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**GETTING TO THE HEART: THE ROLE OF FRONTLINE
WORKERS IN SUPPORTED LIVING**

A Thesis Submitted to the Faculty of Graduate Studies and
Research of Carleton University

By

Thomas J. N. Shepherd, B. A., B.S.W.

In Partial Fulfilment of the Requirements for the Degree of
Master of Social Work

June 2000

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" Getting To The Heart: The Role of Frontline Workers In Supported Living"

submitted by **Thomas J.N. Shepherd, B.A., B.S.W. McGill University**

in partial fulfillment of the requirements for

the degree of Master of Social Work

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ABSTRACT

This study examines the role of frontline workers in supported living through focus groups and individual interviews with a group of adult service users. Supported living is becoming increasingly accepted as a practice of providing housing support to people with intellectual disabilities. Frontline workers have a critical role to play in putting the principles of supported living into practice. This study describes the roles being fulfilled by frontline workers and examines them to determine the extent to which they reflect the principles of supported living and the desires of service users. Future directions for practice and policy in the delivery of supports and services to people with intellectual disabilities are presented along with suggestions for additional research.

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DEDICATION

To the many children, women and men with disabilities with whom I have been privileged to work over the years. You have always been an example to me.

And to those who support them with joy in the fulfilment of their dreams: family members, workers, friends alike.

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Communion is the to-and-fro of love. It is the trust that bonds us together, children with their parents, a sick person with a nurse, a child with a teacher, a husband with a wife, friends together, people with a common task. It is the trust that comes from the intuitive knowledge that we are safe in the hands of another and that we can be open and vulnerable, one to another. Communion is not static; it is an evolving reality. Trust is continually called to grow and to deepen, or it is wounded and diminishes. It is a trust that the other will not possess or crush you but rejoices in your gifts and calls you to growth and to freedom. Such a trust calls for trust in yourself.

Jean Vanier, 1998, p. 43

CHAPTER I: INTRODUCTION

In North America, beginning in the early 1970s, a significant number of people with intellectual disabilities and their families experienced decisive changes in public policy and service delivery in such areas as residential support and vocational training (Polloway, Smith, Patton, & Smith, 1996). With regard to residential support, changes were spurred on by parents, educators, researchers, professionals and public servants who believed that people with intellectual disabilities did not belong in large state-run institutions. These facilities had become the dominant model of public support for people with disabilities. The pressure exerted by these groups resulted in the deinstitutionalization of significant numbers of people with intellectual disabilities across North America. What followed, throughout the 1970s and 80s, was the proliferation of small public and private community-based residences (also referred to as group homes) despite often vociferous resistance from local property owners (Bercovici, 1983). In recent years, however, the group home model of residential support has been criticized for its failure to achieve certain important goals, causing concerned individuals to search for a better alternative to institutional care.

Since the mid-1980s governments and organizations

providing public services to people with intellectual disabilities have begun to adopt a new, decentralized approach to residential services, commonly referred to as *supported living* (Allard, 1996). This approach points service providers away from segregated settings, program-based planning, behaviour modification programs and restrictive practices. It provides a new set of principles and standards to guide staff members at all levels. These principles include a) a rejection of the residential service continuum, b) a belief in empowerment and self-determination for service users, c) the individualization of support mechanisms through person-centred planning, and d) the promotion of full social inclusion through a combination of natural and artificial supports.

Inevitably, service providers and policy makers must rely on frontline support workers (also referred to as paraprofessionals or direct care staff) to implement these principles and goals. In the field of community-based services for adults with intellectual disabilities, 80-86% of all personnel occupy these lower-level positions (Hewitt, O'Neill, & Larson, 1996). These workers have a critical role to play in fulfilling the mandate of supported living. This new direction can only become a reality for people with intellectual disabilities if frontline staff are able and willing to implement the fundamental principles that are at its core.

However, little is known about the role that paraprofessionals actually fulfil in supported living programs and agencies. Research in this area is sparse at best. As a consequence, we are limited in our ability to evaluate the extent to which supported living agencies and programs are able to live up to their commitment to progressive philosophies. I will begin to address this problem through a systematic examination of the roles currently being fulfilled by frontline workers in a supported living program operated by a large multi-service organization for people with intellectual disabilities in Eastern Ontario.

For several years I worked as a support worker in group homes for adults with intellectual and psychiatric disabilities. Through this experience I became intimately familiar with the stresses and potential joys of living and working with adults experiencing significant life challenges. As a frontline staff member I was pulled in different directions by residents, family members, co-workers, supervisors and my own conscience. Having received little structured direction and training, my ability to implement all the various tasks outlined in my job description was limited. This was particularly true with respect to promoting personal independence, inclusion in decision-making and meaningful social integration of service users in community life. I came to understand that there

were major discrepancies between my formal job description and what my work actually entailed. This realization sparked my interest in undertaking research into the role of support workers in this 'new era' of supported living for people with intellectual disabilities.

Statement of the Problem

Researchers have made some effort to describe the role that paraprofessionals *should* play in supported living. In theory, a frontline worker's mandate is to provide a service user with the assistance needed to fulfil her immediate and long-term goals regarding housing, personal relationships, skill development, recreation and more generally, to experience personal well-being. Through person-centred planning and the maintenance of individualized support mechanisms, frontline workers are required to facilitate independence and full social inclusion for the people they support, while respecting the individual's right to self-determination (O'Brien & O'Brien, 1991). Furthermore, workers are expected to make use of informal supports available in the community in order to reduce the burden on service providers and their resources and to promote social inclusion (Leake, James, & Stodden, 1995). Support staff are also required to function in a highly decentralized context which is radically different from traditional community-based living alternatives, such as group homes. Operating

out of organizational headquarters, support workers spend the large majority of working hours visiting service users in their homes and taking them out into the surrounding community.

For various reasons, however, frontline workers may not have the means to translate the philosophy of supported living into reality for many of the people with intellectual disabilities they are paid to assist. These reasons include underlying structural problems such as the relative powerlessness of frontline staff in decision-making processes and the lack of value placed on their role (Hewitt et al., 1996; Knoll & Racino, 1994), relatively high turnover rates and low levels of compensation (Mitchell & Braddock, 1994; Lakin & Larson, 1992; Larson, 1997; Larson & Lakin, 1992; Riediger & Baine, 1987), and a lack of staff education and training (Center On Residential Services and Community Living [CRSCL], 1994; Gardner & Chapman, 1992; Knowles & Landesman, 1986). Furthermore, the current fiscal crisis being experienced by many public agencies in the province of Ontario and across North America has reduced the capacity of service providers to deal with the structural problems listed above (Brown, Renwick, & Raphael, 1999; Federation of Ontario Facility Liaison Groups [FOFLG], 1997; Bradley, 1996).

Currently, however, it is difficult to know what role frontline workers fulfil in supported living and what

results they are achieving. It seems that researchers have made few attempts to explore the qualitative dimensions of support work from the perspectives of service users and/or frontline workers. We have insufficient knowledge of what workers actually do while they are on the job and how their performance affects service users. It does not appear that researchers have been able to investigate in depth a) what roles are currently being fulfilled by paraprofessionals, b) what type of relationships have developed between workers and service users, and c) whether or not these roles and relationships are congruent with the desires of service users and the principles of supported living. These gaps in the knowledge base represent a significant problem for people with intellectual disabilities, their families, support workers, service providers, and policy makers.

Numerous studies recognize the importance of support workers in residential services for people with intellectual disabilities (Henry, Keys, Balcazar, & Jopp, 1996; Knoll & Racino, 1994; O'Brien & O'Brien, 1994; Rice & Rosen, 1991). Support workers interpret and then implement their understanding of organizational policy through personal interaction with service users. Consequently, a man or woman with an intellectual disability experiences the policies of a service provider through his or her worker. This is particularly true in supported living, given the fact that frontline staff are the primary link between the service

user and the system. The support worker, therefore, has a major impact on the capacity of an agency to make a positive difference. The importance of this impact calls for research to further explore the manner in which paraprofessionals interact with service users. Without such research our ability to effectively evaluate supported living's potential (as a model of housing support) to actualize its commitment to core principles is limited.

This research also has a more indirect purpose. In recent years a relatively small number of researchers have made an effort to include people with intellectual disabilities and their families as active members in the research process (Cocks & Cockram, 1995; Heller, Pederson, & Miller, 1996; Hemmeter, Towne, & Hertenzenberg, 1996; Pederson, Chaikin, Koehler, Campbell, & Arcand, 1993; Sample, 1996; Turnbull, Friesen, & Ramirez, 1997; Turnbull & Turnbull, 1991; Zarb, 1992). They grounded their work in the perspectives and daily realities of people with disabilities and their allies. This approach is commonly referred to as participatory research, the basic elements of which are explained in Chapter III. Unfortunately, even now when consumer empowerment, participation and inclusion are touted as the new *raison d'être* of research and service provision, the perspectives of people with intellectual disabilities on issues of importance are often absent from existing literature. In an attempt to mitigate this problem,

aspects of participatory research have been incorporated into the design of this study. In addition, without speaking directly with service users it would have been very difficult to get a complete picture of roles currently being fulfilled by frontline workers.

Research Questions

1. What role do frontline workers fulfil in supported living?

- What activities do support workers and service users engage in together on a regular basis while on the job?
- What activities take place more occasionally?
- What are the processes through which support is provided?

2. Is the role fulfilled by frontline workers congruent with the principles of supported living and the desires of service users?

- Do the practices adopted by support workers and the relationships they develop with service users reflect a commitment to empowerment, person-centred planning and full social inclusion?
- Are service users satisfied with the support they receive and the relationships they have with their workers?

Organization of the Material by Chapter

Chapters II and III lay the conceptual and theoretical foundation upon which this research is based. In *Chapter II* the historical development of supported living as a model of housing support is examined in detail, using Ontario as an example. Particular attention is given to ongoing themes that emerge in the literature on residential services for adults with intellectual disabilities. The purpose of this chapter is to clearly outline the key principles and practices which define supported living.

In *Chapter III* relevant literature on the role of frontline workers in supported living is reviewed. Major issues that have dominated the research agenda on personnel in the field of intellectual disabilities are outlined.

Chapter IV contains a comprehensive description of the research methods employed in this work. Sampling procedures and selection criteria, data collection methods and materials, data analysis techniques and ethical considerations are discussed. Attention is also given to the methodological strengths and limitations of this research.

In *Chapter V* findings from focus groups and individual interviews are presented in detail. This chapter addresses the first research question: What role do frontline workers fulfil in supported living?

Chapter VI provides an analysis of key findings in relation to the principles of supported living and the

desires of service users. This chapter addresses the second research question: is the role fulfilled by frontline workers congruent with the principles of supported living and the desires of service users? Implications for policy, practice and future research are also presented.

Definitions of Key Terms

Service user: refers to a person with an intellectual disability who receives support from a public or private service organization in the activities of daily living.

Person with an intellectual disability: Refers to "individuals who have been variously labelled as mentally retarded, mentally handicapped, mentally disabled, mentally impaired, intellectually impaired, developmentally disabled, and developmentally delayed." (Rioux, 1994, p. 91)

Role: the activities that a worker carries out in order to fulfil her official and/or unofficial mandates. A role consists of two basic components: actions and their underlying purposes.

Support workers/frontline workers/paraprofessionals: paid staff who provide hands-on or direct support to people with intellectual disabilities in a variety of settings. Within the context of supported living, the term support worker refers to frontline staff who provide direct personal assistance to service users within their living spaces and in the surrounding community.

Supported living: For a complete definition of supported living see pages 34-35.

CHAPTER II: THE SUPPORTED LIVING MODEL

Looking back over the last 30 years it is apparent that the field of residential service delivery has been characterized by three major models. Various experts claim that the field has moved from a medical/institutional model to a community residence/normalization model and has recently begun to make the transition to a new supported living model (Bradley, 1994; Bradley & Knoll, 1995; Leake et. al., 1995; Polloway et al., 1996). Each of these different approaches will be presented in the following chapter. Using Ontario as a case study, the purpose is to provide a clear understanding of the ideologies and practices that have driven public residential services for people with intellectual disabilities in North America.

The Medical/Institutional Model

This model of residential service is based on what can be generally described as a curative biomedical theory of disability. The medical model is founded upon the assumption that intellectual and physical disabilities, and by extension any socio-economic disadvantage experienced by people with disabilities, are first and foremost caused by individual biological defects (Mercer, 1992). According to Bichenback (1993):

The most commonly held belief about disablement is that it involves a defect, deficiency, dysfunction,

abnormality, failing, or medical 'problem' that is located in an individual. We think it so obvious as to be beyond serious dispute that disablement is a characteristic of a defective person, someone who is functionally limited or anatomically abnormal, diseased, or pathoanatomical, someone who is neither whole nor healthy, fit nor flourishing, someone who is biologically inferior or subnormal. The essence of disablement, in this view, is that there are things wrong with people with disabilities. (p. 61)

Within this conceptual framework the major problems to be addressed through prevention and direct intervention are inherent or acquired biological abnormalities. The socio-economic determinants of disability and its correlates (unemployment, poverty, social isolation) are not considered paramount within the medical paradigm and are therefore not the focus of public efforts to help the disabled.

The characterization of intellectual disability as a biomedical health issue necessitated intervention by physicians, psychiatrists and other health care providers. These were the professions considered to have the training and expertise needed to treat and/or manage people with physical disabilities and mental health problems (Bichenback, 1993). The logical setting for intervention was the hospital, a place where doctors cared for the sick and infirm. In Ontario, public institutions for people with intellectual disabilities were modelled after hospitals, and were often referred to as hospital schools (Anglin, 1978). The superintendents of provincial institutions for people with intellectual disabilities were almost always physicians, and until 1974, people with intellectual

disabilities were considered the responsibility of the Ministry of Health (Simmons, 1982).

In the institutional/medical model, the initial goal of research and intervention was to cure the insane of their mental diseases. Given the explicit curative function of treatment, therefore, the superintendents of early state-run asylums in Ontario, constructed in the latter half of the 19th century, made a concerted effort to exclude people with intellectual disabilities because they were considered incurable (Simmons, 1982). Providing medical treatment for this group of people, who were otherwise housed in local jails and poorhouses under punitive conditions, was considered a hopeless endeavour and waste of public resources. Due to the total lack of support services in local communities, however, provincial asylums were under constant pressure from families and municipalities to admit 'idiots' or 'incurables' (Simmons, 1982).

As a result, the provincial government allowed people with intellectual disabilities to be admitted to provincial branch asylums for the 'incurable insane'. Eventually the Province of Ontario dedicated specific institutions for the care of people with intellectual disabilities at London (1872) and Orillia (1888) (Anglin, 1978). Given the impossibility of cure through active medical treatment, these early institutions were designed to fulfil basic protective and educational functions (Simmons, 1982). In

essence, the goal of these early institutions was to provide people with intellectual disabilities with a basic level of public care and training that was unavailable elsewhere. In reality however, efforts to provide residents with basic education and vocational training were severely limited or non-existent (Simmons, 1982).

During the first few decades of the 20th century proponents of the eugenics movement appeared to assign public institutions for people with intellectual disabilities a somewhat new role. Instead of providing innocents with protection from a cruel and abusive world, the institution's new purpose was to protect society from the 'menace of the feeble-minded'. During this period public services for people with intellectual disabilities were often seen as having social control and custodial functions. Proponents of eugenics argued that mental deficiency was inherited. They believed people with intellectual disabilities were largely responsible for a wide array of social ills or degeneracies (Wolfensberger, 1972). Of this period, Ryan and Thomas (1994) have written:

Now the animal nature of idiots, once an insult to humanity and something to be pitied, became a danger. Idiots were thought to revel in their brutishness.... this idea led easily to the notion that idiots were a degeneration of the human (i.e. European) race. And from there it was but a short step to demands for their control - particularly control over their reproduction. . . . Idiots came to be regarded as both the result, and increasingly the bearers of all kinds of social degeneration: alcoholism, masturbation, poverty, thieving, illegitimacy etc. (p. 106)

This type of thinking was not uncommon in Ontario circa 1890-1930, and was exemplified by the work of Dr. Helen MacMurchy, appointed *Inspector of the Feeble-Minded* in 1915. MacMurchy argued for the placement of feeble-minded children and adults in custodial institutions (Simmons, 1982).

Institutional populations grew steadily throughout the 20th century until the early 1970s. By 1971 there were 9,000 individuals with intellectual disabilities living in Mental Retardation Branch Institutions and psychiatric hospitals in Ontario, as compared to 200 individuals living in community residences (Williston, 1971). A defining characteristic of these institutions were the hierarchical and paternalistic relationships that developed between staff members, at all levels, and patients. One reason for this is the manner in which the medical model defines the role of those in need of care. Bickenback (1993), citing Parsons (1961, 1972), argues that the medical model gives patients, who are perceived as blameless victims with special needs, a temporary exemption from normal social obligations towards family, employers and the general public. This exemption, however, comes at a price. The sufferer must accept his position as a passive recipient of the expert interventions of others: "the precondition of the role - that the patient cooperate with the source of the help - becomes, for those who are permanently sick, a denial of autonomy." (p. 82) This may be an acceptable precondition of care for empowered citizens

experiencing a brief and curable illness, but for those with an 'incurable mental defect' this denial of autonomy has often meant a life devoid of the personal freedom that many citizens take for granted.

The institution's staff members (physicians, psychiatrists, psychologists, speech, occupational and physio therapists, nurses, social workers, educators and attendants) have traditionally exercised a high degree of control over patients. Professionals make the rules and patients are compelled to comply. Ryan and Thomas (1994) claim that insufficient numbers of staff coupled with high turnover rates exacerbate the need for staff to maintain strict order within the institution. The need to maintain order and routine may prevent the development of positive human relationships between attendants and patients.

According to Ryan and Thomas (1994):

In these circumstances patient-care almost inevitably becomes patient-control, both in practice and in terms of how nurses view their work. "Constant supervision, observation and habit training" is how a nurse in one of the newest and best equipped hospitals described her work. (p. 52)

Regardless of the good intentions of the proponents of institutional care, the net effect of this movement was the segregation, stigmatization and disoccupation of large numbers of people with intellectual disabilities (Bradley, 1995). Institutions became known as places where people were warehoused (Polloway et al., 1996). The analogy of the warehouse is particularly apt as it is a place where objects

are shelved and often forgotten, abandoned for the foreseeable future. Evans (1983) cites two studies (Klaber, 1969; Reuter, 1980) which found that institutionalized adults with intellectual disabilities spent up to half their time doing absolutely nothing, alone or in bed. These findings further indicate that consistent educational and vocational programming was severely lacking in institutional settings.

Leading up to the early 1970s public institutions in Ontario were plagued by the many serious problems outlined above. On June 8th, 1971, Ontario's Minister of Health, A. B. R. Lawrence, commissioned Walter B. Williston to investigate two separate incidents involving former residents of the Rideau Regional Hospital at Smith Falls. One involved a man named Frederick Sanderson who hanged himself with a length of baling twine on the farm where he had been placed. The other was the case of Jean Martel who, after leaving his foster home, was found wandering on a road with frostbite on his nose, ears, fingers and toes. The result of Williston's investigation is a now well-known report entitled *Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario*, released in August of 1971.

After several months of investigation, Williston found the following:

- Most of Ontario's institutions were severely

overcrowded and significantly understaffed, and life on the wards tended to be "dull, monotonous and impersonal." (p. 65)

- Most institutions were located in isolated rural areas, making visits from or to family members infrequent, and leaving little opportunity for social integration.
- Men and women were almost always kept separate.
- Most residents were forced to "use lavatories without doors and often without toilet seats." (p. 65)
- The function of most institutions was custodial, with little active education or training taking place.
- Residents who worked were "paid minimal and completely unrealistic wages. . . - from 4¢ to 8¢." (p. 68)
- Most institutions were perpetually underfunded.

It is clear that Williston was not impressed with what he saw in Ontario's institutions for people with intellectual disabilities. In fact, he concluded that:

a century of failure and inhumanity in the large multi-purpose residential hospitals for the retarded should, in itself, be enough to warn of the inherent weakness in the system and inspire us to look for some better solution. (p. 68)

This sentiment was becoming more and more common across North America in the late 1960s and early 1970s as the deinstitutionalization movement came into its own. During these years the large institution was replaced by smaller community-based residences, commonly referred to as group homes, as the dominant model of housing people with intellectual disabilities.

The Community Residence/Normalization Model

Deinstitutionalization ushered in a new model of residential service. In this model the problem to be addressed through intervention changed, shifting the focus away from *mental defects* within individuals to *structural defects* within the public service system. Simply defined, deinstitutionalization refers to "social policies aimed at moving people with psychiatric or intellectual disabilities from large residential facilities to the community." (Roeher Institute, 1995, p. 1). The miserable and dehumanizing conditions found in state-run institutions, coupled with the stigmatization that resulted from being a resident of one of these institutions, came to be perceived as the primary cause of the low quality of life experienced by people with intellectual disabilities. During this time, family members, social activists and professionals began to speak of the human and civil rights of people with disabilities. For example, many parents began to question why their disabled children were not being educated in the public school system alongside other children. This emerging movement was bolstered by broad-based transformations taking place throughout North American society. According to Willer and Intagliata (1984):

The social climate of the 1960s was also instrumental in preparing the scene for deinstitutionalization. There was considerable unrest during the 1960s as young people opposed the war in Viet Nam, the draft, and most other institutions in society. Minority groups began to demand attention to their rights, and race riots,

student takeovers, and peace marches became commonplace. . . . It is not surprising, therefore, that deinstitutionalization of the mentally retarded population began over concern for the rights of mentally handicapped persons. (p. 11)

In theory, deinstitutionalization was driven by a new non-medical and non-institutional approach to intellectual disability, commonly referred to as *normalization*. In North America Wolf Wolfensberger is widely recognized as the progenitor of the theory and practice of normalization in the human services sector, although he was not the first to use the term in reference to services for people with intellectual disabilities.

The term was first defined in Sweden by Nirje (1969) as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream society." (p. 181, quoted in Wolfensberger, 1972). This early definition is what Greenspan and Love (1995) refer to as a "nonconsequentialist ethical theory in which living a normal lifestyle is seen as a basic human right of people with disabilities." (p. 76). In other words, the original purpose of normalization was not to engineer a predetermined social consequence. It was first and foremost a statement of the intellectually disabled person's right to equality and choice in such areas as housing, education, work and recreation (Emerson, 1992).

Wolfensberger (1972) presented a much more purposeful

version of what he referred to as the principle of normalization, originally defined as the "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible." (p. 28). In Wolfensberger's view, the central problem faced by people with intellectual disabilities was the manner in which society (and public institutions) labelled and treated them. As a result of labelling, segregation and stigmatizing treatment, people with disabilities learned behaviours and took on appearances which reinforced social images of their deviancy. In other words, people with intellectual disabilities took on deviant characteristics because they were *expected* to act and think as deviants, a process Wolfensberger believed was reversible and/or preventable through the practice of normalization. According to Greenspan and Love (1995), this focus on unmaking deviant social images and behaviours represents a "consequentialist ethical theory in which living a normal lifestyle is a means to a broader social end, which is greater acceptance and valuation of people with disabilities." (p. 76).

Simply put, the goal of normalization was to reduce the deviant behaviour and negative social images of people with intellectual disabilities by maximizing their physical and social integration into mainstream society. McCord (1982)

argues that the process of normalization is about providing people with "forms of assistance which help them to achieve patterns of life which meaningfully challenge their abilities and which also stimulate positive perceptions among non-disabled persons." (p. 249). To facilitate this process Wolfensberger advocated for services that did not segregate, stigmatize or promote abnormal behaviour in adults with intellectual disabilities. He also developed evaluation tools named PASS: Program Analysis of Service Systems (Wolfensberger & Glen, 1973, 1975), and later PASSING: Program Analysis of Service Systems Implementation of Normalization Goals (Wolfensberger & Thomas, 1983). PASS/ING is an itemized rating system used to assess the extent to which a service or organization enhances the social image and personal competency of service users. It has also gained international acceptance as a basis for training human service professionals (Lindley & Wainwright, 1992).

Another concept that was popular among proponents of deinstitutionalization and normalization was the developmental model of service delivery. According to Bradley and Knoll (1995), "This construct was based on the assumption that all people, regardless of their abilities or severity of their disabilities, could grow and develop." (p. 8). Such development was to be promoted through the design and implementation of detailed behaviour modification and

skills training programs (Rioux, 1994). It was also believed that people with intellectual disabilities would learn and develop various competencies in predictable and quantifiable stages: "The result was elaborate teaching programs and lock step progressions through prearticulated learning objectives." (Bradley & Knoll, 1995, p.10). The developmental model called for the provision of a continuum of services through which service users would progress as they learned the skills and behaviours needed to become more independent and productive. In the area of residential services this meant that a range of housing options were required. These options would be more or less restrictive depending upon the level of competency and adaptive behaviour that service users attained through training and rehabilitation. Alternatives included community residences of various sizes and levels of supervision, apartment clusters, independent-living programs, foster care, temporary family care, boarding homes, etc. The most popular alternative became the small, community-based residence or 'group home', which, according to Willer and Intagliata (1984) was the alternative most closely associated with the principle of normalization.

In Ontario, changes in the delivery of public residential services for people with intellectual disabilities following the publication of the *Williston Report* (1971) reflected a commitment to

deinstitutionalization and normalization. In fact, while Wolf Wolfensberger was becoming a well-known international figure in the field of human services, he produced many of his influential works as a Visiting Scholar at Canada's National Institute on Mental Retardation [NIMR], (since renamed the G. Allan Roeher Institute). According to Simmons (1982), while at the NIMR, Wolfensberger played a major role in galvanizing key members of the Ontario Association on Mental Retardation [OAMR] against the continuation of the large institution. The OAMR lobbied vociferously for the development of a comprehensive system of community care through which people with intellectual disabilities might become fully valued and participating members of society (Ontario Association for Community Living [OACL], 1996).

From the early 1970s onward the government of Ontario adopted a policy of moving people with intellectual disabilities out of institutions and into the 'community'. In 1973, Provincial Secretary Robert Welch, released a report entitled *Community Living for the Mentally Retarded in Ontario: A New Policy Focus* (Anglin, 1978). This document clearly states the government's support for normalization: "Wherever feasible, services should be provided in a community setting as an alternative to institutionalization ...since a life of normalcy is our goal in caring for the mentally retarded." (quoted in Simmons, p. 203). Further, in 1974, all services for people with intellectual disabilities

were transferred from the Ministry of Health to the Ministry of Community and Social Services (Anglin, 1978). This transfer indicated a major shift away from the institutional/medical model of residential service. However, the process of actually downsizing institutions began quite tentatively. Between 1971 and 1977 the total number of residents in Schedule I and II facilities declined from 7,781 to 7,516, a decrease of only 265. In 1977 the average number of people in Schedule I facilities was 357, the average for Schedule II facilities was 109. During the same period the number of people being housed in community residences went from 260 to 1,560, an increase of 1,300 (Anglin, 1978, p. 71). By 1987 the total number of people being housed in Schedule I and II facilities had declined to about 5,200, a further decrease of 2,316 residents. In 1985/86 the number of people with intellectual disabilities in community-based residential programs had grown to just under 5,000, up from 260 in 1971 (Ministry of Community and Social Services [MCSS], 1987).

Soon after significant numbers of women and men with intellectual disabilities were removed from large, state-run institutions, researchers and practitioners began to criticize the effectiveness and validity of the group home model of housing support. This critique, however, did not represent an abandonment of the principles of normalization, socio-economic integration and independence for disabled

people. Rather, criticism focused on the failure of governments and service providers to actualize their commitment to these principles. Although the location of residential services had changed from the large facility to the 'community', the "social and psychological milieu" characteristic of many group homes was not significantly different from that of segregated institutions (Bradley, 1996, p. xi). In other words, experts began to question the extent to which the quality, rather than the geography, of intellectually disabled people's lives had been meaningfully improved as a result of deinstitutionalization.

One major criticism revolved around the extent to which the dominant position of staff members and the subordination of residents was carried over from large institutions into group homes, workshops, day centres and other community-based settings across North America. During this time, Bradley (1995) asserts, "The person with disabilities became an object to be trained, habilitated, socialized, screened, assessed, and assisted through a continuum of educational, vocational, and residential settings." (p. 8). The role of professional and frontline staff was to direct and monitor this process, with little emphasis put on empowerment and/or participation in decision-making for service users. Chappel (1992) argues that the principles and practices of normalization have done little to prohibit or challenge unequal and paternalistic staff-client relations in the

community service sector. In support, Bercovici (1983) found that relationships between staff and residents in the group homes she studied were often "stereotypically institutional" (p. 143), meaning that they perpetuated the dependency and passivity of residents. Further, considerable social distance was found to exist between staff and residents in group homes: "the content of interaction was predominantly management oriented, that is, consisted mostly of commands, admonishments, etc." (p. 143). My personal experience working in several group homes for people with intellectual and psychiatric disabilities corroborates Bercovici's findings to some extent. As a group home worker my decision-making authority over clients was rarely questioned. A nominal measure of choice for group home residents was considered important, (i.e. "Would you like toast or cereal for breakfast?"), but the power to make decisions of significance (i.e. "How do you think the group home should be run? What rules should exist?") was primarily reserved for support and managerial staff.

The other major component of the critique of the community residence/normalization model concerns the degree to which it has successfully promoted meaningful socio-economic inclusion or 'community membership'. Researchers have begun to question the extent to which being in the community (physical integration) has led to people becoming of the community (social inclusion). Unfortunately, many

people with intellectual disabilities living in group homes experience a high degree of isolation, often having limited social contacts with people in the surrounding community other than direct family members (Bercovici, 1983). Lord and Pedlar (1991), in their longitudinal study of life in the community for deinstitutionalized adults, found that most study participants did not become a part of the social fabric of their communities and had "very limited social networks." (p. 218). The vast majority of people with intellectual disabilities also remained dependent on the state for income support, finding few opportunities for gainful employment in the mainstream workforce (Roehrer, 1996).

The Supported Living Model

In response to the criticisms outlined above, a number of researchers and practitioners have begun to promote what is commonly referred to as the "New Paradigm" or "Support Paradigm" of community services for people with intellectual disabilities (McFadden & Burke, 1991; Middendorf, 1995; Polloway et al., 1996). Proponents of this support paradigm are disenchanted with the status quo, much like those who fought to do away with large custodial institutions. This disenchantment has led them to develop a new set of principles and practices intended to improve the community service sector's capacity to meaningfully increase quality

of life for people with disabilities. Beginning with a description of the founding principles of the support paradigm, supported living will be presented as a practice of providing housing support that is based on these principles.

Rejection of the Residential Service Continuum

A cornerstone of the support paradigm is its wholesale rejection of the belief that people with intellectual disabilities should progress through a series of least restrictive residential and vocational environments based on the successful acquisition of skills and/or behaviours (Howe, Horner, & Newton, 1998; Wolfe, Kregel, & Wehman 1996). Rather than focusing on the elimination of deficits through habilitation and training programs, proponents of the support paradigm accept and value individual difference. In other words, they choose to focus on the strengths and growth potential that each person with a disability possesses (Brown et al., 1999). The goal of service provision is to build on strengths and maximize personal competencies through support in nonrestrictive environments. Service begins, therefore, with placement in a fully-inclusive setting and consists of 'building in' the support necessary for an individual to remain in that setting and to gradually fulfil his personal goals.

Empowerment and Self-Determination

Perhaps the most important component of the support paradigm is its emphasis on the empowerment of people with intellectual disabilities. This focus on addressing power imbalances within the service system, and society as a whole, sets the support paradigm apart from its predecessors (Lakin & Smull, 1995). Empowerment can be seen as a process that consists of two basic steps. The first involves enabling people to take "action to achieve influence over the organizations and institutions which affect their lives and the communities in which they live" (Dunst, Trivette, & Lapointe, 1995, p. 14). Enabling people with intellectual disabilities to take action, or to accept and make good use of power freely given, involves helping them to learn new skills and develop existing capacities. Through this process, it is hoped that the intellectually disabled will gain the confidence and ability needed to take advantage of opportunities to exercise influence over their lives. The second basic step in the process of empowerment involves people with intellectual disabilities experiencing actual gains in power. This is a process through which people "gain mastery or control over their own lives and democratic participation in the life of the community." (Dunst, Trivette, & Lapointe, 1995, p. 14). For this to take place professionals and policy makers (as the dominant group) must take active steps to transfer some control over services and

decision-making to service users (as the subordinate group). It is hoped that through this two-step process people with intellectual disabilities will become more self-determining and independent (Wolfe et al., 1996). Further, proponents of the support paradigm argue that when a person becomes more independent his ability to realize personal goals is increased. The ability to shape our lives in a manner congruent with our beliefs and aspirations is widely recognized to be a key component of quality of life (Brown et al., 1999).

Person-Centred Planning

In large part the purpose of supported living is to provide service users with assistance that is tailored to their individual needs and aspirations. This is meant to be accomplished through person-centred planning, also referred to as personal futures or lifestyle planning (Allard 1996). The core of person-centred planning is an evolving process through which service users, with the assistance of family members, support workers and other allies: a) identify their goals, personal strengths/abilities and existing opportunities/community resources that facilitate goal-attainment, b) develop a plan of action to accomplish goals that builds on strengths and takes advantage of opportunities, c) implement the action plan, and d) on an on-going basis, revise and improve the action plan given

experience gained through efforts at implementation and the changing desires of service users. O'Brien and Lovett (1992) describe the essence of person-centred planning in the following manner:

We have historically been more efficient in providing people for services than services for people. Person centred planning reverses this tradition to create a personalized image of a desirable future and a problem-solving process for moving toward that future... The questions of how best to understand this person and how best to refine this understanding in action are central to the process instead of being the givens of regulations and professional training. (p. 5)

Full Social Inclusion

Proponents of the support paradigm reject the principle that service providers need to construct special environments in which to habilitate and train people with intellectual disabilities, even if the long-term goal of training is full integration into normal settings such as one's own apartment, the mainstream workforce, a regular school, etc. As noted above, people living in group homes often remained isolated from fellow members of their local communities (Bercovici, 1983). To some degree the structure of the community-based public service system has acted as a barrier to meaningful social interaction. In order to mitigate this problem supported living requires that assistance be provided in a manner that fosters meaningful relationships between people with disabilities and others who have no connection to the service system. According to Bradley (1996);

A fundamental task of service providers is to ensure that people make social connections and become fully integrated into the life of the community. These social relationships make it possible for people with disabilities to make use of natural supports in their communities. (p. xii)

Supported Living as a Practice of Providing Housing Support

In theory, supported living programs and agencies are founded on the principles described above. Allard (1996) defines supported living as:

enabling people, regardless of their disabilities, to live in the community where they want, with whom they want, for as long as they want, and with whatever supports they need to do that (p. 102)

O'Brien (1993) describes supported living in the following manner:

a person with a disability who requires long term, publicly funded, organized assistance allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own." (p. 1)

The cornerstone of supported living is that each service user lives in an apartment or house that he owns or leases, alone or with others of his choosing. Any person with an intellectual disability receiving support should possess the keys to his front door. He should also have as much control as possible over what occurs inside the premises (i.e. who to live with, what to eat and when, who visits and when, what to do with visitors, what to do with free time, how to decorate/arrange the living space, when to move and where, etc.).

Another major difference between supported living and

previous models is the belief that living arrangements and support provision should be treated separately. The process of providing housing support to a person begins with helping him secure a home in accordance with his preferences and desires, rather than placement within a 'program slot'.

According to Lakin and Smull (1995):

Supported living begins with the premise that people with developmental disabilities want, deserve, and need a home that is more than the physical space to which they return at the end of a day of school, work or other activity to receive food, shelter, "care" and "training." Like all other members of society they want and need a place where they can be themselves, where they can choose to do what they want, when they want and with whom they want. They want a home of their own that contributes to a lifestyle that they wish to lead.
(p. 2)

Once living arrangements have been secured, a range of other supports are then provided (in fully integrated settings) by support workers. The purpose of support is to ensure that people with intellectual disabilities experience personal fulfilment through the achievement of life goals (as defined by individual service users).

Supported Living in Ontario

The government of Ontario has professed a commitment to the concept of supported living for over a decade now. In *Challenges and Opportunities: Community Living for People with Developmental Handicaps* (1987), the Ministry of Community and Social Services [MCSS] stated that there would be a "major emphasis on supported independent living

arrangements for adults" in their multi-year plan (p. 3).

The Ontario Association for Community Living (OACL) is also a strong proponent of the principles and practices that are characteristic of supported living (OACL, 1996). The extent to which supported living has become a reality for people with intellectual disabilities in Ontario is much less clear at the present time. Nevertheless, descriptive and demographic data contained in *Quality of Life - Dream or Reality: Life for People with Developmental Disabilities in Ontario* (1997) provides some indication of the current situation across the province. The authors estimate that, of all adults with developmental disabilities receiving services from the Ministry of Community and Social Services (MCSS), 11,625 live with family, 6,368 live independently, 4,841 live in small care facilities (up to 10 residents) and 2,639 live in large care facilities. In other words, approximately 25% of adults with intellectual disabilities supported by the MCSS lived in residences "not directly controlled by community agencies or families" (p. 6). Of these individuals, 57% lived on their own and 33% lived with roommates. Further, over 90% of individuals living independently identified staff and/or professionals as a source of practical and emotional support. Therefore, although various programs and agencies may be more or less committed to or successful in the implementation of progressive principles, there is little doubt that supported

living is a popular model of residential service in Ontario.

Conclusion

Dominant attitudes and practices regarding residential service models have changed considerably since the early 1970s. To an extent there has been a visible progression from institutions to group homes to supported living. At the same time, however, many of the problems facing people with intellectual disabilities today, such as unemployment, poverty, inactivity and social exclusion, appear to have followed them from one residential setting to another. The persistence of certain problems indicates that service providers who integrate progressive goals into their mission statements do not always have the capacity to implement them. This reality, coupled with the increasing popularity of supported living as a model of housing support, necessitates a better understanding of the roles currently being fulfilled by frontline workers. As we build this understanding we will be more able to evaluate supported living's potential as the preferred model of housing for people with intellectual disabilities in our communities.

CHAPTER III: LITERATURE REVIEW

The purpose of this chapter is to review current research on the role of frontline workers in supported living, both in theory and in practice. First, the importance of frontline staff in supported living programs and agencies will be addressed, followed by a brief description of the new context within which workers function. Existing literature on the role of paraprofessionals in supported living will then be presented in detail. Studies explaining broader issues concerning direct-support personnel in the field of residential services will also be addressed. This literature describes major factors that may impact upon a worker's ability to implement her mandated role.

A Critical Role

Opinions concerning the purpose and practice of providing residential services to people with intellectual disabilities have changed considerably over the last 30 years (Polloway et al., 1996). Due to a range of factors, however, individuals and organizations have met with varying degrees of success in their attempts to operationalize these concepts. Without question, a major factor in the process of implementing new ideas is the frontline worker (Henry et al., 1996). Regardless of the setting, be it an institution,

a group home, a special school, a workshop, or, as in this research, a supported living program, frontline workers are expected to implement the mission of an organization through direct interaction with service users. If support personnel are not able or willing to meet these expectations, however, service organizations will not to be able to fully accomplish new goals and visions. According to Rice and Rosen (1991);

Every program administrator acknowledges the critical role of direct-care workers in applying sound tenets of learning and development to the daily lives of people with mental retardation. The most carefully conceived residential program applied in the most state-of-the-art architectural structure rests in the hands of direct-care workers. This truism cuts across the issue of large versus small facilities and institutional versus community-living settings. (p. iii)

As this statement indicates, the role of direct-support staff in the field of residential services is critical. This is particularly true when residential service consists primarily of workers providing assistance to service users in their homes and in the community, as is the case with supported living.

A New Context

Supported living radically alters where residential services are delivered. This fact alone has a significant impact on the nature of frontline work (Allard, 1996; Bradley, 1996; Hewitt & O'Neill, 1998). No longer do staff members work shifts in one central location as they would in

a group home or an institution. The workplace is multifaceted. It includes the service user's apartment or house, the local supermarket and other businesses, banks, social service agencies, community organizations, recreational facilities, etc. No longer do staff work in the presence of other staff, or under constant supervision from program coordinators (CRSCL, 1996). Further, in a supported living program it is less likely for residents to have contact with several different workers on a daily or weekly basis as would have been the case in group homes or institutions.

On the one hand, these changes can be viewed in a positive light. Frontline workers in supported living programs may be less likely to be adversely affected by co-workers with negative attitudes. They may be more likely to spend time building positive relationships with service users than with other employees. Workers may be less likely to see the work environment as their 'turf', given that they function as visitors to other peoples' homes rather than as a group of staff who manage a facility. Further, workers who experience increased autonomy from organizational structures may put this freedom to good use, using creative, person-centred planning techniques to help service users accomplish personal goals. Bradley (1996) claims that greater autonomy for staff may also lead to increases in "commitment and job satisfaction" (p. Xii).

On the other hand, one might also perceive certain dangers associated with the highly decentralized context within which many paraprofessionals now find themselves. Workers have less opportunity to absorb knowledge and learn important skills from co-workers, given that they will spend most of their working hours alone with service users. Workers may become isolated from fellow staff members who experience similar challenges (Hewitt & O'Neill, 1998). This isolation may result in reduced opportunities for staff members to support and counsel one another with less time for group discussion and problem-solving.

It is also a fact that workers in supported living programs function with a high level of autonomy from supervisors and co-workers (Allard, 1996). Unfortunately, we cannot be sure that this autonomy, and the increased power it bestows upon the worker, is being used to further the goals and aspirations of services users, or more generally, the principles of the support paradigm. Given the lack of existing research on the role of frontline staff in supported living, it is difficult to know with any degree of certainty how this increased autonomy is affecting relationships between staff and service users.

The Role of Frontline Workers in Supported Living: Theory

Moving toward supported living requires frontline workers to adopt a non-institutional consciousness or

identity (Knoll & Racino, 1994). They must learn a new way of thinking, based on the belief that people with intellectual disabilities, as a social group, will only experience significant gains in quality of life when they are fully included in their communities and empowered to lead self-directed lives (Bradley, 1996).

Service providers recognize, however, that if workers are to promote major gains in quality of life they must also learn a new way of doing their jobs. Researchers at the Human Services Research Institute (HSRI) are among the first to operationally define this 'new way of doing' by developing a set of national skill standards for direct support staff based on 12 broad competency areas. They are;

- **PARTICIPANT EMPOWERMENT.** The competent direct support staff (DSS) enhances the ability of the participant to lead a self-determining life by providing support and information to build self-esteem and assertiveness to make decisions.
- **COMMUNICATION.** The direct support staff (DSS) should be knowledgeable about the range of effective communication and basic counselling strategies and skills necessary to establish a collaborative relationship with the participant.
- **ASSESSMENT.** The DSS should be knowledgeable about formal and informal assessment practices in order to respond to the needs, desires and interests of participants.
- **COMMUNITY AND SERVICE NETWORKING.** The DSS should be knowledgeable about the formal and informal supports available in his or her community and skilled in assisting the participant to identify and gain access to such supports.
- **FACILITATION OF SERVICES.** The DSS is knowledgeable about a range of participatory planning techniques and is skilled in implementing plans in a collaborative

manner.

- **COMMUNITY LIVING AND SUPPORTS.** The DSS has the ability to match specific supports and interventions to the unique needs of individual participants and recognizes the importance of friends, family, and community relationships.
- **EDUCATION, TRAINING, AND SELF-DEVELOPMENT.** The DSS should be able to identify areas for self-improvement, pursue necessary educational/training resources, and share knowledge with others.
- **ADVOCACY.** The DSS should be knowledgeable about the diverse challenges facing participants (e.g. human rights, legal rights, administrative and financial issues) and should be able to identify and use effective advocacy strategies to overcome such challenges.
- **VOCATIONAL, EDUCATIONAL, AND CAREER SUPPORT.** The DSS should be knowledgeable about the career- and education-related concerns of the participant and should be able to mobilize the resources and support necessary to assist the participant to reach his or her goals.
- **CRISIS INTERVENTION.** The DSS should be knowledgeable about crisis intervention and resolution techniques and match such techniques to particular circumstances and individuals.
- **ORGANIZATIONAL PARTICIPATION.** The DSS is familiar with the mission and practices of the support organization and participates in the life of the organization.
- **DOCUMENTATION.** The DSS is aware of the requirements for documentation in the organization and is able to manage the requirements efficiently. (Taylor, 1998).

These 12 competency areas illustrate the primary role of frontline workers in supported living - to help service users identify and achieve short- and long-term personal goals in a collaborative manner that facilitates full social inclusion - and they enumerate the many skills needed to

fulfil this role. In theory, this mandate should inform everything the support worker does with her client, from grocery shopping to finding a new apartment. O'Brien & O'Brien (1994) divide the work of support workers into two basic components: assistance with instrumental tasks and individualized planning:

Each person will have a unique and changing mix of personal assistance based on the person's preferences and needs as they emerge.... Some assistance involves instrumental tasks such as dressing, eating, communicating, using the toilet, keeping house, shopping, going to appointments and activities, and managing money.... Some assistance involves helping a person to plan and coordinate activities and his or her come-in and live-in assistance. This help may involve determining the person's preferences and needs regarding type and location of housing; selection of roommates if they are desired; transportation arrangements; finding and scheduling activities that offer the person opportunities to pursue personally interesting goals; hiring, training, scheduling, supervising, and firing assistants; and personal problem solving. (O'Brien & O'Brien, 1994)

The proponents of supported living have incorporated a strong belief in flexibility, creativity and change (O'Brien & O'Brien, 1994; Knoll & Racino, 1994). Allard (1996) writes that "The job description of a supported living worker has been summarized as: 'Whatever needs to be done - do it'." (p. 112). In other words, workers must be flexible and adaptive so as to respond to a variety of contingencies. Further, flexibility and creativity are essential to the provision of client-centred supports in inclusive settings. In the real world, people with disabilities change their minds and grow in unpredictable ways, their priorities

change with new opportunities, the service system is reformed, and social and economic environments evolve. Support workers must be able and willing to deal with change effectively.

Throughout the support process, paraprofessionals are expected to prioritize the desires and perspectives of service users (O'Brien & O'Brien, 1994) over those of other more influential parties. These parties may include the support worker herself, other personnel, family members and potentially, the sponsoring agency itself. Where there is agreement between the service user and other interested groups and/or individuals, the job of the support worker would appear to be relatively simple - to accomplish goals in concert with service users and third parties. Exceptions occur when the service user is planning activities that will likely result in direct physical or psychological harm to herself or others.

Where there are conflicts of interest, however, the support worker's job becomes considerably more difficult. In these cases she is challenged to negotiate a "shared understanding of situations among people." (O'Brien & O'Brien, 1994) The worker may be required to voluntarily suppress her feelings and beliefs about what is best for the service user and to voluntarily engage in activities that she finds inconvenient and/or uncomfortable. In advocating for her client, conflicts may arise between the worker and

family members or those in authority in public service agencies or the private sector. Take the hypothetical example of a 23 year old woman with a moderate intellectual disability who expresses a desire to have sexual intercourse with her boyfriend of five months. She is attracted to him and feels that he cares for her. She has also demonstrated an ability to use birth control effectively. The young woman's parents, however, have asked the support worker to do her best to prevent their daughter from having sex. The parents do not trust the boyfriend and are concerned that he might convince their impressionable daughter to have sex without birth control. Nonetheless, the young woman has decided to act upon her desire for an intimate sexual relationship. In this case, the worker's responsibility is to support her client's decision while at the same time trying to reassure the parents, whose concerns may be legitimate. However, the worker must first grapple with a series of very difficult questions: If my client becomes pregnant, will I be held responsible? What if my client's boyfriend turns out to be abusive and/or manipulative? In this case, is promoting self-determination more important than protecting my client from potential harm? But at the same time, doesn't my client have the same right to take 'reasonable risks' as others? This hypothetical example illustrates the challenges and dilemmas support workers may face in helping the service user attain personal goals and

an independent lifestyle.

Supported living also promotes the development of assistive staff-client relationships characterized by equality, mutual respect and reciprocity. Researchers claim that such relationships provide a working environment in which people with intellectual disabilities can begin to shape their lives in a manner consistent with their beliefs, desires and hopes for the future. O'Brien & O'Brien (1994) write that:

Most existing services are based on unequal, hierarchical relationships. [Direct service workers] are accountable to those above them.... Often, their relationship with the people they serve mirrors their relationship to the agencies; that is, they behave as if they were in charge of the people they assist and expect the people they assist to be accountable for following the instructions they pass on. (p. 114)

In order to mitigate this problem, supported living agencies and programs should foster reciprocal and inclusive relationships among staff at various levels, so as to encourage frontline workers to do the same with service users.

Building assistive staff-client relationships is an important step in the process of empowerment. 'Top-down' or paternalistic relationships tend to engender passivity, helplessness and dependency in service users, characteristics that prevent people from taking control of their lives. Further, staff who adopt a position of authority over the people they serve are unlikely to possess

the personal qualities that facilitate empowerment. These qualities include;

- Ability and commitment to identifying strengths in people and groups;
- Genuine respect for diverse perspectives and lifestyles;
- A capacity to listen and reflect;
- An ability to subordinate one's own ego (to put one's self aside in the interest of the group);
- Skill and creativity in helping people become more aware of and confident in their own abilities;
- Appreciation of when to step back and the ability to help the individual or group assume decision-making action;
- Ability to analyze power relationships and help others to do so;
- Knowledge about how to gain access to information;
- Ability to reflect on and criticize ongoing process, including one's own role in those processes. (Cochran, 1990, reproduced in Bradley, 1996)

As listed, these personal qualities emphasize that empowerment is facilitated by paraprofessionals who understand the problems associated with power differentials, are self-aware and able to accept difference and diversity in the people they support, and who adopt a strengths-based perspective in their work.

For a variety of reasons, social isolation is a major cause of low quality of life for people with intellectual disabilities (Brown et al., 1999). Social isolation may lead to loneliness and alienation, a lack of emotional and instrumental support from others, below average opportunities for employment and building social networks, and lack of voice and presence in public decision-making processes. In essence, social isolation makes it very

difficult, if not impossible, for people with intellectual disabilities to fulfil their desires for intimacy, friendship, belonging, participation in decision-making and community building, and personal and financial independence.

In order to address problems engendered by social isolation, frontline support workers are assigned the role of facilitating meaningful social interaction between people with intellectual disabilities and others (Allard, 1996). The purpose is also to monopolize 'natural supports' that are available to service users. Natural supports may be provided, for example, by friends, family members, co-workers and supervisors, peers and teachers, staff in generic public service agencies and volunteers. (Leake et al., 1995).

The Role of Frontline Workers in Supported Living: Practice

In the previous section I reviewed documents that outline what is generally perceived to be the appropriate role for frontline workers in supported living, given basic principles like empowerment and inclusion (Allard, 1996; Bradley, 1996; Knoll & Racino, 1994; O'Brien & O'Brien, 1991 & 1994; Taylor, 1991; Walker & Salon, 1991). None of these authors, however, have systematically investigated what role frontline workers fulfil in practice. This may be due to the fact that supported living is a relatively new phenomenon. Allard reports that "the term 'supported living' did not

exist in the lexicon of community residential services until the mid-1980s." (p. 97). Regardless, we are left with little accessible knowledge of working relationships between paraprofessionals and service users in supported living.

An attempt was made, however, to document the role of direct support workers in the context of institutional care. Hile and Wilbran (1991) conducted a study on staff-resident interactions in a large state-operated residential facility serving people with intellectual disabilities. Through 20 consecutive days of participant observation they found that the majority of staff time per hour was occupied by three main activities; supervision of residents (32.5%), staff leisure time (20.7%) and socialization with residents (19.6%). The two activities that occupied the least time were training of residents (1.8%) and punishment (0.2%). Other activities included record keeping, ward management, housekeeping and personal care. According to the authors, if supervision is excluded, only 21.4% of staff time was spent in "desirable interactive activities" with residents (socialization and training), about the same amount of time spent on leisure activities such as smoking a cigarette. These findings are consistent with the findings of other researchers who report desirable staff-client interactions taking place less than 25% of the time (Hile & Wilbran, 1991). To date, however, it does not appear that studies such as Hile and Wilbran's have been conducted in the

context of supported living.

Factors that Affect the Worker's Ability to Fulfil Her Role

Exclusion and Devaluation

As stated above, numerous studies recognize the critical role that paraprofessionals play in carrying out the mandate of community-based residential service providers (Henry et. al, 1996; Knoll & Racino, 1994; O'Brien & O'Brien, 1994; Rice & Rosen, 1991). Given this key function, it would seem logical for frontline workers to be actively included in decision-making procedures, and to be accorded a position of considerable value within the organizations that employ them. The reasons are quite simple. First, researchers have shown that employees are most satisfied and productive when they are empowered to participate in making important decisions, a form of "self-actualization" (Birenbaum & Cohen, 1985). Second, frontline staff members are among those most knowledgeable of the personal, social and economic problems experienced by service users. This fact alone necessitates their active participation in planning and decision-making. Direct support workers must be involved as allies and advocates because they witness first hand the challenges and opportunities that are at the heart of administrative decisions.

Regardless of the apparent need to better value and utilize the day-to-day experience of frontline workers, professionals and service providers have been somewhat slow to do so. According to Knoll & Racino (1994):

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

Having reviewed a large number of studies on residential services for people with intellectual disabilities, and having been employed as a support worker in several group homes myself, I would support Knoll & Racino's assertion. In the literature, lower-level staff are often described more as part of the *problem* than as part of the *solution*, setting up an adversarial relationship between managers and workers. According to Bradley (1996), "The role of direct care staff in traditional organizations is essentially to be the arms and legs of the agency, carrying out orders rather than collaborating to solve problems." (p. Xii). This assertion is echoed by Hewitt et al. (1996) who claim that "Direct support workers constitute somewhere between 80-86% of the developmental disabilities workforce, yet they have

the least amount of power and visibility of all workers in the field." (p. 12). This lack of power and visibility may limit the capacity of workers to provide people with intellectual disabilities the support they want and need.

Turnover and Compensation

High rates of staff turnover have been a long-standing characteristic of public and private residential settings for people with intellectual disabilities in both the U.S. and Canada (Mitchell & Braddock, 1994; Lakin & Larson, 1992; Larson, 1997; Larson & Lakin, 1992; Riediger & Baine, 1987). The staff turnover rate is a measure of the percentage of staff who leave their positions during a given time period. In the U.S., Larson (1997) reports that:

Recent national studies in community-residential settings have found annual turnover rates for direct support workers ranging from 34% in small publicly-operated homes to 70% for small privately-operated homes, with most recent estimates of turnover rates in the 50%-70% range. (p. 1)

In the province of Alberta, Riediger and Baine (1987) found an annual turnover rate of 40% in a sample of both public and private group homes.

The causes of high turnover are numerous. Mitchell and Braddock (1994) found that in public community facilities lower turnover rates were associated with higher wages and unionization. For private facilities, lower turnover was also associated with higher wages and the provision of

health benefits for employees. Lakin and Larson (1992) found that staff instability was associated with relatively low wages and few opportunities for advancement. These studies establish the link between levels of compensation and rates of staff turnover. This is a serious problem given that direct care workers "represent, to a large degree, an economically disadvantaged strata of society." (Rice & Rosen, 1991, p. Iii). Reidiger and Baine (1987) found that group home workers were less likely to leave their jobs if they were a) over the age of 40, b) female, c) not working with "severely mentally handicapped residents", d) not working with residents who required physical assistance, and/or e) were less educated. The negative effects of high staff turnover are also numerous. They include:

discontinuity of treatment and care; withdrawal of important relationships from the lives of dependent people; low productivity and staff shortages; consumption of administrative and financial resources in the personnel replacement process; increased formalization of the rules of conduct; lower participation of staff in primary group relationships; increased job stress; and reduced job satisfaction of staff. (Lakin & Larson, 1992, p. 246)

People with intellectual disabilities and their parents have also expressed a deep concern with high staff turnover, a fact of life that has caused them considerable anxiety and hardship over the years (Hewitt et al., 1996).

Training and Attitudes

Researchers recognize that direct support workers need

extensive pre-service and in-service training in order to develop the skills, knowledge and commitment required to do their jobs effectively. Studies have found that training can have a positive effect on the attitudes of support personnel (Henry et. al., 1996; Sumarah, Maksym & Goudge, 1988), but is often *inadequate, ineffective and inconsistent* (CRSCL, 1994; Gardner & Chapman, 1992; Knowles & Landesman, 1986). The link between training and attitudes is of major importance. Henry et al. (1996) found that direct support personnel who have insufficient training in the philosophy of community living tend to lack a strong attitudinal commitment to its principles (i.e. empowerment, social integration, independence). Without such a commitment, these researchers claim that;

there is little reason to believe that progressive philosophies will have much noticeable impact in the everyday lives of people with mental retardation and/or mental illness. Implementation of this philosophy necessitates changes in job behaviours and attitudes among staff members who work closest with people who have mental retardation and/or mental illness. (p. 368)

To make matters worse, the financial costs of providing quality training opportunities are compounded by high staff turnover rates. There is an "administrative reluctance" to providing extensive training in organizations plagued by high turnover (Knowles & Landesman, 1986), due perhaps to the financial burden involved.

CHAPTER IV: METHODS

The research methods described below were chosen because of their appropriateness in collecting qualitative data within an exploratory and participatory framework. As demonstrated in *Chapter II*, the role of frontline staff members in supported living has not been systematically investigated from a variety of perspectives. Topics that are not well defined and conceptualized in existing literature, Newman (1997) suggests, lend themselves to an exploratory design. Newman explains that we must first have a basic idea of what is happening in any given setting before we can explain why it happens a certain way.

Information was collected within a participatory research framework. Participatory research emerged as:

a practice that attempted to put the less powerful at the center of the knowledge creation process; to move people and their daily lived experiences of struggle and survival from the margins of epistemology to the center. (Hall, 1992, p. 15-16)

By maximizing the participation of the constituency in various aspects of research, from design to reporting, and by broadening the research endeavour to promote a "three part process of social investigation, education and action" (McGuire, 1987, p. 3), participatory researchers aim to produce knowledge in a manner that is inclusive, accessible, empowering and generally beneficial to stakeholders. The

active participation of members of disadvantaged social groups and their allies is believed to produce research that is highly relevant and of greater utility to various stakeholders.

Population and Sample

Sampling Procedure

A non-random purposive sampling technique was used to identify participants for the research. Newman writes that "a researcher may use purposive sampling to select members of a difficult-to-reach, specialized population." (p. 206). This sampling technique was considered appropriate given that the purpose of the research was not to identify generalizable conclusions from findings, but to begin to build a foundation for further research. Participants were selected from within a community support services program (CSSP) operated by a large multi-service association for people with intellectual disabilities in Eastern Ontario. Although the official title of the program is not 'supported living', it meets the basic definition provided in Chapter II. Although the original title of the program was 'Supported Independent Living', it was renamed when service was extended to individuals not living independently in their own homes (i.e. people living in nursing homes). These individuals were excluded from the sample, however, in order to ensure that participants were all involved in what is

commonly defined as a supported living program.

Participants were contacted via their support workers. The supervisor of the CSSP distributed an information letter (Appendix A) to all support staff in the program, along with a memo requesting that they submit names of any interested clients. They were also instructed to read over the consent form (Appendix B) and the oath of confidentiality (Appendix C) with service users. A total of seven adults expressed a desire to participate. With the permission of the prospective participants, their names and phone numbers were given to me by the CSSP supervisor.

I then contacted all seven individuals directly by phone. During these conversations I explained to each person that I was a graduate student in Social Work at Carleton University working on a project exploring the role of support workers in the lives of people with disabilities, and that I had been given his or her name and phone number by the supervisor of the CSSP. I asked prospective participants if they were interested in coming to a first group meeting. All responded in the affirmative and gave me a few possible dates on which they were available. I then called each person a second time to give them the meeting date upon which everyone had tentatively agreed. During this second conversation I asked for permission to call each person's support worker in order to advise them of the time and date of the first meeting. All prospective participants

gave their consent and agreed that this was a good idea. I then gave a number of detailed maps with directions to the first meeting to the CSSP supervisor who distributed the maps to support workers. I also called each worker to remind her of the first meeting. Each participant was contacted a third time in order to ensure that they were prepared for the first group meeting.

Selection Criteria

In order to be eligible for selection, each participant was required to:

- a) have an intellectual disability;
- b) live by himself or herself, or with roommates, in an apartment or house not owned or leased by a service organization;
- b) receive support from a worker in his or her own living space through the CSSP program;
- c) be 18 years of age or older;
- d) have basic oral communication skills;
- e) be able to arrange transportation to a series of group meetings;
- f) be capable of understanding information contained in a letter of consent and an oath of confidentiality.

The Participants

Of the seven prospective participants who submitted their names to the CSSP supervisor, six attended the first meeting. The seventh never materialized. Each participant received assistance from a support worker in his or her own home through the CSSP mentioned above. Four participants lived alone, one lived with his wife, and one lived with a roommate who also received support through the CSSP. All but one of the participants was male and none was a member of a visible minority group. Five of the six participants received income support from the provincial government. One group member was employed full-time in the mainstream workforce, two worked in a sheltered workshop on a part-time and/or full-time basis, one member worked part-time and received assistance through a supported work program, one worked part-time with no on-the-job support, and one was unemployed and working on credits toward his high school diploma through distance education. Prior to their entry into the CSSP, four participants had lived in an institutional and/or group-home setting. The remaining two moved directly from their family homes into their own apartments.

To date I am still unaware of the official medical profiles and diagnoses of the adults who participated in this research. I made no attempt to gain access to their case files. However, given the communication skills

demonstrated by all group members and the levels of personal independence they have achieved in daily life, it is clear that most would be considered to have comparatively mild intellectual disabilities.

Data Gathering Methods and Materials

The data collection process consisted of a series of three focus group meetings followed by individual semi-structured interviews with each participant. Group meetings lasted approximately two hours while interviews lasted approximately one and one half hours. Participants were paid \$20.00 prior to each meeting and/or interview. Group discussions were structured around a series of basic questions (Appendix D) that focused on two major areas. The first involved the type of support participants wanted from workers. In other words, participants were asked to verbalize what they thought the role of workers should be and why. The purpose was to identify the personal preferences of service users with regard to frontline workers. The second area revolved around the roles actually being fulfilled by current and past CSSP workers and the relationships that had developed between workers and service users. Questions posed to participants during individual interviews (Appendix E) were designed to probe more deeply into this second area. During focus groups answers were recorded on flip-chart paper. All group discussions and

individual interviews were also tape-recorded.

Data Analysis

Transcripts of all individual and group discussions were made from the original tape recordings. An inductive content analysis of all verbatim transcripts was then conducted. As transcripts were read repeatedly, major categories and sub-categories began to emerge. All data were then coded according to these categories. Once this process was complete, all verbal statements within categories were analyzed and compared in order to identify themes and issues for analysis.

Ethical Considerations

Informed Consent

In order for research involving human subjects to be considered ethical, consent given by participants must be well informed and entirely voluntary. In order for consent to be informed, participants must be made aware of a) the identity of the researcher and his personal goals and intentions in conducting the research, b) the general purpose and nature of the research, c) any foreseeable risks and/or benefits that may be involved in participation, and d) their option to withdraw from the research at any time without penalty with the opportunity to reengage the project at any time. In addition, it must be clear to the

researcher that the prospective participants understand all the information provided.

In my case, all necessary information was contained in a letter of consent (Appendix B). This letter was read aloud and discussed in detail at the beginning of the first group meeting. Prospective participants were given the opportunity to ask questions about anything that was not clear to them. Although a few of the prospective participants appeared impatient with this process and expressed a desire to "get on with it", the entire document was reviewed before anyone signed it. My impression was that each member of the group understood the information contained in the letter. During this meeting and the several phone conversations I had with prospective participants, each person demonstrated the intellectual capacity needed to understand the relevant concepts contained in the letter of consent.

Confidentiality and Anonymity

Given that a large amount of data was gathered from service users in a group setting, there was no way for me to guarantee that discussions would remain entirely confidential, or that participants would remain anonymous. I made this very clear to group members from the start. As with any focus group, there was a risk that participants would later repeat things heard during meetings or reveal the identity of other participants to outsiders. In order to

minimize this risk participants were required to sign an oath of confidentiality (Appendix C). I read the oath to participants immediately following our discussion of the letter of consent, emphasizing the importance of respecting the privacy of all group members. Participants were advised, on an ongoing basis, to avoid revealing any information about themselves or others that they felt should remain confidential. Further, I explained that if participants were not comfortable discussing something within the group setting they could talk to me in private after the meeting or during their individual interview.

For my part, I did not reveal the names of any participants in my research to any third party. All identifying information was removed from transcripts and written reports. Further, all tape recordings and transcripts were kept locked in a secure place throughout the research process and will be destroyed once the project is complete.

Other Risks

The research process presented no direct risk to the physical well-being of participants. There was some potential risk, however, to their emotional well-being. I was concerned that the more vocal participants might respond to other members in a potentially hurtful and insensitive manner. In order to minimize this risk I began each meeting

with a discussion of the importance of mutual respect, support and equality within the group. In response, group members were very supportive of one another, and statements such as "That's a really good one" or "You know, I think you did the right thing" were not uncommon. To minimize the possibility that the content of any of the group sessions might cause stress and/or anxiety among group members, participants were given my telephone number and encouraged to call me if they were troubled by any aspect of the discussions. It was also made clear that they should feel free to leave meetings at any time if they were upset or disturbed.

Strengths and Limitations

A limitation in the sample was a lack of diversity with regard to gender and ethnicity. Of the six participants there was only one woman, and no one was a member of a visible minority group. It might have been preferable to have a broader spectrum of respondents represented in the sample.

A limitation of the purposive sampling procedure used was the lack of direct contact between the researcher and prospective group members (the population). All information concerning the project was passed-on to service users by frontline workers and one must not reject the possibility that group members could have been selected, or rejected, by

the workers themselves for arbitrary reasons. In other words, there was no way to guarantee that frontline workers facilitated the participation of the whole population equally. Further, due to the non-random sampling procedure, the sample itself can not be said to be representative of the population as a whole. Thus conclusive generalizations can not be made from findings.

The small sample size was both a strength and a limitation. On one hand, a larger sample would have rendered more diverse and potentially more representative results. On the other, the small size of the sample facilitated the group discussion process, while allowing me the opportunity to collect large amounts of data from each individual. With a larger group I would not have had the same capacity for in-depth exploration of issues, ideas and experiences. The size of the sample allowed me to take a close look at the situation of each participant, rather than a brief glimpse at the situations of many.

Another strength of the study was the use of more than one method of data collection. Certain participants appeared more comfortable expressing themselves in a group setting, while others were much more at ease on a one-to-one basis during interviews. Beginning data collection with three focus group meetings also gave participants the opportunity to get to know and trust me, however tentatively. This knowledge and trust facilitated individual interviews.

CHAPTER V: FINDINGS

In the following chapter findings from focus groups and individual interviews will be presented in three categories. First, participants articulate the kind and degree of help they want from support staff members, while presenting their ideas on the general attributes of a 'good' or 'bad' worker. I hasten to point out that responses in this section should not necessarily be considered statements about participants' current support workers. Second, participants tell us what support they receive on a regular and occasional basis in six sub-categories: instrumental support with the tasks of daily living, social support, help building social relationships with other members of their local communities, self-advocacy, housing and employment. Third, participants describe the processes in which support is provided with a focus on assistance with instrumental tasks, communication, pace and decision-making in planning.

The administrative staff that provided assistance in identifying participants for this study asked me to note that these findings represent only one side of a multifaceted story. Administrators felt that support workers might have a somewhat different view of their relationships and interactions with service users that will not be reflected in these findings.

"The Role Support Workers Should Play in Our Lives"

In part, focus groups were designed to give participants an opportunity to speak about their vision of the ideal support worker-service user relationship. The purpose was to provide a basis upon which to determine the extent to which service users receive the help they need in a manner congruent with their beliefs and personal aspirations. It was apparent from the start that participants had not previously engaged in such an exercise. Puzzled by what it was they were being asked to do, some initially reacted with uncertainty. It seemed that they were having difficulty drawing a distinction between 'things as they are' and 'things as they would like them to be'. Within a short period of time, however, participants began to speak quite freely about what they understood to be the qualities of a good support worker. In general, this understanding was expressed by drawing links to past experiences with paid support staff.

All participants agreed that a good support worker is a pleasant, communicative and respectful person with a good sense of humour. In essence, participants want kind, friendly workers who enjoy their work and believe in the capability of service users to grow in positive ways. Participants described ideal support worker-service user relationships as:

...kindness relationships, respect, client-worker respect.

...like a friendship, like a person you can tell your problems to like for instance you're not afraid to tell them your problems like other people.

Others described a good support worker as:

...someone who doesn't yell at you. Someone who has a pleasant voice, or attitude. A pleasant attitude.

I see her and she's pleasant, she's willing to talk to you, she's willing to sit down with me and discuss it.

Well, they should respect me. If they learn to respect me I will respect them. Sometimes they're pushy. Not all counsellors I used to have did, but my worker does, so much, she's sorta different, but I can understand why she's doing it.

...another thing that I find with the support workers is as long as she has a good sense of humour. Sometimes when your doin' something, when your kidding around with them you know. I'm the type to kid around and one thing I understand with my worker is that she has a sense of humour, but some of these support workers...

As one can see, participants generally described the type of relationships they want with workers as "friendships". They made it clear that informal social interaction is a very important element of the support provided by workers. When asked what activities they would like to engage in more frequently participants responded:

P1: Go and have a coffee with them. Go out and talk.

P2: Go for a drink or something.

P1: Go to a restaurant and talk and have a tea or coffee.

I: So you'd like to see them more on a social basis?

P1: No, no this is besides coming over to see you. Like going some evening to have a coffee and talk about how you're doing and that.

P2: Go for a drink or something

I: You mean totally separate from everything?

P3: Ya, get the budgeting out of the way and if you have time go to a restaurant and talk about different

things like what you want to do for your life, you know.

P4: Well I've done that before and it is a good thing to go out with your worker for a coffee or a drink and that. And I've done it before and it is a good thing to do...

P5: Ya its a good thing to do. I used to do that with my other last two counsellors but since I got the support worker I have now we haven't done that. I would like to take her and go out and have a few drinks at a bar...maybe she could meet my uncle.

P2: Or go to a football game or a sports game.

P6: I feel that they can't go drinking. The supervisor has a policy in her program that you can't go out for drinks 'cause of the rules.

P1: What if she's off duty then?

P6: If she's off duty, ya.

P1: You don't do it during work, you find out if she's off duty and then you do it.

I: Anything else?

P3: Take her out to a movie

P1: Go for a walk some place. Go out to the park and sit down and talk.

P2: Watch the birds.

Given that most participants lived by themselves, this desire for increased social interaction with workers is not surprising. There are interesting implications here, however, given that the supported living model emphasizes facilitating social interaction with other members of one's surrounding community, not paid staff. Proponents of supported living may perceive increased social contact between workers and service users as having the potential to reinforce a natural tendency toward emotional dependency in service user-support worker relationships.

Participants were equally clear about the fact that they did not want support from people who were unpleasant, unkind and disrespectful of them or their loved ones. Participants described the type of workers they do not want

in the following manner:

...well, she comes over in a bad mood, and gets mad at you for anything you say, doesn't have a good sense of humour when you talk to her, very rude, doesn't always listen to you.

...they talk back too much to anyone else.

...The worst would be someone that yells. And slamming doors, that's another one. And someone that just picks up things and throws them all around.

...doesn't pay attention.

...I don't beat around the bush. If someone says something to me and I don't like it I tell them to leave. Like if a friend came over to see me, and the counsellor said something bad about him, I'm sorry, if you don't like it leave. Don't talk to my friend like that.

Participants agreed that they want support from a person who is patient with them and who moves at a gentle pace. This was considered very important:

...I want a counsellor that don't get mad too quick. I had a counsellor that got mad so quick I told him to get out.

...when they're worst support workers they go like faster in their work and they don't take the time to explain.

Participants expressed an aversion to workers who "rush through things". They want their workers to take time to communicate effectively and explain ideas in full detail. In doing so, support workers show confidence in the service user's capacity to accomplish personal goals. Support workers who rush through their visits or who appear impatient can leave service users with the impression that their attempts at personal improvement are futile.

With respect to the gender of workers, there was no consensus as to whether or not participants preferred men or women. All participants' current support workers were women. None expressed a clear desire to have a male worker. Two participants did, however, make it clear that they preferred to have female workers. One of the two was the only female participant in the group.

All participants agreed that it was very important to have workers who support the right of service users to be in control of their lives. Personal freedom, for example the ability to "come and go" as one pleases, was highly valued. Respect for the privacy of service users was also considered paramount. Participants were clear that they do not want to be told what to do in their own apartments or have workers who invade their personal spaces:

...what the worst support worker is they dictate, I had a support worker that dictated to me what to do in my place, they dictate.

P1:...they go in to your room without your permission and go through your stuff.

P2: Really? They don't do that to me.

P3: I had that the same with my worker going in my room, its o.k., but going through my stuff, no, you don't touch nothing. If I go away, "do you want me to help you pack?" No, you don't touch it m'am or "out the door".

...some of them threaten you. I've had a few of them threaten me. Oh ya, like anything they say be quiet or I'll do somethin' to ya, oh ya.

...I don't like it when they're bossy, when they tell you what to do and that.

Participants felt that support workers should get along with and listen to their family members. In fact, one participant went as far as to say that he wanted his support worker to be more like his sister, another felt that his father would make the ideal support worker. A third participant felt that support workers should be more like teachers:

I would like my support worker to be more like a teacher. To teach you more things.... I know how to cook but I don't know how to sew.

For a number of participants it seemed obvious that mothers, fathers, sisters and brothers played a crucial role in their daily lives. Those who were not in close and regular contact with members of their immediate family indicated they were unhappy about the situation. In general, participants wanted workers and family members to have close collaborative relationships:

Well she [my sister] helps me a little bit more with me than my support worker, but I think that both of them should, you know, work together because the support worker and parents should work together.

One participant felt that it was very important for his support worker to listen to his parents:

They don't listen to parents. They sit down and they don't listen to the parents. The parents have seen what their son and daughters do. They don't work together. They don't really sit down with the parents and discuss what goes on.

A lack of communication and collaboration between parents and workers appeared to be a source of stress for a number of participants. This makes sense given that service users

tend to depend heavily on both family members and paid staff for support and guidance.

Service users also expressed concerns about conflict between supervisors and frontline workers in the organization that provided them with support. This issue is linked to the relationship between workers and parents given that many parents appear to be involved in the direction of the organization as board members. Many of the non-profit organizations that now provide government-funded services to people with intellectual disabilities were founded by parents' groups. As a result, parents could be more likely to be associated with management rather than unionized frontline workers.

In the year prior to the beginning of data collection for this study, the organization providing support to participants was experiencing conflict between management and the union representing frontline workers. Participants were aware of and clearly troubled by the situation, facing, at various times, a possible walk-out or lock-out and replacement of their workers by "scabbers":

P1: What they doing, you see a lot of the counsellors that we did have have been bumped off or left because they were going to go on strike but they didn't. What they were going to do they were going to lock them out and were going to send scabers.

I: So they were going to go on strike and they got moved around?

P1: Ya, and there's still going to be more cuts back.

P2: Well it depends what the government's doing.

...I needed some support. I was not happy with them sending me a scab... They're still fighting with the

supervisors. They want to kick the supervisors out of the union. Some of them have been there for 20 years or more.

The situation appears to have become so bad that managers and support workers will not even associate on a social basis:

They are having a dispute now...the supervisors and the union are having a dispute now...that's why we don't have a Christmas party, they don't want to associate with management.

This conflict between managers and frontline workers would seem likely to prevent support workers from having a significant role in planning and decision-making.

The views of participants on the issue of staff turnover varied. While it was difficult for most participants to remember the exact number of workers they had been involved with since joining the supported living program, most had clearly been dealt a number of different people. One participant felt that turnover was a major problem for him:

I've had 5 support workers in 4 years. And its like once you get to know them and then they're gone. They change a lot...like I had a support worker before the one I have now that quit, and we went everywhere together. I've had him since last year and I was disappointed that he left the program.

Another participant did not appear at all concerned about the fact that his worker changed from time to time:

Like I was with one worker and then another came along and I got along with both of them.

This latter view was more common. Participants did not generally talk about staff turnover as having a particularly negative impact on the quality of their lives. Turnover seemed to be accepted as a normal and inevitable component of the service user's life experience.

"The Role Support Workers Do Play in Our Lives"

While focus groups tended to be dominated by a discussion of broad-level needs and desires, the primary purpose of individual interviews was to ascertain, in as precise a manner as possible, what support participants were receiving from their current workers.

The amount of support they received varied. The range was from one to three hours of direct support each week with extra time spent on the phone. However, given the relatively mild intellectual disabilities of participants in this research, this may not justly represent the average length of time that service users are allotted in the program as a whole. The timing of visits also varied. For example, one participant saw his worker for one-and-one-half hours twice a week while another saw his worker for one hour three times a week. Five out of six participants saw their support workers on weekdays only, primarily in the late afternoon or early evening. Two categories of support seemed to occupy a large majority of the time that workers spent with participants: instrumental support with tasks of daily

living and social support.

Instrumental Support

For the large part, instrumental support provided to service users included: budgeting, making up grocery lists, shopping for food and supplies, planning and cooking meals, assisting with laundry, recording and arranging transportation to medical appointments, reminding service users of their commitments (e.g. medical appointments) and assistance with a variety of contingencies such as a cat becoming ill or food going rotten.

Support with the basic tasks of daily living was generally in the form of direct assistance with a task itself. This process will be described in detail in the next section of this chapter. Some support workers, however, also fulfilled the more supervisory role of "making sure" that service users engaged in tasks such as cleaning, laundry, physical hygiene, etc. Participants describe this role in the following manner:

...she comes over to budget and she does check to see how clean my apartment is.

...They make sure you go to work with clean clothes, make sure you take a bath, or whatever you want to do the odd time.

P1:...she respects my privacy but there is only one little thing that I don't like, is when she comes over I have to have the house spotless or else I don't get any money out of the bank.

P2: Really? But if you've got an account in your bank that's your own money. She wouldn't have any business

going there.

P3: I know, she doesn't, but she doesn't co-sign her thing for her. It's like me I have a co-signer. She just comes over and does my budgeting that's all because I have problems with money.

P: I do my laundry while she helps me do my grocery list. And then she keeps it...I do my own laundry by myself.

I: If you do your laundry by yourself, why do you do it when your worker comes over?

P: Because she does it different than the other counsellor. She always demands so much, "Oh, time to do your laundry every Tuesday". She keeps saying I should do it once a week...you see I usually forget. But it doesn't matter if I have just a little bit, "Do you have any laundry to do?" "Yup." "How much?" "Nope, gotta do it."

I: Is that OK that she always makes you do it no matter what?

P: No, that's OK, I'm not going to sit and argue with her. Like I did before when I just got her. That's when we didn't get along the very first time.

The above statements exemplify the fact that support workers may put the enforcement of what they understand to be acceptable standards of cleanliness and personal hygiene ahead of the promotion of self-determination and personal independence for service users. To accomplish this, support workers may resort to 'threats' (refusing to co-sign a withdrawal slip for spending money) or simple pressure tactics (telling service users they "gotta do it"). This type of behaviour by the worker could be a result of the policies of the service provider, pressure on support workers from parents and siblings, or the support worker's personal beliefs about appropriate lifestyles for service users.

While the type of instrumental support provided to each

participant varied, a small number of activities appeared to predominate. What participants referred to as "budgeting" was one of them, an area in which all participants received support save one. Budgeting consisted of paying bills for cable, phone, etc., writing rent cheques, filling out and, in some cases, co-signing withdrawal slips:

...basically she comes in, she sits down where you're sitting, and we do budgeting, and then I get her a tea or a coffee.

Well she comes over and helps me with my budgeting, signs my check and that's it...she co-signs my bills and checks and withdrawal slips and that.

...she fills it out and all I do is take the withdrawal slip and my bank book to the bank.

P:...if I still have some money left after I take out my spending money, I usually don't take out any more spending money. Just my grocery money and whatever is left, it is mine.

I: And you can do whatever you want with it?

P: Pretty much

Another significant area of support involved shopping for and preparing food. During home visits workers would make a grocery list with participants. In some cases participants would then shop for and prepare their food independently. In others, the worker would do this with service users:

We make a grocery list every month... We sit down and we pick out things that we need for groceries for the house - for the apartment... I ask, I told her what I need and she puts it on a grocery list.

P: We make dishes

P: You cook?

I: Ya. That's about it. And then we make something, we have these dishes that I use to put in the microwave. I'll show you.

...cook my meals, and my meals. She'll cook them cause she doesn't want me using the stove cause it's too dangerous.

Social Support

All participants received some social support from workers, either during weekly visits or on occasional outings for coffee or a meal. Even so, the extent to which social interaction with workers contributed in a meaningful way to the emotional well-being of services users was questionable. A number of factors appeared to restrict the amount and quality of social support provided. Workers have a limited amount of time to spend with service users: one to three hours per week. In particular, when service users have significant support needs, workers are required to accomplish a number of instrumental tasks in a relatively short period of time. This may result in little time left for social interaction. In addition, as we will see further on in this chapter, support worker-service user relationships can at times be somewhat adversarial. In these cases, there seems to be little foundation to build relationships in which positive social interaction is a core element.

During weekly visits, workers would generally begin with instrumental tasks such as budgeting or list-making and, during some of the remainder of the visit, spend time talking or chatting with service users. With respect to

their weekly visits, participants described their social interactions with workers as follows:

And we talk, we get along now, before we didn't, but we get along now. As long as I don't look at her legs. Don't put that down, ha ha ha! She might kill me!

Whenever I'm frustrated I talk to them about the situation and I talk to them about what I'm frustrated about and they're good help that way, and they're good at helping that way.

... I have a support worker, I got this support worker two weeks ago... and she sits down and talks to me, we sit down and we talk.

...my father and my mum are so far away...they live three hours away and its - um - I don't have the family atmosphere, and anyways, when my worker comes she just makes me feel like...she makes me feel happy and that's why I like working with her.

Oh, she's allot of fun. She's pleasant. Nice to talk to. We joke around and stuff. We just try to get along. We're fine.

One participant felt that it was not right for him to burden his support worker with what he perceived to be his own personal problems:

I: What kind of things do you phone her about?
P: Different things. Not really personal. Anything personal I keep to myself. I don't like telling people. They have problems of their own and I don't feel like giving them my own personal problems. Sometimes its something I have to work out myself. I can't tell anybody, I say "lookit, I have to work this out for myself."

When analyzed from the perspective of support workers much of this social interaction appears to be have been functional in nature. Sitting around in an apartment "chatting" presents an opportunity for workers to gather information needed to assess a service user's physical and

mental wellbeing:

I: What kind of stuff do you talk about?

P: Oh, about herself but mostly about me, you know, am I taking my pills...and how I'm doing...and you know how I'm doing, keeping myself healthy. And how I'm doing going to the dentist. Which I used to be afraid to go to the dentist, and how I'm doing taking my eye drops, and how I'm doing at work.

...We sit down and we talk every week...we sit down and we talk and I tell her all my appointments when I have them - different doctors.

Ya. We sit and chat. Like about things I'm going to eat for the next day.

...and then we what we do after that, we have a cup of tea or coffee and we just have a little chit chat about the day and how its going and how I like it at work, you know, stuff like that. And she asks me if I have any doctor's appointments. And I go 'ya'. And I mark them all down. And she marks them all down in her book...and then after that she leaves, she goes, and she sees somebody else. And that's all she does.

...[We] discuss things, and that, like you know, talk with the counsellor, yup... I tell if there's any problems.

At times, social interaction also appeared to be quite structured:

I: Do you get much of a chance to talk to her?

P: Oh yes, on Wednesdays, but mostly when I go meet her at the mall every Friday.

I: But on Wednesday when she comes?

P: It's just budgeting.

I: Its just work and you don't have a lot of time for socializing or whatever?

P: No, not till Friday. Always we do on Fridays. We do that when we go and do my groceries, and we do her groceries too.

Although gathering information through conversation with service users may be an important part of the worker's job, injecting this functionality and structure into social

interaction may have some unintended negative consequences.

Building Social Relationships with Other Members of the Community

As described in Chapter II, a major component of supported living is the facilitation of social relationships between service users and people in the surrounding community - neighbours, members of local churches and community centres, owners of small businesses, etc. The purpose is to promote social inclusion and the use of informal supports. The role of workers is to make these connections happen - no doubt a very difficult task. This could involve maximizing time spent in the surrounding community in order to facilitate contact and interaction with others present. Alternatively, workers could arrange meetings between individuals with common interests. With regard to the latter method, most participants described receiving some support:

...they help you to meet people and that, if you have problems meeting people and that, you know? They sort of help you in that way, to meet people ...friends, anybody in that way. Cause a lot of times you have trouble talking to people and they help you out in that way.

...my support worker introduced me to new people, basically yes. They introduced me to a friend of mine at the advocacy organization. And then I also remember years ago when my worker introduced me to a woman ... and I haven't seen her in years, about 11 years. And also, they have introduced me to new people.

...My worker introduced me to this guy now that I know...and he has an apartment downtown and we do things together sometimes.

My worker introduced us to this person and we go bowling.

...cause a lot of times you have trouble talking to people and they help you out in that way.

In most cases, those who workers introduced to participants received support from the same association for people with intellectual disabilities.

Support workers did not appear to use weekly visits as an opportunity to build ties with members of the surrounding community. Other than roommates, it was rare for third parties to be present when workers were with their clients. It appeared that the vast majority of contact between workers and service users took place in the service user's apartment with no one else present:

I: Do you ever meet with her or see her outside the apartment?

P: No.

I: Never? You've never met with her outside the apartment?

P: No. Well, we may have gone out once or twice at the beginning.

...no one else is involved but my worker and me.

P: Its always my support worker and me.

I: And there's no one else involved?

P: No.

In one case, a worker went as far as to force a service user's girlfriend out of his apartment because the worker

wanted a "private visit":

P: One day she kicked my girlfriend out of my apartment.

I: Why did she kick her out?

P: My girlfriend came into my apartment and after that she started crying.

I: Why?

P: She gets upset a lot.

I: I don't understand what happened with your worker.

P: She kicked her out and I had to call the supervisor to let her know.

I: Why did she kick her out?

P: She was just visiting me and she likes to have a private visit with me. I don't think budgeting is a private visit to kick my girlfriend out.... She doesn't need a private visit to budget. Its not a big deal, we all budget.

While this was not a common occurrence, it exemplifies a possible lack of commitment to helping service users build or maintain personal relationships.

Self-Advocacy, Housing and Employment

Self-advocacy is generally understood as a process through which people with intellectual disabilities are a) made aware of their rights and entitlements under the law, b) learn the skills needed to assert and defend their rights and entitlements and c) are supported by allies as they make use of this new awareness and skill to actively engage others. In essence, this is a process of personal transformation from a mentality of passive reciprocity to active citizenship. The concept of self-advocacy is understood to be an indispensable part of the broader empowerment process.

Throughout focus groups and interviews participants did not refer to activities that could be deemed part of the self-advocacy process. In part, this may be due to the fact that support workers believe that their role is to engage in advocacy work on *behalf* of service users, not with them.

This being the case, service users might not be aware of advocacy being undertaken on their behalf by workers. It may also have been due to the fact that self-advocacy activities were infrequent and therefore not forefront in the minds of participants. The lack of discussion of self-advocacy activities may also simply indicate that support workers do not engage in this process with service users.

It did appear that some effort had been made by support workers to raise the awareness of participants as to their rights. One participant made it clear that his worker had informed him of his right to exert control in his own apartment:

Like my support worker was saying, if she didn't want to come over, say she came over and somebody else was over, and they started pushing you around, you have the right to tell them to leave. If they get pushy and that, if they start telling you this and that, you have the right to tell them to get out. Like a replacement counsellor if your counsellor is away. Say the replacement came in and started telling you this and telling you that and you don't like it you have the right to tell them to leave.

Participants also referred to help they had received securing a place in public programs but did not elaborate as to how support in this area was given or received. Findings

in this area are quite limited:

...they help you get into different programs.

...they also help you join different activities, if you have problems with that.

...they help us find day programs.

There were similar limitations in the amount of information that participants were able to provide on support received in areas of housing and employment. With regard to housing, participants reported receiving support in dealing with landlords and in securing new accommodations. The extent to which workers and participants collaborated in this area was unclear:

They help me, they help us work out our problems with the landlord at public housing, that's public housing in this case.

...help you look for an apartment, if you have problems.

P1:...what it was at the time like my worker found another apartment cause you see where my roommate and I used to be was getting kind of expensive. And my worker went and found another building for us and then my worker went and found another apartment for me and my roommate.

I: Did you look for the apartment with them or did they find it and you just moved in?

P1: I think they looked for it.

I: Has anyone else had help looking for an apartment?

P2: Yup, yes I did. We looked around in the paper and then it didn't work so I decided to go back to the apartment, back to the supported living and there were apartments available out on...

I: Has anyone else had help looking for an apartment?

P3: Yes I have.

I: Did you look for the apartment with your worker?

P3: Ah, no.

It does not appear that service users received much active employment support from workers. As stated in the

previous chapter, three participants were not part of the mainstream labour force. Two of them spent their days in a sheltered workshop. Both expressed a desire to work in a real job "out in the community" even though they recognized this would not be easy for them:

I hate going to work...because the workshop that I go to, I've been there for 16 years and they only have me going out maybe every third week out in the community.

However, neither reported engaging in the active pursuit of paid employment with their workers.

One participant was engaged in stable full-time employment in the paid labour force while another worked part-time in a supported work program. These two did not appear to have a need for assistance from their workers in the area of employment and were quite satisfied. One participant reported asking for and receiving assistance from his worker in finding a part-time job, but to no avail:

P: Well, I did ask her to help me find part-time jobs because they have only so many hours at the store. That's when I found out after that they did hire me for a little bit more hours, cause I was working Tuesdays and that's about it.

I: So you asked your worker if there were part-time jobs that she knew of.

P: Ya, well, ya. But we didn't find anything part-time.

The Processes Through Which Support is Provided

Throughout both focus groups and individual interviews participants made references to the processes involved in support provision. In other words, they described the how as

much as the what: how workers assisted them with instrumental and other tasks, how workers and service users communicated and how decisions were made about planning. Perhaps most of all, it is the nature of these processes that indicate the extent to which the core principles of supported living have filtered down into support worker-service user relationships.

Instrumental Tasks

For the most part, participants described support staff working with them in a collaborative manner in this regard. Generally, support workers provided assistance with instrumental tasks in a manner that would seem to facilitate skill development and independence rather than reinforce skill deficiencies and dependency:

...they help me they don't actually do it, that's not their job, that's not what they get paid for. My worker does come over but she doesn't clean. It's my responsibility to clean the apartment.

I: So you do it [cook] together?

P: Yes, we do. Well, she was doing it for a long time but now she's telling me how to cook, like what's the ingredients first, then do this, then on and so on.

I: So you're learning how to cook?

P: Yes.

...she's teaching me how to cook and we do a lot of things in my apartment. I set up a grocery list every month I go out to do groceries to the supermarket.

P: I do my studies, I do my grade 10 geography.

I: Do you do it with your support worker?

P: I try to do it with her - she helps me write down things that I need cause I can't even write so I have to count on her to write my uh...

I: Do you spend a lot of time doing that?

P: I do, I spend a lot of time doing that. Its a lesson a day and we send it to my teacher.

This is not to say that workers never do things for service users that could just as easily be accomplished through collaboration. One participant described the following situation:

I: So you do your laundry...

P: And she checks what I need...if I need any more groceries, which I usually do, which I don't buy that much groceries cause I still got quite a bit of food left.

I: She does that by herself?

P: Ya, while I go change my laundry.

I: And she writes the list for you?

P: Ya, and she keeps it until I meet her on Monday.

There were also situations in which conflicts arose over when or how frequently service users engaged in basic activities, cleaning being one major example. Participants appeared capable of doing much, if not all, of their own house cleaning. The cleanliness of a service user's apartment, therefore, had as much to do with his or her desire to have a clean apartment as with his or her capacity to clean. Certain support workers used their position of authority to compel service users to engage in certain instrumental tasks, by "pushing" them or making them "earn" certain privileges:

...I'm 46 years of age and I don't need anyone babying me, treating me like a kid, my mum did that for years and years. It's just the way she did it you see. But if I'm going to live out on my own I have to start doing things for myself, not for the counsellor. They're job is only supposed to help us twice a week or once a month, just to do the budgeting, and I don't mind. But

my support worker...I just don't like the way she pushes me.

P: I had problems with this one worker. She acted like mother, she played mother for a year...

I: What did she do?

P: She played mother for a year...she told me what to do...she told us what to do...and I'm not going to tolerate it. I had to speak to the supervisor a couple of times and I was not happy.

I: What did she tell you to do?

P: A lot of things. When she started I had her on weekends and we cleaned this place...we washed the floors, we did a lot of things together and...we'd go out for coffee, if I earned it and I did not like the system that she set up - I earned my coffees. I'm older now and I don't need to be told when I earn my coffees.

Over an extended period of time the potentially negative impact of this type of coercion, however subtle, could be considerable. For one participant, the result was the creation of an adversarial relationship between him and his worker. They became two competing parties each with their own "terms":

P: My terms: let me do my own things in my own apartment, don't push always "Oh, you gotta clean this, you gotta clean that...I don't care what she does with her other clients but she's not doing the same way what she does with her other clients with me.

I: What does she do with her other clients?

P: I don't know. It's none of my business but I wasn't born yesterday you see. I don't have to go down to her office and spy on her in her office. I know in the back of my head, I got eyes. Because I know what she's like.

I: What's she like?

P: She gets very pissed off if I don't, you know if I don't pick up the phone or if I don't phone and she gets pissed off so often. She shouldn't. She should not get pissed off at her clients so much. Because that looks bad on the whole association including everybody in different programs.

I: So she doesn't bother you any more?

P: No, she do on my own terms and I do her terms.

I: What are her terms?

P: Well she, her terms are to help me budget and just make sure I have enough responsibility to clean my

apartment once in a while if I need it and that's what my terms was... you see I'm not a compulsive cleaner like my family. Because they clean, doesn't matter if there's a little bit of dirt or a lot, they clean. I'm not like that. I guess that's the way she was when she was born but I'm not like that. But I can shove her out of the door if she starts pushing me and I can call the association and have her removed. And if she refused, I could have her removed by the cops.

Communication

A considerable amount of communication between workers and service users took place over the phone. Service users are not permitted to call support workers at home, however:

I: Do you call them at home?
 P1: No you're not allowed, not allowed.
 P2: You call them at work.
 P3: The supervisor gets mad. You're not aloud to call them at home, its their time.
 P2: You call them at work. If they're not in they get the message.

Furthermore, one participant stated that service users are not permitted to call without a "really good reason" given how busy workers are. This implies that workers are not generally available for casual phone conversations. Just wanting to talk or chat is not sufficient cause for a service user to call his or her worker:

...it has to be a really good reason to call them because they're so busy with their other clients.

P: If I have a problem I talk to her about it.
 I: Do you call her?
 P: No, no, no. I wait until she comes over. Or if its something important I phone her.

One participant also reported that the lines of communication between service users and the supervisor of

the program were quite tightly controlled. This participant claimed that it was necessary for her to deal with any problems with her support worker before going to the supervisor, even if the problem was with the support worker himself or herself. While this practice may make sense from a management perspective in a program with a large number of clients, it reinforces the workers' position of dominance by allowing him or her to control the flow of information between service users and managers:

...we can't even talk to the supervisor...we can't even talk to her, we have to go through our counsellor and then talk to the supervisor.

I: What if you want to talk to the supervisor about your counsellor?

P: We still have to go through our counsellor.

I: To get permission?

P: Yup.

I: Do you have the supervisor's number?

P: Ya, but I can't use it. I gotta go through my counsellor. I gotta solve the problem with my counsellor before I can solve it with the supervisor.

Pace

As discussed above, a major concern for participants is the tempo of their visits with support workers. Participants want their workers to communicate and work at a gentle pace, taking sufficient time to work through and resolve issues effectively. However, participants reported that workers often rushed through their visits:

...another idea is, my worker is helping me, and she does the best that she can, but she goes a little bit too fast some days, and some days she goes right on time.

P1: I feel that they go too fast and they think its a waste and its not a waste. It's nice to go fast but our brains can't function when they go too fast. Cause they speed it up...

P2: Well to go too fast, it's how they talk.

P3: I know, I know but the thing is they don't have to race through it.

P2: No, no, that's true.

P3: Some of them talk so fast you'd think they were going to race.

P4: In Mexico they talk fast.

...she's usually in a rush to see other clients cause she has to go home after that. She has to eat and feed her dog.

They're always busy, always go, go, go. Busy in the office.

In part, the reason for a worker rushing through a visit could be a shortage of time needed to accomplish a range of important tasks. According to one participant:

P1:...they don't have enough time. I have a support worker who sees six clients in one day. And she has to share the time, if it's now or one hour, you share the time.

I: Do you find that your workers are often in a rush? In a hurry? Yes or no.

P1: Yes, yes they are.

...um, what do I enjoy about the visit? Well I like it when she comes...I would like a little more time with her.

However, the same was not true for all participants. Two of them reported having more than enough time with their workers. In fact, one reported that his worker generally left approximately an hour before the visit was scheduled to end:

P:...she's got a lot of time. It goes until maybe 7:00 in the evening. But usually she doesn't stay that long. Cause she's got her family.

I: What time does she come?

P: Four-thirty. The others were coming at 4:00 p.m..

I: So she comes at 4:00 p.m.. When does she leave?

P: Maybe 5:30 or 6:00 p.m.

I: But you said she has until 7:00 p.m..

P: Yes. She's paid until 7:00 p.m..

P: Sometimes she stays an hour sometimes less. Depends how long she wants to stay.

I: So there's no set amount of time?

P: No. Sometimes she comes over and watches a programme with my wife. Sometimes she comes over early, like when I come home she's here, she goes in and does my money with me first and then she goes in and watches her programme with my wife...and then she comes out and we talk and she leaves.

Decision-Making in the Planning Process

Countless decisions are made in the process of planning and providing support for people with intellectual disabilities. These decisions revolve around a range of issues including the question of who provides support, what kind and amount of support is provided and when (Who will be my worker? When will she come to see me and what will we do together?), leisure activities and personal relationships (What will I do with my free time? How will I spend my money? Who will I spend my free time with? Will I be intimately involved with anyone?) and living conditions (How often will I clean my apartment, or take a bath?). Added together, these decisions chart the course of a service user's life. *How* decisions are made also has a major impact on the service user's sense of herself. If others make the decision on behalf of the service user this may engender in her a sense of powerlessness and dependency.

Service users did not report being actively engaged in

the formal support planning process, neither did participants describe what could be considered a truly person-centred planning process taking place. In fact, as demonstrated below, the planning process appeared more supervisor-centred than client-centred. Two participants described being involved in a yearly meeting to develop a "general service plan" with their worker and the program supervisor. The purpose of the meeting was to discuss goals, the future and what service users want for their lives. Even so, when asked directly who made decisions about the role of support workers one participant responded:

...the supervisor decides that, she's the supervisor, she's the boss, they [workers] sit down with the her and she allots them so much time per week...to talk with them and they help you with cooking but it's the supervisors decision, she pays, she's the supervisor, she's the big boss of the program, she's been in the agency for 18 years.

In part, this could represent as much an assumption by the service user, built on years of experience in hierarchical living and learning environments, as a description of reality. One would think, however, that if participants were actively involved in a dynamic person-centred planning process this would be reflected in their statements.

When a service user's support worker must be replaced, a difficult yet critical decision follows as to whom the replacement will be. Ideally, the service user has a central role in making this decision, helping to ensure personal compatibility and a sense of responsibility for making the

new relationship work. In addition, when service users are involved, their role as active decision-maker is established from the outset. Alternatively, when the service user is excluded and forced to accept a stranger into her life and home, she might be left with feelings of anger and resentment that could be directed at the new worker.

As a group, participants reported a minimal level of involvement in choosing their workers. In two cases, participants reported having little power at all in this area:

...we don't have choice because they're assigned to your caseload and the supervisor chooses them for you. The supervisor chooses them for you, you have a say but you don't decide.

p: I was not happy with her [the worker]. She told me what to do, she was nagging at me...I told her [the supervisor], she didn't give me a choice to have this worker.

I: She didn't give you a choice?

P: No

I: You had no choice?

P: No. I had no choice. Take it or leave it.

I: When you say take it or leave it what do you mean?

P: I was forced to...the supervisor told me I was forced to take her. She told me I didn't have any choice in the matter. She's the supervisor.

I: Why didn't she give you a choice?

P: I don't want to get into...she didn't give me a choice in the situation. In this situation, take it, take her to have her or else I don't have anyone.

I: Is that what she said?

P: I don't know what the supervisor said, I'm not the supervisor, I can't speak for her.

I: What do you think about the supervisor?

P: She's the supervisor. She's the boss. She calls the shots. She's been there for 18 years...I feel she's been there and she's done her job.

In other situations service users were presented with options in a manner that minimized the likelihood that they

would oppose a decision that, in reality, had already been taken by the administration. In other words, there was little more than an illusion of choice:

I: How did you get the worker you have now?

P: Well, my other one left and so they needed someone to cover my case load - and she gave me the good news one day that I was on her case load...they needed someone to see me, so they picked her to see me.

I: But if you didn't get along with that worker before then what happened? Did they just send her? Do you get to choose your worker or decide? How does it work?

P: No they just send them.

I: They just sent her here even though you didn't like her? Did someone call you and say "is it OK"?

P: Ya, the new worker did.

I: So your new worker called you?

P: And said would I like to take her back and I don't want her they can get me another counsellor. If I say no, I say no and she'll go back and tell the supervisor no go, he wants another counsellor he doesn't want me, because I would have got another counsellor instead of her but its very hard with all these cutbacks.

Service users' involvement appeared to be limited to that of a veto in cases where they were certain that they wanted a different worker:

P1: Well if you didn't want her and you told the supervisor you wanted someone else she'd have to give you somebody else if you don't get along with them. If you don't like em you have a right to change them. See I had this guy and he left and I guess the worker I have now took over from his case, well she took over his clients.

I: But what happened when he left?

P1: Well we met at the house and introduced ourselves to each other before she was my counsellor and that. Then she took over

I: Well, how does it work exactly?

P1: Sometimes with me you talk with each other and see if you get along. If you don't get along you say sorry, sorry I'm not too happy with you but if you get along its OK.

Once a support worker has been selected for any given

service user, decisions are made as to when and where visits will take place and what the content of those visits will be. In supported living, these decisions should be made collaboratively with the goal of assisting a person to accomplish his or her goals. Nevertheless, in this research it seemed that administrators and workers may make these decisions somewhat independently, based on their personal needs or those of the organization. With respect to when support was provided, participants' statements imply that they may not have significant involvement:

I: Did you prefer seeing someone every other day?

P: Not bad, I liked it, that's the time she gives me.

...really the counsellors are really good in what they do but in one way I, well, I have a new counsellor and before that I had another counsellor and she got very very sick... And me and my new counsellor are working very good together but there's only one problem with that is she comes and sees me every week and I wanna see her every two weeks but she won't let me do thatI tried my hardest to tell her to come every two weeks.

I: So you were talking about the worker you had last. What did you like about him?

P: He used to work on weekends...

I: What did you like to do with him?

P: I liked to go out to breakfast in the market...every second weekend.

I: That's nice. Do you ever see the worker you have now on the weekends?

P: She works Monday to Friday.

I: She only works Monday to Friday?

P: Ya.

Certain factors may over-ride the importance of involving service users in decision-making. In the following scenario, three service users, all living in the same apartment

building, had the same worker:

P:...we all have the same support workers in this building now. All of us.

I: She sees you all?

P: Ya. She sees three of us. That's all.

I: Why is she the only worker?

P: She's the support worker. They're trying to save money at the agency. It makes more sense for her to come upstairs to see me instead of doing that.

For managers and support workers this would have advantages: administrative simplicity, reduced travel time for the worker, monetary savings for the employer, etc. The result for service users, however, could be a denial of opportunities to make important planning decisions.

Participants' support workers appeared to have different approaches to deciding what would be done during a visit. Generally speaking, it seemed that participants were satisfied with the manner in which they were treated by workers. It was less clear whether they had a significant role in deciding what activities would comprise the visit itself. In one case it seemed that the worker took it upon herself to direct the process:

P1: Well I see her every Wednesday but see I don't work on Wednesdays so when I see her I have to go get up, have breakfast, feed my cat, and then I have to phone her to make sure that I'm so she'll be able to come and budget with me. That shouldn't be happening because my other two counsellors didn't do that with me, they always sat and talked with me 20 minutes, and you know, they let me have my tea. The first time that I got this worker again, "Well, what are you doing? Watching TV. Well I'm coming over, thanks for phoning me, I got your message but you're not watching TV when I come in and budget with you.

P2: So what?

P3: I don't, I turn it off. With me, the reason is sometimes, sometimes she has troubles, not only that

but sometimes I turn it down. Then I watch the pictures, then when she leaves I turn the sound back up.

P1: That's what I was doing but she said "No I want it off, you're not turning it down or I'm not going to budget with you" and she'd leave and we'd argue. So I don't bother turning it on.

CHAPTER VI: CONCLUSIONS AND FUTURE DIRECTIONS

The findings presented in Chapter V provide an indication of the extent to which the principles of supported living have begun to penetrate service user - support worker relations in the program being studied. In this chapter findings are further analyzed within two main sections. First, the roles fulfilled by support workers are examined to determine the extent to which they reflect the principles of empowerment, full social inclusion and person-centred planning. Second, future directions are recommended for practice, policy and research in the field of supports and services for people with disabilities.

Summary of Conclusions

Taken together, the various roles fulfilled by support workers in this research were neither unequivocally congruent nor incongruent with the principles in question. The core function of support workers could be described as basic maintenance and monitoring with the provision of limited social support, not proactive client-centred goal attainment to facilitate empowerment and full social inclusion. While it is no small accomplishment to move people out of institutions and maintain them in homes of their own, it is possible for such people to experience

social isolation, vulnerability and dependency in their new living environments if no active measures are in place to prevent these conditions from occurring.

The apparent lack of proactive measures designed to empower, include and individualize leads to the conclusion that workers do not consider these measures a core function of their work, or, if they do, are prevented from fulfilling them by forces beyond their immediate control. Workers did not appear determined to empower service users and facilitate their full inclusion in society. In addition, while service users received one-on-one attention in their own homes, it did not appear that a creative person-centred planning process was in place.

Empowerment and Self-Determination

When compared to the often hierarchical staff-patient relationships characteristic of large congregate care facilities, interactions between participants and their workers in this study appear quite balanced and mutually respectful. This indicates some progress toward a commitment to empowerment. With a few notable exceptions, it does not appear that workers dictated to clients when to rise, who to associate with, what to wear, how to make use of their disposable income, etc. This may reflect an understanding of the need for service users to become self-determining citizens. It may also be a result of the structure of

supported living: the work environment belongs to the service user. It is his personal living space into which the worker enters for relatively short periods of time each week. This limited contact means there are less opportunities for workers to restrict the personal freedom of those they support. However, as the supported living model is expanded to include people with more severe disabilities requiring many additional hours of assistance, such opportunities will inevitably increase.

In comparison to relations among independent adult citizens within the broader context of Canadian society, the relations between participants and their workers in this study appear at times to be somewhat imbalanced and unilateral. Findings include examples of support workers treating participants in a less-than-adult manner. For example, one participant was told 'if you don't do your housework you won't get your treat': going out for coffee. Another was told 'if you don't have your apartment spotless when I come over you won't be allowed to get money out of the bank'. In addition, a participant described one visit during which his girlfriend was sent out of his apartment so he and his worker could have a 'private visit'. With regard to decision-making procedures in the planning and delivery of supports, findings did not indicate a high level of service user involvement. For example, participants reported having little direct involvement in the selection of their

worker.

These examples of power imbalance, however infrequent, point to one of the often unmentioned risks of the supported living model. As discussed previously, the worker has considerably more autonomy than in the past given the lack of on-the-job supervision. This situation is made worse when the lines of communication between service users and administrators are mediated by these same frontline workers. There is always a possibility that workers will use their dominant position to take advantage of service users. As the supported living model grows in popularity and is made available to people with more severe disabilities, the likelihood of such abuses of power will inevitably increase. This will be most problematic in organizations with insufficient resources to establish strong mechanisms to ensure that workers are accountable to the people they are paid to support. It will be very important for governments and associations for people with intellectual disabilities to put in place effective checks and balances to protect service users from mistreatment.

Full Social Inclusion

As findings demonstrate, it does not appear that a major component of the daily work of frontline staff is aimed at facilitating social connections between service users and other members of the 'surrounding community'.

Workers spent the vast majority of their on-the-job hours alone with service users, primarily in the service user's home - the location where many of the instrumental tasks of daily life must be accomplished. When support workers did make attempts to introduce their clients to potential friends, other members of the same service organization were selected. While this would seem to be a perfectly sensible practice, it may raise doubts as to the extent to which service users are being helped to build informal support networks consisting of people living in the 'surrounding community'. Findings also indicate, however, that service users generally want to build stronger social connections with their paid support workers and may even want to avoid building relationships with people living around them. For example, one participant reported that she found many of the people living in her building, and in buildings nearby, quite intimidating and unfriendly. Another participant had been cheated out of money by neighbours a number of times - he was an easy target given his good nature and deep desire for acceptance.

This points to one of the underlying weaknesses of the supported living model, particularly for people with intellectual disabilities living in large urban centres. The principle of full social inclusion into 'the life of the community' is founded, to a large degree, on an increasingly mythical North American belief in the naturally occurring

well-knit urban community. Proponents of supported living assume that a) the community has a life, b) that the community's life is something people with intellectual disabilities should want to be a part of and c) that the other members of that community will accept them. It can be argued that in today's cities these are not safe assumptions. Urban neighbourhoods seem to be losing much of their cohesiveness and vibrancy as a result of the seemingly inevitable push toward the suburbs. People living in poor neighbourhoods tend to be more transient than people living in affluent areas, making the development of community ties challenging. People with disabilities may be over represented in low-income areas given the higher levels of poverty within this community (Fawcett, 1999).

As a student I lived in numerous apartments in three different cities, never knowing my neighbours in any meaningful way. However, I never felt that I lacked community. In my experience modern North American communities are not geographic communities. People tend to build their social networks through participation in education, employment, recreation, etc., not through participation in communal neighbourhood activities in accessible public spaces. So the question remains, how do we facilitate full social inclusion for adults with intellectual disabilities for whom normal life patterns have been broken, by institutionalization for example, or who

simply have never had significant involvement in the typical social or economic activities of most citizens?

Until recently the answer has been to create environments, such as community-based residences, that would become communities where people with intellectual disabilities could live together and support one another. Today, however, many leaders in the field reject any form of support that involves building 'artificial' living environments for people experiencing similar life challenges. This rejection represents a loss of faith in our ability to build special settings for people with intellectual disabilities that do not result in further disempowerment and ghettoization. People argue that we built institutions and they failed. We established community residences and many feel that those have also failed. The response to these failures has been a categorical rejection of any attempts to build separate communities of people with intellectual disabilities.

Nonetheless, the fact remains that the quality of life of many people with intellectual disabilities could be enhanced through membership in supportive built communities made up of others, like themselves, with as much need for belonging as independence. Jean Vanier (1995) writes that:

The cry for community from people with handicaps constantly reminds us that we all need community. While it is true that people with handicaps are called to greater autonomy, they need above all a whole network of friendships and community that gives them security and a sense of belonging, awakens each one's gifts,

encourages growth, and develops love and a sense of service. (p. 60)

But will this cry will be answered by the existing supported living model given that it does not grapple with the lack of 'natural' community structures that are accessible to people with intellectual disabilities? My impression is that the proponents of supported living may be 'throwing the baby out with the bath water' by assuming that all artificial live-in communities are bound to recreate the sins of the past: hierarchical staff-client relations, social exclusion, etc.

Finally, it may be unrealistic to expect that support workers will somehow be able to facilitate social inclusion through *proximity*. Is it common sense to assume that people with intellectual disabilities will be able to build long-lasting social relations by spending time in nearby public spaces striking-up conversations with strangers? In my experience people connect and bond when they have experiences in common and are engaged in common tasks. People are wary of those who initiate conversations in public spaces for no apparent reason, wondering what they want. While this may not be the case in towns with populations small enough that most faces are familiar, it seems that people in larger urban centres are becoming more and more insular and socially inward-looking.

Person-Centred Planning

A vibrant and creative person-centred planning process is the cornerstone of supported living. Without it, we can have little confidence that support is being provided to people with intellectual disabilities in a manner that reflects their evolving personal aspirations and life circumstances. Findings of this research do not indicate, however, that such a process was in place for participants. This may be due to a number of factors, including a lack of knowledge of or commitment to person-centred planning within the leadership of the organization, conflictual relations between managers and frontline workers, or a lack of available resources for training.

Person-centred planning was designed to be a very animated, action-oriented and participatory process of goal identification and attainment, involving a range of partners, in which the service user is pivotal. Such a process was not described by service users during focus groups or interviews. References were made to a yearly meeting to develop a general service plan. In my experience working in group homes, such general service plans often have little impact on the lives of people with intellectual disabilities. The plan can become a static administrative formality with little or no power to engender concrete collaborative action among family and community partners.

Another indication of a possible lack of person-centred

planning is the routine nature of the roles fulfilled by workers in this study. Most visits began with budgeting followed by work on household tasks and ended with some time for socializing. On occasion workers and service users went on outings for coffee or a meal. One participant indicated that this had been the pattern of support provided to him since he became a member of the program over five years ago. This standardization may be due to the fact that both workers and service users develop entrenched habits in how they interact with one another. Workers and service users may develop a *modus operandi* that makes sense and is efficient. However, when a worker is selected to support a new client he may simply re-apply this *modus operandi* in the new setting. Person-centred planning is designed to prevent the possibility of such standardization and routine.

Summary of Future Directions

Given these conclusions, there may be a need for changes to current practices and policies in supported living, as well as further research to guide such changes. With regard to practice, a new individualized funding and staffing model could be implemented. In the interim, more incremental changes to current practices could be explored. For example, organizations could allow for greater involvement of service users in hiring and selection of

workers and increased opportunities for on-the-job training. With regard to policy, federal, provincial and territorial governments could provide resources for individualized funding pilot projects. This has been done successfully in the area of self-managed attendant care services for people with physical disabilities.

Future Directions for Practice

Implement a New Funding and Staffing Model

In institutional settings the funding and staffing model approximated that of a hospital; nurses and orderlies were paid by the organization and worked day or night shifts taking care of a number of patients while 'on the floor'. In group homes counsellors were also paid by the organization and worked shifts, generally providing support to a smaller number of residents. Both these models have been criticized for their tendency to create unnecessary power imbalances and distance between paid support providers and recipients. In this research frontline staff were also paid by the organization but did not work shifts in the traditional sense; their on-the-job hours consisted of visits and outings with service users. They also spent time at organizational headquarters attending to administrative tasks. While this structure is considerably more flexible than the traditional shiftwork model, other approaches exist that may have greater potential to facilitate empowerment,

inclusion and person-centred support.

A number of supported living agencies in the United States have taken the approach of helping small, self-selected groups of people with intellectual disabilities purchase or rent a home and hire their own live-in support worker. For example, an organization in Sacramento, California called Training Toward Self-Reliance Inc. (TTSR), founded in 1982, helps people with intellectual disabilities to manage their own personal assistance services (PAS), funded by the state government (Walker, 1997). Individualized personal supports are also available in a few other states, including New Hampshire and Connecticut. The service user receives assistance from TTSR staff in the recruitment, hiring and ongoing management of support personnel, selected from a list of eligible workers produced by the county. In this model agency staff act primarily as service brokers and advocates, ensuring that support workers do not take advantage of those for whom they work. In order for organizations to move in this direction, however, governments must make individualized funding available to people with intellectual disabilities. This issue will be discussed in the following section on policy implications.

Involve Service Users in Hiring and Selection Practices

As findings demonstrate, service users did not appear to have much of a role in hiring staff or choosing who their

personal worker would be. These decisions were made primarily by supervisors, most likely in consultation with existing frontline staff members. In supported living this should not be the case. Without relinquishing final decision-making authority, organizations could take a number of steps to improve the participation of service users in the general hiring process and in the selection of their own workers.

Service users could be directly involved as partners in the hiring of new staff. For example, joint interviews could be conducted by a human resources staff member and a service user who had been given some training in the interview process. There could also be hiring committees made up of service users, frontline workers and possibly even interested family members. After an initial interview, prospective employees could meet with the hiring committee to be questioned and to ask questions. Any one of the participants in this research would have been capable of this type of activity. From the start, this would send prospective employees a very positive message about the role of service users in the support process. When in the past I was hired to work in group homes, I had lengthy involvement with administrators prior to meeting service users. As a result, my first impression was that the service user was the recipient of care organized and provided by agency personnel. I assumed, therefore, that my accountability was

primarily to the organization and the people who managed it rather than to the people with intellectual disabilities being served.

Increase Opportunities for On-the-Job Training

Frontline workers and service users need training to learn how to operationalize supported living principles through interaction with one another. These are not competencies that we can expect support workers to develop on their own, particularly given the major challenges they will face in their efforts to promote empowerment and inclusion through the provision of person-centred support. The difficulty for cash-strapped non-profit organizations is that traditional training courses are costly, and may be seen as a risky investment given high staff turnover rates. Innovative solutions are needed to address this problem as it has plagued the residential service sector from its inception.

I would recommend that organizations put in place new mechanisms that do not involve workers attending training courses and seminars away from work and independent of service users. Instead, more cost-effective and applied on-the-job training strategies could be developed that directly involve service users and perhaps even family members as well. For example, organizations could create a training position to be filled by a support worker who demonstrated a

high level of knowledge and ability. This individual could be sent on numerous courses to receive extensive training on the application of supported living principles in applied situations. This person would then work as a 'roving professional trainer' accompanying each support worker every month or two during their visits or outings with service users. The trainer's purpose would be to talk to workers about challenges they are facing and to devise effective problem solving strategies that make sense in the context of the service user's life. The trainer would become familiar with common problems encountered across the program and would then present these issues to the leaders of the organization. The role of the trainer would not be to monitor support workers or to conduct performance evaluation as this might prevent workers from feeling free to discuss problems and limitations they face.

Future Directions for Policy

The National Policy Context in Canada

In June 1996, Canadian First Ministers identified persons with disabilities as a collective priority in the pursuit of social policy renewal. This commitment was reaffirmed in December 1997. In response to these commitments Ministers of Social Services worked together to produce a national policy framework entitled *In Unison: A*

Canadian Approach to Disability Issues, released in October 1998. The Quebec government did not participate in this process. Since the release of this federal / provincial / territorial (FPT) policy vision, collaborative work has focussed on the development of an accountability framework to measure progress in achieving the *In Unison* objectives. FPT governments will also launch a web-site called Disability Links to provide improved access to information on public programs that provide supports and services to people with disabilities.

The overarching theme of *In Unison* is full citizenship, defined as "the inclusion of persons with disabilities in all aspects of Canadian society." (p. 17) The document also supports the principles of a) rights and responsibilities, b) empowerment and c) participation. Objectives and policy directions are presented within three major building blocks: *disability supports, employment and income*. Within the building block of disability supports, individualization is a major focus.

The Provincial Policy Context

In recent years the Government of Ontario has been moving toward the principles and practices of supported living in residential services for people with intellectual disabilities. In January of 1998 a document entitled

Individual Support Agreements (ISAs) for People with Developmental Disabilities was released by the Ministry of Community and Social Services (MCSS). This document spells out a new province-wide policy requiring service providers to put in place ISAs for all MCSS clients with intellectual disabilities. In theory, the principles upon which the policy framework is based are those of supported living: person-centred planning, personal empowerment, flexibility, responsiveness and accountability. The goal of the ISAs are to "enable a person, with the support of family and others, to live, work and participate in the community as a valued and contributing citizen." (p. 4) ISAs must be developed through a person-centred planning process that involves service users and their family members.

Mandatory ISAs are also an effort by the Ontario government to make service providers more accountable for how they administer MCSS funding. The policy framework states that:

The Individual Support Agreement also provides opportunities for monitoring the accountability of individual service provider organizations in spending public funds in a cost effective, efficient manner that is sensitive to the needs of service users. (p. 4)

Given the nature of this new policy one might argue that ISAs are primarily an effort by government to exert greater control over the spending habits of non-governmental organizations contracted to provide public services. To be clear, ISAs are not a form of *individualized funding* along

the lines of California's personal assistance services (PAS). The policy states that:

The funding of individualized approaches is the process by which funds are earmarked and spent for a specific person to achieve a specific outcome. The funding of individualized approaches does not necessarily involve a transfer of funds to a person, it does however, mean that funds are spent for a person. (p. 3)

Funds will not flow from government coffers directly to service users so that they may purchase their personal supports. At best, ISAs will encourage MCSS funded agencies to move from program-based to more individualized methods.

Governments Provide Resources for Individualized Funding Pilot Projects

With respect to *visions* and *guiding principles* there is a significant degree of congruence between the Government of Canada, the Government of Ontario and proponents of supported living. As mentioned above, FPT work on disability issues since Fall 1998 has focussed on accountability and access to information on public programs. While this is important work, there has been little tangible progress made to achieve the policy objectives of *In Unison* on disability supports: improved access, enhanced portability and improved assistance with disability-related costs. So the question is, with this high degree of congruence why has there been such little direct action?

Many factors have intervened to make collaborative work

on disability issues an uphill battle, not the least of which is the highly conflictual nature of current intergovernmental relations in Canada. Conflicts have been the result of opposing political ideologies and the fall-out caused by reductions in federal transfers to provinces for health, education and social services. The current battle between Ottawa and the provinces over health care spending is a good example. In addition to these basic political realities are a number of other obstacles, including the fact that governments largely deliver disability supports through non-profit organizations, adding another layer of complexity. Within the non-profit sector there are divisions between proponents of different models of support for people with intellectual disabilities. In this environment it is unlikely that a consensus will emerge in the short-term on decisive and permanent changes to the public system.

An intermediate step is required that will bring the various parties to some agreement on what needs to be done and on who should pay for it. I would recommend that a realistic approach is to pilot individualized funding programs for people with intellectual disabilities in a number of sites across Ontario. This was done effectively in the field of attendant care for people with physical disabilities (Yoshida, Locker, Willi, & Parker, 1999). In 1994 the Ontario Ministry of Health launched a Self-Managed Attendant Services Direct Funding Pilot in partnership with

the Centre for Independent Living in Toronto (CILT). This pilot allowed "eligible adults with physical disabilities across Ontario to receive funds individually to recruit, manage and pay for their own attendants" (p. 146). The program was so successful that it was made permanent in 1998. Similar pilot projects could be implemented for people with intellectual disabilities. This would define a new role for agencies: to hire and train frontline workers to act as service brokers and advocates for people with intellectual disabilities in the management of their personal assistance services. The cost of the pilot projects could be shared by Ottawa and the province. This is the type of joint federal-provincial policy and program development that the *Social Union Framework Agreement* was intended to facilitate.

Future Directions for Research

One of the clearest conclusions of this research is the need for an ongoing examination of the application of the supported living model. Findings indicate that we should not assume supported living programs in Ontario, and possibly across Canada, are necessarily achieving the desired outcomes. This is not to say that supported living is a negative direction for public policy. However, more comprehensive research is now needed, using a large sample of supported living programs across the Province of Ontario,

to establish how effectively the model is being applied in both the public and private sectors. Studies could be aimed at the following types of research questions:

- Are supported living programs providing meaningfully person-centred supports, or are programs merely providing supports in a standardized manner to individuals in their own homes?
- Are people with intellectual disabilities in supported living programs being provided with sufficient opportunities to build social relations with others? If yes, are they able to take proper advantage of these opportunities? If no, what factors inhibit or prevent this?
- Are people with intellectual disabilities in supported living programs experiencing real gains in personal power and the consequent ability to direct their futures?
- Are frontline workers and service users knowledgeable of and committed to the well-recognized principles of supported living?
- Are frontline workers and service users being provided with the education and training needed to operationalize these principles?
- With regard to the above questions, what are the differences between the public and private sectors?

In addition, even more basic data is needed on existing supported living programs in Ontario. At present, little current published information is readily available to answer the following questions:

- How many supported living programs, both publicly and privately funded, are operating in Ontario?
- What is the total number of people with intellectual disabilities living in these environments? How many frontline workers are involved? What proportion do these groups represent of the residential service sector as a whole?

- How different are the formal mandates of various organizations providing supports to people with intellectual disabilities in their own homes? How different are the roles being fulfilled by frontline workers?
- What factors, such as the size, age and historical development of supported living programs, are most significant in determining differences in mandate?

I would recommend that relationships between service users and frontline support workers continue to be a focus for further examination. Through continued in-depth documentation of the nature of these relations our ability to answer the various research questions listed above will improve considerably. However, it will be important in the future to conduct interviews and focus groups with other very important partners in the support process: frontline workers, family members and volunteer advocates. In doing so, research will reach conclusions and define future actions that are truly multi-dimensional in nature, and therefore better able to assist policy makers and program developers in dealing with the multi-faced challenges they now face.

I would also recommend that researchers apply increasingly participatory methods in conducting both quantitative and qualitative research on supported living programs. Participatory methods have a number of advantages. Perhaps most important is the fact that the personal resources of participants become available to researchers. People with intellectual disabilities and those who provide

them with support possess a wealth of first-hand information on the residential service sector and the experience of being a research 'subject'. As a result of this firsthand knowledge and experience, they may also have heightened credibility in the eyes of other potential participants, and may therefore be of particular value in recruitment.

Turnbull et al. (1997) argue that the participation of disabled persons' family members in study design and data collection also increases the rigour of research. They claim that the input of family members facilitates:

increased feasibility and acceptability of research procedures, better questionnaire or interview protocol design, more accurate data, and greater longitudinal involvement with the study. (p. 5)

By giving people with disabilities, frontline workers and family members a role in *defining the problem* to be investigated, participatory methods also have the potential to increase the relevance and accessibility of applied research. Turnbull et al. (1997) argue that researchers and stakeholders choose research topics for very different reasons. The major issue for researchers is often "the degree to which there exists a foundation of previous research." (p. 4). Stakeholders, on the other hand, define research questions based on their immediate needs and priorities.

Another benefit of participatory approaches is the manner in which researchers become more *accountable* to those

they study. When a researcher has direct control over virtually all aspects of a project, he is primarily accountable to only one person - himself. By redistributing some of this control over the research process to participants, participatory methods have a positive democratizing affect.

BIBLIOGRAPHY

Allard, M. (1996). Supported living policies and programmes in the USA. In J. Mansell & K. Ericsson (Eds.), *Deinstitutionalization and community living: Intellectual disability services in Britain, Scandinavia and the USA*. London: Chapman & Hall.

Anglin, B. (1978). *Twenty-five years of growing together: A history of the Ontario Association for the Mentally Retarded*. Downsview, Ontario: Canadian Association for the Mentally Retarded.

Barnes, C., & Mercer, J. (Eds.). (1996). *Exploring the divide: Illness and disability*. Leeds: The Disability Press.

Beach Center on Families and Disability. (1989). *Report of consensus conference of family research*. University of Kansas, Beach Center on Families and Disability.

Bercovici, S. (1983). *Barriers to normalization: The restrictive management of retarded persons*. Baltimore: University Park Press.

Bichenbach, J. (1993). *Physical disability and social policy*. Toronto: University of Toronto Press.

Birenbaum, A., & Cohen, H. (1985). *Community services for the mentally retarded*. Totowa NJ: Rowman & Allanheld.

Bradley, V. (1996). Foreword. In J. Mansell & K. Ericsson (Eds.), *Deinstitutionalization and community living*. London: Chapman & Hall.

Bradley, V., & Knoll, J. (1995). Shifting paradigms in services to people with disabilities. In O. Karan & S. Greenspan (Eds.), *Community rehabilitation services for people with disabilities*. Boston: Butterworth-Heinemann.

Bradley, V. (1994). Evolution of a new service paradigm. In V. Bradley, J. Ashbaugh, & B. Blaney (Eds.), *Creating individual supports for people with developmental disabilities*. Baltimore: Paul H. Brookes.

Brown, I., Raphael, D., & Renwick, R. (1997). *Quality of life - Dream or reality? Life for people with developmental disabilities in Ontario*. University of Toronto, Centre for Health Promotion.

Brown, I., Renwick, R., & Raphael, D. (1999). *Quality of life and life changes for adults with developmental disabilities in Ontario: Results from the followup studies*. University of Toronto, Centre for Health Promotion.

Castles, E. (1996). *"We're people first": The social and emotional lives of individuals with mental retardation*. Westport: Praeger.

Center on Residential Services and Community Living (July 1996). *National voluntary credentialing for direct service workers*. (Policy Research Brief). University of Minnesota, College of Education & Human Development.

Center on Residential Services and Community Living (June 1994). *Training issues for direct service personnel working in community residential programs for persons with developmental disabilities*. (Policy Research Brief). University of Minnesota, College of Education & Human Development.

Chappel, A. (1992). Towards a sociological critique of the principle of normalization. *Disability, Handicap and Society*, 7, 35-51.

Cocks, E., & Cockram, J. (1995). The participatory research paradigm and intellectual disability. *Mental Handicap Research*, 8, 25-37.

Directors of Parent to Parent Programs & Beach Center on Families and Disability. (1997). *Research-based participatory action research*. University of Kansas, Beach Center on Families and Disability.

Dunst, C., Trivette, C., & LaPointe, N. (1994). Meaning and key characteristics of empowerment. In C. Dunst, C. Trivette, & C. Deal (Eds.), *Supporting and strengthening families: Methods, strategies and practices*. Cambridge: Brookline Books.

Edwards, P., & Miltenberger, R. (1991). Burnout among staff members at community residential facilities for persons with mental retardation. *Mental Retardation*, 29, 125-128.

Emerson, E. (1992). What is normalization? In H. Brown & H. Smith (Eds.), *Normalization: A reader for the nineties*. London: Routledge.

Evans, D. (1983). *The lives of mentally retarded people*. Boulder, Colorado: Westview.

Fawcett, G. (1999). *Disability in the labour market: Barriers and solutions*. Ottawa: Canadian Council on Social Development.

Fawcett, G. (1996). *Living with disability in Canada: An economic portrait*. Ottawa: Human Resources Development Canada.

Federation of Ontario Facility Liason Groups (1997). *Impact of the conservative government's funding cuts on persons with disabilities and their families*. Paper presented to the Standing Committee on Social Development, Queen's Park, Toronto.

Galligan, B. (1992). Changes in quality of work life for staff members transferred from institutional units to small residential units. In J. Jacobson, S. Burchard, & P. Carling (Eds.), *Community living for people with developmental disabilities*. Baltimore: Johns Hopkins University Press.

Gardner, J., & Chapman, M. (1992). Staffing issues in the early 21st century: Labour supply, program models, and technology. In L. Rowitz (Ed.), *Mental retardation in the year 2000*. New York: Springer-Verlag.

Grassroots Consortium on Disability & Beach Center on Families and Disability. (1997). *Institute-based participatory action research*. University of Kansas, Beach Center on Families and Disability.

Greenspan, S., & Love, P. (1995). Ethical challenges in supporting persons with disabilities. In O. Karan & S. Greenspan (Eds.), *Community rehabilitation services for people with disabilities*. Boston: Butterworth-Heinemann.

Hall, B. (1992). From margins to center? The development and purpose of participatory research. *The American Sociologist*, Winter, 1992.

Hanes, R. (1994). *A Discussion of the politics of disablement within the context of professional and consumer relationships*. Paper presented at the Forum on Consumer-Researcher Partnerships, Hull, Quebec.

Heller, T., Pederson, L., & Miller, A. (1996). Guidelines from the consumer: Improving consumer involvement in research and training for persons with mental retardation. *Mental Retardation*, 34, 141-148.

Hemmeter, M., Towne, J., & Hertenberg, W. (1996). *Participatory action research in classroom settings*. Paper presented at the 13th Annual International Early Childhood Conference on Children with Special Needs.

Henry, D., Keys, C., Balcazar, F., & Jopp, D. (1996). Attitudes of community-living staff members toward persons with mental retardation, mental illness, and dual Diagnosis. *Mental Retardation*, 34, 367-386.

Hewitt, A., & O'Neill, S. (1998). People need people: The direct service workforce. In *Impact: Feature issue on direct support workforce development*. University of Minnesota, College of Education and Human Development, Institute on Community Integration.

Hewitt, A., O'Neill, S., & Larson, S. (1996). Overview of Direct Support Workforce Issues. In T. Jaskulski (Ed.), *Opportunities for excellence: Supporting the front-line workforce*. Washington, D.C.: President's Committee on Mental Retardation.

Hile, M., & Walbran, B. (1991). Observing staff-resident interactions: What staff do, what residents receive. *Mental Retardation*, 29, 35-41.

Howe, J., Horner, R., & Newton, J. (1998) Comparison of supported living and traditional residential services in the state of Oregon. *Mental Retardation*, 36, 1-11.

Knoll, J., & Racino, J. (1994). Field in search of a home: The need for support personnel to develop a distinct identity. In V. Bradley, J. Ashbaugh, & B. Blaney (Eds.), *Creating individual supports for people with developmental disabilities*. Baltimore: Paul H. Brookes.

Knowles, M., & Landesman, S. (1986). National survey of state-sponsored training for residential direct-care staff. *Mental Retardation*, 24, 293-300.

Lakin, K. & Larson, S. (1992). Satisfaction and stability of direct care personnel in community-based residential services. In J. Jacobson, S. Burchard, & P. Carling (Eds.), *Community living for people with developmental disabilities*. Baltimore: Johns Hopkins University Press.

Larson, S. (1997). *A longitudinal study of turnover among newly hired residential direct support workers in small community homes serving people with developmental disabilities*. Dissertation Abstracts International. (University Microfilms No. 9738454).

Larson, S., & Lakin, K. (1992). Direct-care staff stability in a national sample of small group homes. *Mental Retardation*, 30, 13-22.

Leake, D., James, R., & Stodden, R. (1995). Shifting paradigms to natural supports: A practical response to a crisis in disabilities services. In O. Karan & S. Greenspan (Eds.), *Community rehabilitation services for people with disabilities*. Boston: Butterworth-Heinemann.

Lindley, P., & Wainwright, T. (1992) Normalisation training: Conversion or commitment? In H. Brown & H. Smith (Eds.), *Normalization: A reader for the nineties*. London: Routledge.

Lord, J., & Pedlar, A. (1991). Life in the community: Four years after the closure of an institution. *Mental Retardation*, 29, 213-221.

Maguire, P. (1987). *Doing participatory research: A feminist approach*. Massachusetts: Centre for International Education.

McCord, W. (1982). From theory to reality: Obstacles to the implementation of the normalization principle in human services. *Mental Retardation*, 20, 247-253.

McFadden, D. & Burke, E. (1991). Developmental disabilities and the new paradigm: Directions for the 1990s. *Mental Retardation*.

Mercer, J. (1992). The impact of changing paradigms of disability on mental retardation in the year 2000. In L. Rowitz (Ed.), *Mental retardation in the year 2000*. New York: Springer-Verlag.

Middendorf, K. (1995). The shifting paradigm - From rhetoric to reality. *Mental Retardation*.

Milloy, D., & Kreuger, J. (1996). Restrictive practices: Issues in power and control. *International Journal of Practical Approaches to Disability*, 20, 24-26.

Ministry of Community and Social Services (1998). *Individual support agreements for people with developmental disabilities*. Toronto: Queen's Printer for Ontario.

Ministry of Community and Social Services (1987). *Challenges and opportunities: Community living for people with developmental handicaps*. Toronto: Queen's Printer for Ontario.

Mitchell, D., & Braddock, D. (1994). Compensation and turnover in direct-care staff in developmental disabilities residential facilities in the United States. *Mental Retardation*, 32, 34-42.

Nagy, M., & Gates, H. (1992). Decongregating residential programs in mental health: The impact on the staff and clients. In J. Jacobson, S. Burchard, & P. Carling (Eds.), *Community living for people with developmental disabilities*. Baltimore: Johns Hopkins University Press.

Newman, W. (1997). *Social research methods: Qualitative and quantitative approaches* (3rd ed.). Boston: Allyn & Bacon.

O'Brien, J. (1993). *Supported living: What's the difference?* Syracuse University: Center on Human Policy.

O'Brien, J., & Lovett, H. (1992). *Finding a way toward everyday lives: The contribution of person centred planning*. Harrisburg, Pennsylvania: Pennsylvania Office of Mental Retardation.

O'Brien, J. & O'Brien, C. (1994). More than just a new address: Images of organization for supported living agencies. In V. Bradley, J. Ashbaugh, & B. Blaney (Eds.), *Creating individual supports for people with developmental disabilities*. Baltimore: Paul H. Brookes.

O'Brien, J. & O'Brien, C. (1991). Sustaining positive changes: The future development of the residential support program. In S. Taylor, R. Bogdan, & J. Racino (Eds.), *Life in the community: Case studies of organizations supporting people with disabilities*. Baltimore: Paul H. Brookes.

Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, 7, 101-114.

Oliver, M. (1990). *The Politics of Disablement*. Houndmills: Macmillan.

Ontario Association for Community Living (1996). *No better time than now: Saying farewell to institutions in Ontario*. Available on web-site at www.acl.on.ca/briefs/nbtttn.

Park, P. (1993). What is participatory research? A theoretical and methodological perspective. In *Voices of change: Participatory research in the United States and Canada*. Toronto: OISE Press.

Pederson, E., Chaikin, M., Koehler, D., Campbell, A., & Arcand, M. (1993). Strategies that close the gap between research, planning, and self-advocacy. In E. Sutton (Ed.), *Older adults with developmental disabilities: Optimizing choice and change*. Baltimore: Paul H. Brookes.

Polloway, E., Smith, D., Patton, J., & Smith, T. (1996). Historic changes in mental retardation and developmental disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*.

Riediger, E., & Baine, D. (1987). Turnover of staff in residential facilities for people with mental handicaps in Alberta. *Canadian Journal of Rehabilitation*, 1, 29-36.

Rice, D., & Rosen, M. (1991). Direct-care staff: A neglected priority. *Mental Retardation*, 29.

Rioux, M. (1994). Towards a concept of equality of well-being: Overcoming the social and legal construction of inequality. In M. Rioux & M. Bach (Eds.), *Disability is not measles: New research paradigms in disability*. York: The Roeher Institute.

Roeher Institute. (1996). *Disability, community and society: Exploring the links*. York: The Roeher Institute.

Roeher Institute. (1995). *Research issues in evaluating deinstitutionalization: A review of the literature*. York: The Roeher Institute.

Salisbury, C. (1997). *School-based collaborative action research*. Pittsburgh: Allegheny University of the Health Sciences, Division for Early Childhood Research Session.

Sample, P. (1996). Beginnings: participatory action research and adults with developmental disabilities. *Disability & Society*, 11, 317-332.

Simmons, H. (1982). *From asylum to welfare*. Downsview, Ontario: National Institute on Mental Retardation.

Stone, E., & Priestly, M. (1995). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *British Journal of Sociology*, (add volume), 699-716.

Sumarah, J., Maksym, D. & Goudge, J. (1988). The Effects of a Staff Training Program on Attitudes and Knowledge of Staff Toward the Sexuality of Persons with Intellectual Handicaps. *Canadian Journal of Rehabilitation*, 1, 169-175.

Taylor, M. (1998). A call to exemplary service. In *Impact: Feature issue on direct support workforce development*. University of Minnesota, College of Education and Human Development, Institute on Community Integration.

Taylor, S. (1991). Toward individualized community living. In S. Taylor, R. Bogdan, & J. Racino (Eds.), *Life in the community: Case studies of organizations supporting people with disabilities*. Baltimore: Paul H. Brookes.

Torjman, S. (1988). *Income insecurity: The disability income system in Canada*. York: The Roeher Institute.

Turnbull, A., Friesen, B., & Ramirez, C. (1997). *Participatory action research as a model of conducting family research*. University of Kansas, Beach Center on Families and Disability.

Turnbull, H., & Turnbull, A. (1991). *Participatory action research and public Policy*. University of Kansas, Beach Center on Families and Disability.

Tyne, A. (1992). Normalization: From theory to practice. In H. Brown & H. Smith (Eds.), *Normalization: A reader for the nineties*. London: Routledge.

Vanier, J. (1998). *Becoming human* (Massey Lecture Series). Toronto. Anansi.

Vanier, J. (1995) *An ark for the poor: The Story of L'Arche*. Toronto: Novalis/Geoffrey Greenwood/Crossroad.

Walker, P. (1997). *Standing with people in support, not control: Training toward self reliance, inc.* Syracuse University: Center on Human Policy.

Walker, P., & Salon, R. (1991). Integrating philosophy and practice. In S. Taylor, R. Bogdan, & J. Racino (Eds.), *Life in the community: Case studies of organizations supporting people with disabilities*. Baltimore: Paul H. Brookes.

Whitehead, S. (1992). The social origins of normalization. In H. Brown & H. Smith (Eds.), *Normalization: A reader for the nineties*. London: Routledge.

Willer, B., & Intagliata. (1984). *Promises and realities for mentally retarded citizens: Life in the community*. Baltimore: University Park Press.

Williston, W. (1971). *Present arrangements for the care and supervision of mentally retarded persons in Ontario*. A Report to the Honourable A.B.R. Lawrence, M.C., Q.C., Minister of Health.

Wolfe, P., Kregel, J., & Wehman, P. (1996). *Service delivery*. In P. McLaughlin & P. Wehman (Eds.), *Mental retardation and developmental disabilities* (2nd ed.). Austin, Texas: PRO-ED.

Wolfensberger, Wolf. (1972). *The principle of normalization in human services*. York: National Institute on Mental Retardation.

Yoshida, K., Locker, D., Willi, V., & Parker I. (1999). A case study of the Ontario direct funding pilot: Independent living in action. In *Forum proceedings - Research to action: Working together for the integration of Canadians with disabilities*. Halifax: Dalhousie University - Atlantic Health Promotion Research Centre and Canadian Paraplegic Association.

Zarb, G. (Ed.). (1995) *Removing disabling barriers*. London: Policy Studies Institute.

Zarb, G. (1992) On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap & Society*, 7, 125-138.

APPENDICES

Appendix A: Information Letter

If you are a person with a developmental disability or 'mental handicap' and you are able to read this flyer, please feel free to do so. If you are a support worker, a family member, or a friend of a person with a developmental disability, (who is not able to read), please read and explain this flyer to him or her. Thank you in advance for your time and consideration.

Hello, my name is *Thomas Shepherd* and I am a graduate student at Carleton University. This flyer contains information about a research project that I am doing for my Master's degree in Social Work.

In order to be eligible to participate in my research project you must:

- A. Be 18 years of age or over
- B. have a 'developmental disability' or 'mental handicap'
- C. receive personal assistance from a support worker in your own living space or a place you share with roommates (such as an apartment or house), on a regular basis
- D. be comfortable with the idea of talking in a group
- E. be able to arrange transportation to group meetings

I am working on a project about the importance that support workers have in the lives of people with developmental disabilities. I want to talk to you about the impact that workers have on your ability to lead a good life. I want to know what type of support you want from workers to fulfil your goals, and if you are able to get it. As I'm sure you already know, support workers are women and men who provide direct assistance to people who need help in daily life.

If you participate in my project, you will be asked to come to 4 group meetings that will be no more than two hours long. You will be paid \$20.00 at the beginning of each meeting. You will also be served food and beverages. At these meetings, you will be asked to talk about what kind of support you want in your life from staff, at the present time and in the future. You will also be asked if you receive the kind of support you want.

I want these meetings to be fun, enjoyable and relaxing for all participants, including myself! I want everyone who comes to benefit by learning new things, meeting new people and contributing to a research project.

Remember that at these meetings:

- You will not be forced to talk about anything that makes you uncomfortable
- You will not have to talk about private or personal things if you do not choose to
- You will not be asked to read or write anything
- You will not have to write any tests or fill out any surveys

If you want to become a participant in my project you can call me, or have someone else that you trust call me, at (613) 230-8293. When you call me we can talk more about my project. Even if you are not 100% sure about becoming a participant you can just call me for further information.

THANK YOU FOR YOUR TIME

Appendix B: Letter of Consent

I, _____ agree to participate in the study that *Thomas Shepherd* is conducting on the role of support workers. I understand that he is a graduate in Social Work at Carleton University.

I understand that participation will involve:

- coming to 4 group meetings
- talking about my personal goals and hopes
- talking about the help I want from support workers to fulfil my goals and hopes
- talking about whether or not I get the help I want

I understand that Thomas Shepherd will:

- pay me \$20.00 at the beginning of each meeting, (and that if I decide to leave a meeting before it is over I will be able to keep the money)
- give me a free copy of his final report when he is finished
- bring food and beverages to meetings
- pay me back for any money I spend on public transportation (not taxis) to get to meetings
- make a tape recording of everything I say in the group, and then write down everything I say on paper, but that he will not write my name anywhere on this paper
- destroy the tape recordings after his project is finished in order to protect my privacy.
- not reveal my identity as a participant in his project
- provide me with a copy of this letter of consent after it is signed.

I understand that during group meetings:

- I will not have to read or write anything
- I will not be required to talk about any private or personal things that I do not want to discuss
- I will not be forced to answer questions if I don't want to
- since I will be talking in a group setting, it is possible that other members will repeat things I say outside the group

- if I am worried about telling the group something it is best to talk to someone I trust in private before I tell the group
- I can leave at any time if I feel uncomfortable or upset and I will still be paid for my participation
- if I leave a meeting before it is over I will be allowed to rejoin the group later if I want to

Signature of Participant: _____

Signature of Researcher: _____

Date of Signing: _____

Appendix C: Oath of Confidentiality

I, _____ (Participant), will not reveal private or personal information about the other people in the group. In general, I promise to respect the privacy of all the other people who participate in this study.

- I will not say the full names of people who come to meetings outside the group
- If fellow group members talk about personal things in meetings, I will respect their privacy by not telling anyone what they say.
- If I am confused or upset about something I hear in a meeting, I will tell *Thomas Shepherd* about it and ask him for advice about what to do.

I, *Thomas Shepherd* (Researcher), will not disclose the identity of the participant named above, nor will I divulge any information that would identify him or her to others, unless he or she voluntarily decides that he or she would like to be identified as a participant in my research. I will not disclose any personal information concerning any participant in this study to any other without their expressed consent.

Signature of Participant: _____

Signature of Researcher: _____

Date of Signing: _____

Appendix D: Focus Group Guides

Focus Group #1:

1. What is a support worker? Who are they? What are support workers paid to do (and why)? What is a support worker's job supposed to be? What are they there for?
2. In general, what kind of help do you want from your support worker in daily life (and why)? What role/place do you want your support worker to have in your life (and why)?
3. What do you want your worker to do with you on a regular basis? What do you want them to do for you?
4. How do you want to be treated by your support worker? How do you want your support worker to talk to you?
5. What kind of relationship do you want to have with your support worker?

Focus Group #2:

1. Using your imagination, please describe for me your idea of the ideal support worker. Describe to me what comes to mind when you imagine the perfect support worker.
2. In general, what would the perfect worker be like, and why (personality)? What would the perfect worker do for you and with you (and why)? Where would you go together and what would you do there? How would they treat you? How would they make you feel?
3. If you could pick one person that you know to be your support worker, who would it be? Why would you pick this person?
4. Using your imagination, please describe for me your idea of the type of support worker you do not want. In general, what would this worker be like, and why (personality)? What would this worker do to you and with you (and why)? Where would you go together and what would you do there? How would they treat you?
5. In general, what sort of things should a worker never do to you or with you (and why)? In your opinion, what are the most important things that a support worker should avoid doing when they visit you?

Focus Group #3:

1. What are your immediate goals in life? Are there specific things you want to have/do in your life right now?
2. What are the things you like about your present situation that you want to maintain?
3. What are the things you don't like about your present situation that you want to change?
4. What are your long-term goals in life? Where/who do you

want to be 10 years from now? Where/who you do not want to be 10 years from now?

5. What are your hopes and dreams for the future? What would your ideal life would look like?

6. What help/support do you want to accomplish these goals?

7. What should workers not do? (i.e. actions/work habits that make it difficult for you to accomplish these goals)

Appendix E: Individual Interview Guide

1. When do you see your worker and for how long?
2. Please describe for me in detail a typical visit with your support worker:
 - What activities do you generally engage in? What do you do and what does your worker do?
 - What do you do in the house?
 - What do you do out in the community?
 - Do you do anything with your worker and other people?
3. Please describe for me in detail the things you do with your worker only once in awhile:
 - What activities do you engage in with your worker only occasionally? What do you do and what does your worker do?
 - What do you do in the house?
 - What do you do out in the community?
 - Do you do anything with your worker and other people?
4. How did you get the worker you have now? Do you have any choice in who your worker is?
5. What do you like about your worker and the visits you have from him or her? What do you enjoy most about them?
6. What do you dislike about your worker and the visits you have from him or her? What do you enjoy least about them?