THE POLITICS OF INTELLECTUAL DISABILITY

by

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B. S. W., The University of British Columbia, 1986

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SOCIAL WORK
in
THE FACULTY OF GRADUATE STUDIES
(School of Social Work).

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Date Aug 4/98
Abstract:

There is a growing perception in the disability rights movement that traditional ways of thinking about and describing disability serve to oppress people with disabilities. The emerging social theory of disability attempts to describe the social constructedness of disability and views disability from a rights perspective. Informed by this theory and in an effort to give voice to people with intellectual disabilities, a qualitative study asking intellectually disabled self advocates to describe their experiences of life with an intellectual disability was conducted. Based on the findings of preliminary focus group research, individual interviews were conducted with four members of that group. The interviews were recorded, transcribed and analyzed following a narrative technique. Participants discussed their experiences and identified issues of importance. These issues included dissatisfaction with income support services, concerns regarding violence and abuse, inadequate social work support and a general lack of respect. The results of this study have implications for policy development, service provision and social work practice in general.
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Acknowledgements

There are a number of people I have to thank for their support for my work. In no particular order these include my family for letting me move back in; my boss, Lorraine, for letting me rearrange my work schedule every few months to accommodate my classes; my doctor, Giselle, for writing those prescriptions; Michael, Candy, Ernie, Carol and Tim for listening; Susan, Flo, Sonia, Dawn, Doug, Stan and Chuck for showing me what it all means in the real world; and Carolyn who went way above and beyond the call of friendship to provide me with unconditional, if critical, support, grammar lessons and ways out of corners I’d written myself into - I could not have done this without her.

I must also thank my advisor, Richard Sullivan and committee member Brian O’Neill for their support with this thesis and for the ways they challenged my thinking through their teaching.

Finally, this work is dedicated to the self advocates who have given me their time, their thoughts, their trust and, most of all, their continuing and enthusiastic support. This project is not over for us.
Introduction

In the 1981 Speech from the Throne, the government of British Columbia announced a significant policy change with respect to its treatment of people with intellectual disabilities. The emphasis was to change from institutional care to supporting life in the community (Roeher Institute, 1991). This statement was the formalization of a shift in policy which began several years before, in part as a response to increasing pressure from community living advocacy groups which had been lobbying to close British Columbia's large institutions for people with intellectual disabilities for several years (Roeher Institute, 1991). Under this policy, the government established plans to downsize and eventually close the institutions and put in place programs to enable and support people with disabilities to live in the community.

In the years since the Throne Speech, hundreds of British Columbians with intellectual disabilities have moved back into their communities and are receiving a variety of services to support them there. These services, however, rather than promoting the independence and community integration they claim to, have, in fact, been seen by some as perpetuating the poverty and marginalization faced by many people with disabilities (Roeher Institute, 1990). These programs are rooted in a residual welfare orientation and are reflective of an ideology of 'medical individualism'. This ideology promotes the belief that disability is an individual problem that can only be addressed through medical intervention and control.
This set of values has led to the professional management of the lives of people with intellectual disabilities 'for their own good' (Biklen, 1988).

Critics of this 'paradigm of care' maintain that disability is in fact a social construction (for example, see Oliver, 1990) built upon a variety of social and economic factors, rather than a pathology rooted in the individual. This perspective moves private problems in to the sphere of social issues; it restates individual limitations as societal barriers and shifts the responsibility for change and adaptation from individuals with disabilities to the larger society. By doing so, this viewpoint also reaffirms disabled people as integral members of society with the same rights and responsibilities as non-disabled people. People with intellectual disabilities who have been devalued within the traditional framework are re-valued when their experiences are considered from a social constructionist perspective. Progressive theory can then be developed from the perspective of people with intellectual disabilities using their own words to describe their experiences. In this way, theory develops that empowers people with intellectual disabilities to effect positive change in their own lives without being victimized by the dynamics of that change.

People with intellectual disabilities have historically been the focus of an abundance of quantitative medical, educational and rehabilitation research. These disciplines have generally centered on the problem of intellectual disability and have attempted to find
ways to minimize or prevent it (Rioux, 1994a). Until recently, very little research has examined the goals and life experiences of people so labeled and even less has been qualitative in nature. As such, there is very little descriptive, first hand information available to the disability community and service providers upon which to base decisions regarding political action, policy and support services.

This exploratory study attempts to fill this knowledge gap. My preliminary research involved a focus group discussion with people with intellectual disabilities, who describe themselves as self-advocates. The group shared experiences and opinions which were important to them. Using that information as a guideline, I conducted personal interviews with four individuals who participated in the original group. My primary goal was to develop a greater understanding of the experiences of self advocates with intellectual disabilities and to make that knowledge accessible to service providers and policy makers.

One of my assumptions going into this process was that, for the most part, people with intellectual disabilities frequently do not have the opportunity to be heard and express their opinions. It is also my belief that, because of the traditional medicalized view of disability, professionals working with people with disabilities tend to assume 'they know best' and make policy and provide services based primarily on their professional assessment of the desires of

people with mental handicaps must submit to the guidance of other persons or authorities before making important decisions. These include decisions to marry, to vote, to have children, to enter into financial contracts, and to live in independent environments. They must also submit to authorities to receive benefits such as education, income, employment, housing and so on. Other people who have not been [so] labeled may generally make these decisions without obtaining the consent of anyone and this autonomy is protected by the state. (p.1)

Drake (1994, 1996) has documented the lack of involvement and exclusion from power of people with disabilities in voluntary service organizations in Britain and some of the barriers which serve to maintain this inequity, such as the attitudes of non-disabled people who manage the services. Wehmeyer & Metzler (1995), in their analysis of the results of a major survey of intellectually disabled people in the U.S., found that although self determination was important to the people surveyed, they generally felt they had fewer choices and less control over their lives than they wanted. This was found to be especially true concerning larger issues, such as choosing to marry or not, deciding where to live or consenting to medical procedures. In my work with people who have intellectual disabilities, I have seen this lack of autonomy and lack of respect first hand. To a large extent it could be considered the normal state of affairs for many people so labeled. People often have little choice regarding the conditions of their lives and face many disabling barriers when trying to exercise the choices they do have. This study is to be a documentation of some of these barriers.
Although my goals for this project are varied, I hope to make a contribution to the fields of intellectual disability and social work in the process. I would like this study to play a part in the development of a body of qualitative and empowering research for and about people with intellectual disabilities which puts the focus of inquiry on the experiences of disabled people. Finally, I would also like this project to spark more interest in and commitment towards the disability rights and community living movements among social workers, as well as begin to develop a social work research body in this area. Social work has not traditionally played a dynamic and empowering role in the field of intellectual disability (Hanley & Parkinson, 1994); it is my wish that this study helps to change this.

Language Issues:

The labeling of people considered intellectually disabled and the power and consequences of those labels is an area of much concern and discussion (Danforth & Navarro, 1998). Davies & Jenkins (1997) have said that people with intellectual disabilities "carry a label and an associated social identity which is a major determinant of their material prospects and the character of their social relationships" (p. 95). As a result of the growing recognition of the social constructedness of intellectual disability as a concept (Danforth, 1997) and the rejection of terms such as mental


retardation following a process of consciousness raising (Eayrs, Ellis & Jones, 1993; Stockholder, 1994), I will not engage in labeling activities in the course of this study, other than to refer to the respondents as being self-identified as intellectually disabled. How that term is conceptualized by those affected is not for me to decide. To choose any other course would be to engage in paternalism. For too long, people with intellectual disabilities have had their various labels and identities (such as educable, trainable, mildly handicapped, severely handicapped, etcetera) assigned to them by professionals rather than having the right to choose to name themselves (Woodill, 1994). These attitudes are also in keeping with the request made by the participants in this study that certain words (handicapped or retarded) not be used to describe them.

The above notwithstanding, it should be noted that a variety of terms are used and have been used over the centuries to refer to people with intellectual disabilities. As a result, throughout this document there will be references made to people with mental retardation, developmental disabilities, mental handicaps and learning difficulties. As well, historical terms such as feebleminded, idiot, mental defective and moron are also used. All these terms refer to the same group of people. When I use language that is now considered offensive, I do so to accurately represent the periods of time during which they were used. For, as Trent (1994) writes, "these words ... reveal in their honesty the sensibilities of the people who used them and the meanings they
attached to mental retardation" (p. 5). I can only wonder what future writers will think of my use of the term intellectual disability, but I rationalize my choice with the knowledge that, for the first time in their history, people with intellectual disabilities are finally at least involved in naming themselves.
Conceptual Context

History

The goal of this thesis is not only to put forth the experiences and perceptions of people with intellectual disabilities, but to put them into context. By context, I refer to the historical, political, theoretical and policy factors which have combined to create the world in which these individuals live. What follows is a brief attempt to outline some of these trends.

Defining intellectual disability and identifying the population so categorized is not a simple process. Rioux (1994b) notes the difficulties inherent in the label 'intellectual disability':

First, mental handicap is based on a combination of factors (including a deficit in intellectual development and an impairment of social functioning ability) and has a variety of causes. It is not therefore a strictly medical or biological matter, as it is also a social-administrative category. Second, the level of the functioning ability or disability varies significantly, from mild to profound, and is thus not a single dichotomy, as would be needed for legal classification. Third, mental handicap is not a static condition; it is subject to change, as it is a product of the interaction between individual capacities and social demands, and thus creates difficulties for policy purposes. Fourth, it is a label applied to a group of people so diverse they have few characteristics in common apart from classified as having a mental handicap. (p.3)

Since the label has both medical and political dimensions, its meaning and its breadth has changed dramatically through the ages. Despite this variability, however, "mental retardation is a ...
phenomenon that undoubtedly has been apparent since the dawn of man. Any given society, including the earliest tribes, unquestionably contained members who were more capable and members who were less capable than average" (Scheerenberger, 1983 p.3).

In ancient societies, infanticide was regularly practiced on children found to be less than perfect based on the prevailing standards of the time and the community. The Spartans and Athenians in Greece were particularly zealous in their efforts to maintain a strong population (Scheerenberger, 1983). The early Romans followed the Greek example probably into the first century A.D. Rejected infants were also abandoned to the state, and as children, were frequently mutilated by their 'caregivers' in order to increase their effectiveness as beggars. Towards the fourth century, as Christianity's influence increased, infanticide became illegal in the empire and more charitable attitudes towards weaker members of society were developing. In the sixth century, Emperor Justinian declared that those identified as mentally infirm were not responsible for their actions and should not experience the same consequences as others. He also established institutions to provide care for those unable to care for themselves.

In Europe, throughout the Middle Ages, the treatment of people with disabilities varied considerably. Some people with intellectual disabilities were probably able to make places for themselves in agricultural areas where the need for manual labour was high (Nibert, 1995). Others would have joined the ranks of village idiot or court buffoon, surviving off the largess of
wealthier benefactors. More likely however, many would have become beggars, living on the edges of their communities (Scheerenberger, 1983).

The first legal recognition of intellectual disability came about in the thirteenth century in England. A distinction between mental illness (lunacy) and intellectual disability (idiocy) was made at this time as well, at least inasmuch as to the dispensation of the afflicted individual’s estate. In the case of a lunatic, who may regain his reason, property was held in trust by the Crown until his recovery or passed on to this relatives after his death. On the other hand, because idiocy was understood as an inborn and permanent condition, the Crown seized the individual’s property and profits until his death (Rioux, 1994b). This law however, probably had very little impact on most people with intellectual disabilities as very few of them were likely to have been property holders (Scheerenberger, 1983). The majority of disabled people were not legally recognized until the Poor Law Act of 1601 which made their support a state responsibility. People with intellectual disabilities were not specifically dealt with in the law until the nineteenth century (Rioux, 1994b).

There was little change in the treatment and understanding of intellectual disability for the next several centuries in Europe. Many disabled children were abandoned to church operated hospitals or orphanages where the mortality rates were staggering. Those who survived into adulthood often ended up in institutions such as
Bethlem/Bedlam in London or Bicetre in Paris. The conditions in these facilities were deplorable:

chains were commonly employed to treat those who acted out or to restrain those who might hurt themselves. Dark cells were common and sexes mixed. Staff were few in number, many were satisfying prison sentences, and their quality left much to be desired. (Scheerenberger, 1983 p.43)

It was not until the eighteenth century and Phillipe Pinel’s revolutionary ‘moral treatment’ placed the emphasis on humane practices and care that conditions in these institutions began to improve (Scheerenberger, 1983).

Truly significant changes in the treatment of people with intellectual disabilities did not come about until the nineteenth century. Edward Seguin, who was known as the ‘apostle of the idiots’, believed that idiots could in fact be taught and could become independent and involved members of society (Trent, 1994). Seguin’s ‘physiological education’ was based on the notion that the will and the senses of the idiot were underdeveloped and required physical and moral training. As Seguin wrote:

the idiot wishes for nothing, he wishes only to remain in his vacuity. To treat this ill will, the physician wills that the idiot should act, and think himself, of himself, and finally by himself. The incessant volition of the moral physician urges incessantly the idiot out of his idiocy into the sphere of activity, of thinking, of labor, of duty and of affectionate feeling; such is the moral treatment. (1976/1864 pp 158-9)

While Seguin would later lower his expectations for his students somewhat, his techniques and goals would become the standard for the training and care of people with intellectual disabilities in Europe
and the United States in the mid nineteenth century and his legacy would continue into the twentieth (Trent, 1994).

Part of this legacy was the emphasis placed on medicine in the study of idiots and the importance of having physicians act as superintendents of educational facilities. Seguin felt that medical doctors were the best qualified to supervise the training and support of idiots (Trent, 1994). Following this precedent, physicians (and later psychiatrists) would head facilities throughout North America, a trend that would continue until the present day. Coming about at a time when medical authority in general was increasing and having little competition in the field, physicians had little difficulty in expanding their professional domain to include this area. This marked the beginning of the medicalization of intellectual disability and the establishment of medicine’s power over the lives of people with disabilities (Rioux, 1994b).

As industrialization increased and the demand for skilled labour grew, the world outside the institutions became more difficult for Seguin’s graduates to compete in. As well, although it was now established that idiots (or the feebleminded as they were becoming known) could be taught and socialized, those with more severe disabilities were frequently not able to fend for themselves in the community. As such, fewer people returned to their communities and, by the 1880’s, the facilities that had originally been set up as schools became permanent custodial institutions. The stated goal of these institutions was “the protection of vulnerable
people from a world that would take advantage of them" (Trent, 1994 p.94). Soon, however, the emphasis would shift from protection of to protection from.

In the late nineteenth century and into the twentieth century, as Darwin’s work on evolution was becoming widely understood, there was an increasing interest in the role of heredity in human traits and, through heredity, in eugenics (Trent, 1994). It was during this period that people with intellectual disabilities were increasingly seen as a threat to society, both morally and genetically (Nibert, 1995; Simmons, 1982). The feeble minded and the moral imbecile were thought to make up a large segment of socially undesirable groups, such as the poor, criminals and prostitutes. Since these traits were innate and inherited, they would result in multigenerational feeble mindedness which, if left unchecked, could potentially contribute to the deterioration of the human race. These trends in public (and scientific) opinion forced the focus of institutional care to change from providing affected people asylum from the stresses of outside life, to a harshly custodial model which existed to protect society from the threat posed by feeble mindedness (Simmons, 1982).

A proponent of this policy was Henry Goddard who was the head of research at the Vineland Training School in New Jersey at the time (Danforth, 1997; Trent, 1994). Goddard introduced intelligence testing to North America and claimed that, through his testing, he had come to understand that intelligence was “a dominant genetic trait, and that all varieties of mental retardation were due to a
single recessive gene" (Gelb, 1997 p.452). Goddard 'proved' the connection between genetic feeblemindedness and social failure in his portrait of the Kallikak family (1912, cited in Gould, 1981). In it, he followed two branches of the family descending from the same 'respectable' man who had a dalliance with a feebleminded woman (starting the kakos or bad line) and then married an equally respectable woman, resulting in the kallos or good family. The Kakos line deteriorated immediately into feeblemindedness and poverty, while the Kallos branch produced upstanding members of society. Goddard used his study as support for his belief that the feebleminded could not be helped by policies such as mandatory education and that they would ultimately “clog the wheels of human progress” (p. 78, cited in Gould, 1981).

Goddard felt that the threat posed by the feebleminded was so overwhelming that he sought to control that threat wherever possible, through restricted immigration, institutionalization and, if necessary, sterilization of those destined to pass their defective genes on. On the subject of feebleminded people reproducing, he wrote:

If both parents are feeble-minded all the children will be feeble-minded. It is obvious that such matings should not be allowed. It is perfectly clear that no feeble-minded person should ever be allowed to marry or to become a parent. It is obvious that if this rule is to be carried out the intelligent part of society must enforce it. (1914 p.561 cited in Gould, 1981)

While Goddard would later soften his stance on sterilization, the notion had become popular with many and would remain a frequent occurrence in institutions for decades to come (Pfeiffer, 1994;
Smith & Polloway, 1993). Some estimate that over 50,000 people were sterilized in the United States alone (Smith, 1994), and that a large percentage of them were involuntary.

After the lessons of the Second World War and the horrors of Nazi eugenic programs had been learned, support for deterministic and eugenic based policies declined (Nibert, 1995). This change in attitude, coupled with the social reforms of the post war years, resulted in a move from a strictly custodial orientation to one which included more of an emphasis on recreation, training and education (Simmons, 1982).

This period also saw a tremendous growth in the number of admissions, especially of younger children, and in demand for more facilities. This rise in demand for institutional placements was due to conventional medical thought at the time which held that people with intellectual disabilities (and their families) were better served by being in institutions and because of a severe shortage of community services for many families with disabled members (Collier, 1995b).

Despite this growth in the number of placements, the 1950’s and 1960’s saw a number of changes in the way the institutions were being viewed by society as a whole. There were exposes on the conditions in some state operated institutions, such as Burton Blatt and Fred Kaplan’s graphic pictorial study, Christmas In Purgatory (1966) as well as ‘parent confessionals’ in which parents of institutionalized children came out (so to speak) and publicly told their stories (Trent, 1994). Institutions were beginning to be
viewed as a necessary evil; they may not have been the first choice but were often the only choice for young, upwardly mobile families with a disabled child.

It was also during this time that the first parents' groups were being formed (Trent, 1994). In British Columbia, for example, families began to demand community based services and organized to advocate for changes in government policy. The Association for Retarded Children of British Columbia (now the British Columbia Association for Community Living) was established in 1955 (Collier, 1995a). The association's initial goal was to lobby for community-based education programs for children with intellectual disabilities who were not living in institutions. The society's efforts were successful and resulted in the 1959 amendment to the School Act which made the education of the moderately retarded the responsibility of the public school system (Collier, 1995a). Through the 1960's and into the 1970's the provincial association, along with its member regional organizations, began to work for the development of smaller community-based residential programs as alternatives to the large centralized institutions (Collier, 1995b).

However, it was not until the 1970's when Wolf Wolfensberger's 'principle of normalization' (Wolfensberger, 1972) was introduced and embraced by those involved in the movement that there was any large scale questioning of the segregation of people with mental handicaps and the legitimacy of the institutions. Normalization (which I will discuss later in detail) would prove to be a powerful force as it was "a wonderful weapon to use in the political struggle
for better care for developmentally handicapped people - for who could be against it? It had the peculiar quality of appealing to society's sense of fairness as well as having about it a ring of science" (Simmons, 1990, p. 165). Armed with this "weapon", advocacy groups began to pressure governments to close down the institutions and to develop services for people to live and work in their own communities (Roeher Institute, 1991). This was the birth of the Community Living Movement.

The revolution that normalization spawned is continuing to this day (Elks, 1994). All over North America and Europe, institutions are being closed and people with disabilities are returning to their communities. In British Columbia, for example, all three of the large residential facilities for intellectually disabled people have been closed after a process lasting fifteen years and involving all levels of government, parents, professionals and advocacy groups. But, in the community does not necessarily mean of the community. The segregation and marginalization of people with intellectual disabilities that the community living movement hoped to eliminate through this process has not gone away. This has suggested to some that the reasons (and the answers) may lie elsewhere.

In the last number of years, there has been a growing body of research and literature that has analyzed disability from a very different perspective than the traditional individual/medical model. The social model of disability has its roots in material analysis and questions the perception of disability as pathological (Oliver,
1990). It is a critical theory and at its core is demand for rights for people with disabilities. Although this approach is still somewhat problematic, especially regarding people with severe disabilities (Ferguson, 1990, 1994), I assert that it is within the social model that the situation facing people with intellectual disabilities can be best understood and, more importantly, best dealt with. In order for this to happen, however, the social model of disability must be understood and its departure from older theories examined.
Normalization and the Social Model of Disability

Introduction

When the principle of normalization was first introduced in North America in the late 1960's, it quickly became the theoretical standard for organizations providing services to people with mental handicaps throughout the United States and Canada (Brown, 1994; Brown & Smith, 1992; Chappell, 1992; Ippoliti, Peppey & Depoy, 1994). Normalization theory gave service providers, families and others involved in the lives of people with intellectual disabilities an historical and practical analysis of how people labeled intellectually disabled had come to be socially devalued and segregated and, more importantly, what could be done to counter this devaluation and bring people back into the community (Wolfensberger, 1972). The method and function of normalization and its descendant, social role valorization (Wolfensberger, 1983), have been interpreted and, according to Wolfensberger (1983, 1995), misinterpreted by countless individuals, but finally can be summarized as "the establishment, enhancement, or defense of the social role(s) of a person or group, via the enhancement of people's social images and personal competencies" (Wolfensberger, 1983, p. 234). The practices which were guided by the principle since its development have resulted in significant positive changes in the lives of people with intellectual disabilities (Brown, 1994; Smith & Brown, 1992). However, there is a growing perception that
normalization is ultimately inadequate to the task of fully including people with intellectual disabilities into society because of the limitations inherent in it and its ideological base. Primary among these are its lack of recognition of the social constructedness of disability and its lack of analysis of the societal features which serve to oppress and marginalize people with intellectual disabilities (Chappell, 1992). This chapter is an attempt to examine the principle of normalization in light of the developing social theory of disability (Oliver, 1990) and in terms of structural theory (as discussed by Mullaly, 1993) and to explore the consequences for people with intellectual disabilities within these models.

The Principle of Normalization

The concept of normalization was originally developed in Scandinavia in the late 1960’s (Bank-Mikkelsen, 1969; Nirje, 1970, both cited in Wolfensberger, 1972). It was modified and adapted for North America in 1972 by Wolf Wolfensberger and his name has been associated with it since that time. The concept was originally developed during a period of significant change in policy and attitudes towards the living situations of people with intellectual disabilities and concerns about the quality of life for people living in institutions (Wolfensberger, 1972). This coincided with similar concerns developing in North America and Britain and the growing belief that people with intellectual disabilities would be
better served living in the community rather than large segregated facilities. The Scandinavian version of normalization was primarily a method to support community living, whereas the North American variant became a theory (Chappell, 1992) which purported to explain the social devaluation of people with intellectual disabilities and to provide an empirically based method to prevent or ameliorate it (Wolfensberger, 1983).

Wolfensberger saw his original version of the theory as an attempt "to convert the early formalizations of normalization ... into a scientific theory that is universal, parsimonious, and congruent with social and behavioral science" (1983, p. 234). He also envisioned this model being applied to other human services and becoming a "new ideology of human management" (1972, p. 27). The science Wolfensberger based his theory on was that of the sociology of deviancy and it was his belief that this theory was applicable to all services involved in the "management of deviant behavior" (1972, p. 27). In his original North American presentation of the theory, *The Principle of Normalization in Human Services* (1972), Wolfensberger describes the labeling of deviance and then applies it to the historical societal views of people with intellectual disabilities such as *subhuman organism, menace, object of pity, holy innocent, sick, object of ridicule* and *eternal child*. He then goes on to discuss the consequences of each view for the treatment of individuals so labeled (pp. 16-24). For Wolfensberger, the results of these labels were segregation and, ultimately, destruction.
Normalization was then put forward as a method to avoid or minimize this labeling and thus avert the consequences.

In practice, normalization seeks to improve or protect the social value of people at risk for devaluation by using *culturally normative* methods to establish behaviors and characteristics which are as close to *culturally normative* for their age and gender group as possible. By following this principle, service providers can theoretically increase the appearance of normalcy and decrease the perceived deviancy of the intellectually disabled people they work with. According to Wolfensberger, "culturally normative" refers to typical or conventional actions or appearance as defined by the dominant culture.

Normalization was theorized to work on more than simply a clinical level as is illustrated by figure 1 (adapted from Wolfensberger, 1972, p. 32):

**Figure 1**

<table>
<thead>
<tr>
<th>Interaction</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Person</strong></td>
<td>Eliciting, shaping and maintaining normative skills and habits by means of direct physical and social interaction with them</td>
</tr>
<tr>
<td><strong>Primary &amp; Intermediate Social Systems</strong></td>
<td>Eliciting, shaping and maintaining normative skills in persons by working indirectly through their primary and intermediate systems such as family, school, work, service agency and neighbourhood</td>
</tr>
<tr>
<td><strong>Societal Systems</strong></td>
<td>Eliciting, shaping and maintaining normative behaviour in persons by appropriate shaping of large societal systems such as entire school systems, laws and government</td>
</tr>
</tbody>
</table>
As can be seen in the figure, normalization includes applications and expressions at the micro, meso and macro levels of social systems, although, in practice, most of the work of normalization takes place on the personal or clinical level.

**Social Role Valorization**

In 1983, Wolfensberger reformulated and renamed the principle of normalization, dubbing it *social role valorization*. He did so, in part, because he felt the term normalization had developed many different meanings and interpretations and also because of a change in his own view of the theory (p. 234). Wolfensberger changed the focus of the theory from one which included consideration of all three levels of social systems functioning to one which focuses almost exclusively on the clinical due to his:

> recent insight... that the most explicit and highest goal of normalization must be the creation, support, and defense of valued social roles for people who are at risk of social devaluation. All other elements and objectives of the theory are really subservient to this end, because if a person’s social role were a societally valued one, then other desirable things would be accorded to that person almost automatically, at least within the resources and norms of his/her society. (p. 234, emphasis in the original)

The key strategies involved in social role valorization are now those which are aimed at improving an individual’s social image and increasing their competencies (p.236), which should result in an increase in the person’s social role value. The particular methods for doing so remained the same as under normalization (i.e.) the
establishment of culturally normative and age appropriate appearance, activities, living arrangements, behaviour, etc.

**Social Theory of Disability**

While normalization and social role valorization attempt to explain the devaluation of people with disabilities in terms of deviancy and then provide methods to minimize that deviancy, the newly emerging social theory of disability endeavors to address the marginalization of disabled people from a materialist perspective (Erevelles, 1996; Finkelstein, 1980; Gleeson, 1997; Nibert, 1995; Oliver, 1983, 1990, 1996).

A fundamental issue in the social theory of disability is the recognition and analysis of the social constructedness of disability (Oliver, 1983, 1990, 1996). According to Oliver (1990), disability is constructed by a variety of social and economic factors which include culture, capitalism and ideology. An analysis of the cultural production of disability shows that, while impairment and disability exist in many cultures, the experiences of disabled people vary from society to society, ranging from marginalization to exhaustedness (Oliver, 1990). This illustrates the relativism involved in cultural notions of disability, but as Oliver makes clear, cultural definitions can be understood somewhat in terms of the relationship between the mode of production and the values of a given society. For example, a nomadic society may define disability differently from an agriculturally based one and disabled people
living in a society with a religious value system will likely have a different collective experience than those living in a culture which is based on scientific values (p.22). In terms of intellectual disability, Ferguson (1994) has stated that “mental retardation is a plastic concept that is inevitably shaped by shifting forces of historical development and cultural prejudice” (p. xvii). The criteria for the diagnosis of mental retardation are based on estimations and observations of intellectual ability, adaptive functioning and behaviour, all of which are variable and subject to interpretation (Manion & Bersani, 1987).

The rise of capitalism has also had a significant effect on the construction and definition of disability. In particular, the consequences of industrialization and the move to factory based work which often excluded people with disabilities (Oliver, 1990; 1996). In addition to this development (or, indeed, because of it), changes in societal attitudes and relationships occurred that in turn combined to create a view of disability as a social problem which required classification and control. The institution became the solution to this problem and those who would not or could not adjust to the social order were incarcerated and segregated. As time passed, institutions and classifications became more specialized and began to distinguish between different classes of non-conforming or non-contributing people such as children, the sick, the mentally ill, the poor and the disabled. For example, in Canada, intellectually disabled people were generally incarcerated in prisons or asylums for the mentally ill until 1876 when the Asylum
for Idiots at Orilla in Ontario opened (Simmons, 1982). One of the primary motivations for this specialization and separation was the belief that 'incurables' (people with intellectual disabilities) could be maintained at less expense than 'curables' (people with mental illnesses) who required better care in order to recover and become contributing members of society.

As stated, with the rise of capitalism and changes in the nature of work, there also came about changes in attitudes and ideologies which contributed to the construction of disability. The ideologies in present western societies have combined to create the current dominant view of disability. As Oliver (1990) describes it:

> the hegemony that defines disability in capitalist society is constituted by the organic ideology of individualism, the arbitrary ideologies of medicalisation underpinning medical intervention and personal tragedy underpinning much social policy. Incorporated also are ideologies related to concepts of normality, able-bodiedness and able-mindedness. (p.44)

The key ideologies involved in the modern definition of disability are individualism and medicalization. Individualism results in the view of disability (and the inability to compete in the marketplace which accompanies it) as an individual pathology and medicalization is the process by which that pathology is controlled categorized and treated (Oliver, 1990). The practices which come about as a consequence of these constructions lead to the next aspect of the social theory of disability, that of oppression.

To view the situation of disabled people through the lens of oppression is to highlight the similarities disabled people as a
group have with other marginalized groups such as, women, people of colour and gay and lesbian people. However, according to Abberley (1987), one of the features of oppression is that it operates on specific groups in different ways and this requires an investigation of the types of oppression particular to disabled people and the consequences of that oppression.

One type of oppression disabled people face is economic. People with disabilities who are employed are often working in low paying jobs and are at great risk for unemployment (Jenkins, 1991). Most people with disabilities, especially those with intellectual disabilities, however, are not employed and are made dependent on social security benefits. The poverty which disabled people must live with becomes a significant constraint and obstacle in realizing their goals and desires (Chappell, 1992). Poverty also often makes it necessary for people with disabilities to live in state funded residential facilities in order to access the support they require but are not able to afford otherwise (Jenkins, 1991). This systematic poverty results in disabled people being segregated and having less control over their lives. As well, economic marginalization often results in political marginalization. As Jongbloed & Crichton (1990) have written, “our society values the efficiency, productivity and economic usefulness of human beings. Disabled adults who are not performing work-linked economic roles are marginalized and their input into the political debate is consequently devalued” (p. 33).
Psychological oppression is another common feature of the situation of disabled people. One aspect of this type of oppression is the stereotype of disability and the limitations and societal expectations which accompany it (Abberley, 1987). There are several stereotypes of disabled people, but they can generally be divided into two categories, either brave or tragic (Abberley, 1987). The brave disabled person is one who makes an effort to overcome his or her disability or tries to live as if it did not exist. The tragic disabled person, conversely, is overwhelmed by the disability and is embittered, self-pitying and dependent because of it. The important issue in both these stereotypes is that the entire identity of the person is bound up in the disability, yet the “disabled state is taken for granted as necessarily illegitimate” (Abberley, 1987, p.14). This type of psychological pressure, which is closely tied to the individual pathology view of disability, forces the disabled person to see the disability as a personal challenge or battle which can be won or lost.

This view of disability leads to another form of oppression disabled people face, that of physical oppression. Physical oppression takes many forms, but one of the most insidious is abuse which takes place in the name of treatment or rehabilitation (Sobsey, 1994; Abberley, 1987). People with intellectual disabilities are regularly subjected to “treatments” for behaviours identified as inappropriate or violent which involve the use of psychoactive drugs (sometimes where no diagnosis of mental illness exists) and/or aversive behaviour management techniques (Sobsey,
using noxious stimuli or electric shock to reduce the incidents of the behaviours. While there is controversy over the use of such techniques (Rioux, 1988), they are often defended on the basis of efficacy and the professional need to have a range of treatment options (Spreat & Behar, 1994).

A frighteningly prevalent form of violence directed at people with intellectual disabilities is sexual in form. In a review of studies on the prevalence of sexual violence against people with intellectual disabilities, Senn (1988) discovered figures ranging from 39% to 68% of girls and 16% to 30% of boys with intellectual disabilities for experiencing sexual assault before the age of eighteen. An even more disturbing feature of the abuse of people with intellectual disabilities, however, is the chronicity of the abuse. In their study, Sobsey & Doe (1991) found that 79.6% of their sample of disabled people who had been sexually assaulted had been victimized more than once. They also found that of people with more severe intellectual disabilities, 56% had experienced ten or more episodes of sexual violence in their lives. In the same study, Sobsey & Doe discovered that 56% of offenders had relationships with the victims which were consistent with those of non-disabled victims (i.e.) family members, acquaintances, generic service providers, etc. They also found that, in the case of disabled people, 44% of perpetrators were involved in their victims' lives because of the victims' disabled status, for example, personal care attendants, residential support staff, etc. In another study, Sobsey (1994), found this figure to be closer to 50%. If one accepts these figures
as accurately reflecting reality, people with disabilities have double the likelihood of being victimized in part because of their exposure to the service system (Sobsey, 1994).

The types of oppression described above are merely examples of the variety of oppressions particular to people with disabilities. Abberley (1987) sees the effects of oppression as serving the dominant social order in several ways. These include, disadvantaging disabled people economically and psychologically so as to make the disabled identity despised and undesirable, creating a passive welfare class which serves as a warning to others and, finally, presenting this disadvantaged state as a natural consequence of individual deficiency that legitimates the inequities (pp. 16-17).

As can be seen, the social theory of disability incorporates a material analysis of the conditions which create disability as a concept and the factors which serve to oppress people with disabilities (Ervelles, 1996). It is also a challenge to the hegemony which benefits from the continued marginalization and subjugation of disabled people. Abberley (1987) has summarized it in the following manner:

1) [it] recognises and, in the present context, emphasises the social origins of impairment;
2) [it] recognises and opposes the social, financial, environmental and psychological disadvantages inflicted on impaired people;
3) [it] sees both (1) and (2) as historical products, not as the results of nature, human or otherwise;
4) [it] asserts the value of disabled modes of living, at the same time as it condemns the social production of impairment [through unsafe working conditions for example];

5) [it] is inevitably a political perspective, in that it involves the defense and transformation, both material and ideological, of state health and welfare provision as an essential condition of transforming the lives of the vast majority of disabled people. (p. 17)

Critique of Normalization

As stated previously, after its introduction, the principle of normalization became the theory within which the majority of services to people with intellectual disabilities operated. Its popularity can be partially attributed to its seeming ability to identify the disadvantages of people with intellectual disabilities and to provide strategies to change that situation (Chappell, 1992). Another part of its success, however, may lie in the fact that it does so without challenging the established social order. In fact, as it will be shown, normalization works to maintain and support that order by forcing intellectually disabled people to adjust themselves and their behaviour in an effort to fit in to society. From a perspective informed by structural theory and the social theory of disability, this feature renders normalization inadequate to truly meeting the needs of people with intellectual disabilities (Chappell, 1992).

A significant difficulty with normalization from a critical perspective is its emphasis on professional authority and professional control of services (Chappell, 1992). Normalization
has enabled professionals to retain control of the range of services for people with intellectual disabilities despite changes in policy and attitudes, for example the deinstitutionalization process, by providing them with a new model of practice (Chappell, 1992; Fulcher, 1996). As can be seen throughout Wolfensberger's work on normalization and social role valorization (1972, 1983, 1995 for example), services providers are the actors and intellectually disabled people are the objects. Decisions about services and evaluations of the quality of those services are made by professionals and not by the people who use the services (Brown & Smith, 1992; Chappell, 1992). Normalization presupposes a consensus between service provider and client as to goals and methods and does not make allowances for conflicts. This assumption prevents any analysis of the power disparities between people with intellectual disabilities and the professionals in their lives (Chappell, 1992). As the social theory of disability informs us, this focus on professional control is an example of the hegemony of medicalization and medical/professional control over the lives of people with disabilities.

Normalization theory in its emphasis on culturally normative standards for appearance, behaviour, living situations, etcetera, assumes that people with intellectual disabilities are a homogeneous group and does not recognize diversity within that group in terms of culture, gender or sexual orientation. It also does not respect diversity in the larger society by maintaining that normalizing activities should reflect the dominant culture. In this respect,
normalization is conservative and authoritarian (Chappell, 1992). It is also oppressive in that it perpetuates the marginalization of groups such as women, people of colour and lesbian and gay people in the larger society and within the intellectually disabled community as well (see Brown, 1994; Ferns, 1992; Brown & Smith, 1992). For example, in terms of sexual orientation, the standard of *culturally normative* behavior in normalization has resulted in a complete failure to accept any activity other than heterosexual activity and as a result:

frequently men with learning disabilities who have sex with men do so without the benefit of safer sex education and even when their behaviour is known about they are not credited with a gay identity. Their behaviour is likely to be kept covert rather than acknowledged as a positive choice. Lesbian relationships and lifestyles are rarely made explicit as an option for women with learning disabilities. (Brown, 1994, p. 136)

By attempting to normalize people with intellectual disabilities and minimize their deviancy within society, normalization serves the current social order by diminishing the ability and position of people with mental handicaps to make claims (as described by Drover & Kerans, 1993) against that order. Normalization practices work against intellectual disabled people coming together in a collective manner by focusing on individual deviancy and change and by suggesting that friendships and activities involving only disabled people serve to reinforce stigmatizing roles (Brown & Smith, 1992), a position that Wolfensberger continues to maintain (1995a). This leads to Chappell’s (1992) question, “if they are discouraged from associating, how can they develop a collective response to
discrimination?" (p.45). The answer, of course, is that they cannot
and when this function of normalization is combined with the
unquestioned power and control exercised by professionals over the
lives of intellectually disabled people, it becomes clear that many
people with intellectual disabilities are not currently in a
position to articulate claims within society and are dependent upon
others to do so on their behalf.

As already noted, normalization and social role valorization
are based on the sociological theories of deviancy and
interactionism (Chappell, 1992). While these concepts may be useful
in identifying and describing injustices and disadvantages
experienced by people with disabilities, normalization’s failure to
link them to their structural antecedents result in the theory
"never proceed[ing] beyond the level of a descriptive and implicitly
justificatory account" (Abberley, 1987, p.14). By tacitly accepting
the deviance of intellectual disability as natural, the
responsibility for change is placed on the individual. The
intellectually disabled person is to be made more "normal" in order
to meet society’s standards rather than efforts being directed at
changing those structures which do not accommodate a person who is
different (Chappell, 1992; Elks, 1994).

This perspective also brings to light a contradiction inherent
within normalization and social role valorization. The theories
accept that deviancy is a natural consequence of disability and that
this deviancy results in societal marginalization. In order to
achieve the goal of normalization, that of societal integration, the
theories support practices which increase the appearance of normality and thus decrease the perception of deviance. However, if deviance is inexorably tied to disability it cannot be eliminated unless the disability is eliminated. Therefore, people with disabilities, no matter how "normalized" they become, will always be deviant and can never be fully integrated. The best normalization can then offer people with disabilities then is a type of "second class" standing in society, rather than full and equal membership. From a critical perspective, this is obviously an unacceptable outcome.

Critique of the Social Model

The social theory of disability has been criticized within the disabled academic community by some as emphasizing the material aspects of the construction of disability at the expense of the idealist (Barnes, 1996; Priestley, 1998). As Tom Shakespeare (1994) has written:

as a consequence of this position, Social Model writers have rejected social psychologists, anthropologists, and even feminists, all on the basis that such theorizations are 'idealist', and fail to pay attention to material processes and social relations. I would support any argument which suggests that it is vital to consider material relations: a theoretical explanation which neglects the disabling role of society, which ignores socio-economic structures, is a mere fantasy. However, I would equally suggest that mono-linear explanations, reducing everything to economic factors, are misguided. (p. 289)

Shakespeare goes on to identify cultural representations of disabled people as 'other' and 'abnormal' as being expressions of prejudice
against them and that this prejudice arises out of non-disabled people's fear of impairment. It is this fear which creates the prejudice which then combines with material conditions to create the oppression of disability.

Other researchers have also written on the limitations of the exclusively materialist viewpoint, primarily regarding its disregard for the personal and individual experiences of different groups of disabled people (Keith, 1992; Morris, 1991). As a disabled feminist researcher, Jenny Morris has made efforts to bring these experiences to light and to incorporate them into the social model (1993, 1995). Her work has also encouraged a more pluralistic and inclusive trend within disability theorizing by emphasizing the experiences of disabled women and pointing out the marginalization of women within the movement. Barton (1993) has pointed out as well that "the extent to which gay, lesbian, and black disabled individuals or groups feel represented ... has not been adequately addressed" (p. 238). Part of this resistance to 'identity politics' within disability theorizing seems to revolve around a fear that the social model will be weakened in its presentation to the non-disabled world if it attempts to follow a more postmodernist path and incorporate all the variations of disability experience (Shakespeare & Watson, 1997).

Much of this tension regarding individual experiences arises out of a difficulty with the concept of impairment (Crow, 1996; Hughes & Paterson, 1997; Wendell, 1996). The materialist approach emphasizes the construction of disability by disabling barriers and
attitudes in society and tends to regard impairment as a difference which can be rendered at least neutral, if not meaningless, by the removal of these barriers. Writers such as Liz Crow (1996), however, question this portrayal of impairment and insist that impairment is central to the experience of disability. The concern seems to be that to admit to being in pain or being fatigued, for example, will open the door to a return to the medical tradition which will personalize and pathologize without recognizing the social features of disability. For Crow, though, this is not an inevitable result of recognizing the reality of impairment and the consequences of not recognizing it are far more dire:

...by refusing to discuss impairment, we are failing to acknowledge the subjective reality of many disabled people’s daily lives. Impairment is problematic for people who experience pain, illness, shortened lifespan or other factors. As a result, they may seek treatment to minimise these consequences and, in extreme circumstances, may no longer wish to live. It is vital not to assume they are experiencing a kind of 'false consciousness' - that if all the external disabling barriers were removed they would no longer feel like this. (p. 217)

This minimization of impairment makes the strictly materialist perspective problematic with regards to people with intellectual disabilities as well (Ferguson, 1990). Intellectual impairment, especially severe impairment, exists in an absolute sense and people who have intellectual impairments would still be in a disadvantaged position even if all barriers to their full participation were removed tomorrow. As Ferguson writes, "the weakness of the constructivist position in disability studies emerges at those examples where culture seems beside the point; where physiology has
gone so far awry that it threatens to overwhelm the social context” (1990 p.207). Severe intellectual impairment cannot be made benign.

The social model of disability was developed for disabled people by disabled people in the belief that it is only through self advocacy that change will occur. For people with intellectual disabilities, however, a considerable amount of advocacy will always be performed by non-disabled people on their behalf. This is the source of much unease and may also partially explain the marginalization of intellectual disability in disability theory. This discomfort is made explicit in Watson’s (1996) discussion on the absence of intellectual disability in critical sociology when he says:

> a key component of the critical impulse is the desire to avoid a paternalistic relation to disadvantaged and oppressed subjects through an insistence that critical social science elaborates the existing political speech of disadvantaged and oppressed subjects and does not simply speak for them, but very cognitively disabled people cannot speak for themselves. (p. 232)

Watson refuses to shy away from this potentially immobilizing conflict and suggests that researchers accept the risk and take on an “ethic of caring” (p. 246) which allows us to examine the oppression of intellectually disabled people because it is the right thing to do.

**Discussion**

The use of the principle of normalization in services for people with intellectual disabilities has allowed people to identify...
the inhumane treatment and injustices that intellectually disabled people have been subjected to historically and has provided a practical alternative to them. It has been largely due to normalization theory that people have come to see the institution and extended care ward as inappropriate and stifling places for people with intellectual disabilities to live. Normalization has also brought an idealistic vision to services, promoting the idea that people with intellectual disabilities can learn and can become integrated into society rather than hover at its margins. Because of the influence of normalization, people with intellectual disabilities are visible again in the community, not kept behind locked doors.

Normalization, however, has some very serious limitations, especially when viewed from a critical perspective. Normalization and its more recent form, social role valorization, ultimately serve the dominant social order and are not as transformative as they first seem to be. The theories are rooted in the ideological hegemony of individual deficiency and medicalization which interpret the difficulties associated with disabilities as personal pathology which require treatment and correction. Normalization perpetuates professional power over people with intellectual disabilities and blocks opportunities for individuals to come together and make claims for their rights in society. In the final analysis, the most significant weakness in normalization may be its attempt to integrate people with intellectual disabilities into a society which, by normalization's own definition, will never accept them.
The social theory of disability, on the other hand, provides a critical structural analysis of the construction and oppression of disability and disabled people. It is similar to normalization theory in that it seeks to identify and analyze the marginalizing aspects of disability but does so from a material perspective and finds that ideology and economics create marginalization rather than disability and deviance. Both theories also include strategies for changing the current situation disabled people struggle within, but while normalization focuses on professionally dictated personal change in order to adjust to society, the social theory of disability looks to activism within the disabled community to change the social order which oppresses it. In the social theory of disability, social and political action are seen the primary methods to bring about transformative change. Finally, both theories claim to exist for the betterment and improvement of the lives of disabled people. Normalization, however, makes this claim on the basis of determinations of improvement made by professionals rather than those with intellectual disabilities and their advocates while the social theory of disability is grounded in the lived experience of people with disabilities and holds that self determination and full citizenship are the most important claims disabled people can make.
Research Orientation

Introduction

The history of research concerning people with intellectual disabilities has generally been focussed on the 'problem' of disability and has had the concerns of the professional at its center. Disability rights activist researchers challenge this professional domination of research goals and call for disability research which is based upon the experience of people with disabilities and that benefits people with disabilities (for example, Barnes, 1992; Morris, 1992; Oliver, 1992; Ward & Flynn, 1994; Zarb, 1992). As Taylor (1996) says, "the perspectives and experiences of people labeled mentally retarded must provide a starting point for all research and inquiries in the study of mental retardation" (p. 7). There is very little research which does, however, and this may be attributed to a generalized belief that people with intellectual disabilities "lack the capacities to provide coherent reconstructions of their life experience" (Turner, 1980 p.3). In some situations, people with intellectual disabilities may have difficulties being articulate, but this is by no means is an excuse to dismiss their views (Taylor, 1996). Booth (1996), Booth & Booth (1996), and Goodley (1996) all describe the use of narrative techniques with people who are not extremely articulate and provide suggestions and guidelines on how the researcher can assist in bringing peoples' stories out. The value in this kind of research is that "reinforcing the insider's
subjective understandings of their [sic] own position prompts readers to challenge their own (often generalized) understandings of the tellers. In short our own 'truths' are quickly challenged by the personal narrative" (Goodley, 1996 p. 335). My goal is to bring to light the experiences and concerns of people with intellectual disabilities for much the same purpose. I wish to act upon Tyne's (1994) vision of citizen advocacy:

some kinds of advocacy will clearly be about being a "spokesperson". Perhaps the person literally has no voice, or no language. Representing their interest may need an interpreter, or someone who can spend long hours discerning their intent. Perhaps the person has a voice, but it is drowned by dominant people who surround them with overbearing concerns. (p. 251)

Rather than being a spokesperson for people with intellectual disabilities, I would prefer to "serve them by providing a wider 'audience' for these subjugated and marginalised stories" (Gillman et al, 1997 p. 692).

As well, as was discussed previously, the emerging social theory of disability attempts to describe the social constructedness of disability and views disability from a rights perspective. Most of the research discussed which establishes disability as a social issue, however, has done so from the perspective of people with primarily physical disabilities without specific recognition of the experiences of people with intellectual disabilities. Part of the purpose of this study is to help add the voices of people with intellectual disabilities to the chorus calling for change.
Ethical Issues:

The ability to give informed consent is a concern with people with intellectual disabilities (Stalker, 1998; Swain et al, 1998). In part, this was dealt with by selecting subjects who were legally able to give consent (i.e. have not been declared incompetent). All of the people involved in the study were able to clearly indicate their choice as to whether or not they wished to participate. I had also obtained approval for this study by the agency which sponsors the self advocacy committee. In addition, some of the people in this group have been involved in research activities in the past and had some experience on which to base their decision. Care was taken to explain the process thoroughly in plain language to ensure that each participant understood what was being asked of her. As well, the consent letter which each participant signed was written in plain language and was discussed at length with each person (see appendices 1 and 3).

Another factor in obtaining valid consent which was more problematic was the issue of trained compliance or acquiescence which is a feature which may be present among some people with intellectual disabilities, especially in regards to requests made by non-disabled authority figures (Sigelman et al, 1981; Sobsey, 1994). Again, because I selected participants from a group involved in advocacy, this was less of a concern than it would have been with other people. I attempted to minimize this potential problem by emphasizing that participation was completely voluntary and that
there would be no negative consequence for choosing not to participate.

In their discussion of ethics regarding this type of open-ended interviewing with people with intellectual disabilities, Swain et al (1998) identify possible sources of harm to participants. Among these, they list a lack of respect towards the participant, especially in terms of manipulation during the interview (to encourage disclosure of personal information) and in the data analysis (by not respecting the voice or wishes of the participant). Another issue raised is that of a potentially dangerous relationship developing between researcher and respondent. As Swain et al write, "to conduct research of this nature is to become involved in people's lives. The involvement may be peripheral as far as the researcher is concerned, but may not be from the participant's viewpoint" (p. 31). Swain et al suggest that there are no easy or concrete solutions to these potential sources of harm. What they do recommend, however, is an on-going ethical review process through the entire course of the research. A process that recognizes that "ethical principles and obligations are interpreted, and take particular manifestations within specific contexts and between the particular people involved" (p.34).

The primary concern I had in terms of the ethics of my data collection technique was that of the power relationship between the people I wished to interview and myself. Being not only able-bodied but a staff member with the Society (although not directly with these individuals), I was concerned that the people I interviewed
would not be comfortable enough or feel safe enough to express what they truly wish to say. While I had some concerns regarding one interview respondent, in the end, however, I do not believe that this was an overwhelming problem, especially with the focus group. The group clearly had its own agenda and seemed to appreciate the opportunity to make its views clear. The only concern on the part of the participants was the possibility of offending me with negative comments about social workers. Their hesitation disappeared when I made it clear that this was exactly the type of information I was looking for.

Another concern I had with this type of interpretive approach is that it may not be considered particularly empowering or emancipatory. There is considerable literature in the disability rights field condemning research which does nothing to improve the social position of people with disabilities and merely fulfils the researcher's and/or the dominant culture's needs (see Barnes, 1992; Oliver, 1990, 1992; Morris, 1992; Stone & Priestley, 1996; Zarb, 1992). Much of the criticism of interpretive types of research, however, comes from the proponents of a strictly materialist model of disability theorizing (as discussed previously). Others, writing from a more feminist perspective, make it clear that it is only through the expression of disabled peoples' experiences that changes to a disabling society can begin to occur (see Barton, 1993; Morris, 1991; Shakespeare, 1994; Taylor, 1996). Regarding people with intellectual disabilities in particular, Booth (1996) provides this justification:
the 'excluded voice thesis' postulates that narrative methods provide access to the perspectives and experience of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse. (p. 237)

It is from this position that I orient myself and my research.

**Validity/Credibility Issues:**

Maxwell (1996) defines validity as "the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account" (p. 87). He goes on to state that there are three ways of understanding research and that each is susceptible to particular problems or threats which place results in question: description, interpretation and theory. The validity of the data's description can be threatened by inadequate recording of the data collection process which renders suspect the conclusions drawn from the data. The interpretation of the data can be threatened by the imposition of the researcher's own beliefs over that of the participants'. Finally, theoretical validity can be challenged by the researcher's avoidance of conflicting data or alternative explanations.

For my research, the most problematic area has been in the interpretation of the data. My study is highly interpretive in nature and I have been concerned throughout the process that I may have over-interpreted some of the data, in the interview narratives in particular, and Franklin's specifically. My intention in this study was to give voice to the issues the respondents had and not to
'psychologize' and pathologize them (as has historically been done). Yet, despite my discomfort, I believe my interpretations are valid and that the narratives I selected provide clear examples of how the identity of 'intellectually disabled' can construct a life.

In terms of other validity threats, I incorporated a number of techniques (as discussed in Maxwell, 1996) to ensure the credibility of my results. In addition to audio taping the interviews (and video taping the focus group), I made a point to make written notes as well. Also, I had feedback sessions with the informants to check the videotape for accuracy in order to develop an accurate description of the proceedings. As well, the proceedings of the focus group and the individual interviews were transcribed verbatim prior to their analysis.

In order to ensure the validity of my analysis, I performed member checks with the focus group after the initial discussion meeting. I have presented my preliminary findings to the informants and asked them to critique the analysis so as to make sure it was congruent with their attitudes.

I have engaged in the process of peer debriefing throughout the course of this study. I have discussed my work with fellow social work students, co-workers and disability activists in an effort to ensure my research is respectful, valid and logically laid out.

Finally, I feel I can make a reasonable claim for credibility for my study in terms of researcher involvement in the area being studied. I have worked with people with intellectual disabilities
for many years in a variety of settings and capacities. While this does not give me the right to claim insight into or special knowledge about the experience of intellectual disability, I feel that my work and commitment to empowering people with disabilities does give me the ability to listen and begin to understand their issues and demands.
Methodology

Focus Group

Introduction
Focus groups were developed primarily by market researchers to gain information on how products and services are perceived by consumers, but have grown in popularity with social scientists and other researchers in recent years (Krueger, 1994). A focus group "is a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening atmosphere" (Krueger, 1994 p. 6). They generally use semistructured discussion methods and, although they may also provide some level of personal support to the participants, that is not their express purpose (Carey, 1994). The group aspect provides an opportunity for fuller exploration of the topic from a variety of sources. Focus groups are used by social science researchers for a variety of reasons, but Carey (1994) suggests that focus groups are particularly useful for "need assessment[s]" (p. 227) with new populations, which is largely what I have tried to do with my research.

Although my original intention in this study was to use a focus group format as described in Krueger (1994), I now hesitate to call what transpired a focus group in the usual sense of the term. The number of people who wished to participate was quite surprising to me and as a result the group was larger than is generally found in most focus groups (Carey, 1994, for example, recommends 5-12
participants). I allowed this because, in my attempt to make this research relevant and empowering for the participants, I felt that their wish that the group as a whole participate should be respected. I also felt that it would be difficult and discriminatory to select some and not others when the enthusiasm and support for this study in the group was so high. As well, because this is an exploratory study, I decided that gaining information from as diverse a group as possible was of particular importance. Another diversion from tradition was in my departure from my original discussion guide (appendix B). It became evident early on in the discussion that I simply was not asking the right questions of the group, as they had their own agenda and their own issues to bring forward. Rather than spending the session attempting to drag the group back to my agenda, I quickly decided to defer to them as the experts and follow their lead. As Kreuger (1994) notes, a focus group method is adaptable, but it is not infinitely malleable. As a result of these departures from standard procedure, and for reasons discussed below, I would almost prefer to consider this study a group interview rather than a focus group.

I chose a group model rather than individual interviews for the initial, exploratory study for several reasons, most of which relate to my desire to create an environment as comfortable and conducive to discussion with people with intellectual disabilities as possible. Rather than make people with intellectual disabilities work to fit into non-disabled structures and procedures, procedures
need to be changed to reflect the experiences and capacities of those with disabilities. Ippoliti et al. (1994) maintain that:

there is . . . evidence to support the design of structured, nurturing settings for persons with learning difficulties as a most effective way of promoting their capacity to competently participate in planning and decision making. In light of the research, it not only seems worthwhile to further explore the use of similarly well organized, safe settings for people to identify and articulate their own preferences and needs, but seems essential as an acknowledgement of their right to self determination. (p. 455)

Focus groups with people with intellectual disabilities have been used by other researchers (for example Di Terlizzi, 1997) and found to be effective with certain modifications to make the process more comfortable and inclusive, especially for people who do not speak or have limited verbal abilities. Ippoliti et al. (1994) report that:

the focus group methods serve dual purposes which are of great value to professionals and consumers alike: they provide a structured forum in which persons with disabilities can articulate their own ideas and also provide an arena from which data can systematically be collected and then subjected to formal analysis. (p. 460)

Other reasons I chose to interview a pre-existing group have to do with communication. The self-advocates in this group are experienced with issues of advocacy and are committed to speaking for themselves. This is especially important for research with people with intellectual disabilities, because of the inarticulateness which may describe some people so labeled. As Booth & Booth (1996) describe it, it is the inability to use words
in a fluent manner which is due in part to limited language skills, "but is generally overlaid by other factors including a lack of self-esteem, learned habits of compliance, social isolation or loneliness and the experience of oppression" (p. 56). As members of an established group, there was a higher level of comfort between the participants than there would have been if a new group was formed for this study. This was important in order to ensure the involvement of all participants in the research process. Another advantage (for me as the researcher) in this situation was that group members, because of their familiarity with each other, were able to assist me with individuals whose speech and communication method I had difficulty understanding.

In analyzing the text of the discussion, I chose to use primarily a meaning categorization method as described in Kvale (1996). The initial categories came after repeated readings of the text and sub categories were isolated from the main categories. I have also made an effort to not decontextualize statements and stories excessively, so as to maintain the narrative quality of some of the stories (or more accurately, vignettes) I was told as well as the flow of the discussion process.

Sample

A group consisting of 18 people self identified as intellectually disabled was self selected from the self-advocacy committee of a local Society for Community Living. The group was
made up of 12 men and 6 women and their ages ranged from 25 to 58 years old with the median age being 46 years old. Of the members, 13 people lived independently in the community (including one man who lived with his wife and child), 2 lived in group homes, 2 lived with family (parents or siblings) and 1 lived in a proprietary care arrangement. While the group was fairly homogeneous in terms of culture (the majority if participants were white), it was fairly diverse in terms of life experience. Some participants had previously lived in institutions or group homes before living independently whereas others had always lived in the community. Some had gone to exclusively segregated schools while others had attended integrated programs. Others had spent many of their adult years in sheltered vocational/training programs while some members had competitive employment, either currently or at one time.

The discussion session lasted for 1 ¼ hours and was videotaped as well as audiotaped. The audiotapes were transcribed and checked against the videotape for accuracy. Since a number of people in the group did not read, the group decided that they would prefer to review the videotape rather than the written transcripts. The preliminary results and analysis of the findings (in the form of a poster presentation) were also reviewed by the group and found to be accurate. The final version of this study was presented to the group, as well as a plain language summary, and further plans for its distribution and publication have been discussed.
Interview Narratives

Introduction

For the individual interviews, I used a narrative style of analysis and presentation. My interest in a narrative approach developed while I was analyzing the data from the preliminary study. The participants frequently used stories to illustrate the development of their opinions and beliefs and I often felt I was doing these stories a disservice by reducing them to phrases and 'codes'. I used the information from the interviews to discover the issues and motifs which are important to the informants, not to confirm my own beliefs and hypothesis. This choice of analytic method also reflects my desire to dispel the myths about people with intellectual disabilities being unable to understand and discuss the issues which affect them.

My analytic method falls under the broad heading of phenomenological inquiry, in that I am studying a phenomenon (life with an intellectual disability) and that I am doing so in order to begin to understand the experience and its underlying essence (Creswell, 1998). According to Creswell (1998), phenomenology is:

a return to the traditional tasks of philosophy - that is, "a search for wisdom".

a philosophy without presuppositions - the researcher "brackets" her judgments and takes her meanings from the data.

accepts the intentionality of consciousness and refutes the subject-object dichotomy - objects exist only as they are perceived and that perception occurs within the experiences of an individual. (pp 52-53)
The work of the phenomenological researcher begins from the first interview as she sets about to immerse herself in the data to discover the themes and reduce them to their essential nature (Tesch, 1990). Through this “dialoguing with the data” (Tesch, 1990 p. 93), the researcher can arrive at interpretations which then give the reader an understanding of the lived experiences of the respondents (Creswell, 1998).

In my reading on this subject, I was struck by the diversity of approaches which fall under the label of narrative analysis. From rambling life histories to highly structured linguistic accounts, narrative techniques run the gamut. As such, it is difficult territory for a novice to navigate, but there are some categorizations of styles which I found helpful. Booth (1996), writing from a life history orientation, describes five types of narratives:

- *autobiography* - self authored accounts,
- *reminiscences* - recollections of particular events,
- *life review* - an evaluation of one’s experiences,
- *life story* - as described to a writer, and
- *life history* - a life story augmented by information from other sources.

Mishler (1995), on the other hand, breaks narrative analyses into three groups:

- *reference* - which emphasizes the representation of events in a particular order,
- *structure* - which investigates the story text and language used, and
function - which studies the purpose of stories.

However particular techniques are categorized, narrative accounts are useful in research for several reasons. According to Booth (1996), narratives give us a glimpse inside an individual “by treating people as ‘expert witnesses’ in the matter of their own lives” (p. 239). They also provide a ‘reality check’ for theoretical ideas by showing the lived experience. Narrative accounts provide an alternative to depersonalized and generalized studies by keeping the individual as the primary focus. According to Riessman, narratives are “useful for what they reveal about social life – culture ‘speaks itself’ through an individual’s story” (1993 p.5). The highest purpose of the narrative, however, may be the feeling and ultimately, understanding it invokes in the reader. As Goodley says:

We understand an official document intellectually, yet the human document is comprehended emotionally. Empathy accompanies insight – we know another’s life because we feel it. As the informal, anecdotal and personalised elements of a story are internalised, then I would argue that these very qualities provide a direct route to social understanding. (1996 p. 335)

It is my intention that more “social understanding” comes as a result of this study.

I have chosen to follow a derivation of the Labov/Waletzky model of analysis (1967, cited in Mishler, 1986a) as discussed and refined by Mishler (1986a, 1986b) and as followed by O’Neill (1995). According to Mishler (1986a), a narrative “contains the sequence of socially meaningful acts without which it would not be a story” (p.
These stories are made up of components which can be broken down in the following manner (Mishler, 1986b):

- orientation - the description of the time and place of the event,
- abstract - a summary of events,
- complicating action or plot - the action of the narrative,
- resolution - the consequences of the actions,
- coda - the final evaluation.

After repeated readings of the interview transcripts, I found what I consider to be the key stories or core narratives in each interview. These stories were broken down into their basic elements (orientation, abstract, plot, resolution and coda) and they serve as the 'thumbnail sketches' for the larger narrative. Using these core narratives, I identified the key issues in each and then used additional material from the interviews to elaborate on these themes.

Sample

I selected four people from the original focus group for the individual interviews. I did this deliberately and for reasons similar to those I used when selecting the focus group participants. Because of the time and resource constraints on my research, I could only do one interview with each person. I decided that, in order to maximize the effectiveness of the interviews, it was preferable to interview people who were already familiar with me and my research.
The four people I interviewed ranged in age from forty to sixty years old. Two were women and two were men. Two had lived in the local regional institution for people with intellectual disabilities as teenagers while the other two had always lived in the community. I selected them specifically for gender and for having lived in an institution or not in order to ensure that those experiences were represented. At the time of the interviews, all were living independently in their communities in rented apartments with little if any paid support staff directly involved in their lives.

The interviews ranged in length from forty-five to ninety minutes. They took place in the participants’ homes or in local restaurants. The interviews were audio-taped and transcribed by a professional typist. I built my interview guide (see appendices 2 and 4) from the information I was given during the focus group. The themes and issues raised by the group participants provided the general guidelines for the interviews, but I did not use them in a ‘question and answer’ format; they functioned more as prompts in situations where the interviews slowed down.

For the most part, the interviews were unstructured. I began each of them by briefly going over the highlights of the focus group discussion and then asking the participants if they would elaborate on the issues and experiences that were important to them. I then left it to the individuals to decide which issues they wanted to discuss. In some cases, many different areas of concern were covered, in others the discussion was more focused.
interview, for example, I referred back to the interview guide several times in an attempt to move the interview along when I thought a topic had been sufficiently discussed. Bob, on the other hand, made it clear he had not finished with a particular topic and always brought the discussion back to it.
Findings

Focus Group

Issues:

NOTE: Comments in [] are mine for the sake of clarification.

Employment and the difficulty finding competitive jobs were significant concerns among the respondents. Everyone in the group indicated that they would prefer to have "real jobs" rather than sheltered vocational programs or, for some, continued unemployment. Many group members talked about discrimination in the labour market as a reason for their lack of employment.

Miles: My experience, too, that I applied for a job being a janitor and he didn't look into my eyes when he talked to me. He never looked at me and then he said he didn't need me. He didn't really look at me when he was talking to me.

Tina: So, you think he didn't really look at you because you have a disability?

Miles: Yes. That was a long time ago.

Another member had this comment on the situation:

I would like to see employers, you know, like the people who hire people to work in different companies, to hire more people with disabilities. Because right now, there is that big barrier in the way of, you know, they just look at us, because they just look at our disabilities, they don't look at us as people...

The problems faced by intellectually disabled people in the workforce were summed up in this way:
Tracey: It’s tough competition out there for people who don’t have a disability looking for work and people who have a disability and they are looking for work and it’s a vicious cycle.

Lisa: And the people who don’t have the disability get the job

Tracey: and the people who have the disability don’t.

The discussion about employment led to comments about the income support programs people used and their difficulties reconciling the two:

Right now people are kind of afraid to look for [a job], either they don’t get hired because they have a disability or, if they get hired, they are afraid they will make too much money and then it screws up their [welfare] cheque. Because that’s the way it is right now. You are only allowed to make so much over your cheque and then they take it off you.

Many people cited a need to have an income support program which did not penalize people for having part-time or casual work and that recognized that people with disabilities often have additional expenses related to their disabilities:

...they don’t realize that that people with disabilities, they have extra needs, some may have more needs that others. Some may have high medical needs, they might need special diet and they [policy makers] don’t take that into consideration...

Others in the group felt the current rates for income support were inadequate. One respondent put it quite succinctly when he said,

everything else goes up but our cheque didn’t go up, yeah.

While the word poverty was not used by the participants, the implication was clear when others discussed the effects of small
rent increases and the cost of non-prescription (and therefore, not covered through medical benefits) medications such as cough syrup.

Robert: but then you have to pay for the rent out of our own money at the time because some people pay $30 more if they move out at the time and then someone new moves in at the time.

Tina: So a small rent increase or something can mean the difference between whether or not you can stay in that apartment anymore?

Several people: yes, right, that's true,

One participant made this observation on the state of his finances:

...but most of us are living on our own. We’re paying everything out of our pocket. And what are we left with? Nothing...

The discussion then segued into tales of experiences with the bureaucracy and social workers and financial assistance workers in particular. As a social worker, I was quite distressed to hear stories of denial of services, paperwork jungles and accusations of dishonesty:

Elizabeth: Sometimes I get into trouble with [ministry responsible for income support], sometimes they don’t believe us, we are handicapped. [murmurs of agreement from the group] I went to [the ministry] I used to have a fellow and I told him “I’m handicapped and I can’t read,” he said “I don’t believe you” really....

Jon: isn’t that something?

Tina: Does that happen to other people?

Others: Yes, yes.

Another woman’s comments about similar experiences reveals a lack of understanding of and support for her disability:
they say I’m lying, that’s what they tell me, and that really hurts deep down. I know I can’t keep my story straight, but they shouldn’t say I’m a liar.

Many of the participants had ideas and suggestions on what could be done to address these problems. One man suggested that more information on services and rights be available in plain language formats. Several members mentioned sensitivity training for social workers and financial workers. Another man felt that training regarding disability issues should be part of social work education:

... part of it should be taught at the teaching level, like where [the interviewer] is now. Like we should actually get some part of a course where they take people like us and learn to work with them...

At several times during the discussion, I brought up the subject of support in an effort to gauge the members’ feelings and desires on the types of support they received. For the most part, little mention of paid support workers was made, except in terms of specific tasks such as finding employment. Most of the support the participants identified came from family and from peers:

Jon: Well, Bob and myself and Tracy and Billy were on the [provincial community living association] self-advocacy caucus and we kind of support each other with different things.

Tina: So, you guys sort of help each other a lot?

Others: Yeah.

Jon: And as well as our self-advocacy group here.

A major theme among the members of this group was a concern about safety and violence in their lives. All of the participants identified issues about safety at home and in the community:
Tina: Is safety a concern for people?

Lisa: Yeah. Like say if you’re walking by yourself make sure you are in a lighted area.

Tina: Do people feel unsafe when you are in the community?

Lisa: Yeah, all the time.

Several people shared stories of sexual and physical violence and also identified a lack of support as a compounding factor in their experiences:

Jon: I was one time sexually abused in a private boarding school and when I left the boarding school I was 16 and I thought it was over. I was learning a lot through the history [of that school] that came opened and unleashed a lot of emotional side effects about my being abused. I went through a survivors group, but then it’s not, like, good enough because you have to be put on a waiting list for [other programs]. What we need to have is ... a survivors’ group for those who have been physically, sexually and emotionally abused.

Tina: For people with disabilities in particular?

Jon: Right.

Many of the respondents related incidents of violence or threatened violence they had experienced. The perpetrators were caregivers, family members, schoolmates and strangers:

...When I was younger, my brother-in-law tried to rape me and at the time there was only the police officers, there weren’t any lady cops, and they just laughed it off; they thought I was asking for it.

OK, One night I was waiting at the bus stop. I was by myself and two kids came up and started throwing stuff and spitting at me and I had a good friend across the street. She walked over to the phone booth and phoned the RCMP. I’m a smart fellow.
There were many more stories of this type told. It was clear that violence and the threat of violence is an ever-present issue in the lives of the participants. One man summed up this feeling when he said,

sometimes you’re just scared to go out, you know?

Another theme which became apparent in the discussion was one of too little control over certain aspects of life. Housing, for example, came up several times as an issue which people had difficulties with. One man explained his situation, with help from a support staff:

Staff: Richard lives with caregivers and they sort of move around and now, you’re worried about what? They don’t have enough buses at night?

Richard: No, not enough buses.

Staff: They move, he doesn’t choose where he goes and he ended up some place where there is no bus service. Right, Richard?

Richard: Yeah, yeah.

For people who may require more support with daily living activities, the ability to make decisions about major issues may be limited. A solution to this situation was mentioned by one of the participants,

when we get our own separate system in place, we will get the services we need. We can hire the people we want to hire, not the people the government wants to hire for us.

This is a reference to individualized funding schemes which have been suggested for many years as a way putting people with disabilities in control of their services and their lives.
Through out the discussion, an overriding theme was evident; a demand for respect. This was apparent during the discussions on employment and discrimination, problems with the bureaucracy, violence and self-determination. It was also stated clearly and unequivocally at many times:

Treated like a person, not a piece of dirt, right.

Treat us with respect.

That’s the way I feel. The whole system lets you down. They don’t treat anyone with respect...

When I asked what it would look like to be treated with respect by a social worker, a woman had this to say:

That would look like, OK, that means that they totally won’t think of your disability anymore. They will think of you as a person. They will sit down with you and say, “Well, Tracey, what do you need in your life and how do you like them?” and stuff like that. You know, treat you like a person.

The implication of this statement is that this is not the usual course of events when meeting with a social worker, which has important ramifications for the quality of services delivered and the profession.

Comments:

It is evident from the analysis of the discussion that an understanding of the social constructedness of disability existed within the group. Without using those words, the participants made
it clear that they were aware that the difficulties they face as people with disabilities were due, in large part, to other peoples' attitudes about disability and government programs and policies that are disabling and not an inherent condition of their disabilities. The statements made about discrimination in the labour market, inadequate income support, violence and lack of respect from government workers and others show the consciousness that their problems are in fact examples of oppression.

There was also a sense of entitlement which the group expressed. This group did not have any difficulties making claims (as discussed earlier) against the state and society in general in terms of rights and support services, for example, income support. As well, some members of the group also felt that the right to control those services was theirs to claim. This is an important consideration for policy makers and service providers. Policies and programs which are developed without the involvement of people with disabilities are becoming less acceptable to them. Several people in this group are also involved in larger advocacy organizations and are actively demanding a role and a voice in the establishment of policies and programs that affect them.

The group interview method also afforded the opportunity for me to witness and document the power of associations between people with intellectual disabilities. The group sense in the discussion session was very strong and I feel that it was only because of this cohesion and sense of mutual support that I was given the information I received. This is especially true regarding the very
personal stories of abuse and fear I heard. I feel that it is, in part, through the group process that these individuals were able to have come to the point where they could so clearly and unhesitatingly tell me what their issues and complaints were. This supports Chappell's (1992) contention that it is through associations that people with intellectual disabilities can organize to make claims.
Interview Narratives

The interviews the following narratives were taken from were each disparate and at the same time, strikingly similar. The interviews were unique in that, obviously, each person had his or her own stories to tell and each participant had a singular perspective on what it is to live with an intellectual disability. Yet, despite the differences, each respondent expressed similar concerns. Although each example was distinct, all the participants told me stories of abuse they had experienced. Tracey’s complaint that she felt a lack of respect when dealing with social service workers is, in my mind, a variation on the same theme Bob raised when describing how social workers failed to help him find an alternative to his abusive living situation. As well, while Janey and Franklin had very different feelings on their experiences of life in the institution, both stories showed how significant those years were (and still are) to them.

I have included the line numbers from the original interview texts to indicate at what point in the discussion particular comments were made. In some cases, the narratives were in continuous sections of text. In others, however, I had to ‘construct’ the narrative, taking bits and pieces from different parts of the interview. This was the case in Bob’s story, in particular because of the repetitive nature of the interview; details about his specific narrative were scattered throughout the interview.
I have gone to great lengths in the process of organizing and interpreting these narratives to not over analyze or 'psychologize' them. Part of my goal in bringing these stories forward has been to let the words of the participants stand for themselves as much as possible, for I believe that their words are more powerful than mine could ever be.
Bob

Bob is a forty-eight year old single man with an intellectual disability who lives independently in an apartment he shares with a room-mate and his pet bird. Until his mother died seven years ago, Bob had lived with his parents since his birth. After his mother’s death, Bob was placed with several different families who acted as his care givers. Bob was not happy with these situations and eventually decided to try living on his own, which he has done successfully for several years.

My interview with Bob lasted for 50 minutes and, despite my efforts to steer the conversation on to other topics, always came back to the story of his experience of abuse in one of these family care homes. Bob was placed in this home for two weeks shortly before his mother’s death while she was very ill. This experience may have been brief, but it was obviously a key period in his life and it serves as the foundation for the core narrative of Bob’s story.

Core Narrative: They Just Use You

Synopsis: While his mother was ill, Bob stayed in a family care home in fairly isolated, rural area for several weeks. During this time, Bob had his medication withheld and was subjected to physical abuse. Bob felt that his social worker should have known what was going on in the home and should have helped Bob find another
placement. Bob was trapped in the situation until his mother recovered sufficiently for Bob to return home, at which time she assured him he would not have to return to that placement.

Orientation:

97- I don't know what I would do if anything happened to [my mother], I might have to go somewhere.

Abstract:

442- you see they put you in there and they think, well, we will take care of that.

446- You know what caregivers are like, they use you, you know.

703- I guess they must have knew about it, [the social worker] knew about it—so there is something wrong there, isn't there?

712- You just don't do that to people, that's going too far.

Plot:

157- she took my pills away from me and I even told the doctor, and I reported her.

681-684 I thought it was like a—like a gun that he had and when I told her she says you are lying. I says, all right, you don't believe me, ask your son. And then she— and she did that and she punished me.

182- I reported her.

392- I was just ready to, you know, to leave, but I couldn't get anywhere, you see.

413- And it was time, I guess, to get out.
414- There was no way I could get out.

Resolution:

177- And they did, Tina, at the end, they found out what [the caregiver] was like.

193- And [my mother] said don’t worry Bob you will never go out there again.

Coda:

212- I was sure glad to get out of there I can tell you that much.

Issues

Experiences of abuse: The single most significant issue in Bob’s story was his experiences of abuse and threatened violence, while in the first family care home and in other living arrangements. Bob gave this summary of his thoughts on the original placement:

she took my pills away from me and I even told the doctor, and I reported her. She didn’t like anybody swearing. Well, lots of people swear. But boy was she a smoker. It was just like an old farm house, you know.

As we started to discuss specific events, Bob reported that extreme consequences were used to ensure he completed his ‘chores’.

I didn’t have any supper—no, lunch until I got that work done. Now, do you think that’s right doing that?

Bob also related that he was victimized by the caregiver’s son while he was living there.
And I know darn well he brought that whip in, it was something that they use on the horses... and the kid brought it in and he started using it on me. Yeah.

Bob also talked about an exploitive situation he was in while living in another family care home after his mother’s death.

well, when I couldn’t look after myself with the banking, you see they would take my book away and [said] we will take care of that.

Rather than help learn to Bob manage his money more effectively, his care givers took over his finances completely and did so against his will.

As well, Bob had this experience while staying in a group home while his parents were on vacation:

Well, they had these—these miserable nuns, you know, and one of them got mad and smacked me ... Now they are not allowed to do that ... lay a hand on anybody. Now, that was going too far.

For Bob, every living arrangement other than his parents’ house and his own apartments, was fraught with abuse and frustration.

Lack of choice: Throughout the interview, Bob made reference to being in situations he had not chosen, or had changed his mind about and could not escape from. In relation to one residential placement he was in, Bob said:

I think I was there [in a family care home] for two years or three years. But I sure didn’t like it out there.

Bob also made this comment regarding another situation:
I had—I had a chance to try somewhere else and I said now what have I got myself into.

There were several points in the interview where Bob said that he felt trapped in circumstances,

And it was time, I guess, to get out. There was no way I could get out.

but could not find an alternative.

I was just ready to, you know, to leave, but I couldn’t get anywhere, you see.

Bob’s feelings of being abandoned by his mother and by his social workers seemed to express themselves through his repeated references to these situations.

Relations with Social Workers: Several times in the interview, Bob mentioned situations where social workers were helping him or should have helped him.

the Ministry was helping me ... I was hoping to get out of there because I hated this place.

Yet Bob remained in this particular placement for "two or three years".

Bob was not always fully involved or informed about plans being made on his behalf by social workers.

And they [the social workers] were trying to find a place for me, but I didn’t know what was going on.
Despite Bob’s attempts to report the care giver in the first family care home he was in to his social worker, it was ultimately Bob’s mother (who was quite ill at this time) who helped him.

And [my mother] said don’t worry Bob you will never go out there again ... and made sure.

For the most part, Bob was let down by his workers, either through slow responses to his requests or by simply not being there for him.

Well, I had one on ***, she was a good one. They did switch a lot of those social workers, financial workers, the time when you want to get them they are busy or something.

Despite this lack of support, Bob was quite aware that he was being neglected by his workers and that it “wasn’t right”.

I guess they must have knew about it, [the social worker] knew about it—so there is something wrong there, isn’t there?

Distrust of caregivers: Bob’s experience with respite care and later with family care led to his cynicism regarding the motives and intentions of caregivers.

You know what caregivers are like, they use [you], you know.

Later in the interview, Bob repeated his opinion.

And they just use you, you know.

For Bob, the only way out of this problem with abusive and exploitive caregivers was to advocate for himself with them and with his social workers.

And I was so mad [at them] you know, [I decided]I’m moving out, you know ... I was sticking up for my rights.
And boy, I sure—I was sure glad to get out of there.

Independent living was the solution for Bob.

TINA: So how is it now living independently?

BOB: Very fine.

TINA: Yeah.

BOB: Very good, you see. That's when you get out—when you are on your own you can do it.

For Bob, having his own place and managing his own affairs have been rewarding experiences.

BOB: … when you live on your own and you are independent that makes a difference and that's the way it goes, you see.

TINA: It makes a good difference?

BOB: Yeah, that's what I say,

Comments: Bob was thrown into a confusing and sometimes frightening period after his mother's death. He was shuffled between different caregivers who did not meet his needs or expectations, or simply allowed him to be exploited and abused. The social workers in his life did not provide him with the support he felt he should have had in these situations and he often felt isolated and trapped. Bob, however, persevered and eventually managed to take control of his life by finding his own place to live where he felt happy and safe.
Tracey

Tracey is a forty year old woman with an intellectual disability who lives independently in a comfortable townhouse in a housing cooperative. Tracey is a dedicated collector and her home is filled to overflowing with memorabilia from trips, Elvis iconography and garage sale acquisitions. Tracey is also a tireless self advocate and is involved in numerous activities and committees with her local society for community living as well as the provincial organization.

The subtitle for Tracey’s story is ‘you live and learn’, a title she suggested towards the end of the interview. It accurately sums up Tracey’s story which is one of taking chances, making mistakes, learning from them and then moving on. It is one of these experiences which serves as the core narrative of her story.

Core Narrative: You Live and Learn

Synopsis: When Tracey was much younger, she needed a place to live and decided that her only option was to move in with her former boyfriend and his current girlfriend. Tracey was receiving income assistance at this point and what little money she had was going to her ‘roommates’ to cover their expenses. The living arrangement was not a happy or comfortable one for Tracey, so she and a friend decided to find a place of their own. They found an apartment which
was run-down but at least affordable and allowed Tracey to begin to take control of her own life.

Orientation:
852- at the time I didn’t have my own place
858-60- I didn’t have anywhere to live so my ex-boyfriend had an apartment down on *** Street and he was letting me live there. And his girlfriend was living there...

Abstract:
869-73- I was giving him all my money, all my—I was on disability, I was paying him rent, paying him the—paying the bills, buying the groceries and she is laying on her—her fat ass on the couch eating everything out of house and home and bossing me around.

Plot:
883-86- And one pouring down rainy night, it was a Saturday night, and [my friend] and I just got fed up, you know, with the situation and we just said, I don’t know about you Tracey but I get—[my friend] says I am getting the hell out of here.
892-3- And then [my friend] said, well, Tracey, you are on [welfare] and I am on [welfare], let’s do something together.

Resolution:
895-6- So pouring down rain we went looking for a place. And even though it was a dump it was ours.

Coda:
865-6- you might think I am really stupid like, Tracey, how could you do this...
868-9- I can see it now but at the time I didn’t.
Issues

Difficulties with income support: Tracey talked a great deal about the income support system she has had to deal with since she was a teenager.

I have been on what do you call it, the Ministry treadmill—on welfare

In addition to inadequate benefit levels which have forced her into less than satisfying living arrangements over the years, she commented on her frustrations with the bureaucracy of the system:

when you go in for the yearly review, you know, they ask all these silly questions, stocks and bonds and, you know, how much you got in the bank and all that. And I answered all of them. And I said, you know, if I had all that I wouldn’t be on—I wouldn’t need to be on my [disability] benefits cheque, you know. And he goes, he says, yeah, I know but I still have to ask all these questions.

Tracey also felt that workers in the system were not necessarily trustworthy and that she could not be completely honest with them for fear of reprisal.

…it is kind of like a stigma, you know, that social workers and financial aid workers you just tell them what you have to tell them but don’t tell them anything that you do in your personal life because, I don’t know, you are always afraid that, you know, they might use—turn that around or use it against us or something.

A bigger issue for Tracey, however, was the stigma and bias she had
not everybody, um, that walks into the office is, you know, is a bad person, you know. Or they [workers] have in their mind that we are all on welfare, that’s what I got, she was ... treating me like I am on welfare. And I am not saying people on welfare are all bad and people on disability are better than them, but we are two kinds of cats. And I think they really have to do this [change these attitudes] right away, I don’t know if they can put a rush on it but to tell the people that are working in that office that you’re not just dealing with people on welfare, you are dealing with people with disabilities, and you know, you might—you might be hurting their feelings, you know, the way you are treating them.

This quote illustrates exactly how well Tracey has heard and internalized the message that welfare is ‘bad’. Tracey wanted to make it very clear that that she was receiving disability benefits and not welfare. For Tracey, this difference was particularly important because at other times in her life she has received both types of benefits and understands the stigma of being ‘on welfare’.

*Abuse and exploitation:* Tracey’s story, as do all the interviews, also contained accounts of abusive and exploitive situations she had experienced. For Tracey, it began with her mother when she was a child.

well, my mom was really mean to me from day one.

And, um, so I moved out when I was 18 because my family life wasn’t—it wasn’t very, um—my mom was hitting me a lot at home and it wasn’t very good for
me, I was very depressed and—I tried—one day I just had it and I went—because my mom was—one time my mom came at me with a butcher knife and my sister got in the way and she ended up getting cut. And one day I just went in and got a knife and I just tried to cut my wrists and my brother ran in—my brother ran in and saved me. But my brothers didn’t really know what was happening to me because they were always out with their friends and it was kind of like I was alone in this situation.

Tracey moved from her family home into a place with her boyfriend and several years later lived with him again in the situation described in the narrative. Even though she was involved with him off and on for many years and still considers him a good friend, she made this comment on the relationship:

Because my ex-boyfriend he was just, you know, everything for Bill and nothing for Tracey.

Tracey also related this tale of harassment she endured while living in a rented apartment.

TRACEY: And I had a ... landlord and I don’t know it seemed to get in his head that because he is giving me cheap rent that he could have liberties with me.
TINA: Liberties?
TRACEY: Well, trying to—wanting me to have you know what with him.

Support: In Tracey’s story, her support came from her friends and occasionally, her family.

My younger life, well, my boyfriend helped me out a lot ... And he helped me manage the little money I had because I didn’t—I was on welfare at the time.
Tracey also found encouragement through her association with advocacy groups.

if I need support, um, the people at [the provincial advocacy organization] are very understanding.

Tracey’s friend encouraged and helped her to apply for membership in the housing cooperative where she had lived for the last ten years, as well as helping Tracey leave the situation she described in the core narrative.

Nowhere in her story did Tracey talk about receiving any concrete support from the social workers in her life. As a matter of fact, social workers did not seem to play any kind of significant role with Tracey, despite the fact that she had been assigned a worker for many years. In Tracey’s experience, having a good worker was a matter of luck.

TRACEY: I hear it, I mean I get treated like that [disrespectfully] and some of my other friends they are lucky if they have a nice, you know, a nice social worker or [financial worker]. And if they are then you are darn lucky.

TINA: Yeah, so yeah, exactly it comes down to luck rather than you going in and being able to expect to be treated—

TRACEY: Right. (Laughing)

TINA: -- in a respectful manner.

TRACEY: Right.

Tracey also pointed out the ultimately irony in this situation:

Because like I say if it wasn’t for us they would be out of a job, you know.

Self Advocacy: For Tracey, it was been her involvement in
self advocacy which provided direction and strength in her life.

And I am very involved in my self-advocacy stuff too. And that's helped me a lot too, I used to be really shy. And [my friends], um, first told me about the self-advocacy committee at the old drop-in centre and I joined that and eventually I became the chairperson. And then I got involved with [the provincial organization] and I ran for their board and I am on their board again now and on different committees too so—so all of that stuff helps—I feel that it helped me a lot ... It helped me stand up for myself and others like myself.

Tracey had a vision of herself as an advocate for other people with disabilities and was very committed to assisting her peers whenever she could.

TRACEY: Well, they kind of look up to me at the drop-in, Wendy and Elizabeth and Susan and her sister Joanie and sometimes Dale, if they have problems and I say, well, they kind of look up to me as a kind of a counselor that—not in a professional way.

TINA: Um-hum.

TRACEY: And I say don't worry, I won't say anything, you know, just tell me what's the matter. And I notice that the staff there kind of realized that they kind of look up to me in that way, you know, that they can talk to me as a friend and you know I won't—I will give them my opinion but I mean I won't tell anyone else. But that kind of works a two-way street, like if I have a problem like I mention it to them and then they can help me and I can help them.

Tracey was also involved in educating the non-disabled community (as her participation in this research attests) about issues important to people with disabilities.

TRACEY: So I do guest speaking ... at [a local] College, and we have done—we have also gone to some private group homes, um, and done guest speaking [at
disability] rights workshops.

TINA: So mostly for self-advocates—

TRACEY: Yeah.

TINA: -- and other people with disabilities?

TRACEY: Yes. When we went to [a local] College we also had students like yourself in the room and also professionals too.

Tracey also spoke of her efforts trying to educate various community services on the issues particular to people with disabilities.

Yeah, we are trying to get, um, we tried to get, um, advocacy into the professionals too, the police, ambulance drivers, the firemen, the hospitals, because we feel that's very important that they know how to treat people with disabilities.

Tracey credited her experiences and growth in the self advocacy movement with enabling her to manage her life better and to deal with frustrations and challenges more effectively.

TRACEY: And I get along better with my mom now ... but still let her know that she can’t hurt me anymore because I will do something about it now.

TINA: Right. Right.

TRACEY: Yeah. And at the same time I let her know if she ever needs any help, you know, that—because I am connected to—I could get her connected to seniors—senior centres and stuff, you know, at the same time so—so she, you know, she says, oh—she says—she says she needs help with this or that I say oh, mama, let me help you.

Tracey summed up her attitude in this way:

...there is no use just—you know, dragging the past with you. Sometimes you have to move on. I feel like I have kind of moved on, yeah.
Comments: In some ways, Tracey is among the least successful of the individuals interviewed, at least by non-disabled standards. Tracey does not have a job and she is receiving income assistance, as she has for most of her life. For this reason alone, many would dismiss her as non-contributing and residing on the margins of society. Yet, she has managed to work through and grow from her past difficulties and make a comfortable life for herself. She volunteers her time and talents to the self advocacy and community living movements without hesitation. Tracey participates in the activities of her housing cooperative and takes great pride in her community work. She has loyal friends whom she supports and who support her. Tracey is, in my opinion, one of the most 'successful' of all, by any standards.
Franklin will be sixty years old this year and he currently lives in a rented apartment he shares with a room-mate. Franklin works part-time in a competitive job and his income is supplemented by disability benefits. Franklin has lived in the community for the majority of his life, save for a seven year period in his teens when he lived in the local regional institution for people with intellectual disabilities. Prior to that period he lived with his family and immediately afterwards he lived in a family care home for many years before deciding to live independently. Franklin has been involved in self advocacy for many years, both at the local and provincial level. He is also an active member of the Toastmasters' public speaking organization and a fan of many forms of live music.

My interview with Franklin was the most difficult of the four I conducted. Throughout the interview, I thought him to be somewhat detached from the events he was describing. At one point, after he had spent some time describing his experiences at the institution, I realized I had no idea how he actually felt about living there. I finally asked him specifically whether or not he liked it there and he told me "not really — it wasn't a place where I would like to live". I wondered whether or not Franklin actually wanted to do this interview, or if he felt pressured into it. I had taken great care discussing the research with him and had read through the consent letter with him to ensure he understood and agreed with the process. As well, Franklin was a willing and eager
participant in the focus group discussion the year before and, as a result, was familiar with my work. While I am confident that I did not coerce Franklin into participating, I am still not absolutely sure that my being non-disabled (and, as a result, something of an authority figure) did not play a role in his decision. This concern was heightened for me when I divined the core narrative in Franklin's story and I began to see what I consider to be a subtle pattern of deferral to non-disabled people in his life.

Core Narrative: You Have to be Nice

Synopsis: After living in the institution for most of his adolescence, Franklin moved into a family care home. Franklin expected to have more freedom in his new home than he had in the institution, but found that his new caregivers also had strict rules regarding his conduct. As well, Franklin also suspected these caregivers of taking control of his money and keeping any surplus he may have had. Despite these concerns, Franklin stayed with these people for approximately twenty years, until he moved out into his own place.

Orientation:

108-11- But I stayed there [in the institution] until—until I was ready to go because what I understood my parents found a place with a couple that lived [nearby] so that was my home away from [the institution].
Abstract:

149-51- You know, because I wanted a little freedom and do something, you know, like, you know, visit friends and do things like that.

Plot:

127-132- They seemed to be nice. But when I was going to that shelter workshop on *** Street and when I got paid, what happened is I thought I could keep the envelope myself with the money in it, but apparently they were looking after my money and I just took out what I needed. I guess and they kept the rest.

151-5- And I don’t know, this is something—I don’t know what this woman—what this lady was thinking of because when I was—when I was—when I was having a social with a girl she thought that I was having sex with her and I was never able to see her again.

Resolution:

112- So I was—I lived with them for I think it was about 20 years—

134-6- So, you know, when I lived on my own, you know, I didn’t have that problem because I thought that money was mine and mine alone and I could do whatever I want with it …

Issues

Abuse: Franklin’s story contained recollections of abuse he experienced at the hands of caregivers. As he described in the narrative, his caregivers took control of the money he earned at the sheltered workshop.
I thought I could keep the envelope myself with the money in it, but apparently they were looking after my money and I just took out what I needed. I guess and they kept the rest.

These same caregivers also kept Franklin from having relationships with women he was interested in because of their fear that he may have become sexually active.

when I was having a social with a girl, she [the caregiver] thought that I was having sex with her and I was never able to see her again.

Franklin was quite upset by this attitude, but he did not report it to his social worker.

I never talked to anybody about this, not even to a social worker or things like that, you know. So I had to find somebody else, you know, that really upset me that I [couldn’t] continue on with a relationship, you know.

Despite these frustrations, though, Franklin stayed with these caregivers for approximately twenty years.

*Relations with social workers:* Like his peers in this study, Franklin did not have a great deal of positive feeling for the social workers he has had in his life. For the most part, social workers simply did not play a significant role in his life.

FRANKLIN: I had another fellow too but he had to move to another Ministry area and his name was *** but I never talked—talked with my social worker that I have now.

TINA: Really.

FRANKLIN: Yeah.

TINA: Have you met him at all?

FRANKLIN: I can’t remember if I did or not.
Franklin also expressed frustration (or resignation) with the amount of turnover among social workers.

I have never been able to get—or I never talked with my social worker because social workers keep changing sometimes, you know.

Deferral to non-disabled people: As I mentioned previously, the most striking feature of this interview for me was Franklin’s lack of emotion while relating his experiences. I found this very difficult to understand until I had gone over the interview transcript many times and slowly began to see what I now understand to be a pattern of deferring to and apologizing for non-disabled people throughout his life.

In our discussion about his relationships with his social workers over the years, there was this exchange:

TINA: So the social workers haven’t been—it sounds to me like they haven’t been that important for you.

FRANKLIN: Well, it is not that they are not important, I never sat down and talked—talked down with them, you know, but I should, I should, you know, because he probably wants to know a little more about me.

Despite the fact that his workers seldom seemed to make an effort to contact him or to provide a great deal of support, Franklin was still willing to make excuses for their conduct. Moreover, he also felt the need to assume that some of the responsibility for this state of affairs was his and that he should be making more of an effort to engage his workers.

Even when describing his experiences with his caregivers
taking control of his personal money, Franklin indicated that he may have misunderstood the situation and that, again, he might have been partially to blame.

I thought that [the] money was mine and mine alone and I could do whatever I want with it and I didn’t know they were supposed to look after that.

Finally, this lengthy exchange which took place about half way through the interview while we were discussing life with his current room-mate, I feel, illustrates Franklin’s attitude quite clearly.

FRANKLIN: And I don’t know, for some reason I understood that if someone is in the apartment you don’t have to lock the door from the inside, do you Tina?

TINA: That depends, I always do, but then again I am a little nervous sometimes, you know.

FRANKLIN: Well, I understood that—maybe this was something I should talk with [support staff] about this because when nobody is there you lock up.

TINA: Yeah, definitely.

FRANKLIN: But if somebody is at home I didn’t think you had to lock it from the inside.

TINA: Well, it depends because sometimes if someone can get into the building, right, they might try all the doors to see if they can break into the apartment. And even if you are home they can still try your door and the next thing you know you have a stranger in your apartment.

FRANKLIN: Yeah.

TINA: That’s why I always lock my door.

FRANKLIN: Maybe, yeah. Because I always have the key to open the door anyway.

TINA: Yeah.

FRANKLIN: Well, maybe it is for safety precaution I guess.
TINA: Because it is a pretty easy thing.

FRANKLIN: You know, because the door was closed, you know, and of course you knocked on the door, you know, so and let you in, but I don't know maybe-maybe you should lock it from the inside. You know, I was just kind of curious.

TINA: Well, that's my thinking on it anyways, that's what I do, yeah.

FRANKLIN: Yeah.

TINA: Don't want anyone wandering in by mistake, you know.

FRANKLIN: Oh, no. Sometimes people knock on the door, you know, but you have to be nice—you know, you have to be nice when somebody knocks on your door but before you open the door you have to say who is there, you know.

TINA: Well, yeah, that's why—so that's why it helps to have the door locked.

Franklin's comment that "you have to be nice" is another example of how he felt compelled to submit to the will of others. He felt it was necessary to compromise his safety in order to not upset a stranger knocking on his door. As well, it is my feeling that, in this conversation, Franklin was looking to me as a non-disabled person, and therefore, something of an authority figure, and asking for approval for his actions. What is frustrating for me is to see how easily I slipped into that role with him.

Comments: In addition to being the most difficult interview to conduct, Franklin's narrative was the most difficult of the four for me to 'divine'. Because he seemed so disconnected from his stories, I had difficulty determining which were most significant. I finally chose the story of his experience in the family care home
because it seemed to me to be most reflective of Franklin’s life and attitudes. Even though he knew his caregivers were exploiting him and denying his rights, he stayed with them for many years, because, despite it all, they were non-disabled and knew what was best for him.
Janey

Janey is forty eight years old and volunteers one day a week as an aide in a nursing home. Janey lives independently in a rented basement suite in a middle class suburb. Like Franklin, Janey spent a number of years living in the regional institution while she was a teenager. Unlike Franklin, Janey enjoyed living there and remembers her time there as the 'good old days'. After she left the institution, Janey moved back to her family for a year. She found it to be very difficult situation, so she moved to a group home and lived there for two years. As in Bob’s account, Janey was not happy in the arrangement and decided to try living independently which she has done ever since.

I found that Janey’s interview was significantly more emotional and dramatic for me than the other three were. Whereas Bob, Franklin and Tracey had all shared painful experiences from their pasts, at the time of the interviews they were all reasonably content with the current state of their lives and their living arrangements. Janey, on the other hand, has found life since leaving the institution to be very difficult and has very little support to help her deal with it. She has developed mental health concerns and is currently on antidepressant medication. Janey’s core narrative is about her desire to go back to the institution where she felt safe and her ambivalence and guilt about feeling that way.
Core Narrative: If There Was an Institution Open, I Would Go

Synopsis: Janey lived in an institution as a teenager and was a young adult when she left. She had tried very hard since then to be independent and manage her life on her own, and though she has been reasonably successful, she has found it extremely difficult. Janey felt fearful of the responsibilities she had and commented that she sometimes wished she could return to the institution where she felt safe and protected. Knowing that she had very few options, Janey felt she had little choice but to continue on the way she was.

Orientation:

408-10- I don’t know if I should say this but I sometimes feel if there was—if there was an institution open I would go.

Abstract:

382-3- I guess I really—since I came out of the institution I got older I guess life is very hard, I find it very hard.

401-4- And I guess in—I guess in [the institution] I figured I was safe, you know. You get out here where there is people that, you know, that harm people and—and, um, but at [the institution] they have those fences and stuff around.

412-4- And I think in this situation that would be the wrong thing to do because that would be a real put-back for me because actually I have learned a lot since I have been out.

Plot:

385-92- Now I have to do all the decision-making and I have to—
Resolution:

394- So I don’t know what to do in that situation.

Coda:

397- But I mean, otherwise I am—I guess I am doing okay.

400- Trying to anyways, yeah.

Issues

Abuse: Unlike many other people with intellectual disabilities, Janey had no tales of abuse from her time in the institution. Janey’s experiences of abuse occurred after she left the facility and was living in the community.

I did live in a group home and that was—I think I told you at the last meeting when—well, it was actually the tail-end of the meeting where the [caregiver] sort of punished me because I had an accident and I didn’t know where to put the sheets.

Janey described the punishment she received:

Well, right after school I couldn’t do anything. She said after supper I had to go downstairs and get ready for bed and that was -- that’s what I had to do for a whole week, I couldn’t, you know, watch T.V. or anything.

Janey was twenty years old at the time of this incident.
For Janey, the worst situation took place while she was living with a room-mate in an apartment when the building manager began sexually abusing her.

It was terrible. I told him it was wrong. He said Janey, everybody is doing it. I thought oh, no. I said, you know, you shouldn’t be married if you keep this up. And he said, um, oh, gosh, he said, I can’t marry you right now my wife—my wife, I am married. And I said, well, I know that. And it was just terrible.

What made the situation even more difficult for Janey was the lack of support and isolation she felt.

And I didn’t tell mom and actually I didn’t tell anybody. I told my roommate and she said that’s impossible because he is a married man and he wouldn’t do it. So we started to get into bigger arguments and fights because of it.

Because I was sort of handling this on my own. And now the social worker we had, you know, she was terrible. She knew for two months that we were having problems. She didn’t come to see us or talk to us or anything. So here I was trying to fight this all on my own.

Relations with social workers: Throughout the interview Janey expressed her dissatisfaction with and disappointment in the social workers she has had over the years.

But, I mean, you know, a social worker who knew for two years who didn’t, you know, didn’t even bother to come out and see us. And then I got this other social worker and he wasn’t any better

JANEY: So anyways that was that social worker and now I have another one who I never hear from, but she was good enough to get me a counselor.

TINA: Okay, well, that’s something, hey.

JANEY: After five years of waiting for a counselor.
I just know I find it very hard right now. And, you know, the social worker really, you know, they really haven't helped me—

And the social worker I guess really doesn't have the time, they always have too much to do or—but I find sometimes, you know, they have to just sit at their office looking at books or something, I don't know. You phone them and they don't return your calls, maybe for two or three days later. They phone you I guess when they feel like it.

Even more frustrating for Janey was the feeling that she had been neglected by workers who relied on her family to do their job for them.

JANEY: And I feel the social worker should get involved in that kind of thing, you know, it shouldn't be left up to the family, my mom has enough to do. So, you know, the social worker should sort of help me on that. And sort of sit down with you and discuss what kind of place you are planning on and look into the rent and stuff like that. But I mean, you know, I have gone through social workers and the one who said that, you know, you've got family, they will help you, you know, that's not good.

TINA: Right. Right.

JANEY: You know, that really isn't good, they should be doing their job, you know.

Janey was also frightened and distrustful of the bureaucracy her workers operated within. She was concerned that, even when she does get help, it may not last long.

TINA: So how long you been seeing the counselor?

JANEY: I would say about four months.
TINA: Yeah.

JANEY: But sometimes I figure, what the heck sometimes, why should I go see her. Um, you know, I am not going to have her for long because, you know, she is paid by the government. And right now they are sort of (laughing) you know, I guess they are having problems with the money so once she, you know, she doesn’t get paid anymore I can’t see her anymore.

TINA: Right.

JANEY: So I am going to have to try to struggle with [this] on my own.

Lack of support: As can be seen in the core narrative, Janey felt somewhat overwhelmed with demands made of her in her life and was worried that she will fail.

But I mean, I find it very hard nowadays because with the decisions I have to make, you know, I think I am going to make the wrong one.

Janey’s response to this pressure was to long for the old days when she lived at the institution and these decisions were made for her. She used the example of having to manage her finances to highlight this:

You know, I had money when I was at [the institution] but it was put in a place where–an account, and, um, now that I have money I spend it. And, you know, I have a hard time keeping it for the end of the month …

All this led Janey into stating:

I sometimes feel if there was—if there was an institution open I would go.

Considering the history of institutions for people with intellectual
disabilities and the disdain the community living movement as a whole has for them, Janey's statement was quite stunning and revealed how desperate she felt.

Janey was extremely ambivalent about this situation, however. Much as she would have liked to go back, she also knew that she had grown and learned a great deal since those days.

And I think in this situation that would be the wrong thing to do because that would be a real put-back for me because actually I have learned a lot since I have been out. And some people say that some of the—I have seen some of the staff that used to be at [the institution] and they say that seeing me now, they said I should never have been put in there.

Janey also prided herself on her independence.

So basically I do a lot of stuff on my own. You know, the grocery shopping and bill paying and stuff like that I do it all on my own.

I think I like living on my own.

As well, Janey felt quite guilty about her feelings and had a sense that her attitudes had separated her from her peers somewhat.

JANEY: ... And I know a lot of people think differently of [the institution] because the girl I lived with hated it.

TINA: Yeah.

JANEY: Absolutely hated it. But she was older and she went—and I guess sometimes I should feel, you know, like the others about [the institution] but I can't.

Janey's desire to return to the institution seemed to derive from her sense of isolation and the lack of support she had in managing her life. Janey was angry about this, but she also seemed resigned
to this state of affairs.

JANEY: ...But I guess that's what it is when you get out of places like that [the institution], I guess you have to sort of try to fend for yourself.

TINA: It might be nice to get some help sometimes though.

JANEY: Yeah. But my mom, she does help me, but I mean, you know, she is not well, and you can't depend on her, I can't. Like my social worker, you know, she should be doing a little bit more than what she is doing. You know, they should phone and see how you are doing ... But she doesn't.

Comments: Janey's story was very frustrating to me as a social worker. Janey was a pleasant, warm, sociable and considerate woman who obviously had a great deal to offer her friends and her community. Yet, because of the lack of support in her life and her crushing fear of failure, she felt overwhelmed by day to day living and would have preferred to return to the cloistered, but protective world of the institution. My frustration comes from the complete lack of alternatives Janey had. The choice between an independent but isolated and painful life versus the total care of the institution (or many other residential options) is not really any choice at all.

Summary

The participants in the individual interviews raised many issues which should be of great concern to all of us. The participants also clearly showed that they are quite aware of their
position in society as intellectually disabled people and what that identity means in their lives. The stories I was told serve to make explicit how popular attitudes, public policy and systematic discrimination play out in individual lives.

Obviously, the most striking of the findings was the extent of the violence and abuse the participants were subjected to. All the interview respondents reported incidents of victimization of varying forms. Another unsettling trend in the interview results was the poor quality of service the respondents received from social service professionals, frequently social workers. The participants had been treated disrespectfully, ignored and neglected by their workers over the years and were clearly unhappy with this treatment. All four individuals told stories of being trapped in unhappy or even abusive living situations because of lack of support or lack of resources (primarily financial) to find alternatives.

On the other hand, I also heard stories of strength and success. Tracey had found her way out of abusive and manipulative relationships through involvement in self advocacy and the circle of supportive friends she had developed. Bob and Franklin both managed to persevere and find satisfaction and autonomy in independent living. Even Janey, who had the most difficulty with her day-to-day life, was continuing despite her fears. They showed their ability to find inner resources in adversity and survive traumas which could have destroyed them.
Discussion

Introduction

The participants in both the interviews and the focus group were quite cognizant of the fact that they are considered intellectually disabled and that this identity has particular consequences in their lives. There was an unstated understanding that they were vulnerable to exploitation, as witnessed by the repeated stories of abuse they shared. The participants were all willing to discuss their needs for assistance in managing their lives and the difficulties they often had finding it. There were several discussions about poverty, especially in the focus group, and how this fact of their lives limited their options and made their lives unnecessarily difficult.

A significant difference between the focus group data and the interview findings was the highly political nature of the discussion in the focus group which was much less overt in at least three of the four interviews (Tracey’s interview was the most ‘political’ in orientation, while Franklin’s was the least so). In the interviews, difficulties were framed as primarily personal in nature. However, in some of these discussions, hints of the larger political picture emerged. For example, while Bob was describing his experiences with abusive caregivers, he broadened his criticism, saying “they just use you”, and implied that people with disabilities can be exploited by their caregivers and in doing so, made a clear political
connection. My feeling is that this is an example of the process which these individuals with intellectual disabilities are going through in terms of their politicization. In the larger group, the 'big picture' was more clear and the disabling role of society was easier to identify, whereas it was more difficult to see the effect on an individual basis.

The particular issues raised by the participants were varied and have clear implications for those who make policy and provide service. The role for social work as a profession also requires a specific examination. As well, there were specific methodological issues which were raised in this work which deserve specific comment and evaluation. Finally, the value of this particular study and possibilities for future research need to be considered.

Issues

Lack of Choice/Control

In the focus group and the individual interviews, the participants' lack of control and choice in their lives was made clear. This is especially apparent in regards to living arrangements. Bob's story of being trapped with an abusive care giver and Franklin's experience of spending twenty years with care providers who took his money and thwarted his relationships with women show how little control they had in these situations. This is largely due to a service system which does not fully support individual rights and preferences. People with disabilities caught
in this system often have very little control over their services and, as a consequence, over their lives. Because funding is generally tied to services rather than individuals, people must accept services as they are offered, regardless of appropriateness, or risk receiving no service at all (Roeher Institute, 1990). This results in people becoming trapped in inadequate programs that do not meet their needs. This limits their ability to reach their potential as human beings and exercise their rights as citizens. In residential settings, for example, an individual requiring support is often 'dropped' into the first available vacancy, regardless of its usefulness for fulfilling the individual's particular needs. While this could be said of many services for non-disabled people as well, it is more problematic for people with intellectual disabilities because placements are generally long term.

Implications for Policy

A frequently cited solution to this problem is individualized funding (IF) (Roeher Institute, 1993). IF is a blanket term for a number of different funding schemes which vary considerably, but it is based on the notion of tying funding to individuals rather than services. The goal of this arrangement is to give as much control as possible to the individual and to arrange specific services which fit the person's needs, rather than making the person fit into existing generic services.

IF arrangements have the potential to allow people to live in the manner they chose, rather than the way the service providing
agency determines is feasible or appropriate. For example, as discussed earlier, the principle of normalization and the practices which derive from it have created a situation where same-gender relationships are not generally supported (because they may not be seen as culturally valued) (Brown, 1994). This lack of endorsement has resulted in the reluctance of agencies to provide supported living arrangements for gay and lesbian couples (this could also largely be said of heterosexual couples as well). An individualized funding scheme, however, would allow couples (and their advocates) to organize their own living arrangements and supports, without being restricted by the moralistic whims of others.

*Inappropriate Support*

The participants were all quite open about the assistance they required to live their lives and made no apologies for it. An extension of this understanding, however, was the unquestioned acceptance that they will always have professionals in their lives and that these professionals wield considerable power. This 'hegemony of service' which the participants live within is a direct result of the medicalized understanding of disability in our society which dictates that disability requires 'management' (Rioux, 1994b). It is also partially a consequence of the practice of normalization which is, as Chappell (1992) noted, a very professional-friendly principle. Even while criticizing the medical/institutional model of disability, normalization manages to set out a clear agenda for
professionals working with people with intellectual disabilities in order to assist them to integrate into the community.

The difficulty seems to arise from the lack of a compromise or middle ground position regarding support. If it is accepted that many people with intellectual disabilities require assistance with daily living, why does it follow that the support must be global? Or, as in Janey's situation, if a person requires minimal or infrequent assistance with particular tasks, why does that support not exist? There appears to be an all-or-nothing aspect to support services which results in people above a certain threshold of impairment receiving a sometimes excessive amount of services and those below the threshold unable to access what they need.

Poverty

Another issue which contributes to the lack of control that people with intellectual disabilities face is poverty. Poverty, the inadequacy of income support programs and unemployment were topics of interest, either implicitly or explicitly, to everyone in the focus group and the individual interviews. All the participants had experienced the unemployment and poverty which seem to be almost endemic to living with an intellectual disability in Canada.

The process of obtaining income support in our residual welfare system is both intrusive and humiliating for people with disabilities. They are frequently subjected to extensive medical examinations and testing as well as (often) mandatory rehabilitation
programs in order to qualify. The only definition of disability that is acceptable is that of the 'experts' or professionals - the assessment of the individual with the disability is not sufficient. The emphasis on medical identification and determination of disability status set physicians up to act as gatekeepers in order to protect 'the system' and allow only the 'deserving' (or truly disabled) access to income support (Rioux, 1994b).

It is clear that prevailing income support policies and programs dealing with people with disabilities are wholly inadequate to the task of truly supporting community living and community participation. Of all the causes and explanations for the current situation, one of the most important factors may be that people with disabilities were never really considered when these structures were originally developed and disability programs are merely 'add-ons' to existing programs. Because of this, most programs fail to meet the particular needs of people with disabilities. (Roeher Institute, 1990).

Implications for Policy

After several years of researching policy and services affecting people with disabilities, the Roeher Institute (which is affiliated with the Canadian Association for Community Living), developed and released its proposal for reform of the system in 1994. The Canadian Disability Resources Program is a detailed and comprehensive program proposal which would create a national program to provide support for the costs of disability, while still
recognizing concerns about costs and financing of social programs (Rioux & Crawford, 1994).

The program would not be an income support plan, rooted in the current welfare system. Instead, it would be a service which would fund the cost of disability related needs, such as wheelchairs, support workers, technical aids, etc. Use of the program would not be contingent on income level, age, type of disability or employability; eligibility would be based solely on the presence of a disability related need. The program criteria would also not restrict access to other services and opportunities such as education and participation in the labour force. Eligibility would be based on a non-medicalized assessment which involved the individual’s determination of need. Consumer rights and control would be ensured through the use of individualized funding which would also result in increased effectiveness and responsiveness of services (Rioux & Crawford, 1994).

**Violence and Abuse**

One of the most disturbing issues raised by the participants in the focus group and the interviews was the startling amount of violence, sexual, physical and emotional, that they are subjected to. Incidents ranged from public verbal harassment to detainment to overt sexual violence and rape. One respondent described how people who had attempted to escape from an institution were incarcerated in locked rooms as punishment. Much of the sexual violence described
to me was perpetrated by acquaintances of the victims or by support staff. It is clear that these violent behaviours the respondents were faced with arise out of the exploitation of power imbalances between people with disabilities and non-disabled people on personal, community and institutional levels.

Part of this problem arises from societal attitudes that objectify, devalue, marginalize and emphasize limitations that then serve to dehumanize people with disabilities and make violence towards them more likely while minimizing this crime. As well, because people with intellectual disabilities in particular are frequently taught to comply with the wishes of non-disabled people around them, their ability to defend themselves or to report incidents after the fact is often limited (Sobsey, 1994). The example of Franklin and his insistence that “you have to be nice” even if it means not locking your apartment door to strangers, is a clear indication of this kind of ‘trained compliance’.

Implications for Policy

A great deal of the work in this area is being done by self advocates who are already working on solutions to the problem of violence in their lives. In her interview, Tracey described one of the activities she is involved in:

our self-advocacy foundation we put together a book on safety, safety in your home and in your community and we hope that that will help a lot.

Acceptance of and knowledge about violence against people with disabilities seems to be a large part of the solution (Sobsey,
1994). As well, education for professionals involved in the lives of disabled people is necessary. Tracey commented on the role of emergency services in assisting disabled crime victims and the need for education:

I think that’s the whole idea with the community police office is to try and break the ice, that you’re not—you’re not afraid to phone the police because, you know—because you feel like they might think you are stupid or, you know, why you are phoning us. Yeah, we are trying to get, um, we tried to get, um, advocacy into the professionals too, the police, ambulance drivers, the firemen, the hospitals, because we feel that’s very important that they know how to treat people with disabilities.

As well, participants in the focus group were actively lobbying for treatment services specifically for intellectually disabled people who have been sexually abused.

Social Work Role

The implications of this study are broad for social work. The criticisms of social workers raised by the respondents are unsettling. All the respondents, in both the focus group and the interviews, related stories about inadequate or insulting services they had received. Several people told stories of being called liars by workers. Others complained that social workers did not follow through on commitments or were simply not accessible. The participants felt that their most significant concern was the lack of respect they faced when dealing with the service system, either through the attitudes of workers or through the inaccessibility of
resources and services. Certainly, conclusions generated from a study of this nature cannot be generalized, but incidents such as the ones described are unacceptable even if they are isolated.

At the same time, however, the participants had clear ideas on what social workers should be doing to better support people with intellectual disabilities. Janey felt that her social worker should "phone and see how you are doing" as well as helping her in her efforts to find a new place to live, rather than leaving it to family members to assist. Tracey felt that workers would better serve her by not focussing on her disability, but by seeing her as a whole person.

If one of the foundations of our profession is the respect of all people, than this is an example of where we have failed. Part of the failure can be traced, as several of the respondents noted, to social work education and the frequent lack of training in disability issues. A survey of 144 schools of social work in the United States revealed that only 21% of programs offered specific courses in intellectual disability and that most opportunities to study this area exist only in graduate programs (Depoy & Miller, 1996). This has served to keep issues around intellectual disability in general out of the collective social work consciousness. The participants in the focus group were quite aware that their issues were not on the social work education curriculum and one person stated "we should actually get some part of a course where they take people like us and learn to work with them".
While this situation has certainly not helped people with intellectual disabilities, it has not been of benefit to social work either. As Hanley & Parkinson (1994) state:

it is lately of great concern among professionals in this field, however, that social work practice is placed last or seen many times as an ancillary profession in its contributions to the enhancement of the dignity of the lives of individuals with cognitive and/or physical challenge and/or their family members. If professionals in the field of social work continue to react only to the mandates set before professional practice with this population, they will become less able to determine the growth of the profession, set new goals, and gain the knowledge and techniques necessary for working with individuals who have disabilities and their families. (p. 426)

In other words, social work, as a profession, runs the risk of becoming irrelevant in this field.

**Implications for Practice**

Irrelevancy does not need to be the fate of the profession; there are a variety of roles social workers can play in this area which would help improve the lives of people with intellectual disabilities and give the profession direction in this field.

**Direct Service**

As practitioners, social workers need to develop an understanding of intellectual disabilities and the issues facing people so labeled. As case managers, social workers need to be aware of this issue and to ensure that people receive services that are appropriate to their needs, as well as advocating for the development and funding of such services when they do not exist.
Workers must also recognize that all people can exercise some level of personal autonomy and that this is a skill which must be supported and respected. Too often, notions of independence and personal empowerment are considered ideals rather than realities for people with intellectual disabilities.

The Profession

As a profession, social work must move away from the medical/therapeutic model of disability and begin to understand it from a social and political perspective. Social work has long been committed to battling racism, sexism and heterosexism in our communities and institutions; it is time that the profession realizes that ableism is equally as destructive and oppressive. Social work must make a commitment to the disabled community to begin to work with it to change the structural conditions which operate against people with intellectual disabilities and threaten their physical, social and economic well being.

Methodological Considerations

It has been both a blessing and a curse for me in that there has been very little qualitative research done with people who have intellectual disabilities. It has been a blessing in that I have had a great deal of freedom in determining my methodologies and I have felt no guilt in adapting traditional techniques for use with people who intellectual disabilities. This follows the dictates of the social model of disability which states that it is non-disabled
structures and attitudes which must change to become accessible to people with disabilities and not the other way around. The curse, however, has been in the lack of guidance I have had throughout this process in terms of specific methodology. It is well and good to speak of informed consent and to have respondents sign consent forms, for example, but how is that relevant for someone who does not read and has difficulty understanding lengthy sentences? One of the most time consuming aspects of my research has been the process of making it accessible and meaningful to the participants.

Consent:

In order to obtain what I considered informed consent from the respondents, I went through several steps. First, I met with the self advocacy committee at one of their regular meetings simply to introduce myself and give a brief description of my research. I did this specifically to personalize the research and try to make it more 'real' and less abstract to the group. After I left the meeting, the group discussed their participation and informed me of their decision several days later.

The consent letters each participant signed were more difficult. The university has a very specific format for consent forms which must be adhered to. I took the format supplied by the university and rewrote it into plain language (Canadian Association for Community Living, 1997) (see appendices A and C) which would be more accessible to the participants. Plain language refers to a type of writing which is straightforward and jargon free, but is
not condescending or simplistic (CACL, 1997). Even with this modification, since there were participants who did not read at all, more adaptations were called for. To address this, I spent approximately twenty minutes prior to the beginning of the focus group (and usually about five minutes before the interviews) discussing the research and reading over the consent form, line by line, with the participants before they signed the form.

Focus Group/Narrative Techniques:

As I noted earlier in this paper, people with intellectual disabilities, especially those with limited verbal skills, have generally been considered poor choices for these kinds of research methodologies (Booth, 1996), primarily because they were deemed to not have the requisite insight or ability to articulate their insights. While I obviously disagree with this attitude and believe that this study has shown otherwise, there are issues with these techniques that do require consideration and modification in order to be successful for people with intellectual disabilities.

The single most important adaptation to the process is the increase in the time spent in the data gathering process. Booth and Booth’s (1994) study of patents with intellectual disabilities was narrative in nature and was the result of many hours of interviews and many months of involvement with their participants. I did not have the luxury of time or resources enough to follow their model and I consider this to be a major weakness of my study, especially in the narrative section and with in particular and Bob and
Franklin. Had I been able to spend more time with them, I believe I might have been able to get a more complete picture of Bob's life and might possibly have gotten past Franklin's deferral to me as a non-disabled person.

Another issue which is related to the amount of time spent with the process is the depth of the relationship between researcher and respondent, which leads to a better understanding of the respondent's stories. Because some of the people in the focus group and in the interviews had limited verbal abilities, there were many times when a type of verbal 'shorthand' was used. It was often assumed by the participants that I understood what they were talking about when they made reference to certain services, programs, or even individuals. Since I work in the same community as most of the participants lived, I generally did understand who and what they were talking about. Another researcher less familiar with this community, however, would likely be at a loss a good deal of the time and would miss many of the subtleties in their stories. The only way to combat this is familiarity with the lives and particulars of each participant which can usually only be gained through time and involvement.

Transcripts/Findings:

Part of my research design included member checks with the participants in order to ensure the accuracy of the transcripts and the findings. Again, because many people in the group did not read
and even among those who did, not many would be willing to read through a forty page transcription, I was compelled to find other ways of making the data accessible. The most successful technique was to use the videotape of the focus group proceedings as the transcript. Several weeks after the meeting, I arranged for the group to meet again and played the videotape of the discussion for them. I asked them to watch and to make sure that what was said was accurate and reflected the issues they wanted raised. The group enjoyed the video immensely and was quite happy with it. I did not videotape the individual interviews, so I decide to use the core narratives as transcripts and go over them with the participants.

Probably the most difficult aspect of this process has been discovering ways to make the findings accessible to the participants. I attempted to accomplish this in two ways. Part of the course requirements in this program was the creation of a poster which displayed the results of the study. Once I was done with the poster myself, I presented it to a meeting of the group and went over it with them in detail. At that point I gave it to the self advocacy committee who have since used it as a more visual representation of the research at other events. The final report for the focus group research was more problematic because it was written in academic language and did not lend itself to easy plain language translation. I resolved the dilemma by putting the document into a parallel text format. Parallel text is a method to make complicated documents more understandable by putting a simplified summary of the main ideas along side of the main text
The process of making my research methodology and the findings accessible to people with intellectual disabilities has been a challenging one and, to some, it may appear to be overwhelming. I found however, that it was not as difficult as it first seemed. Most of the modifications were common sense solutions and did not require any special skills or techniques on my part. Certainly, it was time consuming work, and more time consuming than if I had been doing research with non-disabled people, but I found the results to have more than justified the effort.

Directions for Future Research

The potential for research in this area is significant. As I stated earlier, my intention is that this study help to contribute to a growing body of research that is based on the experiences of people with intellectual disabilities. I hope it has dispelled some of the myths regarding interview research with people so labeled and shown some of the possibilities which exist for further studies. Some of these possibilities include interviews with people who are in receipt of more services than these participants were, for example, people living in group homes or other facilities and attending vocational support programs. I believe that there would be significant differences in the experiences of these people and
this is an area which is largely unexamined. As well, research with people who are not as involved in self-advocacy (and as such, not as experienced with speaking out) or people of other cultural groups may also bring out different issues.

Another group which has been sorely neglected by social researchers has been people with more severe disabilities (Watson, 1996). As all people with intellectual disabilities have frequently been dismissed by many researchers as impossible to research in a qualitative manner, people with severe disabilities have been completely ignored because of their lack of verbal skills and because of difficulties in obtaining informed consent. I admit to being complicit in this silencing as well with my own research. I specifically chose self advocates because they are generally more verbal, more outspoken and, to be blunt, easier to research. People with severe disabilities, however, should not be deemed ineligible simply because they are more work. Research has been done which shows that they can participate in and understand qualitative research (see Booth & Booth, 1996 and Stalker, 1998), including narrative studies. The biggest modification which must be made to enable people with severe disabilities to participate is to the researcher's timetable. In order to ensure the accuracy of the data, time must be taken to get to know the participants and their lives. For, as I discovered, there is far more going on in the lives of people with intellectual disabilities than first meets the eye.
Conclusion

This thesis is the result of a long, frequently frustrating, but finally rewarding process. When I first began work on my MSW, my vision was to develop theory and practice techniques for use in counseling people with intellectual disabilities because there were (and still are) so few psychotherapists in the community who were willing or able to support them. I soon realized that the more important question was why do people with intellectual disabilities have such a need for therapy in the first place? In trying to answer this question, I discovered the literature which describes disability as a social phenomenon rather than a solely medical one. I came to understand that the depression, violence and self-injurious behavior I had seen in so many people for so many years was partially a consequence of living in a society which despises them rather than a result of their impairments.

What was missing from this new understanding though, were the voices of people with intellectual disabilities. Certainly, as disabled people, those with intellectual disabilities have a good deal in common with those who have physical disabilities, but I could not believe that their experiences were equivalent. I set out to do this research with that as my goal; to find out what their experiences were and how they felt about their lives as intellectually disabled people.

I feel that my research has been valuable in three specific ways. First, I believe I have helped add the voices of people with
intellectual disabilities to the disability rights literature and have shown that the social model is incomplete without an analysis of their experiences. I also believe I have shown that qualitative techniques (and traditionally verbal-skill dependent techniques, at that) can be used successfully with people with intellectual disabilities without compromising the integrity of those techniques. Finally, I believe I have drawn a rough map for social work practice in this area. I hope that others will find it and follow it.
References


Appendix B

Focus Group Question Guide

*These are general guidelines for discussion only*

1. What are your dreams for the future? What would you like to be doing in a few years?
   Possible Prompts:
   Would you be working? Where?
   Where would you be living?
   What would you be doing for fun?

2. Would you have people helping you do these things?
   If yes: ① Who would help you?
   Possible Prompts:
   Paid staff?
   Families?
   Peers?
   Social workers?

   ② How would you want them to help you?
   Possible Prompts:
   Would you want to live in a group home?
   Would you want live-in staff in your home?
   Would you want to have someone around only when you need them?
   Would you want one person to be a helper or lots of people?
   Would you decide what help you need or would your helper?
   Would you want to organize and hire your helpers/staff or would you want someone else (like a social worker/family member/advocate) to do it?

   if no:
   ① Would you do these things on your own?

   ② Are there any reasons why you wouldn’t want any help?
Appendix D

Interview Question Guide

*These are general guidelines for discussion only*

When we had the discussion group in February, we discussed a number of different things. I would like to talk some more about those things with you to get a better idea of what it's like you.

1 What have been your experiences with ...

   school?
   finding a place to live?
   finding a job?
   social workers?
   financial workers?
   institutions?
   your family/foster family/caregivers?
   personal safety and violence?
   friends/social networks?

2 What things do you think need to change? What would make your life better?