Summary of Research on Disability in Canada: Toward Autonomy and Integration.

John Lord & Peggy Hutchison

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I. Introduction

A large number of Canadian citizens with disabilities experience many of the indicators associated with poor health - powerlessness, unemployment, social isolation, and poverty. This paper presents some historical trends in systems and services designed for citizens with a disability. It then outlines the ways in which paradigms of disability have been shifting dramatically in the last two decades. Key conclusions from research and literature related to determinants of health are presented, along with a number of "promising community practices" or success stories for supporting people with a disability. Finally, policy implications for children, families, and adults are proposed.

1.   Defining Disability

The World Health Organization defines disability as:

> *...any restriction or lack (resulting from an impairment of ability to perform an activity in the manner or within the range considered normal for a human being.*

Within this definition, and most acceptable definitions of disability, the focus is on limitations of performance or activities. Defined in this way, disabilities are not necessarily handicapping.

The major contribution of the World Health Organization's (WHO) model of disablement has been the conceptual distinction among three levels of disablement outcomes: 1) impairments (at the organic level), 2) disabilities (at the personal level), and 3) handicaps (at the societal level). However, some Canadian researchers have been critical of the WHO model because of its implied linear causalities of the disablement process. Whiteneck and Fougeyrollas (1995) point out the importance of the environment in defining disability:

> *The WHO model has emphasized disablement as originating with pathology, leading to impairment, which in turn produces disability, and finally handicap. While this conceptualization is well-grounded in the medical model, it fails to*

> *acknowledge the importance of the environment as a major contributor to the disablement process, acting to either restrict or facilitate the importance of the individual.*

These authors note the importance of considering internal factors (impairments, abilities, disabilities) and personal identity, as well as external factors (environmental factors) and their interaction in the degree to which a person with a disability is actually handicapped.

2.   Disability in Canada

According to the last Canadian census, 13.2% of the population, or over 3,300,000 Canadians, reported some level of disability (Statistics Canada, 1988). Disability is a vitally important health issue for several reasons:

• The majority of Canadian families are touched by disability in one way or another.

• Disability is costly in Canada, where almost 250,000 Canadians with disabilities were residing in health related institutions and homes for senior citizens in 1988.

• There is some research which shows that people with disabilities are less likely to be employed, more likely to be poor, and often have limited social support.. These factors, important determinants of health, will be discussed throughout the paper.

Statistics Canada information shows that disability increases with age. In the 0-14 age group, the disability rate is 5.2%. In the 15-34 age group, the rate is 5.7%. The adult prevalence of disability (age 35-64) is 15.5%. Thereafter, the rates of disability rise dramatically with people over 65 having a disability rate of 45.5%. In addition, in the population over 65, the percentage of disabled people reporting multiple disabilities was 76%.

Of Canadian children with disabilities, the vast majority (99%) live in private households. Approximately 2,400 disabled children resided in health care institutions in 1986. The emphasis in all provinces is to support families to keep their children with disabilities at home. This figure is undoubtedly lessening.

Employment provides one indication of the level of social and economic status of disabled adults. Of persons with disabilities age 15-64 living in private households, 39.2% were employed in contrast to approximately 70% of non-disabled persons in this same age group. 49.3% of the total reported their labor force status as "not in the labor force". While many of these people had never worked, the majority indicated that their condition or health problem completely prevented them from working.

In the last two decades, our awareness of disability has increased dramatically for a number of reasons:

- Adults with disabilities who have organized into consumer advocacy and support groups.

- The fact that physical and mental disability are both in the Canadian Human Rights Code and in the Charter of Rights.

- Families of children with disabilities who have increasingly demanded that their children have the right to go to regular schools and participate in the community in the same way that it has been enjoyed by other children.

- The increased pressure of our aging population on facilities and support systems which are designed to help elderly Canadians who have significant more disabilities than younger Canadians.

II. Shifting Paradigms of Disability

1.   A Brief Look Back

Understanding historical perceptions can be quite instructive in knowing more about the barriers and health problems experienced by citizens with disabilities. The past 150 years has been characterized by three dramatic trends. The first began in the mid-1800's as asylums began to be built across Canada. Although originally built for the "insane", they soon became total institutions for a wide variety of citizens who were

disabled or marginalized (Goffman, 1961; Rothman; 1981). During the next hundred years, the institution was central in disability policy, despite the fact that the majority of families kept their children with disabilities at home. It is significant that the residue of this period is still very influential in disability policy, particularly in Quebec and Ontario where thousands of citizens with disabilities continue to live in institutions.

Second, during the 1950's, 60's, and 70's, service systems were developed for a variety of disabilities. These systems were often rehabilitation oriented and under the jurisdiction of health systems and services. An extensive body of professional knowledge and expertise accumulated during this period. In fact, professional interventions were often seen as central for people with disabilities to be able to "adjust" and "cope" (Wright, 1989). Although the focus during this period was on "community based services", the reality is that most of these services were "in" the community, but few nurtured people with disabilities to be part "of" the community (Lord & Pedlar, 1991).

Third, in the last twenty years, the traditional dominance of professional intervention and the medical model in the disability field has been gradually giving way to a broadened view of disability knowledge and intervention. Some critics have seen the focus on rehabilitation and professionalization as being "disabling" (McKnight, 1995). This trend is part of a "paradigm shift" in the disability field, which is focusing more and more on family and consumer control, independent living, individualized control over support funding, empowerment, social networks and support, and community inclusion (Schwartz, 1992). Many of these elements can also be considered determinants of health, although this awareness is not usually conscious in disability movements or health policy. The "voice" and "participation" of citizens with disabilities has also grown dramatically during this period, both in terms of policy consultations, community planning, and consumer leadership in projects that provide support (Oliver & Zarb, 1989).

2.   Broadened View of Knowledge

The changing nature of knowledge in the disability field parallels the shift that is occurring in our understanding of health. Whereas we once thought that health was primarily associated with health services and individual health patterns, valid disability knowledge was for most of this century seen to be professionally based and medical/clinical oriented. The notion that there are other sources of knowledge that might contribute to our understanding of disability remained unchallenged for years. The new *Framework for Support* from the Canadian Mental Health Association outlines the contribution of four sources of knowledge: medical/ clinical, social science, experiential, and customary/traditional (Trainor, Pomeroy, & Pape, 1993).

The power and importance of experiential knowledge has perhaps been the most controversial part of the paradigm shift. Whether expressed in the "independent living movement" (Carpenter, 1991) or through "consumer participation" efforts (Church, 1995), people with disabilities are increasingly saying they can best determine their own needs, and that their perspective and experience has legitimacy. Qualitative research has been particularly useful in tapping the "direct" voices of citizens with disabilities (Lincoln & Guba, 1985; Lord, Hutchison, & Schnarr, 1987). Qualitative studies have illustrated the importance of listening to people with disabilities and their families in order to gain deeper understanding of people's needs, strengths, and dreams. Significantly, this research has illustrated that consumers often have a "different" perspective on issues than do service providers or policy people.

3.   Shift From Treatment to Promotion

Most community services and interventions on behalf of people with disabilities have been assessment and treatment oriented. As such, they have been designed to somehow improve or "fix" the problems that the person or the family is experiencing. Such interventions have typically been "deficit" oriented and have paid little attention to

the contexts in which people are living (McKnight, 1987). Recent research and interventions have focused more on the ecology of the person and their situation (Albee, 1981). It is increasingly being recognized that people exist in families and within a variety of social relationships and that one of the most effective ways to assist people is to promote the capacity and functioning of those interactive systems. In some innovative family support programs, for example, the goal is to promote and strengthen individual and family capabilities in ways that promote family functioning and effectiveness (Dunst, 1991). This move from treatment to promotion is not easily understood or practiced in the disability field, but there is growing support on the efficacy of promotion interventions from research in the health promotion field (Epp, 1986; World Health Organization, 1986).

4.   Key Elements of the New Paradigm

A variety of writers have suggested that there is a paradigm shift occurring in the disability field (deJong, 1979; Lord, 1993; McKnight, 1990; Oliver & Zarb, 1989; Schwartz, 1992). The key elements in this paradigm shift are outlined in the following chart.

It is significant that many of these elements relate to determinants of health. The focus on enhancing social support networks, increasing the control of the person, and expanding community participation are all areas that have been shown to enhance health and well-being. In the next section of this paper, we identify the key conclusions from research and literature related to the historical and theoretical trends outlined above.

Key Elements in a New Paradigm of Disability

FROM	**TO**
Systems & facilities	Community & relationships
Deficit Orientation	Strengths/Capacity Orientation
Management Driven	Customer Driven
Service Oriented	Support Oriented
Program Designed	Individually Tailored
Fix the Person	Focus on Person & Social Network
Passive Clients	Participating Consumers
Ad Hoc or No Planning	Futures Planning and Visioning
Professionally directed & controlled	Consumer directed & controlled

III. Key Conclusions from Research & Literature Related to Determinants of Health

A. Independent Living: Concept and Movement

Institutional and rehabilitation approaches to disability began to be challenged in the 1970's. The rehabilitation paradigm for people who have disabilities was seen as being professionally controlled, focused on deficits and remediation, and treating people as dependent clients (Canadian Association for Independent Living Centres, 1991; Schwartz, 1992). Independent living was introduced as an alternative to traditional services (De Jong, 1979). The concept of independent living reflects many of the attributes of the new disability paradigm. The independent living paradigm emphasizes that the problem lies in the environment, in segregation, discrimination and in a

dependency upon professionals and others (Carpenter, 1991; Crewe & Zola, 1984; Robinson, 1991). Instead, disability needs to be understood in a political and sociological context, rather than an individualistic view separate from any sense of power and social structure (Jongbloed & Crichton, 1990). In order to fully understand the role that independent living plays in the lives of people with disabilities, it is important in this section to present literature which describes independent living, its outcomes, connections to health, and implications for children.

1.   The Concept of Independent Living

The independent living paradigm emphasizes that people with disabilities can best identify their own needs and can have productive lives in the community via self-help, empowerment, advocacy, and the removal of environmental, social and economic barriers (Crewe & Zola, 1984; Lord, 1991). The independent living (IL) paradigm has been an important part of new thinking about how to provide community supports and what role the consumer has in that process (Racino, 1992). During the last decade, social policies and practices related to disability issues have begun to change as a result of these concepts. Dunn (1994), in a major Canadian study with provincial governments, noted that language and some policy directions now reflect the independent living concept.

In Canada, consumer advocacy groups were responsible for the initiation of the Canadian Association for Independent Living Resource Centres (CAILC) and its local affiliates (ILRCs). Now a major force in the promotion of the independent living concept, ILRC's offer individuals with disabilities a consumer controlled, cross disability, community based model as an alternative to traditional rehabilitation services (Canadian Association for Independent Living Centres, 1991; COPOH, 1986; DeJong, 1993; Enns, 1991; MacPherson, 1990; Valentine, 1994; Winter, 1993).

**2.   Consumer and Community Outcomes of
          Independent Living Resource Centres**

Research on independent living identifies several outcomes associated with determinants of health. In Canada and the United States, ILRCs have been the vehicle for much of this research.

Control over their lives. Recent health research has identified the importance of people having control in their lives in the workplace, in families, and in the community (Frank & Mustard, 1994; Marmot, 1994).   Within ILRCs, the majority of the staff, volunteers, board members and membership are persons who have disabilities in order to ensure consumer controlled policy directions (Canadian Association for Independent Living Centres, 1990).

In a recent study (Hutchison et al., 1996), consumers of ILRCs identified that they are treated differently by the ILRCs, not as clients and disabled persons, but as valued citizens and full contributing members of the community. This treatment contributes to a sense of empowerment for consumers. People talked about the dignity that comes from being cared for and listened to; treated with respect, equity and fairness; having full access to information; having good communication; and being able to count on the ILRCs for support while trying to achieve more independence. Participation in the ILRCs gave consumers more control over their lives; the ILRCs recognized that people are in charge of their own lives, and in turn begin to feel more control over their lives. These findings have been reiterated by other reports (Budde, Petty, & Nelson, n.d.; Carpenter, 1991; Lord, McGeown, Taylor, & Young, 1992).

Connected to their communities.   Social support is a strong indicator of health (Barrera & Ainlay, 1983; Gottlieb, 1985; House, 1986: Lord & McKillop Farlow, 1990; McIntyre, 1987; VanLeer, 1989; Wyngaarden, Kraus & Erikson, 1988). There is also a growing recognition in the literature of the importance of increasing one's own independence through building community and having strong social networks (Hutchison

& McGill, 1992; Pedlar, 1991; Seed & Montgomery, 1989). The experiences at ILRCs suggest that they are having a positive impact on people's sense of community connectedness. As individuals become empowered, participation in community life increases (Friedmann, 1992; McKnight, 1998); in turn, the community becomes educated and significant changes occur, both within the life experiences of the individual and the community as a whole.

Skills and confidence. Personal empowerment is often characterized by increasing competence and confidence (Lord, 1991). People with disabilities who are involved with ILRC's acquire a variety tools, resources and skills which make it possible for individuals to achieve their personal goals. For example, self-management skills, leading or facilitating groups, problem-solving skills, career skills, writing, and public speaking have all been identified (Hutchison et al., 1996). Consumers involved with ILRC's gained a sense of accomplishment through making a contribution, through volunteering, involvement in committee work, and participation in education sessions and peer support groups (Hutchison et al., 1996). Finally, people's self-esteem was higher, as reflected in greater self-confidence and assertiveness. It appears that fostering consumer control and choice is a powerful means towards building skills and promoting autonomy (Canadian Association for Independent Living Centres, 1990; Lord, McGeown, Taylor, & Young, 1992; COPOH, 1986).

Despite the empowering treatment at the ILRC, people felt they continued to be devalued in the community (Hutchison et al., 1996; Robertson, 1991). Improvement in the quality of life for people with disabilities requires both skill development as well as the removal of environmental, social, and economic barriers (Carpenter, 1991; Robinson, 1991).

A preventative, consumer controlled, community based approach to health promotion and quality of life is seen as being much more effective in the long run (Wallerstein, 1992; Watt & Rodmell, 1988). ILRCs, for example, often support

individuals who have been disempowered due to their experiences with social isolation, institutionalization, poverty, and discrimination; for many of these people, disempowerment is accompanied by poor physical and mental health (Iso-Ahola, 1994; Labonte, 1994; Lord & Farlow, 1990).

3.   Implications for Independent Living for Children with Disabilities

Independent living in adulthood has not always been a goal for children with disabilities and their families. Many people with disabilities remain living with their families into adulthood, being dependent on family members physically, financially and emotionally.

Many families have overprotected their children with disabilities and failed to involve them as active participants in their schools, neighbourhoods and community groups. This overprotection has not only contributed to many children with disabilities being inactive and isolated, but has also left them inadequately prepared to live independently in the world as adults (Active Living Alliance for Canadians with Disabilities, 1992). While there has been a trend to social integration, research also indicates that there are barriers. As children get older, the demands of participation increase (Wall, 1989) while children with poor motor skills often have difficulty being included (Evans & Roberts, 1987; Watkinson, 1994). The lack of preparation of young people in turn has made many adults with disabilities more vulnerable to physical, health and emotional problems. Recent research shows that people with disabilities, especially woman, are more likely to experience abuse than other citizens (CAILC, 1995; Roeher Institute, 1994).

The research suggests that there is a tremendous responsibility on the part of both parents, as well as adults who are currently experiencing successful independent living, to provide support, modelling and encouragement to children with disabilities. Children

must be gradually equipped with skills, confidence, and social support which will lead them towards an independent, empowering life in the community as adults.

B. From Institutions to Community - Re-allocation of Resources

Research on deinstitutionalization has given us insights about moving from an institutional service system to a community service system. The impetus for deinstitutionalization in Canada has come from an understanding of the new paradigm, as well as economic considerations. During the 1970s, voluntary advocate associations and family groups began to call for the dismantling of large institutions. Although a major mental health facility closed in Saskatchewan in the 1960s, the first systematic institutional closures began in the early 1980s as part of economic restraint measures. This followed a decade during which time many people with mild and moderate disabilities moved out of institutions. In 1986, at the time of the last Canadian census, 239,000 Canadians lived in institutions, a decline of almost 40,000 since 1980. Deinstitutionalization has continued steadily into the 1990s, with current estimates that indicate that close to 200,000 Canadians remain in facilities.

1.   Health and Family Dilemmas of Institutionalization

The issue of health is complex. Some of the concerns raised about institutional life have focused on health related: food is often lacking in nutrition and variety; people are rushed through meals in order to meet staff timetables; minimal dental care is provided; activity is restricted; there is a high incidence of smoking, particularly in mental health facilities; and social isolation from families, the community, and from other

residents in the setting occurs.   Research has identified the culture of the institution, which is primarily custodial and medical care, as affecting both individuals and staff (Bogdan & Taylor, 1982; Burstow & Weitz, 1988; Gubrium & Buckroldt, 1982; Hall, 1983).

Despite these criticisms of institutional life, families continue to need to institutional their families' members. Many valid reasons have been identified: the need for respite because of the wearing down of family members; ill health of the care giver; family break-up; lack of community support services; the specialized equipment and services only available in the institution (Lord, McGeown & Ochocka, 1993; Singer & Irvin, 1991; Turbull, Brotherson & Summers, 1985; Willer & Intagliatea, 1979).

2.   Research on Outcomes

The outcomes of deinstitutionalization are varied, generally showing better quality of life than institutional living, but not necessarily a very high quality of life. In other words, when people move to the community with support, their living environments are less restrictive (Lord & Hearn, 1987), many negative symptoms are reduced within two years (Anderson, et al., 1993), more opportunities are available (Leff, 1994), and social networks expand slightly (Gollay et al., 1978;   Hoffman, 1993;   Carling, 1995). However, several authors raise cautions, because when compared with non-disabled citizens, these results far less positive. In Canada, in recent years, most individuals leaving institutions, return to communities where they are part of a formal human service system. Taylor, Biklen, & Knoll (1987) argue that the research illustrates that living in a community service system does not necessarily enhance quality of life. Community based services do not, by definition, mean that people are connected with the community or that people have more control in their lives. The authors suggest that we must be careful not to continue to simply replace large institutions with smaller "community institutions."

This dilemma is illustrated by recent Canadian research. In a longitudinal study at the Centre for Research and Education (Lord & Pedlar, 1991), people who left an institution in 1985 were re-visited four years later. Although quality of life had improved for most people, it was evident that there was a dilemma of replicating community services in a manner that had several "institutional" features. In other words, "in" the community did not mean "of" the community. The move from institutional to community based services can best be seen, not as an end point, but rather as part of the evolution toward the creation of supportive communities that will be truly empowering for citizens with disabilities (Nirje, 1980; O'Brien,1987).

3.   Costs, Community Living, and Re-allocation

Large facilities may require as much as fifteen to twenty million dollars a year to operate, which is a huge resource in times of financial restraint. In several provinces, governments have been reallocating institutional funds to community alternatives.   This has been most widespread in the area of developmental disabilities; in Newfoundland and British Columbia, all institutions will be closed in the next two years. Only in Ontario and Quebec are there significant numbers of people left in institutions. Deinstitutionalization has been slower and more cautious in the mental health area. Advocates and consumer/survivors in the mental health area have called for a major re-allocation of funds from psychiatric institutions to community mental health (Pape and Church, 1987).

The research on the cost effectiveness of deinstitutionalization is somewhat mixed given the complexity of the various disabilities and the differing social contexts (Canadian Council on Social Development, 1985). Mental health studies generally show that community living is somewhat less expensive for people with significant mental health problems (Carling,1990; Hallam et al.,1993; Lafave,1993; Leff, 1994). Lafave (1993) and his colleagues at the Brockville Psychiatric Hospital found that there were

significant savings when a case manager was assigned to monitor and support the person, which included planning and connecting activities.

In an extensive review of the research in developmental disabilities, costs were shown to be slightly less (Mitchell et al., 1990). The authors point out, however, that many of the studies they reviewed had methodological problems and did not include many hidden community costs. As more provinces embrace downsizing for economic reasons, they would do well to remember that they will need to spend during the deinstitutionalization process itself to ensure that the necessary community infrastructures are in place. The Canadian Mental Health Association (Pape and Church, 1989) has completed some important research on the viability and related strategies of reinvesting resources from institutional structures to community support systems. Their work draws lessons from key U.S. states and Europe noting the importance of building community support systems during the process of deinstitutionalization. They found that there are various models associated with various costs in re-allocating resources to the community.

4.   The Process of Deinstitutionalization

Experience in Canada and the United States has produced some excellent research and documentation on the deinstitutionalization process (Anderson, et al., 1993; Carling, ; Des Lauriers & Clair-Foyer, 1982; Lord & Hearn, 1987; Roeher special issue on deinstitutionalization). Lessons from closures in Quebec, British Columbia, New Brunswick and Ontario also point to the need for a comprehensive approach to deinstitutionalization (McWhorter, 1986). Individual planning approaches, worker retraining, parental and family involvement, and individualized community service development are all part of the growing thrust towards deinstitutionalization *and* community integration.

Recent research is showing that the most effective deinstitutionalization *starts* with a focus on the individual and the valued outcomes the person wants to realize.

Building personalized community supports evolves from the dreams, strengths, and preferences of the person and his/her social network. This is especially important for the many individuals who have weak social networks and who rely mostly on staff in the service system for social support (McGeown, 1993; O'Brien, 1986; Taylor et al., 1987).

Leadership is required in all areas, including government policy and funding, family leadership, external advocacy, person-centred planning, and community integration strategies (O'Brien, 1989; Pandiani, 1994). Consumer participation is an essential component in all aspects of the process (Church, 1992).

Despite extensive deinstitutionalization, the people who remain in facilities throughout Canada tend to be individuals with severe disabilities and complex needs. Similarly, it is estimated that nearly three thousand people with physical disabilities are living in chronic care hospitals because they are perceived to be "too severely disabled" to live in the community. This is a controversial issue in the disability field and in the literature.

For example, in mental health, consumer survivor groups and the Canadian Mental Health Association have strongly supported deinstitutionalization (Chamberlin, 1978; Pape & Church, 1987). On the other hand, some professional groups and family groups have been more cautious about people with severe chronic mental illness living in the community. The Ontario government, for example, spent about eighty percent of the mental health budget on institutional services and twenty percent on community based services in 1993; as part of their mental health reform, the Ministry has set the goal of reversing this by the year 2003 to forty percent on institutional services and sixty percent on community (Ministry of Health, 1993). Consistent with other provinces, these policy directions continue to identify a significant role for institutions.

There is more consensus in developmental disabilities, especially regarding larger institutions. Much literature is critical of institutional services and presents arguments in favor of community living (Meyer, Peck & Brown, 1991; Taylor et al., 1987). The

research showing that citizens with the most significant disabilities can live in the community when appropriate supports are provided raises important policy questions (Taylor, Biklen & Knoll, 1987; Carling, 1995). This emerging literature suggests that focusing on a continuum of services, placement, and "bricks and mortar" is no longer the only way to identify the most appropriate supports for people (Taylor, 1988). By de-linking housing and support, much more flexibility and creativity is possible.

As part of deinstitutionalization, significant efforts have been made towards increased family involvement with very positive success (Conroy & Bradley, 1985; Gollay, 1978; Turnball, Brotherson & Summers, 1985). As earlier work in British Columbia has demonstrated, families who are cautious about community living tend to become quite supportive of community alternatives when they are involved in the planning process for their son, daughter or sibling (Conway & Bradley, 1985; Lord & Hearn, 1987). Family involvement can also be important as a way to expand the person's social network and relationships. Many families are no longer connected with their family member or with the institution, and may require extensive outreach from the people who are facilitating the down-sizing. Of course, it is not always appropriate to involve family, and this is where the principle of consumer preference is so critical. Many people who have been living in institutions have no family connections.

5.   Consumer Initiatives

To ensure that deinstitutionalization does not simply lead to "more of the same" in the community, thoughtful alternatives are now being demonstrated. Some of the most promising work has been done by the National Office of the Canadian Mental Health Association. In a series of documents that are part of their *Framework for Support*, their analysis indicates that too many resources are invested in formal systems and that a major shift is required to build the capacity of other sectors (Trainor, Pomeroy, and Pape, 1993).

They argue that developing the consumer sector, the family sector, and community based support systems will reduce the dominance of formal systems.

The province of Ontario has picked up on the *Framework for Support*, and three years ago began funding consumer/survivor groups throughout the province. This Consumer/Survivor Development Initiative has been very well received by consumers and has been quite empowering for many. The initial evaluation showed that consumer/survivors also had less days of hospitalization since the program's inception (Consumer/Survivor Development Initiatives, 1993). It has also led to the development of a variety of consumer/survivor initiatives, including:

- peer support groups
- community economic development (e.g., businesses)
- research activities
- advocacy initiatives

C. Inclusion and Participation in School, Recreation, Work

There is growing support for the idea that participation in the life of the community is essential for children's health and well-being. Children need strong social networks, full membership in their neighbourhood schools, opportunities to participate in and contribute to community life (McKnight, 1990; O'Connell, 1988). Research shows that when these opportunities are lacking, children with disabilities become isolated, lonely, inactive, and vulnerable to physical and emotional health problems (Bogdan & Taylor, 1989; Gottlieb, 1985; Lutfiyya, 1988; Taylor, 1988).

1.   Relationships and Networks

Over the last decade, a great deal of literature on the friendships and relationships of children with disabilities has emerged. This relatively new awareness of the importance of close relationships in people's lives was a response to the previous decades

which focused more on physical integration into community settings than on full inclusion in community life (Stainback, Stainback, East, & Sapon-Shevin, 1994). In the early days of integration, it was assumed that if people were integrated into the community, that social relationships would naturally follow.

It is now known that many children with disabilities have weak social networks (Belle, 1989). While family relationships are often strong, being without friends, especially peers, can result in loneliness and isolation (Lyons, 1987; 1989). There is an increasing awareness that people with disabilities often experience physical, mental health and behavioral problems as a result of segregation, loneliness and isolation from family, friends and community life (McGee, Menolascino, Hobbs, & Menousek, 1987). Thus, inclusion has been seen by many as a much more involved concept which goes beyond involvement in the community to include acceptance, friendship, and full participation (Eigner, 1995; Hughes & Lyles, 1994; Jacobsen & Sawatshy, 1993; Lewis, 1992). Concrete "inclusion" strategies call for ways of ensuring that children with disabilities are in the right places to meet people and that supports for making and keeping friends are provided (Pearpoint, Forest & Snow, 1992; Partin, 1994; Strully & Strully, 1989).

When children with disabilities have friends, especially with non-disabled peers, parents, teachers and children all agree that numerous benefits are accrued. The children with disabilities become more social, self-confident, assertive, and willing to take risks, at the same time as learning how to be a friend; they have access to everyday opportunities other children are involved in; and they improve their communication skills, which can extend to relationships in adulthood (Heyne, Schleien, & McAvoy, 1993; Giangreco et al., 1993; Perske, 1988). On the other hand, their non-disabled friends develop a strong sense of humanness, equity, fairness, acceptance and commitment; increased confidence, self awareness and self esteem (Bogdan & Taylor, 1989; Lusthaus, Gazith, & Lusthaus, 1992; Peck, Donaldson, & Pezzoli, 1990).

The research shows that the reality of supporting and facilitating friendship development is difficult and complex.   Adults are often not comfortable supporting friendships because they see friendship as a natural process, not to be interfered with (Hutchison, 1990; Kishi & Meyer, 1994); children with behavioral problems are not well accepted by peers (Breslau, 1985; Mitchell, 1982); family stresses may limit parents' capacity to initiate integration and support relationship development (Dunst et. al., 1988; Schilling & Schinke, 1984); for children or adults living in group home settings compared to family homes, there is much less interaction in the neighbourhood and community (Crapps & Stoneman, 1989); and when children participate in the community they are often accompanied by a support worker or other adult, which limits opportunities for relationships (Hutchison & McGill, 1992; Intagliata, Crosby & Neider, 1981)

2.   Inclusion in Education - Emerging Outcomes

The issue of school integration has been the focus of much debate over the past decade (Salend, 1994; Winzer, 1993).   Some believe that it should be the right of the parents and child to choose integration, but progress towards this end has been slow (Bailey, 1994; Smith & Lusthaus, 1994). Advocates of school integration feel so strongly because they believe school integration is an essential early intervention strategy for children, increasing the likelihood of having an ordinary life as an adult in the future (Stanley, 1993). Research shows that several key principles need to be followed around educational integration: children should attend their neighbourhood schools with their siblings; individualized goals and support are needed;   children should be in regular classrooms with age appropriate peers; strategies for socialization and making friends need to be considered; teachers need support to learn curriculum adaptations; and finally, carefully thought needs to be given as to whether a teacher's aid would benefit the overall class to complement peer teaching (Brown et.al., 1989; Giangreco et al., 1993; Jackson, 1993; Jacobsen, & Sawatsky, 1993; Kennedy & Itkonen, 1994; Klassen, 1994; Nevin, 1993; Pearpoint, Forest, & Snow, 1992; Putnam, 1993).

Research on outcomes indicates that children who are integrated have improved responsiveness to school routines and higher academic performance (Giangreco et al., 1993); the opportunity to participate in social life and extracurricular activities of the school (Lusthaus, Gazith, & Lusthaus, 1992); a chance to practice the roles for the future (Bradley, 1994); and improved social skills, self-esteem and sense of belonging (Ministry of Education, 1992).

Others also benefit from integration as well. Peers have an opportunity to develop tolerance and caring, important skills for future parents, service providers and community members (Stainback and Stainback, 1985; Stanley, 1993). They learn to appreciate each other's strengths and need to support one another (Biklen, 1992). The earlier this process of integration begins, the more of these benefits are gained (Gould, 1994). Teachers experience increased confidence and a sense of pride; as well as a willingness to learn from the students and change teaching methods to benefit all, such as the use of cooperative learning approaches, peer tutoring and support circles (Brown et al., 1989; Giangreco et al., 1993; Gold, 1994; Graden & Bauer, 1991; Putnam, 1993; Salisbury, Palombaro, & Hollowood, 1993; Zey, 1990); and an increased understanding of the importance of strong parent/teacher relationships (Stanley, 1993).

Despite the positive literature on integration, there are significant challenges in creating inclusive systems. Few school boards have policies on integration; segregated classes and segregated schools are still prevalent; training for teachers is limited; with budget cutbacks, teaching assistants are being eliminated; some parents feel that their children require specialized support in segregated settings; low expectations exist on the part of teachers and parent; and there is often concern about the impact of having children with severe disabilities in the classroom on other students (Bilken, 1992; Davern & Schnorr, 1993; Dyson, 1994; Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993; Gould, 1994; Grenot-Scheyer, 1994; Guralnick, Connor, & Hammond, 1995; Hamre-Nietupski, Hendrickson, Nietupski, & Shokoohi-Yekta ,1994; Hunt, Farron-

Davis, Beckstead, Curtis, & Goetz, 1994; Lewis, 1992; Sharpe, York, & Knight., 1994; Sobsey, Dreimanis, & MacEwan, 1993).

3.   Recreation Participation and Leisure

Research has clearly indicated the importance of spare time activities, friendship and personal competence to people's overall life satisfaction, quality of life and health (Headey, 1988). While personal competence is important, it is difficult for people who are poor, live in substandard housing, are socially isolated, and unemployed to feel personal competence (Rosenfield, 1992).

Leisure has been highly valued as a contributor to health and quality of life because of its numerous benefits (Argyle, 1987). However, leisure is not always a good thing. It is unhealthy when it leads to apathy, boredom and anxiety; or when it leads to unhealthy practices such as excessive television watching, consumerism, sun exposure, alcohol and drug problems, and crime, all of which are indicators or uprooted communities and lack of value system (Carruthers & Hood, 1994; Csikszentmihalyi & LeFevre, 1989). Youth and people with disabilities in particular are susceptible to leisure related problems; if leisure time is wasted, used inappropriately, or if people are not adequately prepared, poor health and quality of life can occur (Walker, 1994).

The health benefits of leisure are diverse. Active living and leisure experiences can result in *positive mood*, which in turn improves the immune system (Folsom, et al.,1985; Hull, 1990).   Leisure produces *flow experiences*, which are any activities that challenge people to develop new skills; they are characterized by enjoyment, deep concentration, and loss of time (Csikszentmihalyi, 1990).   *Self-esteem and self actualization*, especially when linked to increased competence, are enhanced through leisure participation, as has been demonstrated widely in the adventure therapy and outward bound research (Berman & Davis-Berman, 1993).   Leisure contributes to stronger *social networks*, which in turn, have been shown to relate to more positive

health. When people have friends, they are less isolated, less bored, less lonely and less dependent on professionals (Larsen, Mannell, & Zuzanek, 1986). Leisure *reduces stress* by acting as a buffer or mediator between stressful life events and illness (Coleman & Iso-Ahola, 1993). Finally, leisure contributes to *self-determination,* because it encourages choice, freedom, decision-making, all leading to a sense of control over our lives (Coleman, 1990). The Active Living Movement in Canada recognizes all of these connections and has played an important role in promoting change at both the individual and community level (Caldwell & Smith, 1988; Quinney, Gauvin & Wall, 1994).

Integration into leisure has perhaps been less controversial than integration in other areas of life. Generally leisure is seen as more informal and flexible and therefore condusive to integration. A growing amount of literature is focusing on the integration process, benefits, strategies, and outcomes (Bullock & Howe, 1991; Certo, Schleien, & Hunter, 1983; Gold, 1988; Heyne, Schleien, & McAvoy, 1993; Lyons, 1991; Morgan, 1989; Pedlar, 1992; Potschaske, 1988; Sandys & Leaker, 1987). When coupled with our understanding of leisure and health described above, the literature on recreation integration provides a promising avenue for enhancing some determinants of health.

4.   Community Contribution and Preparation for Work

Over the past decade, it has been shown that when people are denied opportunities to contribute in a meaningful way to society, their mental and physical well-being is drastically affected (Canadian Mental Health Association, 1984; Pedlar, Lord, & VanLoon, 1989). This includes the unemployed, retirees and older persons, people with disabilities who are considered unemployable, and youth.   In addition, a critical determinant of health has shown to be the participation and control at work (Ochocka, Lord & Roth, 1994; Syme, 1994).

While society as a whole has fluctuated in its attitude toward work, it is still generally accepted that meaningful work is a valued activity that should be available to

anyone, including people who have disabilities (Hagner & Dileo, 1993; Sandys & Leaker, 1987).   Proponents of work for people who have disabilities have demonstrated how people, including those with severe disabilities, *can* work in the community and make a contribution (Bellamy, Rhodes, Mank, & Albin, 1988; Gardner et al., 1988).   They believe the practice over the past several decades of treating people with disabilities as trainees and clients in segregated, sheltered workshops, rather than employees has been devaluing (Brown, et al., 1991; Worth, 1988).

People with disabilities experience a high rate of unemployment and are often seen as unemployable (The G. Allan Roeher Institute, 1988). As a result, many are living below the poverty level, receiving only a pension.   Many find themselves living at home with their parents, in sub-standard housing, or in residential services designed for other people with handicaps.   They experience not only the stigma of their particular impairment, but also the stigma related to being labelled permanently unemployable and poor (Ontario Ministry of Community and Social Services, 1988). Poverty is an issue which is highly related to unemployment and health (Bridge & Gold, 1989).

In order to prepare people with disabilities for making a contribution in adulthood through employment, there has been greater emphasis on prevention with children and youth with disabilities.   School integration, co-operative work placements at school, school to work transition programs, part-time work, and volunteer work have all been seen as important preparation. When expectations are high and children have the maximum opportunities to develop to their fullest and be seen as valued contributing members of their communities, they are healthier and happier as children, youth and adults (Panitch, 1988).

Research also points to the argument that not all people with disabilities will be employed in the labor market. There are several rationale provided in the literature. A combination of factors, such as the nature or severity of the person's disability and difficult economic conditions, are the basis of this belief (Browne, Connors, & Stern,

1985; Revaud, Madiot, & Ville, 1992). For example, for people with severe handicaps, the belief is that the person would be unable to work in the community, let alone in sheltered employment, and contribute in any meaningful way. The cost and effort of providing supports would far outweigh the benefits accrued to either the person or the community. Alternatives to work would be more realistic and could contribute significantly to the quality of life of people who have developmental disabilities.

The current economic climate is seen also as a significant barrier to employment of people with developmental disabilities (McLoughlin, et. al., 1987). Society is becoming desensitized to hearing about unemployment rates of well over 10%. Employers and unions are seen as being resistant to the idea of hiring people with disabilities, particularly when they are having to lay off other workers. If this trend continues, finding employment, particularly for those who have in the past been considered unemployable, will increasingly be seen as a barrier. Instead, people with disabilities, as well as a lot of other citizens who are finding themselves with a large amount of discretionary time, can enhance their overall quality of life by pursuing a variety of non-work alternatives (Reid, 1990).

The argument is also put forth that people with disabilities should have the choice of whether or not they wish to work. This argument is based on the assumption that all citizens essentially have the right to work and the right not to work (Farina, 1982). While making this choice often results in less income for the individual, and sometimes a reliance on social assistance, some people on welfare, stay-at-home parents, and older persons have made the conscious choice not to work, at least for a period of time (Guest, 1985). These decisions have been made for many reasons including: dissatisfaction with the work place, inadequate income, a desire to raise children, or an interest in pursuing non-work alternatives.

D. Enhancing Family Well-Being

1.   Family and Disability

Growing up with a child with a disability in this culture is filled with paradoxes and dilemmas (Turnball, 1985). Historical perceptions of disability cloud all efforts to raise one's child the same as other children. While children with disabilities often require "extra support," this has typically been provided in professionalized, clinical settings. Adults with physical disabilities often remember their childhood filled with "visits to the clinic" and "little involvement with other kids" (Lord, 1991). Ironically, families are a site of nurturing and care, as well as a place of risk as demonstrated by recent Canadian data on the amount of violence perpetuated against women and children within families (Roeher Institute, 1994).   There a multitude of reasons identified in the literature regarding why families require support (Dunst et .al, 1988; Roeher, 1994).

Families whose children grew up in the 50's and 60's faced a very different situation from families who are raising young children in the 1990's. The threat of institutionalization has diminished and a variety of community based family support options have emerged. These family support alternatives, while usually quite limited and poorly funded by governments, provide one of the most cost-effective interventions for addressing determinants of health.

Advocacy on the part of families has been significant in the emergence of this new disability paradigm in the last thirty years. As Simmons (1982) has pointed out, people with disabilities, unlike the organized working class, have never made their own history. Simmons emphasized that it was only because people with developmental disabilities started to be represented by interested groups and families since 1945 that their presence has been felt on the political scene. Families as advocates have had more of an indirect role in shaping government policy and social change, by presenting a vision of what could be possible for people with disabilities. The vision of these advocacy groups is

typically well ahead of government policy and presents a challenge for government and communities. For example, the Canadian Association for Community Living *Vision 2000* paper proposed in 1980 that all children should have access to neighbourhood schools and regular classrooms. Similarly, families who have a family member with a mental health problem have presented many briefs to government recommending that effective community support services be put in place for their loved one.

2.   Family Support: An Emerging Vision and Principles

Recent research shows that there is a growing diversity among Canadian families. Despite differing family structures, all families "need to be acknowledged, recognized, supported so that they can perform their many functions more effectively" (Vanier Institute on the Family, 1992, p. 16). Industrial society has significantly changed the roles which families have to play in the culture. Because of the changing nature of families, according to the Vanier Institute on the Family (1992), every government has a family policy if only by default:

> (It is) in the nature of modern industrial society (that) no government, however firm might be its wish, can avoid policies that profoundly influence family relationships. This is not to be avoided. The only option is whether these will be purposeful, intended policies or whether they will be residual, derivative, in a sense concealed ones (Moynihan, 1986, 12).

Numerous family support principles, as distinct from other human service initiatives, can now be found in the literature (Center in Human Policy, 1986; Family Resource Coalition, 1987; Hobbs, Dokecki, Hoover-Dempsey, Moroney, Shayne, & Weeks, 1984; Dunst, Trivette, & Deal, 1988). Examples include:

- Create opportunities for enhancing the acquisition of competencies that are necessary to promote individual and family development.
- Create linkages amongst people that can be of mutual benefit to one another.
- Permit and encourage families to make informed decisions about themselves and their children.
- Ensure that families have the necessary resources, time, energy, and information to perform child-rearing functions well.

•   Employ partnerships and parent professional collaboration that explicitly enable and empower families to become more capable and competent.

In a similar vein, the Family Support Institute of Ontario, a parent-driven organization has emphasized six guiding principles for family support related to families with a child with a disability:

•   Family supports must be based on the principle "whatever it takes".
•   Family supports build on existing social networks and natural sources of supports.
•   Family supports maximize the family's control over the services and supports they receive.
•   Family support includes the entire family.
•   Family supports encourage the integration of individuals with disabilities into the community.
•   All families, regardless of disability, need enduring family relationships.

These kinds of family support principles are creating an emerging vision of family support. Increasingly, family support programs are seen as being "empowerment" oriented, by trying to provide the resources and supports that families need to enhance their own control and competence and to make best use of their resources in collaboration with their communities. Dunst (1991) note five critical questions for analyzing family support policy and practice.

1.   Does the policy or practice enhance a sense of community amongst its members?
2.   Does the policy or practice promote the flow of resources and supports to and from the family?
3.   Does the policy or practice strengthen and protect the integrity of the family unit?
4.   Does the policy or practice operate according to enabling and empowering principles and enhance and promote the confidence of the family in individual family members?
5.   Does the policy or practice encourage adaptation of human service delivery approaches that are supportive of the previous principles?

An emerging vision of family support can thus be seen as a series of comprehensive, interdependent policies which would enhance the determinants of health by enabling families to have more control over the resources and relationships they may
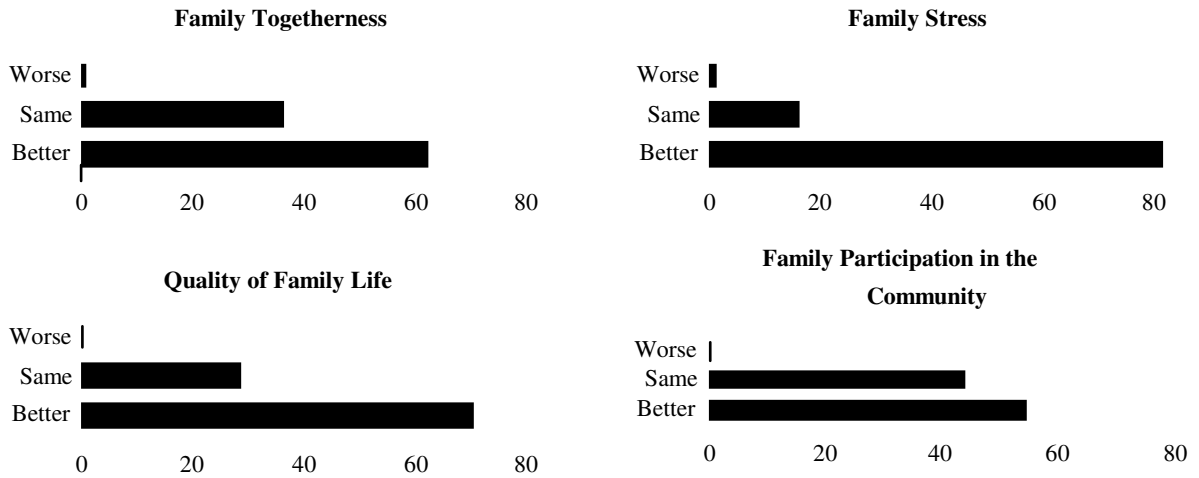
require to support their child with a disability to be a participant in community and school life.

3.   Individualized Funding and Family Support

In the last decade, there has been an increased interest in the development of individualized funding programs to meet the support needs of people with disabilities and their families (Agosta, 1989;   Pape and Church, 1987; Salisbury, Dickey & Crawford, 1987; Torjman, 1991). In individualized funding initiatives, money goes either directly to the family from the government or to the family through an agency. In both cases, the individual needs of a particular family are used to guide the amount of money and the resources that are being made available.

Research is demonstrating many positive outcomes from individualized funding programs. In one major study, the *Review for Support Services for Ontario* (Lord, Hutchison, & Farlow 1988), 78% of the consumers agreed with the concept of an independent living allowance. In another study, outcomes for families of the Special Services at Home program, sponsored by the Ontario government and the Ministry of Community and Social Services, were very positive (Lord and Ochocka, 1995). Table 1 shows the percentage of families who feel things have become better, stayed the same, or become worse since they began receiving funding with this program.

Table 1: General Family Outcomes

Family Togetherness

Worse	▌
Same	████████ (~37)
Better	████████████ (~62)

Scale: 0, 20, 40, 60, 80

Family Stress

Worse	▌
Same	████ (~16)
Better	████████████████ (~82)

Scale: 0, 20, 40, 60, 80

Quality of Family Life

Worse	▌
Same	██████ (~29)
Better	███████████████ (~72)

Scale: 0, 20, 40, 60, 80

Family Participation in the Community

Worse	▌
Same	█████████ (~44)
Better	███████████ (~55)

Scale: 0, 20, 40, 60, 80

There were strong indications from the data that it is often the mother's stress that is most significantly reduced as a result of this program. This is consistent with research related to institutionalization that has shown that the crisis related to stress and institutionalization is often related to "the wearing down of the mother" (Bullock, 1990; Lord & Hearn, 1987).

Individualized family support programs, such as Ontario's Special Services at Home, provide a new and exciting mechanism for families and children with disabilities. Family-centred support services give families control and participation in critical issues which affect their lives. Even though research identifies positive outcomes for individuals and families, these types of family support programs are currently very limited in terms of scope and impact. In addition, families report some problems such as lack of responsiveness of agencies to accommodate family strengths and overall needs; lack of appropriate services to purchase with their money; or where the system fails to recognize that all "families may not wish to play such an empowered role" (Agosta, 1989, p.8).

E. Empowerment, Control and Participation

Several fields of endeavour have begun to incorporate the language of empowerment. Health promotion, for example, is defined by the World Health Organization (1987) as "the process of enabling people to increase control over, and to improve their health (p. 1)." In social work, empowerment is seen by some critics as an alternative to the professional control exercised by social workers and the systems within which they work (Freire, 1985). And in the area of disability (and especially family support), there is a growing network of researchers and practitioners interested in the concept of empowerment (Dunst et. al., 1988; Rose & Black,1985; Siegel & Laosa, 1983)

1.   The Process of Empowerment

We can begin to understand empowerment by examining the concepts of power and powerlessness. Power is defined by the Cornell Empowerment Group (1989) as the "capacity of some persons and organizations to produce intended, foreseen and unforeseen effects on others (p.1)."

At the individual level, powerlessness can be seen as the expectation of the person that his/her own actions will be ineffective in influencing the outcome of life events (Kieffer, 1984). Rappapport notes that empowerment, "conveys both a psychological sense of personal control or influence and a concern with actual social influence, political power and legal rights" (Rappaport, 1987, p. 121)· In this sense, empowerment can exist at three levels; at the personal level, where empowerment is the experience of gaining increasing control and influence in daily life and community participation; at the small group level, where empowerment involves the shared experience, analysis and increasing influence of small groups on their own efforts and their community; and at the

community level, where empowerment revolves around the utilization of resources and strategies to enhance community control.

In recent research on empowerment, the focus has been on citizens with disabilities who have experienced extensive powerlessness in their lives and who have recently gained more control and participation.   Five research themes which emerged from a series of empowerment studies has solidified our understanding of the need for new approaches to community services (de Boer, 1992; Lord, 1991; Lord & Hutchison, 1993; Lord & McKillop Farlow, 1990).   Each of these themes will be presented with related research and implications.

Powerlessness.   Most research on empowerment describes in great detail the anguish of feeling powerless.   No single factor or experience creates a sense of powerlessness; rather, it is a build-up of factors and experiences that develop into a disempowering situation. For most of the people with disabilities, their social isolation began early in life - at home, school, and in the community.   As Foucault (1984) has pointed out, one of the cruelest myths experienced by people with disabilities is that their difference is somehow not socially acceptable.

Early intervention which prevents children with disabilities from experiencing powerlessness as adults is a critical prevention strategy.   A number of studies have demonstrated the importance of working with young children with disabilities and their families (Cochrane, 1986; Dunst et al., 1988; Shipe, 1984).   The primary function of early intervention is the prevention of impairments or disabilities becoming serious social handicaps.

Impetus to empowerment.   The transition towards personal empowerment is a uniquely individual and ongoing process.   For most participants, their impetus to empowerment is not a conscious decision. Instead, it is motivated by concrete factors that participants, in reflecting back, were able to identify.   These factors or situations act like catalysts for the empowerment process, helping individuals to become aware of their own

capacities and of alternatives to the experience of powerlessness. The main factors which
participants identified as providing the impetus for change were:

- being involved in a crisis or "life transition."
- acting on anger or frustration.
- responding to new information.
- building on inherent strengths and capabilities
- a change in context

Support from people. Personal supports are vital in expanding personal
empowerment. Three main types of support were identified as being particularly
significant; practical support, moral support, and mentoring. Most research participants
identified at least one significant person as being important to his or her personal
empowerment.

Several studies have shown the power of social support in relation to health. To
summarize the reviewed literature, the intrinsic value of social connections is thought to
reside in four basic characteristics: emotional concern and caring; practical aid; access to
and exchange of information; and, social comparisons and appraisals (Barrera & Ainlay,
1983; Gottlieb, 1985; House, 1986: Lord & McKillop Farlow, 1990; McIntyre, 1987;
VanLeer, 1989; Wyngaarden, Kraus & Erikson, 1988). As well, most would agree that
such relationships are "supportive" when they involve a "flow" of valued resources
between parties (House, 1986; Lord & Farlow, 1990; Wellman & Hall, 1986). People
with disabilities have a long history of experiencing social isolation and very small social
networks. We know that living with a disability in our society increases one's
vulnerability. The addition of weak social networks creates a "double jeopardy" that
increases powerlessness.

An innovation in the disability field is the growth of strategies for "building social
support networks" including support circles and support clusters (see section III, success
stories), and strengths based case management. These strategies, while often informal
and always community oriented, provide a collective approach to vulnerability, and

appear to contribute to the families' sense of security and to the empowerment of the person with the disability. There has been a phenomenal growth in self-help during the last decade (see entire Special Issue of the Canadian Journal of Community Mental Health, fall, 1995). Similar to the research on empowerment, this work shows the importance of peers and mentors.

As people gain more control in their lives, a substantial element of health, they often attribute their change to themselves and to a small number of individuals or groups. This work is supported by the positive impact of the disability consumer self-help movement. Whether it be the independent living movement, People First for citizens with a developmental disability, or consumer/ survivor initiatives in mental health, the power of peer support, mentors, and self-help groups has both health and social impacts (see section III for success stories).

Access to valued resources. When people experience powerlessness, most have access only to resources which they perceive as being different or specifically for "rehabilitation" or "welfare." The research shows that beginning to have access to the same valued resources and opportunities as other community members is important for people's empowerment process. For example, gaining employment is a pivotal point in people's lives as a way of expanding their economic power and gaining respect. Other examples of valued resources include independent housing, technical resources such as a motorized wheelchair, and money.

Participants in the research are highly critical of systems which are bureaucratic, congregating, and controlling. Pinderhughes (1983) points out that too often service workers and systems see people as victims and keep people in inferior, powerless positions. Services that are of value have some common qualities, including being personalized, responsive, interactive, and providing a degree of self reliance and consumer control. It is significant to note that the health and social service workers who

are seen as helpful in the research are characterized as "a good listener", "an equal", "a guide", and a person "who really cares".

Participation. Participation significantly advances the process of empowerment for most people. As people gain in self-confidence, they seek more avenues for participation. The experience of the research participants shows that participation contributes to personal empowerment by reducing isolation through participation, and by expanding participatory competence and confidence. Other research has also noted that "getting involved" is a particularly important way for people to feel affinity with others (Bellah, Madsen, Sullivan, Swidler & Tipson, 1985). Other literature also supports the idea that having an opportunity to experience a range of valued roles is empowering because it reduces isolation, increases social interaction, and enhances the person's feelings of self-worth (Wolfensberger, 1983).

For citizens with disabilities, participation is double-edged. There is the "consumer participation" that is so often required to ensure that their "voices are heard" (Church, 1995). There is also the "community participation" that is an essential part of quality of life and health. While both kinds of participation can be "empowering," consumer participation doesn't necessarily lead to increased control. Too often, consumers are expected to support service practices that are disempowering. While "consumer participation" as a way of working is gaining support, its "unsettling" nature for service providers means it is often in jeopardy (Church, 1995).

2.   Empowerment Principles for Community Practice Related to People With Disabilities

Many organizations that support people with disabilities espouse the words "empowerment." Increasingly, principles for facilitating empowerment with vulnerable citizens are being identified (Lord & Hutchison, 1993; Dunst et al., 1988; Labonte, 1990; Rose & Black, 1985; Whitmore, 1988). Interestingly, the central principles identified in the research on empowerment focus on areas that are essentially determinants of health; shifting focus of control to the person; enhancing social support; accessing valued resources; and facilitating participation. According to these authors, these principles

work in concert with each other; no one principle by itself will have enough impact to empower individuals and groups.

3.   Consumer Initiatives and Health

For the past two decades, self help initiatives by consumers with disabilities have played an active role in Canadian policy analysis. Strong national groups such as the Council of Canadians with Disabilities, People First, Mental Health National Network, Canadian Association of Independent Living Centres, and Disabled Women's Network have done extensive research, policy analysis, and represent the consumer perspective on a number of issues. The substantive issues related to health that have been addressed by these groups include:

• social security reform, which is focused on poverty and disability and proposals that will ensure that people with disabilities will have adequate income and safety net (CAILC, 1995; CCD,   ).

• choice and control in treatment and services; for example, in mental health where consumers have been active in mental health legislation reform

• vulnerability of people with disabilities to sexual and physical abuse both in institutions and the community; in particular, women with disabilities face a double jeopardy (Roeher Institute/Family Violence, 1994;

• ethics regarding mercy killing, assisted suicide, reproductive technologies, forced sterilization compensation, (ARCH)

• accessibility (physical, economic, social) in education, employment and training, housing, and community participation

III. Success Stories

A. Special Services at Home: A Provincial Individualized Family Support Program

Actions on Non-Medical Determinants of Health: The Ontario Special Services at Home Program was initiated in 1982 to avoid the institutionalization of children with developmental disabilities and to keep them living at home. The program was expanded several years later to include children with physical disabilities and more recently adults with developmental disabilities. The Special Services at Home Program (SSAH) focuses on two broad areas of family support; personal development and growth of the family member with a disability and/or relief and support for the family generally. Typically, SSAH interventions involve a paid person coming into the family home and providing relief for the family by giving the parents and siblings a break, and/or providing one-to-one support for the individual with a disability by involving the person in community activities. Families apply for SSAH funding directly to the area government office in their community. Once an application is approved, the government provides funds either directly to the family or to the family through an agency.

This individualized family support program is addressing determinants of health in several ways; by keeping children with disabilities out of institutions where they are much more likely to see their health deteriorate; by providing resources directly to families to enhance their quality of life; and by providing a mechanism for children with disabilities to be integrated into community activities, thus increasing their capacity for expanded social networks and control.

Principles and values underline the Special Services at Home Program include:

• Children with disabilities should have the right and opportunity to remain with their families wherever possible.

• Families should have an opportunity to have control over the resources that are utilized for their own family support.

• The needs and issues facing families are extremely varied, making it impossible for one program to meet all needs. Thus, the individualized nature of SSAH is paramount to its success.

Reasons for the Initiative: This is the only province in Canada with a comprehensive individualized family support program. Prior to its inception in 1982, the previous decade was characterized by tremendous growth of community services for people with disabilities and their families in Ontario. Family support workers, developmental programs, respite care, assistive devices program, and handicapped children benefits were all a part of a major shift in terms of program and service delivery. Despite the growth of community service infrastructures, family support advocates during that period argued that these initiatives were extremely limited and "institutional" for families.

Actors: Each area office of the ministry appoints a SSAH officer, who invites families who met certain criteria to submit applications. In the second year of the program, the ministry released program guidelines, which were updated in 1991. It is interesting to note that between 1984 and 1991, a SSAH Family Coalition was formed in order to advocate for increased funding and improved guidelines for the program. The 1991 guidelines certainly reflected much more input of families. Although the locus of power for the SSAH program is within the Ministry of Community and Social Services, families that receive individualized funding do have a great deal of "control" over the resources they receive. In fact, this is the characteristic of the program that families most appreciate (see evaluation below).

Analysis of the Results: From a major evaluation completed in 1993 by the Centre for Research & Education in Human Services, it is clear that the goals and objectives of the SSAH program were achieved to a large extent. This is partly reflected

in the wide number of outcomes from the program identified by families. These outcomes were identified in four major areas: general family outcomes, community integration outcomes, family life outcomes, and skill and behavioral development outcomes. Within these four areas, some of the key findings included reduced family stress, more prevention of institutionalization, and increased integration into community recreation. According to families, the goals were achieved for several reasons, including the individualized nature of the program. Families identified the motivation of the worker as being critical to enhancing their family life. This program appears to be an example of forward thinking policy and simple implementation that can effectively meet individual and family needs.

The evaluation research also shows some unsettling aspects of this kind of program, particularly when it is implemented in such an uneven fashion across the province. Families that have trouble finding workers, for example, are less satisfied and find that the program meets their family needs less effectively than those families who have been able to find workers. It appears that this "failure" is best remedied by insuring that informal family networks can be developed to insure that there is a community "infrastructure" that includes information sharing and pooling of workers.

The issues from the SSAH evaluation raise important questions for the implementation of individualized programs of this type. Typically, human services for people with disabilities have emphasized the "supply" side of delivery. In other words, services and programs with particular criteria were made available. The SSAH program invokes more the "demand" side of the service system. Consumers, who are given a resource (government money), are able to purchase the needed support. In theory, the consumer demand should "create" appropriate services. As noted in this evaluation, however, families who were the most dissatisfied were those who could not access adequate supports (either because of unavailability of workers or high worker turnover).

This finding suggests that careful attention needs to be paid to both the "demand" side and the "supply" side of the service system.

Replicability of the Initiative: The Family Support SSAH Alliance in Ontario believes that this program can be expanded to include adults with disabilities who live on their own in the community. Currently the program is only available to children or adults with disabilities who live with a family. It is the "individualized" components of the program which are particularly appealing to the Alliance and others who believe that people with disabilities are too often "congregated" and "segregated". The principles of the SSAH Program can likely be replicated in other provinces and with different populations. The extensive provincial evaluation, and other documents produced by the government and the SSAH coalition would be helpful to others who are considering replicating the program. When combined with other informal support mechanisms, this individualized support program can have an important impact on health determinants of families and individuals with disabilities.

Funding: The Ontario Ministry of Community and Social Services provides ongoing funding for this program, which was 26 million in 1994. Interestingly, the demands of families for this service did not "pick up" until the early 1990's. As part of the provincial evaluation completed in 1993, it was determined that this program is very cost effective. The amount of money which families receive (maximum of $10,000) is far less than group home living or institutional placement. In addition, the evaluation research showed that quality of life is much greater for individuals who are staying at home and being part of their community.

Evaluation: An extensive fourteen month process and outcome evaluation was completed on the SSAH Program in 1993. The evaluation was completed by the Centre for Research and Education in Human Services, with funds provided by the Ministry of Community and Social Services. As noted above, the results of the evaluation indicated very positive outcomes for this program, with some "problems" in the delivery of support

services. The evaluation produced an executive summary (in French and English), and a full report (in French and English). These reports are available from the Ontario Ministry of Community and Social Services.

Reference: Centre for Research & Education in Human Services. 1993. *Family Directed Support: Diversity, Hopes, Struggles, Dignity. Special Services at Home Evaluation.* Toronto: Ministry of Community & Social Services.

B. Support Clusters Network of Ontario: Building Partnerships, Enhancing Social Support

Actions on Non-Medical Determinants of Health: The Support Clusters Network of Ontario was originally a three year demonstration project entitled Support Clusters Project. The original project was to designed to explore the effectiveness of working with the support networks of persons with complex disabilities. These individuals were people with developmental disabilities who were experiencing mental health problems and had been labeled as having a "dual diagnosis". The intervention itself was not specifically aimed at helping the individual with a dual diagnosis, but rather indirectly by working with the support network or "cluster" around the person. The intent of the project was to improve the mental health, health status and function, and the quality of life not only of the person with a dual diagnosis, but of everyone within the support network or cluster. A "support cluster" consists of the family members, friends, and professionals who are involved with the person with the complex disability. The central values and principles underlying this intervention are:

•   Support for supporters is essential to providing effective community intervention with the person with complex disabilities.
•   Ecological or holistic thinking needs to be part of thinking about the person and their social environment.
•   Empowerment of the support cluster is the desired process.

- Families, friends, and professionals can work in partnership to enhance quality of life of the person and their network.
- Education and learning can provide important support to clusters.
- Action research ensures ongoing learning and support.

Reason for the Initiative: People with developmental disabilities who are experiencing serious mental health problems often have significant health issues. Despite the best intentions of all involved, present practice for service delivery can best be described as fragmented, insensitive and ineffective. It is not unusual for citizens with such labels to be over medicated, frequently hospitalized, and generally be experiencing a poor quality of life.

With continuing institutional closures across Canada, the responsibility for daily support for these individuals with very complex and difficult disabilities has fallen with increasing frequency upon a network of well-meaning, but ill-prepared families and social/health providers. Most initiatives in this field call for more services, but the founders of the Support Clusters Network of Ontario believed that this solution seldom addressed the underlying problems. Clearly, the founders of the Support Clusters Project realized, people with a dual diagnosis required an intervention which would address their consumer health needs, would reduce inequities in health status, and demonstrate a cost-effective, community-based method of delivering services. Paradoxically, the awareness of the need for change became most apparent when the initial founders began to think of what was "actually needed" instead of focusing purely on "getting more services".

Actors: The group that originated the Support Clusters Project had many of the qualities which are required by small groups that are initiating community change. Each member had wide credibility and extensive social networks in the community. The early meetings themselves uncovered another reality; people's personal motivations sparked them to find alternative ways to resolve serious issues for the community. Several of the group also had qualities of "innovators" which include the ability to see beyond the traditional ways of doing things. A funding opportunity from Health Innovation Fund of

Ontario was clearly a catalyst that sparked this small group of service providers, family members and researchers to design a new innovation.

Analysis of the Results: The goals of the Support Clusters Project, to increase social support within the networks of people with a dual diagnosis, was met for twenty support families and individuals over a three year period. There were several factors associated with successful support clusters:

- Balance in support clusters between informal and formal support.
- Involvement of the person a complex disability.
- Willingness and capacity to work together.
- An informal approach to interactions among clusters members.
- Establishing and useful goals.
- Effectively facilitating the process of achieving the goals.
- Shared leadership/development of partnerships.

Families especially were extremely satisfied with the support clusters intervention. Most families reported a marked increase in their ability to cope with stress. In addition, families reported strengthened relationships with both their informal and formal supporters in the cluster. Many families believed they had a real sense of input and control in the project and for many families it was a novel experience having control and relationship with professionals. Many cluster members including professionals, agree that the new network of people developed in the clusters helped them to deal with difficulties and stress. An important finding is the fact that many cluster members reported greater understanding of the person and her or his family-life context and strengths. Finally, the research found that effective, paid facilitators helped circle members to work together toward common goals.

Replicability of the Initiative: The three years of research on the Support Clusters Project produced some long-term change in the communities of which it was a part. For twenty support clusters, for example, 86 professionals and 75 informal supporters attended more than two cluster meetings. The extensive amount of participation produced a kind of "ripple effect", in which an individual support cluster

might have affected eight or ten different people. By the end of the three years of research, many agencies identified the project as a beginning point for positive change in their organization and the community and indicated a willingness to stay involved with the cluster approach. This intervention can clearly be replicated with people with complex disabilities or a dual diagnosis label. The extent to which it can be replicated with other populations, such as people with Alzheimer's, or people with serious mental health problems is still uncertain, but is currently being used.

The legacy of the Support Clusters Project is the Support Clusters Network of Ontario in which education and training opportunities are now provided for people across Ontario who are interested in utilizing the support clusters model. The findings to date suggest that the support clusters principles are what can be replicated.

Funding: The three year Support Clusters Project was funded by the Health Innovation Fund of Ontario. Since that time a Support Clusters Network of Ontario has received three year funding from the Trillium Foundation. In addition, the Ministry of Community and Social Services now funds a dual diagnosis consultant in an agency in Kitchener. This agency uses a support clusters intervention as part of the consultant's work. The efficacy of the intervention would be more effectively developed if funding were ongoing and secure, but at this point there are two years left in the second three years of funding. Several of the initiators of the project continue to be involved which is a good sign for this project.

Evaluation: The three year Support Clusters Project had an extensive evaluation research component. This included a process evaluation and an outcome evaluation of each of the clusters. The evaluation was conducted by the Centre for Research in Human Services and was released as a report entitled Support Clusters Project: Evaluation Report of the Research Demonstration Project (1993).

C. Circle of Friends/Support Circles

Actions on Non-Medical Determinants of Health: In 1983, the first documented circle of friends described the life of Judith Snow and her "Joshua Committee" (Forest & Snow, 1983). At the time, Judith, a woman who is a quadriplegic, was living in a chronic care hospital, ready to die due to loneliness, frustration, and malnutrition. A Toronto professor visiting with her students, Dr. Marsha Forest, met Judith and immediately developed a bond. It took some time, but the circle of friends which was developed around Judith secured funding from an Order in Council to get her out of the hospital and living in her own place. Judith has fulfilled many of her dreams since that time, including completing a Master's degree in psychology, getting married, working, and teaching people about the importance of friends and circles. Throughout all of the frustrations and struggles that accompany community living, Judith has maintained strong support from her circle of friends (Pearpoint, 1990). This model of support and friendship has been replicated all across Canada, the U.S. and Australia.   Circle of friends has been of particular significance as a support system for school integration (Forest, 1987; Pearpoint, Forest & Snow, 1992).

Reason for the initiative: Circles of support or friendship, which provide an important co-ordination role in the person's life, are initiated for any one or more of the following reasons:

•   the complexity of the person's disability or situation requires a level of support and facilitation that cannot be left to chance.

•   lack of accessibility in the community is severely limiting the person's options and leading to tremendous frustration.

•   because of lack of human contact due to isolation or rejection, the person has developed behaviours that are disturbing to others, and which make participation in the community complex.

- ongoing decisions about the person's life have not been individualized; they have been based on stereotypes about the needs of people with that disability or particular behaviour; the result is personal needs, goals, and dreams are not met.

- the person has lost all confidence and motivation to be involved.

- the person is lonely and isolated because of a lack of friends.

- the person, friends and/or family are frustrated with both the dependence on human services and the lack of responsiveness of professionals (Hutchison & McGill, 1992).

This model of support and friendship seemed to provide a significant contrast to other models such as peer tutoring, leisure buddies, and citizen advocacy, which were more one-to-one volunteer models and seemed to have less potential for strengthening the person's social network and providing real friendships (Hutchison, 1990; Snow, 1989).

Actors: The make-up of circles of support varies according to the needs and desires of the person with a disability. Some circles have family members, friends, and potential friends. Other circles also include a few trusted professionals from the person's life, such as a health care worker or teacher, who are there, not because they are being paid, but because they have been invited to get involved with the person in a different and deeper way. Members are sometimes known to the person and are individuals who the person believes would be willing to make a bigger commitment to the person's life. Sometimes members use their own personal networks to identify potential new members (Mount, Beeman & Ducharme, 1988).

Analysis of the results. There has been extensive documentation and anecdotal evidence of circles (Falvey, Forest, Pearpoint & Rosenburg, 1994; Forest, 1989; Haring, 1991; Perske, 1988), their important, and their strategies, however, very little research has been conducted on circles. The one major study on circles (Gold, 1994) found several interesting findings: the ethos of a group is quite strong - that is, the ideals that pervade the group. A circle attempts to make its activities seem as natural and normal as possible,

integrating the social and support aspects; in a way, they don't see the need to separate support from friendship.   The circle itself means little to the members, but their friendships with the person are the most important. Further research is obviously needed to complete this picture of how the most natural ways for people to develop friendships and support (Shaffer & Anundsen, 1993; Uditsky, 1993). Certainly more work on the circle concept is also needed, but the idea of "constructed social support" appears to have a lot of merit for increasing health and friendships.

D. Gerstein Centre:
Community Mental Health Crisis Support

Actions on Non-Medical Determinants of Health: The provision of community based crisis services for persons who experience significant mental health issues is considered to be crucial in the spectrum of services that are available in the community. Alternatives to the use of institutions for mental health crisis are not only seen as "less restrictive" but are seen to be more economical. The rise of community based alternatives to hospitals have led to the development of several models including non-medical crisis centres, home treatment services, respite services, and consumer-run safehouses. The Gerstein Centre in Toronto is an innovative approach to a non-medical crisis centre, which enhances consumer control and quality of life. The principles guiding this support service are:

• enabling people, whenever possible, to remain in the community while receiving

the support needed to get through their crisis.

• responding as soon as possible to people in crisis.

• encouraging clients to work together with staff to identify their needs and to

decide upon an agreed plan of action.

• respecting the individuality, dignity, ability and autonomy of the people who use
our services.

Reasons for the Initiative: Concern about the welfare of individuals who have been discharged from hospitals and who suffer from serious mental health issues in the City of Toronto, and the lack of services and appropriate accommodations motivated the city to establish the "Mayor's Action Task Force on Discharged Psychiatric Patients" chaired by Dr. Reva Gerstein. In March, 1984, the task force recommended the establishment of a non-medical crisis service centre in the community. In May, 1986, the Crisis Centre Subcommittee submitted a proposal for funding to the Ministry of Health following a lengthy consultation process which included clarification of the goals of the Centre and agreement on the ways to achieve those goals (Phillips Evaluation, Final Report, 1991)

The Centre began operation in September, 1989, initially providing a crisis line to the community and a mobile team. The residence opened in February 1990, providing 24 hour telephone, mobile and residential services.

Key Actors and Elements: The Gerstein Centre offers a 24-hour, seven day a week crisis intervention service, usually initiated by self-referral through the crisis line number. Services are voluntary and non-medical.

The Centre is staffed by community crisis workers with a broad range of experience. Services are free of charge and confidential. The staff is complemented by well-trained, committed volunteers who enhance the Centre's services by preparing in-house meals, publishing *Leaflettes*, the Centre's newsletter and offering telephone follow-up and support. Services include**:**

1. **Telephone Crisis Intervention**: Crisis workers are available 24 hours per day. Medical emergencies are not dealt with by the centre. The goal is to help callers experiencing crises to work out some effective ways of addressing their immediate problems.

2.   **Mobile Crisis Team:** Staff can meet people in their own community through a mobile team visit which is arranged during the crisis telephone call. The meeting place can be where the person is calling from, or a mutually chosen convenient location.

3   **Residential Crisis Intervention:** The Centre has 10 crisis rooms for both men and women, with one wheelchair accessible suite. A short stay at the Centre is intended to provide a safe, supportive environment to help people through a crisis. When needed, there is the opportunity to get linked up with ongoing community supports and services through information and referral.

4.   **Telephone Follow-up and Support:** Volunteers who have completed a thorough training program offer telephone support for people who have recently used the Centre's services. The volunteers maintain contact with individuals for about one month after they have used the crisis services.

This non-profit organization, which must have one-third of their board of directors be consumers, has demonstrated that a consumer oriented approach to mental health crisis is workable and cost-effective. The following chart illustrates the difference between this approach and more traditional models.

**How the Gerstein Centre differs from more traditional
approaches and crisis intervention models.**

Gerstein Centre	Traditional settings and models
self-referral and second party	professional referral (usually medical)
strictly voluntary	voluntary, involuntary
client-centred approach. e.g. some people prefer to be left alone while staying at the Centre.	Approach depends on worker's credentials (e.g. medical, social worker, nursing, therapist etc.) and usually does not involve the client's stated needs and wishes.
non-credentialed staff, including qualified consumer/survivors	credentialed professional (with degrees)

early intervention--whenever the person calls--going by the client's assessment of the crisis--no separation between intake and intervention	usually intervention when an emergency stage has been reached-- usually involves a wait for admission
no diagnosis or formal psycho-social/medical assessment	formal assessment, diagnosis and treatment.
non-clinical	clinical
involve usual supports when available	mostly isolated from the community
home-like setting	institutional
encourage usual routines (e.g. kitchen always open, no set wake-up/lights out)	routines depend on the setting (e.g. hospital rules)
no waiting list; no triage accessible	appointments, repeated assessments
minimize "patient" or "client" aspect-- seen as a person.	clear differences between worker and person in crisis (e.g. patient/ therapist)
not limited by having to be "professional" intervention (e.g. can provide practical assistance through emergency fund.	usually limited to therapy, medication and treatment
mobile team allows contact where the person feels most comfortable	usually set, usually formal setting (e.g. hospital emergency dept. or worker's office)
supportive, practical approach	formal therapy or counselling
unstructured setting--no designated activities, schedules, requirements. Rules are based on safety and comfort of all.	structured
open not closed setting-- person is encouraged to keep appointments and to come and go as needed.	usually limited--person cannot leave during the designated stay.
community connections encouraged	person may be removed from his/her community and usual routines
transportation budget to allow people to make and keep appointments etc.	de-emphasis on the community
flat management--involves staff, users, board working together in making decisions	usually hierarchical, top-down approach to policies, major decisions, protocols etc.
all complaints responded to -- consumer input is encouraged and listened to	consumer usually does not have a forum -- may be labeled for complaining (e.g. non-compliant).

(Barbara Fitchette, Gerstein Centre)

Evaluation: The Phillips Evaluation Report of 1991 indicates that the Gerstein Centre is an effective organization which is generally meeting the expectations of consumer/survivors, Board, staff and to a lesser degree, community agencies. It provides a cost-effective service for consumers who would otherwise seek hospital admission. The

statistical information regarding the users of the service indicates that it is those who would have used hospitals in the past who are using the Centre. Perhaps most importantly, are statements by consumer/survivors that indicate that the Centre is a preferable alternative to hospital. The net result is a service that costs less than hospitalization and provides crisis intervention in a manner preferred by many consumer/survivors.

E. A "Constructed" Deinstitutionalization Story:
Good planning, Re-allocation of Resources

Actions on Non-Medical Determinants of Health: Between 1980 and 1985, thousands of Canadians moved out of total institutions and chronic facilities to community housing and supportive living projects. This is an important story in understanding the determinants of health, because the changes in health status that have occurred are dramatic. The unfortunate reality is that there are thousands more Canadians who continue to live in total institutions and chronic care facilities that deserve an opportunity and the support to become "deinstitutionalized". This "constructed story" draws its inspiration from the experience of deinstitutionalization in four provinces (British Columbia, Saskatchewan, Ontario, and New Brunswick). Although the majority of effective deinstitutionalization in Canada has occurred in the area of developmental disabilities, parts of the story are drawn from pockets of excellence in the mental health field and in aging.

Effective deinstitutionalization enhances determinants of health by improving the quality of life for people who have left the institution, increasing their control over resources and supports, and in many cases reconnecting them with family and community life. This, of course, is a success story of deinstitutionalization. Too often, tragically our

deinstitutionalization stories are about "dumping", continued dependence, and cost-saving measures that do not lead to enhanced quality of life.

Some say this is a unique story because the benefits for individuals living in the community far outweigh the powerlessness that people feel while living in an institution. It is also unique because deinstitutionalization, when done effectively, can contribute to the determinants of health and play a substantial in reallocating resources from the institutional sector to the community sector.

Research and evaluation across Canada shows that when deinstitutionalization is done well it involves the movement of people and resources to community. The key principles which guide the process are partnership, planning, and participation.

Reasons for the Initiative: Deinstitutionalization became an urgent policy initiative in the early 1980's in several provinces because it was becoming clear that the desire of people with disabilities for participation and citizenship could not be realized in institutional settings. Deinstitutionalization was often twinned with economic realities, which was seen as an opportunity to build community options and save money. In British Columbia, a ten year plan was developed in 1985 to close all institutions for citizens with developmental disabilities. This will be realized by the year 1997. In 1993, the Ministry of Health in Ontario announced that over the next seven years to the year 2000, Ontario will dramatically shift resources from psychiatric hospital settings to community mental health alternatives. There are few jurisdictions to date which have made this shift but those that have show great promise. For example, the state of Vermont over less than a ten year period has moved from 90% of state mental health budgets being consumed by institutions to less than 40%.

Many reasons have been identified for deinstitutionalization initiatives:

• Poor quality of life for residents.

• More abuse in institutions than in community.

• Deteriorating health status of many people in institutions.

- Very costly to keep an institution running.

- Family and consumer advocates demanding of change.

Actors: Whenever deinstitutionalization in Canada has been successful it has involved a partnership involving the person with a disability, their family or other members of their social network, people from the institutional setting, and people from the community that is welcoming them home. This process of partnership needs to be facilitated by a person who cares deeply about the individual. These facilitators are effective at person-centred planning that brings together the partners to develop goals and strategies for community involvement and participation. When deinstitutionalization has failed, it has been because one or more of the partners have been left out and facilitation has been lacking.

Analysis of the Results: Generally, unions and unionized workers from the institution have not been very supportive of deinstitutionalization. However, in certain jurisdictions, their participation has been extremely positive. The actual setting of a date for an institutional closure, and the allocation of resources for the deinstitutionalization process have enable unionized workers, families and others to participate fully.

The other great failure of many deinstitutionalization stories occurs because the planners see their job to simply "replicate" the life in the institution. This has occurred in all fields of disability, and is best personified by the "large group home" which replaces the institutional setting. A key facilitator in the process of change is resources. Deinstitutionalization costs more for the short term, involving double funding for twelve to twenty-four months. In otherwise, while the institution is downsizing, initial dollars will be needed to hire community facilitators and resources for community building and housing. Once the institution is closed, however, the amount of money required for community living is less than the money required to keep institutions going.

Successful deinstitutionalization stories are being replicated in several sectors. People with developmental disabilities and their networks are the most advanced in

implementing all aspects of partnership planning, person-centred approaches, and individualized housing and support opportunities for people in the community. People with significant mental health problems have also developed strategies of reallocation, which are outlined and reflected in several documents produced by the National Community Mental Heath Association. It is interesting that some of this work has been replicated the area of aging, where "frail, elderly" citizens have been moved from nursing homes that are closing to apartments where the individuals can access support services when they need it.

Funding: Deinstitutionalization does require three commitments. First, it requires a policy commitment from the provincial governments, which could be supported by cost-sharing agreements with the federal government. Second, it requires resources in the short term that can help animate an effective process, and third, it requires a fairly reasonable but rapid time frame so that communities, families, and professionals can mobilize to make the process happen in an effective way.

There are now enough deinstitutionalization projects completed across Canada to identify a variety of critical principles and strategies. After fifteen years of effort, we do now know how to do this effectively. The will of federal and provincial governments could go a long way in enhancing quality of life for the thousands of Canadians who remain institutionalized.

IV. Policy Implications

The research presented here reflects a substantial criticism of many common practices. As we think about policy implications, it is clear that "more of the same" will not contribute to the determinants of health. The paradigm shift that is occurring in the

disability field has significant implications for the future of community supports and the health of Canadians with disabilities.

There are numerous implications to the conclusions that have been drawn from the review of research and literature presented. Obviously, given the extent of the field, it has been impossible to review all research and literature. Only those areas that have been pointing to new approaches which contribute to the determinants of health have been selected. There is also an enormous body of literature on rehabilitation and traditional service systems which did not seem appropriate for this review.

Our recommendations for policy consideration are based on several assumptions including:

- that many people with disabilities live in poverty and have poor health status.
- that it takes exceptional resources to support a child with a disability to grow up in a way that allows them to lead full lives as adults.
- that most segregated service systems are dysfunctional and inappropriate for enhancing the health status of Canadians with disabilities.
- that there are many policies and programs which currently act as disincentives for families and people with disabilities to have more control and participation in their lives.
- that the decision-making ability and independence of people with disabilities depends on the personal supports that are made available to them, not on their disability or intellectual functioning.

Our recommendations are in the form of principles for policy action and are outlined in four areas.

A. Policy changes that enhance individualized family support for families who have a child with a disability.

1.   *Provide incentives for provinces to implement individualized family support*

programs. Only Ontario currently has a comprehensive provincial family support program for families with physically and developmentally disabled children. Positive outcomes from the Ontario Special Services at Home Program point to

the need for this type of initiative in every province. The federal government could provide incentives to the provinces with adjustments to future cost sharing agreements.

2.   *Redistribute resources to ensure that families receive money and support directly.* Typically, governments provide block funding to agencies for the implementation of specific programs. Families increasingly have been asking for more control over the support they receive. Currently in Ontario and Alberta there are several projects that provide individualized funding for family support and for adults with disabilities. Other provinces need to learn from these initiatives and implement their own projects that would enhance family support and control. The federal government could play an important leadership role in co-ordinating these developments.

3.   *Promote, through demonstration projects and research, initiatives which foster health and determinants of health for children with disabilities and their families.* The fact that so many Canadian citizens with disabilities are poor, unemployed and vulnerable demands attention. Federal government projects Brighter Futures and the Community Action Program for Children are excellent examples of nationally initiated prevention oriented demonstration projects. Any subsequent funding of these pilot projects could be strengthened to focus more on the lives of people with disabilities. There would need to be government collaboration with family and disability groups in the development of this initiative

4.   *Provide more flexibility in the support funding to families and individuals with disabilities, so that people are not penalized for working and or for trust funds developed on their behalf.* Currently, most funding to people with disabilities, such as the Family Benefits Allowance (FBA), provides penalties for families and individuals who acquire other funds, such as through employment or through wills and estates. This dilemma keeps many people with disabilities in a perpetual state

of poverty and welfare dependency. Governments at all levels need to collaborate to develop more flexible legislation.

B.   Policy changes that enhance community involvement of children with disabilities.

5.   *Work toward the implementation of "zero admission" policies to institutional settings.*   Currently only three provinces have such policies (Newfoundland, British Columbia, and New Brunswick), which have been part of fairly rapid down-sizing of large institutions in those provinces. This policy change requires that the development of community supports be ensured, including adequate respite for families and individualized family support programs. It also must recognize that not all families will be able to support their family member with a disability at home. Small selected community residential service may be required for specialized needs.

6.   *Implement educational policies that ensure inclusion of children with disabilities in their neighbourhood schools.* Although education is a provincial responsibility, it is important to recognize that the inadequate and segregated education of many children with disabilities is a contributing factor to poor health. As a national initiative, the federal government could develop a task force to examine lessons from the experience with the American Disabilities Act, U.S. legislation which has created some constructive change for citizens with disabilities south of the border.

7.   *Develop rehabilitation services to become more family centred.* Many children with physical disabilities spend a lot of time in rehabilitation. The latest trends in rehabilitation call for services to be family centred. This way of working in Canada is quite rare, and needs support to be fully developed.   Funds for

conferences and research would provide strong incentives for more provincial initiatives in this area.

8.   *Develop effective school-to-work transition programs for adolescents with disabilities.* Many youth with disabilities are unemployed and "unemployable," which severely limits independence and health status. Research shows that participation in school-to-work programs greatly enhance the possibility of being employed in the labour market. At a time when employment equity programs are being reduced or eliminate, the need for these programs is paramount.

C.   Policy changes that re-allocate resources from institutions to community in a way that builds family and consumer initiatives and provides direct funding to adults with disabilities.

There are two cornerstones to this policy initiative

9.   Re-allocate resources from the institutional sector so that individuals with disabilities can access funds directly for their support needs.

10.   *Re-allocate resources so that funding is provided to consumer groups, so that self-help, consumer and family sectors can implement creative initiatives and build their strengths and capacities.* As we have noted, in some areas of disability the majority of funds go to the institutional sector. The need to re-allocate resources is widely recognized, but there is not agreement on how to do this. One promising approach is to use a "framework for support" (Trainor, et al., 1993) that builds a community resource base of various stakeholders. National mental health forums in the last few years have been an instrumental federal initiative in this area. More of this work combined with adjustments to future cost sharing agreements could assist the provinces in building the consumer and family sectors.

D.   Policy changes that enhance independent living and the development of ILRCs.

11.   Institute a national home ownership program for people with disabilities.

12.   Continue to financially support Independent Living Resource Centres across Canada that can provide education, peer support and information to people with disabilities and their families.

13.   Support the development of consumer participation principles at all levels of decision-making (community, agency, system, government).

14.   Remove barriers that limit access and choice in relationship to employment, education, and culture.

References

Active Living Alliance for Canadians with a disability. 1992. *A blueprint for action.* Ottawa.

Advocacy Resource Centre for the Handicapped. 1995. *ArchTYPE*. Toronto.

Agosta, J. 1989. Using cash assistance to support family efforts. In G. Singer and L. Irvin (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 189 - 204). Baltimore, Maryland: Paul H. Brookes.

Albee, G. 1981. Politics, power, prevention and social change. In J. Joffe and G. Albee (Ed.), *Prevention through political action and social change.* Hanover and London: University Press of New England.

Anderson, J., D. Dayson, W. Wills, C. Kooch, O. Morogolius, C. O'Driscoll, and J. Leff. 1993. The TAPS Project 13: Clinical and social outcomes of long term stay psychiatric patients after one year in the community. *British Journal of Psychiatry* 19:45-56.

Argyle, M. 1987. *The psychology of happiness.* London: Methuen and Company.

Bailey, L. 1994, January. Are we finally getting there? Integrating students with developmental disabilities. *ARCH-TYPE* 2-4.

Baker, D. 1990. *The quest for independence: Lessons from the Americans with Disabilities Act.* Toronto: Advocacy Resource Centre for the Handicapped.

Barrera Jr., M., and S.L. Ainlay. 1983. The structure of social support: A conceptual and empirical analysis. *Journal of Community Psychology* 11:133-143.

Bellah, R., R. Madsen, W. Sullivan, A. Swidler, and S. Tipton. 1985. *Habits of the heart.* New York: Harper and Row.

Bellamy, G., L. Rhodes, D. Mank, and J. Albin. 1988. *Supported employment: A community implementation guide.* Baltimore: Paul H. Brookes.

Belle, D. (Ed.). 1989. *Children's social networks and social supports.* New York: John Wiley.

Berman, M., and J. Davis-Berman. 1993. *Wilderness therapy.* Dubuque, IA: Kendall-Hunt Publishing Company.

Biklen, D. 1992. *Schooling without labels: Parents, educators, and inclusive education.* Philadelphia: Temple University Press.

Birenbaum, A., and H. Cohen. 1993. On the importance of helping families: Policy implications from a national study. *Mental Retardation* 21:75-77.

Bogdan, R., and S. Taylor. 1982. *Inside out: Two first-person accounts of what it means to be labeled 'mentally retarded'* Toronto: University of Toronto Press.

Bogdan, R., and S. Taylor. 1989. Relationships with severely disabled people: The social construction of humanness. *Social Problems* 36:135-146.

Bradley, D. 1994. Moving into the mainstream. *The Educational Forum* 59:81-91.

Breslau, N. 1985. Psychiatric disorder in children with physical disabilities. *Journal of the American Academy of Child Psychiatry* 24: 87-94.

Brown, L., A. Udvari-Solner, E. Frattura-Kampschroer, L. Davis, C. Ahlgren, P. Van Deventer, and J. Jogensen. 1991. Integrated work: A rejection of segregated enclaves and mobile work crews. In L.H. Meyer, C.A. Peck, and L. Brown (Eds.), *Critical issues in the lives of people with severe disabilities.* Baltimore: Paul H. Brookes Publishing Co.

Brown, L., E. Long, A. Udvari-Solner, L. Davis, P. VanDeventer, c. Ahlgren, F. Johnson, L. Gruenewald, and J. Jorgensen. 1989. The home school: Why students with severe intellectual disabilities must attend the schools as their brothers, sisters, friends, and neighbors. *JASH* 14:1-17.

Browne, S., D. Connors, and N. Stern. (Eds.). 1985. *With the power of each breath : A disabled women's anthology.* Pittsburgh, PA: Cleis Press.

Budde, J., R. Petty, and C. Nelson. 1986. *Problems and benefits associated with consumer satisfaction evaluation at Independent Living Centers.* Kansas: University of Kansas Research and Training Center on Independent Living.

Bullock, A. 1990. Community care: Ideology and lived experience. In R. Ng, G. Walker, and J. Muller, (Eds.), *Community organization and the Canadian state* (pp. 65 - 82). Toronto: Garamond Press.

Bullock, C. and C. Howe. 1991. A model therapeutic recreation program for the reintegration of persons with disabilities into the community. *Therapeutic Recreation Journal* 24: 7-17.

Burstow, B., and D. Weitz. (Eds.). 1988. *Shrink resistant: The struggle against psychiatry in Canada.* Vancouver, BC: New Star Books.

Caldwell, L., and E. Smith. 1988. Leisure: An overlooked component of health promotion. *Canadian Journal of Public Health* 79:544-556.

Canadian Association for Community Living. 1980. *Vision 2000.* Downsview.

Canadian Association for Independent Living Centres. 1990. *A guide to Independent Living Centres.* Ottawa, ON.

Canadian Association for Independent Living Centres. 1991. *Guidelines for Independent Living Centres in Canada.* Ottawa, ON.

Canadian Association for Independent Living Centres. 1994. *A time for change: A time for choice.* Ottawa.

Canadian Association for Independent Living Centres. 1995. *Responding to Abuse: An independent living approach.* Ottawa, ON.

Canadian Council on Social Development, 1985. *Deinstitutionalization: Costs and effects.* Report from an Invitational Symposium. Ottawa: C.C.S.D.

Canadian Mental Health Association 1984. *Work and well-being: The changing realities of employment.* Toronto.

Carling, P. 1990. Major mental illness, housing, and supports: The promise of community integration. *American Psychologist* 45:969-975.

Carling, P. 1995. *Return to community*. New York: Guilford Press.

Carpenter, S. 1991. The role of Independent Living Centres in the lives of Canadians: Colouring outside the lines. *Abilities* 35-36.

Carruthers, C., and C. Hood. 1994. Alcohol use in leisure. *Journal of Leisurability* 21:3-12.

Center on Human Policy. 1986. *A statement in support of families and their children.* Syracuse: Division of Special Education Rehabilitation, School of Education, Syracuse University.

Certo, N., S. Schleien, and D. Hunter. 1983. An ecological assessment inventory to facilitate community recreation participation by severely disabled individuals. *Therapeutic Recreation Journal* 17:29-37.

Chamberlin, J. 1978. *On our own*. Toronto: McGraw Hill.

Church, K. 1992. *Moving over: A commentary on power-sharing.* Toronto: Ministry of Health Community Mental Health Branch.

Church, K. 1995. Forbidden narratives: Critical autobiography as social science. Luxembourg: Gorden and Breach Publishers.

Coalition Against Institutions as Community Resource Centres. 1987. *Institutions: New forms, new fears.* Unpublished discussion paper, Ontario.

Cochran, M. 1986. The parental empowerment process: Building on family strengths. In J. Harris (Ed.),*Child psychology in action: Linking research and practice* (pp. 12-33). Brookline, MA: Croon Helm Publishers.

Code, L. 1991. Special issue on women and disability. *Entourage* 6.

Coleman, D. 1990. *An analysis of stress buffering effects of leisure based social support and leisure dispositions.* Unpublished Master thesis, Maryland: University of Maryland.

Coleman, D., and S. Iso-Ahola. 1993. Leisure and health: The role of social support and self-determination. *Journal of Leisure Research* 25:111-128.

Consumer/Survivor Development Initiatives. 1993. Report on activities. Toronto: Ministry of Health.

Conroy, J. and V. Bradley. 1985. *The Pennhurst longitudinal study: A report of five years of research and analysis.* Philadelphia: Temple University Developmental Disabilities Center.

Consumer Survivor Development Initiatives. 1996. *Consumer Survivor Development Initiatives: Project evaluation.* Toronto: Ontario Ministry of Health.

COPOH. 1986. *Defining the parameters of independent living.* Winnipeg, Manitoba: COPOH.

Cornell Empowerment Group. 1989. Empowerment and family support. *Networking Bulletin* 1:2.

Council of Canadians with Disabilities. 1995. *A voice of our own.* Winnipeg.

Crapps, J., and Z. Stoneman. 1989. Friendship patterns and community integration of family care residents. *Research in Developmental Disabilities* 10:153-169.

Crewe, N., and I. Zola. 1984. *Independent living for physically disabled people.* San Francisco: Jossey-Bass Inc.

Csikszentmihalyi, M. 1990. *Flow: The psychology of optimal experience.* New York: Harper Collins Publishers.

Csikszentmihalyi, M., and J. LeFevre. 1989. Optimal experience in work and leisure. *Journal of Personality and Social Psychology* 56:815-822.

Davern, L., and R. Schnorr. 1993. Public schools welcome students with disabilities as full members. In K. Hulgin (Ed.), *Resources on inclusive education* (pp. 22-25). Syracuse, NY: Research and Training Center on Community Integration.

DeJong, G. 1993. Three trends to look for in the American Independent Living movement in the 1990's. In A. Neufeldt (Ed.), *Independent living: An agenda for the '90's.* (pp.109-120). Ottawa: Canadian Association for Independent Living Centres.

DeJong, G. I A. Batavia, and R. Griss. 1989. America's neglected health minority: Working-age persons with disabilities. *The Milbank Quarterly* 67:311-351.

de Boer, M. 1992. Women and empowerment. Unpublished master's thesis, School of Social Work, Wilfrid Laurier University, Waterloo, ON: .

Des Lauriers, G. and M. Clair-Foyer. 1982. Deinstitutionalization in action *Canadian Journal of Mental Retardation* 32:20-24, 30-36.

Dunn, P. 1990. The impact on the housing environment upon the ability of disabled people to live independently. *Disability, Handicap and Society* 5:37-52.

Dunn, P. 1994. *Government policy innovations in barrier-free housing, accessible transportation and personal supports.* Winnipeg: National Independent Living Conference.

Dunst, C.J. 1991.   Family support principles: Checklists for program builders and practitioners. *Family Systems Intervention Monograph* 2(5), Morganton, N.C.: Family Infant and Preschool Program, Western Carolina Center.

Dunst, C., C.M. Trivette, and A.G. Deal. 1988. *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, Mass: Brookline Books.

Dyson, L. 1994. Social integration in an elementary school and its implications. *Exceptionality Education Canada* 4:13-28.

Edgerton, R.B. 1984.   *Lives in process: Mildly retarded adults in a large city.* Washington, D.C.: American Association of Mental Deficiency.

Eigner, W. 1995. The most effective means of combating discriminatory attitudes. *Inclusion International* 1:2-3.

Enns, H. 1991. Introduction to independent living. *Compass,* 2:1.

Epp, J. 1986.   *Achieving health for all: A framework for health promotion.* Ottawa: Minister of Supply and Services.

Evans, J. and G. Roberts. 1987. Physical competence and the development of children's peer relations *Quest* 39:23-35.

Falvey, M., M. Forest, J. Pearpoint, and R. Rosenburg. 1994. *All my life's a circle.* Toronto, ON: Inclusion Press.

Family Support Institute of Ontario. *Newsletter.* Toronto.

Farina, J. 1982. The eighth deadly sin. *Journal of Leisurability* 9: 12-14.

Film Images Production. 1995. *Voices of experience: Community economic development.* Toronto.

Folsom, A., C. Caspersen, H. Taylor, D. Jacobs, R. Luepker, O. Gomez-marin, R. Gillum, and H. Blackburn. 1985. Leisure time physical activity and its relationship to coronary risk factors in a population-based sample. *American Journal of Epidemiology* 121:570-579.

Forest, M. 1989. *It's about relationships*. Toronto, ON: Frontier College Press.

Forest, M. 1987. *More education integration.*   Downsview, ON: G. Allan Roeher Institute.

Forest, M., and J. Snow. 1983. The Joshua Committee: An advocacy model. *Journal of Leisurability* 10:20-23.

Foucault, M. 1984. *The Foucault reader*. P. Rabinow (Ed.), New   York: Pantheon Books.

Frank, J., and J. Mustard. 1994. The determinants of health from a historical perspective. *Daedalus: Journal of the American Academy of Arts and Science* 123:1-19.

Friedmann, J.   1992.   *Empowerment: The politics of alternative development.* Cambridge, Massachusetts: Blackwell.

Freire, P. 1973. *Education for critical consciousness*. New York: Seabury Press.

Giangreco, M., R. Dennis, C. Cloninger, S. Edelman, and R. Schattman. 1993. "I've counted Jon": Transformational experiences of teachers educating students with disabilities. *Exceptional Children* 59:359-372.

Goffman, E. 1961. *Asylums*. Garden City, N.J.: Anchor at Doubleday.

Gold, D. 1994. "We don't call it a 'Circle'": The ethos of a support group. *Disability and Society* 9:435-452.

Gold, D. 1988. A look at Leisure Buddy programs. In D. Gold & J. McGill (Eds.) *The pursuit of leisure.* Toronto: G. Allan Roeher Institute.

Gollay, E., M. Freedman, Wyngaarden and N. Kurtz. 1978. *Coming back: The community experiences of deinstitutionalized mentally retarded people.* Cambridge, Mass: Abt-Books.

Gottlieb, B. 1985. Social networks and social support: An overview of research, practice and policy implications. *Health Education Quarterly* 12:6-22 .

Gould, A. 1994, September. The integration challenge: Kids with special needs. *Today's Parent* E23-E24.

Graden, J., and A. Bauer. 1991. Using a collaborative approach to support teachers in inclusive classrooms. In S. Stainback and W. Stainback (Eds.), *Curriculum considerations in inclusive classrooms* (pp. 85-100). Baltimore, USA: Paul H. Brookes Publishing, Co.

Grenot-Scheyer, M. 1994. The nature of interactions between students with severe disabilities and their friends and acquaintances without disabilities. *JASH*, 19: 253-262.

Gubrium, J. and D. Buckroldt. 1982. *Describing care: Image and practice in rehabilitation.* Cambridge, Mass.: Oelgeschlager, Gunn, and Hain Publishers Inc.

Guest, D. 1985. *The emergence of social security in Canada.* Vancouver, B.C.: University of British Columbia Press.

Guralnick, M.J., R.T. Connor, and M. Hammond. 1995. Parent perspectives of peer relationships and friendships in integrated and specialized programs. *American Journal on Mental Retardation,* 99: 457-476.

Hagner, D., and D. Dileo. 1993. *Working together: Workplace culture, supported employment, and persons with disabilities.* Cambridge, MA: Brookline Books.

Hall, I. 1983. *Playing for keeps: The careers of front-line workers in institutions for developmentally handicapped persons.* Unpublished master's thesis, University of Waterloo, Waterloo, ON.

Hallam, A., J. Beecham, M. Knapp, and A. Fenyo. 1994. The costs of accommodation and care: Community provision for former long-stay psychiatric hospital patients. *European Archives of Psychiatry and Clinical Neuroscience* 243:304-310.

Hamre-Nietupski, S., J. Hendrickson, J. Nietupski, and M. Shokoohi-Yekta. 1994. Regular educators' perceptions of facilitating friendships of students with moderate, severe, or profound disabilities with non disabled peers. *Education and Training in Mental Retardation and Developmental Disabilities* 102-117.