

Aging Parents' Perceptions of Planning for the
Future for their Adult Child with an Intellectual Disability

by

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A Thesis Submitted to the Faculty of Graduate Studies
in partial fulfillment of the requirements for the degree of

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**Aging Parents' Perceptions of Planning for the Future for their Adult Child with an
Intellectual Disability**

BY

Jennifer Taylor

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree**

of

MASTER OF SOCIAL WORK

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On to the next project

ABSTRACT

A qualitative research study was conducted in order to deepen the understanding of how aging parents plan for the future for their adult child with an intellectual disability. Interviews were utilized to gain the perception of the parents directly. The results show how the parents contributed greatly not only to the lives of their children but also to the services and programs which support them. The parents interviewed have planned for their adult sons and daughters with an intellectual disability; somewhat dissimilar to the literature presented. Parents who faced their situation, acquired the information and found the support they needed are enabled to care for their child well past what is expected and can plan for their future appropriately. However, the parents did experience obstacles, which made planning difficult and left their plans for their adult children incomplete. Recommendations are given to further enhance the planning process and to assist with the further development of inclusive communities.

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CHAPTER ONE

INTRODUCTION

There will be an increasing percentage of older people in developed nations, as infant mortality declines, life expectancy increases, and the median age at death work inexorably upward (Janicki & Ansello, 2000). Statistics show that between the years 1999 to 2050, the world population aged 65 and over is expected to triple (Scharlach, Damron-Rodriguez, Robinson & Feldman, 2000). Older Canadians make up more than one tenth of the population today and experts predict that this proportion will grow to almost 25% by the year 2031 (Statistics Canada, 1990). Canadians question how they will maintain social security and health care for those aging and disabled no longer working.

The United Nations named 1999 the International Year of Older Persons. The agenda that was set urged the global community to facilitate collaboration across sectors and nations and to reach out to the development community, the media, the private sector and the younger generation in the efforts to create a society for all ages (Keigher, 1999).

People with intellectual disabilities are not excluded from these changing demographics. There are an increasing numbers of children with severe disabilities living at home and living into later life. The presence of children with formerly life-shortening disabilities is in part the result of improved medical care (Bradley, 1992), improved hygiene, and improved levels of education. The way in which social institutions such as government, education and services in the community respond to the extended life span and the changing way life is lived

also assists in more individuals being able to remain in the community and live longer (Ansello & Janicki, 2000).

Theories and concepts, such as the Principle of Normalization have assisted in shaping the way parents and professionals have developed supports for individuals with intellectual disabilities, and in turn have played a role in dramatically altering the disability field over the last several decades. Individuals with intellectual disabilities now will most likely out live their parents. Parents may be in the parental caregiving role until their death or when they are incapable of continuing care. As parents age, they face the dual strain of their own aging process and the aging of their own children with disabilities (Heller & Factor, 1991).

Growing old with a lifelong intellectual disability is an unexpected event for the parents who have raised children with intellectual disabilities, and a challenge to policy makers, and to professionals who deliver the various community support services for individuals with disabilities residing in communities (Ansello & Janicki, 2000).

There are an estimated 33, 000 Manitobans who live with an intellectual disability, of whom approximately 5000 receive formal services (Presentation by Community Living Program, Manitoba Family Services and Housing, 2001). Families have become the major single providers of support to individuals with intellectual disabilities (Fujiura & Braddock, 1992). Therefore when aging parents are no longer able to support their adult child, formal services will be called upon to provide support.

The pressures placed on long-term support systems for adults with disabilities can only grow over the next several years. A national ARC (Association of Retarded Children) study in the United States concluded that the short fall of community support services has reached crisis proportions for people with intellectual disabilities and their parents.

“What will happen when I’m gone?” is a commonly asked question by parents. Increased attention is focused upon how parents and professionals can work together to achieve safe and flexible future plans for persons with intellectual disabilities. The topic of parents of children with intellectual disabilities and planning for life after the parent’s death is a growing concern across the nation (Maclean’s, 2001)). The relevance of this topic is emphasized given the recent tragedies portrayed in the media that tell the stories of the parents who felt they and/or their children had to die because they could not foresee a positive future for their children with disabilities. The Globe and Mail (February 16, 2001) published an article describing a variety of families’ experiences with the systems involved with their children with intellectual disabilities in which one father stated, “that I’ve got to live forever – I have no choice”.

The researcher’s purpose in developing this thesis was to explore the perceptions of aging parents and their experience with planning for the future for their adult child with an intellectual disability. Gaining an understanding from the parents directly can reach past a professional’s experience, and focus on the parent and determine what the parent can bring to the process of planning.

Qualitative methods will be used to explore the topic of planning. The questions for the study were as follows;

- What are parents' experiences related to planning for their son or daughter with an intellectual disability?
- Is there anything about their experience they would change?
- Is there anything they feel professionals should know about their experiences?
- What advice would they give other parents experiencing a similar situation?

The following definitions are used to further clarify the area of the discussion.

Planning for the future: Any area that will concern the individual once parental care is no longer desired or possible. This may include, but is not limited to; guardianship, finances, residential placement and social/recreation.

Intellectual disability: According to the American Association on Mental Retardation (1992), mental retardation refers to substantial limitations in present functioning. It is characterized by: significant sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas; communication, home living, community use, health safety, leisure, self care, social skills, self direction, functional academics, work. Mental retardation manifests before the age of 18.

The term intellectual disability will be used instead of mental retardation because the researcher felt that mental retardation is an out dated term and has been used in a negative way to describe people.

The research will focus on parents who have been involved with their children with intellectual disabilities. The use of the term family will be used interchangeably with the term parents.

Social workers are viewed as catalysts in solving or alleviating problems. They help individuals, families, groups and communities to enhance their skills and abilities to use their own resources and those of the community to solve problems. Thus, social work should focus upon the issue of planning for the future with individuals with intellectual disabilities and their families.

The discussion in Chapter two shows the advancement in the disability field in the last several decades. Theories and concepts that were developed to guide parents and professionals to work with individuals with intellectual disabilities are incorporated. Other literature is reviewed in the areas of planning, aging and social work interventions.

In Chapter three the method employed in the research are described. Chapter four outlines the findings of the research. Direct quotes and the stories of the parents are organized into categories to achieve a better sense of the parent's experiences. Chapter five is a discussion of the findings and presents recommendations and conclusions.

CHAPTER TWO

LITERATURE REVIEW

Introduction

When parents engage in planning for their adult child with an intellectual disability, there are many facets to consider. Using the definition stated in the introductory chapter and confirmed by Seltzer & Seltzer (1985), planning can involve activities such as financial and guardianship and finding out-of-home placements.

However, parents in the day to day activities of raising a child with an intellectual disability have encountered challenges. These challenges are created when services are either not available or are hard to locate, examples would include respite care, school programming, and inclusion in activities other people can be involved in. Parents have had to advocate for themselves or create the services that their child needs. As the child is growing older and parents begin to plan for their future, challenges of a similar nature seem to be met again and need to be explored in order to allow for proper planning.

The following literature review provides a background on the disability field and the involvement of parents. The reader will be provided with a philosophical basis for what the parents have wanted to accomplish with their children with intellectual disabilities to ensure they are able to expand their experiences in life. Research in the area of planning will also be presented to show what has been discovered about planning thus far, how planning can be important and what can

assist parents in planning. Areas in which social workers have assisted and where their role could be extended will be explored.

Family Support Movement

Individuals with an intellectual disability are vulnerable to being ignored, abused and not adequately supported (Stengle, 1996). Parents have often struggled to find the best situations for their child with disabilities. As the population ages and family demographics alter, new approaches are emerging to support parents to continue in planning for son or daughters with disabilities.

Parents have always initiated programs for their sons and daughters with an intellectual disability because they have been frustrated by the lack of opportunities and services. The disability field has categorized the last several decades by the emergence of the family support movement (Bradley, 1992).

The family support movement has three distinct phases; institutionalization and segregation, de-institutionalization and community development, and community membership. The era of institutionalization and segregation, which roughly ended in the late 1960s considered individuals with intellectual disabilities as sick, vulnerable and in need of extensive medical care that could only be provided in institutions. The view was that the individuals (and the rest of society) would be safer if they spent their days in institutional settings (Bradley, 1992).

Canada's first residential institution for people with intellectual disabilities was established in 1859 (Simmons, 1982). Prior to this time, all individuals

viewed as degenerates of society including people who had a mental illness were placed in the same facility. Families had two choices, either to maintain their child in the home 24 hours a day or to place their child in an institution. After World War I, large institutions were applauded by parents, professionals, service planners and politicians and seen as an advancement in public service to people with disabilities and their families (Rioux, 1996)

Legal rights and parental responsibilities of children with disabilities were given to the facility where their children lived. Although parents may not have been held responsible for causing their child's intellectual disability, they were nonetheless considered destructive influences in their child's life and/or as impeding a professional's treatment and training plans (Kaufmann & Payne, 1975). Parents were often considered emotional, neurotic and overreacting to their child's intellectual disability. In view of these destructive stereotypes, professionals' approach to these parents was often less than helpful (Kaufmann & Payne, 1975).

The era of de-institutionalization and community development began to emerge when stories about the poor treatment institutions were discovered, views changed on how to support the residents and the cost of the facilities were reviewed (Simmons, 1982). This era existed from the 1970s to the mid-1980s. The shift was based on the increasing acceptance that people with intellectual disabilities could grow and learn with specialized training and therapeutic services. The provisions of more services, such as speech therapy, physiotherapy and behavioural interventions, became mandated for children to

receive (Bradley, 1992). These services were viewed as best provided in the community and not in the established facilities.

The Principle of Normalization

During this era, Wolfensberger introduced his 'principle of normalization', which has been widely applied in the work with people with intellectual disabilities. Wolfensberger (1972) defines normalization as "the utilization of means which are as culturally normative as possible, in order to establish or maintain personal behaviours and characteristics which are as culturally normative as possible" (p. 28).

The principle of normalization challenged human service personnel to allow people with intellectual disabilities to be fully integrated in their own communities. This would include living arrangements, work placements and social situations. According to Wolfensberger (1972), "integration is achieved when the person lives in a culturally normative community setting in an ordinary community housing, can move and communicate in ways typical for his or her age, and is able to utilize, typical community resources; which would include developmental, social, recreational, and religious facilities, hospitals and clinics, the post office, stores and restaurants, job placements, and so on" (p. 48).

Families and professionals in the disability field are often required to be extremely creative to achieve the many facets of the principle of normalization. Individuals with unique needs, especially those, who can not communicate independently, are vulnerable to exclusion from society. Wolfensberger

challenges those in this field to assist individuals to reach their full potential and to set goals.

The principle of normalization assisted in building the third and current period, the era of community membership. The third phase emphasizes enhanced community integration, quality of life, and individualization. Supports are offered to create a network of formal and informal services to allow the person to meet the day to day demands in the home and in the community. These supports are offered to the child as well as the entire family. This approach operates under the premise that the presence of a child with a disability affects the functioning of the family as a whole and if normal family functioning is not nurtured, the child is at risk for an out-of-home placement (Bradley, 1992).

Today approximately 90% of children with intellectual disabilities live with their families (Fujiura & Baddock, 1992). Many children live with their families their entire lives and families have become the largest single providers of support to individuals with intellectual disabilities (Fujiura & Braddock, 1992). Families, usually parents, are the backbone of their adult children's support system. However, changes in the family, such as increased dual parent employment outside the home (Dunst, Trivette, & Deal, 1996), increased numbers of single parents, smaller family size, and lack of available extended family, suggest there are reduced resources to care for a member with a disability. These demographic changes, coupled with the decreased mortality of children with severe, multiple disabilities and complicated medical conditions, has resulted in the need for greater and better support of families (Bradley, 1992).

Due to changed expectations among families, an evolution in values in the disability field and concurrent shifts in program approaches, family support programs have increased in number and have improved resources. Parents who provide care base their arguments on the fact that family care is the most cost-effective way of integrating children into communities and programs by utilizing supports that already exist, rather than creating specialized services (Bradley, 1992). Advocates for persons with disabilities have urged that social policy should reflect the importance of family, and that disincentives to home living for persons with disabilities should be abolished (Singers & Powers, 1993). The current goals of the family support movement are to deter unnecessary out-of-home placement, return persons living in institutions to their families and to enhance the caregiving capacity of families.

The ideology of the family support movement represents a considerable divergence from the focus solely on de-institutionalization and the establishment of community-based programs. The third phase emphasizes that all families have strengths, and have the capacity to change and grow. The focus is on community membership and meeting supports needs of individuals in their family home and their communities. There is a belief that family members with disabilities are positive contributors to their families and their communities. Practitioners try to identify resources and match them to the needs directed by the family, rather than trying to fit families into rigid, already established programs (Singer & Powers, 1993).

Social Role Valorization

The focus of the third era of the family support movement is consistent with a recent concept known as Social Role Valorization (SRV). Wolfensberger also developed SRV, which he has stated replaces the principle of normalization. SRV is interpreted as a high-order empirical social science theory that informs people about the relation between the social roles that people hold and what happens to them as a result. SRV specifically emphasizes how to valorize the social roles of people at risk of social devaluation (Wolfensberger, 1995). Social role valorization is defined as “the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people, particularly for those at value risk, by using as much as possible, culturally valued means” (Wolfensberger, 1992, p.32).

SRV has been used as a teaching tool for professionals and families to assist individuals with an intellectual disability to participate in socially valued activities and to realize the importance of such activities. SRV challenges people in the field to take the extra step to be creative in offering support.

Wolfensberger states that “if one consistently engages handicapped adults in childish activities and routines, then they will probably be viewed by many observers as overgrown or eternal children.” This in turn will mean that persons with an intellectual disability may be denied appropriate developmental challenges or adult roles.

SRV theory makes assertions about what can be expected to happen if a certain course of action is, or is not pursued. The theory presents people with

one or more action decisions that affect a person, group or class, usually one that is socially devalued or at risk for such devaluation. Based on their view of what is needed for and by the party at issue, the decision-makers can then decide what 'costs' would need to be paid to obtain this end, and whether the 'costs' are worth the intended outcome. A price will be paid for doing certain things like violating societal laws.

Wolfensberger (1995) states that if one wants devalued people to be accepted in society, then an emphasis needs to be placed upon enabling individuals to have positive appearances, such as paying attention to personal habits. Examples of behaviour that facilitates the valorization of social roles of individuals with disabilities includes, not congregating large numbers of individuals as to make the community feel uneasy; encouraging age appropriate activities, and integrated employment and opportunities to live in the community. Wolfensberger continues that if one decides not to pay the price for greater societal acceptance negative consequences must be expected such as the continued devaluation, rejection, and segregation of individuals with disabilities from larger society.

SRV concept can be related to planning for the future for an individual with an intellectual disability. When parents allow their children to remain in the family home and do not plan for the future, which is usually a typical life event, we can expect crisis to happen when the caregivers die. Families can follow SRV principles to argue that individuals with intellectual disabilities have the right to experience valued roles, such as home ownership and living with peers.

The Concept of Inclusion

The community membership era of the family support movement has embraced the concept of inclusion. Parents are not satisfied with supports based on segregated and custodial models and fulfilled their beliefs by avoiding institutional care and maintaining their children in the family home for as long as possible.

Bradley (2000) recognized the efforts of practising inclusion in promoting developments such as; the exposure of the pitfalls of institutional care, creation of alternative residential and day supports in the community, passage of legislation for the rights and protection of people with disabilities and the provision of supports to families to maintain the individual with a disability in their home.

The system now is being challenged to allow people with disabilities to lead lives that are available to all citizens. Bradley (2000) states the basis for measuring inclusion is whether people enjoy such privileges as relationships, friendships, home ownership, real jobs, spiritual fulfilment, and exercise of personal choice. The vision of inclusion is to increase the quality of life and to help connect and appropriately support the individual in school, work, community and home (Knoll & Paterson, 1992).

Bradley (2000) suggests the focus of practice is now on ways to assist in maximizing each individual capacity and to increase their participation in community activities. The disability field has begun exploring ways of improving services such as empowering the person with a disability to take control of their

allotted funds to purchase or to create the services that would best serve them. Giving choices and involving the individual in planning can increase the person's self-determination and focuses services on the person, not the system. Another example would be incorporating the use of informal supports in a person's life, instead of always relying on staff. "Circle of support" is the practice, which surrounds the individual with unpaid people to naturally assist with making social connections, and obtaining access to needed services.

The notion of inclusion further challenges professionals to continue to improve the lives of individuals with intellectual disabilities and enhance the changes in the field that have occurred steadily over the last several decades. Individuals are now living and working in communities, the next step is to ensure they are truly included in daily activities and are viewed as having choices, and a high quality of life.

Ecological Systems Theory

The purpose of social work, as stated by Pincus and Minahan (1973) (as cited in Kirst-Ashman & Hull, 1999, p.8), is: 1) to enhance the problem solving and coping capacities of people; 2) to link people with systems that provide them with resources, services and opportunities; 3) to promote the effective and humane operation of these systems; and 4) contribute to the development and improvement of social policy.

Social workers can turn to the Ecological Systems theory to provide a conceptual perspective to further understand the disability field and planning for the future. According to Compton & Galaway (1989) ecological systems theory

shifts attention from cause and effect relationships between paired variables to the person/situation as an inter-related whole. In the theory person and situation are a whole in which each part is inter-related to all parts in a complex way through a complex process, in which each element is both cause and effect. These dynamic interactions, transactions, and organizational patterns that are critical to the function of the individual and the system are only observable when the whole system is studied. When attempting to understand a problem in social functioning, social workers cannot achieve understanding by assessing the individual and then assessing the environment. To strive for a full understanding, one must attempt to understand the complex interactions between the individual and all levels of social systems and the meaning the client assigns to these interactions. Rather than focusing on an individual's pathology, problems of dysfunction are explored in the transactions, lack of fit, opportunities and limitations among the individual and the various levels of the environment that make up his/her social system (Compton & Galaway, 1989).

In using systems theory, workers view people as active, capable of self-initiating behaviour and thus able to contribute and alter their behaviour and create a new environment. Systems theory allows the worker to reinforce the importance of client self-determination and client participation in the change process, emphasizing the necessity of considering client goals in assessment and planning of interventions (Compton & Galaway, 1989).

The activities within a particular system rely on the performance of all systems at lower levels and that activity of a system at any given level is a part of

and may be controlled by systems at a higher level. There are many systems individuals are a part of, one of which would include the family system. The family as a larger system relies on each individual member to play his/her own part, if it is to function successfully as an entity in the community. A member of the family who cannot fill his or her own function will require that the family make some adjustments (Compton & Galaway, 1989) as in having a member with an intellectual disability. Members of the family will need to alter their behaviour and the community and government may be called upon to offer additional support.

Ecological systems theory has contributed to the recognition that the individual is part of a broader family system, and cites a drawback of focusing only on the person with a disability as neglecting those other affected family members. The concentration on the family member with a disability is also short sighted because the nature of the family functioning is ignored. The problem experienced by one family member affects the entire system (Seligman & Darling, 1997).

Dunst, Trivette & Deal (1988) have identified three key conditions to working with families as being proactive, offering enabling experiences and empowering the person. To enhance helping relationships people are viewed as competent or as having the capacity to become competent. Furthermore, if the person fails to display competence, it may not be due to the deficit within the person but rather the failure of social systems to create opportunities for competencies to be displayed. Additionally, the person who is the help seeker,

learner or client must attribute behaviour change to his or her own actions if one is to acquire a sense of control necessary to manage family affairs.

Systems theory states that some systems have more power than others, which may limit, in the case of the family, the family's power to select appropriate solutions to problems and social functioning. According to the principles of systems theory in relation to planning with families with intellectual disabilities, workers must meet the clients where they are and to work to develop their goals and needs. Together then they will want to work with others systems, such as residential agencies and government, to reduce isolation and open systems to negotiate an appropriate plan for the adult with an intellectual disability.

Large systems need to recognize the impact they have on families and change as the families and individual needs change. Larger social systems may deprive the smaller system of adequate and effective social solutions to problems of growth and development and thus may act to decrease the family's power to select appropriate alternative solutions to problems of social functioning. Families may have the ability to cope but the larger system deprives them access to do so (Compton & Galaway, 1989). An example would be a family wanting to keep their child with an intellectual disability in the family home but the mother feels that she would need to stay home and would have to quit her job. However, the agency that supports their family will not provide enough financial support for them to sustain them, making her choice more difficult.

Ecological systems theory assists social workers to be aware of the concept of power and its impact on the smaller social systems that is embedded

in the larger one (Compton & Galaway, 1989). The theory describes systems as dynamic and the problems and issues are forever changing. Social workers working in this system need to be flexible and ready to address new intervention strategies. In assessing the problem, the social worker will determine whether intervention is best pursued by the individual, family, group, organization or community avenues (Kirst-Ashman & Hull, 1999).

Aging Parents Caring for their Adult Children

Perspectives of Old Age

There has been considerable amount of research on aging. Holosko & Feit (1991) suggest the concept of old age should be expanded to several sub-groups. The age range of older individuals is likely to be from 50 to 90 years of age.

Negative stereotypes of old age which may include incompetence, less able, decreased autonomy and effectiveness are common (Novak, 1997). Some myths about aging are that older people cannot learn new roles or skills, alienate their families, talk about their glory days when senile or do not give in return (Holosko & Feit, 1991). North American society has generally promoted these negative attitudes through establishing segregated living for elderly, mandatory retirement policies and idealizing youth (Novak, 1997).

Despite the negative views, research has shown that the elderly are unique and are not a homogeneous group. Each has an individual history and life experiences and relationships with a unique meaning and importance to

them. Society denies that old age is a viable, dignified and hopeful stage of life, complete with diverse biological, physical, emotional and psychological changes (Holosko & Feit, 1991). In one study between 90-95% of seniors felt satisfied with their families, marital status, friends and housing. Gautier (1991) states that old age looks more attractive than the stereotypes suggests.

Loss is a central theme of aging and is often much more difficult than in other stages of life. Losses often follow each other in rapid succession, such that the elderly have little time to adapt to one before they face another. Some examples would be loss of physical and mental functioning, lifestyle, hope, and self-esteem. Special attention to these losses and how the older person reacts to them are important in practice. To reduce stress and minimize change, the elder could be offered some options and some involvement in decision making which are crucial in successful adjustment (Holosko & Feit, 1991).

Researchers have found that older people who describe their lives as satisfactory and happy, seem to also have a sense of autonomy and have effective coping skills. They did not put up barriers between the formal and informal systems because they felt there was nothing to hide. Similarly, adapting to life in a flexible manner, showing openness to life experiences and stressing positive aspects of life seemed to also contribute to happiness. Positive older people tended to have an inner control, had the ability to constitute a natural support system throughout life and had a blend of interests (Ruth & Oberg, 1996).

For many people, old age is the first time that either they or their families will have to contact, engage social, health or medical services on a regular or continuing basis. These families are likely to need help to understand and sort through the various programs they require. The expectations of families are often not achieved as they learn of the limitations of the systems. Frustration and discouragement are two common outcomes many families realize when needed community services do not exist, are inadequate in number, have waiting lists or are poorly funded and staffed (Holoski & Feit, 1991).

Preuda & Lachman (2001) found that when seniors plan for the future they have leads to a greater sense of control, an increased perception of well-being, and an overall sense of life satisfaction. Research shows as age increases, a person's future orientation planning decreases. If the events of the future are uncertain or if life is viewed as stressful, people tend not to plan for the future. Society places value on autonomy and independence, therefore when older people are in the position of needing help, they view it as a sign of weakness, do not see a need for services and do not initiate contact for help (Holosko & Feit, 1991). Encouraging older people to continue to plan, even if there are uncertainties or a view of becoming dependent, may lead to greater satisfaction (Preuda & Lachman, 2001).

Introduction to Planning

A substantial number of people with intellectual disabilities live with their parents throughout their adult life (Seltzer & Krauss, 1993). Seltzer, Begun, Seltzer, and Krauss (1989) noted that in the United States fewer than 20% of

individuals with intellectual disabilities live in residential settings and 60% live without any formal services (Rose & Ansello, 1987). Doty, Jackson, and Crown (1998) using data from the 1989 National Long-Term Care Survey (USA) reported that almost half of the primary caregivers of older people with disabilities are themselves age 65 or older. The statistics are estimated to be consistent with what is occurring in recent years.

Families that raised their children prior to 1975 did not have formal services on which to rely. They were given the choice between keeping their son or daughter at home or placing them in an institution. The families that chose to keep their child in the home dealt with the social stigma, life long caregiving, financial responsibility and the impact on other children in the home (Hanneman & Blacher, 1998). Family and family caregiving are central to supporting aging adults with lifelong impairments in the community (Seltzer, Begun, Mogun & Luchterhand, 1993). These families have only begun to be studied in the last decade.

Seltzer and Krauss (1989) found that these older caregivers live relatively satisfactory lives and experience only an average level of burden when compared to other older people. They were found to be resilient, optimistic, function well with multiple roles, and are healthier and happier. In comparison to other caregivers, the mothers studied were healthier and had higher morale. Although Seltzer and Krauss (1989) could not generalize their findings to show how integrated these families were into formal service, they seem to suggest that

the parents that adapted the best to their circumstances would be able to provide long term care.

However, Seltzer and Krauss (1989) suggest that if parents had a high degree of active involvement with their children with little or no outside help, that it would lead to burnout and less community integration of the individual. Seltzer and Krauss (1989) found that the mothers in the study had smaller support networks than did same age peers who were not caring for their child with an intellectual disability. The researchers also found that the salience of the parental role remaining central to the mothers identity well into old age, diminished family social climate, including relationships with other family members than for their age peers.

Turnball, Patterson, Behr, Murphy, Marquis and Blue-Banning (1993), refer to various parents' stories of raising children with disabilities. Parents revealed that the transition to adulthood created tremendous stress for their family and there were serious issues regarding exploring the future. Some of the parents held the belief that they received less support after their child transferred to adult services. The parents suggest a lack of sufficient adult services especially when exploring residential placements for their son or daughter.

Importance of planning

Heller & Factor (1991) found that the greatest but least met formal support service needs of caregivers is future planning. Families lack information regarding residential programs, do not have access to information on

establishing guardianship or making appropriate financial arrangements. Also absent is information on legal implication of financial plans.

Planning for out-of-home placement can be a complex and time consuming process. The overwhelming consensus in the literature is that many parents will continue to care for their child with an intellectual disability throughout their life, as they themselves age and become frail. Many of these parents are not known to the service system because they are fearful and suspicious or unaware of services for which they qualify (Clarke & Susa, 2000). During a time of crisis, such as a death of a caregiver, parents tend to begin to approach the system for assistance. Case managers spend their time locating emergency placements and adding names to the already long waiting lists (Heller & Factor, 1991).

For aging parents and their older children with intellectual disabilities, there may seem to be no place to turn for assistance in meeting their unique and interrelated needs (Clark & Susa, 2000). Although future planning may generate anxiety for parents caring for a person with an intellectual disability, planning for that person's future is essential in preventing crisis placement in inappropriate settings (Heller & Factor, 1991). The goal of planning may not achieve a secure, permanent residential situation but rather ensure parents remain involved with the person with intellectual disability and monitor the quality and appropriateness of services (Seltzer & Seltzer, 1985).

When placement does occur, Essex, Seltzer and Krauss (1997) found that some parents made that decision because they viewed it as a normative life

process and wanted to increase their child's independence. However, the most typical predictors of out-of-home placement were; failing parental health, death of mother or age related changes in the son or daughter. Parents stated the following reasons for not planning for future living arrangements: they were happy with current arrangements, feared the unknown, or they had few satisfactory options. There is an obvious need to plan and these families need more information on residential agencies, financial planning and possible legal arrangements (Heller & Factor, 1991).

Aging parents have lived through three paradigm shifts in services. The shifts are referred to as institutionalization and segregation, de-institutionalization, and community integration and membership. As well, many parents have had to work with many workers due to frequent staff turnover and may find it difficult to believe and trust that community inclusion with supports will work. The paradigm asks them to trust that there will be enough supports and to give up their life long value of "taking care of their own". The parents of this cohort have also experienced the impact of institutionalization and may have difficulty forgetting how poorly they were treated by the system. (McCallion & Tobin, 1995).

Although parents find thinking about the future challenging and logistically complex, the process can be used for completing unfinished business and can be therapeutic. Planning is a very important task, which should include diverse goals and involve reliable people. Planning well can avert crisis from an ill-

prepared transition, ensure security and stability, and forecast future service demands (Bigby, 2000).

Parents tend not to plan

For parents with adult children with an intellectual disability, planning usually includes making financial and guardianship arrangements and finding appropriate out-of-home placements. This emotionally laden and complex process is compounded by the fact that an adult may survive his or her parents by several decades, therefore plans must be sufficiently flexible and adaptable to meet the changing residential, financial, and legal requirements (Seltzer & Seltzer, 1985).

Bigby (2000) categorizes planning for adult children with an intellectual disability in three ways: avoidance, ambivalence and active planning. Some parents make plans but want to remain the caregiver and therefore they do not actually implement the plan. This can cause problems, as residential settings may not be available on demand.

Parents are usually looking for security, and for the care of their child to continue the way they provided it. Bigby (2000) found that families want placement but not until the death of the parents. The preferred placement was with a sibling of the person with an intellectual disability. Often this is an assumption never discussed or planned for, meaning siblings may have to assume care for their brother or sister without training or preparation (Heller & Factor, 1991).

Parents are frequently paralyzed because of complicated issues with caregiving decision making in which they feel are no satisfactory solutions (Grant, 1990). Parents fear that their wishes will not being carried through because of some unforeseen circumstances such as; termination of public funding or problems with the residential agency (Stengle, 1996).

Grant (1990) suggests avoiding planning may be due to the fact that problems aging parents' face are complex and potentially psychologically distressing. Stengle (1996) agrees saying planning brings parents face to face with their own morality. Furthermore parents are coping with their growing limitations imposed by their own physical aging at the same time as they are faced with chronic and periodic stress of caregiving. For most elderly whose current situation is stable, concrete planning and preparing for their future impairment is associated with anxiety (Heller & Factor, 1991). Parents must deal with the emotional issues of relinquishing care and agonize over choices to be made. Additionally, they are concerned that their child does not have the skills to enter the world yet. Parents also have a feeling that no one will ever love their child, understand their needs and comfort them, they way they do (Stengle, 1996).

Residential planning

Parents worry about what will become of their son or daughter when they are no longer able to provide care. Perhaps the most challenging aspect of future planning is to make decisions about where the adult child will eventually live (Freedman, Krauss & Seltzer, 1997).

Residential planning bring to awareness unresolved or unspoken concerns of the parents, including continuing family responsibility, separation, and independence. Making residential plans may signify the beginning of the launching stage as they finally prepare to relinquish their active parenting role (Carter & McGoldrick, 1989). The launching stage of children with intellectual disability is among the most stressful transitions for parents and is often accompanied by interpersonal turmoil, fluctuations in parental well-being, and dis-equilibrium in the family (Seltzer, Krauss, Choi, & Hong, 1996).

The tendency for families to make future residential plans is linked to parental hopes and desires for their adult child's future, stage in planning process, and the perceived urgency of the current circumstances. Freedman, Krauss, & Seltzer (1997) longitudinal study explored aging families' future plan preferences and parental psychological and social factors. The study found that less than half of the families made residential plans and the majority were content to having their adult child remain in the home for another couple of years. In the case of the families that did want to place their adult child, they believed it would just occur and were not aware of the long process that placement involves.

Despite the increased emphasis within the service system to engage in person-centred planning (Bradley, Ashbaugh, Blaney, 1994), and for parents and adults with intellectual disabilities to be active participants in such planning (Dybwad, 1990), there appears to be substantial reluctance among parental caregivers to begin placement planning. The results of the study suggest that having a residential plan, proved a greater probability of obtaining a placement.

However having a plan does not guarantee the preferred placement when needed because the system responds to the crisis situations as a priority (Freedman, Krauss & Seltzer, 1997). The awareness of long waiting lists and the long process involved in residential planning were identified as potential deterrents to motivation to begin planning.

Another reality of residential placements is staffing issues of which parents become aware of and worry about. Direct care staff in community homes are frequently stretched to the limits, having the role of nurturer, recreation activity aides, behaviour specialists, cooks, and financial managers. Staff turnover is a major problem as the typical person hired for these jobs are students or are biding their time until they can find a more lucrative job. The effects of turnover on people with intellectual disabilities can be disturbing. They rely on staff for social contacts and they may see them as their friends and when the friend leaves, it can cause the person to be confused and to go through a grieving process (Stengle, 1996).

Gordon, Seltzer & Krauss (1997) urge professionals and families to “marshal the energy and vision to engage in planning for the future”. The researchers want families to consider the considerable investment they have already made in securing the well-being of their child and planning is the only way to keep that intact. Comfort and easier transitions may be the result of taking a careful look at the options available for the adult child with an intellectual disability whose future depends on the quality and capacity of the community-based service system (Gordon, Seltzer & Krauss, 1997).

Financial Planning

Financial planning is the most common type of planning that is undertaken by families (Bigby, 2000). There are two arrangements made 1) leaving monies to relatives with the understanding that they would provide or pay for the care of the relative with an intellectual disability; and, 2) leaving monies directly to the person with an intellectual disability with another family member as a trustee (Bigby, 2000). Further education is needed to ensure that families have all information that is needed to secure financial plans. Pitfalls in financial plans have been cited as the trustee having a different idea than the parents on how the money should be spent (Heller & Factor, 1991).

Predictors of Placement

The literature stated has shown that parents find residential planning for their children difficult, however this activities is found to be a critical need since the adult child will out live the parents. Exploring when parents usually place their children may be beneficial.

Numerous studies have been done on the predictor of out-of-home placement. Only a few predictors seem to consistently appear in the literature, which includes demographics such as having an older child, a single parent household, an ill family member, or when the parents are elderly. (Hanneman & Blader, 1998).

A study by Heller and Factor (1991) provides various factors families consider when placing their child which include; perceived demand placed on the family (Hanneman & Balder, 1998), the availability of resources, and the extent to

which the family perceives the caregiving situation as stressful (Hanneman & Balder, 1998). The study indicated that placements tend to be more prevalent when the child has a severe disability, maladaptive behaviours, parents who are older and in poor health, higher socio-economic status, few social support and there is a perception of caregiving burden. Hanneman and Balder (1998) suggests additional placement predictors as disruption of family harmony and having more than one child in the home.

Asking parents what assists them in taking the step toward placement may be useful in determining what is helpful to avoid a crisis. The researchers suggest families who were less able to count on relatives for support were more likely to make plans for placement because they were less likely to have a relative with whom the family member with an intellectual disability could eventual live (Heller & Factor (1991). Greater involvement of formal services actually increased the chances that caregivers would access residential placement. Families who used respite care were more likely be in favour of out-of-home placement. Use of the service system resulted in less hesitation to access the service system and may have decreased apprehensions towards existing residential programs. Heller & Factor (1991) continue to suggest that formal services, such as family support programs, can help introduce more formal services and assist with coping for the transition process.

Support in Planning

Due to the complexity of this very important process, professionals and researchers have begun to develop ways of assisting families to continue the

care for their adult children and to develop plans for a time when they will no longer be able to do so. Ansello and Janicki (2000), state that parents need reinforcement, recognition, and reliable resources for the support they provide their children with intellectual disabilities. Family caregivers are the unrecognized resource of the long-term care system, saving government billions of dollars and saving the aging and developmental disability service system from becoming further overwhelmed. The authors further suggest that tax cuts and stipends may ease the financial burden of providing life long care. To enhance the lives of both parents and their son and daughter with disabilities Clark and Susa (2000), identify the need for trained staff, collaboration of the aging and disability fields, and assistance making concrete plans.

What is essential when developing plans for the future, is to keep the family and the person central to the ideas and involved wherever possible. Adults with intellectual disabilities and their parents can be empowered to enhance their decision-making abilities by being provided information, skills training, and opportunities to experience new options and make informed choices. Successful intervention requires the involvement of families and professionals. O'Brien and O'Brien (2000), urge when working with such experienced families to respect their knowledge and acknowledge their strengths. Stories of the individual's life needs to be told by the people who know them best in order to achieve dreams and direction towards a positive future.

Informal Support and Community Membership

Adults who remain in the family home with their parents have smaller, less diverse informal networks in which their parents fulfil a more central role compared with those who have left parental care (Krauss & Erickson, 1988). Grant (1986) suggests that networks of adults with intellectual disabilities living at home are typically family embedded and community insulated. The individuals often share the same friendships group as their parents and when their parents and their peers age and die, the adult child's informal support are vulnerable to be disrupted and lost. The role of the parents including advocacy, monitoring and negotiating with agencies is crucial to ensure the overall well being of the older person and indispensable for this group of people who are highly reliant on formal services to replace this direct primary care previously provided by parents (Bigby, 2000). The nature and quality of this formal support may be a crucial determining factor of a person's informal support. Formal services find it difficult to replicate tasks vital to safeguarding life, such as advocacy, monitoring well being and provision of emotional support.

Stengle (1996) suggests that people with intellectual disabilities need unpaid advocates who will not be swayed by budget crunches or lured away by better jobs. People with intellectual disabilities need to be loved and being loved by someone who is being paid to love and care for them is not adequate. Stengle (1996) offers that "I am convinced the best answer is to rely on other people. What your child needs is a supportive, caring group of advocates who want to look out for her after you're gone". She counsels that to improve the

likelihood of finding someone who will take a lifelong interest in your child, parents need to match him/her with as many different environments and situations as possible in the hope that someone will connect with them and want to be involved. Potential supporters should be unpaid, or give of their time freely (Stengle, 1996).

Formal and informal sources of support are both necessary and complementary for older people with intellectual disabilities to replace care previously provided by their parents. A challenge for the whole community is to ensure the development and delivery of optimal quality formal sources. However, the limitations of these must be recognized. The greater challenge will be to foster the recognition, respect and maintenance of informal support and provide resources and conditions that encourage and sustain their development (Bigby, 2000).

Professional Intervention

Although families make plans independent of formal supports, social workers in the system who function as case managers, are the primary professionals who have the responsibility of assisting families in such plans (McCallion & Tobin, 1995). The service system has persisted in focusing on clients with intellectual disabilities rather than on the family needs in making future plans. Until recently, there has been little consideration of the changes that case managers must make when assisting older parents and their adult child in making future plans (McCallion & Tobin, 1995). Seltzer and Krauss (1989) conducted a study where they found only a few programs that focused on the

entire family and there was a very small amount of outreach to individuals not already known to the system.

Smith and Tobin (1993) conducted a pilot study in which case managers in a disability department were interviewed. Although case managers admired the parents, they also criticized parents for treating their adult children like children and for their resistance to making alternative residential plans for the future. The fear is that this attitude will conflict with providing counselling and direction to these families. The case managers also commented on the lack of administrative support they received for working with aging families. (Smith & Tobin, 1993).

McCallion and Tobin (1995), studied social workers who had a modest agreement that caseloads be assigned to specialists in geriatric issues and stronger agreement that expertise must be provided on issues regarding working with the aging. The social workers felt comfortable working with older parents but wish they had more support in doing so.

A critical component of social work practice will inevitably involved the interweaving of social services with medical care and health services. To be effective in this regard social work must be able to move fluidly from one system to the other, in an integrated community service network. Social workers will need to find a working relationship between clients' rights and to need for self-determination, proper social work practice, the mandate of the agency and opinions of family members and other professionals working with the client (Holosko & Feit, 1991). Not unlike the disability field, knowledge in areas such

as pharmacology, debilitating illnesses, domestic relationships, mental health and community resources, will be essential for social workers to learn when working with older clients (Novak, 1997).

The lack of alternative housing services has frequently 'forced' older parents to keep their sons or daughters at home (McCallion & Tobin, 1995). The need to create appropriate housing for adult children and for their parents is another issue that needs to be addressed. An administrator interviewed for the study suggests changing the systems to support the aging as well as the person with developmental disabilities by sharing resources and expertise for this newly emerging population (McCallion & Tobin, 1995). Similarly, in supporting these families with programs, services from both aging and the developmental disability service system can promote more effective collaboration and communication between them, in keeping with emerging trends. This service system can promote co-ordination and ensure a more complete and satisfactory response to the entire family than to those of only one individual or generation (Clark & Susa, 2000).

Social workers are interested in working with older parents and recognize that they have been under served, and understand that different service approaches must be considered (McCallion & Tobin, 1995). Practitioners need to work with the entire family, including siblings when planning for the individual with an intellectual disability. Professionals need to spend time building relationships with older parents and suspend judgement and to get to know their client's needs. Outreach services are important to overcome resistance to

planning and avoidance of services to bring older parents into contact with case managers who could assist them in planning. An example of outreach is offering informational meetings sponsored by non-profit organizations to bring families together to meet and discuss issues (McCallion & Tobin, 1995).

Clark & Susa (2000) provide a good example of how to further support families with future planning. They describe the Rhode Island Family Futures Planning Project which was an extensive educational program to empower caregiving families to think, feel and act in new ways to overcome the dilemmas that prevented them from engaging in planning. The intervention was based on the core values respect, competency and of supporting community involvement. Participants were encouraged to develop skills and change behaviours to eventually assume control over their lives and to achieve their life goals. Similarly, since providers and professionals were challenged to work together more closely in the support of these family goals and as a result change their own knowledge, feelings and actions related to interagency collaboration and the empowerment of families.

Summary

The family support movement has played an important role in how services are provided to people with intellectual disabilities. Together with concepts such as the principle of normalization, social role valorization and inclusion have assisted to view institutionalization and segregation are less than

ideal for individuals with intellectual disabilities and created ideas such as community integration and the recognition of the need for quality of life.

Parents have been found to be the main care providers and advocates for their adult children with intellectual disabilities throughout their life. As the individual outlives their parents and needs to find further care, many issues surface with planning for the future. Parents are worried about the future and are at times immobilized and do not take the necessary steps to secure placements and establish them with their adult child with the necessary resources. Waiting until the parents are elderly, ill or have become widowed, is commonly when a parent feels forced into planning and could create a crisis in the formal services that are overwhelmed and may not be trained or have the time to assist the families.

There is recognition that the increasing number of older people will require the system to change or that people and the required services will be seriously compromised. Collaboration of the aging and disabilities field is necessary in order to ensure the family as a whole is properly supported in making plans for the future. Creating proper services, flexible plans and ensuring the quality of life continues for the adult child with an intellectual disability after the parental involvement is not longer available, is a challenge for parents and professionals. Social workers require specific training to build relationships with the aging parent and the older adult with an intellectual disability. The community has a role to ensure the individual is safe, has friends and is accepted.

CHAPTER THREE

METHODOLOGY

Research Design

The methodology used in the study will be highlighted in this chapter. Topics included will be the source of participants, participants, interviews, compilation and the analysis of the data. Qualitative research was chosen as the most appropriate method for studying older parents' perceptions on planning for the future for their adult child with an intellectual disability. The nature of qualitative study assisted the researcher to explore with parents their own experience and to achieve a deeper understanding about the topic of discussion. In a natural setting, qualitative research provided a framework for the researcher to build a complex, holistic picture of the phenomenon, in order to explore its' meanings to the participants (Silverman, 2000). According to Creswell (1998), a qualitative design is often used with participants who are marginalized and with topics that are potentially emotion laden.

Creswell (1998) suggests a phenomenological approach can be used to focus the inquiry on the structure and essence of the subject explored, in this case we will focus on what the parents' experienced and how they interpret this experience to develop their own sense of the world.

Since the proposed study was an area that needed to be explored in detail, the variables were not easy to define and the open nature of the research questions all suggested the use of a qualitative method. Potentially the results of the study can be shared with other parents' experiencing similar circumstances

and who may find the outcome helpful. Relevant definitions for the research can be found on page four in Chapter One.

Researcher's Experience

To successfully gather and interpret data, the researcher must recognize any biases or pre-judgements and rely on intuition, imagination, and universal structures to obtain the picture of experience (Creswell, 1998).

I have worked in the disability field since 1995. I have worked in community work programs, for government and most recently for a program that assisted families with an adult child with an intellectual disability living in the family home. The majority of my time was spent with elder parents who have been referred from Family Services for assistance with residential planning and issues relating to transitions. As the literature suggests, families are fearful of the system and of the future of their child who they never thought would out live them. A large amount of time my spent explaining the system, and then advocating for families who were not always receiving resources they felt they needed. The inflexibility of the system and the lack of available information created frustration.

For a worker to experience frustration is one issue, but for families trying to find appropriate help and to access information frustration could be debilitating. My interest in how families experience planning, prompted the idea behind the thesis. I recognized that I would have biases, so I relied on the

literature, the family's experiences and other's opinions to ensure I was not only focusing on my concerns.

I expected to find many families that were blaming Family Services for the lack of services for their children with intellectual disabilities. I also thought they would be negative toward the staff that worked within Family Services. I also expected that many of the adult children of these parents would still be living at home and the parents would be having trouble navigating through the maze of services to find the best situation for their son or daughter. I thought the parents would be exhausted and present as being stressed.

Source of Participants

Continuity Care Inc., whose mandate is to assist families plan for the future for their family member with a intellectual disability, was approached for the use of their mailing list of parents involved with their organization. The Executive Director, Mr. Bob Manwaring, agreed to be involved in the research. Mr. Manwaring organized the mailing list to select the parents who fit the criteria of being 60 years or older and who lived together with a son or daughter with an intellectual disability. Age 60 and older was chosen because according to Hanneman & Blacher (1998), the parents similarly may not have had access to many formal services while raising their children. Additionally, the parents on the mailing list will have experienced or is experiencing planning for their son or daughter with an intellectual disability. Mr. Manwaring was also viewed as a source of information as he is a parent of a daughter who is labeled with Down's Syndrome. He reviewed my definitions and interview questions. I viewed this as

my pilot interview. Bob was able to provide direction and a few suggestions on how to ask a few questions differently.

Thirteen letters were sent to potential participants (See Appendix A). Included in the letter was my phone number so participants could ask questions or to set up interviews. Three people responded to the initial letter. After a reasonable amount of time the remainder of the prospective participants were contacted and seven additional interviews were arranged. One interview had to be canceled and was not able to be rescheduled due to the participant being too busy. After a few interviews were completed and a meeting with my advisor, four more letters were sent out to expand the potential for gathering information. Three more interviews were established, making for a total of twelve.

Participants

Once agreement was made to be a part of the study, most participants seemed eager to start the interview. A few individuals needed further information and some clarification regarding the questions. The questions regarding financial arrangements were concerning to some which I felt was because they did not want to share if they were leaving money or how much money they were leaving for their adult child. I said that there were not questions of that nature and if they still felt uncomfortable they did not have to answer the question I did ask about financial planning.

All of the interviews were set up in the homes of the participants. The participants were all Caucasian and two couples had immigrated to Canada

when they were first married. Sixteen people were interviewed which included four couples. Two of the women interviewed were married but their husbands were not available to be interviewed. Many of the women did not work outside the home for pay and all participants were retired except for two men. Table 1 describes the participants' characteristics.

Table 1: Participant Characteristics

Participant	Age	Status	Age of Child	Child at home
A	75	widowed	50	no
B	62 (h) 60 (w)	married	27	no
C	82	widowed	33	no
D	83(h) 79(w)	married	48 & 52 & 57	no
E	60	married	40	no
F	76	widowed	31	no
G	75	widowed	44	no
H	79	widowed	38	no
I	74(h) 73(w)	married	42	yes
J	65	married	42	no
K	68	widowed	39	no
L	60(h) 59(w)	married	30	no

Through observation of the homes and the professions of the participants, the parents probably ranged economically from being quite affluent to more modest incomes. The label of their child with an intellectual disability ranged from

profound intellectual disability to mild. One family had three children all of who had a diagnosis of an intellectual disability, and the rest had one adult child with an intellectual disability. Most families had other children, and whose current involvement with their sibling with an intellectual disability, as stated by the participants, varied from each family.

All participants appeared to be quite open and articulate regarding the topics explored. I was made to feel very comfortable in all the homes and was always offered refreshments and snacks. Many of the participants were concerned about taking up too much of my time and were concerned they would not be of any assistance to my study. I re-assured all of them that their time is what I am concerned about and any information they had to offer would be helpful.

Interviews

I followed the direction from Patton (1990) and provided a framework in which the participants felt comfortable to respond to the interview questions in a manner which accurately and thoroughly represented their point of view. Seven open-ended questions were developed prior to the interviews (see Appendix B).

Before each interview began I gave a background on myself and explained why I wanted to interview them. All of the participants except one would be interested in viewing the findings after the study was complete. Many had been part of previous studies and assessments and were disheartened when there was not follow up afterwards.

I defined what I viewed as 'future planning' and explained that it could be anything that they felt was planning for their child and that it did not have to be limited to how I defined it. Most participants were ready to start the interviews right away.

The interviews ranged from taking 45 minutes to just over two hours. The average was about one hour and a half. All participants were asked to sign a consent form (see Appendix C). Participants were advised that they could withdraw from the study at any point and refuse to answer any question. They were assured that their confidentiality would be protected. Most had questions about my involvement with Continuity Care Inc. Some had called Mr. Manwaring to get his opinion on participating or to tell him that they were involved. Most participants were not concerned with their confidentiality. However, I reassured them that I would not reveal any information in regards to their involvement. Each interview was assigned a number in relation to the order that I interviewed them.

The first interview was scheduled for the afternoon of September 11, 2001, only hours after the terrorism attack on the United States. All of the participants with scheduled interviews around the tragedy were asked if they wanted to re-schedule; however all wanted to proceed. Many people talked about the events prior to the interview beginning.

The use of the interview guide ensured that the same questions and issues were explored in the course of the interview with each participant. The interview guide provided topic areas which the researcher was free to probe

about in order to enhance the information revealed (Patton, 1990). Rapport and a conversation with participants was able to be developed throughout the interview.

Only one interviewee seemed to be saddened by the discussion. The sadness was not due to current planning but on past choices they had made. We were able to discuss the topics and their feelings further. I spent time with all participants to determine if the interviews left them feeling uneasy. Generally, the topics explored were something all of them had thought of before and it did not appear to bring on any bad feelings. At the request of one couple, I sent some information regarding sexuality training following the interview. One woman invited me to her daughter's sharing circle so I could see how they operated. Most people said that it was motivating to talk about the topics because it prompted them to think more about what else they needed to do.

Most participants were open and excited to talk about their situations, especially their children. I was shown pictures of their children and was told stories of their accomplishments. On a few occasions we shared a tear or two because of some of the touching experiences they had had.

Most individuals had thought long and hard about the topics discussed, previously to being approached for the research project. Some chose to be interviewed for a chance that someone influential would hear their stories and help make changes. I felt it was obvious that the parents enjoyed sharing their story and that it was important to allow families to have a chance. There seemed to be an overwhelming response to the second question, which asked about the

parents biggest concern with planning. Much of the data that was gathered surrounded the issues and problems the parents had encountered when planning for their adult child with an intellectual disability.

All participants were thanked for their participation and were applauded for their commitment to their adult child. I gave them an approximation of when they could expect some follow-up information on the findings.

Compilation

All interviews except one were tape recorded. The participant who did not want to be recorded felt uncomfortable with saying names of organizations that she wanted to talk about on tape. I took notes for her interview. During and after all interviews, I took notes about my thoughts and observation about the interview and any future considerations for upcoming interviews. A professional transcribed three interviews. Due to the contents of the interviews, she was asked to keep confidential any information that was learned from the tape. I decided due to cost, time and the professional having problems understanding the tapes, to do the rest of the transcribing myself. This proved to be a positive experience, allowing me to learn how to improve interview skills, be reminded of any pauses or changes in the voices of the participants, as well allowed me to begin thinking about what all the data meant.

I found that after about eight interviews, the information had become repetitive. Four more interviews were completed with the idea to find different information.

Interpretation/Analysis

According to Patton (1990), ideas for analysis can begin in the course of gathering data. I began thinking about what the data was telling me and I started taking notes on my thoughts. However, I did not want to start that process too early for fear of not keeping an open mind when presented with data that contradicted what was already found. I attempted to follow the inductive analysis which means, "that the patterns, themes, and categories of analysis come from the data; they emerge out of the data rather being imposed on them prior to data collection and analysis" (Patton, 1990, p. 306).

The raw data were transcribed verbatim in order to preserve the original context and meanings of the interviews as much as possible. I also found that using direct quotes in the body of the write up proved to be a way of adding authenticity when describing the participant's experience. Patton (1990) describes it as way of providing a holistic picture of what is happening in the activity or event. The format of the transcripts allowed for enough space to write notes in the margins during first level coding and include non-verbal communication that may have been noted.

The volume of data that was gathered was overwhelming and organizing it in a sensible manner seemed daunting. Following guidelines and establishing a routine is necessary in order to fulfill the data analyzing stage.

First-level Coding

After re-reading the transcripts, I proceeded to first-level coding. Tutty, Rothery, and Grinnel Jr. (1996), define first-level coding as "a combination of

identifying meaning units, fitting them into categories, and assigning codes to the categories” (p.100).

I began going through the transcripts identifying meaning units from the words, sentences and paragraphs which best answered the questions from the interviews. Different colour tabs or highlighted colours were given to each category developed through this process. I went through all the transcripts until no new meaning units were classified and no new categories emerged. Patton (1990) states this occurs when sets of categories have been saturated so that new sources lead to redundancy. I then went through the transcripts one last time.

Immersing myself in the data was very helpful with becoming familiar with the context of the data. I found that in one answer to the question, I could identify a few categories. As well, a meaning unit could fit into more than one category. However, the meaning unit that best suited the category was chosen. Additionally, throughout this procedure, I encountered some meaning units that did not fit exactly into the categories but proved to be significant. I marked them as such and would include them in the findings. Patton (1990) refers to Guba (1978) to state that a large number of “unassignable or overlapping data items is good evidence of some fault in the category system” (p.311). However, I did not find that there was many meaning units that did not fit into the categories that I defined.

By assigning each category a different colour, I was able to find each category and assign it a code. The list of codes was written on a page. After

first-level coding was complete, I gave three transcripts to my advisor and the list of the categories that I had created. He was able to determine if he found the same categories as I did in the data. This check was conducted to ensure that the categories and their codes reflected the information in the interviews (Silverman, 2000). Using more than one coder to assess qualitative data is a well-accepted approach to add trustworthiness and credibility to the research.

Second-level Coding

At the end of first-level coding I was able to manage and analyze the data collected in the interviews much more easily. I felt that I was able to start organizing the categories and began to develop my Findings. As I worked I was able to begin contemplating the data and find themes. Themes are patterns that continually appear in the data and develop the major conclusions of the study. Regularities and irregularities in the data were noted. I further organized the data into themes and labeled them with new names or codes. The effort of uncovering patterns and themes is a creative process that requires making carefully considered judgments about is important in terms of the objectives of the research. Since qualitative analysts do not have statistical tests to tell them when a pattern is significant, they must rely on their own intelligence, experience, and judgment (Patton, 1990).

Overall, the development of themes assisted me in examining the data in a much broader context. I found that I continually consulted the original transcripts in order not to lose sight of the original categories and data. I also

began relating the data to the purpose of the study and the literature based in the topic to find interpretations of the data.

The findings or the results of the study emerged through second-level coding and allowed for the further interpretation of the data.

CHAPTER FOUR

FINDINGS

The purpose of study was to explore parents' perceptions of planning about the future with their son or daughter with an intellectual disability. The questions for the study were as follows;

- What are parents' experiences related to planning for their son or daughter with an intellectual disability?
- Is there anything about their experience they would change?
- Is there anything they feel professionals should know about their experience?
- What advice would they give other parents experiencing a similar situation?

This chapter is organized in four sections based on the themes, which emerged from the interviews with the parents; what has been the parents' experience, what has helped the planning process, what areas of planning are incomplete and what has been the impact of the system. When asked the questions about planning for the future for their adult children with an intellectual disability, the parents seemed to feel compelled to share their initial experiences with developing supports for their child. For some parents this meant telling the stories about schools and pediatricians.

The first area, parents' experience with planning, shows what the parents have encountered over the years. Sections explaining how the parents have been creative, spent many hours volunteering and contributed financially to services, creates a background on what activities parents found important and necessary to be involved in over the years. The hurdles the parents

encountered, such as having to endure staff turnover and the parents having to act as their child's advocate, are important to mention and to understand in order to explore what the parents have gone through and how it will impact on the future of their children.

Parents share what they feel has been helpful with the process of planning in the second section. To learn what the parents found positive in planning, how they worked with professionals, and met with other parents, assists in understanding what the parents felt they needed to do to be successful in planning and implementing their plans.

In the third area, parents discuss what remains to be accomplished for the future of their adult children. Sharing concerns and fears, assists in understanding what these parents feel are still important to explore and to solve. The incomplete portions of the parent's plans are large areas of concern for parents and they discuss how these areas can be completed in the current ways services are delivered.

The final area explored is the impact the system has had on the experience with the parents. Learning about the interactions between the parents and formal services shows a fuller understanding to the issues presented. Recommendations by the parents to other parents and professionals are also given.

Parents' Experiences with Planning

The first question asked of the parents was what was their experience with planning for their adult children. Most agreed that they started thinking about planning when their children were young. Based on what the parents expressed, parents were and still are heavily involved in the lives of their children. Examples will follow to show how parents were creative, made financial contributions, spent many hours volunteering and being advocates for their children. Their experience with hurdles in planning will also be explored.

Parents are required to be creative

Parents found that their children did not always fit into the services that were available for them. Therefore they found that they needed to take it upon themselves to develop services and resources for their children that supported their unique needs.

A mother explains about when her daughter started swimming as part of her day program,

We discovered that the pool she was going to did not have the mechanisms for her to get into the pool. So I knew what I needed but it took me heck of a lot of time to get it. I called many places and finally discovered this old trolley thing at Rehab Services – way in the back under a pile of old equipment. I took it home and painted it up. K goes swimming three times a week and uses it every time and we are able to leave it right at the pool. It's funny the great thing about our daughter is that she challenges us to be inventive.

Two women I interviewed knew each other and were very good friends. They both told me the story of how they met at church. The mothers eventually developed their own type of bible study and church services so their children

could benefit from going to church. Their adult children liked to talk out loud about what they were studying and would not be able to in the regular church setting. Therefore the parents created a space in the regular church where they could meet and go over the lessons. Each of their children has tasks that they are responsible for completing each Sunday. Both of the children interact with the other parishioners, who have accepted them, for the most part, into the church setting. The parents are currently looking for ways to expand and invite more people to their group.

Other parents, in their quest to assist their children to be as independent as possible became inventive on how they taught their children skills. One father told me the ways that he teaches his forty-two year old son about grocery shopping and how to get the most out of his money. He takes him to the grocery store on a frequent basis to explain the differences in buying bulk and buying convenience foods. The father explains to me that it would not be the end of the world if his son eventually buys the smaller box of cereal instead of the economy size but maybe one day he will get it. The father also sits down with their son every pay day to go over his budget for the next two weeks. They draw out a calendar so his son can visualize how much spending money he needs to have to cover his costs until the following payday.

Another family, who had lived in a rural setting, wanted their son to attend a regular school but there was nothing in their area. They found a school approximately 45 minutes away. The parents drove him to school every Monday and picked him up every Friday after school. Their creativity came in finding

people with whom their son would stay throughout the week. The teachers would often help to find an individual to help and the family would pay the transportation and the portion of the room and board.

For one family no amount of creativity seemed able to assist them and they felt they needed to place their children in an institution.

We have three children that are disabled. The two girls were described as having moderate retardation and I think our son is profound. He has been at Portage (meaning the Manitoba Developmental Centre) since he was 6 years old. The girls lived there for 10 years and were taken out when ARC started the Welcome Home Project. At the time MDC was the only thing ...I think if we didn't do it that my wife would have had a nervous breakdown. I think it would have been different if we only had one.

The parents explained how they did not know their first child had a disability until she started school and by then they had the two other children. They explained that they were both carriers of a recessive gene and if they would have had children with other people they may not have had children with a disability. They explained that their daughters are living in a community residence and visit very regularly and the parents are very involved in their life. The parents visit their son regularly as well.

Parents need to spend many hours volunteering

The parents who were interviewed have devoted countless hours volunteering to maintain the boards, programs and agencies that support or eventually will support their children. One father explains, "there is no staff there during the day, so my wife takes the girls to their dentist and doctor appointments – she helps out with a lot of things like that".

Every parent had been or is still very involved in an agency that supports their children. In the group that I interviewed parents were involved and spearheaded the following programs in Winnipeg; Citizen Advocacy, Manitoba Marathon, Winnserv, Network South Enterprises, ACL- Manitoba, SPIKE, Continuity Care, In the Circle of Friends, Sturgeon Creek Enterprises, and L'Avenir Housing Co-op. Literally, almost all these parents were in the ground floor of these organizations. One explanation that was stated by a father was, "some of the smaller agencies, they do some really good stuff, but the Executive Director tends to be the secretary, the accountant, a jack of all trades ... and generally wear out after a number of years because of the workload is so heavy. So I think that the parents need to be involved or the programs will suffer."

Parents also contributing financially

In addition to volunteering parents who were able to, contributed financially to projects which would allow their son or daughter to be supported in a home of their own. Working within the guidelines Family Services impose, can add time to when projects can be started and may not always be enough to provide extras that some situations require.

Some families elected to start their own agencies and be very involved in the day to day activities. One woman explains "before my husband died he started a foundation by giving it \$15,000. We established a budget and requested additional funding. Then we hired the staff. By 1972 we were running three group homes. It doesn't take long when you know what you are

doing and you have the money". She further describes the night they received approval for the first home. "It was like my stomach started on the 100th floor and fell to the bottom. It felt very risky. Just to ensure that everything was for real I spent the first night in the house, sleeping in the sleeping bag. I just wanted to say that I was serious and to feel like it was really happening."

Another woman describes that after they established their daughter in her own apartment, they paid the first months rent because they did not receive their funding yet, and then additionally her husband and she were the first staff. She told me that they stayed over from Monday to Friday and would have staff come on the weekend so they could go back to their own home. They continued to provide the support until they hired staff. Now, the parents can visit their daughter or have her over at their place without providing direct support in the home.

One woman who was particularly creative says: "There was nothing in Winnipeg, at the time to support my daughter. We created the agency which became the first agency that supported people with really significant needs and we started it around my daughter and a gentleman who was coming out of Portage (meaning the Manitoba Development Centre)". This mother did not want to think in the ordinary "group home" sense that were available at the time. She wanted to have a co-op situation, "with my daughter on the ground floor and where people who liked her and paid a sort of low-end room and board like a co-op. Her situation was unique in the world, absolutely unique". The mother also

added that the home eventually needed a porch, for which her husband and she were able to pay.

Parents experience hurdles in planning

Historically, until the 1980's the only options available for work for individuals with intellectual disabilities had been sheltered workshops. This created problems for those that cannot work under those specific circumstances.

He started getting sent home because he would be slapping someone or grabbing someone. We tried to intercede but one day we got a phone call that our son had just quit. We were quite surprised he knew what that was. So we had him at home with us for about 3 months before we found something else.

And the other thing is that it is very large and B does not like the noise – so we are looking for something smaller for him. I would like to see him doing something that has more verbal interactions because I feel some of his verbal skills have been lost.

The other side of the situation was having a child that did not fit into the more community-based programs that were becoming the new way of supporting people. One mother describes how her son was expected to take the bus and work independently. The mother explains that it was not possible for her son to be able to handle the responsibility. After trying for a number of months, she requested her son be supported in a sheltered experience.

A large part of parent' planning was devoted to securing a placement in a residential agency. A very common problem was the necessity to change residences as well as roommates: "We had to change the residence a few times, when something wasn't working she has had to move and has gotten new roommates".

Another parent explains,

I think one of the hardest things was finding matches in roommates. I think it was a lot harder than I thought and the whole process, in retrospect is very artificial, they go mini golfing, the parents chat..... everyone is on their best behaviour... it's not like living together, eating together, sleeping in a home together and doing things. I didn't like all of the decisions that were made but I had to compromise a little. The roommate compatibility was the difficult part and we had to change that a fair bit in the beginning.

Additionally another mother shares,

The first roommate didn't work out so well. They lived together for a year – we really wanted to pull him out of there but we didn't want to lose the spot. His roommate use to get up in the middle of the night and start fires and stuff.

Relevant also in community residence are the staff who are hired to work within the homes. They are often young and inexperienced people who consider this as a way to make some money while going to university or a stepping stone into another career. The position inside community residence tends to turn over quite often as well. One father explains,

Children, like our son, live best in a highly structured environment, they are creatures of habit but what you have here, is in the two years plus that Tom has been in the house, he's probably had 15 to 18 different care providers. There's a young man who has been part of Tom's life, a wonderful care provider, you know he does the best he can but, he says, well this has been a real experience for me, I've never had to do any cooking before in my life. And he is preparing meals for my son?

Parents would often run into staff that did not share their philosophy. One parent describes a staff: "He was the type that would say well it is their choice if they want to do anything. So they would just stay home and never go anywhere. I am not sure exactly what happened but they eventually got rid of him".

One mother explains the difficulties with turnover, "K gets attached so fast then she loses the people that have become her friends. I think the agencies should figure out how to keep good staff so they don't lose the good ones."

Due to the high staff turnover, there always seem to be problems hiring staff people who were good a match for the residents, "Some of the staff were bossy and they always looked mad. Not a good match for G", as one mom explains.

Some parents know it is best to achieve a safe and stable placement for their adult child prior to a time when the parents are ill or have died however, sometimes the adult children are not ready to make the changes. Experiences such as this may make it harder on the parents to follow through with the placement. One father explains, "I remember when we brought him home for a visit after he had moved, and in his limited speech, basically told me he wanted me to take our utility trailer, hook it up to the car, take it over to that place, put his furniture in and bring it home."

Unfortunately a few individuals have experienced a form of abuse in their transition to a community residence. One mother told me the story of how her son's bank account had been depleted, "I am not sure how it happened, if it was my son over spending or if the controls the staff had were out of sorts?"

Some parents did pull their child from the service that they were in because of ill treatment. One father explains,

We noticed that he wasn't himself anymore ... He never ate well because he missed supper because they ate before he got home from work. I think there was 11 people living there. It was run by kids. We complained but they never did anything about it....I stopped in one Saturday and I found

him vacuuming the whole place, everyone else was gone I said go and get your bags we are taking you home.

Another mother describes the physical abuse that her daughter experienced;

Then one Friday night we went through a time. W. was crying – she told me in her own words that she had experienced getting hurt. She was hit on the back of the head. We knew immediately that she couldn't live there anymore. I took her to the doctor and she had blood in her ears.

Bad experiences or hearing about them may make the parents feel guilty about what they are making their adult children endure. These thoughts may slow down the planning process by making the parents very cautious about how they choose supports for their adult child and when they allow the plans to proceed.

Sometimes the hurdles in planning are created by the attitudes of community that surrounds the family. One mother explained to me her thought that her son could work at the local grocery store, collecting carts, when he was done school. She went down to ask but was turned away because her son would not fit into the union that was involved with the store.

Parents need to be advocates

In addition to being very involved in the lives of their children, parents described many situations that they had to advocate on behalf of their children. They advocated mostly to government representatives. Often times, the purpose was to try and explain their need or wants in a way someone would understand and they could receive what they felt they needed. One mother states, "It is

frustrating that nothing is easy and that we have to fight for everything for our children”.

One mother explains about her experience in trying to receive funding, “Professionals cannot totally advocate because their jobs could be on the line. The story comes better from the families. It is more serious when a parent shows that they are frustrated than a professional explaining a family is frustrated”.

A father explains his insight; “I think as a parent you have to be dogged, you have to be very determined and push and shout, do what you have to do. There will always be somebody there that is saying this individual isn’t worth the cost”

One mother shared her experience about establishing a new day program, where her son and others would be supported. She explains “sometimes they would not give us what we needed so we would have to write letters and make phone calls to our MLAs. We eventually got most of it but it was never easy.”

A mother whose daughter has significant needs described interactions with the medical profession, “I am certain on numerous occasions if I wasn’t there K would have been dead. I am sure it happens to people that don’t have an advocate to speak up for them”.

A father of a son who is fairly independent explains how he wanted his son to live in a particular building, even though the son’s worker said it was too expensive. The father approached the building manager who in turn was able to get the apartment subsidized. The father rented the apartment before it was

approved by Family Services and in the end by their own account has been a successful arrangement for the family.

Helpful to the planning process

The accomplishments by the parents are important to explore to determine what contributed to their success. Many parents have mentioned what they have found useful in the process and what has helped them achieve what they have. Parents continually sought out other parents for support and from whom to learn. They took time to find the positive in their situations. In some cases, professional also have been helpful.

Parents seek out other parents and information

Continuously throughout the interviews it was apparent that the biggest support for parents came from other parents. Parents have come together to share their stories, to band together to create a service, to understand the system and to provide moral support to each other.

One woman remembers when her daughter was young and she joined Association of Community Living – Manitoba (ACL-MB). She attended the parent information night with her neighbour who also had a child with a disability,

I guess that is where we also met Jane. I would pick them both up and we would go to the meetings. They told us about what ACL was doing and when the next conference was. Then I would drive them home but we would end up sitting in the car until 3am discussing with each other our stories, it got a lot out but we would compete to be heard because there was so much to share.

Although the mother later said that sometimes hearing the stories became quite stressful because there was so much heartbreak, for the most part it was helpful and they still remain friends today.

A father states,

I think that the other things that was really helpful, just when we got involved with ACL, cause then we had opportunities to hear speakers. I think probably the best thing was meeting other families and even seeing what happens when families let decision making go to long. If you want to prepare for the future of your young child this is the information you need, you're getting valid information, information that works.

Parents could compare and contrast their situations to understand what they needed to do to help their children. Also gathering at places such as ACL-MB and Continuity Care brings in specific information for parents of children with disabilities. The information would include lawyers specializing in disability issues, programs and further upcoming seminars.

Gathering with other families is specifically helpful when the parents were searching for a residence for their child. Seeking out information and parents that feel the same way as they did helped in choosing agencies in which to work and potentially helped them find roommates for their children. One mother explains, "We heard a presentation about one agency, I thought it sounded good. We asked lots of questions and they answered all of them – so you know they were really good. We did look at other agencies and have heard horror stories about some of them – so would never choose those ones if my life depended on it." Another mother suggested,

My friend N – we have been friends for years – you know we are both widows. We are practically like sisters. And after C lost her husband we all worked together. She has helped me through all of this and she is the

one that really pushed and shoved to get our children placed – if it wasn't for her I probably would not have done it.

A couple explains further "ARC (Association for Retarded Children) was very helpful. We became friends with lots of people that were in the same situation as us." Another parent explains, " I think Parent to Parent is good. I don't think there is another place that you can get that type of information – we would not know as much as we do without it"

Another mother suggests,

I think that being aware of other people and making connections is very helpful. Maybe not conferences because people don't always like them. When we first started we just had monthly school meetings – people would talk about what their needs were and out of that SPIKE and WASO started. They were off shoots of CAMR (Canadian Association of the Mentally Retarded).

Another parent had the same experience,

There was a meeting held with a number of parents that were getting concerned about residential and work after school. She had about 20 people in the room..... they talked about a 5 year waiting list for the program I wanted and I went aaaaahhh I only have 3 years – and that's how NSEI came about – that's the short version.

Parents found it important to receive information specific to Will and Estate planning for children with disabilities as it is difficult and complex. One father explains,

I didn't know anything about – every time I brought it up they said there is no use making a Will with a handicapped child because the government will step in and take it. Then all of a sudden I got this letter from Continuity Care and I took my Will to him, he made a few suggestions and then I took it back to my lawyer. He fixed it up free of charge.

Parents showed initiative to gather information they wanted regarding their child and other relevant topics. One mother explains, "I had a long talk with the

woman that started Prairie Places – she was a parent. She was so nice about giving information and told us how they worked their co-op. We took notes and visited their set-up. I have more notes on that kind of thing than you would believe.”

Another mother shared that when she did move her daughter into a residence that the parents of all the children that were moving in, banded together to ensure that the home started. She said one family painted and did repairs and others would provide moral support.

A few parents suggested that in recent years, there does not seem to be parent groups congregating as much as they had in the past. Some suggested this has occurred because the larger group has split into smaller more separated groups. The concern is that parents do not know each other like they used to and this could affect accessing government money. One father states, “I’m sure there are many more out there, we have never met some of the people we see walking down the street ... we can’t go to the politicians and say look there are 2500 people with Down Syndrome living in Manitoba... because we don’t know the numbers.”

Many of the parents interviewed attend Senior Parent to Parent, which is an informal group that meets monthly and is organized through Continuity Care Inc. Although the group is somewhat small, the parents report it as being helpful. A speculation is that younger families may not be meeting together as the parents interviewed did when they were younger and getting organized.

Experience with professionals

The accounts of working with professionals in planning varied from parent to parent. Some professionals were found to be helpful and other hindered the planning process.

Parents found comfort with receiving support from professionals for some of the big decisions that had to be made. One mom tells, “the hardest decision was to do with my daughter’s hysterectomy. It was a big decision. Her staff were very supportive.”

Another parent says, “We received lots of advice from the people from ARC and from Dr. L – he was great”.

Another couple discussed their experience with residential agencies that would eventually support their son, “we like the approach that the individuals at X agency that we dealt with... they were very supportive, they have been very accommodating of our inquiries and concerns. It’s reassuring to know that some of our concerns are also their concerns, and that is good”.

One woman says about her experience with placing her daughter, “It then took two years to get funding, it wasn’t too bad at all. The agency did a good job at getting to know K and we felt so comfortable with them so we wanted to stick it out”.

In the data it was rare to find a professional that initiated the planning process for the family. One mother did experience this, “D and I had sort of been friends, and he said one day – you know it’s about time that you started planning for K. So that’s when I started thinking about it”.

Most parents at some point found it difficult to get information from the Community Services Worker (CSW) that has been assigned to them. In the adult system everyone in the Community Living Program has a worker that is there to provide direction, make application to programs, and monitor the family's functioning. The overall goal of the program is to maintain the child in the home for as long as they can. Additionally in practice, due to high number of caseloads, the majority of attention has to be paid to families in crisis. Therefore, making it hard for older families who need assistance with planning and who are not in crisis, to receive the attention they may need.

One couple explains a time when they needed support and did not receive it. "I called her (CSW) to tell her I was undergoing surgery. She said there was nothing she could do for me, giving me the impression that she could not do something for one client and not do it for another. So in other words she was saying call back when you are die". The parents believe that it is important for professionals not to make judgments and they should not impose their personal philosophy on families.

The fact that the CSW have large caseloads has been a great concern to most parents interviewed. One mother states, "with one guy we had a problem getting our phone calls returned. We got after him one day and then it was better – professionals need to be responsive to parents' concerns. They also need to be open and provide appropriate information."

Another father states his experience, "There is always a big turnover and the family services worker is over burdened with cases. We can't count on them

to be responsive. We have had some excellent workers over the years. But everything takes so long, people are on holidays, or they take too long to finish the paperwork, it all effects the services we receive.”

One mother gives a solution, “I don’t think they have time to plan a future with you. Just the financial stuff, and getting respite care, but not with the coping with the change and setting out a plan – which is important and does take time. Maybe they need a separate entity from the main department – a place that does long range planning – just that for the families – especially the older ones.”

One mother said that it is helpful to be perceived as having some authority, “it is one thing to threaten you are going to make some phone calls to get action, it is another thing to actually be able to do it.”

Some parents believe that they would get better service from a department if someone higher up had a family member with a disability. Parents suggested that all people working in the field should have experience or knowledge in the disability area. This would include doctors and other medical personnel.

Some parents did not complain about their interactions with professionals, but rather spoke of more positive experiences:

I have had good experience. There were years that would go by and I would not hear from them but if I needed something they would help out. And there have been somethings in the residence that I haven’t been satisfied with but I find that if I go in and talk to them about it they will make reasonable efforts to change.

We have had pretty good relationship with professionals – personally I can’t complain. I have seen people get very upset when their workers don’t agree with them – I have seen parents sabotage everything – I think this is not the way to solve problems.

Two parents stated their opinion of staff that work in the community residence with their children,

if we could pay the staff a decent wage we would get better qualified people and maybe they would stay longer. We have had some wonderful staff that love their job but who just can't stay because they can't live off what we pay them. We don't value, as our society, our people enough.

there should be educational or occupational standards for individuals who work in this field – perhaps then we could pay them more and they would stay longer.

Another father suggested that the service you receive is never guaranteed, "some social workers should not be in social work, and others you can't thank them enough." Additionally he stated that the service can affect the planning that the parents will go forward with, "I think some could be an awful lot more ethical and be honest to the parents. I think some parents have had a bad experience and they get turned off and say to heck with it I'll just keep Johnny or Susie at home."

Parents experience positive consequences

The families that have been able to see their planning actualized have generally been satisfied with the outcomes. Celebrating and sharing successes becomes important, following the long process of searching for information and making the many required decisions.

One father who had recently helped arrange for his son to move into a community residence stated,

I think the biggest thing for me, and its' been two years in April, and I can tell you openly and honestly that I miss T very much, not having him here.

I really do. But I know in my heart we've done the right thing for him... he continues to be happy, he is content and comfortable. I think our planning, where this is concerned have gone on without a hitch. I never expected it would because nothing has gone that well.

Another mother says,

K has been away from home for 5 years and I can't believe the skills that she has developed. She has done very well. Her social life has increased, she has gone on trips. Her quality of life has been maintained or maybe even improved since she moved. They sure make sure they get her to the doctor when she needs to.

One mother suggested that having her son involved in the planning was helpful. And although he was cautious, his involvement assisted in making the transition easier.

Long term employment situations are also a concern. One father spoke about the job that took a lot of planning but has turned out to be very successful, Once the program started – it has worked out well. His job at X company has really introduced him to a lot of people – he likes to get out and meet the ladies.”

Parents are proud that they have their children somewhat settled in a place and they can still be involved to see the progress. Many speak to their children on a regular basis and have them home on Sundays, long weekends and for the holidays. Parents saw this as a huge accomplishment and were able to develop similar relationship and involvement like they have with their other children.

Many of them are pleasantly surprised how happy their children are away from home, one mother tell us, “I am surprised how happy he is, he likes where he lives and most of the staff, he still goes bowling – he likes that. Some of the

staff are good cooks and they say that he is gaining weight". Another mom commented, "I think I am happiest realizing that G has accepted that he has his own home and that he can come to my home for visits."

Parents find it comforting to see their children established. One mother said, "W is now looked after. It was really hard to let go but she has staff that are so good – so honest and caring. She is working all over the community – she went fishing all summer. I don't worry about W. like I used to – I trust these people." In some instances it seemed to bring a great conclusion to part of planning and they were able to see all of their hard work pay off.

Many of the parents strived to achieve a real life for their children and give them a sense of community, somewhere where they feel safe. One woman revealed a moment that she had between her and her son that she connects to successful planning.

It was the morning of my husband's funeral. B said to me that he hoped some of his own friends would be attending the funeral. I told him that all of the people would be his friends and his family. But I knew what he meant, he wanted his roommates and his staff to attend. And they did come and he knew that they were there just for him. That's exactly what you want – for them to have their own life.

The same mother added:

It is very important for people to know that they see you with your handicapped child and they think that you are a martyr but they don't realize that they are a source of joy- just like your other children. They teach you things.

Planning that is Unfinished

Despite what they have achieved, many of the parents see their plan as incomplete. The parents still worry and have some decisions that have not yet been made.

Replacing the parents advocate role

Parents revealed that they had made financial and legal arrangements for their children. Some were not able to leave money for their children due to their own financial constraints. A more difficult decision was to find a person that was able to remain involved as they have been to advocate for their child or to be there to ensure that life continues as it had when the parents are alive.

The issue of finding a non-paid care provider to be involved in the life of the person with an intellectual disability was a worry for many parents. Many parents that were interviewed revealed that they came from very small families and it was hard to find someone that would be able and willing. They felt the key is to find someone that knows or will get to know the adult child and can begin to understand the complex system.

One mother shares, "her guardian is her sister, however the last time she was in town she did not go and visit J. I hope that will change after I am not around anymore."

Another couple says, "we really didn't want to make our other two children restrict their lives because they had to assume responsibility for their brother.

We want them involved, but we just couldn't fathom that we should make T a burden for them rather than a brother."

The worry of not being able to be there for your children is overwhelming for some parents, however one father admits,

if you truly love your childand if you know your time is short, try and find someone who can advocate on our behalf because the system is there but it is only as good as the people in it. And however it is we can assume they might not do as good of job as we think we are doing but someone who will have a sincere interest, who will make an effort to get to know them. Someone who says 'you know you haven't visited your brother in awhile so we are going to send you on a plane to go and do it or they will suggest they get dance lessons, or go see a concert or whatever

Some parents do not try to find someone and are satisfied that the agencies that support them will take care of the needs of their children. Or they just trust the family will take over without a formal commitment in place, "I have infinite confidence that things will be all right and things will be taken care of – if I am not here I know there is a number of people that would jump in."

Another mother explains, "the discretionary trust is done. And I know his sister will be there to monitor over all but I want someone that will come and take my son out to the things that he and I have enjoyed. We haven't had our sharing circle yetit's hard to figure out who to include that aren't all my age – which makes you realize you really have to do this."

A father shares the same view point,

I keep listening to Continuity Care and I agree with them, that you can't depend on paid services to perform this role. And we don't want just our daughter – we need other people around our son. The real tricky thing the only people that we know and are around our age, and that's not suitable enough.

The issue of not being able to find someone has almost immobilized this couple into not planning. They are scared to move forward to moving their son out without knowing who is going to be there when they are gone. They went as far as exploring the future with a clairvoyant. The person they consulted said that they did not have to worry about planning because their son would die before them. At the time they felt that they could just continue with him living at home because of the clairvoyant's prediction. However, through further discussion they stated they know that they have to start making plans but do not know where to begin, as they do not feel they have someone that could take over their advocate role and feel worried about placing their son due to his complex care needs.

Parents have continuing worries

Even though many of the parents interviewed had accomplished almost complete plans, there are many issues that still worry them. After working so hard to develop lives for their children they do not want it to fall apart after they are not around to ensure that it continues.

These worries represent various degrees of concern however, they all do contribute to the quality of life of the individual. One mother says, "I think my biggest concern is that she will gain weight or that she won't get her teeth checked every 6 months. I also would like to find someone to meet her on the street every winter to ensure that she is wearing a proper winter coat. I would like a guarantee that she will be dressed properly".

Other parents also stated eating healthy and medical concerns as worries. One woman worries about the health of her daughter due to a family disposition for heart disease. To address this concern she wrote a letter to the doctor to make sure that periodically someone would check for the warning signs.

One couple explained to me the details of their son's care and his vulnerability. They worried so much that they had not made a choice of where their son would live:

If he is not taken care of he gets skin breakdown that take 3 months to heal and are really uncomfortable. He requires 7 catheters a day. Each one takes 20 minutes to do – so you have to be really organized. You also have to really watch for cleanliness and hygiene – he could easily get an infection. He can't take antibiotics anymore so it would be a real problem for him. He is not the type to complain. He is the type to accept everything. If he is not being treated properly there, he couldn't tell us – we would never know. So we would like to keep him here and try and get him out as much as possible.

The couple continued to speak of the extreme vulnerability of their son and what it would be like if he lived in a residential home, "he is not the type to complain. If he were not being treated properly there, he couldn't tell us – we would never know. That's why I would rather keep him at home and do as much as we can for him."

Vulnerability is a large issue for some families. One mother explains about years previous when she was worried about her daughter being sexually assaulted,

When she was going to ARC, the manager told us that some of the girls were getting raped once a week. Some of them had boyfriends and they didn't have families. So this in my mind, I talked to my doctor to see what I could do. He said that there was sterilization. I thought that was the answer..... So we had a bunch of meeting. He sent us to a psychologist.

She wasn't in agreement with it but she let us go away and think about it. So we never did it. Thank goodness – but that's how scared we were.

Ensuring the lives the parents envisioned for their children continued was very important to the parents. One couple states, "I think one of the things that bothers me is just the uncertainty of the funding to provide the supports that he needs for his day program and residential." A few parents hope their children will be able to stay at their day programs for awhile and that their skills are maintained. Another important one is that they are able to continue going to the same church they always have.

One father told me that the reason they wanted to be interviewed was to explain about their biggest worry and that maybe someone would read it and do something about it.

Our biggest concern is what they are going to do when they (daughter) retire. The home they live in only operates after work – nothing is available during the day. We have tried to get answers – everyone says that they will taken care of but I want something on paper. We want to participate in the decision. I don't want them to have to move or be separated from each other.

One mother thinks that there is more to be done, "Now of course I am never happy – I am now thinking about co-housing that she would own her own home and co-exist with other people in a complex – some with disabilities and some without."

Other families hoped that the residential agencies that supported their children would ensure that they would make contact with other family members on their children's behalf. The parents had been responsible for making sure contact with an extended family member happened. If their child with an

intellectual disability was unable to do this they hoped that someone would assist them with it.

One mother who was elderly and whose son was now living in a residential home, felt she had done what she could and somewhat become an observer of the situation. She said, "I hope when I am not around my daughter will take him on weekends I hope they remember to arrange his transportation for the winter time."

A mother described her unfinished goals as hanging over her head like a cloud and she wished that she had a magic wand.

Some families had to figure out a way to continue some of the activities for their adult child. One father explains his creativity for when he and his wife are no longer around to assist their daughters to go on a vacation every year.

We have taken the girls on a trip every year to the states. We having a standard reservation – we get the same room by the pool and they swim and they can also go shopping. They look forward to every year – they love it. Well, we have made provisions in our will for someone to do that when we are gone. We have found the individual. She is going to take them, so that doesn't have to end for them once we are gone.

To combat all the uncertainties, a few families recognized that they are not going to get everything exactly in place, "nothing is going to be perfect. I think maybe because I am older I don't get excited about things anymore – I know it will all get worked out." And, "And you have to take risk, recognizing that things are not going to be perfect".

Parents are impacted by the system

Just as the parents have affected the way services have been delivered, parents and their children are impacted greatly by the changes, deficits and disorganization of the systems that they are forced to work within.

Parents have stated that they feel that the intellectual disability cause would receive more attention if the government employees had personal experience with the issues or at least had hands on experience with someone with an intellectual disability. One mother explains, "Government people that are making decisions should have had experience with someone with a disability. If they know someone with a disability they may be able to have reasons behind the decisions they make." Another father agrees adding "otherwise you've got someone at arms length making decisions without really understanding the day to day needs of our people." Another mother states, "I would like everyone dealing with our special needs community to recognize that all of our special needs people, every one of them, is a human being that has value, that can make contributions."

The parents explained that finding information they needed to make decisions regarding their child was not easy. One mothers states, "Government needs to be more open so families can figure out where they need to go for information. It is very complex to figure out, they need to make it more accessible, reorganize and make less stringent rules."

Another father expresses his experience; "Economic security was very reluctant to put any of their information and numbers down. They wanted to be

as vague as possible and it was very difficult to get information from them, because no one wanted anything really in black and white. "

Other comments included; "parents need help understanding the system, it is very complex and many misconceptions of how things work" and "they also didn't explain everything so I could understand it. They seem to only respond to crisis."

Parents had experience with figuring out the system that caused some set backs in their and others planning. One mother states,

There is a lot of misinformation out there. A lot of people wouldn't take government assistance because relief was a dirty word. Therefore they wouldn't be touch with their social worker...which would create isolation and the system not knowing about them until a crisis happens.

Another says,

Some people think that they can never see their kids again after they place them – things like that – government needs to give more information out. We got the list of services that are available but it was on this old piece of paper – information could be on a fancy pamphlet so people can get into planning for their kids.

One parent shares a solution,

I really would love to see some kind of a handbook for parents... these are the agencies, and numbers. There are parent support groups that you can access but I think the difficulty is when parents are living or families are living in isolation in the community and sometimes some families just don't have the time to go out and seek information... but at least they could be provided with information.

Parents expressed concern and confusion about the idea of discretionary trusts and other ways of leaving money for their children. The worry is that their children will be taken off assistance until the inheritance is used. This would

cause problems with the benefits they receive such as the dentist and medication. There also could be ramifications for where the person is living.

One father states, "if the girls have too much money they will get cut off their assistance and benefits. I worry about leaving them too much". His solution was to leave some to them and some to the agencies that support his child.

Others decided not to leave any or make plans and just hope that it works out.

Trying to find individualized service for their adult children was another continued problem that parents faced.

I think that I'd like to see happen that there would be people allowed to live without a roommate and still have enough support or just two people then the matching would be easier. Often times you get a worker who has 4 clients that all need a placement and the just negotiate them to fit into any available openings. Fitting square pegs in a round hole.

Another parent comments on individual planning, "professionals should make sure everyone has a plan every year to make sure everything is getting done for them."

Some families felt that they should be allowed or requested to pay for part of their children's care. Some families do this automatically but one mother said that if they were required to pay even \$100/month, their children may be able to have a better quality life. One woman also said that she would like to be able to save up RRSPs for her daughter so when she also retires she can assist with her care and for extras like trips.

Another parent suggested that since they were caring for their children longer than expected, they should receive tax breaks of some form of payment for their efforts.

Some parents raised concerns about the current legislation concerning adults with intellectual disabilities. One mother states, "we wanted to get some information but the Act made people scared, and things aren't open enough, that's not right." Another father, "Today being a parent isn't good enough. We have decision making power which allows us more input and access to more information that we wouldn't have otherwise. Before we had it the doctors would be asking who we were to be making decisions."

ADVICE TO PARENTS AND PROFESSIONALS

Parents were asked what advice they would give parents in a similar situation as them and to professionals they will be working with families like their own.

For Parents

To other parents, the parents interviewed offered advice in many areas. In general about the future, the parents recommend that they start planning early, before they or their children start getting older and before a crisis occurs. They felt that adult children need to have a life of their own. One parent suggested starting a bank account for their child that could go toward future costs.

The parents suggest a good place to start is to inform oneself and to gather information. Suggestions on good places to start are non-government agencies, such as Continuity Care and the Association of Community Living, were made. These agencies can provide information and also assist the parents in meeting other parents who are experiencing similar issues.

The parents felt getting together with other parents was helpful for three reasons; to share information, support one another and to find out if any of their children would be compatible together as friends and potentially as roommates.

In regards to advocacy, parents suggested coming together with other parents so they could fight the issues together and support one another not to give up. When planning and implementation of the plan occurs, parents urge to stay involved and to find others to stay involved with the adult child when the parents are no longer able to be. Parents suggest trust the services with intelligence and make sure that they speak up and share their feelings.

For professionals

When working with parents of adult children with intellectual disabilities, the parents suggest that professionals educate themselves fully about the services, programs and rights of the parents. Parents would like to work together with professionals and suggest that professionals listen to the parents and get to know their adult children. The parents also suggest that professionals should urge and support the parents to tell their own stories and to express their needs freely.

The parents suggest that the systems, such as Family Services should share information openly with parents and assist in making the finding suitable programs easier. Parents feel that professionals should have experience with working with people with intellectual disabilities and to continue to find ways of enhancing public awareness.

CHAPTER FIVE

DISCUSSION

While fulfilling the purpose of finding how parents plan for the future for their adult children with intellectual disabilities, more information than expected was found. Parents shared the struggles they endured and what they accomplished during their child's entire lifetime. Parents have contributed greatly to the enhancement of their adult children's lives. In order to access services for themselves and their child, parents had to advocate for them or create the services themselves. The parents interviewed were pioneers in many aspects of planning and service development, as they forged forward to develop and implement many of the services that still exist today.

The parents mentioned that many of the activities they performed were not done because they were required to do so but were meant to enhance the quality of life of their adult child and to give their child access to what most citizens already had access to. The parents seemed to demonstrate the beliefs that their children should be included in their own communities and they were someone people could learn from. The parents also expressed and seemed to feel important to share that that they generally have had positive lives and enjoyed the challenges their lives have brought.

In addition to other areas in their children lives, the parents have had to take the initiative in developing future plans for their children. They considered residential placements, vacation arrangements and how their child could stay in touch with other family members. These efforts were made to assist their child in

maintaining the quality of life that they had committed to developing over the years.

Parents' earlier involvement with formal services had enlightened them regarding the resources that are available but also made them aware of the problems and limitations that are attached to relying on government-supported services such as day programs and residential support. The parents had already experienced some hurdles in implementing their future plans such as having to live with high staff turnover and to deal with abuse toward their child.

Parents plan

The literature review suggested that the majority of aging parents do not plan for the future, either avoiding it or feeling ambivalent about planning (Bigby, 2000). However, despite the barriers encountered, the parents interviewed continued to implement portions of their plans such as finding somewhat satisfactory living arrangement for their adult child.

At the time of the interviews, only two adult children were still living in the family home. One of the men was ready to move out within a month and the parents of the other man were not prepared to have their son move but were in the beginning stages of developing a plan. Many of the parents found that the residential placement was a long process, taking over two years after a decision to move was made to become a reality. Four of the individuals had to move twice in an attempt to find a satisfactory living environment and a few parents felt their adult child was at risk of having to move again. The age the adult child was at the time of moving out of the family home varied, ranging from 18 to 42 years

of age with over half of them being over 30 when the placement occurred.

Although the parents had some difficulty with the placements, they did follow through with their plans and did not wait until they were ill or in another crisis, which the literature had suggested might occur.

There are many explanations for this occurrence. Firstly, the parents who were interviewed were all connected to Continuity Care Inc. whose mandate is to assist families with future planning. Therefore, they have received information and support to develop plans and to implement them.

Secondly, the parents discussed their early connections to formal services such as school, Association of Community Living, and day programs. The literature does state that an involvement in formal services does assist parents to feel easier about using services and helps connect them with other families (Heller & Factor, 1991). The parents felt comfortable working with and developing services and seemed to recognize the need to plan in order to avoid a crisis.

Thirdly, literature which outlines the predictors of placement states that parents do plan for the future if they are widows, are feeling overwhelmed, or they and their child are aging (Hanneman & Blacher, 1998). These three characteristics are consistent with the parents that were interviewed.

However, the parents did experience the placement of their child as a long process, which included finding an appropriate agency, roommates and waiting for funding, which is stated in the literature. As well, for most parents planning is largely unfinished and parents are fearful and ambivalent about some areas.

Continuing fears

Many parents revealed that the plans they have developed for the future may be unfinished because of the continued struggle to ensure quality of life for their child will continue after their deaths. Many felt that the agencies that support their children residentially may not be able to remember the details for maintaining the comfort and quality of care, which included, ensuring good dental care, warm coats, learning new things and maintaining contact with other family members. The concept of inclusion speaks to why these details are important. Current society has placed individuals in what appears to be "normal" lives; now the question becomes if they are enjoying their lives, and how can we further enhance the quality.

The parents established that planning for the future is much larger than only finding a placement for their child and having financial arrangements in place. Their necessary role as advocate and the problems experienced finding the necessary information and resources, has direct implications on how parents will plan for the future of their adult child with an intellectual disability.

Ecological Systems Theory

When attempting to fully understand a problem in social functioning, such as planning for the future, social workers must attempt to understand the complex interactions between the individual and all levels of social systems and the meaning the client assigns to the interactions. Ecological systems theory recognizes that individuals are part of many systems, one of which is the family. Within the context of this theory every individual in a family affects each other

and the systems that surround them; in turn the systems influence the family. Understanding and exploring how parents see these relationships was an important component of this research study. These systems can be informal resources such as extended family and friends or formal services such as non-government agencies and government.

The parents interviewed were not satisfied with the existing resources or found there to be a lack of services. They seem to suggest that their children deserved more and therefore they created their own programs. Not only did this impact how they spent their time and how their child obtained opportunities but the disability field was impacted, gaining programs and services that might not have existed otherwise.

Larger systems, such as the Department of Family Services impacted upon how the parents were able to support their children with intellectual disabilities in their own homes. Many of these parents made a deliberate choice to continue to have their child live at home with the rest of the family. The parents explained that in order for their child to receive support, they had to advocate, in some cases quite strongly, to receive those services that suited their situation; for example community based day programs. The larger systems were found to be unresponsive to the parents, and similarly these systems have not anticipated what the parents, who have kept their child in the family home, would eventually need in the way of planning for the future.

Currently the parents are growing older and are planning for the future of their adult child. The parents seemed to continue to experience similar

roadblocks or hurdles as they have for years; for example, finding appropriate and adequate information. In spite of their fears, they pursued their goals and many of them by their own account found satisfactory living arrangements for their children. They were confident to continue implementing their plans because they were available to fill in the gaps of services; for example one couple renting an apartment for their daughter and being her first staff. However, working within a formal system that is not always responsive, leaves the parents fearful of what the future holds for their adult children.

The Future

The question of what will happen to the adult children when the parents are gone remains. The parents are fearful because they recognized many years previous that the formal systems had limits and that a person who may not be able to advocate on their own may need assistance in obtaining what they need. However, the parents seem to find the informal services had proven to be successful and responsive.

The parents found comfort in seeking out other parents and to obtain information from people who had experienced similar events. The parents also suggested that they found great difficulty in finding someone to replace them as their adult child's advocate. Therefore parents may find it helpful to explore Stengle's (1996) notion of expanding the network of unpaid individuals around their adult children. People who are acquainted with the needs of the individuals may be able to feel comfortable with eventually taking over the advocacy role in

the future. As parents found a benefit in surrounding themselves with informal supports, their adult child may benefit from a similar network.

Parents may come to the conclusion that advocacy and creating services will be a part of parenting a child with a disability. Informal supports had help with providing information, resources and could be used to create a larger network to voice their issues louder. However, further enhancing the involvement of formal services and to increase the recognition of the needs of these parents may begin to eliminate some of the struggles that have been encountered.

The following are recommendations that may assist in enabling the different systems to work together to enhance services and support, including planning for the future, for parents and their adult children with intellectual disabilities.

Recommendations for Social Work

This purpose of social work which was stated earlier; 1) to enhance problem solving and coping capacities of people 2) to link people with systems that provide them with resources, services and opportunities, 3) to promote the effective and humane operation of these systems and 4) to contribute to the development and improvement of social policy (Pincus & Minahan, 1973, p.8 as cited in Kirst-Hall & Ashman, 1999). These social work guidelines will be incorporated into recommendations resultant from the study.

1) Assist parents to gather the information they require to make decisions and to feel comfortable with their decisions.

The parents that were interviewed found it difficult to navigate the systems and to access information they needed to access services and plan for the future. The parents might have experienced less frustration and perhaps had a better experience if the information was readily available. An effective way to solve this problem might be to develop a handbook of services that are available. Included also could be information on how to make financial and legal arrangements for people with intellectual disabilities. Discussing early on with parents the importance of unpaid individuals in the lives of their children could be helpful.

Some government departments were cited in the Findings as not being open to providing information to people who were wanted to understand what they needed to do to follow the department guidelines. These types of changes might be required in these departments if they were going to be helpful to the people they serve.

2) Ensure parents find support from other parents.

Aging parents supporting their adult children is a unique situation and can probably be best understood by other parents in similar situations. The parents interviewed spoke at length about how helpful the Association of Community Living and Continuity Care Inc. meetings were in sharing information and to meet other parents. Friendships developed out of these meetings and assisted people in finding support and to know they are not alone. Social workers can enhance coping skill capacities of parents by connecting to already established groups or

to develop new groups to meet unique needs. Continuing to promote workshops or creating workshops that provide specific information to parents may also be beneficial.

Through obtaining information and meeting other parents, parents may learn how to further enhance the network of people in their son or daughter's lives. Important may be to establish groups that can work together to assist individuals in the future. Exploring options on how to involve non-governmental groups in the future lives of the individuals may also be necessary; for example how to leave instructions and money in a Will.

3) Acquaint social workers with knowledge about the populations they are working with and the systems they are working in.

The parents commented on having professionals assisting them who did not know some of the programs/services offered or where to obtain information. In order to assist someone appropriately, social workers could understand what is available, how to access services, and offer suggestion if the services do not exist. Parents who are in unique situations, such as the parents in this study, may need more assistance than what is perhaps normally allocated to families. Perhaps, as suggested in the literature, training specialized workers to work with these populations might be helpful. Ideally, social workers would be aware of issues and resources related to both the disability and aging populations. Professionals' approach to working with these parents may be improved if they recognized the strength and capacities of the parents. Understanding what they

have accomplished in their lifetime and what they continuing to struggle with, would also be beneficial in meeting the parents needs.

4) Create policies to allow flexibility within the system and to recognize parents for their contributions.

The parents interviewed revealed that they struggled with being limited to only receive services that were available in a certain way. Allowing for some flexibility could improve the quality of those services; for example, persons with an intellectual disability should not largely penalized in terms of income security if they receive funds from their parents' estate. Perhaps professionals and systems are not the ones to promote these ideas, but creating an environment in which the parents could more easily establish a satisfactory situation for their child would be helpful.

Tax credits and stipends had been suggested to assist with recognizing parents for the support they provide their adult children. Recognition could also come from involving parents in partnerships with professionals so they are more in control of the services/programs they receive.

Future Research

Future research could explore a number of different areas related to planning. Exploring with younger families who are beginning to plan for the future of their child with an intellectual disability and to discover if they struggle with similar issues as their older cohorts do may be interesting. Also exploring the perceptions of individuals with intellectual disabilities and how they see the

future and what they would like to plan for might be beneficial. Exploring the approach of residential agencies to parents and how they see their role when working toward the future may be necessary. Another important area to expand would be how day programs are approaching the future needs of their clients in the area of retirement. There seems to be a significant amount of literature regarding siblings, therefore would be beneficial to explore how they fit into planning for the future.

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APPENDICES

APPENDIX A
LETTER TO PARTICIPANTS



UNIVERSITY
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Faculty of Social Work

521 Tier Building
Winnipeg, Manitoba
Canada R3T 2N2
Telephone (204) 474-7050
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Social_Work@UManitoba.CA

Dear _____,

I am writing to you because I am undertaking research as part of a Masters of Social Work thesis at the University of Manitoba. Your address has been provided to me by Continuity Care Inc., however they will not know whether or not you agree to participate in the research. Should you agree to participate, all information will be kept confidential. My thesis advisor is Denis Bracken.

I am interested in speaking with parents, one of whom must be 60 years or older, and who have planned or is planning for their adult child's future in regards to guardianship, finances and living arrangements. If you agree to participate, you will be asked to sign a consent form allowing the information to be used only for the purpose of research. One visit will be established at a time that is convenient for you and the visit should take no longer than two hours. I will be available to visit you in your own home or another mutually agreed upon location.

The interviews will be very informal and will cover topics such as: what has your experience been with planning, would you change anything about the process, is there anything professionals in this area should know and what advice would you offer other parents in the same situation. I would like to tape record the interview session and I may take notes. Any information that you may need following the interview, I may be able to provide or can refer you to an appropriate resource. Should you agree to participate in the research, you would be free to withdraw at any point.

Following the interview the information given will be analyzed with the information gathered from the other participants. Every attempt will be made to ensure that your identity is not revealed. I will be the only person who knows who will be involved in the research. The information given by you will be stored in a locked cabinet and will be destroyed after the research is complete. Even though measures will be taken, it may be possible that an informed individual may be able to determine who was involved in the research. A final report will be made available to you and it will be on display at the University of Manitoba.

If you are interested in hearing more about this research or are interested in participating, please contact me _____ . I will follow-up this letter with a phone call in a few days.

Sincerely,

Jennifer Taylor

APPENDIX B
INTERVIEW GUIDE

Interview Guide

1. During your child's life what has your experience been developing a plan for their future?
 - Is the planning ongoing?
 - who was involved?
 - where did you obtain most of your information?
 - how does/did your son or daughter feel about planning?
 - was there a time when you spent more time planning?
2. What has been the main focus? Or your biggest concern?
3. In your experience thus far, has there been anything that you are most happy with how it worked out?
4. In your experience thus far, is there anything that you would have done differently? Anything missing?
5. What/who was the most helpful to you when trying to establish a concrete plan?
6. What do you think professionals should learn from your experience?
7. What would you want other parents who are in a similar situation know before they start planning for their son or daughter?

APPENDIX C
RESEARCH PARTICIPANT CONSENT FORM



UNIVERSITY
OF MANITOBA

Faculty of Social Work

RESEARCH PARTICIPANT CONSENT FORM

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Title: Aging Parents' Perception on Planning for their Adult Child with an Intellectual Disability

You have agreed to participate in a study about parents' experience with planning for the future for their son/daughter with an intellectual disability. The researcher is a Master of Social Work student Jennifer Taylor. Her thesis advisor, Denis Bracken,

This study was developed to explore the experience parents' have had with future planning and with the hope to provide information to other families that experience similar circumstances. This research will allow the researcher to complete her thesis. You are one of a number of parents who have been invited to participate in this research.

Your participation is voluntary. You do not have to participate in the research to gain access to any resources for your family. Your participation will not be revealed to anyone including Continuity Care Inc., so that your privacy will be respected. If you decide to participate, any information you provide will be placed with the information from the other families so that your answers are impossible to identify. Any information that could identify you will be changed or will not appear in the study. All information that you reveal will be stored in a locked cabinet and will be destroyed after the study is complete. Despite assurances of confidentiality, an informed reader may be able to identify some of the participants in the study. If the researcher receives information that a vulnerable person is being neglected or abused, or that they are in any danger from themselves or others, she is required by law to report this information.

If you decide to participate, you will be asked to discuss your experience with the researcher. You will be asked if the interview can be tape recorded and if the researcher can take notes. It is hoped that the information to be covered will be completed in only one visit taking approximately two hours. The outcome of the study will be made available to you and will also be on display at the University of Manitoba. If you experience stress when answering these questions or have questions after the study, the researcher will provide information on topics discuss or will be able to refer the family to an appropriate resource. You can refrain from answering any question you would rather omit and will able to withdraw from the study at anytime without consequence.

The Joint-Faculty Research Ethics Board has approved this study. Any complaints regarding the procedure may be reported to the Human Ethics Secretariat, or to the Head of the Social Work department (Don Fuchs,) for a referral to the appropriate Research Ethics Board.

I have read the above information and agree to participate in the study exploring my experience with planning for the future of my son/daughter. My confidentiality will be respected and I can withdraw from the study at anytime after signing this form.

Signature of Participant

Date