PERSPECTIVES FROM THE MARGINS:
ISSUES IN DAYTIME SUPPORT PROVISION

By

Karen D. Schwartz

A Thesis submitted to
the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
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Abstract

Adults with intellectual disabilities rely greatly on others to help them with various aspects of living. The quality of support they receive directly affects their quality of life. Yet the people providing this support find themselves at a crossroads as their roles are re-defined. My purpose in this qualitative research was to examine and analyze the issues faced by daytime support providers in Manitoba from their own perspectives. Participants discussed four major areas of concern including a) problems associated with community-based supported employment, b) agency issues such as adequate staffing and role clarity, c) professional issues including education and compensation, and d) systemic matters, particularly transportation, community attitudes, funding and policies. In reviewing these issues, I have considered how the implementation of the human rights model of disability can lead to changes in the way supports are provided.

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Dedication

This work is dedicated to five very special people whose unconditional love and support have made this dream possible.

To my loving partner, Debbie, who assures me I can do anything I set my mind to and stands beside me in every endeavor I undertake.

To my amazing children, Rebecca and Ryan, who have inspired me by their example to always give my best.

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Chapter 1: Introduction

Imagine that you find it difficult to understand the world around you. Like everyone, you want to make decisions for yourself about where will you live, what you will do during the day, who you will spend time with, and what kinds of hobbies or recreation activities you will do in your spare time. Yet however hard you try to make sense of things, you find you simply cannot manage everything on your own. You need help with life's daily realities such as finding a place to live, banking, grocery shopping, finding and learning how to do a job and taking the bus. You know what you like to do and who you like to spend time with. The main problem is that your family and other people in your life don't always think you can make your own choices, no matter how hard you protest. Now imagine that you cannot protest in the way others around you do. You cannot speak out. You must rely on whatever communication methods you can to get your point across. Sometimes when you try to make your point in ways others do not understand, you are ridiculed or punished. You can be misunderstood on all levels.

Individuals with intellectual disabilities[1] rely on others to help them with many or sometimes all aspects of living. The quality of support directly affects the quality of life an individual with an intellectual disability will have. Poor quality support or the unavailability of adequate support can result in an individual feeling disconnected from and/or disengaged with life. Involved and reliable support can lead to the experience of a full life, well lived. The importance of providing and receiving excellent support cannot be over-emphasized.

I became interested in doing research on support provider perspectives for two reasons. First, I was enrolled in a two year Disability and Community Support program at Red River College, in Winnipeg. Although I chose instead to enter the Master's program in Disability Studies at the University of Manitoba, I continued to be interested in how people with intellectual disabilities are supported.

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[1] I use the phrase "individuals with intellectual disabilities". These individuals have been labelled over time as idiots, morons, imbeciles, the feebleminded, the mentally retarded and, more recently, people with mental, developmental, learning or intellectual disabilities.

Second, my university studies led me to an opportunity to be involved in the second phase of a community-based action research project entitled "Perspectives in Change", as project coordinator. The mandate of the project focused on issues and opportunities supporting broader participation in work, life and community for adults with intellectual disabilities in Manitoba. The goal of that research was to identify key issues affecting the provision of community-based supports and services to adults with intellectual disabilities in work and community participation (Mactavish, Lutfiyya, & Schwartz, 2004). Data were collected from a number of focus groups, including support providers working in direct and in-direct support provision. The project partners were challenged in the analyzing of the data from the support provider focus groups, primarily because there were diverse perspectives and a wide range of supports provided, including both daytime and residential support. I was asked to take the support provider aspect of the project in a new direction, and this piqued my interest and became the focus of my thesis work.

Adults with intellectual disabilities find themselves in a complicated position as they set about the business of living their lives. The nature of their disability dictates that they require at least some form of support in order to fill their daily needs and desires. The type and amount of support each individual needs depends on his or her circumstances.

What exactly do I mean when I refer to someone as having an intellectual disability? The American Association on Mental Retardation, whose mission is to promote "progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities", defines an intellectual disability as a "disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills.

This disability originates before age 18" (http://www.aamr.org/index.shtml). In Manitoba, an individual is deemed to have an intellectual disability if he or she "has significantly impaired intellectual functioning existing concurrently with impaired adaptive behaviour and manifested prior to the age of 18 years" (*The Vulnerable Persons Living with a Mental Disability Act,* s. 1(1)).

There are two basic types of formal services and supports available to adults with intellectual disabilities in Manitoba, residential and daytime supports. Both types are provided by Manitoba Family Services and Housing (FSH) in the Supported Living division.[2] Residential supports enable adults with intellectual disabilities to receive assistance with personal care, meal preparation, housework, shopping and evening and weekend recreation and leisure activities. Daytime supports focus on assisting individuals during weekdays at a variety of recreation or work-based endeavours. Each support component is equally important and helps to build a well-rounded life. In addition to this more formal means of support, individuals may also rely on informal support from family or friends.

Generally, services and supports are provided to adults with intellectual disabilities through provincially-funded social service agencies. In Manitoba, the vast majority of these agencies are not-for-profit. FSH, on behalf of the government, enters into service purchase agreements with the various agencies. The government agrees to provide funding for the agency to carry out this responsibility. Agencies hire support providers to provide and manage supports. Ideally, adults with intellectual disabilities become affiliated with the agency they feel will best provide them with the services and supports

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[2] For detailed information about the Supported Living division, please see FSH website at http://www.gov.mb.ca/fs/pwd/supported_living.html

they require. In practice, many people are directed by others in the system to a particular agency. The same principles apply to agencies providing residential support, agencies providing daytime support and agencies providing both. Each agency has its own mandate, philosophy and mission. Traditionally, the creation of agencies has been driven by families of individuals with intellectual disabilities who have been unable to find the kind of services and supports they envision for their family member among existing agencies (O. Backstrom, personal communication, April 15th, 2004; G. Sutton, personal communication, June 29th, 2004; D. McPherson, personal communication, September 28th, 2004; B. Block, personal communication, January 11th, 2005).

There are two pieces of legislation that govern the provision of services and supports for adults with intellectual disabilities in Manitoba, the *Social Services Administration Act* (*SSAA*) and *The Vulnerable Persons Living with a Mental Disability Act* (*VPA*). Both laws indicate that providing services and supports are discretionary in nature, suggesting that the government has no legal obligation to provide services and supports. Thus adults with intellectual disabilities are not entitled to them.

Because the focus of my thesis is *daytime* services and supports, I will begin by outlining how these services and supports are organized. Services and supports for adults with intellectual disabilities are provided on the basis of a continuum from most restrictive to least restrictive environments (Nova Scotia Report, 2004)[3]. The premise of the continuum theory is that as people learn and develop they progress from more

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[3] In 2002-03 the Nova Scotia Department of Community Services began a review of their Community Supports for Adults Program. As part of this process they completed a cross-Canada review of how supports are provided to adults with disabilities. The information provided by the Province of Manitoba is a helpful summary of the way in which services and supports are provided to adults with intellectual disabilities.

restrictive settings to less restrictive settings over time (Taylor, 1988). At one end of the continuum is the most restrictive daytime setting, services provided to individuals in institutional or segregated environments.

For adults living in the community, the next step in the continuum is participating in activity-based day programs, described by FSH as "Individualized Development Services", which are "aimed at developing, maintaining, and maximizing an individual's personal care skills, emotional growth, physical development, socialization opportunities, and communication skills through the provision of in-house or community-based activities" (Nova Scotia Report, 2004, p. 18).

Individualized Development Services are followed on the continuum by "Services with a Vocational Focus", which FSH describes as being "aimed at developing, maintaining, and maximizing an individual's vocational and social skills. The ultimate goal is competitive employment in integrated community settings" (Nova Scotia Report, 2004, p. 18). Notwithstanding the use of the term "individualized" by FSH, I classify the services I have discussed so far as "congregate". I use the term "congregate" because people using these types of services are grouped together with other people with intellectual disabilities, creating a day time environment that is more segregated from larger society.

The least restrictive form of daytime services and supports is "Supported Employment and Follow-Up Services", which FSH describes as being,

> aimed at supporting individuals in jobs in community settings. Individual support and training are provided at employment settings within the community. Once a job is secured and training is complete, follow-up services which include those activities

that need to occur for the worker to maintain the job, are provided (Nova Scotia Report, 2004, p. 18).

I classify supported employment as "individualized". I use the term "individualized" to denote a service where adults with intellectual disabilities spend their days in more integrated day time environments with many people who do not have intellectual disabilities.

This review is not a complete list of all daytime opportunities as it is often difficult to compartmentalize the various daytime options into neat categories. It is useful, however, in providing a basic understanding of the array of daytime supports and services that may be offered to adults with intellectual disabilities in Manitoba.[4]

I will now move from the discussion of services and supports to the role that support providers play in the lives of adults with intellectual disabilities. The roles have not stayed constant over time. Quite the opposite is true. When the vast majority of people with intellectual disabilities resided in institutions, the primary role of the support provider was to care for people (Hewitt & Lakin, 2002; Taylor, Hewitt & Silver, 2003). As individuals began to move back into the community in the 1950's and 1960's, a need grew for community support. Once people were established in their own homes, the need for meaningful daytime pursuits began to be addressed. This meant that, not only were support providers required to assist in residential settings, they also were required to help individuals participate more fully in all aspects of community life, including employment (Governor's Commission on Mental Retardation Staff Report – Commonwealth of Massachusetts, 2000; Hewitt & Lakin, 2001).

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[4] Please see page 45 for a figure illustrating the Manitoba daytime continuum.

This new challenge for support providers has not been an easy one. Some of the major issues that have been and continue to be faced include a) a lack of formalized training standards, b) poor wages and benefits, c) low status, d) high staff turnover rates, e) staff shortages, f) difficult and challenging work without sufficient professional support, and g) a failure of community attitudes to keep pace with de-institutionalization and community inclusion (Mactavish et al.,2004; Larson, Lakin & Hewitt, 2002; Hewitt & Lakin, 2001; Knoll & Racino, 1994; Mitchell & Braddock, 1994).

Unfortunately, insufficient attention has been paid to the issues of support providers who provide support to adults with intellectual disabilities, either in practical terms or in the research literature. Community and government initiatives to examine increasing compensation and benefits to support providers and the setting of minimum training standards have made some progress, but there is still much work to be done.

From a research standpoint, much of the work in this area has focused on residential supports or a combination of residential and day supports (Hewitt et al., 2004; Test, Flowers, Hewitt & Solow, 2003; Governor's Commission on Mental Retardation, 2000; Larson, Hewitt & Anderson, 1999; Mitchell & Braddock, 1994; Larson, Hewitt & Lakin, 1994), with primary emphasis on the areas of wages, training and retention. In the day time supports literature, supported employment concerns such as the role of the job coach or the use of natural supports at the workplace have predominated (Conley, 2003; Rogan, Banks & Howard, 2000; Parent & Unger, 1994; Park, Shafer & Drake, 1993; Moore, Godbolt, Schwartz, Moriber & Salzberg, 1991; Grossi, Test & Keul, 1991). There has been very little discussion or analysis of the range of issues affecting daytime support

providers specifically, from their own points of view. Even less of this research has been Canadian-based.

As I began to do some research, I was struck by a number of issues. Because the provision of services and supports is not mandated by law, and because of the systemic structuring of the daytime continuum, I began to wonder whether the way in which services and supports are organized affects those people providing the support. If the organization of services and supports does affect support providers, how are they affected? I also began to think about the organization and provision of services and supports from a human rights perspective. If we see adults with intellectual disabilities as citizens, in the same way we see other adults on our society, why are they not entitled to supports to live their lives? This way of thinking encouraged me to explore and use a human rights theoretical framework to analyze and make sense of my research findings.

Statement of Purpose

I could not find any discussion in previous research that offered answers to my questions. I therefore chose to make daytime support provider perspectives the focus of my thesis research. My primary purpose is to examine the issues facing support providers and determine whether these issues affect their ability to do their job in the best possible way. My secondary purpose is to compare issues facing daytime support providers who work primarily in congregate settings with the issues facing those who work primarily in individualized settings. This comparison will help enhance understanding about the influence of different contexts and forms of service provision in the experiences of day

time support providers. It will also help to re-conceptualize services and supports for

people with intellectual disabilities using a human rights lens.

Chapter 2: Research and Literature

I will begin a review of the research and literature with an historical overview of how services and supports for adults with intellectual disabilities have evolved over time in North America. This context is essential for understanding the issues faced by support providers. This overview includes the policies that have guided the provision of these services and supports and the role that underlying social values have played in shaping them. It also touches on a new paradigm for providing services and supports as a way to reconcile policy and practice. I will look at the human rights model of disability in order to set the stage for the subsequent analysis of my findings using this framework. I will outline today's policies for service provision and how these services and supports are put in place for adults with intellectual disabilities in Manitoba. I will then turn my attention to the support providers themselves reviewing the literature from Canada, the United States, and other jurisdictions. This review will help explain the changing role of the support provider and to emphasize the vital yet undervalued role that they play in the lives of adults with intellectual disabilities. Finally, I will highlight the support provider issues that have been studied and documented. Finally, I will look at the human rights model of disability in order to set the stage for the subsequent analysis of my findings using this conceptual framework. My purpose in reviewing the existing research is twofold. I will show the lack of emphasis on Canadian issues in daytime support provision generally and I will demonstrate the gap that exists in understanding the perspectives of support providers and the range of issues that affect their ability to do the best job they possibly can.

A History of Support Provision in Canada

The Institutional Model

"*In Greek mythology we encounter a somewhat overly friendly character by the name of Procrustes. He wanted very much to be a good host to weary warfarers, and when a traveler journeyed past his dwelling, Procrustes would insist that he stay the night with him. After some wining and dining, Procrustes would show his guest to bed. Trouble was, there was only one bed, of one certain size, and Procrustes was a perfectionist. The bed just had to fit the guest. So if the guest was tall, Procrustes chopped off his legs until the guest and bed were exactly of the same size. If the guest was too small, the host strapped him into a rack and lengthened him out a few inches. Obviously, by doing things his own way, Procrustes was prepared for all comers. The moral of the parable: our institutions have been Procrustean. It did not matter who or what the resident was…we took them all, by the thousands, 5,000 and 6,000… We had all the answers in one place, using the same facilities, the same personnel, the same attitudes, and largely the same treatment. And if our guest did not fit, we made him fit!*"[5]

The way in which services and supports have been provided to adults with intellectual disabilities in the past is crucial to understanding how we support these individuals today. Simmons (1982) writes of the "policy palimpsest" where "not one but a series of mental retardation policies were superimposed on one another, with newer policies obscuring, blurring or relegating older policies to minor importance, although never entirely replacing them" (p. 43). In the Oxford English Dictionary a palimpsest is defined as "a parchment or other writing material written upon twice, the original writing having been erased or rubbed out to make place for the second; a manuscript in which a later writing is written over an effaced earlier writing." Similarly in painting, an earlier image may show through a later work, often when a part or all of the painting becomes transparent with age. This is known as "pentimento". In the case of providing services and supports to adults with intellectual disabilities, policies have changed over time, yet "the structures

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[5] Wolfensberger, W. (1975). *The Origin and Nature of our Institutional Models.* Syracuse, N.Y.: Human Policy Press at p. 69.

put into place at one time, which reflect the values of that time, frequently persist into a later period when ideas have changed" (Jongbloed, 2003, p. 207).

Canada, following the lead of the United States, historically provided services to adults with intellectual disabilities in institutional settings. This practice began in the 1840's and continued to be the predominant means of providing these services until the 1950's. Initially, "mental retardation policy conformed to two models in North America: an educational model and an asylum model" (Simmons, 1982, p. 16).

The educational model, most prevalent from the 1840's to the 1860's, was based on the belief that certain individuals with intellectual disabilities could be trained given the right set of circumstances. On the basis of this belief, some individuals were removed from society on the understanding that beyond the pressures of everyday life and with special training, they would be able to be returned to society with the ability to make a contribution (Simmons, 1982). These early institutions were, in fact, called "training centres". "There was never any intention, at least at the beginning, that mentally retarded people would remain in these schools on a permanent basis" (Simmons, 1982, p. 17). Not every adult with an intellectual disability, however, was placed in an educationally focused facility. Most were placed in asylums. Originally, asylums served the purpose of protecting and providing a haven to lunatics (known today as people with mental health issues). Over time a variety of society's undesirables were destined to live out their days in asylums.

The idea of the training school fell by the wayside. As the schools became overly crowded due to "immense pressure... to admit a wider variety of people..., it became

increasingly difficult for the schools to maintain their educational role, and they were inexorably pushed toward the asylum model" (Simmons, 1982, p. 17).

Not only did training centres lose their educational focus, asylums also changed. As the 1880's arrived, Canada's social policy was ill-equipped to deal with people who were poor, elderly, disabled and insane. They were transformed from the unfortunate to the masters of their own misfortune.

> With the increasing suspicion that poor, unemployed, and mentally ill and retarded persons were somehow responsible for their own fate, as well as causing some of the major social problems of the time, the asylum model was gradually being replaced by a custodial model (Simmons, 1982, p. 22).

Thus the emphasis changed from protecting these individuals from society to protecting society from these individuals.

Towards the end of the 19th century and the beginning of the 20th century, a number of world-wide theories and events converged to redefine people with intellectual disabilities into the "menace of the feebleminded". For example, social darwinism, intelligence quotient testing, early genetic "research" and eugenics all had a significant and negative impact on how people with intellectual disabilities were and continue to be conceptualized in North American society (Trent, 1994). Parmenter (2001) says,

> Educational approaches to training persons with an intellectual disability were influenced by the rising discipline of psychology...Theories propounded by Francis Galton (1822-1911), William James (1842-1910), Arnold Gessell (1880-1961), Charles Spearman (1863-1945), Cyril Burt (1883-1971), and Jean Piaget (1896-1979)

had a profound effect on the way people with intellectual disabilities were assessed and classified (p. 272).

Similarly, the

publication in 1859 of Charles Darwin's *Origin of the Species* and its interpretation by his cousin Francis Galton, the attribution of the causes of intellectual disability to the sinful behaviour of parents…the documentation of mongolism and cretinism, and the genetic discoveries of Gregor Mendel (1822-1884) gave rise to the science of eugenics (Parmenter, 2001, p. 273).

Parmenter (2001) thus argued that the history of people with intellectual disabilities has meant that

their humanity has often been denied, they have been seen as a threat and a danger to society, they have been oppressed and segregated, and despite some enlightened attempts to provide them adequate care and succour, the perception of their 'otherness' continued well into the twentieth century (p. 275).

Wolfensberger (1975; 1998) has listed a number of role perceptions in which people with intellectual disabilities have been seen as a result of their classification by society as "deviant". Some of these include the sick person, the subhuman organism, the menace, and the eternal child (1975; 1998). He argues that "the relationship between these role perceptions, and the management of the retarded, and the design of their life space" are of "crucial significance" (1975, p. 5).

For people with intellectual disabilities, the provision of services within institutions has meant living apart from the rest of society. It has meant being singled out on the basis

of one or more characteristics, removed from family, friends and community and placed together with others of the same or similar characteristics.

Wolfensberger describes how role perceptions shape service provision. "When the retarded are viewed as diseased organisms, residential facilities are structured on the (medical) hospital model" (Wolfensberger, 1975, p. 5). This leads to an environment where medical professionals wield power over all aspects of people's lives, programs are called "treatments" or "therapies", and intellectual disability is seen as something to be cured (Wolfensberger, 1975, pp. 5-7). Where people are thought of as "subhuman" and a "menace" all manner of degradation is excused. Thus residents are seen as violent and unable to control themselves. They live in an atmosphere which does not "provide opportunities for further growth and development" and denies basic human rights (Wolfensberger, 1975, pp. 7-12). One of the most horrific examples of the inhumane treatment of people with intellectual disabilities was the legal, forced, non-consensual sterilization of men and women living in several Canadian institutions from the 1920's through to the 1970's.

Bradley (1994) has discussed a number of key words which help define what she calls the "institutional era". In this era, the individual with an intellectual disability was identified as a "patient". Services were delivered in an institutional setting, organized in "facilities" and called "care". The model was "custodial" or "medical" in nature. The highest priority was a person's "basic needs", with control of the disability or, optimally, outright cure, being the ultimate objective of the services (p. 14).

Not all people with intellectual disabilities ended up in institutions. Some parents simply refused to send their family member into institutional care and instead decided to keep him or her at home. For example in 1961, a doctor recommended to Nicola Shaefer (1999), mother of a daughter with an intellectual disability that she "…go home, put this baby in an institution and then have another." She recalls thinking, "The things this madman in a white coat said to me were so ludicrous that they didn't deserve a serious response" (p. 6). There were no supports in the community at the time for parents who chose to keep their children at home, however Ms. Shaefer recalls meeting other parents in similar situations.

> Meeting these parents made me realize several things. First, there were very few kids around as badly handicapped as Cath who were living at home. Second, apart from the meagre physiotherapy service at the Children's Hospital, there was absolutely nothing going on in Winnipeg for such children. There was, of course, custodial care…Nobody in authority thought it worthwhile to do anything at all with our children (p. 43).

The Developmental Model

"May I say a few words on behalf of our backward children, and their bewildered mothers. There is no school for such children, no place they could get a little training…"[6]

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[6] Neufeldt, A. H. (2003). "Growth and evolution of disability advocacy in Canada", in D. Stienstra & A. Wight-Felske (Eds.), *Making Equality,* Concord: Captus Press pp. 11-32 at p. 20. (An unsigned letter to the *Toronto Daily Star*, 1948).

Slowly, as the human rights movement began to grow in North America in the 1950's and 1960's services and supports began to change for people with intellectual disabilities. As Pedlar and colleagues (Pedlar, Haworth, Hutchison, Taylor & Dunn,1999) point out, "Much of the current services structure for persons with developmental disabilities can be traced back to the efforts of parents in the 1950's and early 1960's" (p. 15). As the first parents began to meet and talk, they formed parent advocacy groups, local chapters of what is now the Canadian Association for Community Living.

> It was only when the voices of parents, banding together on behalf of their children in the context of a rising social interest in the rights of all citizens, sought schooling for their children, and better medical advice, that real change started…As their children grew older, the agenda broadened to include issues that were age appropriate – employment preparation and training, and group homes in the 1960's as children approached adulthood (Neufeldt, 2003, pp. 20-21).

Parents were not the only people to advocate for people with intellectual disabilities. Change also was aided by the emergence of self-advocacy groups such as People First, who "challenged the dominant systems of support – from institutional care to large group homes to employment in sheltered workshops for extraordinarily low wages" (Pedlar, et al. 2000, p. 330). The goals of People First of Canada are to "Promote equality for all people who have been labelled, Speak for ourselves and make our own decisions, Teach the community about our movement and our issues." Some of the roles self-advocates play are a) "protect the voice of the people", b) "act on what people say", c) "identify issues about which people can speak", and d) "bring people together so they can help each other" (http://www.peoplefirstofcanada.ca).

In addition to the advocacy component, the principle of normalization, which had its origins in Scandinavia, also reached North America. The driving forces behind these new concepts in Europe were Bengt Nirje of Sweden and Niels Erik Bank-Mikkelsen, of Denmark. Nirje was influenced by Bank-Mikkelsen's emphasis on the legal rights of people with intellectual disabilities and by the idea of human rights (Parmenter, 2001, p. 276). This principle "addresses the most fundamental issue of concern – the basic humanity of people with an intellectual disability that had been historically denied them" (Parmenter, 2001, p. 276). Nirje describes the normalization principle as meaning

> that you act right when making available to all persons with intellectual or other impairments or disabilities pattern of life and conditions of every day living which are as close as possible to or *indeed the same as* the regular circumstances and ways of life of their communities (Parmenter, 2001, p. 277).

The normalization principle was reformulated in North America by Wolfensberger, and at its heart, meant community integration, both physical and social, for people with intellectual disabilities. Although differing from the original Scandinavian notions, Parmenter (2001) suggests that it was Wolfensberger's approach that "was embraced by policy planners and service providers in much of the English-speaking world. The influence of his writings and public lectures was a seductive force in the deinstitutionalization movements, as governments legislated to provide support for community-based options" (p. 277). The trans-Atlantic crossing of normalization resulted in a loss of its underlying emphasis on human and legal rights.

Whereas the institutional model was based upon the societal values of providing custodial care to adults with intellectual disabilities, the policy of providing services in

the community was originally based on what was called the developmental model. This model encouraged the belief that people with intellectual disabilities can learn, develop and grow. This belief can be traced to the earlier notions that some people with intellectual disabilities could be trained in training centres and become productive members of society.

Unfortunately, the old "care" mindset of the asylums did not totally disappear, paving the way for community-based services that still clung to institutional ways of thinking about people with intellectual disabilities. "The principles of practice that had shaped care in institutions were often carried over into community, with the result that residences in community were sometimes described as 'institutions without walls'" (Pedlar et al., 1999, p.16).

Bradley (1994) has classified the hallmarks of the developmental period or "era of deinstitutionalization". In this era, the individual with an intellectual disability was identified as a "client". Services were delivered in settings such as group homes, workshops, special schools or classrooms and organized into a "continuum of options". They were now called "services". The model was "developmental" or "behavioural" in nature with the highest priority being the development of skills and the managing of behaviours. The objective of the services was to alter behaviour (p. 16).

The developmental model requires that a range of services and supports be provided. This range has been called a "continuum". As Mary (1998) explains,

> The major focus of intervention shifted from care and maintenance to skill
>
> development and behavioural change. Underlying service delivery in the
>
> developmental model was the notion of 'client readiness'. Certain skills were

assumed to be best learned under specific conditions and had to be acquired before the client made the next move along the developmental continuum (p. 249).

Although the developmental model signalled some significant changes in the way in which society thought about people with intellectual disabilities, and brought about the deinstitutionalization movement which led to the provision of supports within the community, there were still a number of difficulties in providing services and supports using this model. The most significant difficulty was the model's reliance on behaviour modifications and its emphasis on "readiness". Bradley (1994) points out that the behaviour specialist "identified the behaviour that interfered with a person living in a community setting and then developed a program to remove that behaviour from his or her repertoire" (p. 17). Unfortunately this process "ignored the total context of behaviour and usually did not respond to the point of view of the 'client'" (p. 17).

Bradley (1994) also discusses the fundamental problem that "…the traditional developmental model also assumed that skills could be learned in isolation from the ultimate reality of community living. It also presumed that true integration is earned after multiple hurdles in a therapeutic sequence of treatment" (p. 17). Thus people were "taught" to live in the community using artificial settings that only hinted at true community participation.

Bellamy, Rhodes, Bourbeau and Mank (1986) have discussed the origins of daytime services, particularly sheltered workshops and day activity programs. Sheltered workshops were developed in response to the presumption that people with intellectual disabilities could not work in integrated, competitive settings. The objectives of the

workshop were to "1) provide sheltered employment, and 2) move individuals into competitive jobs" (p. 259).

Day activities were created for individuals with more complex needs. These individuals had been excluded from sheltered work due to the nature of their disability. The interplay of these services is described by Bellamy et al. (1986) as a situation where,

> individuals not considered ready or able to benefit from job preparation are referred to day activity programs or work activity centers, which are expected to develop readiness to benefit form [sic] workshop programs. As such readiness comes about, consumers are expected to move through the continuum of vocational services until they reach the goal of independent employment in the competitive sector (p. 259).

Taylor (1988, 2001) is highly critical of providing services and supports based on the principle of least restrictive setting (LRE), the hallmark of the continuum. I will highlight his five points here in order to demonstrate the underlying societal values and presumptions behind offering services and supports to adults with intellectual disabilities in this way. First, Taylor (1988) says that "The LRE principle legitimates restrictive environments" (p. 45). Because the concept of "least restrictive" is open to interpretation, "some people will continue to support institutions and other segregated settings…" (p. 46).

"The LRE principle confuses segregation and integration on the one hand with intensity of services on the other" is Taylor's (1988) second point (p. 46). He goes on to point out that "some of the most segregated settings have provided the least effective services" (p. 46). Just because an adult with an intellectual disability receives services in

an institutional setting, therefore, does not mean that those services are effective or intense.

Third, Taylor (1988) says that "The LRE principle is based on a 'readiness model'" (p. 46). The theory is that adults with intellectual disabilities will proceed through the continuum, learning new skills and readying themselves for the ultimate daytime goal – employment in the community. The irony of this assumption, as Taylor notes, is that "the most restrictive placements do not prepare people for the least restrictive placements…segregated day programs do not prepare people for competitive work" (p. 47). Bellamy et al. (1986) demonstrate why the continuum is an unrealistic model of support provision.

> If each consumer had an equal probability of movement along this continuum and was placed in a day activity program, he or she would require an average of between 47 and 58 years to move through program levels before realizing community employment; for clients in work activity centers it would take, on the average, 10-19 years to obtain a job (p. 262).

Taylor's (1988) fourth point is that the LRE principle "sanctions infringement on people's rights" (p. 47). It is difficult for adults with intellectual disabilities to begin from the premise that they are required to earn a place in the community when such a place is guaranteed for other citizens. From a human rights perspective, finding a place for everyone in the community is a key starting point.

In the fifth and final point, Taylor (1988) argues that "The LRE principle directs attention to physical settings rather than to the services and supports people need to be integrated in the community" (p. 48). He goes on to say

the field of developmental disabilities has defined the mission in terms of creating 'facilities,' first large ones and now smaller ones, and 'programs,' rather than providing the services and supports to enable people with developmental disabilities to participate in the same settings used by other people (p. 48).

Wehman, Revell and Brooke (2003) have questioned why the "vast majority" of people with intellectual disabilities continue to participate in "segregated day programs" (p. 165). They cite Albin, Rhodes and Mank (1994) when they suggest that these types of services continue to "remain deeply entrenched, as they have for decades" (p. 165). Pedlar et al. (2000) suggest that in Canada, there is a "mixture of traditional and new approaches" to services (p. 338).

Pedlar et al. (1999) describe Canadian policy in supporting adults with intellectual disabilities in terms of the "four philosophies and principles of service" (p. 17) that have guided services and supports for adults with intellectual disabilities since the deinstituionalization movement and, as they discovered during the course of their research, continue to guide them today (p. 20).

The first philosophy of practice is "quality service" which was a carry over from institutionalized services. Quality service "was seen to exist when agencies worked effectively within their budgets, to deliver services to people that ensured client safety and comfort" (Pedlar et al, 1999, p. 17). This can be contrasted with the notion of agency accountability where agencies must be accountable for the relevance and intensity of the services and supports they offer to adults with intellectual disabilities.

The second philosophy is advocacy. "Advocacy has been utilized as an attempt to ensure that people with disabilities are able to receive the sort of supports and services

that will enable them to live decent lives alongside other people in the community"

(Pedlar et al., 1999, p. 18). As I pointed out earlier, advocates have included parents,

concerned community members, and people with intellectual disabilities themselves.

Pedlar et al. (1999) question the effectiveness of this process "when it is often carried out

by the more powerful on behalf of the less powerful" (p. 18).

Normalization and social role valourization is the third philosophy. Pedlar et al.

(1999) argue that although

> some agencies began to look beyond the need to keep people safe, and asked how
>
> service could best incorporate training and development of people...normalization
>
> and social role valourization, in and of themselves, have not been able to ensure that
>
> service systems function in ways that ensure self-determination (p. 19).

This may be because these concepts have strayed from their original foundation of justice

and rights.

The final philosophy is "capacity building", and is "based on the assumption that

individual growth had more to do with building on the strengths and abilities that

individuals had, and less to do with trying to 'fix' their problems or minimize their

limitations" (Pedlar et al., 1999, p. 19). This more progressive way of viewing disability

is closely allied with the social model of disability, which looks, not to deficits in the

individual, but to the shortcomings in society, as a way to re-examine societal attitudes

about disability. The focus therefore shifts from one of impairment of the individual to

one of socially constructed disablement (Zarb, 1995).

The concept of Quality of Life (QOL) is another force that has begun to appear in the literature. It "has been adopted as a challenge to respond to in terms of theory and applied research regarding social policy, the design of program supports to individuals and groups, and service evaluation" (Schalock et al., 2002, p. 457). Schalock and colleagues (Schalock et al., 2002) describe QOL as a "new way of looking at issues of disability" and as a "useful paradigm that can contribute to identification, development, and evaluation of supports, services and policies for individuals with intellectual disabilities" (pp. 458-459). The term refers to two concepts. The first, "quality", "makes us think about the excellence associated with human values, such as happiness, success, wealth, health, and satisfaction" (Shalock, et al., 2002, p. 458). The second word, "life", concerns "the very essence or essential aspects of human existence" (Shalock, et al., 2002, p. 458).

Some of the ideas imbedded in this QOL include a) the notion that people know what is important in their own lives, b) a recognition that QOL will be different for different people, and c) the idea that people ought to be empowered to exert choice and control in their lives (Shalock et al., 2002). In a practical sense, these ideas mean that adults with intellectual disabilities should live in safe environments, have friendships and intimate relationships, be able to partake in further education and employment, be entitled to health care, live self-determined lives, and participate in society (Shalock, et al., 2002). Most importantly, QOL "makes us think differently about people with intellectual disabilities and how we might bring about change at both the individual and societal level to enhance their well-being and reduce their exclusion from the mainstream of society" (Shalock, et al., 2002, p. 463).

The Era of Community Membership

"*It is evident, however, that the gap between the community living ideology and social policy persists and the evolution of services from custodial care to individualized support is protracted indeed.*"[7]

In concluding this discussion of the history of support provision in Canada, I will say a few words about the direction in which services and supports may be heading. Teasdale (1987) argues that "This idea – that the places we have now are so bad that anything else must be better – goes far to explain the lack of clear positive principles on which a community-based service for the mentally disabled should be founded" (p. 214). In terms of daytime pursuits, Inge, Banks, Wehman, Hill and Shafer (1988) note, "If work partially defines the worth that society ascribes to a person, then individuals who do not work or who are relegated to segregated, sheltered environments due to disabilities are seen as having decreased worth" (p. 97).

Smull (1989) argues that community supports were facing a crisis as a result of the

transfer of institutional patterns of service development and service delivery to

community programs. Resolution of the crisis requires a reconceptualization of these

patterns…It is time for us to give up the paradigm of programs and adopt a paradigm

of support (p. 1).

Butterworth (2002) highlights the American Association on Mental Retardation's position when he discusses the "supports paradigm" and distinguishes it from the idea of "services".

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[7] Pedlar, A., Hutchison, P., Arai, S. & Dunn, P. (2000). Community services landscape in Canada: Survey of developmental disability agencies. *Mental Retardation,* 38, 330-341 at p. 339.

The new supports paradigm suggests that individuals should first, without restrictions, define the lifestyle they prefer and the environments they want to access. Their goals and priorities then become the basis for intensity and types of support that they need in order to succeed in those environments (p. 85).

Pedlar et al. (2000), however, note that there are pockets of change in Canada in the way in which services and supports are being provided. "Our snapshot of the landscape provides a picture that reflects a complex and diverse service system. Services are beginning to adopt approaches that seek to incorporate individualized funding, individualized planning, empowerment, social networks, and community participation" (p. 339). Lemon and Lemon (2003), argue that more progress is still needed.

As many people with intellectual disabilities prove over and over that they are capable of far more independence than many had expected, they, and we, gain a vision of greater changes that are possible. Group homes, sheltered workshops and other day programs were steps away from asylums, but now we see that, as originally conceived, they are not enough (p. 415).

What will services and supports for adults with intellectual disabilities ultimately look like? They may evolve into something similar to Bradley's (1994) "Era of Community Membership" where the individual with an intellectual disability is identified as a "citizen". Services, now called supports, are delivered in people's homes, neighbourhood schools and community businesses and are organized "through a unique array of supports tailored to the individual". The model is individual support with the highest priority being "self-determination and relationships". The objective of supports is "to change the environment and attitudes" (p. 21).

Bradley (1994) quotes Kuhn when she says that a paradigm shift "occurs when the consensus regarding the paradigm of any field of endeavour breaks down and another emerges" (p. 13). Because, as Jongbloed (2003) says, "societal values (and society's way of conceptualizing issues) shape policies" (p. 207), our society must be prepared to re-conceptualize the way adults with intellectual disabilities are seen before a new paradigm of services and supports can emerge. To date, "the growth in competitive and supported employment has not been sufficient to meet the demand. People with disabilities have an unemployment and non-participation rate which is unconscionably higher than the general population" (Parmenter, 1999, p. 329). The challenge in moving toward a new paradigm lies in making a commitment to shred the palimpsest of past institutional policies and move forward with a clean parchment. One possible first step in this process is to go back to the European origins of normalization and explore the human rights model or approach to intellectual disability.

Humans Rights: A Conceptual Framework

"I think there's a very good reason to extend the franchise, to widen the conversation, to democratize our debates, and to make disability central to our theories of egalitarian social justice. The reason is this: a capacious and supple sense of what it is to be human is better than a narrow and partial sense of what it is to be human, and the more participants we as a society can incorporate into the deliberation of what it means to be human, the greater the chances that that deliberation will in fact be transformative in such a way as to enhance our collective capacities to recognize each other as humans entitled to human dignity."[8]

"We want to push our rights forward, and we want to let other people know that we are here. We want to explain to our fellow human beings that we can live and work in our communities. We want to show that we have rights and responsibilities...Above all, we

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[8] Bérubé, M. (2003). Citizenship and disability. *Dissent*, Spring, 52-57 at p. 56.

demand that you give us the right to make choices and decisions rewarding our own lives.[9]

Models of Disability

Using a human rights lens or model helps to illustrate from where we have come, helps to provide an understanding of where we are and helps pave to way toward a new paradigm for the future. This section will help to critically analyze preconceived notions about intellectual disability.

There are a number of models or ways of understanding the concept of disability which I will refer to as models of disability. I will explore and will later discuss why the human rights model of disability is appropriate for addressing the issues faced by support providers and those they support.

First it is important to outline the fundamental premises and underlying values of each of what Rioux (2003) describes as "four identifiable social and scientific formulations of disability" (p. 45) in order to see the effect that these premises and values have on the policies and practices of providing services and supports to adults with intellectual disabilities.

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[9] Barb Goode, Canadian self-advocate speaking to the full General Assembly at the U.N., 1992 as quoted in Mittler, P. (2003). Meeting the needs of people with an intellectual disability: International perspectives in S. Herr, L. Gostin & H. Koh (Eds.), *The Human Rights of Persons with Intellectual Disabilities: Different But Equal*, Oxford: Oxford University Press pp. 25-48 at p. 25.

Table 1

Approaches to Disability

Individual Pathology	Social Pathology
Biomedical Approach	Environmental Approach
Functional Approach	Human Rights Approach

The first two formulations, identified as the biomedical and functional approaches, fall under a more general understanding of disability as an "individual pathology". Quinn and Degener (2002) refer to this categorization as the "medial model" of disability, which is "characterized as being fixated on persons' medical traits such as specific impairments. It is said to have the effect of subtly but effectively locating the 'problem' of disability within the person" (p. 14). Literature from the Roeher Institute (1997) says that with this approach "the condition itself becomes the focus of attention...the individual...is viewed as sick, injured, afflicted or deficient" (p. 14). This literature goes on to suggest that the "biomedical model of disability has been a powerful influence determining disability policy and practice" (p. 14).

Linton (1998) discusses how the medicalization of disability has impacted upon people with disabilities and the societies in which they live. It

casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy. Society, in agreeing to assign medical meaning to *disability*, colludes to keep the issue within the purview of the medical establishment, to keep it a personal matter and 'treat' the

condition and the person with the condition rather than 'treating' the social processes and policies that constrict disabled people's lives (p. 11).

By focusing on curing, fixing and rehabilitating people with disabilities, the medical model rejects difference as being unnatural or abnormal.

The environmental approach, or Rioux's (2003) third formulation of disability, is grounded in "social pathology. This approach stresses that "disability is not a feature of an individual's body or mind; in short, it is a socially constructed complex of relationships, some intrinsic to the individual and some part of the physical and social world" (Bickenbach, 2001, p. 567). Roeher Institute literature (1997) says that "increasingly, researchers and people with disabilities are demonstrating that the failure of ordinary environments to accommodate people's differences exacerbates the impacts of disability" (p. 16). Thus disability also can be seen as "a social phenomenon shaped by historical, cultural, linguistic, political, and economic forces" (Bickenbach, 2001, p. 567).

This approach, also referred to as the "social model" of disability can be problematic for people with intellectual disabilities. No matter how accommodating the physical environment is made, the fact remains that these individuals will continue to have difficulty participating in society unless they receive the ongoing supports necessary to live their lives. Their disability cannot be eliminated by removing barriers. There is a need to look "beyond particular environments to focus on broad systemic factors that keep certain people from participating as equals in society" (Roeher Institute, 1997, p. 17).

Rioux's (2003) fourth formulation, or human rights approach, is a very appropriate model for addressing the issues faced by people with intellectual disabilities and their

support providers. This "policy from a rights outcome approach constructs an analysis of how society marginalizes people and how society can be adjusted to respond more effectively to the presence and needs of those who have been systematically marginalized" (Rioux, 2003, p. 296). Furthermore, a human rights approach rejects the traditional belief that charity is the appropriate response to disability. Bickenbach (2001) says that "disability law and policy should not be a matter of charity, professional need, compensation, or economic necessity but instead must be grounded in human rights" (p. 567). Whereas models falling under the umbrella of the individual pathology approach see disability as a defect that needs to be eliminated, cured or treated, the rights outcome approach simply sees disability as "inherent to the human condition" (Rioux, 203, p. 295). This viewpoint helps reframe disability from a stigmatized condition to a natural variation whereby certain people require supports "in order to gain access to, participate in and exercise self-determination as equals in society" (Rioux, 2003, p. 295).

Human Rights Values

As Quinn and Degener (2002) point out, it is important to understand the values upon which human rights are based. They illustrate four basic human rights values – human dignity, autonomy, equality and solidarity. I will briefly review these as a means to understanding why human rights have historically been denied to people with disabilities and why it is so important to frame services and supports to people with intellectual disabilities within a human rights context.

The value of human dignity means that everyone "is deemed to be of inestimable value and no person in the world is insignificant" (Quinn & Degener, 2002, p. 14). Thus

the ultimate goal is the "creation of societies on genuinely inclusive terms – terms that value difference and respect the dignity and equality of all human beings regardless of difference" (Quinn & Degener, 2002, p. 16).

The second value Quinn and Degener (2002) emphasize is autonomy. Many people with disabilities do not enjoy the ability to make their own choices and live self-determined lives, either because of hasty presumptions of incompetence or because "society often fails to take seriously the autonomy of persons with disabilities…it is as if their life choices are not as worthy of social support as those of the non-disabled" (p. 16).

The third value is equality, which entails "a commitment to the ideal that distinctions between persons stemming from factors that are arbitrary from a moral point of view (race, gender, age disability) should be treated as having no rational foundation and therefore invalid" (Quinn & Degener, 2002, p. 16). I will return to a more comprehensive discussion of equality in the next section.

The final value is solidarity, which is "based on the acknowledgement that mutual ties and obligations exist between people by virtue of their shared membership of the political community…The main aim of solidarity should be to prime people to participate in all mainstream processes of society" (Quinn & Degener, 2002, pp. 19-20).

Models of Equality

I wish to return now to one of Quinn and Degner's (2002) basic human rights values, that of equality. Rioux (2003) discusses three models of equality, each of which "makes different claims to the meaning of equality. The choice of model has importance for

people with disabilities, particularly in light of the ways in which disability has been perceived" (p. 296).

The first model of equality is "equal treatment" where "likes be treated alike" and difference "justifies limiting claims to entitlement" (Rioux, pp. 297-298). Unequal treatment can be justified on the basis of differences among people in society. This view of equality is premised on the understanding of the biomedical model of disability as an individual pathology. In the case of people with intellectual disabilities,

> therapeutic interventions, for example, prevocational training and sheltered
> workshops, have met this standard of equality based on the reasoning that segregating
> people or failing to provide access to usually provided public programs is legitimate
> in the case that a person has a capacity that can be differentiated from the norm
> (Rioux, 2003, p. 298).

The second model of equality is "equality of opportunity". This model recognizes that there has been an inequality of opportunity for certain groups in society at certain times in the past. A good example of this type of inequality is in the context of race. Rioux (2003) says equality of opportunity "removes the necessity for the disadvantaged group to prove they are the same with the same skills and abilities as others" (p. 299). It does not, however, adequately address the issue of discrimination based on disability because "there is no obligation to address disadvantage inherent to the structure of social standards" (Rioux, 2003, p. 299). An example of a practice currently used to address past unequal treatment is affirmative action employment policies. For people with intellectual disabilities, however, giving preference to individuals with disabilities in the hiring process does not address the issue of the kinds of supports that might be necessary for

that individual to perform the tasks required. Thus the chance to apply for a position is insufficient to enable an individual with an intellectual disability to work in a community-based setting.

The third model of equality is "equality of well-being". It is premised on the notion that all human beings have the right to be included in society. This model recognizes that because of individual differences, people may require different degrees of accommodation to ensure an equal outcome. "…the programs or means to ensure equality should justifiably be targeted to enable support on a temporary or long-term basis for those least able to achieve well-being" (Rioux, 2003, p. 300). Rioux argues that the best way for people with disabilities to make a claim for equality is based on their humanness. They deserve to be treated on par with their fellow citizens because they are people and they have the right to whatever supports will allow them to participate in society as such. Not only are they given the opportunity to apply for a job, they are also entitled to the support that will allow them to perform the tasks required.

Disability Typologies

Models of disability and models of equality are starting points for an examination of why services and supports for adults with intellectual disabilities are provided in the manner they are. As well, these models help explain why we have the policies we do in this area of human services. Rioux (2003) recognizes the impact and intersection of the models of disability with the models of equality. She says,

In practice, the diverse ways of perceiving, diagnosing, and treating disability combined with the differing models of equality lead to identifiable legal, clinical, and service treatment modalities and differing standards and measures of quality of life and entitlements to human rights (p. 301).

She therefore explores three "typologies of disability" that arise from these models, a) civil disability, b) compensatory privilege, and c) well-being.

"Civil disability" is based on society providing protective care to people with intellectual disabilities. "The protection may include both entitlement to minimal material goods such as welfare and to the limitations of rights normally accorded citizens" (Rioux, 2003, p. 303). Because this notion of disability relies heavily on the biomedical approach and sees disability as a problem that resides within the individual, civil disability encourages the scientific and medical communities, as professionals, to maintain a high degree of control over people with disabilities. It therefore encourages policies that eliminate, ameliorate or cure disability. It also encourages what Rioux (2003) calls "paternalistic decision making" (p. 304) resulting in policies that promote segregation (institutionalization, sheltered programs and employment) and severely limit personal choice and decision-making under the guise of incompetency laws.

Restrictions on the exercise of human rights, lifestyle choices and self-determination are legitimated both because of the portrayal of disability as a characteristic particular to the individual and because the individual is then differentiated from others in ways that are portrayed as material to rights and social goods (Rioux, 2003, p. 305).

"Compensatory privilege" arises out of a combination of understandings about disability, which recognizes environmental causes as a discriminatory factor but

continues to rely on medicalized views of disability. It is based on the historical view that caring for people with disabilities is a charitable act. Paternalistic thinking carries over from the civil disability typology in that professionals are still seen as gatekeepers who make decisions on benefits people may be eligible to receive. "To the extent that an individual is able and can show abilities to exercise rights in the manner of other citizens and function in society as others, he or she is entitled to equitable treatment and rights" (Rioux, 2003, p. 305). Although there is recognition that certain injustices have an underlying social cause and need remedying, there is also an understanding that society has no obligation to provide the same outcome for people with disabilities as for non-disabled citizens, "because difference can be attributed to the individual" (Rioux, 2003, p. 305).

Rioux's (2003) final typology is "well-being", where the provision of services and supports to people with disabilities is based on "entitlement to citizenship rights and *equal outcome*" (p. 307). Individual pathology is erased from the equation. Thus the need for professionals to make decisions is eliminated and the need for entitlement as the basis for services and supports is highlighted. Well-being "...takes into account the historical disadvantages that people with disabilities have faced, the current structure of society, which maintains systemic discrimination, and the reformulation of non-disability specific policy, programs, and services" (Rioux, 2003, p. 308).

Reframing disability as a human rights issue allows for the recognition that "removing the barriers without also redressing associated disadvantages does not result in significant change" (Rioux, 2003, p. 308). A disconnect occurs when people with intellectual disabilities are called "citizens" but continue to be supported using traditional models of

disability and equality which do not move the equality agenda forward. Reinders (2002) refers to this kind of situation as "rights talk" and cautions that it is important to "see what rights can do and what they cannot do" (p. 1). Rioux (2003) refers to the assumption "that the achievement of civil and political rights will ultimately lead to a democratic polity ensuring that people will be treated equitably in relation to their economic, social, and cultural rights" (p. 313). The reality is that people with disabilities have not yet achieved this equality.

A discussion of human rights is not complete without considering how notions of human rights and equality might practically be used by people with intellectual disabilities and their advocates to guarantee or enforce rights to fight discrimination and inequality.

Legal Expressions of Human Rights

Bickenbach (2001) describes several "legal expressions" of human rights for people with disabilities in advancing their claims. The first legal expression is "enforceable antidiscrimination legislation". This legislation "identifies grounds for discrimination… and areas of protection… [it] also sets out complaint and adjudication procedures and provides some form of enforcement mechanism, usually financial compensation" (pp. 568-69). Examples of this legal expression are the *Canadian Human Rights Act* and its Manitoban equivalent, the *Human Rights Code*. Bickenbach (2001) argues that because a complainant must prove that the unequal treatment experienced is discriminatory and because this legislation is "complaint driven", "invariably the process of determining whether discrimination has occurred is a long and costly one that becomes entangled,

very quickly, in complex and often subtle legal argumentation" (p. 570). The complaint process may be problematic for people with intellectual disabilities, notwithstanding possible support from advocacy organizations. Individuals may be unaware of discriminatory practices and may have to rely on the support of others to file the complaint and go through the process. The cost of launching a complaint might also be a barrier.

Bickenbach's (2001) second legal expression is constitutional guarantees of equality. Canada has enacted the *Charter of Rights and Freedoms* with a specific prohibition against discrimination based on disability in section 15(1).

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

As Bickenbach (2001) says, "…entrenching human rights into constitutional documents endows them with the strongest legal and political commitment possible" (p. 570). However, section 15 of the *Charter* does not guarantee that discrimination will not occur. Peters (2004) cautions that

> …sophisticated, abstract legal principles, no matter how cutting edge, do not alone ensure that persons with disabilities will have the services, housing and income security they require to live with equality, independence and dignity, unless they are taken seriously by all levels of government (p. 28).

In addition, it is important to remember that constitutional guarantees are broadly worded and are always open to interpretation in each case. Such interpretation depends, ultimately, upon who is sitting on the Supreme Court of Canada at the time of the challenge and how broadly or narrowly the Court makes its interpretations. As with any constitutional challenge, the court costs are considerable, cases are complex and it takes a substantial amount of time to reach a conclusion.

> Because cases involving the equality provision of the constitution will form part of the body of law interpreting the highest law of the land, there is an understandable reluctance on the part of judges to move too quickly or too far (Bickenbach, 2001, p. 571).

Before I discuss Bickenbach's (2001) third legal expression, I will point out several serious pitfalls in relying solely upon the anti-discrimination legislation described above. The notion of an anti-discrimination complaint presupposes that someone is prevented from accomplishing something by reason of artificially constructed barriers, thus presuming that "each individual has the motivational and other merit-creating abilities required for full participation in all areas of life and can plausibly argue that he or she would succeed but for these artificial and irrational obstacles" (Bickenbach, 201, p. 577). Yet, the removal of such obstacles will not necessarily help an individual with an intellectual disability as he or she may not be able to succeed without additional supports.

Another, as Bickenbach (2001) points out, is that people with disabilities face a large number of obstacles that can be described as "…social ills brought about by a maldistribution of power and resources. However, they are not forms of discrimination"

(p.578). Thus, challenges for people with intellectual disabilities can arise that are beyond

the scope of anti-discrimination legislation, even though they result in unequal treatment.

Enforcing existing rights can be another difficult process for marginalized groups.

Chouinard (2001) has argued that

> exercising rights is an embodied, geographically uneven, process which makes some
>
> citizens much more able to exercise their rights than others. This is an important
>
> lesson for rights struggles. For it reminds us that law is a slippery and contradictory
>
> realm of struggle...(p. 188).

She goes on to say that a person's place in society may limit his or her ability to enforce

rights. Many people with intellectual disabilities continue to live on the fringes of society.

This social position means that these individuals are likely to be impoverished, poorly

educated, and lacking in any political power. Thus "...rights as represented do not

necessarily correspond to rights as lived... in practice justice is often denied to those who

need it most" (Chouinard, 2001, p. 188). Blomley and Pratt (2001) echo these sentiments.

They say that in Canada, "rights are hotly contested by individuals and groups" and

declare the "politics of rights" to be "slippery" (p. 154).

The third legal expression identified by Bickenbach (2001) is specific entitlement

programs. These are programs developed to provide special entitlements for

disadvantaged people, including people with disabilities. Unlike the first two legal

expressions, "...here the focus is on positive provision of resources and other facilitators

to full participation rather than on the removal of discriminatory obstacles" (p. 571).

Bickenbach (2001) calls this "distributive justice", which is designed to eliminate "an

unfair or irrational distribution of resources and opportunities that has resulted in

limitations of participation in social life for some" (p. 578). A major drawback in relying

upon entitlement legislation is the fact that "all entitlement programs arise from

legislation that is subject to political and ideological trends, sometimes shifting the focus

of the program radically" (Bickenbach, 2001, p. 572).

As I discuss the data in this research, I will refer back to these concepts of human

rights, models of disability and models of equality in order to understand how the issues

raised by participants in this study may be reconciled in the future.

Policies, Services and Supports in Manitoba

Because my study is being conducted in Manitoba, it is necessary to describe

Manitoba's laws, policies and the services and supports provided to adults with

intellectual disabilities. Nationally, the *Canadian Charter of Rights and Freedoms* and

the *Canadian Human Rights Act* expressly prohibit discrimination on the basis of

disability.

In 1998, the government of Canada and the provinces and territories (with the

exception of Quebec) generated a document entitled, *In Unison: A Canadian Approach to*

Disability Issues, which is self-described as "a vision made up of values, principles and

building blocks that affirms the importance of ensuring the full participation of persons

with disabilities in society." It recognizes the need for people with disabilities to live and

participate as "full citizens in all aspects of Canadian society" (p. 4).

In 2001, the province of Manitoba produced a White Paper called, *Full Citizenship: A*

Manitoba Strategy on Disability, which also acknowledges, "Any complete

understanding of citizenship requires the full inclusion of persons with disabilities. When full citizenship exists, persons with disabilities will have access to the social, recreational and employment systems and programs open to others" (p. 4).

The FSH vision, mission, and principles can be found on their website (www.gov.mb.ca/fs/about/vision.html) and in their Annual Reports. They are committed to "social, economic and labour market inclusion of all citizens." Their mission is to "support citizens in need to achieve full participation in society." Their principles include providing opportunities for "equal access to valued outcomes, self-determination, meaningful involvement and valued roles."

These various federal and provincial laws and policy documents present people with intellectual disabilities as "citizens", in accordance with Bradley's (1994) "era of community membership". Reinders (2002) warns, however, that

It is a mistake to think that we have achieved the goal of inclusion by creating new institutional roles for our clients as citizens… The good life for ourselves as human beings requires that we be appreciated by other people who accept us as a matter of their choice (p. 3).

The laws that govern people with intellectual disabilities in Manitoba, specifically the *Social Services Administration Act* (SSAA) and the *Vulnerable Persons Living with a Mental Disability Act* (VPA) tell a different story than the policies set out above. As I pointed out earlier, both laws are discretionary in nature and do not *entitle* adults with intellectual disabilities living in Manitoba to any services or supports. It is up to the Minister of Family Services and Housing to decide whether or not a particular individual is entitled to assistance. For example, section 10 of the *SSAA* says, "The minister, through

the department, *may* provide assistance; provide social services and develop programs of social services..." Similarly, section 9 of the *VPA* states, "The minister *may* provide or arrange for the provision of support services for a vulnerable person" (emphasis added).

In the Nova Scotia Report (2004), FSH was asked how program eligibility was determined for adults with intellectual disabilities. They responded as follows: "The Supported Living program is a discretionary program (not a program mandated by statute), and the availability of service to an eligible individual is contingent on the urgency of the need and the availability of funding" (p. 17). When asked about the range of services and supports provided, the Department said,

> The services offered through the Supported Living Program are intended to provide participants with the opportunity for independence in a community setting to the extent possible for each individual. A person's eligibility for these discretionary services is generally assessed with the use of an interview process and recognized psychometric tests (p. 17).

As Kaplan, Hasiuk and Martens (2001) state, "This lack of entitlement means that service provision is dependent on available government funds" (p. 22).

The *Employment and Income Assistance Act* does entitle people to income assistance by reason of "physical or mental incapacity or disorder that is likely to continue for more than 90 days" (section 5(1)). However, an individual who is collecting benefits under this Act is limited in the amount of net monthly earnings he or she can retain. This restriction is a disincentive to people to seeking out and enrolling in an employment opportunity where a competitive wage is offered. Employment income also affects medical and drug coverage, a further disadvantage to adults with intellectual disabilities who have more

complex needs. People in sheltered workshop situations are not adversely affected by these restrictions, as their monthly income is negligible.

Although rights for people with intellectual disabilities have been clearly enunciated by the Province of Manitoba, it is may be difficult to exercise these rights if there is no legal obligation on the part of the government to provide services or supports. Sundram (1999) cautions, "If there is one thing that history has taught us, it is that government is not always a reliable safeguard for those who need its protection most desperately" (p. 62).

In terms of the services and supports provided, the continuum model of service delivery is still very evident in Manitoba today. Day services fall into a progression as Figure 1 illustrates.

Figure 1

Manitoba Daytime Service Continuum

Most Restrictive ————————————————▶ Least Restrictive

| Institutional Settings | Day Activity Programs | Sheltered Workshops | Work Experience | Supported Employment | Competitive Employment |
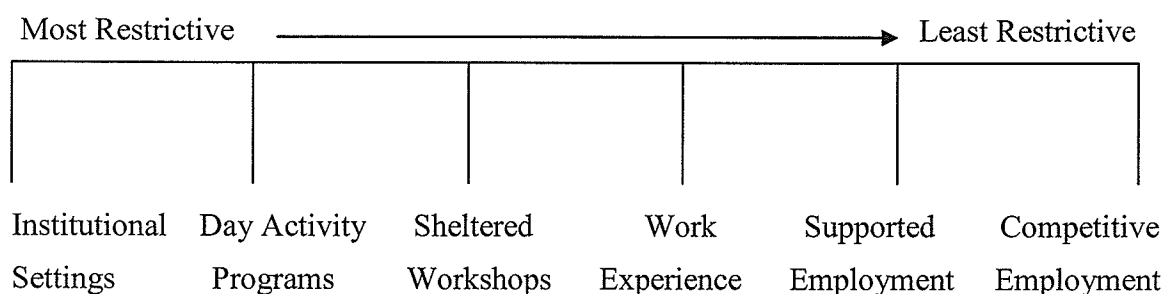
In Manitoba, adults living in institutions are in the most restrictive and least integrated setting. They experience their daily activities within the institution, although some programs may take trips into the community. Some individuals participate in recreation-based programs and others may be involved in sheltered work. (K. Lepischak, personal communication, January, 13th, 2003). There is little actual chance that these individuals

are going to progress beyond the institution's walls. Even "educational" components lack any realistic expectation of advancement, as Bellamy et al. (1986) have shown.

Moving to the right on the continuum, the next level of services and supports are the Individualized Development Services. Although this option operates within the community, it is segregated. This is also a recreation-based program. Individuals attending this type of program are "developing, maintaining, and maximizing" personal skills and abilities but may never move to the next stage of the continuum, vocational work. This setting is largely an opportunity for adults with intellectual disabilities to socialize with one another. Choice in activities can be limited based on staff availability and outings into the community are often made in groups with other people in the program. Some individuals might have a volunteer or work experience component built into their day program which would enable them to work in an integrated community setting, possibly several times a week for a few hours.

Services with a vocational focus can be either in-house sheltered workshops or work in community-based enclave settings. The in-house work that is available largely depends upon contracts that the agency providing the service is able to secure with local businesses (K. McIntyre-Leighton, personal communication, October, 15th, 2004). If there are several contracts, individuals have some choice in what they work at each day. Sometimes recreation components are also built into the day. Adults are paid an honorarium, often a small monthly stipend that does not reflect the hours worked or the provincial minimum wage standards.

Enclaves are another type of work option. An enclave is a setting in which a number of adults with intellectual disabilities work in a community business, doing specific tasks

but remaining segregated from the remainder of the company's employees. Members of the enclave do not make the same competitive wages as other employees of the business. A small recreation component may be part of the work week.

Supported employment and competitive employment are on the far right end of the continuum. Although the terminology can mean different things to different agencies or people, I use the term "supported employment" here to signify work ("work that would be done by a non-handicapped worker if it were not done by a handicapped worker"), in an integrated setting ("where the proportion of handicapped workers is roughly equivalent to the proportion of handicapped persons in the general population" or natural proportions) with ongoing support ("job support services that are theoretically **not** time limited") (Kaplan, Hasiuk & Martens, 2001, p. 9). Work can be full or part time. In a competitive employment situation, an adult with an intellectual disability is gainfully employed in a community business and in a completely integrated environment. He or she is also earning at least minimum wage.

Adults with intellectual disabilities also may be supported in volunteer positions in the community or in work experiences. A work experience is similar to supported employment in that an individual is supported to work in the community in an individualized setting. These individuals, however, generally are either not compensated for their work or are paid an honorarium. Often the hope is that someone working at a job experience will either get hired by the employer or build experience to find paid employment elsewhere.

The number of individuals involved in the different types of services and supports in Manitoba is shown in Table 2. It is interesting to note that according to Pedlar et al. (2000), at 48.2%, Manitoba had the second highest proportion of agencies supporting people in "training centres" (sheltered workshops) in the country.

Table 2

Number of Individuals Supported in Programs (Manitoba) [10]

Day Activity	2001/02 Active Files	2002/03 Active Files	2003/04 Active Files	2004/05 Active Files
Competitive Employment	138	151	174	216
Supported Employment and Follow up	342	333	330	362
Services with a Vocational Focus	1,144	1,133	1,175	1325
Personal Development Services	869	806	820	929
In the Company of Friends	42	45	45	47
Attending School	346	633	630	513
Retirement program	89	65	70	98
No program	833	780	800	776
Totals	3,803	3,946	4,044	4,266

[10] This table was compiled from data in Manitoba Family Services and Housing Annual Reports 2003/04 and 2004/05 (p. 67) (http://www.gov.mb.ca/fs/about/annual_reports.html). Written permission to use this information was obtained on August 15th, 2006 from the Department of Family Services and Housing, Government of Manitoba

In addition to these figures, approximately 600 individuals with intellectual disabilities receive their services in institutional settings.

Now that the policies, services and supports in Manitoba have been reviewed, I will turn to an examination of the support providers themselves.

Support Providers

"To us it is really simple – if agencies have good staff, we have good lives. If agencies have bad staff who aren't trained, don't understand our disabilities or have attitude problems we suffer the effects."[11]

"When I was a direct care worker, we were not expected to do what we ask of people now. Direct care staff wasn't expected to deal with families, with communities, with the nursing issues. (Now) they are expected to go into the community and act politically savvy."[12]

As I stated at the outset of this thesis, support providers have a direct impact on the quality of life of the adults with intellectual disabilities they support. "Research and reports of direct experience by service agency administrators identify attitudes, knowledge, and skills of direct support professionals as a central element in variations in community living experiences" (Hewitt et al., 2004, p. 122). The ways in which a society provides services and supports to people with intellectual disabilities fundamentally affects the way in which these individuals live their lives. Although assisting people has historically and traditionally meant attempting to fix, rehabilitate, care for and protect, the

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[11] Consumers of services as quoted in Larson, S.A., Lakin, K.C. & Hewitt, A.S. (2002), "Direct support professionals: 1975-2000" in R.L Schalock, P.C. Baker & M.D. Croser (Eds.), *Embarking on a New Century: Mental Retardation at the End of the 20th Century,* Washington, DC: American Association on Mental Retardation pp. 203-219 at p. 203.

[12] Governor's Commission on Mental Retardation – Commonwealth of Massachusetts. (2000). *Focus on the Front Line: Perceptions of Workforce Issues Among Direct Support Workers and Their Supervisors* at p. 5.

goal of service provision today ought to be providing supports that enable people to become and remain closely connected and intertwined with their community (Harkins, 1998). Bradley (2000) describes this as allowing people with intellectual disabilities to live as other community members do, by enjoying "such shared 'goods' as relationships, friendships, home ownership, real jobs, spiritual fulfillment, and exercise of personal choice" (p. 192).

Historically, the role of service providers was to take care of individuals with intellectual disabilities. As Hewitt and Lakin (2001) have written, this job involved carrying out "structured programs of health, safety, training and basic care" (p. 4), with a role similar to nurses aides today (Larson et al., 2002, p. 2045). Taylor et al., (2003) describe the evolution of service provision. "In those days, the mission was to keep people safe and comfortable (in custodial care) and apart from the rest of society" (p. 300). It is also important to remember what the work environment for the support providers was like in institutional settings. They worked with "coworkers, supervisors, administrators, and the medical and therapy professionals" (Larson et al., 2002, p. 204).

Today, however, as service provision has evolved, so have the roles and expectations of those who provide the services. Larson et al. (1999) refer to support providers as "the backbone of service provision to people with developmental disabilities" (p. 36). Sundram (1999) emphasizes that the quality of the support providers is "critical" (p. 63). The Governor's Commission on Mental Retardation Staff Report – Commonwealth of Massachusetts (2000) reports, "The skills required to provide direct support in the community have vastly increased" (p. 5). Hewitt and Lakin (2001) talk about the change in "expectations and roles" (p. 4). They note that today, in addition to meeting basic

needs, support providers "have responsibilities to support people to develop and achieve their own personal goals, to balance risks with choices, to connect with peers, friends and family members, and to be full and active citizens in their communities" (Hewitt & Lakin, 2001, p. 4).

The role of support providers is crucial to any discussion about connecting people with intellectual disabilities with their community. Grossi et al. (1991) discuss the importance of the job coach in supported employment situations when they say "the 'quality' of services provided is heavily dependent on the person's skill level" (p. 37). Moore et al., (1991) emphasize the need to have sustained support providers in employment situations in order to keep the rapport with employers and coworkers and because "job training skills are complex and require extensive time to learn" (p. 47).

"A vast array" of services is now offered to people with differing needs in a variety of settings (Test et al., 2003, p. 283). Daytime support providers might assist people at day activities, sheltered workshops or in the community helping with supported employment. Even within the community, support providers might assist one individual or several individuals working in an "enclave" setting. They might also help with leisure and recreation activities. In an effort to help achieve greater community participation, support providers also are becoming responsible for interacting in different environments that include local businesses, neighbourhoods, and community facilities. Beyond being carers, they are also required to be facilitators and advocates for those they support (Parent & Unger, 1994; Governor's Report, 2000). They must help their clients to build skills (Rogan et al.,1999), "to develop and achieve their own personal goals, to balancing risks

with choices, to connect with peers, friends and family members, and to be full and active citizens in their communities" (Hewitt &Lakin, 2001, p. 4).

In congregate settings, support providers are usually responsible for larger groups of people. They may help with personal care, administer medications, teach skills, organize assembly line work, plan recreation events, and conduct educational sessions. They may plan the day's activities, arrange for community activities and take people out to enjoy various community facilities and experiences.

In individualized settings, there is usually more of a focus on employment. Support providers may be responsible for a) job creation and development and b) teaching job searching skills, resume preparation and interview skills. They may be asked to a) break down components of a job and teach these skills, b) negotiate with employers and c) educate employers and co-workers about the individual they support. Support providers may also a) provide support at the workplace, b) teach individuals how to get to work by bus and c) model appropriate workplace decorum (O. Backstrom, personal communication, April 15th, 2004).

In addition to specific duties, support providers may also provide support beyond the "program" by a) teaching advocacy skills, b) communicating with family members, social workers and other professionals, c) being involved in career and future planning, d) acting as sounding boards to a range of problems and issues and e) constantly educating the public about the abilities of people with intellectual disabilities.

Notwithstanding this impressive list of responsibilities and the recognition that support providers are pivotal players in supporting adults with intellectual disabilities,

there remain a number of issues that stand in the way of excellent service and support provision. The first issue is the societal perception of support providers.

> The direct care worker in the field of developmental disabilities has been regarded with a remarkable degree of ambiguity…At times the literature and the rhetoric of professionals highlights the interaction of direct care personnel and people with disabilities as the crucial relationship in any program. Yet professional behaviour in team meetings as well as in the literature on effective programs tends either to totally disregard the individuals providing direct care or to regard them with disdain as mere ciphers. This latter attitude and the dubious title of 'paraprofessional' reflects the marginal status that this culture typically confers on people who fulfill these caring roles (Knoll & Racino, 1994, p. 308).

Almost all of the literature on support providers focuses on a number of key issues. Although research from the United States, Britain, Australia and New Zealand all raise similar points, the vast majority of writings on support provider issues is from the United States. With the exception of the work by Pedlar et al. (1999, 2000), relatively little research on support providers has been undertaken in Canada. According to the literature, the major issues facing support providers are a) poor wages and benefits, b) lack of proper training, c) poor staff retention and high staff turnover. Hewitt and Lakin (2001) highlight the significance of these issues. "What was once a problem viewed primarily as a service provider agency problem must today be viewed as a broad systems problem for which there are no easy solutions…" (p. 3). I will look briefly at each issue in turn.

Salaries are a huge issue for support providers. Mitchell and Braddock (1994) say "Low pay of direct care workers has long been a problem in the developmental

disabilities field" (p. 289). Larson et al. (2002) agree. "Wages in community settings have been considered problematic for most, if not all, of the past 25 years" (p. 208). They go on to point out that there is a significant discrepancy between support providers working in institutional settings earning more than those working in community settings. This is a major problem in Manitoba as well. Support providers working in institutional settings are unionized and can generally make approximately $6.00 or more per hour than support providers working in the community.[13] To put this in context, the minimum wage in Manitoba is $7.25 per hour.

Mitchell and Braddock (1994) list three factors for low wages. They attribute the first factor to wage discrepancies between male and female workers. Historically, women have dominated the field of support provision (p. 290). The second, is the "low esteem given to most service provider occupations" (p. 290). The third factor is historical, because early agencies depended on volunteers and parents, and this reliance served to subsidize the cost of the care. Thus "many of the early reimbursement systems developed by state agencies utilized methodologies that locked in these low compensation levels" (p. 291).

Closely tied to the issue of wages is that of benefits. Larson et al. (2002) cite several American studies on benefits available to support providers and have concluded that "only some direct support professionals are eligible for basic benefits, such as paid time off or health insurance" (p. 208). In Manitoba, it is only in the past few years that benefits have been provided to support providers working in the community.

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[13] Personal communication (October 3rd, 2005) with Mr. D. McPherson, Executive Director, Arcane Horizons Inc., a non-profit residential support agency in Winnipeg.

The second issue facing support providers is a lack of training. As the majority of studies in this area are American, rules and regulations around training support providers is largely dependent upon the area in which the support providers work. In Manitoba, there are no mandatory education requirements for support providers. (B. Jones, personal communication, November 12th, 2004). There is a one year certificate or two year diploma course at Red River College, a local community college in Winnipeg, but this is optional. Individual agencies may also offer their own training, but this is done on an *ad hoc* basis and is not uniform or mandatory. As Hewitt and Lakin (2001) point out, although "Philosophies and values in community human services are frequently changing…Training programs struggle to keep pace and many do not move beyond the care-taking, health, safety and the developmental focus of the DSP training originally developed for care facilities" (p. 10). In addition, because training may be provided by individual agencies, there is no way to determine what is being taught or the values being imparted.

The final issue is staff retention and turnover rates. Obviously, an inability to keep staff is very disruptive to an agency or organization. Any skills taught to staff have to be re-taught with each change in support provider. Expertise gained on the job is also lost when a staff person leaves. The greatest problem in staff turnover, however, is the effect it has on the adults with intellectual disabilities being supported. The American Association on Mental Retardation has said, "there is a correlation between turnover and vacancies (and, therefore, direct support staff compensation) and the quality of life of people with developmental disabilities" (p. 2). Data from several studies have indicated that people feel sad when staff leave and have trouble developing trust with new staff.

With the social workers, our position, there is such a big turnover that they're

constantly facing a loss, you know, because they don't have any friends so they

consider us their friend. Sometimes that line is thin because the turnover is so high

that they're always, there's nothing constant for them (Mactavish et al., 2004, p. 51).

In addition,

Consumers reported that they experienced sadness when direct support staff members

left their job. They also noted that they needed time to build trust with direct support

staff and that the high turnover rate meant having to continuously develop new

trusting relationships (Test et al., 2003, p. 280).

Gaps in the Literature

Although there are a number of studies, literature reviews and reports involving

models of service delivery and issues faced by support providers, there are two major

gaps. The first gap is a lack of Canadian perspective. Although Pedlar et al. (1999) have

done a fascinating piece of work, the aim of their study was, first, to determine the

service provision landscape in Canada, and second, to talk with adults with intellectual

disabilities "to explore with them the impact of these approaches on their day-to-day life"

(p. ix). Support providers were interviewed during the second phase of the study, but the

focus was on the individuals being supported.

The second gap involves a lack of support provider perspectives on the *range* of issues

that affect their ability to do their job well. I mentioned several issues that seem to

dominate the literature. What I have not been able to find is much research that

specifically addresses issues beyond the major focus of compensation, training and retention. In a field that has changed so dramatically, where responsibility is increasing and community membership has now taken centre stage, there must be other issues that support providers view as relevant. It is important to highlight the studies I have found and to look very briefly at the focus of each study and how the data in these studies were collected and from whom. This will better illustrate the gap.

Ford and Ford (1998) conducted an Australian study which looks at self-reported training needs of program managers in the field of supported employment. A questionnaire was mailed to program managers in order to "identify their priorities for training and support" (p. 103).

In terms of American research, Mitchell and Braddock (1994) discuss compensation and turnover rates of "direct care staff" in a national survey. They used a "survey instrument" and their focus is limited to compensation in the form of wages and benefits, and turnover.

The purpose of Hewitt, Larson, O'Nell, Sauer and Sedlezky's (1998) Frontline Supervisor Competencies and Performance Indicators Project is "to identify those competencies required of frontline supervisors providing support services to people with developmental disabilities in order to foster the development and implementation of excellence in service provision" (p. 6). They used focus groups comprised of direct support personnel and frontline supervisors.

Larson et al. (1999) look at staff recruitment challenges and interventions. The method they used was sending surveys to agencies providing services and supports to people with developmental disabilities in Minnesota.

In 2000, the Governor's Commission on Mental Retardation from the Commonwealth of Massachusetts issued a staff report on the "perceptions of workforce issues among direct support workers and their supervisors". This study is the most encompassing that I found, in that the focus of the study was broader than those studies previously discussed. The method of data collection was focus groups. Interestingly, these groups "evolved into forums for direct support staff to express their seldom heard voices on such issues as wages, career advancement, and status and recognition of the front-line workforce" (p. 4). Although this report captures a wider range of issues, training is still the focus. No individual interviews were held to elicit more personal opinions.

Test et al. (2003) undertook a state wide study (one mid-Atlantic state) of the direct support workforce. They say, "The present study was designed to provide insight into the role of direct support staff from the perspective of the people who do this work" (p. 277). The methods they used to collect their data were focus groups with direct support staff (among others) as well as mail surveys to collect additional data. It is important to point out that the purpose of the focus groups was "to gather detailed information regarding direct support staff recruitment, retention, pay, and benefits as well as the impact of these direct support staff issues on the lives of people who received services" (p. 277).

Finally, Hewitt et al. (2004) studied roles and essential competencies of frontline supervisors. They also used focus groups to identify "the skills and competencies needed by frontline supervisors in community residential and vocational programs supporting individuals with intellectual or developmental disabilities" (p. 129).

I would add, for the sake of completeness, that I found several studies which looked at a) job coaches and their roles (Moore, et al.,1991; Grossi, et al, 1991; and Parent &

Unger, 1994), b) employment specialists (Park et al., 1993), c) supported employment in Maryland (Conley, 2003) and d) residential services personnel (Larson et al., 1994). All of these studies are fairly specific in their focus on supported employment issues in particular.

Although these studies do provide some valuable insight into support provider issues, they do not present a complete picture. The studies employing questionnaire-type methods of data collection can have shortcomings in that there is a lack of opportunity for participants to discuss issues beyond the parameters of the questions posed and participants have no opportunity to clarify or expand upon their answers. Similarly, participants in focus groups may feel ill-at-ease when discussing certain issues, particularly among co-workers or in the company of their own managers or supervisors. Sometimes, individual interviews can encourage participants to share information more freely, without fear of sanctions or reprisals.

In addition, studies that look into specific issues may not be able to uncover the wider range of issues that support providers face. There are a number of research initiatives that seek to understand views on wages, benefits, retention, turnover, and training, but fewer studies that open the floor to the participants to discuss issues of concern to them.

Notwithstanding my efforts, I was unable to locate any studies that dealt with the perspectives of Canadian support providers on the issues affecting them, using individual interviews as a method of collecting data. I hope to begin to tackle the complex task of understanding support provider issues in a Canadian context, and examining whether the way in which services and supports are offered, affect the support providers' ability to do the best job they can. I am confident that my addition to the research undertaken thus far

will help to increase awareness of support provide issues. In depth, individual interviews

will help to bring voice to a group of people who have stood almost silently in the

margins for too long.

Chapter 3: The Qualitative Research Approach

"There once lived a man in a country with no fruit trees. A scholar, he spent a great deal of time reading. He often came across references to fruit. The description enticed him to undertake a journey to experience fruit for himself.

He went to the marketplace and inquired where he could find the land of fruit. After much searching he located someone who knew the way. After a long and arduous journey, he came to the end of the directions and found himself at the entrance to a large apple orchard. It was springtime and the apple trees were in blossom.

The scholar entered the orchard and, expectantly, pulled off a blossom and put it in his mouth. He liked neither the texture of the flower not its taste. He went quickly to another tree and sampled another blossom, and then another, and another. Each blossom, though quite beautiful, was distasteful to him. He left the orchard and returned to his home country, reporting to his fellow villagers that fruit was a much overrated food.

Being unable to recognize the difference between the spring blossom and the summer fruit, the scholar never realized that he had not experienced what he was looking for."[14]

I will begin this chapter by discussing and providing a rationale for the research methods I used when I conducted my study. I will then locate myself within my research to provide an understanding of my orientation and biases. Next, because I make very deliberate use of certain language, I feel it is important to provide some definitions and explain my choices. Then I will outline my research design. Finally, I will discuss data analysis.

Methods

My study is qualitative in nature. Creswell (1998) defines qualitative research as "an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem" (p. 15). He says that qualitative researchers

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[14] Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods* (3rd ed.). Thousand Oaks, California: Sage Publications at p. 3

"strive for understanding" (p. 193). I am using this research strategy in order to explore

support provider perspectives, in all their "complexity" (Bogdan & Biklen, 2003, p.2). I

am concerned, as Taylor and Bogdan (1998) say, with "the meanings people attach to

things in their lives" (p. 7). I think it is important to understand the participants of my

study from their own "frames of reference" (Taylor & Bogdan, 1998, p. 7), or to

experience their daily reality from their own *perspectives*. The theoretical perspective I

take in my study is described by Taylor and Bogdan (1998) as "interpretivist" in nature

(p. 3). They use Weber's term "verstehen" to describe the approach of "understanding on

a personal level the motives and beliefs behind people's actions" (p. 4). I think this

theoretical perspective has allowed me to draw out the perspectives of support providers

and to better understand the issues that affect their ability to do their job in the best

possible way.

Researcher's Location

I believe it is important for me to acknowledge my "location". Bogdan and Biklen

(2003) describe this term as the researcher's "way of looking at the world, the

assumptions people have about what is important and what makes the world work" (p.

22). Both Creswell (1998) and Brown (2001) discuss the philosophical assumptions and

beliefs that guide the qualitative researcher and I will refer to both authors in my

discussion.

The underlying purpose of my research is to understand the perspectives of support

providers whose views are certainly not well-documented in the literature to date.

Because I believe the world is made up of infinite "truths" or "realities" depending upon

who is doing the "telling", no definitive truths or realities will be uncovered in this work in order to accomplish my goal. Brown (2001) describes the ontological belief of the qualitative researcher as "multiple, socially constructed realities" (p. 148). As Creswell (1998) says, "Reality is subjective and multiple, as seen by participants in the study" (p. 75).

As a researcher, I think my role is to ask questions and listen. In the end, I have tried to understand all of the issues in a meaningful way that is beneficial to those who provide supports to adults with intellectual disabilities. I do not see myself as objective or as the expert or professional in these discussions. I recognize that the support providers are the experts. Brown (2001) calls this epistemology an "interactive link between researcher and participants" (p. 148). I feel the participants and I are a team who have worked together to uncover and bring their experiences to light.

In an abstract sense, my location is aligned with critical theory because I seek "not just to study and understand society but rather to critique and change society" (Patton, 2002, p. 131). More specifically, I use disability studies as an avenue to understand how disability has been seen in the past and how it continues to be seen today. Disability studies can be used to critique the traditional models of disability and re-conceptualize disability as an inequality in the way in which society views and treats people with disabilities in its political, economic, legal and social constructs. Linton (1998) describes disability studies as a field that "explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state" (p. 2). I believe it is only by critically

challenging current but outdated notions of disability that we can move forward to creating a new paradigm of support provision for adults with intellectual disabilities.

I became involved in the Perspectives in Change project as the Phase II project coordinator. Because I am a Master's student in the field of Disability Studies, I also took on the role as researcher in the support provider perspectives initiative. In addition to my affiliation with Disability Studies, I also have a law degree. I have had some experience in private practice with civil litigation, as well as experience with the Department of Justice as a student and as a Provincial Court magistrate. This legal training and background allows me a certain familiarity in reading statutes and case law. It also gives me an understanding of the legal system and its applicability in a number of situations. Thus I take a certain approach to the concept of "disability". Specifically, I agree with Rioux's (2003) human rights approach to disability, as outlined earlier in this work. I feel that people with intellectual disabilities are equal citizens of Canada and I believe that they ought to be not only recognized, but treated as such. Therefore, I think that laws such as *The Canadian Charter of Rights and Freedoms*, and policy documents such as Canada's *In Unison: A Canadian Approach to Disability Issues* and Manitoba's *Full Citizenship: A Manitoba Strategy on Disability* ought to be implemented into practice. It is not enough to suggest that all Canadians are equal citizens. Supports and services must be implemented in such a way as to give meaning to equality.

I share Taylor's (1988, 2001) concerns about providing services based on a continuum model. I do not believe society has any right to remove people with intellectual disabilities from society by virtue of their disability alone. Because of this belief, I do not condone services that are provided in institutional settings. From a human rights

perspective, I do not believe adults with intellectual disabilities need to prove their societal worth in order for them to be treated as equal citizens. I believe enough research has demonstrated that activity based programming and sheltered work do not prepare people for living and working in the community.

I feel that if the government of Manitoba implemented its *Full Citizenship* policy, it would fund supports based on individual needs and would hold agencies and organizations accountable for the quality of support being provided. As long as institutions, day programs and sheltered work are seen as acceptable ways of providing supports to adults with intellectual disabilities, and as long as supports are seen as discretionary, it becomes difficult to provide meaningful support to these individuals.

I also favour higher salaries, better benefits and mandatory education and training for support providers. It is only by recognizing that what these people do is vital and relevant that change will take place. In addition, the government must ensure that it closes the wage gap between support providers working in institutional settings and support providers working in the community. There can be no real commitment to community living without ensuring, through adequate and fair salaries, that adults with intellectual disabilities receive the best quality of support possible.

I went into this research with some pre-existing assumptions about what I might find when talking with day time support providers. Because I believe that the way in which services and supports for adults with intellectual disabilities are structured in Manitoba is contrary to notions of human rights and equality, I feel that many of the issues arising as a result of supporting these individuals are systemic in nature. I thought that support providers working in individualized settings would have a greater understanding of the

issues and that they would characterize the majority of these issues as a result of the way in which services and supports are organized. I suspected that people providing support in congregate settings would not face as many issues or pressures as their counterparts working in individualized settings. Finally, I assumed that support providers working in individualized settings would feel a greater sense of professional purpose and satisfaction than those working in congregate settings.

I recognize that there is a possibility that my own perspectives can overwhelm my ability to ensure that I have analyzed what the participants have actually said. Patton (2002) refers to this as reflexivity. "Reflexivity reminds the qualitative inquirer to be attentive to and conscious of the cultural, political, social, linguistic, and ideological origins of one's own perspective and voice…." (p. 65). In order to avoid problems in this area, I tracked my own perspectives using a memo writing process. Strauss and Corbin (1998) describe memos as serving "the dual purpose of keeping the research grounded and maintaining that awareness for the researcher" (p. 218). They argue that memos also "act as reflections of analytic thought" (p. 220). I wrote memos to myself on each transcript as I read the transcript over. In these reflective memos, I highlighted my thoughts and ideas, as well as summarized what I read. The memos also helped as I looked across the interviews to develop themes. This process helped me articulate what I thought had gone on during the various interviews and enabled me to ensure I separated my own perspectives from those of the participants.

I wish to add a final word about my deliberate use of certain language. The wording I have chosen reflects my perspective in favour of a human rights approach when providing supports to adults with intellectual disabilities. First, I refer to people with

"intellectual challenges" as people with intellectual disabilities. I do this because it is a respectful term and reflects the notion that people with intellectual disabilities are people first, and not simply defined by their disability or condition. I also refer to these individuals from time to time as "clients", which is a common way for support providers to refer to adults they support. I use the term "client", as opposed to a term like "employer" as it is often the language of the participants and lessens confusion in discussions about supported employment situations.

Second, there are many instances where supports for these individuals are described as "services" or "programs". O'Brien (1993) describes the difference between "services" and "supports",

> Instead of controlling people with disabilities in order to fix (train, habilitate, rehabilitate, treat) them, supported living workers seek to cooperate with people with disabilities in order to develop the assistance they need to get on with their own lives (p. 1).

Smull (1989) discusses the issue of programs and says that the "unintended result of the transfer of institutional patterns of service development and delivery to community programs" has resulted in a "crisis in the community" (p. 1).

I prefer the word "supports" as I believe that adults with intellectual disabilities need and deserve support to live and participate in the community. For me, the word support implies interdependence (as opposed to dependence) upon others. It also implies that individuals ought to be responsible, to the greatest extent possible, for their own self-determination and choice-making.

The word "support" also suggests that thought has been given to what each person needs on an individual basis, and not merely as a group of people who have intellectual disabilities. Just because someone requires support, does not mean that he or she ought to simply be slotted into a generic mold of services or programming that ought to suit anyone with an intellectual disability. Bradley (2000) and Sundram (1999) have said that service delivery is a system of "spaces". Bradley (2000) describes the dominant approach to providing services: public money is allocated to service providers within the community to "purchase program 'slots'" for "those deemed by the system's gatekeepers as eligible and in need of such services" (p. 192). This can be contrasted with true supports that strengthen "the web of connections among people with disabilities and their communities" (Harkins, 1998, p. 163).

I refer to people providing the support as "support providers". Again, I do this because I think they are doing more than serving people. These providers are supporting individuals to live a meaningful life. As Pedlar et al. (1999) say, "support is about interpersonal interactions that help the interacting parties to sustain or restore a sense of shared meaning" (p. 3).

Finally, in this research, I wish to clarify the terms "individualized" and "congregate", which I use to identify the two types support providers. When I use the term "individualized", I do not mean one-to-one support. I use the term "individualized" to denote support provided by agencies whose primary purpose is to help individuals find employment in a community setting. The term employment can be full or part time and can mean competitive work, supported work, work experience or volunteer work. The feature that distinguishes this type of support is that adults with intellectual disabilities

work in the community in settings where people without disabilities work. There may be recreation components to individualized support, but the activities are done either individually or with small groups of friends and take place in community settings such as a gym, library, coffeehouse or other type of recreational facility.

I use the term "congregate" to denote support provided by agencies that primarily provide this support to adults with intellectual disabilities in group settings. The term refers to the fact that people with intellectual disabilities are grouped together for work or recreation activities. The type of support provided may involve a) recreation-based programs in the community or in in-house settings with a group of adults with intellectual disabilities, b) employment in sheltered settings, with other adults with intellectual disabilities, c) employment in enclave settings within the community with a group of adults with intellectual disabilities, and d) community employment or volunteer opportunities. Those being supported may divide their time between community settings and in-house settings.

Research Design

My 2005 study involved collecting data from people in Winnipeg who provide daytime supports to adults with intellectual disabilities. In order to draw the attention of support providers to my study, I sent a letter to each agency in Winnipeg that provides primarily daytime support to adults with intellectual disabilities. I identified agencies through personal knowledge and the CONTACT directory (2004), which is a directory of agencies and organizations providing services and supports to adults with intellectual disabilities in Manitoba. The letter explained the research and asked agency

administrators to post an invitation to participate in their workplace. I also asked that agency administrators hand out invitations to participate to their staff. I asked prospective participants to contact me directly by telephone or e-mail if they wanted more information and/or wished to be involved. I did not contact agencies providing residential support or both residential and daytime support.

My initial goal was to include five people who primarily provided support using a congregate approach (sheltered workshop, enclave setting or day activity program) and five people who primarily provided support using an individualized approach (supported employment in the community). I am aware that data saturation, which Bogdan and Biklen (2003) define as "the point of data collection where the information you get becomes redundant" (p. 62), is the best way to ensure completeness in the research when the purpose of the research is to "maximize information" (Lincoln & Guba, 1985, p. 202). I have chosen, however, to limit the number of participants in this study. As Patton (2002) says,

> There are no rules for sample size in qualitative inquiry. Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with available time and resources (p. 244).

He cautions, however, that it is important for the researcher to fully describe, explain and justify sampling procedures and decisions "so that information users and peer reviewers have the appropriate context for judging the sample" (p. 246).

In term of this research, I can justify my decision to use ten participants for two major reasons. First, as this is a Master's thesis, I felt it was appropriate to limit the scope of the

research to a manageable level, knowing that I had to collect and transcribe all of the data myself within a reasonable period of time and without financial assistance. Second, I was unsure of how many people would want to volunteer their time to participate in this research. As I began to field telephone calls and e-mails in response to my recruitment letters, I realized that I might have had more than ten people willing to participate. I am aware that the views of support providers are not well represented. For this reason, I decided to ask the Ethics Review Board to amend my request of collecting data from ten people so that I could collect data from all the support providers who were interested in participating. Although at one point it looked like I may have as many as 15 participants, I ended up having 11 people who wanted to take part. Furthermore, as I began to collect the data, I realized that many support providers worked at more than one job and were very busy. For this reason, I realized it might be difficult to convince more people to take the time to be involved. In the end, I feel there was a sufficiently wide range of opinions and issues which have enabled me to analyze a significant amount of data.

In order to recruit people for this study, I used a purposive sampling technique (Patton, 2002) for my overall selection of participants. This term refers to the fact that I did not select participants randomly, but rather on the basis of the characteristics and experiences they have. I think this type of sampling is appropriate as I wanted to select what Patton (2002) calls *"information-rich cases* for study in depth…from which one can learn a great deal about issues of central importance to the purpose of the inquiry…" (p. 230). More specifically, I used criterion sampling (Patton, 2002). The criteria I chose were individuals who provide a) *daytime* supports, b) to *adults* with intellectual disabilities c) in Winnipeg. I was interested, not only in issues identified by support

providers, but in possible differences in issues between those working in congregate settings versus those working in individualized settings. Therefore I also used a stratified purposeful sampling technique to categorize participants by the type of support they provide. Patton (2002) says this method is useful "to capture major variations…Each of the strata would constitute a fairly homogeneous sample" (p. 240). I collected data from five individuals who provided support in congregate settings and six individuals who provide support in individualized settings.

After reviewing letters of consent with all participants, I obtained written consents from them before undertaking any data collection. I did not offer an honorarium to any participants.

One way to achieve my purpose of understanding the issues affecting daytime support providers was through the use of in-depth interviews. I chose to use the in-depth interview process in my study for several reasons. Bogdan and Biklen (2003) deem the in-depth interview to be appropriate when "the researcher is bent on understanding, in considerable detail, how people…think and how they came to develop the perspectives they hold" (p. 3). As Seale (2004) says, in-depth interviews "are often used to encourage an interviewee to talk, perhaps at some length, about a particular issue or range of topics" (p. 181). Seale acknowledges that interviewing "is particularly useful as a research method for accessing individual attitudes and values – things that cannot necessarily be observed or accommodated in a formal questionnaire" (p. 182). I believe that the attitudes and values of the support providers are the key to understanding the issues they face. I come from the position that the knowledge of support providers has inherent value and is "meaningful and worthy of exploration" (Seale, 2004, p. 182). Because there has not

been a great deal of research conducted around support provider opinions and experiences, particularly in Canada, I consider these perspectives to be coming from the margins. Seale (2004) says that "… qualitative interviewing has been particularly attractive to researchers who want to explore the voices and experiences which they believe have been ignored, misrepresented or suppressed in the past" (p. 182).

I used an interview guide during the course of my data collection. Table 3 is a sample question guide.

Table 3

Sample Question Guide

Type of Question	Question
Welcome Remarks	Thank you for agreeing to participate in the "Perspectives in Change: Issues in Community Support for People with Intellectual Disabilities – Phase II" research project. Today I would like to ask you some questions about your role as a support provider, helping people with intellectual disabilities in their daytime pursuits.
Introductory Questions	What made you choose to work with people with intellectual disabilities?
Background Questions	How long have you been involved in this kind of work?
	What is your educational and/or work background? *Prompt*: What kind of positions working with people with intellectual disabilities have you held? Tell me a bit about your current position and the work you do now. *Prompt:* How long have you held this position? Can you describe what your role is in supporting your client(s)? *Prompts:* What are the typical things you do each day? Are there any "extraordinary" things you might be required to do occasionally?
Main Questions	Are there any particular stresses associated with your job? If so, can you describe them and why you find them stressful? Are there any particular issues associated with your job that make it difficult to perform, or that stand in the way of making it easier to perform? If so, can you describe them? We have talked a lot about the issues associated with your job. What are the benefits or things that make your work worthwhile for you?
Closing Questions	Is there anything you would like to add about your job that we haven't touched on?
End Remarks	Thank you for taking the time to talk with me this morning/afternoon/evening. I really appreciate it.

I used what Patton (2002) refers to as a "general interview guide approach" where the guide "serves as a basic checklist during the interview to make sure that all the relevant topics are covered" (p. 342). I chose to use an interview guide because it ensured that I covered similar topics and issues with each participant, leading to a "more systematic and comprehensive" process (Patton, 2002, p. 343). As a novice researcher, I feel it was very helpful to follow a guide so that nerves and unfamiliarity with the interview process did not prevent me from collecting the best data I could. Taylor and Bogdan (1998) say, "…an interview guide is useful when the researcher has already learned something about the informants…" (p. 106). My work in the larger Perspectives in Change project and my familiarity with Phase I data allowed me to become knowledgeable about issues facing support providers. This knowledge enabled me to devise an appropriate and useful interview guide.

I conducted one interview with each participant. The interviews I conducted lasted anywhere from 20 minutes to one hour, with the majority lasting around 45-50 minutes. I took notes during each interview. Patton (2002) says that note taking serves several purposes including assisting in formulating new questions during the interview process (p. 383). I found this to be particularly helpful as I was able to jot down a point to come back to later, rather than interrupting the flow of the conversation. I tape recorded each interview and later transcribed all sessions. I assigned each participant a pseudonym. I also changed the names of any agencies, organizations, people and locations mentioned during the course of the interview that might identify the participants. This enabled me to ensure confidentiality to all participants. All of the transcription tapes were kept in a locked, secure location and were destroyed at the end of the research.

Data Analysis

In order to make sense of all the information I collected, I looked for key themes in the data. Seale (2004) identifies this method as "qualitative thematic analysis". He describes this approach as

> analysis based on the identification of themes in qualitative material, often identified by means of a coding scheme. A widely used approach to qualitative analysis, generally treating accounts as a *resource* for finding out about the reality or experiences to which they refer... (p. 509).

Although coding schemes "may be informed by the principles of a particular methodology...a great deal of qualitative analysis is done without particular reference to such specialist methodological approaches..." (Seale, 2004, p. 314). He says that the term "qualitative thematic analysis" was coined as a response to novice researchers who are anxious about providing legitimacy to the approach they take with their analyses.

Patton (2002) uses the term content analysis, in its generalized form, to denote "any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings" (p. 453). My analysis process has involved looking for meaning in the data by seeking out themes. Patton refers to this process as "inductive analysis" which involves "discovering patterns, themes, and categories in one's data. Findings emerge out of the data, through the analyst's interactions with the data..." (p. 453).

Following Creswell's (1998) "data analysis and representations" matrix (p. 149) I began by organizing my data ("create and organize files for data" p. 149). Then I

reviewed all the transcripts several times. As I read and re-read the transcripts, I wrote memos of impressions I had. I also used these memos to keep myself on track, in terms of differentiating what I thought respondents might say, what respondents actually said and how I felt about their responses. I made colour-coded notes in the margins to help me uncover themes ("read through text, make margin notes, form initial codes" p. 149). As Seale (2004) says, "Initial coding consists, then, of reading through material and identifying where themes of particular interest are illustrated by the data" (p. 313). Noting discussions about issues in providing daytime support, I highlighted key comments on the different issues that arose for each participant. After completing this process with all eleven transcripts, I used large poster paper and coloured markers to divide the issues according to larger themes ("find and list statements of meaning for individuals" Creswell, 1998, p. 149). Once the major themes were identified, I looked at all the comments within each theme and created sub-themes.

Next, I grouped the data into issues that arose from participants working primarily in individualized settings and participants working primarily in congregate settings. I then used large poster paper and coloured markers to group issues into key themes for each group. Once the posters were finished, I was able to see what key themes were the same and what key themes were different for both groups. I was able to do the same with sub-themes.

In addition to looking at key issues, I also looked beyond what the participants had actually said and inductively looked for broader issues that the data may only hint directly at. I think this added a depth to the analysis that merely listing key themes would

have lacked. This allowed me to "develop an overall description of the experience, the 'essence'" (Creswell, 1998, p. 149).

By using these analysis strategies, I identified the relevant support provider issues, denoted which issues were relevant to which category of participant (if applicable) and provided the overall "essence" of the data. I was then able to begin to consider whether or not systemic issues affect the groups of support providers differently, or at all. I was also able to analyze how the issues raised by support providers could be reflected through a human rights lens to better understand how such an approach to disability may alter the practicalities of providing supports to adults with intellectual disabilities, thereby promoting the kind of equality enjoyed by society's more privileged citizens. I believe this collection of data will help convey a better understanding of a marginalized voice - support provider perspectives.

Credibility and Trustworthiness

Although many authors have discussed the verification processes in qualitative research (Creswell, 1998, p. 200), I prefer what Wolcott has to say about the place of validity in his work. As Creswell (1998) says,

> Wolcott's goal is to identify 'critical elements' and write 'plausible interpretations from them'… Wolcott claims that the term *validity* does not capture the essence of what he seeks, adding that perhaps someone will coin a term appropriate for the naturalistic paradigm. But for now, he says, the term *understanding* seems to encapsulate the idea as well as any other (p. 200).

I used data triangulation as means of making use of "multiple and different sources, methods, investigators, and theories to provide corroborating evidence" (Creswell, 1998, p. 202). More specifically, I relied on the experiences of eleven different support providers in order to make sure that I included multiple perspectives.

Both Seale (2004) and Creswell (1998) discuss ways in which qualitative data can be enhanced (Seale, 2004, p. 80) or verified (Creswell, 1998, pp. 201-203). Although Creswell (1998) recognizes eight verification procedures, he recommends that "qualitative researchers engage in at least two of them in any given study" (p. 203).

In order to ensure trustworthiness of my data, I used several strategies. As I already mentioned, I tape recorded all interview sessions. This step enabled me to collect trustworthy data as I had a very good representation of the conversations. I should note that sometimes, when transcribing the tapes, words or phrases were difficult to understand. One participant, in particular, had a heavy accent and this made transcription more difficult. I tried, wherever possible during the course of that interview, to clarify what the participant had said to make sure I understood the issues accurately when I came back to the transcription process.

I also took written notes during the interviews. These notes provided me with an opportunity to double check some of the major points people made against the transcripts, in the event the tapes were difficult to hear.

I used member checking or validation to ensure trustworthiness of the data. Lincoln and Guba (1985) say that member checking is "the most critical technique for establishing credibility" (p. 314). I sent ten of eleven participants a copy of their transcript by regular mail. I was unable to reach the final participant to obtain an updated

address. Telephone messages to that participant's last known phone number were not returned. Among transcripts sent, no envelopes were returned to me as unopened. I asked the participants for feedback and gave them at least three weeks to clarify or correct anything in the transcript that they felt was inaccurate or in further need of clarification. All participants had my home telephone number and e-mail address.

Only one participant responded. She asked a) that I omit the name of her job position as it might identify her, b) that I generalize a statement she had made, also to avoid identifying her, and c) that a point she made be clarified. I can only speculate on why most participants did not respond to my request that they review their transcripts. It was not easy to recruit people for this study. After having spent an hour in the interview process, people may not have been prepared to read a lengthy transcript and invest more time. Support providers have very busy schedules, often working overtime or more than one job. Time simply may not have allowed people to either read or comment on the interview. There was also a significant delay in some participants receiving their transcripts from the time of the initial interviews. This delay occurred because three interviews were set up three or four months before the rest. It also took some time to transcribe the interviews, given other commitments I had at the same time. Participants may have lost interest in the study in the interim. Finally, there may simply have been no changes to be made to the material forwarded to them.

At the end of my study, I sent each participant a brief analysis of the research. Again, one participant did not receive a summary due to my inability to obtain an updated address. There was another delay in getting the summary out to people as it took time to

analyze the data and prepare it for presentation in a brief format. I invited participants to respond to this summary with any comments they might have. I received no responses.

I think there were two problems with keeping in touch with participants during the course of this thesis work. First, the interviews themselves were spread out over a seven month period. Then it took another four months to complete all transcriptions. Finally, it took a further four or five months for me to be satisfied with my analysis to put together a summary to send out. I would have preferred to have a tighter time frame and will endeavor to remedy these issues in a more satisfactory manner in future research.

Chapter 4: The Data

"Analysis finally makes clear what would have been the most important to study, if only we had known beforehand."[15]

"It wasn't just curiosity that killed the cat. It was trying to make sense of all the data curiosity generated."[16]

Overview

I will begin the analysis of my data with an overview of its participants. I will then

identify and describe the themes and sub-themes that were derived from this analysis,

leading to a better understanding of a) what issues face daytime support providers in

Manitoba today, b) which of those issues are systemic in nature, and c) whether or not

people providing different types of support identify and understand the issues in the same

or different ways.

Before I begin, it is important to be reminded that services and supports for adults

with intellectual disabilities in Manitoba are provided within a continuum model. The

very nature of a continuum means that there are no clearly delineated places to mark the

end of one type of service and the beginning of the next. Services and supports are more

fluid in nature. Thus individuals who provided recreation and on-site work may also have

played a community-based or supported employment role as well. I will discuss the data

by providing relevant information about the participants in my study. I have already

stated that six people provided support in an individualized setting and five participants

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[15] Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods* (3rd ed.). Thousand Oaks, California: Sage Publications at p. 431.

[16] Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods* (3rd ed.). Thousand Oaks, California: Sage Publications at p. 440.

provided support in a primarily congregate setting. An overview of participants is set out

in Table 4.

Table 4

Overview of Participants

Participant	Work Setting	Years Experience	Role	Involvement
1	Individualized	Less than 1	Direct support (supported employment)	Friend with disability
2	Individualized	10 years	Supported employment	Employment counselling
3	Congregate	3 years	Direct support (facility-based)/ job developer	Helping people
4	Individualized	8 years	Supported employment	University degree
5	Congregate	10 years	Direct support (facility-based)/ job developer	Friends/parental involvement
6	Congregate	7 years	Direct support (enclave)	Wife in field
7	Individualized	12 years	Supervisor (supported employment)	University (Recreation)
8	Congregate	16 years	Direct support (facility-based)	Friend with disability
9	Individualized	30 years	Direct support (supported employment)	Social justice/ University degree
10	Individualized	Less than 1 year	Job developer	Employment-related
11	Congregate	10 years	Direct support (facility-based)	Family members with disability

I asked participants, whose work experience averaged just over 8 ½ years as a group,

to discuss the issues they faced when supporting adults with intellectual disabilities. Of

the eleven participants, nine support providers worked directly with the people they

supported. The tenth was in a supervisory position, although he had considerable

experience with direct support as well. The final support provider held the position of "job developer" and had had minimal experience with direct support. Some support providers had worked with more than one agency or organization and others had experiences with residential support, educational support and recreation support, in addition to their current role in daytime support. I encouraged them to talk about issues that came up in former roles, but only if those roles involved some type of daytime support.

In terms of the support roles interviewees fulfilled for their agency, some spent time in the community with the individuals they supported. That time consisted of supporting employment, volunteer and recreational opportunities. Some of these employment opportunities were part-time and others were full-time. Other interviewees supported individuals during recreational programs, in sheltered workshops or in enclave settings.

Participants' educational backgrounds varied greatly. While three people had some background with disability courses and training specifically, most did not. Education included degrees, diplomas or certificates in human ecology, psychology, recreation studies, child care and employment counselling. Two participants had no particular training or education.

As I spoke with these eleven support providers, I found it interesting to discover why they became involved in working with people with intellectual disabilities. Six interviewees mentioned personal reasons for their involvement. Personal reasons usually meant a relative or friend had a disability, leading the interviewee to become interested in pursuing a career in human services with people with disabilities. One person had a family member in the field and also became involved, first by volunteering, and later as a

paid employee. One individual began her career in the employment counselling field. Another simply saw this field as a way to help people. Yet another participant took some disability-related courses that sounded interesting and loved the field. Finally, one participant became involved in the disability field because it was the only job offer she had received after graduating from a degree program. She had had no intention of working with people with disabilities and was essentially waiting until another employment opportunity presented itself. At first I worried because that interview did not go at all as I had hoped. However, as I typed up the transcript and thought about it, I realized that this participant was actually able to tell me quite a bit about the importance of motivated people working in this field.

<div align="center">Support Provider Issues</div>

I will now turn to the issues themselves. I grouped all of the issues mentioned by the participants into four major themes. I identified these as 1) issues around supported employment in particular, 2) agency or organization-specific issues, 3) professional issues and 4) systemic issues, or issues arising out of the way in which services and supports are organized and delivered. In addition to organizing the issues facing support providers into themes, I also looked at all of the comments within each theme and classified them into what I call sub-themes.

Within the theme of supported employment, issues were raised about a) employment for people with intellectual disabilities and b) supporting these individuals in their endeavours. Within the theme of agency/organization, there were two sub-themes, a) staffing and b) the roles held by support providers. The professional theme had three sub-

themes, a) how a support provider fits into his or her role, b) the need for training and/or education and c) financial compensation. In the final theme, systemic, I uncovered four sub-themes, a) transportation issues for people with intellectual disabilities, b) funding issues, c) community attitudes and d) government policies. Table 5 summarizes the themes and sub-themes, which I will discuss in the next section.

Table 5

Themes and Sub-Themes

Themes	← Sub-Themes →			
Supported Employment	Employment	Support		
Agency/ Organization	Staffing	Roles		
Professional	Good Fit	Training/Education	Compensation	
Systemic	Transportation	Funding	Community Attitudes	Government Policies

In Figures 2 to 5, which follow, issues in bold type are common issues shared by support providers working in individualized settings and congregate settings. Issues that are underlined are specific to support providers working in individualized settings. Issues in plain type are specific to support providers working in congregate settings.

Supported Employment

I call the first key theme in my research "supported employment". Figure 2 outlines

the two sub-themes brought up by participants, a) employment and b) support.

Figure 2

Supported Employment Issues

Supported Employment

Employment
- attitudes of potential employers are barriers
- agencies need to find employers in new fields (eg. unions, government)
- co-workers need to change attitudes
- potential employers need to know about supported employment
- agencies need to maintain good relationships with employers
- co-workers need to set positive examples and role modeling
- individuals need to work more hours

Support
- individuals need to want to work
- individuals need to be well-suited to their job to cut down problems
  at the workplace
- individuals need to be realistic about working hours and the job they
  want
- individuals need family support

It follows that issues around supported employment would emerge from my discussions with support providers. Six participants worked at agencies specializing in providing support to adults with intellectual disabilities to enable them work in individualized community settings. In addition, several support providers working primarily in congregate settings were also involved in supported employment to some extent as the agency for which they worked had a supported employment component in addition to the in-house program.

In general, the roles played by support providers in supported employment situations included a) helping individuals with day to day tasks on site, b) soliciting businesses to determine their employment needs, c) creating employment opportunities for adults with intellectual disabilities, d) helping individuals put together resumes and obtain job searching and interviewing skills, e) training individuals on the job to perform the required tasks, f) training individuals to take the bus to and from work and g) providing intermittent follow up support to individuals already employed and trained.

Employment. One issue for many participants was the attitude of potential employers towards hiring adults with intellectual disabilities in community-based settings. Generally, negative attitudes and a lack of awareness by these employers are a huge barrier to finding jobs for these individuals. One participant said, "The main problem with that was the amount of people that were actually willing to listen to what we had to offer, you know. People just not being open-minded…in terms of community employers." Another participant agreed.

> …when I go into a business where someone isn't open to it, it's kind of hard for me to see past that and see the business aspect… Like when I go in and say 'you know

I'd like minimum wage for someone that's doing part of a receptionist job', it's hard

for me to see why they don't want to pay that person that minimum wage just because

I see so much potential in these individuals... I get frustrated and I'm thinking 'you

know, why not, if this was your daughter or son you'd want the same thing for them,

you know'...

Until people with intellectual disabilities are seen as potential employees, convincing

employers to hire them remains an uphill battle. Stereotypical images of people with

intellectual are still alive and well. "What I've seen from employers of people that I

support and coworkers, there is a lot of the perception of them being a child."

For many participants, finding jobs for the people they support was a huge issue as

employers refused to hire either out of fear or ignorance or both.

It's very frustrating. You have to deal with a lot of rejection and people who don't

understand. Like, 'Oh, a person with a disability, well, oh, well no then we're not

hiring' kind of thing, or they have misconceptions in their head.

Another interviewee thought the key was

To somehow let them know that people with disabilities can work and contribute and

just to get the foot in the door to say 'OK let's try this'... I think they don't know what

to expect, I think is the biggest thing.

The abilities of people with intellectual disabilities are underestimated. The concept of

supported employment is also foreign to many employers, as they do not understand the

role the support provider and agency can play in helping the individual, the employer and

co-workers to create a positive and productive work environment. One participant

described the challenge.

I guess just trying to get in with employers and help them to understand more about supported employment and that we're here to help them as well as help our clients because a lot of them get really defensive when they hear the words 'person with a disability'. An image comes up in their mind and they just close right off, like, 'Oh we're not hiring' or 'I don't have time right now' or something like that. It's challenging in that way.

Another said,

They feel that we should, they don't necessarily understand the disabilities that we're dealing with and they feel that we should be able to just be flexible and be able to do all these things at the drop of a hat, and that we can use the same type of disciplines that they might use with their employees.

Even after an individual has been hired, misconceptions and a lack of understanding can continue to be an issue.

I guess when I was doing supported employment, a lot of the employers don't necessarily view the individual as the employee, they see the support staff as the employee and they would talk mostly to the employee – the support staff I mean – because they know that they're hearing what you're saying, they know that you're responding and you're able to, you know, they understand how you communicate, whereas a lot of the individuals have a different style of communicating.

Although some individuals with intellectual disabilities have jobs in the community, many work only a few hours a day and a few days a week. One participant who worked at an agency offering individualized and congregate services was discouraged by the lack of hours many of the supported individuals were able to secure. "As far as hours, yeah,

hours are limited. So that would be the issue. Sometimes hours are very limited, where there could be more possibilities." She went on.

> And there's one individual that works two days and he works from 10 to, he's supposed to work till one but sometimes he's sent home and sometimes he only works till 11 or so. So very minimal for him. Um, there's one lady that works one morning for an hour. There's one, there's one gentleman that works for two days, for three hours or two hours. One lady that just started, she works one hour per week.

There is the additional problem, especially for support providers in supervisory and management positions within their agencies, of maintaining good working relationships with enrolled employers after these employers come on board. Agencies do not want relationships to end if one employment situation does not work out. "That's certainly a frustration point when you're trying to create relationships with employers so that you can have that long term situation where you know that if something doesn't work out you still have that relationship with the employer..."

There was also an acknowledgement that there is an imbalance of power when it comes to discussing problems that arise with supported employees. "And if the employer decides to let the person go, it's, we try to kinda negotiate things but it's typically out of our control in the end."

The reality for many people with intellectual disabilities seeking employment is that there are some fields or areas from which they have been largely excluded. "...certain fields of work are difficult to get pay in." Support providers whose job it is to find new employment opportunities bemoaned the fact of the difficulty of securing a union job or a job in any level of government for the adults they support. For example,

The City of Winnipeg is all unionized and she said that there was no way to have an

individual come into their work place because of them being unionized they can't just

create a job within the company kind of thing.

Another individual said,

Unions form a barrier to our being able to get our clients employed in a certain place

because a lot of them have rigid rules around the job descriptions and who can do

what job and who can do the training.

Participants also realized the limits of employment equity policies.

I think another one of the things that would make my life easier is employment equity

kind of stuff. We've had just a significant issue with getting jobs within ten or more

significant companies like Hydro, Government of Manitoba – that's been a real

struggle.

These barriers, particularly in situations where the employers espouse employment

equity practices, led some participants to comment on the unlikelihood of finding such

employment for individuals with more than a minor disabling condition.

Jobs in large corporations and government are very hard to come by as well even

though they have employment equity policies and they're all talk, it seems that they

are more favorable towards the physical disabilities or visible minorities instead of

people with learning disabilities.

Negative attitudes and a lack of understanding about supported employment were not

limited to potential employers. Co-workers were also seen as a potential problem. Some

co-workers simply did not understand the purpose of the supported employment process.

So not only do you have to teach your client how to do their work but you have to educate the coworkers too. And that is a sort of frustration because they don't have the patience or they don't want to hear anything. Or they have their own way of doing things and they figured that the clients should learn that there is a certain way or a certain limit, timeframe, and you have to explain, 'No, I'm sorry but our client has certain limitations, it may take a little bit longer to learn the task'. That is the point of conflict that I may have is because they don't understand exactly what your role is or what technique you have to use when you're working with clients.

Sometimes co-workers can set bad examples for employees with intellectual disabilities. "But you also run into coworkers who are setting bad examples so the clients then will be saying, 'Well, she does this', then you're trying to explain…"

Support. The second sub-theme concerns the logistics of providing support to adults with intellectual disabilities in an employment setting. Support providers hope the individuals they support will be satisfied with their jobs, but this is not always the case. Two interviewees were concerned about individuals not wanting to work at all. One person said,

Um, sometimes individuals are in the program but they don't want to work and that's very difficult… Maybe they say they would like to work and come into our program, but then they, they call in sick a lot or they show up late to work or they're not motivated when they're there.

Another person echoed these thoughts.

…now that's where sometimes you feel like you're getting work for people that maybe really aren't interested in work, because they really haven't expressed it. It may

be something maybe that their parents have wanted for them, and not really that individual. So that's where sometimes it's a bit of a struggle.

For some individuals, not wanting to work can manifest itself in habitual lateness or boredom. An interviewee said,

> There's issues like certain frustration points are like when clients jump ship when you've got an employment situation that seems stable and then all of a sudden the client doesn't show up for work, doesn't call, and you don't know what's going on, and having to try and find them and see if there's a reason.

Another interviewee gave a different example. "Some of them, they really hate their job to be honest. They just do it for money, period, not because they like it. It's quite monotonous, it's tedious, it's boring."

One participant stressed the importance of having the individual understand the hours that an employee in a similar position would have to keep.

> Sometimes what can be a challenge for some individuals is they come from high school having this 9:30 or 9:00 to 3:00 or 8:30 to 3:30 perspective of the world. And the type of positions our clients are looking for, the busiest times often are evenings and weekends, particularly in retail. Anything in the service industry. And so it's kind of opening their minds of the fact that well if you want to pursue a job in, let's say, retail, Saturday's are their busiest day. You may be expected to work. Or we may be expected to work into the evening.

These problems may well be connected with the difficulty in finding the right employment situation for people and ensuring that personalities mesh with the working environment.

So I find that a little bit I guess stressful because I feel like I'm squelching his

strengths to get him focused on something else. I sometimes wonder if that's the best

placement for his personality, you know, that kind of work.

Because it is so difficult to find an employment placement, some adults with intellectual

disabilities may end up working at jobs they do not care for, which makes it difficult to

provide good support.

Finally, one participant mentioned the importance of family support in encouraging

their family member to work hard and ultimately, succeed. "I have noticed…that family

support is sometimes there and sometimes it isn't, and gosh I wish that every dad and

mom will be there for their children."

Agency/Organization

I have classified the issues in this theme as those relating more specifically to the

agency or organization employing the support provider. Some issues that arose during the

interviews are common among agencies, regardless of the type of support the agency

provides or the mandate they have. Other issues are more specific to the services that the

agencies provide. The two sub-themes in this key theme are staffing and roles. The

details are set out in Figure 3.

Figure 3

Agency/Organization Issues

**Agency/
Organization**

Staffing
- **shortages**
- lack of time to do all that needs to be done
- difficult to teach new skills with too few staff
- group members must do the same thing whether they want
to or not

Roles
- dealing with families of people being supported
- connecting with other support providers
- getting contract work done
- dealing with repetitive nature of job
- dealing with employers and roles in enclave setting
- supervisor/management roles and direct staff roles can
become
  blurred, causing tensions
- dealing with agency management (preconceptions and
attitudes)

Staffing. I have labelled the first sub-theme "staffing". This term refers to staffing issues internal to the agencies or organizations represented in this study. The problem of staffing is also a systemic issue and will come up again under the systemic key theme.

For the participants, insufficient staffing was a key concern. In practice, employing too few staff members has several ramifications. In a congregate setting, too few support providers means that the individuals being supported have little opportunity to learn new skills.

> ...it's hard to take a very small group where you can take two or three people and have that time where 'let's try to train you on something new', because you have ten people that you've got to watch, and it's really hard to have that one-on-one to try to have that teaching and learning.

It also means that where support providers deal with large groups of individuals at one time, some of the people they support must do what the majority of the group does.

> Well that would be, of course, ratios. I mean individuals sometimes sitting there doing something they're really not interested because staff ratios are just too low, or you know what I mean, you've got one staff for three to four participants and of course their interests are not gonna all be the same, and you know...

Another issue for the participants was simply not having the time each day or each week to do all of the work they needed or wanted to do. One said, "Lack of time is the biggest thing that jumps into my head...Not being able to support the people how I think they should be supported." Another agreed.

Time, for sure…Um, if several people are hired or even just two people are hired in a

position at once, you have to kind of juggle things with your own schedule. Plus at

the same time you're supposed to see all your other clients during that week's…

When a support provider is responsible for looking after different individuals at

different employment sites, it can mean very long hours in order to ensure all individuals

are properly supported.

In the past, not now, but in the past there was a situation where I needed to work with

two clients at the same time. That was sort of a stress. I remember once I started at

6:00 in the morning with one client, finished by three, and then I started at 4:00 and

finished by 12:00 with the other client. So it was one full day. Two places, different

tasks, different clients. I think that was sort of a stress on me.

Roles. Another sub-theme of agency/organization is the role participants play as

support providers in various settings. Different roles bring with them different stresses

and issues. I will outline the issues that arose during the interviewing. These issues were

primarily individual concerns.

In some congregate settings, support providers may have two tasks to perform. They

must support people with intellectual disabilities but they must also meet certain

deadlines with contract work. So, "There's always that pressure of not getting your

contract done on time."

One individual working in a congregate setting recognized the repetitive nature of the

job.

I guess the listening part can get – because with some of the clients it's very repetitive

and you want to make sure that you're listening to what they're saying but it's hard to

focus if in your mind you're hearing the same thing over and over again...You're repeating yourself constantly, which is tiring.

However, this comment can be juxtaposed against another made by a participant in an individualized setting. "...it's never the same everyday. It's always changing with new individuals coming in, new work environments, meeting new people all the time. That makes it very dynamic and interesting."

A participant working in an enclave setting discussed the problem of ensuring the employer company understands the role of the support provider. "...we also have to work with the needs of the company, of XYZ Company, and sometimes XYZ Company themselves don't understand. They expect us to, they almost look at Ted and myself as being employees of their company." Similar issues are faced by support providers working in individualized settings when employers and co-workers do not understand that the adult with the intellectual disability is the employee, not the person providing the support.

A rather challenging issue for support providers is dealing with a client and that client's family. Usually, information on people supported in the human services field is confidential. However, in cases where the people being supported have an intellectual disability, their family can also be involved with decision-making and other matters. This can result in problems when there is a conflict between the individual and the family. "Sometimes I think because we're not just dealing with the client, we're dealing with the family, which I think is really unique in social services."

Support providers working in individualized settings need time to connect with others in their field. Job isolation can be difficult for those who spend their days out in

the community with the individuals they support. "I think it's important for companies to make sure that they really either make sure they create enough opportunities for people to meet and interact with each other, like just workers like myself."

In some agencies, tension builds when support providers are asked or expected to carry out both supervisory and direct support roles within an agency. This demand places stress on the support provider and co-worker relationships. "It's like you're wearing two different hats. The hats is, 'You're in charge today when the boss is away, but tomorrow you're not'".

A support provider working in a congregate setting spoke about management attitudes. She seemed disappointed in her perception that management expected support providers to be controlling in their relationships with agency clients. "I found that management really wanted you to play the role, like the controlling." She also spoke of management's fear of placing certain individuals with intellectual disabilities into community work situations.
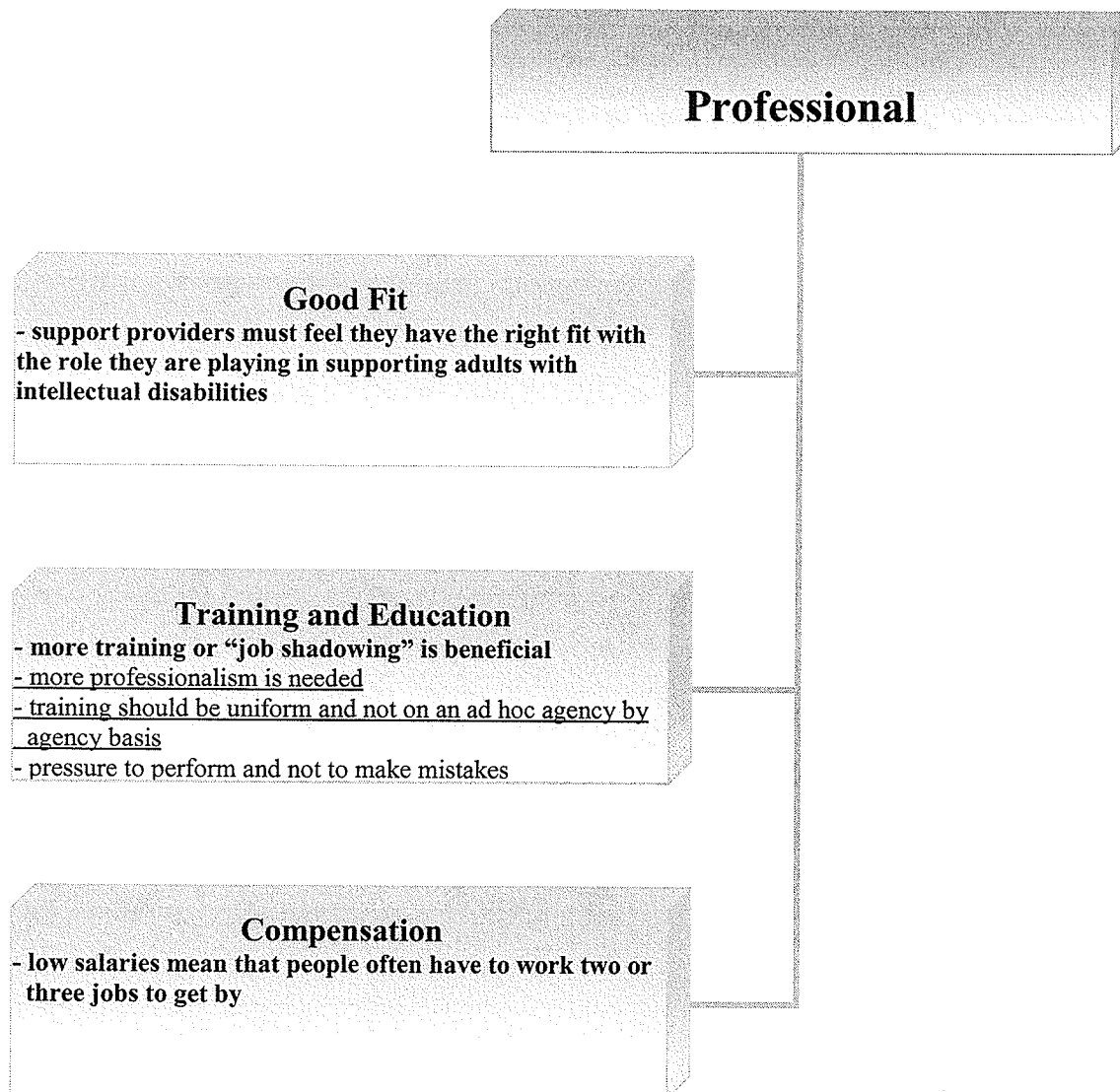
I recognize that every job and profession has a number of issues or stresses that makes it difficult for employees to carry out their responsibilities. Every employee will have at some time issues or stress. However, I think it is important to set out these role challenges as many of these challenges can be linked to the systemic issues I will explore in due course.

Professional

I have entitled the next theme "professional". Figure 4 highlights the sub-themes the participants discussed during the course of the interviews as, a) a good fit, b) training and education and c) compensation.

Figure 4

Professional Issues

Professional

Good Fit
- support providers must feel they have the right fit with the role they are playing in supporting adults with intellectual disabilities

Training and Education
- more training or "job shadowing" is beneficial
- more professionalism is needed
- training should be uniform and not on an ad hoc agency by agency basis
- pressure to perform and not to make mistakes

Compensation
- low salaries mean that people often have to work two or three jobs to get by

Good fit. The first sub-theme is one I describe as a "good fit". This is one of the most important things that I gleaned from the participants. After delving into the issues, we discussed why participants were doing what they were doing. The message I received, loud and clear, was that there has to be a good fit between the support provider and the role he or she plays in supporting adults with intellectual disabilities. A good fit has two components. First, a person must be well-suited to supporting adults with intellectual disabilities. Second, support providers must also be able to provide that support in an environment that they feel meshes with their own values and beliefs about people with intellectual disabilities.

Nine of the participants were well-suited to their role of supporting people with intellectual disabilities in that they felt strongly about the work they did. It did not matter how they provided support. I will quote extensively from participants here because their words are far more powerful than mine could ever be.

I think a lot of it comes down to do you have a personality where you can do this kind of work? Do you feel this is an important kind of work which will definitely help that support worker do a good job if, they feel it's important, rather than just some kind of, just a job just to make a few bucks.

I'm actually quite happy with this work. The benefits... I just, I also get some satisfaction with, with knowing that I'm doing something that, helping someone who is in need.

...just seeing the successes of individuals and how far they've come is probably the most rewarding thing. You know, perhaps three years ago an individual had never

taken a bus on their own, came into our program and wouldn't open up, and now they're working at a place where they have friends that are coworkers, and they're thriving and they're earning money, like what better reward than to see that.

I love my job. I really enjoy working with people with mental and physical disabilities. I find it very rewarding and it gives me the sense that I'm helping and I'm doing something good, and they're a great bunch of people. I learn a lot from them and they learn a lot from me, and they are hard working and they're just like anybody else.

Basically the people and the relationships that you form. I guess for me I always think the way I live my life is you just need something to do, something to believe in, and something to love. So that's kind of my job.

I think I have the social inclination of helping people first of all, by nature. I came from a society where I could see the disparity among social classes, and I have this idea of justice, social justice, so it was well imprinted since my childhood, these sort of do the right things, you know, help people.

I did interview one participant who did not have any particular affinity for her job. She found the pace of the work very slow, with few positive results. This confirmed for me that providing support to adults with intellectual disabilities must be consistent with a particular world view.

As I mentioned earlier, support providers also must provide that support in an environment that suits their values. During one particular interview, a participant was

quite disillusioned with the role she was required to play at the agencies for which she worked. The support role she was required to play did not seem to mesh with how she thought adults with intellectual disabilities ought to be supported. She enjoyed working with people with disabilities but said,

> The work is rewarding when I'm doing something with somebody that they really love to do… I'm not happy when I'm pushing people to work for the sake of working. And I don't agree in just make jobs like 'OK, the floor needs to be cleaned.' 'Well the floor was mopped yesterday.' 'Well he needs to do something so let's mop it again.' I, it's very frustrating and I see the frustration in the participants and I don't like that. I took this job to help people to feel good, not to feel uncomfortable…I love working with the people, when I'm helping them to do something that's rewarding for them.

It was clear to me, as I re-read the data from this participant, that she enjoyed the people she supported, but did not agree philosophically with that agency's mandate or values. This made it difficult for her to provide support in a way that gave her job meaning.

During one particular interview, the participant did not seem to have any issues at all to discuss with me. If I asked her about anything in particular she simply said it was a part of her job. I was puzzled by this response. Even the one participant who was anxious to leave the field had an understanding of many issues facing support providers. However, the more I mulled this problem over, the more I realized that this support provider was actually telling me that she was comfortable with her role at the agency she worked for. She saw her role as providing support and she loved doing it. She enjoyed the people she supported and enjoyed the way in which she supported people. She had what I call a "good fit", a most important criterion for a support provider.

Training/education. My second sub-theme is the training and education of support providers. The general consensus among support providers was that more training is always beneficial. In some cases, there simply was not enough hands-on training for the support providers to feel comfortable in their positions. They tended to be thrown into a situation that often led to problem-solving on the spot, a concern for them when those they support have challenging behaviours, medical issues or other complex needs.

> …that makes it kind of difficult and a little stressful when you kind of have to be thrown into a situation and you may be given guidance and help, which is really great, but maybe you're not given the tools or all the information that you may need that may help you along the way.

Another of my interviewees said, "There's always a pressure of asking for help." This statement may result from a person who is reluctant to ask for help. It might also, however, be the result of informal, voluntary and possibly insufficient training strategies for support providers.

From a supervisory view point, one participant felt that it would be beneficial to have uniform training, rather than agency by agency training which is done on a more *ad hoc* basis. This uniform training would also free up agency resources to deal more directly with the needs of the people they support.

Another participant stated that there simply was not enough professionalism shown by some support providers. "…I know there's a staffing crisis and I know people's hearts are in the right place, but I just feel like there could be better people to support individuals with disabilities."

Although support providers play a crucial role in supporting individuals with intellectual disabilities, their role is undervalued. This is reflected in the lack of mandatory training or education. It can lead support providers to lose sight of the important roles they play, causing their professionalism to suffer. Training and education would help support providers and those involved with them, to understand that they are indeed professionals with the huge responsibility of helping others to lead a fulfilling life. It might also help them feel more confident about taking on some of the many different roles demanded of them.

Salaries. Salaries were a huge issue for all of the participants in my study. The type of setting in which they worked was not relevant to this issue. Every support provider I interviewed mentioned the fact that salaries were too low. "I think just the salary…" Another said, "It's not the greatest. You definitely don't get into the field for the money. It's not going to get you rich in any way."

One individual linked salaries to professionalism and the actual work support providers must do each day.

> …it would be more wonderful though if the financial aspect would be better. I mean I could be selling cars in a car dealership or whatever, maybe trying something else, but I like what I'm doing. That's the thing. Yeah but I feel bad when I look at, in comparison to other professionals. I feel we should be more rewarded economically… commensurate of what we're doing, you know.
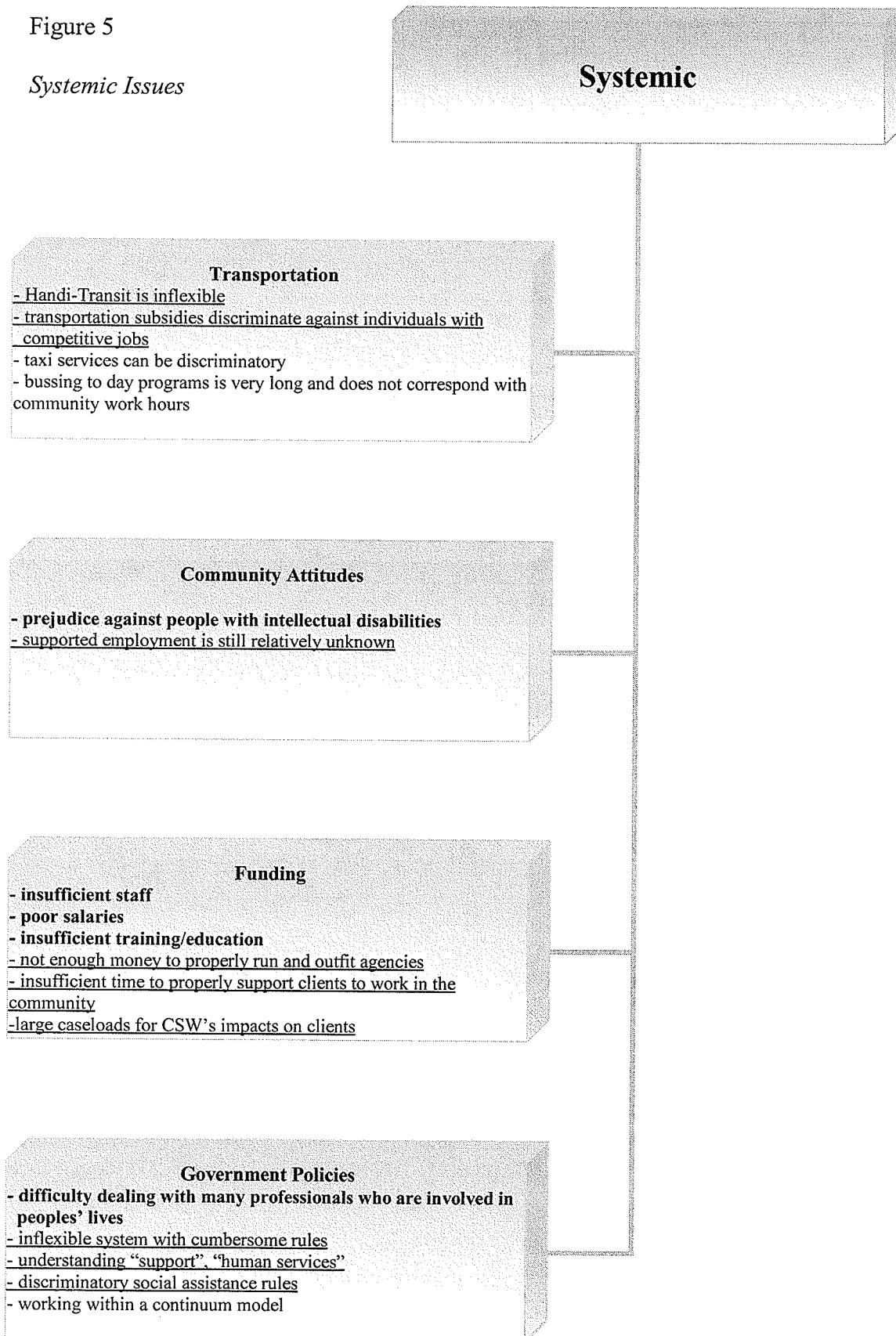
Some participants reported having to resort to taking a second and sometimes a third job in order to make ends meet. "…we have to work a second job because we don't get paid enough, and then, you know, when do you get your downtime?" Many worked for

the agency during the day and provided respite and other support in the evenings and on weekends. "And then I think that's one of the stresses is that if you have to work here full time and then you're picking up an extra job here or there, or two jobs, then that makes it very difficult."

Systemic

Systemic issues, my final key theme, are those issues that arise because of the way in which services and supports for adults with intellectual disabilities are organized. Figure 5 highlights the sub-themes of transportation, funding, community attitudes and government policies.

Figure 5

Systemic Issues

Systemic

Transportation
- Handi-Transit is inflexible
- transportation subsidies discriminate against individuals with
  competitive jobs
- taxi services can be discriminatory
- bussing to day programs is very long and does not correspond with
community work hours

Community Attitudes

- prejudice against people with intellectual disabilities
- supported employment is still relatively unknown

Funding
- insufficient staff
- poor salaries
- insufficient training/education
- not enough money to properly run and outfit agencies
- insufficient time to properly support clients to work in the
community
-large caseloads for CSW's impacts on clients

Government Policies
- difficulty dealing with many professionals who are involved in
  peoples' lives
- inflexible system with cumbersome rules
- understanding "support", "human services"
- discriminatory social assistance rules
- working within a continuum model

Transportation. The first sub-theme I noted in my study of systemic issues was transportation. This issue arose for both groups of support providers, although in different ways. Some support providers providing individualized support were concerned with Handi-Transit, the parallel transportation system for people with disabilities operating in the City of Winnipeg. Because this system is stretched thin with demand overtaking supply, Handi-Transit rides are prioritized and must be booked well in advance. Thus

It's difficult to work with at times and it's not to say that I'm getting bad service but I think it's a whole system...people who rely on that...are really given no allowance for spontaneity, because...everything needs to be booked well in advance and it's not even certain that what you ask for will even get booked.

Subsidized transportation was another issue. Transit bus passes for adults with intellectual disabilities are subsidized by the government only if people are enrolled in certain day programming. This can act as deterrent to taking a competitive employment opportunity for those who are self-supporting but only just getting by on their salaries. "...once individuals graduate from the competitive employment program, we don't have funding for a bus pass, so they have to pay for that themselves."

Support providers working in congregate settings also discussed transportation issues. One participant mentioned problems with a taxi cab company who employed drivers who refused to pick up individuals, even after the ride had been booked and confirmed. The interviewee described this as a discriminatory practice.

...transportation with cabs and pick-ups and stuff, and Handi Transit, sometimes that can be a bit stressful too... A lot of the things that we see where the client gets kind

of railroaded... they just tend to try to take advantage of the person because they're handicapped.

Another participant mentioned that getting people to their daytime program in a congregate setting was very time consuming. Some people must ride on a bus for an hour and a half or more each way to get to and from their day program. This wasted time has an impact on what the individual can do in terms of community-based work.

So a lot of them may get picked up at say 7:30 in the morning but then it takes them an hour and a half or two hours to get to the program so that kind of really puts a kibosh on how early they can start sometimes. So we usually, like if someone's looking for a paid position, we try to do something like 10 to 2 is what our general full work hours are because that allows for them to get to our program and then still have time to get themselves situated for their day, get to their office of where they're employed and then also that 2:00 also because they would have to come back to our program again to finish their day, and then get their ride to go home.

These comments all illustrate that transportation for adults with intellectual disabilities is often problematic and can have a significant impact on how these individuals get to and from their recreation program or work site.

Community attitudes. The second sub-theme in my study concerns community attitudes which I consider to be a systemic issue. How society thinks about people with intellectual disabilities is reflected in how services and supports are organized and provided. Seven participants spoke specifically about a lack of awareness on the part of the general public toward people with intellectual disabilities. Their frustration about community attitudes was evident notwithstanding which type of support they provided.

One participant suggested,

Educate the people. That's the best answer I could give you. A well-educated person

will understand OK, this kid has disabilities so we should be a little bit patient, we

should give them a chance, we should help them if there's any need and so on.

Another participant described her experiences being out in the community with people

she supported.

It's more so pity, like if people within the community will be like, they'll say stuff

like 'it must be so hard to do your job' kind of thing. 'I don't know how you can do it

every day'… So I guess it's just more education needed, you know, for community to

see that just because they may do something differently than how we would normally

do it, that doesn't mean it's any different. So you get a lot of stares, a lot of head

turns, and stuff.

Assumptions are often made that certain people either do not belong or cannot

participate or make contributions in their community. With this attitude, it can be difficult

to make a significant advancement in integrating people with intellectual disabilities into

the community. This is especially true for those individuals who desire to be employed in

their community.

I think some of the things that [advocacy organization] is doing, like in terms of just

general education, just general public education. There's a lot of people still that

don't understand what supported employment is and it's a foreign concept to them. If

there were more people that had knowledge of what it is and why it's a benefit for the

community that would be a positive thing.

Another interviewee said,

> ...just the attitudes of people still. Like even though there's all this employment
>
> equity out there and oh yeah, you know, hire people with minorities and physical
>
> disabilities, I just find that intellectual disabilities are really at the bottom rung.

Funding. The next sub-theme, funding, was a key issue for every participant in my study, although it was expressed in different ways. Insufficient staffing, the need for more training and/or education and low salaries are all essentially funding issues. If there were enough money to fully support adults with intellectual disabilities, agencies would be able to hire enough support providers to enable the realization of individual outcomes for all people being supported. This would also help to alleviate the stress of finding the time to support people in the appropriate manner. Instituting a mandatory training policy would not only raise the quality of support, it would also help in raising wages to more professional levels. As long as funding remains low, support provision suffers. For example,

> It's tough just in terms of keeping good staff. From my perspective there's times
>
> when it's almost impossible to give raises or whatever because there's no money
>
> coming in...We've lost good staff before because we just can't increase salaries at the
>
> level that some of the private for-profit places can.

Funding, however, is not limited to these three issues. Several participants providing individualized support mentioned the difficulty in working for and managing an agency with limited financial resources.

> In terms of funding situations, as a non-profit organization, we try to do things as
>
> efficiently as possible and our funders – it's tough to get any new money... Our

contract with the government, there's been no increase in any funding for probably

been five or six years…So we're operating with five or six years ago contract, but

we're dealing with increased rent, increased costs for hydro, whatever.

Another participant said, "And there are other initiatives that we'd like to maybe

undertake, or hire more employees or serve more clients, but it's hard to do that too with

limited funds."

A participant working in an individualized setting mentioned the problem of

community service workers (social workers) who can be overworked and carrying large

caseloads. He said that this situation has two consequences. First, it allows people with

intellectual disabilities to fall through the cracks of the social service system. Second, it

has a negative impact on those people who are part of these caseloads. "I'm sure social

workers have huge caseloads and you know it's tough to follow up on everything and it's

not that you can blame specific a bad social worker or something like that."

Government policies. My final sub-theme is the policies developed by the

government to provide services to adults with intellectual disabilities. Several participants

felt they were dealing with an inflexible system whose rules were cumbersome.

One said,

…maybe some more flexibility with the follow-up would help… our money comes

from, a lot of our money comes from follow-up because we bill for those follow-up

visits. I'm not sure what the current rate is, it used to be $24.83. And we typically bill

for 50 days a year, which is practically weekly because the client usually takes at least

two weeks vacation. And there's some pressure to make sure you fill in those 50 days

as much as you can… So that works out to weekly. In some ways, I mean this is

going through Family Services so it's not something you can easily change… And I

think that's always been an issue here because sometimes people don't need that level

of support.

Another commented,

> So we've been kind of locked with them trying to get them to agree to, three years is
>
> a short period of time in someone's life. If we can get follow-up funding for beyond
>
> that – I mean, we just want to support them. If we can get a little bit of money just to
>
> kind of keep doing that it will just make the bottom line easier for us to do that and
>
> we feel that people are going to keep their jobs longer, they're going to be able to live
>
> on their own longer and those types of things, whereas if those supports aren't there it
>
> may fall out. We've had this kind of ongoing battle with them about that.

A third participant said,

> So we get so many hours from our funder, so like this individual person can be
>
> supported for five hours a month because we can only get this much money to
>
> support them for five hours a month. And there is a maximum. And so if they need
>
> more support, we can only support them for five hours because that's all we can get
>
> paid for. And what do you do? Like I see that they need more support so I'm probably
>
> gonna give it to them. But then we still bill for five hours.

One support provider questioned the way in which services and supports are organized

and pondered whether or not the government even understands what providing services

and supports in a human services environment actually means.

> So that for me is a frustration point. Even in terms of the way the government sees
>
> issues around supporting the people with disabilities. Like we do follow-up

regardless, like I was telling you, but we've kind of had this constant discussion with

Family Services and with Voc. Rehab. about people with mental disabilities, like

even if they don't require a lot of assistance down the road, there still generally are

situations that will come up where they'll need this kind of thing and if we're not

around they won't necessarily have a resource to help deal with that.

Another participant took aim at what the concept of "human services" means.

I in particular don't like that system because it looks like you're dealing with cattle

herds. I mean we're dealing with human beings... It's very cool, very frosty kind of

things, and mechanical type of work...and that detachment, as a human being, it

affects me a little bit, because I would like to know, or say 'hello' again after a couple

of months to see how they are doing, and it's not there anymore.

One participant mentioned the punitive social assistance rules as a way in which the

system discriminates again people with intellectual disabilities who decide to work in a

competitive setting for a competitive wage.

Sometimes there are concerns about social assistance... If they, let's say they went

from working 20 hours to 30 they're concerned about social assistance being cut off,

particularly when they have, they live alone, they have rent to pay. They may have

monthly prescriptions to be filled that are costly and they don't have a benefits plan at

work. Those are real concerns for them and particularly going off social assistance

completely when they've always been on it. That's a real fearful thing for them.

Government policy continues to dictate that people with intellectual disabilities have

certain professionals in their lives, a holdover from the institutional era. Some of these

include social workers, residential support providers, daytime support providers, medical

professionals, psychiatric professionals, and the like. Several participants from both groups mentioned the difficulty in dealing with so many people in order to coordinate services and effectively assist the people they support. For example, there is sometimes tension between residential staff and daytime staff.

> Sometimes some of our stress is dealing with the families – not so much even the families, but group homes. We have a lot of stresses there. We may have clients that come in that are clearly sick and we try to deal with the houses about, 'Well the person shouldn't have been sent in. They were sick', and we find that there's a lot of stress there because just trying to get the communication between the group homes and us, we find that the group homes don't necessarily want to listen. Sometimes we wonder exactly whose interest – like you know it should be in the client's best interest and sometimes we don't see that.

Another participant mentioned the general difficulty of communicating with all of the government-designated professionals to ensure that an individual's best interest is looked after.

> I guess just having to maybe inform so many people or work with so many people, like the individuals that I support generally have residential support, they have a social worker, they have respite workers, they have quite a large paid support network, that you need to keep in touch with and work together with. So there may be pressure from them.

One interviewee, working in a congregate setting, really had a difficult time reconciling services and supports provided based on the continuum model. The agency she worked for provided a range of supports to adults with intellectual disabilities. There

was a recreation component, sheltered work and some opportunity for individuals with intellectual disabilities to work in the community. However, these individuals had few hours and mostly worked in a volunteer capacity or for an honorarium. While she agreed with the need to direct resources to supporting people working in the community, she found it difficult to support people on-site with insufficient resources for programming.

> Well, I think if a lot more money was spent on maybe bringing in different craft ideas just, that are available to people, because most individuals aren't gonna be working eight hours a day, or even part-time. So in that time, there needs to be more available, while people are there... But management is afraid that if we have things available for people to do in Rainbow Place, the focus is gonna be lost for the community.

The support providers in this study provided me with a number of significant issues, some of which have been addressed in the literature and some of which have not. I will now turn my attention to an interpretation of what these issues mean for daytime support provision in Manitoba.

Chapter 5: Interpreting the Support Provider Data

"I love it. I mean I couldn't see myself doing anything different. It is very rewarding. You know, you go home at the end of the day, I guess, and you just feel a sense of, you know, you've done something with someone else's life, you know what I mean, you've enhanced it in some way..."[17]

This research was an attempt to understand the broad range of issues and perspectives of daytime support providers supporting adults with intellectual disabilities in Manitoba. It also was meant to analyze these issues across two specific groups of support providers, those working primarily in congregate settings and those working primarily in individualized settings. I will begin this chapter with a brief summary of the major themes I encountered when analyzing the support provider data. I will then relate these themes back to the exiting literature on support providers in order to give my research some context. I also will make some personal observations about the data.

Overview of the Data

I will preface my theme overview by saying that different participants had different understandings of the issues facing them as they support adults with intellectual disabilities. Two individuals were able to discuss a wide range of issues. A third had a grasp of many challenges faced. Four participants had some understanding of the issues. Four individuals had what I would call a limited understanding of the issues and mainly discussed issues that were central to their own personal work experiences.

The participants had a range of what I call "disability values". While I was analyzing the data, I sensed that different participants seemed to have different feelings and beliefs

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[17] Comment from one participant in this research

about people with intellectual disabilities. These feelings and beliefs helped me understand how participants felt about the individuals they worked with and how they reacted to society's devaluation of these individuals. Although I cannot point to a specific set of comments by participants, I came away from reading and re-reading the data with a sense of the extent to which support providers values might reflect a human rights approach to intellectual disability. Generally, I drew my conclusions from comments made about employer attitudes, community attitudes, agency/program values and attitudes toward the people being supported.

Six participants seemed to have a very strong belief that people with intellectual disabilities have inherent worth. They felt they were really helping to support these individuals. They also felt frustrated at society's lack of understanding about people with intellectual disabilities and the contributions that they can make. This was the case whether they worked in primarily individualized or primarily congregate settings. Three interviewees seemed to have a belief in the people they worked with but their feelings did not come through as strongly as those six participants mentioned above. The last two participants seemed to value people with intellectual disabilities to a lesser degree. The participant who did not rally want to work in the field did not come across as having particularly strong beliefs about people with disabilities. The other participant seemed to approach people with disabilities from a behaviourist position, which, to me, implies a different set of values about disability.

Years of experience did not necessarily equate with a better understanding of how services and supports are provided and what issues affect support providers doing their jobs to the best of their abilities. Those participants with a limited understanding of the

issues were not necessarily the support providers who had the least experience. The three participants who described the widest range of issues were all involved with providing individualized support. This did not surprise me as I anticipated that support providers working in individualized settings would have a greater appreciation for the issues, particularly systemic ones. Only one participant felt that there really were no issues she faced as a support provider. She worked in a congregate setting.

Support provider issues fell into four broad categories or themes. These themes involved a) issues that arose in supporting adults with intellectual disabilities in community employment, b) agency or organization-specific issues, c) professional issues and d) systemic issues.

Not surprisingly, the majority of issues within the supported employment category were discussed by support providers working in individualized settings, although issues such as negative employer and community attitudes were acutely felt by both groups.

Issues within the agency/organization theme, particularly around roles, were raised more often by participants working in congregate settings. The major exception was staff shortages, a concern for most of the support providers interviewed.

Professional issues such as salaries and training were discussed by all participants in this research. Another concept that I discovered in the data collection and analysis was the need for support providers to feel an affinity for the work they do. Affinity means both a commitment to supporting adults with intellectual disabilities and a philosophical harmony with the agency or organization that the support provider is affiliated with. Ten of eleven participants spoke at length about all of the things that made their job worthwhile and encouraged them to remain in this field.

The majority of daytime support provider issues fell under the theme of systemic issues. I found it interesting that of all eleven participants, three people demonstrated an understanding of the policy issues faced in providing support to adults with disabilities. Four other interviewees identified some important policy issues but they did not discuss the larger issues. Six of these participants were involved in providing individualized support. The other four people I interviewed did not seem to be aware of any specific policy issues.

The systemic issues that were mentioned include transportation issues, community attitudes, a lack of funding and government policies and rules. Many of the issues that fell into the supported employment, agency/organization and professional themes also relate, in some way, to the way in which services and supports are organized and provided. For example, the cluster of concerns around finding the right job for an adult with an intellectual disability speaks to the problem of a narrow range of employment opportunities. This narrow range, in turn, may be related to a general lack of understanding about intellectual disability and a failure to hold higher expectations of what these individuals can accomplish. Similarly, the problem of insufficient staffing relates both to a lack of funding and to the structuring of services along a continuum. When people are offered congregate programming, it is easier to structure support to groups of people, which, in turn, require fewer staff members. As a final example, salaries and training and education can be seen as systemic issues. Paying people low salaries and not requiring any mandatory training may imply a lack of recognition or even a devaluation of the importance of the role of support provider.

The Data and the Literature

The data in this research both confirms and expands upon the existing literature on support provider issues. It confirms that concerns such as salaries, staffing and training and education that have been raised in the United States and other countries also apply in Manitoba. This data does not specifically address staff retention and staff shortages in the workforce. Direct support staff, however, would not necessarily be aware of the difficulty in retaining or attempting to hire support providers. These would be primarily the concerns of management.

What my research does offer, however, is both a look at a wider range of issues than has been addressed by the literature and an examination of issues particular to daytime support providers. I believe I was able to accomplish this by collecting data from participants in an interview setting. This setting allowed me to open up a dialogue with interviewees on a one-to-one basis, where participants were able to discuss issues and explain themselves at length, in a confidential setting. This kind of detailed conversation allowed me to get a fuller understanding of how daytime support providers feel about their work.

Yet asking about the issues or stresses associated with their jobs only gave me part of the picture. One of the keys to understanding the participants was asking about what makes their jobs worthwhile to them. Many of the responses I received were quite moving and gave me a deeper appreciation of the kind of person that takes on the challenges of providing support to adults with intellectual disabilities. These comments made me realize that, notwithstanding all of the challenges, there are people who care deeply about adults with intellectual disabilities and strive to support them in spite of the

difficulties. The data also allows for a full appreciation of personal responsibility many support providers feel toward those they support.

> ...in a lot of ways, almost like a family type of situation when you've been with the clients long enough. I think a lot of the clients it's a really transient type of thing for them. Even group homes staff change continuously and if you're dealing with an individual that that's their life, you can imagine never having somebody that you've got something in common with, something that you can talk about. Like, 'three years ago Christmas, remember Christmas three years ago we did this?' Well that's just starting now because I've been there four and a half years. We're starting to have the history, and that, there isn't a money figure or anything you can put on that.

Not only do support providers care about the people they support, they want to make a difference in how society thinks about intellectual disability.

> And I think that I'm making a difference for people with disabilities in a more global sense, again. So the more people see people with disabilities in the community, the more understanding they're gonna have and I'm hoping generally, life will be better for people with disabilities. And my being able to affect so many people's attitudes around people with disabilities.

Personal Observations

As one of the purposes of this research was to compare the perspectives of daytime support providers working in congregate settings with those working in individualized settings, I will discuss some personal observations on these similarities and differences I

discovered. As I stated earlier during a discussion of my location, I originally thought that support providers working in congregate settings would feel unsatisfied providing support in this type of setting. I was surprised to learn, however, that there are people who work in congregate settings who feel fulfilled by the work they do. Coming from the background I have and holding the beliefs I do, I felt certain that these support providers would feel dissatisfied with their role. However, this was the not the case with four of the five participants I interviewed who worked in congregate settings. Given that the vast majority of adults with intellectual disabilities are in congregate settings, I discovered in my data that support providers believe that they are providing a high quality of support and feel a deep dedication toward the people they assist. Similarly, simply working in an individualized setting does not guarantee job satisfaction, as was evidenced by the interviewee who found herself working with people with intellectual disabilities as a last resort.

One of my questions when I began this research was how support providers providing different types of support see the issues and how they are affected by them. Again, I assumed that support providers working in individualized settings would be more adversely affected by the issues than those working in congregate settings. However, after analyzing all of the data, I now understand that the way in which services and supports are organized in Manitoba can and do affect both groups of support providers. I believe my original thinking was too simplistic because I failed to recognize the diversity that some support providers face, even though they are working in primarily congregate settings. I also failed to fully understand the complex, multi-faceted service system. There are a number of people who work for agencies providing many different types of

support. One individual can provide support on-site and out in the community. Therefore, his or her understanding of the issues is not limited to only one set of circumstances. Even for people providing support primarily in one congregate setting, either on-site or in an enclave, interactions with employers, co-workers and people in the community all affect how they do their job.

There are many frustrating issues for daytime support providers in all settings. Most recognize that they are affected by these issues in at least some way. What has become of interest to me, as my research has developed, is attempting to understand how all of the issues raised by daytime support providers can be analyzed and given some meaning. Because so many of the issues raised by support providers are systemic in nature, I will use a human rights approach to disability in order to begin a dialogue on possible directions to ease the issues faced by people supporting adults with intellectual disabilities in Manitoba.

Chapter 6: Implications for the Future

"...it is clear that...the nature of legislation that would provide protective rights, has been profoundly affected by who has the power to decide what issues will be placed upon the public agenda, as well as who is in a position to occupy a place of power."[18]

The literature has shown that there are some fundamental and recurring issues that have been plaguing support provision for adults with intellectual disabilities over the past several decades. The simplistic response to many of the issues faced by support providers is to argue that more funding ought to be made available to providing supports. This would have a significant impact on the issues raised in this research. Agencies that provide the services and supports would have more money to run their offices, hire more staff and pay staff more in salaries and benefits. Higher salaries and benefits would, in turn, encourage mandatory education and training as a means of securing this investment. Unfortunately, under-funding in human services, and elsewhere, is a perpetual problem that is likely to remain consistent over time. More importantly, I do not believe that money alone is the answer to the support providers' dilemmas.

Rather than relying on an infusion of funds to solve these problems as a "band-aid" style approach, I think the key lies in an examination of the values underlying the laws and policies driving services and supports for adults with intellectual disabilities. Becoming familiar with notions of equality and equal outcomes may enable society to rethink more traditional attitudes about intellectual disability in order to make some progress in addressing support provider issues. This progress will ultimately lead to a better support system for adults with intellectual disabilities.

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[18] Kobayashi, A. & Ray, B. (2000). Civil risk and landscapes of marginality in Canada. *The Canadian Geographer*, 44, 402-417, at p. 407.

One starting point might be to view support as a societal responsibility. In other words, "to provide political and social entitlements that are equal in outcome to those of other citizens" which are "built on the acknowledgement that disability is a consequence of social, economic, and political organization, not individual pathology" (Rioux, 2003, p. 308). Problems arise where there "is evidence of a lack of entitlement or the limitation of the exercise of fundamental human rights and freedoms" (p. 308). Thus it is vital to look at "the quality of the act rather than the quality of the actor" so it is "the nature of the activity itself, including policies, social programs and services, that comes under scrutiny" (p. 308).

In this thesis, I have illustrated that Manitoba has specific legal expressions of human rights for adults with intellectual disabilities, including the *Charter* and a *Human Rights Code*. Manitoba also has a policy document that promotes full citizenship for people with disabilities. The prevalent systemic issues discussed by support providers in this research, however, also have shown that these expressions and policies have not necessarily resulted in a change to the way society views adults with intellectual disabilities or the people who support them.

Using a human rights approach to address support provider issues might begin with the premise that adults with intellectual disabilities are entitled to supports. Although the establishment and continuation of entitlement legislation relies upon the philosophy of the political administration of the day, it is one concrete way of ensuring support for adults with intellectual disabilities. This entitlement could elevate the status of the support provider, whose role would be a key to achieving community inclusion as a valued societal goal.

More specifically, an elevation of status would likely result in the resolution of several key issues in the agency/organization and professional themes, such as a) increases to salaries and benefits, b) mandatory education and training, and c) adequate staffing with an emphasis on choice-making for the people being supported.

Another result of entitlement might be a recognition that people with intellectual disabilities belong in the community. This could address the attitudinal problem described by all participants as a general lack of understanding about intellectual disability and supported employment.

Rioux (2003) mentions the need for people with intellectual disabilities to have the "opportunity for inclusion in non-segregated activities" (p. 310). Current government policy for supporting adults with intellectual disabilities is premised on the continuum model, which encompasses a range of support options, including segregated options. Today, these policies have been rationalized by suggesting that segregation is the best way some people with intellectual disabilities can be supported. Christine Melnick, FSH Minister, has said, in defending her government's decision to spend $40 million to upgrade the Manitoba Developmental Centre,

> This is the surrounding they know. We have to weigh that out with moving people to an environment they wouldn't be familiar with. I have to strike a balance between community living and having facilities such as this available to individuals (Janzen, 2004, p. A3).

However, if a human rights approach to disability were adopted, segregated policies would no longer be advisable as they violate the notion of equality of well-being.

Some participants in my study struggled with the ways in which the current service system operates. Many suggested that the rules established do not make sense for the people being supported and hamper more effective support strategies. One interviewee wondered if the government even understood the basic support needs of people with intellectual disabilities. Another participant questioned what people with intellectual disabilities were doing or learning in the agency for which she worked, which provides primarily congregate support. When I asked her how much was actually being done at the agency to help people learn new skills to use in the community (a goal of the continuum model), she replied, "very, very minimal." She went on describe in some detail what adults being supported did during the day.

> You know, like going to clean the fridge if there's nothing for somebody to do. Well, let's encourage them to go and clean the fridge. Or…I find sometimes just trying to find work, keep people busy and it's one thing I was always uncomfortable with, keeping people busy. A lot of times people are communicating they don't wanna do it, but it's pretty much demanded and I'm very uncomfortable with that… So the struggle to me is, management wanting them to keep busy and just finding work for them. Like I was saying, you know, well, let's mop the floor or let's clean, just make sure nobody sitting down doing nothing. It's program time.

I believe one of the reasons why these systemic issues persist may be because of the policy palimpsest that exists where new policies are simply written over older ones but never completely replace them. The result can be a confusion of direction and purpose.

A commitment to a human rights approach to disability will be recognizable with a) the enactment of entitlement legislation, b) a commitment to eradicate segregated,

congregated programming and c) a focus on furthering community inclusion. Through

education and personal interaction, community members can come to know what it is like

to live and work along side people with intellectual disabilities. More opportunities could

open up for adults with intellectual disabilities to find meaningful roles in the community,

allowing for increased expectations together with opportunities to meet or exceed those

expectations.

Chapter 7: Conclusions

"These are places of 'shadow citizenship and entitlement'...lived as places of profound exclusion in which basic human rights are routinely denied."[19]

Although this research has added to the literature on daytime support provider issues from their own perspectives, it does have its limitations. This study was small and exploratory in nature, including only eleven participants. To give a more complete understanding of the issues, the participation of more support providers would be beneficial. It would also be relevant to ensure representation from a wider range of roles and positions within agencies, including more supervisors and managers.

In addition, there was representation from only a few not-for profit agencies in Winnipeg. Thus the inclusion of a wider range of agencies and organizations would be appropriate, as would the addition of rural support providers. There is also no representation from support providers working in institutional settings or for-profit organizations. Again, all of these variations would provide a more complete set of support provider data.

The notion of "support" is not limited to paid staff. Perhaps people offering more informal types of support to adults with intellectual disabilities, such as members of support networks, would provide different perspectives as well.

With a larger pool of participants, perspectives could also be broken down into groupings based on gender, age, experience and cultural background.

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[19] Chouinard, V. (2001). Legal peripheries: Struggles over disAbled Canadians' place in law, society and space. *Canadian Geographer*, 45, 187-192, at p. 187.

There are a number of different directions and future steps that could be undertaken to further this research. One possible step would be to carry on further research by broadening the participants as outlined above.

Another interesting avenue of inquiry would be a closer examination of the underlying values held by support providers, agency supervisors, managers and even directors. These values may or may not be consistent with agency mandates and mission statements. This type of inquiry might lead to a better understanding of a) how people providing support feel about people with intellectual disabilities, b) the role that formal education and training can and do play in providing better quality support and c) opportunities to direct that type of education.

Broader understandings of the values held by other stakeholders such as family members, advocacy organizations, community service workers, support networks, employers, friends, educators and government would also illustrate how much understanding of human rights values exists and may lead to a greater discussion of support provision based on this model in the future.

Finally, bringing a human rights approach into more discussions about intellectual disability might open up new dialogues on the various models or approaches to disability within the academic community. It may offer a useful critique of the bio-medical, functional and social models of disability so prevalent in academic writings in the field of disability studies today.

Over fifteen years ago, Smull (1989) declared that "community programs for people with mental retardation are entering a period of crisis" (p.1). He named the symptoms of the crisis as "not enough money; insufficient qualified staff; inadequate training; and too

few program alternatives" (p.2). These sound remarkably similar to the issues facing Manitoba's daytime support providers today. Smull (1989) argued that fixing the existing system "requires a more fundamental change. We must change the way we think about service delivery and the way we provide services. We need a paradigm shift" (p. 12).

Many experts and academics in the field of intellectual disability have argued in favour of a paradigm shift. Unfortunately, such a shift has yet to occur. In order to truly address support provider issues as we enter the 21st century, society must change the way it understands and responds to people with intellectual disabilities. One of the ways in which to do this is to expand upon Canada's well-entrenched concepts of human rights and equality. In undertaking this expansion, however, society must understand the need for the "unmasking of the structural and systemic context of people with disabilities" (Rioux, 2003, p. 313).

In order adequately address daytime support provider issues there is an urgent need to move beyond the current paradigm, the policy palimpsest, and the continuum of service programming and delivery. An effective way to do this is to recognize and reject the values inherent in traditional beliefs about people with intellectual disabilities, understand how those values affect and restrict the provision of services and supports to these individuals, and discover how the notion of equality of well-being can help resolve support provider issues while giving real meaning to the concept of "Full Citizenship".

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Appendix 1 – Ethics Approval Certificate

APPROVAL CERTIFICATE

20 October 2004

TO: Zana Lutfiyya
           Jennifer Mactavish
           Karen Schwartz
           Principal Investigators

FROM: Stan Straw, Chair
           Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2004:088
           "Perspectives in Change - Phase II: Issues in Community Support for People with
           Intellectual Disabilities – Support Provider Perspectives"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note that, if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

Appendix 2 – Amendment Approval Certificate

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AMENDMENT APPROVAL

08 November 2004

TO: **Zana Lutfiyya**
Jennifer Mactavish
Karen Schwartz
Principal Investigators

FROM: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2004:088**
"Perspectives in Change - Phase II: Issues in Community Support for
People with Intellectual Disabilities - Support Provider Perspectives"

This will acknowledge your e-memo dated November 5, 2004 requesting amendment to
the above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be
reported to the Human Ethics Secretariat in advance of implementation.

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