved back home and began treatment for depression and anxiety.

Emotionally, she has come a long way during that time. Judy will often say, "it is nice to have the old Hope back again," as she is finding joy in the things that were so much a part of her life before she fell into a depression.

With the latest crisis over, Judy and Allan are starting to think about planning for the future. As older parents, they feel it is critical to ensure that Hope experiences happiness and security in her next home. Having experienced a great deal of success with the individualized supports she receives during the daytime, Judy and Allan would like to ensure that Hope's home support is also individualized to best meet her needs. While the future remains uncertain, there is a great deal of positive energy among Hope's family.

A Profile of Hope's Individualized Supports

At the age of thirty-six, Hope is living with her parents in the home in which she grew up. Despite the mental health challenges she has faced, her parents have encouraged her to stay active and involved in community life. She has a busy and varied weekly schedule and receives one-to-one support from her worker Colleen with her daytime activities and responsibilities. Hope spends every other weekend with her support worker Jane at her home and on Wednesday evenings she has dinner with her support worker Tracey. The remainder of the time she is supported by her parents.

All of her workers have provided her with support for a number of years. They are employed by Organization B which is a government funded organization that is committed to enhancing well-being for people with developmental and physical disabilities. The workers are recruited, hired and paid by Organization B, and they receive direction from Organization B as well as Hope's parents.

Flexible Support Means Choice and Control

In determining why Hope has experienced success with individualized supports, participants interviewed frequently spoke of the flexibility of the supports as being an important factor. With her current support arrangement, Hope has a lot more say over what she does at any given time. Unlike a traditional day program where the participants are expected to adhere to a set schedule and accommodate the needs of other participants, Hope has more choice and control over her daily life. Having these feelings of control over her environment is essential in maintaining a sense of empowerment and mental well-being for Hope. A support worker shared her experiences of how this flexibility of support has been important.

> *I think for her (Hope), it is such a benefit, just the flexibility. And on days when she is not in the mood to do something...when you don't have other people to worry about it's easy to say okay we are not doing this today because it is just going to set her up or it is not going to be a good situation, we will do this or we will keep it low key. So, for her, that is the biggest thing.*

Many of the participants felt this flexibility was particularly important given that Hope experiences a great deal of anxiety and depression which can make it difficult for her to be in social situations and participate in her regular activities. On the day I joined Hope and Colleen when they had plans to go to the gardening club and volunteer at the nursing home, Hope became quite upset as she wanted to stay at home. After having some time to relax and with some encouragement from Colleen and her mother, Hope changed her mind and decided to go ahead with the plans for the day. Since Colleen did not have to be concerned with supporting other individuals or following a rigid routine, she was better able to respond to Hope's needs and support her to have a choice about what she would do that day. Consequently, these feelings of control helped to lessen her anxiety so she was able to continue with her original plans. One service provider emphasized Hope's need for this flexibility by stating:

> *Hope needs a day program that is flexible enough to shift to accommodate her changing needs. So if Hope is having a bad day or she is not feeling well, or if she is really anxious, you know they can watch a movie. If she is doing better, they can run errands or whatever, so it is the flexibility.*

Furthermore, the flexibility of the individualized supports has given Hope the opportunity to participate in activities that are more meaningful to her and to have more variety in her days. It was clear that any activity that Hope was involved with was shaped around her personal interests, such as spending time with seniors while volunteering at the nursing home and with Meals on Wheels. Hope's sibling made this observation about her supports:

> *Once the funding was in place, you could personalize things. It was a combination of things that that helped to figure out what to do, but the important thing was that there was somebody there to do things with as opposed to sitting around in a centre doing nothing all day.*

On Tuesdays, Hope has many things which she is involved in. She starts her day with the gardening club, volunteers at the nursing home, and then goes for a brisk walk at the local sports facility. It is this variety that also meets Hope's unique needs:

> *...I also think that with her concentration and her focus on certain tasks and activities, because she can't stay with one thing for very long, she needs that flexibility. If she is done with one thing, she can go off and do another thing.*

People who have known her for a long time can see how individualized supports have contributed to Hope's well-being. Since Hope is not always able to talk about how the supports have made a difference to her, those who know her well have found other ways to determine how individualized supports have had a positive impact on her life:

> *It (an individualized day program) certainly seems to meet her needs really well. And one way we can assess whether or not its meeting Hope's needs is by the kinds of behaviors we are seeing from her...when she is under stress, she gives really clear indications and you can read it in her behaviour. There are specific behaviours that she engages in...So the presence or absence of these behaviors acts as a barometer of how well she is doing. Currently the absence of those behaviours would seem to indicate she is doing fairly well.*

From an administrative and management perspective, a local service provider discussed how Hope would further benefit if the funding she received was individualized along with her supports:

> *...if it (Hope's funding) was individualized funding, then I think the administration of the funding would be different in terms of it could be held by an agency and administered totally by the family...somehow they'd form a committee or circle...on Hope's behalf so that they could work out how things were going to be funded and what the plan would look like to support her.*

With this approach, the people closest to Hope, guided by her needs and interests, would have the flexibility to use the funding in a way that most benefits Hope. As it stands, Hope's funding remains connected to an established program.

Belonging to a Community

In1972, a Canadian sociologist named Wolf Wolfensberger released his book *The Principles of Normalization* which emphasized the importance of supporting people with intellectual disabilities to have life experiences that were comparable to others who were of the same age and gender. Wolfensberger's work had a great impact on how services were provided to people with an intellectual disability. The emphasis on the segregation and institutionalization of people with disabilities gave way to supporting individuals to have more typical lives through community integration and playing valued social roles.

During my discussions with the participants, it became evident how individualized supports have made it possible for Hope to participate more fully in the life of the community and take on different roles in her life. Participants often spoke about the importance of Hope living a life like most thirty-six year olds by being supported to live independently from her parents.

Although traditional services such as group homes also provide people with disabilities the opportunity to live independently from their families, individualized supports make it possible for people to choose where and with whom (if anyone), they would like to live and have a home to call their own. One participant gave more insight into Hope's experience with an individualized approach to independent living:

> *When she was living independently, when that situation was working, it was nice because she is so proud of having her place. We go to her house, it is her house, it is not mom and dad's, it is not Moore Crescent. She could talk about that and things she did at her house, like her T.V., her stuff. I think that is very important to her.*

Living in a co-operative housing community, Hope was initially an active co-operative member:

> *I think that Hope has become a part of her community. She is part of that co-op community, people say hi to her. When she is well, she walks around the community, she used to go and sit by the playground and watch the children playing. She has become part of that community. I think that is an important piece.*

In addition, individualized supports have enabled her to be included in her community as a volunteer and employee. Hope has been a volunteer as a friendly visitor at a nursing home and a delivery person for a number of years. She also works one day a week at a church folding bulletins. On my visit with Hope and Colleen, I had the opportunity to see Hope volunteering at the nursing home and delivering for Meals on Wheels. Hope appeared happy and comfortable in both settings. At the pick-up point for Meals on Wheels, there was a team atmosphere among the staff and volunteers of which Hope and Colleen were definitely a part. Hope appeared to enjoy visiting the seniors who lived in the nursing home and who were on her Meals on Wheels route.

One participant emphasized how Hope's support arrangement, contrasted with a traditional day program and was more effective in facilitating her inclusion in the community:

> *Hope and Colleen were going to Meals on Wheels and visiting grandmas at nursing homes and they were doing all these things, well I had to work with ratios of four to six people, so I didn't have that flexibility.*

Participants also cited the many advantages of Hope's community involvement such as having acquaintances. Hope's support worker spoke about how connections with other people had materialized:

> *When she (Hope) would do bulletins, she always stopped at the mall to talk to the lady in the card store. I used to take her to the library. There was one woman that she would never leave the library until she got a chance to talk with her. She makes little connections in different places she goes, Meals on Wheels and where she does her bulletins...I know the one woman at the library always says "she always makes my day."*

The opportunity to develop skills and be more involved with the life of her family was also seen as an advantage of Hope having one-to-one support to participate in her community. Hope's siblings discussed how being supported to participate in the community has helped Hope to acquire new skills:

> *The advantages (of individualized supports) are that she can live a life comparable to everyone else. When she was living in a group situation, it wasn't like that at all. Her ability to socialize and learn appropriate skills for socialization and becoming involved in the community there wasn't the same opportunities for her…*
>
> *Her (Hope's) ability to communicate with others and interact with other people is enhanced significantly because of her supports. And the fact that she is involved in the community and doing things and spending time with everyone and being a part of the community and a part of a family…*

Supported employment has also provided Hope with the opportunity to participate in the workforce and receive some compensation for her work. Not only is she able to lead a life more like a typical thirty-six year old, she is also able to have contact with other people other than her family members and provide a valuable contribution to the work of the church. Hope's employer at the church shared her perspective:

> *I think it is important for her (Hope) not to be sitting watching T.V… it is really good for her to interact with the community. I think it is really good for the community to interact with her…In terms of being like me, I come to work and I get a paycheque at the end, Hope gets a symbolic paycheque. I like that part of it, to feel like we are being fair to her. I think it is really important for people like Hope to have meaningful work, to the best of their ability.*

With individualized supports, Hope has been able to take on a variety of valued social roles. Now she is an employee, a volunteer, a friend and an acquaintance. She is a member of the gym, the library, and a housing co-operative. As a daughter, sister and aunt, she is more involved in the life of her family. However, as Hope's support worker pointed out, these roles and connections cannot develop without the support:

> *I think that the important thing is that she makes connections and the supports are there, but they just don't happen overnight. It is kind of a work in progress…I think it is amazing…the supports are in place and everything to make it successful…She (Hope) is such a highly anxious woman, it could*

> *easily be that she wouldn't be successful in the community, but she is and she has great connections and has done things.*

Furthermore, Hope's service provider emphasized how these supports are critical to ensure a certain lifestyle:

> *Hope's independence is always connected with someone supporting her...Hope's independence requires a support worker, but that is Hope's independence...And she is able to move away from her family because of her support. I think for Hope, her adult life depends upon helping her to get these supports.*

Focus on Support Workers.

In hearing Hope's story, it was evident that Hope's support workers play a critical role in ensuring her success. In this section, I will discuss themes that emerged from my discussion with participants, primarily the role of Hope's support workers, relationships with workers, and issues around the recruitment, training and retention of support workers.

Relationships with workers.

Hope has worked with her support workers Colleen, Linda, and Tracey for many years. Their continued involvement has given Hope continuity in the support she receives and a sense of security. Participants emphasized how having long term workers has impacted on Hope's well-being and involvement in the community:

> *I think certainly Colleen has been involved with Hope for a number of years, so they have developed a really close relationship and that benefits Hope and her ability to become involved in the community is really dependent on those supports and people to be able to assist her with that.*
>
> *I think it is a comfort level of who she is with. She knows Colleen is there (at Meals on Wheels), she is not going anywhere. She can wander off and go and talk with John who is going to be leaving for a delivery while Colleen has the bags to deliver the meals...She has had this comfort level which she may not have had a few years back.*

During the time I spent with Hope and Colleen, the rapport Colleen had developed with Hope was evident, as she understood Hope's needs really well and encouraged her to actively participate in the community, but always respected her feelings and choices. If Hope expressed any hesitation about participating, Colleen would remind her of the reasons why she typically enjoyed a certain activity. If Hope still resisted, she would suggest alternative things they could do that would Hope would feel more comfortable doing that day.

In Hope's circumstance, the involvement of the support workers often goes above and beyond their professional role. Hope's support worker Tracey spoke about her involvement after Hope's mental health crisis.

> *I decided that I would still come once a week even though I would be there with her (Hope) and her family. She wouldn't stay with me alone, there just wasn't that comfort level. So, up until just a few months ago, I have been going just strictly having dinner with them. I wasn't on the time clock I guess you could say...*

A service provider shared her observations:

> *Hope has developed friendships with people who have supported her in the past. People will often send cards and visit. When it is a good fit between the worker and Hope, it actually fosters a friendship.*

Hope's workers have also broken down professional barriers by connecting her with their own family and friends. These connections have helped to enhance her relationships with workers and broaden her social network. A local service provider spoke of the importance of this openness:

> *She (Hope) responds very well to people who, once the know Hope and once she knows them, when she has developed a level of trust over her own time, she responds very well to people who will embrace her into their own circles. ...Her previous worker who lived with her for seven years, Tom, he was very ...easy going. Hope just loved that. And you know he had a circle of friends who would pop in and Hope was just involved with everything.*

While many participants felt that it was very important that workers having a personal connection with Hope, they also expressed the opinion that there were times when maintaining some professional distance was more advantageous. Hope's sibling made this observation about support workers:

> *I just see them as being somewhat removed from her family and friends, someone who can be a little bit more professional when the time comes. And I know as a sibling, sometimes it is different for me going out with Hope and doing things with her than it has been for me in a working role, I have worked as a support person for someone else in the past. And it was totally different being in different roles for me rather than being in a sibling role. So, I think just having that little bit, although they are close to each other, Colleen, Jane, and Hope, they have that relationship, they are still paid people. I think it is different, there is a different relationship there.*

Recruitment, training and retention of workers.

Issues surrounding the recruitment of support workers arose often among participant responses. Many participants emphasized the importance of ensuring that workers develop a rapport and take a certain approach to working with Hope:

> *...when any new support person comes into Hope's life, they make a point of getting to know her on a personal level. Not as an authority figure, if people start coming in and laying down the law with Hope, then she gets defensive and she rebels...because she doesn't trust them. So that individual, personal relationship with the support workers is absolutely crucial for Hope.*

It was evident from the interviews that the recruitment of workers does not come without challenges. Workers who have some knowledge and experience working with people who have an intellectual disability and a mental illness, and who have a more democratic, respectful approach to working with individuals are hard to find. One participant attributed this lack of qualified workers to the way that people who are entering this line of work are trained and educated.

A service provider spoke about the challenges that have been faced in finding workers who are willing to connect with Hope on a more personal level:

> *It's very difficult because what we are trying to recruit here are people who will go the extra mile. And everyone has to feed their family and everyone has certain bills and commitments to meet and also timelines to meet as well. That is very difficult to recruit for because... it is very difficult to say to people, well, " you really need to go the extra mile" type of thing.*

Furthermore, participants pointed to additional challenges faced by individuals and families in their efforts to recruit support workers. Often times, support workers are underpaid and devalued, making it difficult to attract people to this line of work. One participant stated:

> *I think that probably the job itself doesn't have the pay or status it deserves in terms of the value of the work. I think that is probably a barrier (to finding support workers).*

Finding individuals who are interested in being live-in support workers was also seen as a challenge by a service provider:

> *I think it is difficult finding anybody that wants to move in, you know, it's a challenging role. And I guess another piece is that you know that's the kind of role that might fit will for support people or caregivers when they are in a transitional part of their life, but, I mean is that a lifestyle that people want to maintain long term? So, I don't know it's difficult.*

With regards to retaining workers, there was a strong emphasis on finding ways to support the supporters. A sibling felt that since individualized supports were less structured, both an advantage and disadvantage of individualized supports, supporting workers was more critical:

> *I think fewer people become more valuable in the role that they play. I think the way you probably need to work to get around the disadvantage is to really support the people in the individualized program who are providing the support. That you really need to find out what they need in order to best make it work for them.*

After spending time Hope, her family and support workers, it was evident to me how much the family had a role in providing this support and facilitating relationships through their positive interactions with workers. One support worker shared her experience:

> *I can speak for myself. Would this be so successful with Hope and I if I didn't have a bond with the family too?... It is kind of that whole picture, it is Hope and her family. They are such good people and they are good to everybody around and you know they appreciate everything you do for them which just make it all the more strong.*

In Hope's circumstance, her parents play a significant role in ensuring that workers understand their roles and responsibilities and the best approach to supporting Hope. While workers may come with their own qualifications and experience, they spend a considerable amount of time with Hope establishing a relationship. Her parents are role models to workers as they have a strong presence initially. In time, their involvement decreases as trust is established between Hope and the worker and the worker learns how to best support her. In addition to learning the clinical approach which was developed by a behavioral therapist in collaboration with the family, workers are also introduced to the philosophy of community inclusion and respect for all people which guides their work. These values are instilled through their involvement through Organization B and influence from the family. As one service provider observed, "*having the philosophy to start with creates fertile ground for training.*"

Role of support workers.

People who are paid to support Hope have many roles that they play. In Hope's specific circumstance, there is a high expectation that workers will be community connecters. In this role, they facilitate opportunities for Hope to participate in the life of her community and meet other community members. For Colleen who supports Hope with her daily activities, this is a large part of her job. At the nursing home and Meals on Wheels where Hope volunteers, Colleen would encourage interactions between Hope and the seniors. On her Meals and Wheels delivery route, Hope had developed a closer relationship with one woman in particular. When she became ill, Colleen supported Hope to connect with her friend during this difficult time by ensuring she had the chance to visit her in the hospital. In addition, Jane, Hope's weekend worker, has supported her to broaden her social circle by introducing Hope to her family members. The support worker's role as a connector is critical, as Hope not only needs support to meet people for friendship; she also needs someone who will help her to nurture her friendships.

Furthermore, Hope's involvement in various activities in the community would not be possible without the support of her workers. The worker ensures that Hope has the transportation she needs to get to her destination and assists her to complete the requirements of her paid and volunteer work such as folding bulletins and delivering meals. Hope's employer expressed how this arrangement has always been successful during her time at the church:

> *Hope could not do it without the support. The worker and Hope, it is their job to complete the task...Times when Hope has not been well enough to come, the support worker has always done the job.*

One support worker interviewed felt that the time that she and Hope spent together was much more relaxed. It was more about having fun doing things they both enjoyed and giving Hope the chance to be with people her own age and have new experiences. She spoke about the rapport she had developed with Hope:

> *I was doing her hair and make-up. People were asking me "you put make-up on her? You curled her hair? You blow dried it?" They couldn't believe that she was allowing somebody to do this with her.*

In addition, the support worker ensured that Hope remained connected with her home. Although she is living with her parents, Hope and Colleen make weekly visits to the co-op. Colleen prepares lunch and assists Hope with chores around the townhouse. When Hope was living independently from her family, it was the live-in worker who would support Hope with daily living.

Family Experiences

Hope's parents, Judy and Allan, are very involved in Hope's life. In addition to being Hope's primary caregivers, they are her strongest advocates. Many participants spoke about how their support and advocacy efforts have been critical:

> *They (Judy and Allan) are pretty knowledgeable and will get the information they need, they are pretty creative. They have, to a large extent, driven any movements toward a better life for Hope. They do what they need to do.*
>
> *I have always said, even when I was working at Agency A, if people had even half the support network that Hope has, they could do anything, but you just need really strong advocates and Hope has that.*

Since establishing an individualized program for Hope, Judy and Allan have faced many barriers to maintaining this arrangement as funders have not been supportive of individualized supports. This resistance from funders and agencies in their community that provide supports to people with a disability has created a great deal of stress for Hope's family as they are constantly fighting to protect what they have already established and enlist the support of service providers. Hope's sibling spoke about how individualized supports and funding have been an option of last resort:

> *It feels like there have been so many attempts, let's try this, it fails, let's try this. I think the thing that has upset me about what has taken to get to this place is that it has been a matter of you need to try the standard routes and see that they fail before a person actually gets individualized supports.*

Having individualized supports has created additional roles and responsibilities for Judy and Allan. In contrast to traditional support arrangements, they have more input into the hiring and training of workers and are responsible for supporting workers. As a result, there is more collaboration between family members and service providers in order to support Hope effectively. In addition to participating in support worker interviews, Judy and Allan also work closely with the behavioural therapist to develop a crisis prevention and intervention program and were instrumental in establishing her community activities and independent living arrangement in partnership with the support workers and Organization B.

Judy and Allan have always monitored Hope's support arrangement very closely during both stable and unstable times. This role has been ongoing over the years. Judy and Allan's daughter shared her thoughts around this reality:

> *Certainly when things are going well, I know my parents worry about it just because Hope is such a vulnerable person and they're constantly looking for signs because Hope can't always tell us straight out what's going on or she is not happy...so the constant vigilance of making sure that everything is okay and that can be a very draining role to be in...*

When Hope's funding was withdrawn and she was forced to attend a traditional day program, Judy's monitoring role intensified in order to solve problems that arose in that environment:

> *I think she has gotten by in some of those other programs and approaches with a heck of a lot of behind the scenes work on the part of, well mostly, my family. The Agency A program for example…it was a disaster…the lid was kept on enough it wasn't blowing up everyday. That was maintained with a lot of energy on the part of my mom, on the part of Hope's support worker who would be there to trouble shoot at pick ups and drop offs…*

During the most recent crisis when Hope's live-in support worker left and a replacement could not be found, Organization B, the primary service provider involved with Hope, increasingly began to rely on Judy and Allan as back-up support. A service provider shared her perspective:

> *So I think when the support started to deteriorate, that had a huge impact on the family…I guess the external supports were breaking down and not being as effective, parental support started to shore up more and become more important…And I think we got to stage where we sort of hit a crisis level and then really most of the decisions…like her day to day living decisions were totally out of our realm now. We were no longer an agency and support people making any of those decisions with Hope. It was really totally up to the family.*

In looking to future plans to maintain and expand on Hope's individualized supports, Judy and Allan will continue to play a very central role in the co-ordination of these supports. In addition to planning, they will also continue to be involved in the implementation of the plan, monitoring of the support arrangement, and stepping in as a back-up in the event the arrangement does not work out, roles they have always played.

While Judy and Allan are committed to taking on these roles as long as they are able, other family members expressed concern about who will take on these responsibilities when they are no longer able or here to do so:

> *…it just worries me the amount of time and energy…that my mom spends worrying and problem solving…it's a huge amount of positive energy, like trying to problem solve and support whoever is supporting Hope. That's a*

> *full time job. She's very central…I know there will come a time when she can't continue in that position, will there be somebody who can do all of that, it's hard.*

Despite the additional roles Judy and Allan play in ensuring Hope's supports are effective, they experience time away from caring for Hope when she is able to stay with her support worker on alternate weekends. Hope's sister shared her thoughts:

> *I will often say to John on the weekend… this is a Hope weekend. So my mom and dad will be able to do whatever. So, I will actually think about what they are doing and if they are having time to themselves or not. When we have had family events on the weekend, Hope will come with Jane and it is so much more relaxed for my mom.*

People who know Judy and Allan well recognize how important it is for their well-being to have a time away from their caregiving roles:

> *I think there was a real need for that (a stable independent living situation) as they could go away for the weekend, they could do things like that together…so they kind of got back into just that Judy and Allan mode…and I suspect that, for any parent to know that your child is happy and well cared for, freed them up to enjoy their lives as a couple again and not have that constant stress and worry or that concern you are going to get a phone call…*

While Judy and Allan recognize the importance of taking time for themselves, the vision of a full and meaningful life that they have for Hope keeps them highly involved in her day-to-day life.

Sibling Experiences

Hope's siblings also spoke about individualized supports having impacted on their relationships with Hope and their role in supporting her. With the increase in individualized paid support in Hope's life over the years, her siblings have recognized how this has contributed to the development of more typical sibling relationships.

> *My relationship (with Hope) improved a lot when I wasn't relied on as much to provide her with support. As a child, supporting her wasn't the most exciting thing I could be doing and probably wouldn't have been my choice.*

While Hope's siblings recognized the importance of their involvement in her life, they were able to identify the disadvantages of a sibling providing direct support in the community:

> *I always feel a certain degree of responsibility for how Hope behaves. I think as a family member you are closer to that then someone who is paid to support her. If I were in the role of having to facilitate community relationships for Hope instead of a paid person, I would feel more inhibited.*
>
> *I know as a sibling, it is different for me going out with Hope and doing things with her than it has been for me in a working role. I have worked as a support person for someone else in the past. And it was totally different being in that role than being in a sibling role.*

Furthermore, with support workers facilitating relationships and more family input and involvement, individualized supports have allowed relationships to flourish with family members. Hope's siblings shared how being a more traditional support arrangement prevented Hope from participating in family life:

> *There was a time, when I didn't fully understand who Hope was. When I was young and she was living in the institution, she would only come home on the weekends to visit.*
>
> *...certainly when we were younger and growing up, Hope was in a group home, she was rarely here during the week and weekends as well, when someone is not home day to day, you cannot develop a relationship in the same way with somebody when you are there two days a week as opposed to seven days a week.*

At a time when Hope's future seems uncertain, concerns for the future arise. Hope's sister expressed her feelings about the fragility of Hope's support arrangement:

> *I think just finding the situation where that, the supports will be more stable in the future is scary at this point. You know that worries me. I don't ever want Hope to be without what she really needs in terms of trusting, stable relationships.*

Challenges with Individualized Supports

While the participants spoke of the many benefits of individualized supports for Hope, they were also clear that this approach to disability-related supports did not come without its challenges. A commonly cited disadvantage was the lack of structure in an individualized approach that made it difficult to secure replacement workers when primary workers were ill, on vacation, or left their position. Hope's sibling highlighted her concerns:

> *Well, I guess that one thing that strikes me is that it is pretty reliant on individual people, so that there is less of a, in Hope's case, there is less of a fall back I guess...The supports become only as good as the individual people are in the system whereas in a more standardized care approach...where the staff are interchangeable, it's always a guarantee that someone is going to be there...But with the individualized support, the basic structure is not there. There is not sort of an easy replacement for a particular person. And so you rely on individual people to be there.*

A service provider also pointed to the difficulties in finding ways to ensure there is someone to support Hope when her workers are not available and how this lack of structure impacts Hope's well-being:

> *One of the things that has always been a problem is we may have someone who will be with Hope...but if someone goes off sick or someone goes on vacation, or something happens in an emergency, we don't have any resources for back-up. So when anything happens, it is always a mad scramble and Hope, in the process becomes very stressed because something is happening out of the blue.*

Another disadvantage seen by a participant was a lack of planning support from service providers available to families who choose an individualized approach. Consequently, Hope's parents have shouldered most of the work in this area:

> *I think that one thing that has been lacking for my parents...is someone to assist them with planning for Hope...Ideally someone could take on that role. Absolutely my parents would have to be involved. How could you develop an*

> *individualized program for somebody unless the people closest to them had input…Leadership with the planning process from the service providers has been lacking. I think that will have to change if an individualized program is going to work.*

Hope's Photo Voice

The old adage "a picture says a thousand words" is certainly true. So much of Hope was seen in the photos of scenes from her everyday life. It is clear that her relationships with others are an integral part of her life. Many of the photos depict her with the important people in her life: family members, friends, acquaintances, colleagues, and support workers. Pictured with her mother, Hope seems to ignore the camera as she beams at Judy and touches her hand. With her support worker Tracey, Hope is laughing as she circles her arm around her. Hope's love of children, her nieces and nephew in particular, comes through in a photo at her home. Hope embraces diversity, as she enjoys friendships with people from a variety of age groups, cultural backgrounds, and abilities. Pictured in the grocery store with her friend whom she calls Grandma Pam, there are smiles all around. It is evident that Hope brings a great deal of joy to her friends. While it takes some time for Hope to feel comfortable with people new to her life, once you are familiar, she is a caring and devoted friend.

Despite the challenges she has faced in recent years, Hope continues to find pleasure in her life through her weekly pursuits. Hope is smiling in a picture of her regular visit to the library where she looks forward to bringing home a new movie to enjoy during her free time. A trip to the local video store is usually on her agenda where she can indulge her interest in the Olsen twins by renting their most recent release.

In an effort to stay active, Hope enjoys swimming at the local YMCA where she recently became a member. In the warmer weather, Hope is eager to take walks through a nearby park where she may run into neighbours, old friends from the day program or wildlife. She is known in her neighbourhood and looks forward to seeing familiar faces and receiving friendly greetings. When it is cold outside, trips to the local sports facility give her the opportunity to take walks in comfort.

In the picture of her workplace in the church, Hope is seated in front of a pile of papers which is her responsibility to fold. This is the church bulletin which, without Hope's efforts, would not get folded. Hope has a good relationship with her supervisor who gives her the time and space she needs to complete her work. Hope is comfortable here with the support of familiar people and the freedom to take walks around the church when she needs a break from her work. For Hope, in addition to contributing to the work of the church, it is the social aspect of work that gives her a great deal of satisfaction.

Hope has a passion for food and her days would not be complete without taking time to stop for a quick snack and to quench her thirst. With the money she receives for her work folding church bulletins, Hope usually purchases a muffin and a drink. This is Hope's money to spend as she pleases.

Hope is surrounded by a fellow volunteer and staff member from a photo at the Meals on Wheels pick-up location. It is here she is part of a team who work together to benefit the community. She is surrounded by the hustle and bustle of people picking up meals for delivery. There are pictures of friends she has made on her delivery route as people who have come to know her welcome her into their homes when she brings them their meals.

It is through photographs that others can reflect on the successes and joys in Hope's life. They act as a reminder of the strength of Hope's spirit and, despite struggles and disappointments, how the efforts of a committed and caring support network can open closed doors in the community.

CHAPTER NINE

Discussion

Self-Determination

The perspectives and stories shared by this small group, while more detailed and in-depth, are in some ways consistent with research with individuals and families in similar circumstances. Like the people who participated in the Ridley and Jones (2003), Williams et al. (2003), and Carmichael and Brown (2002) studies, individualized supports have given Hope, with assistance from her family, more choice and control over her life. She is able to have input into how supports are provided and where and with whom she lives. Furthermore, she participates in community life and has relationships with people outside of her family and paid workers.

The choice and control that have resulted from individualized supports have enabled Hope's parents to distance Hope and themselves, in some respects, from the formal service system and it's limitations. As mentioned in the results section, while Hope and her family have experienced the advantages of individualized supports, her funding remains tied to an established program. This reality limits their ability to exercise further control over Hope's supports and establish an arrangement that the family feels will provide Hope with opportunities as well as security over the long term.

In a study on the ability of adults with an intellectual disability, Wehmeyer and Garner (2003) discovered that people's living and working environments had a strong impact on their self-determination. According to their findings, people living in more congregate settings exercised less self-determination than people supported to live independently. Furthermore, people who had higher needs as a result of their disability were more likely to live in restrictive, congregate environments, while people who were seen as more capable were given more opportunities to live and work in the community and thus exercise self-determination. It would appear that the current system, while attempting to promote self-determination for people with a disability, is structured so that only a select group is given this opportunity. For people with higher needs for support, exercising self-determination remains elusive. With individualized supports and funding, the opportunity to live and work in less restrictive environments is a possibility for anyone, regardless of their needs. With her individualized supports, Hope has defied the traditional systems requirements that she be supported in a group setting. In her circumstance, receiving support has not meant she has to sacrifice self-determination.

While self-determination is often defined in individualistic terms, Kennedy (1996), a self-advocate, points to the importance of people with disabilities having support from others in exercising their self determination:

> What I consider to be self-determination for people with disabilities is to work collectively, with the person with the disability at the top. The person's family members, friends, agency staff, and anyone else the person wants involved become the collective, along with the person themselves (p. 11).

Quality of Life

Hope's family's interest in finding a way to support Hope outside the traditional service system has been motivated by their vision of a life of quality for her. For Hope, a life of quality is one where she: is part of a close-knit family; has caring friends; has a safe and comfortable home; has security with the opportunity to take risks and pursue her interests; spends her time in ways that are meaningful to her; lives in a community where she is known and valued; has the support she needs from family, friends and paid workers; has financial, emotional and physical well-being and has choices in and control over different aspects of her life. Individualized supports have been a critical in helping her to achieve quality in these areas of her life.

Quality of life is a concept that has gained popularity among professionals working with individuals with a disability as a paradigm shift in thinking about the lives of the people they serve. Not emerging in isolation, this approach is an extension of the ideas of social role valorization, inclusion, anti-discrimination and rights practices that have existed in the disability field for many years. Defined, by Brown and Renwick (1997) as the "quality, goodness or excellence of life" (p. iii), and that the idea is subjective to some extent and will have different interpretations among individuals and groups of individuals. Shalock (1997) expands on this definition by identifying the core dimensions of quality of life as emotional, material, physical well-being, interpersonal relations, self determination, social inclusion, rights and personal development. The choice and control that Hope and her family exercise with a flexible individualized approach is what provides Hope the opportunities to realize quality of life dimensions such as emotional and physical well-being, community inclusion, relationships and self-determination.

Quality of life principles support people with a disability in their struggle to gain citizenship in the community (Brown & Brown, 2005). While some agencies claim that quality of life principles guide their work with individuals there has been little change in the field (Brown & Brown, 2005). In this context, it is understandable why individuals and their families are looking for alternatives to the current service system.

For Judy and Allan, the work involved in maintaining a good life for their daughter has always been balanced with attention to their own needs and interests. Hope's sister expressed concern that, over the years, her experience of services provided to individuals and their families has focused primarily on the family member with the disability with very little attention paid to the needs of other family members. This shortcoming is particularly important for older parents such as Judy and Allan. In the past, there was less expectation the parents would still be primary caregivers as their children made the transition into adulthood. However, in more recent decades, governments, in times of fiscal restraint, have increased expectations that parents will be primarily responsible for supporting their adult children at home. Unfortunately, little has been done to ensure that programs and services are more family-focused so that so that the quality of family life is also taken into consideration so that families can remain strong in order to meet the demands of life-long caregiving.

In a study by Brown, Anand, Fung, Isaacs, and Baum (2003) that examined the quality of life of families with a child with a disability, many parents expressed a great deal of dissatisfaction with services for a variety of reasons. Parents often found the service system difficult to navigate while others did not know where to begin to look for services and there was no one available to assist them. Furthermore, parents expressed frustration with long waiting lists for service, lack of available services and services that do not meet the needs of families. Parents also stressed that they did not receive very much practical support whether it be from family, friends, neighbours or service providers which left them with very little relief from caregiving. Through individualized supports, Judy and Allan have been able to secure the practical support they need and have time away from their responsibilities. With day supports that are tailored to Hope's needs and interests, there is less concern that her family will have to intervene as a result of supports that are inappropriate.

Summers, Poston, Turnbull, Marquis, Hoffman, Mannan and Wang (2005), point to the benefits of ensuring that family quality of life becomes an important outcome of supports and services. They argue for policy reform based on quality of life dimensions, along with changes to supports and services at the agency level that would better meet families' needs. Furthermore, they suggest that continued funding of agency programs would depend on evaluation of quality of life outcomes for families and individuals. Based on the results of this case study, developing policy that upholds individualized funding and supports would be an important step to achieving quality of life outcomes for both individuals and families.

Including Siblings

While a lot more has been done in the way of understanding the experiences of siblings of individuals with a disability in recent decades, more work needs to be done to support siblings over the life span. There is no doubt that having people outside of the family be primarily responsible for Hope's day to day support and care has made it possible for Hope and her siblings to have more typical relationships with her. As part of an individual's support network, siblings can chose to play an important role in their life when parents are no longer able to provide support. By focusing on family outcomes and quality of life through family-centred services, the well-being of siblings who are involved over the long term will be made a priority.

Relationships in Community

The work of building relationships and connections in the community with Hope has resulted in change on many levels. For Hope as an individual, her life has been significantly enhanced by the people she knows and her participation in community life from which she would otherwise be marginalized. I also discovered in my conversations with people who know her best that Hope brings a great deal to her relationships. These connections are not just about preventing isolation and loneliness in Hope's life, they are about giving Hope the chance to share her uniqueness with others and enrich their lives.

Hope's friendships have resulted from her involvement in segregated programs and community activities. She has had relationships with people she came to know in the day program, some of these friends she has known for many years as they have attended other schools and programs together. A participant shared that Hope would often ask about certain people as well as a staff member from the day program. Currently, however, she does not have a great deal of contact with the people she called her friends as their relationships did not go beyond the confines of the day program. Friendships have also resulted with people who she has come to know through her volunteer work with seniors and her visits to the YMCA. Grandma Pam, a senior, and George, a worker at the gym have both become important to Hope. In addition, she shares friendships with past and current support workers and looks forward to seeing family members of her support workers during the time she spends with them. All these relationships have enhanced Hope's life. However, further steps by Hope and her support workers could be taken to invite friends of her choosing to become active members of her support network. Including friends would help her circle membership go beyond her parents, siblings and paid professionals.

Furthermore, Hope's presence in community has also been the catalyst for a number of local organizations and groups to examine how they can be more inclusive of people with intellectual disabilities. Breaking down barriers often involves encouraging changes in peoples' attitudes towards people with a disability and overcoming a fear of difference.

On a societal level, the presence of people with an intellectual disability has the ability to bring out compassion in others and create a society that is less concerned with competition and personal success and more focused on co-operation and concern for others. Vanier (1998) shares his perspective of inclusion of people who are marginalized:

> The excluded, I believe, live certain values that we all need to discover and to live ourselves before we can become truly human. It is not just a question of performing good deeds for those who are excluded, but of being open to and vulnerable to them in order to receive the life that they can offer; it is to become their friends. If we start to include the disadvantaged in our lives…they will change things in us. They will call us to be people of mutual trust, to take time to listen, and be with each other. They will call us out from our individualism a need for power into belonging to each other and being open to others. They will break down the prejudices and protective walls that gave rise to exclusion in the first place. Is this a utopian vision? If it is lived at the grassroots level, in families, communities and other places of belonging, this vision can gradually permeate our societies and humanize them (p. 84).

While Hope has experienced success in this area of her life, these connections have not materialized without a concerted effort. The work of breaking down barriers to friendship and building community for people with a disability, although appearing straightforward, is often complex and involves hard work. Friendships and community connections do not happen overnight and often need continual support and nurturing by family members, supporters, and other friends in order to be sustained.

The realities of today's world often contribute to challenges faced by people involved in the important work of facilitating relationships for people with an intellectual disability. Individuals and families overwhelmed with the rising cost of living and increased expectations of employers are often busy and find it difficult to become involved in their community and extend themselves to others. As society becomes increasingly individualistic, it is difficult to find others who invest in relationships with people who require them to step outside their familiar circles.

Furthermore, Yates (1994) emphasizes the danger of romanticizing the community by hoping it will be the answer to the loneliness and isolation that people experience. He argues that the community is fallible and that it cannot be controlled. However, he feels it is the "only place you can sing together and the only place you can die together, the only place you can never abolish suffering and the only place you can never abolish joy" (p. 34).

Supporting the Supporters

The findings regarding support workers in this case study warrant further research into the experiences of supporters in an individualized approach. Along with the family, the role of support workers in helping Hope to achieve a quality of life is critical. It is clear the workers take on many roles in Hope's life. In addition to playing a community development role, Hope's support workers are there to assist with daily activities such as preparing meals, maintaining her home and providing transportation.

The close relationships that have developed between Hope and her workers reflect the finding of Pedlar et al. (1999) that friendships between workers and individuals are more likely to happen with individualized supports. Furthermore, the willingness of Hope's workers to facilitate community connections and friendships, along with the flexibility that an individualized approach gives them to facilitate and nurture friendships, has given her many more opportunities in this area of her life. Hope and her family have been fortunate to secure people who are effective in supporting people with a dual diagnosis and have adopted a philosophy of community inclusion. However, finding workers who work well in an individualized approach in partnership with individuals and families among people trained in the area of developmental services continues to present challenges. Current training curricula can be revised by incorporating input from individuals and families and providing opportunities for learning with individuals and families. Furthermore, promoting an approach to supporting people based on inclusion, rights, and quality of life would better prepare people for working alongside families and help families to resolve the difficulties they face in finding appropriate candidates.

While the importance of Hope's support workers was highlighted by many participants, the family still faces many challenges in retaining and recruiting workers, a finding which is consistent with findings from the study conducted by Lord and Hutchison (2003). The ability of families to more adequately compensate workers is compromised by the limits that are placed on wages by government funders. It is clear from the results of this research that the work of supporters is invaluable. Funders need to assist families and agencies to overcome the challenges of attracting and retaining people to this female-dominated profession of directly supporting individuals with a disability by providing funds for adequate compensation and health care benefits.

Working within an individualized approach does not give workers as many opportunities to connect with others doing similar work or for professional development which occurs more often in a traditional setting. The support provided to Hope's workers by Organization B provides these opportunities to some extent. Providing a venue for workers to secure these opportunities is also an important component in recruiting and retaining workers. Further research in this area would help us to understand the perspectives of support workers working with families in an individualized approach.

Making Individualized Funding and Supports a More Viable Option

The disadvantages of individualized supports, such as the difficulties of the recruitment and retention of support workers, the time involved in establishing a back-up arrangement for existing support workers, and a lack of support from service providers in the area of planning that were shared by participants, are consistent with findings in other studies of individualized supports and funding. For some individuals and families, not being able to fully implement plans for community living because of limits on individualized funds has been disappointing. It is important to address these shortcomings in order to make individualized funding and supports a more viable option for families. By providing access to planning, co-ordination, and monitoring services, families would feel more supported in the management of the funding and supports. Having someone to assist with developing a plan, recruiting, training and supporting workers, and organizing back-up arrangements in the event that a worker is not available would ease the workload for families who feel individualized funding and supports are the best alternative for their family member.

For Hope and her family, being able to access back-up workers, has been a continual challenge. It is critical that Hope is familiar and comfortable with whoever is supporting her. As a result, people who are asked to fill in for steady workers must already have a relationship with Hope. Perhaps families who are supported with an individualized approach would benefit from establishing a network of support workers who are willing to better acquaint themselves with other individuals and be available to work for other families when the need arises. Alternatively, by partnering with agencies that have an established group of workers, families would be able to access support workers more readily. A service provider discussed the option of establishing an intentional community of families who could share resources and act as back-up supporters if the need should arise. Finding creative solutions to this problem which is common among families who have individualized supports will provide more security for both individuals and their families. It is certain that the combined efforts of those who are involved in Hope's life will contribute to the establishment of this security.

Despite the challenges they have faced with individualized supports, the family is certain that this approach has provided the best outcomes for Hope. As a result, they continue to look for ways to resolve these shortcomings as they begin, once again, to consider how Hope can be supported in her own home in the future. At this time, success is critical as their well-being as a family depends on establishing an arrangement that is going to provide stability over the long term. This is a daunting task and one that will require thoughtful planning and careful steps forward by Hope's support circle of family, friends, support workers and service providers.

Implications for Policy and Practice

It is evident that the findings of my research have important implications for social policy and practice in the field; primarily for the establishment of policy that supports and invests in a system of individualized funding for people with an intellectual disability in Canada. The first step in realizing this goal on the local level is the Ontario provincial government investing additional funding into existing individualized funding programs and looking at ways to bring individualized funding to all areas of the province. Furthermore, broadening the eligibility criteria of the Ontario Direct Funding Project for people with a physical disability to include people who would like assistance to direct and manage their supports would make this individualized funding program more accessible to people with an intellectual disability. In Ontario, large scale facilities remain open despite the fact that the provincial government has promised to close institutions. Keeping these promises by closing at least one of the three remaining facilities and reinvesting the cost savings from their closures into individualized funding programs would also facilitate movement toward this goal.

In order to resolve some of the issues that families face in recruiting and retaining support workers, government funders would need to remove limits they have placed on wages for workers which makes attracting people to this line of work a challenge. In addition, revising current training programs for Developmental Service Workers needs to be considered. Incorporating practical experience working with families and facilitating community inclusion as well as basing programs on quality of life principles would ensure that workers would be more prepared to work with families in an individualized approach.

Steps can also be taken to reduce the amount of work for families who have individualized supports and funding. Streamlining the funding application process by establishing a centralized office and simplifying the funding review process would be helpful to families. Also, creating a program that provides a wage to parents who are required to give up employment to care for a child with a disability would also go a long way in lessening the financial burdens of families.

In the field, service providers can also take initiatives to improve the way services and supports are provided to individuals and families and address the challenges they face. Agencies need to examine ways in which current funding and supports can be individualized for the people they serve and how they can adopt a more family-centred approach to service provision. To address gaps in service, planning and support circle facilitation as well as co-ordination and monitoring of services need to be provided to families. In order to enhance quality of life for individuals, agencies should train staff members in the facilitation of friendships and community involvement and make such facilitation a large part of their role in their work with people. Furthermore, evaluation of programs and services based on quality of life outcomes would help service providers to determine the effectiveness of their services.

To further address the challenges families face in securing and maintaining support workers, agencies need to work in partnership with families to develop a support worker recruitment strategy and establish a support worker registry. Professional development and networking opportunities can be provided by agencies to supporters working in an individualized approach.

I have made a number of policy recommendations that are based on the findings of my research. It is important to acknowledge, however, that there are limitations to using this case study as a basis for social policy as it only examines the experiences of one family. Not all individuals or families would be able to take on the additional roles and responsibilities associated with individualized funding and be as successful as this particular family. In establishing a system of individualized funding, particular consideration must be given to individuals and families who wish to have individualized funding, but are not able to take on the additional work. Any new system of individualized funding must provide individuals and families with the support they need to ensure their success.

Strengths and Limitations of My Research

I feel that, through qualitative methods, I have been able to capture a more in-depth account of the family's experiences than I could have achieved otherwise. By posing open-ended questions, the participants were free to expresss the complexity of the situation. I also feel that the case study method has afforded me the flexibility to explore the themes that emerged from the information that may not have been addressed by my original research questions. As a result, it is clear that my study has a more human and meaningful quality.

The limitations of my study also need to be addressed. By working with a single family, my study does not include the diversity of experiences that would result from gathering information from a larger number of families. As a result, it would be difficult to generalize the findings of my work. Furthermore, my research may be seen by others as biased, both from a researcher and participant perspective. Participants, with the knowledge that the family would be viewing their transcripts, may have withheld information. There was also the possibility that participants told me what they felt I wanted to hear. Researcher bias may be present since I was the only person analyzing the data.

Personal Thoughts and Reflections on the Thesis Journey

Thinking back on the start of my thesis work, I can remember feeling plagued with doubts about how it would all unfold. Would I be able to work with Hope and her family in a way that was respectful and sensitive to their circumstances while, at the same time, meet the expectations of the university? I strived to uphold my values by being accountable to the family throughout the research process. As a researcher, I did not want to enter into the life of the family, ask them to share their personal experiences and not be able to provide them with something that would be meaningful and relevant to them. In the beginning, I questioned if I could make a difference, but now that my research is complete, I see the value of my work and the power of their story.

By working with one family over an extended period of time, I have developed a deeper understanding of the lived experiences of all the family members and people who are a part of their network. In my role, I realized the importance of being nonjudgmental; of being open to listening to their story and understanding their experiences. Being the holder of their story, I was always sensitive to their need for privacy. I have also learned the importance of working in partnership with families by honouring their experiences and knowledge of their child with a disability. I hope to continue to work in ways that allow me to uphold Community Psychology values and use my skills as a researcher to tell people's stories and advocate for change.

CHAPTER TEN

Concluding Thoughts

Historically, families have had a strong influence on social policy and the way services are provided to people with an intellectual disability. Parents were among those who recognized the shortcomings of institutional care and their united efforts to create alternatives for their sons and daughters were supported by those who had the power to create social change. By sharing their story through this study, the voices of these parents once again call for change. To have the opportunity to shape social policy and a service system that upholds individualized funding and supports would allow families to move towards a good life. It is critical that social policy, in order to be responsive to the people it is intended to serve, is built on the lived experiences of families.

Appendix A

Interview Guide

(Third Party Participants)

1. What is your relationship to the focus participant?
2. How long have you known the focus participant?
3. How did you come to know the focus participant?
4. What do you feel are the benefits of the focus participant's support arrangement?
5. What do you see as the challenges or disadvantages of this arrangement?
6. How has the support arrangement impacted on your relationship with the participant/your role?
7. In what ways has the focus participant's support arrangement impacted on her relationships and life in the community?
8. From your perspective, what impact have individualized supports had on her parents?
9. Is there is anything else you would like to share?

Appendix B

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

(Third Party Participants)

Community Living: One Family's Experiences with Individualized Supports

Researcher:
Alison Baxter
Master's of Arts Candidate
Community Psychology

Advisor:
Juanne Clarke

You are invited to participate in a research study. The purpose of this study is to gain an in-depth understanding of the impact of individualized disability related supports from the perspective of a person with intellectual disability and her family and support network. Currently I am a Master's of Arts candidate at Wilfred Laurier University in the Community Psychology program.

INFORMATION

This study will mainly be comprised of individual, face-to-face interviews as well as observation and document reviews. As a third party participant, I am asking for your consent to interview you regarding your relationship with the focus participant and your perspective on her supports and living arrangement. The interview will take approximately one hour. The total duration of the study will be approximately two months.

The number of participants that will be participating in the research *is* approximately 10-15. It is possible, because of the small number of participants, that participants may be identifiable in the report despite that names will not be mentioned.

With your permission, I will audiotape all the interviews for the purpose of research only. I, the principal investigator, will have access to the tapes and will transcribe the tapes by listening to each tape and writing them out using word processing software. You will have the opportunity to review the transcript from your interview to ensure accuracy. Once the study is complete, the tapes will be erased and transcripts will be shredded. Both the tapes and transcripts will be discarded. If you choose to withdraw from the study, any tapes or transcripts will be returned to you.

RISKS

The risks for participants involved in this research are a disruption of routine along with the revelation of personal information to the interviewer. In order to minimize these risks, I will complete the study in timely manner to avoid further disruption of your routine and take measures to ensure confidentiality and anonymity.

BENEFITS

I am hopeful that this project will strengthen the efforts of the focus participant and her support network to secure additional funding for community living supports. Furthermore, I am hopeful that other individuals with an intellectual disability will benefit from the advocacy work in that more individualized supports and funding will be available and supported by social policy. Lastly, it is possible that other individuals and their support networks will be inspired by the experiences of this individual and her family to establish more meaningful, inclusive futures.

CONFIDENTIALITY

I will ensure confidentiality and anonymity of participants by not divulging personal information in my conversations with others about my thesis work. In the data and final document, I will change names and avoid mentioning personal details (geographic location, connections to agencies or institutions) that may reveal your identity. As the primary researcher, I will have access to the data along with the focus participant and her parents who will have the opportunity to read the transcripts once you have reviewed your personal transcript for accuracy. The tapes from interviews and transcripts will be kept in a locked drawer and under computer password. Once the study is complete, I will erase and dispose of the tapes and shred and dispose of transcripts. All of the participants of the study will be provided a copy of the final thesis document or a summary report. In addition, a summary report will be given to the service resolution committee on behalf of the focus participant. Results of the study will also be presented at my thesis defense, at the university, which you are welcome to attend. It is possible that I may quote you in the thesis document. Quotes will be used to strengthen and clarify points made in the thesis by providing examples. If you are quoted, efforts will be made to conceal your identity by omitting personal details and changing names. If it is possible that you may be identified through a quotation, I will ask for your written permission to use this specific quote. By signing this consent, you are giving me permission to quote you in final thesis document.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Alison Baxter, at Wilfred Laurier University, Psychology Department, 75 University Avenue West, Waterloo, ON N2L 3C5, 519-884-0710 Ext. 2983, baxt1992@wlu.ca or my advisor Juanne Clarke at Wilfred Laurier University, 519-

884-0710 Ext. 3516. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. You have the right to omit any question(s)/procedure(s) you choose.

FEEDBACK AND PUBLICATION

Once the study is complete, I will provide copies of the final thesis document or summary report to all of the participants. If participants are interested, I will organize a meeting where the results of the study will be discussed. In addition, participants will be invited to the thesis defense at the university where the results of the study will also be shared. Lastly, a summary report of the findings will be prepared and submitted along with a funding proposal to the Ministry of Community and Social Services on behalf of the focus participant. My intention is have the feedback available by July 2005.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature______________________________________

Date ____________________

Investigator's signature____

Date ____________________

Appendix C

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

(Focus Participant)

Community Living: One Family's Experiences with Individualized Supports

Researcher:
Alison Baxter
Master's of Arts Candidate
Community Psychology

Advisor:
Juanne Clarke

You are invited to participate in a research study. The purpose of this study is to gain an in-depth understanding of the impact of individualized disability related supports from the perspective of a person with intellectual disability and her family and support network. Currently I am a Master's of Arts candidate at Wilfrid Laurier University in the Community Psychology program.

INFORMATION

This study will mainly be comprised of individual, face-to-face interviews as well as observation and document reviews. As the focus participant, I am asking for your consent to do the following: interview you about your supports and living arrangement, observe some of the activities you are involved with in the community, read some of your personal documents (life plan, communication books) and interview members of your family as well as members of your support network. The interview will take approximately one hour and there will be three separate observations which will take two hours each. The total duration of the study will be approximately two months.

The number of participants that will be participating in the research *is* approximately 10-15. It is possible, because of the small number of participants, that participants may be identifiable in the report despite that names will not be mentioned.

With your permission, I will audiotape all the interviews for the purpose of research only. I, the principal investigator, will have access to the tapes and will transcribe the tapes by listening to each tape and writing them out using word processing software. As the focus participant, if you wish to review the transcripts of your interview and other participant interviews, you are welcome to do so. Once the study is complete, the tapes will be erased and transcripts will be shredded. Both the tapes and transcripts will be discarded. If you choose to withdraw from the study, any tapes or transcripts will be returned to you.

RISKS

The risks for participants involved in this research are a disruption of routine along with the revelation of personal information to the interviewer. In order to minimize these risks, I will complete the study in timely manner to avoid further disruption of your routine and take measures to ensure confidentiality and anonymity.

BENEFITS

I am hopeful that this project will strengthen the efforts of the focus participant and her support network to secure additional funding for community living supports. Furthermore, I am hopeful that other individuals with an intellectual disability will benefit from the advocacy work in that more individualized supports and funding will be available and supported by social policy. Lastly, it is possible that other individuals and their support networks will be inspired by the experiences of this individual and her family to establish more meaningful, inclusive futures.

CONFIDENTIALITY

I will ensure confidentiality and anonymity of participants by not divulging personal information in my conversations with others about my thesis work. In the data and final document, I will change names and avoid mentioning personal details (geographic location, connections to agencies or institutions) that may reveal your identity. As the primary researcher, I will have access to the data along with the focus participant and her parents who will have the opportunity to read the transcripts once you have reviewed your personal transcript for accuracy. The tapes from interviews and transcripts will be kept in a locked drawer and under computer password. Once the study is complete, I will erase and dispose of the tapes and shred and dispose of transcripts. All of the participants of the study will be provided a copy of the final thesis document or a summary report. In addition, a summary report will be given to the service resolution committee on behalf of the focus participant. Results of the study will also be presented at my thesis defense, at the university, which you are welcome to attend. It is possible that I may quote you in the thesis document. Quotes will be used to strengthen and clarify points made in the thesis by providing examples. If you are quoted, efforts will be made to conceal your identity by omitting personal details and changing names. If it is possible that you may be identified through a quotation, I will ask for your written permission to use this specific quote. By signing this consent, you are giving me permission to quote you in final thesis document.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Alison Baxter, at Wilfred Laurier University, Psychology Department, 75 University Avenue West, Waterloo, ON N2L 3C5, 519-884-0710 Ext. 2983, baxt1992@wlu.ca or my advisor Juanne Clarke at Wilfred Laurier University, 519-884-0710 Ext. 3516. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. You have the right to omit any question(s)/procedure(s) you choose.

FEEDBACK AND PUBLICATION

Once the study is complete, I will provide copies of the final thesis document or summary report to all of the participants. If participants are interested, I will organize a meeting where the results of the study will be discussed. In addition, participants will be invited to the thesis defense at the university where the results of the study will also be shared. Lastly, a summary report of the findings will be prepared and submitted along with a funding proposal to the Ministry of Community and Social Services on behalf of the focus participant. My intention is have the feedback available by July 2005.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature____

Date ____________________

Investigator's signature_______________________________________

Date ___________________

Appendix D

WILFRID LAURIER UNIVERSITY

AUTHORIZATION FOR RELEASE OF INFORMATION

I, focus participant, authorize my family members, friends, support workers and service providers to release to Alison Baxter, Community Psychology Student, Wilfrid Laurier University, 75 University Avenue West, Waterloo, ON N2L 3C5 information concerning my individualized supports, community involvement and relationships for the purpose of conducting a research study. I understand that this information will be provided to the researcher verbally or in written form through documents such as life plans, communication books or journals.

This authorization is effective until July 2005 at which time it will expire.

I understand that I have the right to revoke this authorization at any time.

I have read (or have had read to me) the above authorization and I understand my rights.

______________________________	______________________________
Signature of focus participant	Date

Appendix E

75 University Ave. East
Waterloo, ON
Date

Participant Name
Address

Dear Participant:

I hope you are keeping well. Please find enclosed a copy of the transcript of our interview on date. I have changed names with the document in an effort to maintain anonymity. If you would prefer that I use your real name or a different pseudonym, I can easily make that change.

Please review the transcript at your earliest possible convenience. I will contact you the week of date to see if you would like to make any changes to the transcript. As mentioned in the consent form, once I have revised the transcripts, I will be sending them to the family so they can have input into what will be in the final thesis document.

If you have any questions or concerns, I can be reached at 884-1071. Once again, thank you for taking the time to participate in this study.

Yours truly,

Alison Baxter
Masters of Arts Candidate
Community Psychology
Wilfrid Laurier University

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