

DEVELOPMENTAL DISABILITIES: POLICIES FOR THOSE AT THE MARGINS OF
SOCIETY

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**Jessica Chicoine, Master of Arts, 2007
Public Policy and Administration
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Abstract

This thesis examines Ontario's disability policies- the Ontario Disability Supports Program Act, the Ontarians with Disabilities Act, and the Accessibility for Ontarians with Disabilities Act, and assesses the extent to which the legislation provides supports for individuals with developmental disabilities who have both the desire and the capacity to live independently. It uses content analysis to identify the purported aims of the legislation and assesses outcomes through qualitative interviews with executive directors of community agencies that serve individuals with developmental disabilities. A key theme is that there is a tendency to homogenize disability so that barriers to accessibility are defined with a focus on "visible" physical disabilities with considerably less attention to "invisible" developmental disabilities. It concludes by pointing to appropriate housing, adequate income supports, availability of transportation and appropriate employment as critical areas to facilitate the choice of independent living. These areas are underdeveloped in current legislation.

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DEVELOPMENTAL DISABILITIES: POLICIES FOR THOSE AT THE MARGINS OF SOCIETY

In the 1994 Hollywood blockbuster film about a person with developmental disabilities, Forrest Gump muses: “life is like a box of chocolates, you never know what you’re going to get”. Historically, the state at best stayed out of life’s assortment of chocolates, leaving individuals and their families to cope with various emotional and physical challenges. At worst, the state sanctioned institutionalizing and isolating those with developmental disabilities to “protect society” from individuals traditionally stereotyped as dangerous and unpredictable. More recent attention to human rights, social justice, equity and ethical dimensions of inequalities have precipitated a change in the course of government actions. One example of this can be found in Ontario, which has recently passed three separate pieces of legislation aiming to promote equal opportunity in the workplace and equal access to housing, community support, public places like restaurants and movie theatres, and services like public transportation. These are: *The Ontario Disability Support Program*¹ (ODSP); *The Ontarians with Disabilities Act*² (ODA); and the *Accessibility for Ontarians with Disabilities Act*³ (AODA). The preamble of the ODA states that “...the people of Ontario support the right of persons of all ages with disabilities to enjoy equal opportunity and to participate fully in the life of the province” (ODA, 2001). Ontario’s disability legislation falls under the *Ontario Human Rights Code*⁴ which strives to “recognize the dignity and worth of every person and to provide for equal rights and opportunities”, creating “a climate of understanding and mutual respect for the dignity and worth

¹ S.O.1997, c.25, Sched.B.

² S.O.2001, c.32.

³ S.O.2005, c.11.

⁴ R.S.O. 1990, c.H.19, Preamble

of each person so that each person feels a part of the community and able to contribute fully to the development and well-being of the community and the Province”.

Looking specifically at individuals aged 18 to 35 with developmental disabilities, this thesis assesses the degree to which these three pieces of legislation facilitate independent living for people who have both the desire and the capacity to do so, by providing access to key components of independent living. Rather than viewing people with disabilities as “wards” of the state, the stated purpose of Ontario’s disability policies is to reinforce a positive sense of self worth by encouraging individuals to feel that they are contributing constructively to their own and society’s development. For many people with disabilities, dignity and self-worth is integrally connected with the capacity and choice to live independently. In examining the purported aims of the legislation through content analysis, this study touches on clinical aspects of developmental disabilities only insofar as it relates to policy issues. In order to deepen the analysis, qualitative interviews were conducted with five Executive Directors (or their representatives) of community service agencies providing supports to individuals with developmental disabilities. Data compiled from key informant interviews reflect the policy outcomes by drawing upon the experiences, reactions and observations of executive directors working within the legislation. Finally, this thesis points the direction for further policy research. Currently, there are few studies evaluating Ontario’s disability policies, and fewer still among the Canadian literature that look at whether legislation supports the demands of disabled people to live independently.

An understanding of the impact of current disability policies can be contextualized within the broader framework of neoliberalism and its ideology of fiscal restraint. While it is true that there is a long history of policies that have marginalized persons with disabilities before

neoliberal policies were implemented, marginalization under neoliberalism has its particular characteristics. For example there is some evidence that fiscal restraint flat-lined funding for over a decade. Competitive calls for proposals, have affected the quality and quantity of supports and services that voluntary agencies can provide, their philanthropic ethos, and their capacity to retain employees (Lum et al., 2002; 2003a; 2003b). Providing services to enable independent living cannot be sustained by voluntary agencies alone. Hall and Reed (1981) argue that the voluntary sector grew with support from government funding. Stable government funding assured that voluntary agencies could serve groups regardless of their religious or moral suasion. Nonetheless, neoliberal policies of fiscal restraint, which can too often mean meeting demands by off-loading responsibilities to families, communities, charities and non-profit agencies, can also find enormous appeal in the ideals of independent living. Demands for independent living may be welcome news for governments seeking to contain costs. The problem then is that the policy agenda of persons with disabilities and their advocates too easily coincides with the agenda of governments seeking to cut health costs and offload responsibilities. Policies and programs that support independent living affirm individuals' rights to the choice to live with community supports. They may also contribute to the sustainability of the health care system. Medicare is a sacred trust and few governments would propose a frontal attack on Canada's most popular social program. Numerous studies have demonstrated that serious health system restructuring is necessary to sustain Medicare (Armstrong & Armstrong, 2003; Armstrong et al., 2001). Rather than off loading responsibilities to the families and overburdened community agencies, this thesis argues that when governments support independent living, they can also sustain the broader health care system in a cost effective way.

This is a compelling theme raised elsewhere in research on community supports and deserves further exploration but is beyond the scope of this thesis.

Recent trends have pushed for a rethinking of health policy generally and policies around disability specifically. These include medical advances, demographic changes, and value changes.

First, advances in medical technology are allowing greater numbers of elderly people to live longer and more at risk fragile infants to survive. For example, genetic testing has made it possible to detect chromosomal anomalies, allowing for the development of preventative measures such as special diets free of certain proteins, which can prevent future brain damage in babies who are born with PKU (Phenylketonuria). Advances in diagnoses of developmental disorders such as those found on the Autism spectrum have made it possible for early interventions to improve language and communication skills, opening up the possibility of living a “normal” life for these individuals. Babies who are exposed to alcohol or drugs in vitro (due to maternal addiction) can now undergo detoxification procedures preventing potential brain damage, e.g., Fetal Alcohol Syndrome (FAS). Together these advances, along with innovations in the fields of genetic medicine, biology and psychology have made it possible for individuals born with disabilities, as well as seniors who develop cognitive and physical limitations, to live longer.

Secondly, Canada is aging. People aged 65 and over constitute approximately 13% of the population in Canada but are projected to make up about 25% by 2031. The proportion of people over 80 years will also increase sharply from an estimated 1 in 30 in 2005 to 1 in 10 Canadians by 2056 (Statistics Canada, 2005). This means that the number of persons living with disabilities in Canada will also rise as Canada’s population ages.

In Canada, statistical projection suggests that by 2026, the majority of people with disabilities will be 65 years of age or older (~3.05 million people) (Canada, Office for Disability Issues, website, 2005). Over half of seniors aged 74-84 are currently reported to have difficulty with one or more of the activities of daily living, as do three-quarters of the over 85 age group (Canada Mortgage and Housing Corporation, 2000). As the population ages, more people will need help with daily living activities.

In 2001, 3.6 million Canadians (12.4% of Canada's population) reported having activity limitations or disability(ies) (PALS, 2001). In addition, within the larger population of people with disabilities, individuals with developmental disabilities are the fastest growing sub-population in North America and Western Europe. With technological advancements, life expectancy within this cohort has risen (Bigby, 2004). Today, the average life expectancy is approximately 70 years as compared to the 1930's when life expectancy was approximately 20 years (Janicki, et al., 1999; Strauss & Kastner, 1996; Strauss & Eyman, 1996; Strauss & Zigman, 1996; Hayden, 1998). Although not necessarily a normal consequence of aging, incidences of mental illness also rise with age (Williams, Salib, & Lum, 2006). Examples of mental illness affecting seniors include depression and dementia related illnesses like Alzheimer's and Parkinson's disease. Mental illness further complicates the types of supports required by an aging population.

Society's values have also changed. Changing values mean that individuals with disabilities, whether developmental or physical - like seniors who require help with their activities of daily living - demand choices in their living and caring arrangements. There is no question that some will require institutional care. Some however want to live independently- to be self-determining and empowered by managing the supports they receive. One barometer of

these changing values is the Independent Living (IL) movement which responds to the increasing demands for independence among persons with disabilities. The basis for the IL movement is the idea that individuals can and should have the choice to live independently in environments where they can access assistance in daily living activities if required while having their changing needs monitored and managed. Changing values have given a voice to people with disabilities and have turned the policy debate and advocacy agenda from seeing people with disabilities as a homogeneous group to seeing them as individuals with very diverse and varied support and service needs.

Defining “developmental disabilities”

Before reviewing the policy literature in this area, it is necessary to define developmental disabilities. Individuals with developmental disabilities can be differentiated from individuals with physical disabilities, such as individuals requiring wheelchairs or scooters because of mobility limitations. Individuals with developmental disabilities may have critical medical needs, as well as needs for around-the-clock support in some cases. In addition to having a developmental disability, intellectual disabilities may also be present among this cohort of individuals.

The two most common definitions of ‘developmental disability’ as reviewed by Biersdorff (1999) originate from the United States. U.S. federal law⁵ provides the following definition:

IN GENERAL.—the term “developmental disability” means a severe, chronic disability of an individual that—

- 1. is attributable to a mental or physical impairment or combination of mental and physical impairments;**
- 2. is manifested before the individual attains age 22;**
- 3. is likely to continue indefinitely;**
- 4. results in substantial functional limitations in 3 or more of the following areas of major life activity:**
 - i. Self Care.**
 - ii. Receptive and expressive language.**
 - iii. Learning.**
 - iv. Mobility.**
 - v. Self-direction.**
 - vi. Capacity for independent living.**
 - vii. Economic self-sufficiency; and**
- 5. reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.**

⁵ 42 USC Sec. 15002

The American Association on Mental Retardation (AAMR, website, 2002), soon to be known as the American Association on Intellectual and Developmental Disabilities, defines mental retardation, an alternate term for developmental disabilities as “a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”.

The AAMR also provides an overview of five main assumptions that are essential in the application of the definition for diagnostic purposes:

- 1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.**
- 2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors.**
- 3. Within an individual, limitations often coexist with strengths.**
- 4. An important purpose of describing limitations is to develop a profile of needed supports.**
- 5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.**

In Canada, the majority of researchers have substituted the term ‘mental retardation’ for the term ‘intellectual disability’. Nevertheless, the term developmental disability is not interchangeable with the term mental retardation. Not all conditions and or syndromes which are classified as developmental disabilities include the presence of intellectual disabilities (Roehrer Institute, 2006, p.3). Nonetheless, some examples of developmental disabilities co-morbid with intellectual disabilities include Down Syndrome or Trisomy-21, Autism Spectrum: Autism,

Asperger's Syndrome, and Rett's Syndrome, Cerebral Palsy, Fragile X and Fetal Alcohol Syndrome. Individuals with developmental disabilities are also susceptible to conditions such as obesity, diabetes, and cardiovascular disease (Janicki et al., 2002; Hellers & Marks, 2002) and are at greater risk than the general population for a number of medical conditions, including mental health problems, epilepsy, dementia, and osteoporosis (Krahn et al., 2006; Gill & Brown, 2002). The Roeher Institute (2006) reports that over 40% of individuals with developmental disabilities may also have mental health challenges (referred to as a dual diagnosis) at least once during the course of their lives, compared to less than 20% of individuals with other kinds of disabilities. These health conditions, together with the developmental disability, complicate care giving even further and can seriously strain an already stressed health care system.

Demographic overview

The province of Ontario has the largest population of persons with disabilities. In 2001, 1,514,380 or 13.5% of Ontario's total population reported having activity limitations. A Statistics Canada survey (PALS, 2001) found that Ontarians with disabilities have a yearly total income of \$22,543, compared to \$34,144 for the non-disabled population, a difference of over \$11,000. Forty-six percent of individuals with disabilities had an income of less than \$14,999 compared with 32% of non disabled individuals. Income falling below \$19,261 for a single individual living in an urban area (with a population greater than 500,000) is said to be below the poverty line or at the low-income cut off (LICOs, 2002), meaning that individuals with disabilities who require additional supports for living will have little disposable income to pay for these supports. Statistics Canada calculates the LICO by estimating the income threshold at which individuals spend more than 20 per cent than the average person on food, shelter and clothing. Statistics Canada considers individuals or families living below the LICO to be in "straitened

circumstances”. The Roeher Institute (2002) found that adults with developmental disabilities are likely to have incomes well below the poverty line. In a 2006 report, this cohort of individuals was much less likely than the general population to be employed at any time during their lives (Crawford, 2000).

Looking specifically at people with developmental disabilities, a Roeher Institute survey (Crawford, 2000) found that persons over the age of 14 with a developmental disability comprise 1.1% (123 394) of the total population living in Ontario (11 217 630). Nearly 20% (24 979) of those individuals are over age 55 and nearly half (61 697) are between 35 and 54 years of age. More than a third is likely never to marry and to live with one or both elderly parents. Because people with disabilities are generally living longer, caregivers who typically are family members and parents become less able to provide care as they also age.

Individuals with developmental disabilities tend to live in urban centres. More than 35% (43 188) of Ontario residents with a developmental disability live in the Toronto area, while 50% (61 697) live in other urban areas in Ontario (Crawford, 2000).

Disability discourse: From the “Cuckoo’s Nest” to today

Before the 18th century, disability was defined through religion, myths, and legends (Barnes, 2003). The tradition of discriminating and marginalizing individuals with visible abnormalities or flaws can be found as far back as ancient Greece and Rome (Garland, 1995, as cited in Barnes, 2003). Foucault’s book, *Madness and Civilisation* documents the history of psychiatric asylums in Western Europe (Foucault, 1964). Up until the 1900s, individuals with disabilities were believed to be “dangerous”, needing to be locked away in institutions to protect society (Crichton, 1998, p.105-110). The rise of capitalism created a new form of marginalization for those unable to participate in the workforce. During WWII Social Darwinists practised a form of eugenics, contained within the philosophy of the National Socialist German Workers’ Party (Nazi), to rid humanity of inferior and flawed human beings. Systematic non-consensual sterilization was practiced world-wide during the first half of the twentieth century. In Canada, non-consensual sterilization was practiced in the province of Alberta between 1928 and 1972 before the Alberta government repealed its *Sexual Sterilization Act* (1928). During this time period 2822 procedures were officially authorized, although this estimate is thought to be a conservative one (CCNE, 1996). Non-consensual sterilization was performed as “therapeutic” means for preventing menstruation and pregnancy, as well as sexual aggression in people with intellectual disabilities. There is evidence that this practice continues today, despite laws preventing such practices (Price, 1990).

The Australian government conceded that between 1992 and 1997 two hundred women with intellectual disabilities were sterilized without their knowledge (Dutter, 1998, as cited in Savell, 2004, p. 1100). And in France, over fifteen thousand females were sterilized between the 1970s and 1990s (Herbert, 1997, as cited in Savell, 2004, p.1101). In Austria, it is not illegal to

sterilize individuals with parental consent and it is alleged that hundreds of women and children have been sterilized against their will (Leidig, 1997, as cited in Savell, 2004, p.1100). In 2000, despite legislation which requires consent for all medical procedures, there was at least one court case on non-consensual sterilization (consent was given by parent) of a person with an intellectual disability in Canada (*Ottawa Citizen*, 13 June 2002, A16, as cited in Savell, 2004, p.1098). Although the preceding examples may refer to isolated incidents, federal statutes in Canada, as recently as the 1990s still contained terms such as “imbecile” and “lunatic” to describe people with intellectual and developmental disabilities. These terms which appeared in the vernacular as slurs were originally medical terms, which were later removed from the diagnostic criteria in 1994 when the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) was published.

Definitions of disability have since evolved from viewing people with disabilities as sub-human and “dangerous lunatics” from whom society should be protected to people with rights who require legal protection. Increased understanding and knowledge of the aetiology of disabilities have shifted the disability discourse. Disability is now cast in the language and framework of the *Canadian Charter of Rights and Freedoms*⁶ as well as provincial human rights legislation. In 2002, the Canadian federal government published a document entitled *A Way with Words* which suggested appropriate terminology when writing about “the disabled” or “the handicapped”, namely, “individuals or persons with disabilities”. The World Health Organization (WHO) defines disability as follows: “...any restriction or lack (resulting from an impairment) of the ability to perform an activity in the manner or within the range considered normal for a human being” (WHO, 1980). Human rights legislation in Canada similarly uses a broad and liberal definition of disability to encompass learning, cognitive, emotional or

⁶ The Constitution Act, 1982, Sched.B., part I.

psychiatric disability. Statistics Canada used this expanded definition in a recent comprehensive survey on disability in Canada (Environics, 1989, p.11).

Models of disability

The history of disability policy in Canada can be divided into roughly three different stages: before WWI, between WWI and the 1980s and the post 1980s period. Each stage is primarily but not exclusively associated with the development of different paradigms or models of disability. These are the “dangerous lunatic”, the “worthy victim”, the “medical”, and the “socio-political” models.

The Dangerous Lunatic Model

Protecting society from individuals with disabilities who were labelled “dangerous lunatics” dictated the treatment of individuals with disabilities up until WWI. Disability policies took the form of laws requiring individuals with mental illness and/or intellectual impairments to be institutionalized. Except when individuals were institutionalized (whereupon the state paid the bills), families covered the costs of care (Crichton, 1998).

The Worthy Victim Model

Before WWI, persons with less severe disabilities who were not deemed “dangerous lunatics” lived in the community if willing and able caregivers were present. The worthy victim model of disability is for the most part associated with sentiments expressed by parents and family members who sought to “protect” the disabled person from society. The worthy victim perspective views disability as an individual impairment, where people with disabilities have special needs but deserve support and accommodation (Rioux & Prince, 2001). By viewing disability as a deprived state, the worthy victim model ignores the varying abilities and skills possessed by persons with disabilities, thus giving them a dependant role in society. Nowadays,

there is a greater understanding of the capacities of individuals with disabilities to develop skills and abilities which allow them to work. Nonetheless, disability advocates and families continue to express the worthy victim model, in their demands for a full range of services to be provided by government.

The Medical Model

The medical model sees disability through the scientific knowledge of experts and professionals (Cameron & Valentine, 2001, p.4). This view is consistent with the belief that persons with disabilities are suffering and that this suffering can be remedied through rehabilitation and medical treatment. The medical model views disability as a condition that can be controlled, managed and possibly cured through proper diagnosis, treatment, and institutionalization, where necessary (Rioux & Zubrow, 2001, as cited in Bunton, 2006). This model relies on the assessments of experts to determine a person's incapacity and consequently the supports and services to which a person is entitled. The medical model is also sometimes referred to as the rehabilitation model since individuals are expected to "change" or rehabilitate to "normal" conditions in order to fit into society.

The medical model goes back to the First and Second World Wars during which time individuals acquired disabilities as a result of sustaining injury. With the rise of the welfare state, government increased its role in the lives of citizens who had sustained war injuries. The rationale was that these individuals needed medical treatment and rehabilitation in order to return to a normally functioning status. Concurrent with the growing number of work-related as well as war-related injuries resulting in long term disabilities, there was an increasing social awareness of the difficulties faced by individuals living in institutions. The result challenged policy makers to recast policies to accommodate "deserving citizens" (Crichton, p.120).

This stage of policy development came after WWII paralleling the rise of the welfare state when government was concerned with supporting people through social programs. The Canadian government subsequently rewarded “deserving citizens”. For example, individuals who were injured as a result of war or work related injuries could receive compensation, either through private independent sources (workers compensation) or federal government programs for war veterans. Federal funding for improved health care and education was a benefit to individuals with disabilities as well as the majority of Canadians. This era is also noted for recognizing the visually impaired (then referred to as blind persons) and long term invalids’ supports. But according to Crichton (1998), the policies and support programs developed during this period focused primarily on rehabilitating individuals who had sustained physical injuries during the world wars (p.121). As Stone (1984) points out, these programs existed to help “deserving people” return to work as soon as possible. Those who had never worked because of an intellectual disability or could not find work because of the extent of their intellectual and/or physical disabilities were not affected by these policies (Guest, 1980). The individuals who did not benefit from these policies were diagnosed with “permanent disabilities” which prevented them from contributing to Canada’s economy. According to Bickenbach (1993), the medical model focuses on the interaction between disability and the market, proposing that in order to reduce the “cost of disability”, government policies and programs must concentrate on the cultivation of the skills necessary for an individual to re-enter the workforce (p.62). This is evident in the definitions of disability in Canadian policies which classify the inability to work, as a disability. In contrast, The World Health Organization does not associate disability with the incapacity to work. According to Hanes and Moscovitch (2002, p.127), this is an important contrast demonstrating that Canadian provinces have held on to “age-old criteria that were used

to distinguish the deserving poor from the non-deserving poor”. To be disabled and potentially employable was viewed as an acceptable social status, deserving of support, whereas being able-bodied and unemployed was viewed as an unacceptable social status, undeserving of social support. By successfully “curing” a person’s disability, the medical model minimizes the interventionist role and social obligations of government in the long run, while increasing the role of clinical diagnoses and interventions by professionals like medical doctors and psychologists in the lives of persons with disabilities. As can be seen, the medical model significantly increases the role of experts (Cameron & Valentine, 2001).

The medical model of disability is arguably the most commonly used paradigm in public policy and in service delivery today (Crichton, 1998). This model has on the one hand supplanted the “dangerous lunatic” model of disability by replacing myths around the causes of disabilities (e.g., sin) with scientific explanations (Bickenback, 1993, p.62). On the other hand, this model minimizes the important role of the social and political environments in constructing how society views and conceptualizes disability. The medical model of disability tends to create public policy “directed towards the remedying of physical impairment with little regard to the context within which the impairment is experienced” (Crichton, 1998, p.151). As a result, many of the supports and services available to Canadians with disabilities have failed to meet needs as persons with disabilities define them (Crichton, 1998, p.151). Persons who had disabilities not acquired through injuries who were thus ineligible for insurance payments were opposed to the policies developed under the medical model. This group also began demanding for disability rights.

The Socio-political model

The socio-political model of disability focuses on societal and political barriers rather than individual impairments (Driedger, 1989; Oliver, 1990). There are two parts to the socio-political model.

The social aspect of this model insists that disabilities are social phenomena. The paradigm proposes that disability results not so much from deficits in individuals but more so from the failure of the external environment to adjust to the equally valid and complex needs of people with disabilities (Bickenbach, 1993, p.154, 159). A striking image on the cover of “The Politics of Disablement” (Oliver, 1990) captures this model. A man in a wheelchair is pictured in front of a polling station that is inaccessible because there is only a staircase to enter the building. This image depicts the exclusion of people with disabilities from taken-for-granted civil and political rights. Individuals with impairments are further “disabled” by the environmental and physical barriers that society creates.

Aside from physical barriers, there are socially constructed barriers. The socio-political model of disability calls for a re-examination of the old images and stereotypes associated with the medical model where individuals are dependent on expert judgements and assessments regarding their need for supports. Research on the medical diagnoses and classification of people with disabilities has shown that the concept of disability as a “handicap” is a social creation with real social consequences, more so than an actual state of being or condition (Bickenbach, 1993, p.48). Hahn (1985) states that improvements in the status of persons with disabilities were only made possible through increases in the understanding of the underlying aetiology of disability and the recognition of social, political, cultural, economic and environmental barriers, which together form the foundation of the socio-political paradigm.

As mentioned above, the socio-political model of disability critiques “the deeper structures in society- social, political, and economic, which contribute to the disempowerment of large groups of people”, such as persons with disabilities (Spindel & Nugent, 2000). Spindel and Nugent (2000) advocate an empowerment model. By empowerment they mean:

a process by which power is developed, or sanctioned in order that subordinated individuals and groups can increase resources, strengthen self-images, and build capacities to act on their own behalf in psychological, socio-cultural, political, or economic domains”. By focusing on the theme of empowerment the socio-political model incorporates “rights to self-determination, privacy, autonomy, and dignity” (p.93).

The authors criticize treatments (e.g., Assertive Community Treatment) which purport to empower individuals with mental illness by teaching them life skills management. Spindel and Nugent argue that such treatments have the opposite outcome and tend to be “paternalistic”, “coercive”, and “disempowering” (2000, p.97). They perpetuate the myth that all persons with disabilities can never develop decision making capacities (p.98). Like the medical model of disability, such treatments put experts at the centre. For example, the process of labelling or applying a medical diagnosis reduces clients to an almost child-like status, in which their role is to do what the “experts” say.

The socio-political model clearly pits itself against the medical model. The socio-political model seeks to empower individuals with disabilities with the authority to make their own decisions concerning care needs, whereas the medical model authorizes experts to “help” rehabilitate individuals according to preconceived definitions of “normality” developed by the medical community. Similarly, the worthy victim model views disability as a deprived state of being which deserves state support and/or family care. The worthy victim model sees people with disabilities as dependent and lacking in capacity to make decisions about their care needs.

Under the assumptions of the medical model, individuals with disabilities often have little alternative but to rely on the decisions of professionals, who control access to resources and “exercise professional discretion about the use of these resources” (Biehal et al., 1992, p.109, as cited in Bunton, 2006). In contrast, the socio-political model posits that individuals should have a stronger role in deciding the provision of their care. The model acknowledges that decisions rendered by program workers who assess consumers’ eligibility to public programs may not always be accurate, and otherwise eligible beneficiaries may be prevented from receiving benefits (Alcock, 1989, p.35).

As mentioned above, there are two parts to the socio-political model. The social aspects of the model address the social and environmental barriers to disability whereas the political aspects address the definition of citizenship where “persons with disabilities are [also] citizens of communities with rights” (Driedger, 1989; Oliver, 1990).

Historically, even in human rights thinking, social rights have been treated conceptually separate from civil and political rights. In fact, the protection of social rights through charities traditionally served marginalized sectors including women, children and the poor (Hyland, 2001, p.42). The welfare state attempted to establish social rights as rights recognizing that civil and political rights often were not enough to sustain social well-being.

T.H. Marshall’s (1950) essay on social citizenship states the following:

Equality of status is more important than equality of income, such that each citizen has equal “claim rights” or rights to access resources within the welfare state based on their individual needs, i.e. universal citizenship.

According to Marshall, citizenship encompasses civil, political as well as social rights, which are defined as “a right to a modicum of economic welfare and security and the right to...live the life of a civilized being according to the standards prevailing in the society”

(Marshall, 1950). Marshall asserted that class division based on socio-economic status would not disappear through advances in the form of citizenship, but that gaining social rights as well as civil and political rights remained imperative for any individual or group in claiming the status of citizenship (Barbalet, 1988:5, as cited in Rummery, 2002, p.8-9).

Many authors suggest that current human rights legislation prioritizes civil and political rights to the detriment of social rights (Hyland, 2001, p.30)⁷. Human rights legislation in Canada, both federally and provincially falls short of addressing the demands of persons with disabilities in that legislation provides for negative rights, primarily. Human rights legislation provides freedom *from* discrimination, rather than freedom *to* a full and productive life. It can be argued that in this regard, people with disabilities are no further behind the general population. The difference however is that disability legislation has been cast within a broader discourse of equal opportunity to “participate fully in the life of the province” (ODA, 2001). Similarly, as was mentioned above, Ontario’s disability legislation, consistent with the *Ontario Human Rights Code*⁸ speaks about “dignity and worth of every person” and enabling each person “to contribute fully to the development and well-being of the community and the Province”.

Although the socio-political model has been criticized (Bickenbach, 1993, p.135) for lacking clarity and a single voice or framework representing persons with disabilities, the socio-political model unlike the medical model of disability has encouraged policy makers to recognize the broader term of citizenship which advocates for equality of outcomes. Most importantly, the model requires the voice of individuals with disabilities in creating policies that affect them. By considering the broader term of citizenship the socio-political model sets a benchmark in the policy making process, a benchmark that includes consultation with persons with disabilities in

⁷ See for example the work of Jane Jenson, Iris Marion Young and Anna Yeatman.

⁸ R.S.O. 1990, c.H.19, Preamble

policy areas such as housing, education, labour and welfare. As Doyal and Harding (1992) argue, access to social rights for people with disabilities can be made meaningful if the individuals themselves assert the right to procedural fairness against program workers and clinical professionals. Individuals with disabilities should be recognized as the primary authority when it comes to the experience of disability. This study uses the socio-political framework to examine and assess the purported aims of Ontario's current disability policies.

Disability Policy in Canada

Few studies offer a comprehensive overview of Canadian disability policy. Brown's (1977) book and a more recent text by Crichton (1998) are good examples. The following quote refers directly to American disability policies but seems applicable also to Canada:

the only avenue of fundamental reform [has been] to add another program to existing programs and to cope with the resulting confusion...Because of these tendencies, our disability policy viewed in historical context, consists of layers of outdated programs.

This quote by Berkowitz (1987), cited in Crichton (1998, p.226-227) sums up policy reform by increments which in large part explains the lack of a national overarching policy to address health and social welfare for persons with disabilities in Ontario and the rest of Canada.

As reviewed in the previous section, disability policies prior to WWI by and large were concerned with the institutionalization of people with mental illness and/or intellectual impairments. The growing number of individuals with long term disabilities due to war-related injuries as well as the growing social awareness of the living conditions in psychiatric institutions presented a challenge for policy makers. As a result, improvements to the health, welfare and education systems were made. Canadian social policies up until the 1960s continued to be dominated however by the principles of segregation and institutionalization of persons with disabilities. Policies focused on the development of special schools, training programs, as well as the expansion of already existing hospitals and institutions for persons with disabilities. The gradual shift in ideology to a socio-political model of disability in addition to the development of New Public Management ideology which offered solutions during a time of increasing fiscal restraint were instrumental in changing the program delivery process at a provincial level. Provinces went "from providing disability supports and services through institutionally based

programs to providing them through community based programs” (Hanes & Moscovitch, 2000, p.134).

The 1970s civil rights movement of African Americans and women, as well as the battles waged in creating separate anti-discrimination legislation for each group, was instrumental in supporting the disabled people’s movement in the US, Canada, and around the world (Oliver, 1990, p.115). Later, the policy stage for the worldwide recognition of disability rights was set in 1981, when the United Nations called for recognition of minority groups and declared 1981 the International Year of Disabled Persons.

The year 1981 also stands out in Canada’s disability rights history, marking the release of the Canadian government’s report entitled *Obstacles* which addressed a variety of societal barriers facing persons with disabilities. This report was a product of consultations with the disability community, advocacy groups, health care professionals and government agencies.

Two very important recommendations (recommendations 75 and 76) were given:

Recommendation 75: That the Federal Government promote a more suitable and cost-effective alternative to institutionalization by introducing enabling legislation for cost-sharing with provinces and municipalities the provision of comprehensive services to assist disabled persons to live and function independently in the community.

That the proposed legislation included the following features:

Independent living services to be made available to disabled adults by non-profit organizations which are managed by disabled persons or their representatives; and family support services to be made available on a sliding fee scale to assist families with a disabled dependent.

Recommendation 76: That the Federal Government, together with interested provincial governments, make a commitment in 1981 to assist in the funding and establishment of demonstration projects which would provide Independent Living services to disabled persons.

These recommendations reiterated many of the demands of individuals with disabilities participating in the “consumer movement” which were partially addressed with the *Canadian Charter of Rights and Freedoms*. The Charter provides that persons with disabilities, whether physical or mental, are equal before and under the law and have the right to the equal protection and equal benefit of the law. In addition, each province has its own legislation pertaining to health and social welfare policy which must be consistent with the *Charter of Rights and Freedoms*⁹ (e.g., *Ontario Human Rights Code*¹⁰).

At least six sectors of program development form the central themes of disability policy in the provinces: (1) habilitation or rehabilitation; (2) employment; (3) shelter; (4) income support; (5) access; and (6) social supports. Habilitation and access themed policies are specific to the other policy development areas and are shared with the general population. “Disability supports and services refer to the wide range of goods and services that are used by persons with disabilities to assist them in their daily living” (Hanes & Moscovitch, 2002, p.122). Examples of supports and services persons with disabilities can access (if available) are wheelchair, prosthetic devices, hearing aids, and provision of dietary foods.

As with health and welfare policies, disability policies fall under provincial legislation, therefore differences exist among the provinces (Crichton, 1998, p.2). Although the availability of these services vary from province to province because of differences in eligibility requirements, amounts of funding, degree of health coverage, etc., the types of supports and services provided do not vary significantly. In addition to these basic supports and services provided by the provinces, income and employment supports are available in most provinces for

⁹ The Constitution Act, 1982, Sched.B., part I.

¹⁰ R.S.O. 1990, c.H.19

individuals who can prove that “financial resources are insufficient to provide for needs for daily living” (Hanes & Moscovitch, 2002, p.125). Other disparities in supports among the Canadian provinces are largely due to geography. For instance, the majority of supports and services are located in larger municipalities. Persons with disabilities living in rural or isolated parts of a province may not have access to required supports and services (Hanes & Moscovitch, 2002, p.131).

As mentioned above, there are few studies offering a comprehensive overview of Canada’s disability policies and fewer still that document disability policies at a provincial level. The literature that does exist consists of government documents and websites, describing a myriad of policies and programs for people with disabilities. What follows is a brief overview of a variety of programs, aside from the three pieces of legislation which are the focus of this thesis, which help form the framework for the delivery of supports and services in the government of Ontario.

Ontario

In Ontario, supports and services for persons with developmental disabilities as well as children are delivered according to a framework established by the Harris Conservative government. The document entitled “Making Services Work for People” (1997) produced by the Ministry of Community and Social Services sets out directions for reshaping children’s services and developmental services. This document was produced in response to the demands for new methods of service delivery and better coordinated services by service providers (agencies) and users.

One program provided through the Ontario Ministry of Community and Social Services to support families and individuals with developmental disabilities is called *Special Services at Home*. This program provides funding for families to purchase services for personal development or respite care. As of December 2005 important policy changes were made such that individuals not living at home or not residing in a ministry-funded home are now eligible for this program. The program allows individuals to purchase services that are not already provided by a community agency. It also allows eligible family members who provide these services to be compensated.

Another program, *Passport*, was created specifically for individuals who have developmental disabilities as a means of participating in their communities once they leave school (age 21). Through Passport, individuals can receive funding for personal development to ease the transition from school to living as an adult in the community. This program is for individuals who are not receiving employment supports through the Ontario Disability Support Program (ODSP). It allows individuals to participate in community job skills training programs while promoting community participation. Individuals receiving these supports can be living

independently or in supportive housing; however, priority is giving to individuals living with their families. This system of funding like Special Services at Home allows the individual to access supports and services delivered through community agencies or to receive the funding directly to make their own arrangements to purchase supports and services.

A Mentoring Initiative program, delivered through *Passport*, is available for students aged 14-21 who have a developmental disability. This program exposes students to the range of options once they leave the education system. Students are paired with adults who have a developmental disability to learn skills needed to achieve life goals after completing school.

Other regulations that affect the daily lives of individuals with disabilities, which are not discussed in this paper, include the *Assessment Act*¹¹. This policy provides property tax exemptions where improvements, alterations or additions to existing homes or designated portions of new homes are made or built to accommodate persons with disabilities who would otherwise require care in an institution. The *Blind Persons' Rights Act*¹² prohibits discrimination in services, accommodation, facilities or occupancy against blind persons using guide dogs and prohibits persons who are not blind from using white canes. The *Building Code Act*¹³ and accompanying regulations establishes standards related to the accessibility of buildings and structures for persons with disabilities, as well as general standards for the construction, renovation and change of use of buildings and structures. As an incentive to encourage employers to hire persons with disabilities, the *Corporations Tax Act*¹⁴ allows employers an additional deduction for the costs of modifying buildings, structures and premises, acquiring certain equipment and providing special training in order to accommodate persons with

¹¹ R.S.O. 1990, c. A.31

¹² R.S.O. 1990, c. B.7

¹³ S.O. 1992, c. 23

¹⁴ R.S.O. 1990, c.40

disabilities in the workplace. Finally, the *Income Tax Act*¹⁵ also provides a similar credit to unincorporated employers.

Besides offering incentives for employers to hire individuals with disabilities, the province of Ontario, through the Ministry of Community and Social Services has created legislation which governs the operation of housing facilities and community agencies. *The Developmental Services Act*¹⁶ overrides the *Mental Health Act*¹⁷ where an individual with developmental disabilities and their care is concerned.

In addition to basic housing needs, the *Education Act*¹⁸ includes provisions to address the needs of students with disabilities who have been identified as “exceptional pupils”. School boards must provide special education programs and services to these students up until age 21.

Finally, the *Ontario Human Rights Code*¹⁹ consistent with the Canadian Charter of Human Rights and Freedoms protects the rights of all individuals including individuals with disabilities. The Code recognizes that attitudinal barriers need to be addressed and therefore guarantees equal treatment with respect to employment, housing, access to goods and services, facilities, and membership to a trade or vocational association. It also expands the definition of handicap as existing since birth, resulting from an accident, or developing over time. It includes disabilities which are not necessarily visible, such as people with epilepsy, as well as individuals with intellectual, mental, or sensory disabilities. It also protects individuals against “social handicapping”, discrimination based on the perception that an individual has a disability.

While human rights legislation and various disability policies and programs across Canada protect individuals with disabilities from discrimination, promote participation and

¹⁵ R.S.O. 1990, c. I.2

¹⁶ R.S.O. 1990, c. D.11

¹⁷ R.S.O. 1990, c. M.7

¹⁸ R.S.O. 1990, c. E.2

¹⁹ R.S.O. 1990, c.H.19

ensure access to private and public spaces and provide some income and employment supports, there are no federal overarching policies that guarantee entitlements for persons with disabilities. The three pieces of legislation which are the focus of this thesis form the basis of disability rights in the Province of Ontario. These rights do not guarantee equal outcomes for the individuals who are affected by the legislation. For instance, individuals must meet eligibility requirements financially and meet the diagnostic criteria for being “disabled”, as outlined in the legislation. The Ontarians with Disabilities Act, while providing redress for individuals who feel that they have been discriminated against because of their disability, does not always provide financial support for court cases to be presented to the Tribunal. Additionally, private and public spaces, which will be made “accessible” by 2025 through the enactment of the Accessibility for Ontarians with Disabilities Act, will be assessed according to standards which the government has developed and not by the larger population of individuals with disabilities. The rights that these policies provide, may advantage some groups of individuals with disabilities more so than others and assumes that individuals have family and community support systems in place. For instance, individuals with obviously identifiable impairments will receive a diagnosis of disability sooner and will therefore be eligible to receive supports faster. Furthermore, individuals who do not have intellectual impairments can speak for themselves; they will therefore be more likely to shed light on cases of discrimination, as well as suggesting where accessibility should be improved.

While policies in one province can differentially affect the lives of individuals living with disabilities, differences among policies across provinces can also differentially affect the lives of individuals with disabilities. As mentioned above, access to supports and services can vary from province to province because health and social welfare policies fall under provincial jurisdiction.

Although generally speaking, all provinces provide income supports to persons with disabilities. There are some distinguishable differences among the provinces, however. For instance, with the passing of the Accessibility for Ontarians with Disabilities Act in 2005, Ontario distinguished itself as the most accessible province in Canada. Access to supports and services vary according to differences among the provinces in eligibility requirements and in coverage of prosthetics, housing costs, and certain prescription drugs by the province's health system. Indeed the Canada Health Act does not promise that Canadians will receive funding for all medical treatments, only medically necessary treatment which may vary provincially. For example, in Ontario ABA therapy for Autism, a developmental disability is covered for children under age 6. In contrast, in British Columbia, there is no coverage (CBC News Online, October 2 2006).

A National Initiative: Disability Policy in the United States

The disability framework in the US provides an interesting contrast to that of Canada. Whereas Canada's disability policies and the supports individuals are entitled to, vary from province to province, the US with a different division of powers has introduced an all-encompassing disability policy at a national level. The *Americans with Disabilities Act* (ADA)²⁰ calls for accessibility and accommodations in the workforce, in public spaces and in transportation. These accommodations must respect a diverse set of needs and abilities. The ADA focuses primarily on employment supports for persons with disabilities. While removing barriers in the workplace for individuals with disabilities, the US government also encourages the choice to work instead of receiving disability benefits. As mentioned in the section on Ontario's disability policies, not all policies affect all groups of individuals with disabilities equally. Post-ADA (1990) research suggests, that people with permanent disabilities such as those with developmental disabilities are less likely to benefit from employment supports because of the lack of employment opportunities for workers who have a small skill set (Schwochau & Blanck, 2000). The ADA benefits individuals with developmental disabilities insofar as it provides some income supports but its focus on providing employment supports does not seem to have had as great an impact on this particular cohort of persons with disabilities because generally speaking, work is not geared to individuals who have intellectual impairments or disabilities. Typically, persons with intellectual disabilities were employed in positions where they performed routine like tasks. Technological advancements have significantly reduced the requirement for low-skill labour, e.g., the use of email in corporations has significantly reduced the need for mailroom services (Personal Communication, October 31, 2006).

²⁰ Pub. L. 101-336, July 26, 1990, 104 Stat. 327 (42 U.S.C. 12101 et seq.)

Despite the ongoing debate concerning the positive and negative impacts of the ADA, the US has taken steps to recognize the widening spectrum of disability (Turnbull et al., 2001). Disability is no longer considered a consequence of old age or a rare occurrence.

Before the ADA was introduced, the *Rehabilitation Act*²¹ was passed in 1973. The Rehabilitation Act authorized funding for employment supports for individuals with severe disabilities and recognized the needs of individuals with disabilities and their demands for independent living, by authorizing funding for states to establish and maintain independent living centres and individualized rehabilitation services (Turnbull et al., 2001). The US has since passed other legislation which acknowledges the critical medical needs of some individuals and their inability to pay for life saving care. For instance, the US has enacted home care for disabled children waivers (also known as Katie Beckett waivers), as part of the *Tax Equity and Fiscal Responsibility Act*²².

In 2000 the *Developmental Disabilities Assistance and Bill of Rights Act*²³ was signed by President Bill Clinton, ensuring that individuals with developmental disabilities will participate in the design of and access to culturally competent services, supports, and services in order to promote independence, productivity, inclusion and integration into the community (Turnbull et al., 2001). The last important piece of federal legislation with respect to individuals with disabilities living in the US was passed in 2004. The *Individuals with Disabilities Education Improvement Act*²⁴ was enacted to ensure free public education that emphasizes learning and learning techniques that are designed to meet individuals' unique needs and prepare them for further education, employment, and independent living.

²¹ Pub.L. 93-112, 1973.

²² Pub. L. 97-248, 1982.

²³ Pub. L. 106-402, 2000.

²⁴ Pub.L. 94-142, 2004.

Through its legislation, the US recognized independent living as a right of persons with disabilities and the distinctive rights of individuals with developmental disabilities. In contrast, Canadian policy, despite demands from advocacy groups, has failed to address both these issues. More importantly, like Canada, US disability legislation does not guarantee entitlements for individuals with disabilities. For instance, the right to access health care in the US does not guarantee that all Americans will be able to get a doctor or be able to afford certain treatments and medications. Thus, while the US has indeed passed legislation protecting the rights of persons with developmental disabilities and the right to choose to live independently, it does not guarantee that individuals will in fact have the capacity to live independently which depend on level of care needs, financial situations, available support systems, presence of caregivers and community resources.

The Independent Living Movement

Independent living (IL) has been given many definitions over the years, all emphasizing key characteristics of living which include freedom of choice, personal control over one's life, and participation in significant roles of worker, homemaker, and provider (Rice et al., 1983). Independent living can be described as "the ability of a severely disabled person to participate actively in society, to work, to own a home, to raise a family, to participate to the fullest potential possible in normal activities, and to exercise freedom of choice and personal control over one's life" (Cole, Sperry, Board, & Frieden, 1979, p.3).

An important aspect of the IL perspective is recognizing that individuals vary in their need for attendant care, home modification, job modification, assistive devices, health maintenance, transportation, and other services essential for independent living. Independent living is not achieved overnight. In fact, achieving full independence can be achieved through graduated objectives such as living in a nursing home setting, moving to a larger group home setting such as in an independent living center, moving to a small self-help group complex, living with family or friends in an apartment to finally transitioning into living alone or with an attendant in an apartment or home (Rice et al., 1973, p.4).

Independent Living (IL) is a radical concept that challenges popular beliefs about disability. A reaction to the medical model of disability, IL evolved from the socio-political interpretation of disability where disability is seen additionally as a societal problem and not solely an individual one. This view emerged during the 1970s but also finds its origins in the civil rights movement as well as in the consumer rights movement during the 1960s (Crichton, 1998). The concept was described and developed by Gerhen DeJong, a Dutch scholar who worked in the U.S. during the period when the discourse on disability was beginning to embrace

the socio-political conception of disability. DeJong theorized that the Black civil rights movement reached beyond the scope of benefiting only racial minorities, empowering many other disadvantaged groups in the process. DeJong advocated for individuals with disabilities not to be seen as deficient or as people in need of rehabilitation-as the medical model suggests. Instead, he pointed out the deficiencies in society which needed fixing in order to allow all individuals equal rights and freedoms, including the removal of cultural, social or attitudinal, physical, and environmental barriers. More importantly, DeJong believed that individuals with disabilities need to control their own lives, to make decisions about which services to receive, what medical treatment to get, and where and how to live (Martinez, 2003).

At the core of this ideology is an idealized notion of citizenship. As citizens, individuals with disabilities have the same right to participation, individual freedoms and control that other citizens take for granted. Proponents of the movement advocate for the consultation of disabled individuals in the policy process in order to advance the understanding and modes for defining disability. Note that consultations with disability groups is a complex undertaking given there are varying voices in the disability community*. In the same way, IL philosophy also suggests that individuals with disabilities are best at defining their own needs and should take the initiative to direct their own care. "Independence does not mean doing everything without help. It involves having control over one's life and doing the things one wants or needs to do. If help is required, it should not take away the person's autonomy or self determination" (Paquin, 2000, p.18).

The first IL centers in the United States opened in Berkeley, Boston, and Houston, in 1972. Later, US federal legislation provided for IL services and centers (Title VII,

* In fact, the consultations in Ontario, resulting in the proclamation of the Ontarians with Disabilities Act in 2001 took over 5 years. Consultations concerning how to improve the legislation are still taking place. For more information see: <http://www.aodaalliance.org/oda-committee/>

Comprehensive Services for Independent Living, 96-602) in the 1978 Amendments to the *Rehabilitation Act*. The American legislation concerning independent living also outlines the numerous services that can be provided through such programs that will “enhance a handicapped individual to live independently and function within his/her family and community” (*Rehabilitation Act*, 1973, Title I). At a minimum, core services that need to be provided are information and referral services, housing referral, peer counselling and financial benefits counselling. Other services that can be provided include vocational training, social activities, housing and health maintenance.

The changing disability discourse sparked IL movements in Canada, Great Britain and Europe as well in the US. Unfortunately, the literature documenting the history of the Independent Living movement elsewhere is scant.

Independent Living in Canada

Canadian scholars such as Henry Enns and more recently, Fraser Valentine have been at the forefront in documenting the Independent Living (IL) movement among persons with disabilities in Canada. Accordingly, the consumer advocacy movement, from which the IL movement grew, emerged in the early 1980s, marking the beginning of the Canadian Independent Living Movement (Enns, 1981, as cited in Valentine, 1994, p.7-9). The consumer movement in Canada, developed in Western Canada, advocated a new philosophy concerning the role of service providers and consumers, characterized by self-help approaches to social policy (Enns, 1981, as cited in Valentine, 1994, p.11).

The main objective of the IL movement is to “...promote and enable the progressive process of citizens with disabilities to take responsibility for the development and management of personal and community resources” (CAILC, 1989b, p.2-3, as cited in Valentine, 1994). The

movement's philosophy recognizes the individual's capacity to self-manage, thereby challenging the traditional medical model which believes that experts know best. This self-help approach clearly brings a new kind of social and political power to individuals with disabilities, such that the individuals, as everyday consumers, can direct their resources and in turn achieve recognition and dignity.

By 1985, five centres were operating in Canada. IL centres were located in the cities of Waterloo (ON), Winnipeg, Thunder Bay, Calgary and Toronto. A formal definition of a Canadian Independent Living centre was developed:

Independent Living Centres promote and enable the progressive process of disabled citizens [sic] taking responsibilities for the development and management of personal and community resources (CAILC, 1989, p.2).

As of October 2006, 28 Independent Living Resource Centres (ILRC) were located in every Canadian province except in Manitoba and PEI. In Ontario, 12 such agencies are currently registered and recognized as ILRCs. Having the largest number of established ILRCs, Ontario was the first province to set up a provincial network. The Ontario Network of Independent Living Centres (ONILC) functions as a communication or information network linking up the many ILRCs within the province of Ontario (Thunder Bay, Toronto, Sudbury, St Catharines, Parry Sound, Ottawa, Kitchener-Waterloo, Kingston, Collingwood, and Kapuskasing). The network aims to focus on provincial government policy which concerns persons with disabilities, as well as developing funding networks at the provincial level (ONILC, 1993). These centres continue to work with the national organization, the Canadian Association of Independent Living Centres (CAILC) in order to improve and establish resources that help people with disabilities take control of their own lives and live independently. Consistent with the IL philosophy, ILRCs

are located in the community, encouraging persons with disabilities to become full and equal citizens in their own communities and on a larger scale, the Canadian society. By being located in the community, the centres play an important role in raising community awareness and on a larger scale societal awareness. The greater goal of ILRCs is to alter community awareness as persons with disabilities obtain full participation in the social, political, and economic and cultural life of Canadian society (Valentine, 1994, p.6).

Independent living does more than contribute to an individual's sense of self-worth and sense of belonging. There is a growing body of research which suggests that independent living with appropriate community care also has a positive impact on the health and well-being of individuals and, in the long run, of health systems by reducing complications due to illness, reducing the demand for emergency and long term care, thereby reducing demands on an already strained health care system (Challis, 1993; Hollander & Prince, 2002; Hollander & Chapell, 2002; Weissert, 1992). Community services as part of the larger continuum of care can foster a path toward independence and contribute to sustaining the broader health system. In the following section we will examine and assess the extent to which Ontario's current disability policies support independent living for persons with developmental disabilities who have both the capacity and the desire to do so.

Method

This study utilizes qualitative methods of analysis as a tool for exploration primarily because it attempts to assess the purported aims of the legislation according to the lived experiences of individuals (executive directors or their designated representatives) who work within the legislation. Qualitative approaches are best suited for this type of research which aims to assess opinions, attitudes and responses to the various pieces of legislation. Additionally, the goals of this exploratory study are to define a set of criteria that key informants identify as necessary to support independent living among persons with developmental challenges. The information gathered in this study will establish the foundation for future studies and larger scale evaluation and impact investigations.

Using content analysis, this section first examines the provincial legislation affecting individuals with disabilities living in the Province of Ontario. These policies are: the Ontario Disability Support Program Act (ODSP; 1997); the Ontarians with Disabilities Act (ODA; 2001); and the Accessibility for Ontarians with Disabilities Act (AODA, 2005). This thesis then assesses the outcomes of these policies through qualitative interviews with five key informants.

Research Design

The study uses content analysis to identify the focus, goals and policy choices reflected in legislation as well as a semi-structured qualitative interview methodology to tease out the criteria considered necessary for successful independent living. All methods have been approved by the Ryerson Research Ethics Board (see Appendix A for letter of Ethics Approval).

The legislation was first examined through content analysis which helped to identify the objectives, the statutory provisions and the implementation order. Policy outcomes based on the legislation's purported aims could then be inferred. This method of analysis was limiting as it

did not allow for confirmation of outcomes, post-implementation. Qualitative interviews were thus instrumental in assessing those outcomes.

Interviews were conducted with executive directors or designated representatives of community agencies, located in the Greater Toronto Area, serving individuals with developmental disabilities. Data compiled from key informant interviews was essential to the qualitative nature of the study as it draws upon the experiences, reactions and observations of executive directors working within the legislation, shedding light on the actual policy outcomes. Although some bias was removed by interviewing more than one person, there are still limitations with the study sample because the experiences of the executive directors or designated representatives who were interviewed may not be generalizable. Their experiences may not reflect the actual day-to day experiences of persons with disabilities.

Interviews were tape-recorded and transcribed with the permission of respondents. Two of the five respondents did not agree to be tape-recorded. Qualitative data from the interview notes and transcripts were aggregated and analyzed by identifying key themes raised in the interview schedule. The written report contains aggregate data to prevent respondents from being identified. Tapes, notes and transcripts will be destroyed upon the successful defence of this thesis.

Respondents

Interviews were conducted with executive directors or designated representatives of five community service agencies within the greater Toronto area (GTA) that serve young people between the ages of 18 and 35 with developmental disabilities. The supports and services provided by target agencies included respite or group home services as well as day programs. All respondents had at least five years experience serving a disabled population in Ontario, ensuring

the respondent's familiarity with Ontario's disability legislation. Respondents were recruited regardless of gender.

Executive directors were selected for interview because they know the shortcomings of the legislation. These agencies were targeted because they specialize in providing supports for persons with developmental disabilities. There are 32 such agencies providing services in the Greater Toronto Area, therefore stratifying the sample would not have increased the reliability of results.

Recruitment

The original list of potential agencies was found under the heading of developmental services in the accessibility directory of Accessibility Directorate of Ontario (Ministry of Community and Social Services, website). Agencies were selected through a respondent-driven sampling technique where respondents were contacted on the basis of referral.

Community service agencies were contacted by the principal investigator by telephone and followed up through email (see Appendix B for telephone recruitment script). All interviews were conducted on site in the respondent's organization. At the beginning of the interview respondents were asked to read and sign the consent form describing the purpose of the study, risks, and benefits (see Appendix C for consent form). Respondents were given ample time to address any concerns they had regarding the study. After the interview process, time was given to answer any additional questions not addressed during the interview. All respondents were provided with the investigator's contact information as well as Ryerson University Ethics Board's in case of further inquiry.

Key Questions for Investigation

Interview questions were designed in order to assess respondents' opinions regarding the outcomes, thus far, of Ontario's three disability policies. The questions focused specifically on individuals with developmental disabilities, the impact of the legislation on their overall lives, identifying which supports and services are necessary for independent living and whether or not the legislation supports the choice to live independently. A copy of the Interview Schedule is included in Appendix D.

Findings

The Ontario Disability Support Program Act

Background: The Ontario Disability Support Program Act (ODSP), in addition to the Ontario Works Act, was implemented under the Social Assistance Reform Act (SARA), by the Harris Conservative government in 1997 (S.O.1997, c.25, Sched.B). It created a mandatory work-for-welfare program, Ontario Works, and a separate income support program for persons with disabilities, the ODSP. By creating a separate benefits program for persons with disabilities, the government endeavoured to remove the negative connotations associated with receiving welfare, recognizing that their inability to work was due to physical limitations.

Aims and Purpose of the Legislation: The Ontario Disability Support Program Act, 1997 provides that its purpose is to establish a program that:

- (a) provides income and employment supports to eligible persons with disabilities;**
- (b) recognizes that government, communities, families and individuals share responsibility for providing such supports;**
- (c) effectively serves persons with disabilities who need assistance; and**
- (d) is accountable to the taxpayers of Ontario.**

Delivery: The ODSP is run through the Ministry of Community and Social Services. There are currently nine regional offices delivering services. Applications for the ODSP can be made through a local ODSP or Ontario Works office. Individuals already receiving benefits from the Assistance for Children with Severe Disabilities program administered through the Ministry of Children and Youth Services will automatically receive ODSP benefits once they reach 18 years of age. Ontario residents, aged 65 and older, who do not qualify for Old Age Security are also eligible to receive ODSP benefits.

Eligibility: In order to be eligible to receive income support benefits under the ODSP Act, individuals must be 18 years of age, a resident of Ontario, meet financial need requirements and must be “a person with a disability” as defined in section four of the ODSP Act. Persons with a disability aged 16 and over can qualify for employment supports provided through the ODSP.

Accordingly, an individual is a person with a disability if:

- (a) the person has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;**
- (b) the direct and cumulative effect of the impairment on the person’s ability to attend to his or her personal care, function in the community and function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and**
- (c) the impairment and its likely duration and the restriction in the person’s activities of daily living have been verified by a person with the prescribed qualifications.**

Income supports are provided for both the individual and his or her dependents. In addition, the individuals’ assets (excluding the individual’s residential property), including that of their spouse (if married) must not exceed a prescribed amount (amount is subject to change). Similar regulations apply for individuals living alone. The Act also restricts eligibility if an individual is drug or alcohol dependent and the restriction in activities of daily living is attributable to the use or cessation of substance abuse. Chapter 25, Schedule B (s. 5(3)) does not apply to individuals who in addition to being dependent on, or addicted to a substance, have a substantial physical or mental impairment.

What is delivered: Currently, under the Ontario Disability Support Program the maximum total monthly allowance is \$959 which includes general income support and an allowance for shelter. Comparatively, the maximum total monthly allowance for a single person under Ontario Works is \$536. Additional support may be provided for the spouse and dependents of an eligible

applicant. The recent budget announced a two per cent increase of social assistance, which will come into effect on November 30, 2006 for Ontario Disability Support Program and December 1, 2006 for Ontario Works. Individuals who are ineligible for ODSP may receive benefits from Ontario Works.

As of December 2005, according to the Ministry's quarterly report, 294,354 individuals and their dependents (213 494 family units or cases) were receiving benefits through the ODSP, a 9.68% increase for individuals and a 12.7% increase for total family units, respectively since the launch of the program in June 1998. (Calculations from the quarterly statistical report put out by the Statistics and Analysis Unit, Social Policy Development Division, Ministry of Community and Social Services).

The Ontarians with Disabilities Act

Background: The Ontarians with Disabilities Act (ODA) was passed in 2001 (S.O.2001, c.32). The ODA was enacted by the Harris Conservative government after over five years of back-and-forth deliberations with the ODA Committee, a voluntary coalition of individuals and community organizations who submitted the blueprint- "Making Ontario Open for People with Disabilities" for this legislation in 1998.

Aims and Purpose of the Legislation: The purpose of this Act is to improve opportunities for persons with disabilities and to provide for their involvement in the identification, removal and prevention of barriers to their full participation in the life of the province (c. 32, s. 1.).

Importantly, the term "disability" was redefined within this legislation to encompass the broad spectrum of disabilities that are recognizable under law because of the ambiguity of the definition found within the ODSP Act.

Delivery: The ODA applies to all government buildings, government goods and services, government employees who have accessibility needs, government internet sites, government publications, and government-funded capital plans. The ODA established the Accessibility Directorate of Ontario (ADO) which is the acting office in disability issues in Ontario. The Act's enforcement comes under the Ontario Human Rights Commission which investigates and settles cases on an individual basis. If the case is not settled, the Commission can, if it wishes, present the complaint to a full hearing before the Ontario Human Rights Tribunal.

Eligibility: In the Ontarians with Disabilities Act (ODA), "disability" means:

- (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,
- (b) a condition of mental impairment or a developmental disability,
- (c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
- (d) a mental disorder, or
- (e) an injury or disability for which benefits were claimed or received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997*; ("handicap")

What it delivers: The ODA provides opportunities for redress where individuals feel that they have been discriminated against by a public agency, school, university or hospital. The ODA includes a penalty (a fine of not more than \$50,000) for municipalities, agencies, organizations, as well as organizations providing public transportation, convicted of contravening the Act. The

Act also promotes accessibility by providing funding under a government-funded capital plan for new buildings which meet and exceed to the standards outlined in the Building Code Act, 1992.

The Accessibility for Ontarians with Disabilities Act

Background: In 2005, the Accessibility for Ontarians with Disabilities Act was proclaimed (S.O. 2005, c. 11). While recognizing the history of discrimination against persons with disabilities in Ontario, this Act applies to all public goods and services including those in the private sector, such as restaurants and theatres.

Aims and Purpose of the Legislation:

The Act's purpose is for:

- (a) developing, implementing and enforcing accessibility standards in order to achieve accessibility for Ontarians with disabilities with respect to goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025; and**
- (b) providing for the involvement of persons with disabilities, of the Government of Ontario and of representatives of industries and of various sectors of the economy in the development of the accessibility standards. 2005, c. 11, s. 1.**

The AODA also asks for the removal of barriers which consist of:

anything that prevents a person with a disability from fully participating in all aspects of society because of his or her disability, an architectural barrier, an information or communications barrier, an attitudinal barrier, a policy or practice; ("obstacle").

Delivery: In establishing the AODA, the Accessibility Directorate of Ontario which was established under the ODA (2001), broadened its functions to include giving advice to the Minister in the proposal of standards, as well as in the development and enforcement phases.

The Accessibility Directorate is primarily responsible for consulting with organizations on

accessibility reports and ensuring that the report complies with the laws and standards set out in the AODA. The directorate is also instrumental in educating the public on accessibility issues and legislation, as well as an information source (MCSS, 2006). The AODA also established an Accessibility Standards Advisory Council and subcommittees, which determine long term objectives and time frames for individuals and or organizations to follow. It also creates Municipal accessibility advisory committees. The AODA stipulates that consultations with individuals who have disabilities should be made and the majority of the members of Accessibility Advisory Committees, established in Ontario municipalities, should consist of persons with disabilities.

Eligibility: The definition of “disability” in the Accessibility for Ontarians with Disabilities Act remains unchanged since the passing of the ODA in 2001.

What it delivers: The AODA maintains the ability for redress, established by the implementation of the ODA, in cases where individuals feel that they have been discriminated against. The main function of the AODA is that it provides a specific timeframe (by 2025) to remove barriers to accessibility. Adherence to the accessibility standards is enforced by requiring accessibility reports to be produced by public institutions such as universities, including information such as the amount of money spent on installing wheelchair accessible bathrooms, as well as the number of students with a disability in attendance at the institution. All persons and/or institutions that are affected by the legislation are also subject to inspection by the Advisory Council. Where persons or institutions are found guilty of an offence under the Act, a fine of \$50,000 is applicable, for each day or part of a day the offence occurs or continues to occur. For corporations, the penalty is \$100,000 per day.

Analysis: Where are the gaps?

Content analysis

Overall, these three pieces of legislation potentially form the basis for a strong foundation for independent living by providing income supports, employment supports, a discrimination free workplace and accessibility to all public spaces by 2025. There are however a number of key weaknesses which were identified through a content analysis of the legislation.

First, the policies do not consider regional or individual variations in providing supports and assume caregiver and/ or community agency subsidies. For example, ODSP income supports together with shelter allowance do not take into account the cost of living in varying locations. Consider the cost of living in Toronto. Individuals who rely on government funding as their sole source of financial support would live below the poverty line or Low Income Cut Off (LICO). The LICO for 2002 was \$19,261 for a single person in Toronto; below this figure, individuals may be considered to live in poverty (Lum et al, 2005; LICOs, 2002). For individuals receiving the maximum ODSP benefit of \$959, their annual income is only \$11 508. Financial situations may also be directly related to the severity of disability and the level of care required, including special diets, physiotherapy, medications or domestic help. Eligibility is based on means tests which often result in inadequate supports for individual cases. In situations where an individual is living with another person who is eligible to receive ODSP supports, it is financially advantageous to retain non-marital status.

Looking at the issue of accessibility, the policies assume the capacity to negotiate the system. The process can involve filling out forms, communicating with program officers, reading legislation and even seeking information regarding individual entitlements. For example, the ODA ensures that the Ontario government will provide accessible government publications and

documents, but will only make available documents in an accessible format if a request is made by, or on the behalf of, a person with a disability. This “catch 22” complicates the process for individuals with developmental disabilities to learn about their entitlements.

Furthermore, that there are three separate disability policies instead of a coherent overarching policy increases the complexity for individuals with disabilities, as well as their families and/or caregivers to navigate the system. The absence of a comprehensive policy increases the difficulty for individuals, caregivers and community agencies to find out about entitlements.

The ODA also mandates municipalities, public transportation organizations, educational institutions, including universities, as well as hospitals to prepare accessibility plans while consulting with individuals with disabilities. The AODA extends this mandate to all private organizations and service sectors. Both policies (the AODA and the ODA) while asking for consultations with persons with disabilities, do not stipulate whether the individuals with disabilities sitting on these committees should represent the wide spectrum of disabilities, including individuals with developmental disabilities or their advocates. As is the case with policies dealing with other disadvantaged groups, there is the tendency to homogenize categories. As can be seen, consultation and representation will likely exclude those already most disadvantaged. While it is true that both policies provide a definition of the spectrum of barriers which can impede individuals with disabilities from living a full and equal life, they do not provide actual recommendations. The AODA does not guarantee that all such barriers will be removed by 2025. Instead, the decision is left in the hands of the Accessibility Advisory Council and its sub-committees.

Together these policies fail to acknowledge vulnerable individuals like those with developmental disabilities, who often lack the critical faculties required to navigate the system. The policies thus leave individuals with developmental disabilities with very few mechanisms to prevent them from falling through the cracks. Where the ODSP is concerned, individuals have had to wait unreasonably long periods of time to receive supports. Some of the most serious cases were identified by the Ontario Ombudsman in his Annual Report. Because there are regulations concerning retroactive benefits, individuals may only receive up to 4 months of retroactive support, even if certain individuals are waiting up to eleven months in some cases to have their file approved. The “waiting game”, as coined by Ombudsman Andre Marin, can have detrimental effects on health (not being able to pay for medication) and overall well being (lack of access to personal supports, such as social programs and personal hygiene) (Ombudsman Report, May 2006).

Most significantly, while the three policies together with the Ontario Human Rights Code reflect a broader definition and understanding of disability, there is no mention of the concept of independent living in the legislation. As reviewed in a previous section (see US disability policies, pp.31-33) the Americans with Disabilities Act (1990) as well as its predecessor, the Rehabilitation Act (1973), legislate entitlements to independent living which includes providing funding for independent living centres. The Ontario Human Rights Code protects individual rights and freedoms. It does not however view independent living as an entitlement like it does equality in the workplace or access to education, for example. The ODSP provides the opportunity to access income and employment supports, for those who require it. The ODA provides the right to access public transportation, educational institutions, hospitals, and government buildings. Government websites as well as government publications were made

more accessible by publishing alternate versions with larger text. Government publications can be translated into Braille for individuals who request hard copy versions. And finally, the AODA provides the right to access all public services and commercial establishments within the province of Ontario. There is however no mention in Ontario's disability policies of the right to independent living in any of the legislation.

In fact, as opposed to facilitating independent living, the very complexity and fragmentation of the system under the three policies ironically may act as a barrier to independent living. Individuals with developmental disabilities who have the capacity to make decisions but may lack the communication skills (reading and writing) necessary to negotiate the system, have no choice but to rely on a support person to navigate the system for them. These policies marginalize individuals with developmental disabilities more so than other disability types because the policies fail to provide the infrastructure and the tools necessary for all individuals to seek information concerning entitlements- to choose which services that individual should receive and how those services are going to be delivered. Hence, these three policies together seem to be disabling for independent living.

Interview analysis

What follows is an analysis of the qualitative information gathered in interviews conducted with executive directors from community agencies that serve individuals with developmental disabilities. First, interview respondents discussed each piece of the legislation and the various themes or issues that have arisen in seeing the actual outcomes of these policies. Secondly, interview respondents commented on which key supports they felt facilitated independent living for people with developmental disabilities. Finally, the discussion turned to whether or not the legislation provides for these supports.

The Ontario Disability Support Program Act (ODSP)

Generally speaking, four themes emerged from the discussion surrounding the *ODSP* legislation. These themes were: 1) individualized funding as a model for distributing benefits; 2) the amount of income support persons receive; 3) employment for persons with disabilities; 4) The application process and the maintenance of supports.

1. Individualized funding

Two out of five respondents referred to ODSP as a move toward adopting an individualized funding model for distributing benefits. Respondent 3 discussed the positive aspects of introducing the ODSP: “By abolishing the Family Benefits [the government] established the individual with a disability as an independent adult and increased the amount of supports individuals are eligible to receive [compared to Ontario Works beneficiaries]”. With the recognition of individual needs and the publication of the “Making Services Work for People” document by Ontario’s Ministry of Community and Social Services, funding is now allocated on an individual basis, instead of allocating monies to a group home, for example. The funding remains with one individual for the rest of his or her life. Depending on which community agency from which the individual receives services, the monies are funneled through the individual to pay for services delivered by the agency.

According to Respondent 1, individualized funding is positive and is consistent with the philosophy of independent living: “The concept is based on the individuals’ input and identification of their needs, with the support worker, their family, the volunteer, and whoever is involved in their life.” Respondent 1 confirmed that this mode of funding would become more prevalent as the current liberal government moves toward what they are calling consumer driven or individualized funding. When asked about competition among agencies that could result from

these reforms in the program delivery process, Respondent 1 remained positive, stating that with the present changes “Families and individuals will have a lot more control about the services that they receive”. While Respondent 5 recognizes the benefits of individualized funding, she also points out that individualized or consumer-driven funding “automatically puts the onus on the parent to navigate the system. In addition the services parents choose will also be limited according to how much they know is out there”. Similarly, as reported by Respondent 1, parents need to be informed of other legislation that governs service arrangements (e.g., like workers’ compensation) in cases where they hire workers to provide extra help for a dependent with disability.

2. Income support

All respondents acknowledged that the income support received through ODSP paid for rent and little else. As Respondent 5 mentioned “the maximum ODSP benefit of \$959 is not enough to live on your own”. “Not all medications are completely covered, so community agencies try to accommodate people by not charging more than \$500 per month so that the individual can pay for other necessities”. Respondent 4 stated that although living in urban areas does cost more, in the long run it is more beneficial to the individual to be living in the city rather than in suburban Toronto. Respondent 4 also suggested that being surrounded by a younger population which tends to be more comfortable interacting with persons with disabilities is the main motivation for his agency to place people in apartments in the city rather than in the suburbs. Indeed having services located in close proximity to individuals’ residences also aids in facilitating access and integration into the community. Although the majority of individuals with disabilities who are unable to seek gainful employment may not accumulate substantial savings, this policy change nonetheless still benefits all individuals with disabilities.

Three of the five respondents acknowledged that ODSP is the most important policy with regard to independent living. According to respondents individuals with disabilities require a trust fund of some sort to ensure a successful transition to independent living. Respondent 5 pointed out that the ODSP legislation, since its implementation, has increased the ceiling for allowable assets to \$5000 (not including the individual's principal residence, if owned). Individuals with assets greater than \$5000 are penalized or may not be at all eligible to receive income supports through ODSP. All respondents agreed that ODSP income supports alone are not sufficient for an individual to live independently, regardless of the nature of the disability.

Finally, two of the five respondents discussed some of the gaps in the ODSP consultation and application process. Respondent 4 stated that "as an organization we find ourselves repeatedly trying to inform the workers as to what the entitlement is for the individuals that we support. Similarly, Respondent 5 stated that "if you don't have a support worker who is informed, you may miss out on certain benefits because the Ministry does not send out letters or actively advertise what benefits are available". In addition, as mentioned in the Ombudsman's Report (2006) and confirmed by Respondent 4: "There is often a discrepancy as to [the] entitlement or understanding of [the] entitlement and the actual payment amount"- meaning that there are often calculation errors in the dollar amounts of ODSP income support cheques. Appeals made because of miscalculations, although usually rectified quickly can sometimes result in delays for the delivery of the supports an individual is entitled to. All respondents remained optimistic however, suggesting that this may be due to the lack of experience of the ODSP workers, and it may just be "a matter of settling in".

3. Work

As of November 1st of this year (2006) the Ontario government made important reforms to eligibility requirements for the employment supports provided through the ODSP. All respondents were enthusiastic about the changes. They acknowledged that receiving ODSP benefits tends to be a default position for most individuals with disabilities. Before November 1, 2006, individuals would have been less likely to leave the ODSP because they might have required prescription drugs or special diets which are covered by the ODSP's health benefits. Additionally, the regulations concerning the maximum amounts of income earnings and savings that an individual can have might have impeded those who wished to leave the ODSP to live independently. After November 1, 2006, individuals could "experiment" (as Respondent 2 put it) with different employment opportunities, without fearing that they would no longer be able to afford medication or dental care. ODSP recipients now retain health and dental benefits until employer coverage is available. If the employment situation does not work out, individuals may be rapidly reinstated, allows them to leave employment and receive income supports quickly. The November 1st changes also increases the one-time employment start-up funds from \$253 to \$500. The employment start-up funds allow people to purchase appropriate clothing and pay for transportation costs. In the cases where individuals earn more than \$160 a month, they may retain a portion of ODSP income supports but are subject to a 50% deduction of ODSP support if they earn more than \$160 per month. As an incentive, individuals will also receive an extra \$100 per month from ODSP regardless of employment earnings.

A major issue brought up by two respondents concerned rules around confidentiality in the workplace. Respondent 5 outlined a case where "*Debbie*"- an individual with a developmental disability had no problem doing routine-like work. Once supervisors saw how

well she was doing, they gave her more work. In order to cope, *Debbie* threw out important data. This individual was immediately fired, without any explanation to the community agency who had arranged the placement. According to the respondent, *Debbie* needed someone to be her interpreter because she needed the process explained in a clear step-by step fashion. No one contacted the agency that had arranged the placement because of employer-employee confidentiality agreements, preventing the community agency from intervening to anticipate and prevent such mishaps.

Some individuals with developmental disabilities can maintain gainful employment where employment supports are available. Employment supports, however may not benefit everyone. Respondent 4's client portfolio consists mostly of individuals with critical medical needs, and therefore "employment is not an option for them". This is a prime example of a policy which may not advantage all individuals with disabilities. These changes while positive, respond to the needs of individuals whose "dis-Abilities" can be adapted to the demands of the workforce.

4. The process: Forms, forms and more forms

All respondents brought up the subject of the amount of paperwork involved in the ODSP. All respondents were adamant that individuals with developmental disabilities, who have successfully made the transition to independent living, require a support or social worker to handle their cases. Social and/or support workers are necessary because all form filling and communication with an individual's assigned ODSP branch is through standard forms and letters which are written at a seventh or eighth grade level. Respondent 3 and Respondent 5 suggested that while individuals with developmental disabilities can be literate to some extent, the language skills they obtain are different from the rest of the population. Both respondents suggested that in

order to facilitate independent living, letters and forms would need to be re-written in a simpler format.

With the increase in the amount of monthly income an individual can earn, more form filling is required, which involves mailing pay slips in every two weeks. If the paper work is not filled out properly or in time, the ODSP office can suspend the individual's benefits.

Respondent 5 said that "in the cases where an individual is thrown out, it can take two to three months to get back on". Respondent 5 also mentioned that the ODSP program delivery process has improved somewhat. In cases where the individual cannot be present for a supports assessment interview, a telephone interview can sometimes be arranged. But two of the five respondents discussed the delivery process as becoming more disconnected, with ODSP workers moving around cases, and most of the paper work done by email, fax, etc. Respondent 5 discussed a particular case where their agency had been sending documents to an employee at the ODSP office for months but that person had changed departments without telling anyone. No one had forwarded the client's documents to the new case worker. The numerous forms and layers of often changing personnel increase the likelihood that people with developmental disabilities will fall through the cracks of this very fragmented system. The onus is on the individual to navigate the system. All respondents agreed that it would be next to impossible for an individual with a developmental disability to do all the paperwork to apply for, receive and maintain supports that the ODSP office requires. As three of the five respondents confirmed, individuals with developmental disabilities will always need an "advocate of sorts".

The Ontarians with Disabilities Act (ODA)

The key theme that emerged in the discussion surrounding the ODA legislation was that “accessibility” for individuals with developmental disabilities” means more than ramps.

Respondents generally agreed that the passing of the ODA was a positive step because it provided individuals with the right to redress in cases where they feel that they have been discriminated against because of their disability. Yet, the legislation underscores the tendency to homogenize disability. There is still little understanding about the different needs of people with developmental disabilities. The ODA perpetuates this lack of understanding by not recognising the different needs of diverse disability populations. Respondent discussion focused primarily on developmental disabilities as “invisible” disabilities. Two themes formed the discussion concerning the consequences of the “invisibility” of individuals with developmental disabilities: 1) the lack of input in lobbying government and as a result legislation tends to address the needs of persons with visible disabilities, and; 2) employment opportunities for individuals with developmental disabilities.

Invisible disabilities

The theme of invisibility was raised by all respondents. It was offered as an explanation for the lack of legislation uniquely directed toward providing services for individuals with developmental disabilities. As Respondent 4 stated:

You can have someone in a wheel chair that has a university degree. You can gather a whole bunch of people in wheel chairs for a rally on Queens Park but you are not going to get a bunch of people with developmental disabilities pull together and have a rally, unless they’ve been directed to or supported in doing so. Persons with developmental disabilities don’t have the same kind of voice or profile as some of the other groups of people with disabilities would have.

Respondent 3 concurred by explaining that “invisibility” was applicable in the sense that there is a lack of understanding of what developmental disabilities are and the wide spectrum of abilities individuals are able to manifest. All respondents spoke candidly about the ease with which important changes could be made. Instead of ramps, accessibility for persons with developmental disabilities might mean modifying the language in the legislation so that it is accessible to individuals who read at less than a seventh or eighth grade level or increasing the number of pictorial directions and signs in public places for persons with minimal language abilities.

In addition to having a lower voice in advocating for policy changes, individuals with developmental disabilities face additional hurdles in the conceptualization of their disability. Respondent 4 commented on the number of voices in the disability advocacy movement. For instance, one group advocates promoting growth and opportunities. Another wants to protect this “vulnerable” population. There are disagreements on how much the government should provide and whether the government should be providing services directly. “Some say, just give me the money, and I’ll do my own thing; another says the government should provide everything for people with a disability, because god forbids what will befall on them; and finally you have more moderate people who want a little bit of both” (Respondent 4; Interview, October, 26, 2006). As can be seen, persons with developmental disabilities have diverse spokespersons with often conflicting views –all of which may limit the power of their lobbying activities.

1. Legislation for persons with “visible” disabilities

Respondent discussion regarding the changes in the developmental services field since the ODA was passed can be best described by the following statement: “The legislation has not impacted the developmental services sector in the way it would impact someone with more

physical disabilities. So we certainly don't see, or I haven't seen any benefits from it for the folks that we support. We are still going about our business in the way that we do (Respondent 1: Interview, October 12, 2006)".

The legislation contains pages and pages of specifications, where ramps should go, increasing the amount of crosswalks in different municipalities, but in terms of accessibility, as Respondent 5 mentions, "it does not talk about literature that's simpler or introducing visual aids for people to understand or know how to access supports". Respondent 4 provided an example: "When you look at areas like here in Toronto, the TTC and just general accessibility to public buildings, the ramps are all there, the elevators are all there, the automatic doors are all there but sometimes the signage is not there. There isn't the same kind of explanation or the understanding that people need to cater to a wide spectrum of disabilities". Two of the five respondents likened the situation to the experiences faced by newly arrived immigrants in Toronto, where explaining things in a way that is much more understandable by using visual aids for instance would serve a larger audience than just persons with developmental disabilities.

All respondents commented that individuals with developmental disabilities cannot even read the legislation which was supposedly created with them in mind. Respondent 5 did mention, however, that for Ontario's *Passports* program a simpler version of the information pamphlet, with illustrative pictures, etc. was created. Respondent 5 also pointed out that the actual application still needs to be filled out by a parent or care giver.

In addition, respondents agreed that in theory the new rights and appeals process guaranteed by the legislation is a positive step for persons with disabilities. Yet the legislation underscores the tendency to homogenize disability. There is still little understanding of the spectrum of disabilities and the differences in individual abilities among people with disabilities.

The legislation does not affect individuals with developmental disabilities in the same way as someone with exclusively physical disabilities. All respondents agreed that individuals with developmental disabilities will always need an “advocate of sorts” to navigate the system for them.

2. Employment for persons with developmental disabilities

All respondents agreed that the legislation provides greater employment opportunities for individuals with disabilities. The legislation prevents discrimination and provides incentives to employers to make workplace accommodations. Yet, individuals with developmental disabilities do not always benefit from these changes. The sorts of routine and predictable jobs that were once available for persons with developmental disabilities have now been taken over by machines (e.g., email replaced the need for mailroom employees in some corporations) (Personal Communication, October 31, 2006). In addition, as Respondent 3 outlined, “the job placement has to be realistic”. In some cases an individual with a developmental disability might receive a placement in a child care centre, but that individual would not have the abilities necessary to complete an ECE degree which would qualify him or her for full-time work. Similarly, Respondent 4 said, “We have to give people opportunities but [at the same time] we have to give people realistic expectations”.

In some cases, clear discrimination is experienced. Respondent 5 suggested that some employers would refuse to hire workers with visible disabilities fearing negative customer reaction. Other employers may prefer to hire persons with visible disabilities over those with invisible disabilities, perhaps to publicize good will and good public relations. Respondent 4 admitted that there are still considerable attitudinal barriers. He stated that “the legislation is one way of saying ‘that’s too bad because you are going to have to accept it’”. The same respondent

spoke about differences in the generations and tolerance. For instance, many older individuals can still be quoted as saying that “I shouldn’t have to look at someone like that next door to me, or I shouldn’t have to share a swimming pool with someone with a disability”. Four out of five respondents were optimistic however that these attitudes will change over time and that the legislation is an important step toward such changes.

Accessibility for Ontarians with Disabilities Act (AODA)

All respondents agreed that the AODA legislation is more specific in regulations and timelines, extending them to the private sector. They also agreed that the legislation improves accessibility for people with physical disabilities rather than for people with developmental disabilities. Discussion focused on the importance of: 1) removing physical barriers; and, 2) providing crucial supports for independent living including housing, transportation and health care.

1. Removing physical barriers

All respondents acknowledged that the AODA seems to address the same issues addressed by the ODA legislation. The key difference however is in making time commitments (by 2025) to creating barrier free environments in public spaces. Respondent 1 conceded that tapered sidewalks and automatic doors will no doubt help individuals with developmental disabilities as they age, but these entitlements do not stem directly from the needs and demands of the developmentally disabled. Respondent 4 echoed Respondent 1 stating: “I think the focus has been primarily on physical disabilities ...people with developmental disabilities are ...an invisible minority so to speak. I think as well with the emphasis on accessibility it seems to be more respect to barrier-free [the removal of physical barriers] as opposed to making it for people

who may have a cognitive disability”. For instance, Respondent 2 mentioned that for individuals with autism, it’s not just physical accessibility that matters. Drastic changes made to the environment can be very disruptive for an individual with a developmental disability like autism. For example, some settings may be too busy or noisy. Some would say “they shouldn’t go there, if they are going to react in that way.” In any case, there seems to be a bias toward addressing physical disabilities in accessibility legislation. Even so, as Respondent 2 said, “There are still brand new buildings being built that aren’t accessible [for people with mobility limitations]”.

Supports for independent living

One of the main objectives of this study was to establish which supports are necessary for independent living. What follows is a list of key criteria that were identified by respondents as essential for individuals with developmental disabilities who have both the desire and the capacity to live independently. These are: 1) housing, 2) transportation, and 3) health care.

1. Housing

Respondent 4 pointed out that the lack of affordable housing was a barrier to independent living for individuals with developmental disabilities. There is a shortage of rent-geared-to income housing for individuals with developmental disabilities. Individuals with developmental disabilities face a conundrum: they can best access support services by living close to an urban centre where there is a high density of service providers. Unfortunately, housing in the city core is also very expensive. In 2006, rent for a 1-bedroom apartment in the City of Toronto’s averaged about \$896 per month (Canadian Mortgage Housing Corporation, 2006). Indeed the Ministry of Community and Social Services has responded by partnering with the City to build housing for people with disabilities. Approximately twenty units have been reserved for people

with a developmental disability (Respondent 3: Interview, October 27, 2006). This is one example of the role municipalities can play in facilitating independent living. On the other hand, because of regulations concerning the number of supportive housing units that can be built in certain areas, municipal zoning by-laws can be a barrier to independent living for individuals who have both the desire and capacity to do so (Respondent 3: Interview, October 27, 2006). Also, there are fire-code rules, as well as additional codes that make it extremely difficult for agencies to retrofit a home for individuals with developmental disabilities (Respondent 3: Interview, October, 25, 2006).

2. Transportation

Access to public transportation is an entitlement under the legislation. Transportation has been a subject of discussion time and time again for individuals with all kinds of disabilities in their fight for independence. Unlike people with obvious mobility limitations, individuals with developmental disabilities do not qualify for Wheel Trans, a service provided through the Toronto Transit Commission (TTC) in the City of Toronto. Not only does the TTC not provide escorts (there's an assumption that many developmentally disabled individuals need accompaniment), it does not allow people with developmental disabilities to access Wheel Trans service. An excellent example, provided by Respondent 4, is a case where "*Richard*" - an individual with a developmental disability was turned down twice by the Wheel Trans program even after an appeal. Only later when *Richard* had hurt his leg and went to the interview with a cane could he become a Wheel Trans client. In another case, an individual with a developmental disability qualified for Wheel Trans only because he had to wear a hearing aid (Personal Communication, October 31, 2006). Both the ODA and the AODA established Accessibility Advisory Committees for transportation. According to Respondent 5, this TTC task force must

include individuals with various disabilities (visually impaired, mobility issues requiring use of a wheelchair). The TTC task force does not however include individuals with developmental disabilities, and hence that perspective is absent.

3. Health care

The accessibility legislation does not include provisions for timely medical care for individuals with disabilities. Four out of five respondents noted that delays in obtaining timely medical treatment could have serious consequences. It was suggested that the failure to recognize medical problems in persons with developmental disabilities is in part to blame (Personal Communication, October 31, 2006). For example, a person may take several hours to use the toilet. Medical doctors may attribute this to bad behaviour, when in fact medication prescribed for high cholesterol may cause constipation in some individuals. This sort of false attribution (bad behaviour), rather than recognition of an underlying medical problem (constipation) has a lot to do with a general lack of medical understanding of the health complexities faced by people with developmental disabilities. Respondent 3 worries that medical doctors generally receive very little training around treating and caring for individuals with developmental disabilities. While Canadian medical schools have improved their curriculum and have included seminars on developmental disabilities, medical doctors are still not adequately prepared to treat individuals with developmental disabilities in a holistic way.

In addition, two out of the five respondents mentioned that because of the shortage of family doctors, some will refuse to take on clients with developmental disabilities. As for designated specialists such as audiologists in Toronto, there is a 6 to 12 month waiting list. Respondent 2 added that psychiatrists are even more difficult to access. Psychiatrists may be hesitant to take on persons with developmental disabilities who require longer consultations and

who may also be more difficult to treat than clients without disabilities. Respondent 4 gave an example where a medical doctor, while accepting of clients with developmental disabilities, arranges to see his clients with developmental disabilities early in the morning or late in the evening because he is uncomfortable with some of the behaviours that might be witnessed by his non-disabled clients. This scheduling can be very restrictive for some individuals who rely on public transportation or escort services provided by community agencies.

Discussion

“The Government of Canada has recognized that the legitimacy of public institutions, the quality of public policy, and the responsiveness of public services will require new and better mechanisms for engaging citizens and civil society in governance...A challenge of all governments is to ...find innovative ways to put citizens at the centre of the governing process, to engage youth in public enterprise, and to give voice to those who find themselves on the margins (R. Hon. Jean Chrétien, June 2000).” It is suggested here that putting citizens at the centre of the governing process also includes giving voice to people with developmental disabilities who often find themselves on the margins despite well-meaning policies. This thesis argues that basic to enabling civic participation, are public policies to enable independent living.

Because policies are increasingly constructed after consultation with stakeholders, they should also be deconstructed in the same fashion. Interviews were thus instrumental in the method of policy analysis that this thesis employs.

Looking back on the methods of analysis, this study would have benefited from a participation-based research design. Participation-based methods which demand the involvement of persons with disabilities in every stage of the research process are consistent with the socio-political model of disability. In *Exploring theories and expanding methodologies: Where we are and where we need to go* (Barnartt & Altman, 2001), the authors suggest using a participation-based methodology to avoid misrepresenting the lives and experiences of persons with disabilities. For this work, consultations with individuals with developmental disabilities regarding possible gaps in policy and program delivery would have been challenging for a number of reasons. First, there is the difficulty of communicating interview questions with individuals with varying levels of intellectual abilities. Second, given time and resource

constraints, questions could not be reviewed by speech and language pathologists and then pre-tested for validity and reliability with individuals with varying levels of mental ability. Finally, the consent process would have delayed the research since it would have been necessary to obtain the consent of subjects as well as their guardians.

The quality of the analysis could also have been improved through a larger sample of respondents. Nonetheless, key barriers to independent living were identified to include access to health services, transportation and appropriate housing. While it can be argued that many Canadians need health services, transportation and affordable housing, the problem here is that people with developmental disabilities experience double, perhaps triple jeopardies (e.g., issues such as race and gender have not even been addressed in this study), making these issues all the more challenging.

The data point to the following main conclusions.

- 1) The ODSP does not enable independent living because the maximum allowable benefit of \$964 per month which includes shelter allowance seriously underestimates the real costs of living, particularly in Toronto. Individuals, regardless of their disability type, who live independently, can do so only because they have access to an independent trust fund. This however disqualifies them for public programs and income supports.
- 2) The ODA facilitates civic participation for people with disabilities. Making public transportation as well as public schools and universities physically accessible has also positively affected their everyday lives. A serious oversight is that Wheel-Trans service is not accessible to people who do not have obvious mobility limitations. The lack of public transportation is one of the largest barriers to independent living for individuals with developmental disabilities.
- 3) The removal of barriers in private and public places will benefit all individuals with disabilities regardless of disability type and the AODA has set 2025 as the deadline to achieve these goals. It remains to be seen whether the barriers identified by the Accessibility Council will address the needs of individuals with developmental disabilities. As outlined above, since developmental disabilities are “invisible,” the barriers which affect their day-to day lives are not remedied by installing ramps or automatic doors. Rather, policies that provide Wheel Trans services or encourage simplified information pamphlets, signs and alternate modes of communication would

greatly enhance accessibility and civic participation. Such changes would facilitate the choice to live independently for individuals with developmental disabilities.

- 4) Currently, the patchwork of disability policies in Ontario makes it difficult for consumers to make informed choices as to where and how to live. Furthermore, the language of the Acts is not accessible. Although alternate formats of government documents can be made available under the ODA, a request must be made. As well, the process is overly complex. Finally, because the three pieces of legislation assume that the family and or community will be partially responsible for supporting an individual with a disability, the legislation fails to support the general definition of independent living which suggests that individuals, regardless of their disability, should be able to: "Live with dignity in their chosen community; participate in all aspects of their life; and; control and make decisions about their own lives" (Community Living Toronto, website).
- 5) The belief that individuals with developmental disabilities can never be capable of making decisions and are therefore incapable of living independently continues to be held by some policy makers, family members, caregivers and advocates. Whether or not legislation is needed to protect disabled individuals' choices in where and how they should live has been the subject of debate since the beginning of the independent living movement in Canada. While policies are increasingly being created with the consultation of stakeholders, policies continue to promote the role of experts as to what constitutes quality of life for persons with developmental disabilities.
- 6) The policy community for people with developmental disabilities is highly fragmented making any unified policy voice to government decision makers difficult and unlikely. For example, some advocates believe that all persons with developmental disabilities should be deinstitutionalized. In the next 2 years, the Ontario government will close the last three institutions for persons with developmental disabilities (Ferguson, Toronto Star: January 27, 2006, A.16). Others however fear deinstitutionalization especially if a person has only known an institution as home. Changes in living arrangements for persons who have lived all their lives in institutions may do more harm than good (Crawford, Toronto Star: November 17, 2006, C.4). Another area where fragmentation in the disability policy arena has resulted in conflict is in the funding mechanisms for supports and services. Some disability groups ask for intensive state involvement in order to set quality and service standards, while others demand minimal state involvement in the form of direct payments to individuals on the basis of need. It is argued that this individualized or consumer driven funding allows choice among services and providers (community-based, non-profit, for-profit, family, friends, etc.). As a result, governments respond by homogenising disability in policy making.
- 7) Individuals with developmental disabilities require a wider range of family and community supports than other disability types in order to live independently. Respondents argue that with appropriate supports, many individuals with developmental disabilities would be capable of living independently and would wish to do so.

Finally, aside from these seven main conclusions, an unexpected theme emerged around rules and policies concerning confidentiality. Recall that the theme of confidentiality was raised by Respondent 5 (see page 59) in the context of work and employer-employee relationships. As described above, consistent feedback and communication among the employer, placement agency and the individual could have anticipated and avoided problems without breaching confidentiality.

Other areas where confidentiality issues may arise, according to Respondent 1, is in health care. Doctor-patient confidentiality dictates what information community agencies can receive about their clients. The problem is that agencies, case workers and providers may have to work in an information vacuum with serious repercussions. The question is this: Under what conditions can confidentiality policies be construed as barriers to independent living? How can case workers and agencies provide adequate supports without violating confidentiality which respects clients?

The key findings of this thesis are consistent with the findings of Tanya Hyland in her 2001 MA thesis (Carleton University). Hyland conducted a critical analysis of the Ontario Disability Support Program (ODSP) Act and social citizenship rights in Ontario. Even though her work predates the passing of the Ontarians with Disabilities Act (2001) and the Accessibility for Ontarians with Disabilities Act (2005), many of her observations are still relevant today.

Hyland (2001) interviewed 14 individuals with various disabilities, consisting of mostly blind and hearing impaired individuals. Individuals in Hyland's study differ from those with developmental disabilities (the focus of this thesis) because they require more resources and supports to live independently. Nevertheless, Hyland found similar themes in analysing the ODSP act and program delivery. For instance, many of the interview respondents expressed

frustration concerning the lack of information on available ODSP benefits. Another similar finding with regards to the ODSP was the comparison of the cost of living for the individuals interviewed versus the amounts of ODSP income supports received. More than half of Hyland's interview participants were employed at the time of the interviews but all participants agreed that they would not be able to support themselves without ODSP income supports. As the findings presented in this thesis suggest, the health and income supports provided through ODSP are crucial and without them, individuals with disabilities have difficulty supporting themselves while also having to pay for health care costs. As of this year (November 1, 2006), ODSP recipients are allowed to maintain health and dental benefits until employer coverage becomes available. Although Hyland's thesis did not focus on independent living, her work demonstrates the concerns of individuals with disabilities where their desire for independence and not relying on family members for support is essential to their sense of self worth and identity as citizens.

The socio-political model and empowerment

Is the paradigm shifting from institutionalisation and expert professional control advocated by the medical model of disability to one of self determination, empowerment and community involvement as advocated by the socio-political model of disability? The Independent Living movement which stresses consumer control and active community participation to ensure rights and citizenship appears to be one step toward such a paradigm shift (DeJong, 1993; Hutchison et al., 2001). At the same time, as pointed out later in the discussion, the demands for individualized care by independent living advocates are strikingly similar to neoliberal policies of fiscal restraint which have moved the delivery of health and social services to the community and voluntary sector to cut costs in the name of better responsiveness to individual needs.

The literature suggests that the Independent Living movement has had a positive impact on the disability community. The demands of the movement are simple: services to improve the capacity of the disabled individual to gain independence and function with dignity in the community. Individuals with developmental disabilities can successfully live independently with appropriate supports.

For example, Stancliffe (1999; 2001) found that people who had choice in living and caring arrangements demonstrated high physical and mental well-being. He noted that smaller more individualized living arrangements are linked to greater choice and self-determination among persons with developmental disabilities. Stancliffe and Keane (2000) reviewed other positive outcomes that have been linked with independent living, including improvements in quality of life, self-determination, autonomy and self-esteem. They also noted that when loneliness, personal safety, money management and health issues arose, it was because of insufficient supports and/or inappropriate housing (e.g., housing located in more rural or isolated areas). Nevertheless, when supports were appropriate and based on the individual's care needs, the transition to independent living was successful. The independent living movement recognises the spectrum of disabilities that exists and hence the varying needs of individuals with disabilities. Because the movement focuses on individual needs, the ideology of independent living is consistent with the current individual-needs based directions of Ontario and Canada's overall health care system.

State support of independent living makes good fiscal sense. Research has linked increased choice and self-determination among persons with developmental disabilities who live semi-independently (living with part-time support) to positive outcomes in the health of persons with disabilities (Stancliffe, 1999; 2001). Improving the health and mental well-being of

individuals with disabilities can reduce costs related to long-term care and in so doing, play a role in sustaining the broader health care system. The improved health status of persons with disabilities will reduce future health care expenditures in caring for individuals with disabilities as they age. Increases in self-esteem and reported quality of life for persons with disabilities who live independently will also result in a reduction in the incidences of mental illness reported among persons with disabilities and will also reduce the life-long costs involved in caring for individuals suffering from mental illness.

Government support of independent living can be a fiscally responsible means of continuing to provide social services for individuals with disabilities while also sustaining Medicare. Supporting independent living does not mean that there should be fewer resources for community agencies. Note that Hall and Reed (1981) argued that state supports work hand in hand with community and voluntary agencies supports. In fact, there is increasing evidence that cutting back on state funding to community agencies that reduces the capacity of the community sector to support at risk individuals (e.g., seniors) at home in the community increases the burden on the formal health system. The irony is that individuals will end up requiring higher cost services in hospitals or institutional facilities (Lum et al, 2005; Hollander & Tessaro, 2001). Furthermore, not all individuals with disabilities desire independence or have the capacity to live independently. There will still be a demand for community agency services and supports by individuals with critical needs who are not likely candidates for independent living even with supports. State support of independent living will make certain that resources are not exhausted in areas where individuals have both the desire and the capacity for independence and the overall allocation of community resources will be made more efficient by providing supports only where they are needed.

Stancliffe and Keane (2000) found that per-person expenditures (in Australia) were substantially lower in semi-independent living settings* compared to group home and institution settings. The mean annual service cost of a person living in a group home was \$64 105 (SD=\$33 301; range= \$21 488- \$123 251). Comparatively, the mean annual service cost of a person living semi-independently was \$14, 602 (SD=8,531; range= \$5 268- \$44 371), resulting in an annual savings of \$49 503. The authors argue that because supports for semi-independent living are calculated and assessed according to an individual's needs, supports are provided at a lower cost than the whole range of supports which are automatically provided (regardless of need) to all individuals living in group homes. Moreover, the authors posit that some residents of group homes and institutions may not need the high levels of support they receive and can achieve similar, and in some cases improved outcomes, by living semi-independently with part time supports.

The above example which compares the costs of maintaining individuals in group homes and the costs of supporting them in live semi-independent living suggests that independent living is cost effective. Moreover it is effective in increasing self-determination and empowerment, both of which, it is suggested, have lasting positive effects by increasing individuals' overall health. Together, the benefits of costs savings by providing choice in living arrangements that facilitate independent living and the potential benefits of costs savings to the health care system form the basis of an argument for government support of independent living.

If the state aspires to cut costs by providing community/independent living services based on individual support needs, considerable restructuring of existing funding and services is required. Independent living advocates demand individualized funding, claiming that current

* Caveat: these conclusions may not apply to individuals who have high/24 h support needs.

methods of funding limit self determination and direction by the individuals and families (Roeher Institute, 1991). Currently, there is no research that examines individual control of funding and its influence on choice and self-determination in major aspects of life- residence, living companions and employment (Stancliffe, 2000).

Lord and Hutchison (2003) assert the importance of individualized funding (IF) as a means of empowering individuals with choice, as opposed to the current funding arrangements which involves government funding for agencies that plan and deliver programs and services. The authors acknowledge that IF is a relatively new concept that has garnered some criticism (Maglajlic *et al.*, 2000) and the jury is still out on whether IF experiments in fact build the “capacity of individuals, families, and communities” (Lord & Hutchison, 2003, p.71). IF is considered to be integral to empowering individuals with learning difficulties and or physical disabilities (Laing, 1991; O’Brien, 2001; Stainton, 2000; as cited in Lord & Hutchison, 2003, p.72). As reviewed in the section on Ontario’s disability policies, the province has already initiated an individualized funding based program for persons with developmental disabilities, namely, Passports. Individuals or their families can apply for direct funding for various day programs for respite or personal growth and development, such as taking golf lessons.

It is necessary to insert a cautionary note here. The demands for independent living, when focused on individualized funding (IF) as the key or sole tool for facilitating individual management of care needs can parallel governments’ push toward downloading or offloading responsibilities to the individuals and communities. Under the guise of catering to individual needs, individualized funding (IF) may be a mechanism for cutting costs (Mowat, 1997). In fact, *individualized funding (IF) for individuals with disabilities except for those with mental health*

issues has been implemented in Alberta since the mid-1980s. There are some telling lessons from this experience.

Alberta's community support services have become increasingly privatised because the province has failed to establish the infrastructure necessary to support service delivery and service providers. Lord and Hutchison (2003) report that community resources slowly became privatised because the Alberta government allowed individuals to hire their own service brokers (p.79). They add that Alberta's experiences with individualized funding could be avoided if infrastructure is put into place.

Frameworks based on self-determination, community, and individualized approaches must stress capacity building as the goal, rather than service reform. In the projects we studied, this has meant strengthening choice and control of consumers, developing social networks with individuals and families, and expanding community connections. A framework must also provide a direct funding mechanism and infrastructure support for individuals, such as facilitators and brokers (Dowson & Salisbury, 2000; Pedlar *et al.*, 1999; Ontario Round Table on Individualised Funding, 2000).

Individualized funding (IF) may not necessarily lead to the marketisation of community services; however, there are important consequences that need to be considered if other Canadian provinces choose to follow in Alberta's footsteps.

Respondents 1 and 2 acknowledged that the Ontario government is heading toward individualized funding for individuals with disabilities to access programs and purchase supports according to their own needs. By allowing the laws of supply and demand to dictate the operations of the community sector, the Ontario government will be ignoring the philanthropic philosophy that has guided the voluntary sector in Canada since the 1900's when the Victorian Order of Nurses began working in the community. Under this new "IF" framework, community

agencies or “service brokers”, as they will be referred to, will be forced to operate under a business model. Community agencies will have to attach a cost to each service they provide, and the services offered will no longer be based solely on need but on an individual’s ability to pay (NUPGE, 2001). In order to stay competitive, service brokers will have to reduce front-line workers’ salaries, which could result in an overall shortage of workers willing and able to work in the disability sector. Moreover, there will be little incentive to develop specialised services and programs that meet the increasing demands for independence among persons with disabilities through IF. In fact, the marketisation of community services will result in an overall decrease in the “basket of services” and availability of programs and supports. Only services “in demand” and needed by the majority, can be sustained and offered, while services and programs not “in demand” but needed by a minority, will be cancelled. The laws of supply and demand may adversely affect persons with developmental disabilities who have needs that are far different from the majority of individuals with disabilities.

Like Medicare, “social services for individuals with disabilities are an implicit social contract between [the state] and its citizens” (Drache, 2004). With continued growth of the individualized funding model in the voluntary sector, the state will slowly back away from its collective responsibility toward Ontarians, and the philanthropic, not-for profit, voluntary sector will necessarily give into the market model of operation (NUPGE, 1998, p.6).

In sum, the conclusions reached through the analysis here suggest that while Ontario’s disability policies- The Ontario Disability Support Program Act, the Ontarians with Disabilities Act and the Accessibility for Ontarians with Disabilities Act reflect a broader definition and understanding of disability, there is still a lack of appreciation for accessibility needs that extend beyond automatic doors, handrails and ramps. Currently, accessibility standards are directed

primarily toward the removal of physical barriers. The development of such standards may be a consequence of the vocal lobbying efforts of individuals with physical disabilities. The failure of policy makers to recognise sufficiently other kinds of barriers may be in large part result from the fragmented voices of individuals with developmental disabilities and their carers.

Furthermore, while there is much in the IL movement that has pushed the developmental disability agenda forward, demands for individualized funding may be misguided. There appears to be little understanding about the implications of individualized funding for the community service sector and the availability of a full range of supports. There is also little understanding among the disability community of the possible collusion between neo-liberal cost cutting goals and demands for independent living.

As well, while individuals with all kinds of disabilities face discrimination, there remain attitudinal barriers which stigmatise individuals with developmental disabilities specifically. Individuals with developmental disabilities are still treated as children who will never be capable of making their own decisions, despite research to the contrary. Research suggests that individuals with developmental disabilities are capable of making their own decisions and able to live on their own with varying levels of supports (Stancliffe, 1999; Neumayer & Bleasdale, 1996; Jenkinson, 1993; Jenkinson et al., 1992). As respondents 2 and 3 reported, it may just be that they have problems with budgeting, but are fully capable of dressing themselves, holding down a job, and maintaining friendships.

Finally there is no direct mention of independent living in the legislation. In fact there is no mention of independent living in any of the Canadian provinces' disability policies. Recall that the *Ontario Human Rights Code*²⁵ strives to "recognize the dignity and worth of every person and to provide for equal rights and opportunities" creating "a climate of understanding

²⁵ R.S.O. 1990, c.H.19, Preamble

and mutual respect for the dignity and worth of each person so that each person feels a part of the community and able to contribute fully to the development and well-being of the community and the Province”. People with developmental disabilities argue that “dignity and worth” should include the choice to be supported in independent living.

Contributions and Recommendations for Future Research

This thesis is the first step in a methodological approach to analysing Ontario's disability policies. The five key informant interviews conducted in this study form the foundation for future research in the area as it identifies key criteria for independent living that can be fine tuned for future impact evaluation studies. This thesis also raised the issue of invisible disabilities and the need for a broader definition of barriers to accessibility.

Future research in this area should strive to include all 32 developmental service agencies located in the greater Toronto area in order correct biases and to get a more complete picture of the supports and services that facilitate independent living. Focus groups, case studies and participation-based methods should also be used in order to deepen the analysis. Using the Australian methodology (Stancliffe & Keane, 2000) quantitative studies should do a cost comparison of group homes in Canada for persons with disabilities compared to individuals living independently.

Further analysis of the successes and failures of the removal of barriers to make Ontario accessible for individuals with disabilities will be possible once the Accessibility for Ontarians with Disabilities Act (AODA) achieves its mandate in 2025. Impact analyses and consultation with stakeholders regarding recent (November 1, 2006) changes to the Ontario Disability Support Program should also be conducted.

There is a lack of input from the Canadian disability community concerning the potential impact of individualized funding on the supports and services available for persons with disabilities. While it may be too early to draw any conclusions, future work should focus on evaluating the implications of the government move toward an individualized funding model on community services in Ontario.

Finally, any changes to existing policies or the creation of new policies should emphasize an all-encompassing definition of accessibility that corresponds directly to the variability inherent in disability so that disability may be seen as “an extension of the natural, physical, social and cultural variability of the human species” (Scotch & Schriner, 1997).

Appendix A



To: Jessica Chicoine
Politics and Public Administration
Re: REB 2006-123: Independent Living? An Evaluation of Ontario's Disability Policies
Date: September 28, 2006

Dear Jessica Chicoine,

The review of your protocol REB File REB 2006-123 is now complete. The project has been approved for a one year period. Please note that before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required.


This approval may be extended after one year upon request. Please be advised that if the project is not renewed, approval will expire and no more research involving humans may take place. If this is a funded project, access to research funds may also be affected.

Please note that REB approval policies require that you adhere strictly to the protocol as last reviewed by the REB and that any modifications must be approved by the Board before they can be implemented. Adverse or unexpected events must be reported to the REB as soon as possible with an indication from the Principal Investigator as to how, in the view of the Principal Investigator, these events affect the continuation of the protocol.

Finally, if research subjects are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research.

Please quote your REB file number (REB 2006-123) on future correspondence.

Congratulations and best of luck in conducting your research.


Nancy Walton, Ph.D.
Chair, Research Ethics Board

Appendix B

Telephone Recruitment Script

To be contacted by telephone:

Executive Director of the agency or Administrative Assistant.

Introduction:

“Good morning my name is Jessica Chicoine. I’m a graduate student at Ryerson University currently conducting research for my master’s thesis. My project is being supervised by Dr. Janet Lum, who teaches in the Department of Politics and Public Administration at Ryerson University. I am interested in community agencies who serve the disabled community here in Toronto and surrounding areas. May I take a moment of your time to provide you with some further information concerning my study?”

If yes, proceed with the research summary.

If no, ask if there is a better time for you to call.

Summary of Research:

My thesis will explore the impact of Ontario’s current disability policies, the Ontario Disability Supports Program (ODSP, 1997), the Ontarians with Disabilities Act (ODA, 2001), and the Accessibility for Ontarians with Disabilities Act (AODA, 2005) on individuals with developmental disabilities. In particular I hope to focus on evaluating the legislation and the services it provides in supporting young adults who choose to live independently.

I will be interviewing 5 executive directors drawn from multi service community agencies involved in policy development and service provision in the area of disability.

And finally, the project’s core objectives are to evaluate Ontario’s disability policies with regards to:

- The issues that individuals with disabilities face on a day to day basis.
- The role of community care in supporting people with different disabilities.
- The role of government and/or supports in supporting young adults in their choice to live independently.

The questions in this interview will take approximately 45 minutes to answer. For your information, a lot of the information I am interested in, is already included in your agency’s annual report, would it be possible for me to have a copy? An example of a question I might ask, for example would be:

What would you identify as the most fundamental changes to have occurred in the policy and service fields relating to disability since the implementation of the Ontario Disability Supports Program?

Or

In your work experience have you noted differences in accessibility that may depend on disability type?

Interest in participating:

I will be beginning interviews in early October. Would your organization be interested in participating? *If yes, book a time for interview stating that you will confirm by email, which will provide them with further information about the study.*
If no, thank them for their time.

Appendix C

RYERSON UNIVERSITY CONSENT AGREEMENT

This interview constitutes part of a research project evaluating the services and supports provided for individuals with developmental disabilities in the province of Ontario. The study is being carried out by Jessica Chicoine, B.Sc. under the direction of Dr. Janet Lum (Politics and Public Administration, Ryerson University), in partial fulfillment of the thesis requirements for the M.A. Public Policy and Administration program at Ryerson University. The project runs from August 2006 to December 2006 and is entitled *Independent Living? An Evaluation of Ontario's Disability Policies*.

Purpose of the study: The study explores the impact of Ontario's current disability policies, the Ontario Disability Supports Program (ODSP, 1997), the Ontarians with Disabilities Act (AODA, 2001), and the Accessibility for Ontarians with Disabilities Act (AODA, 2005) on individuals with developmental disabilities. In particular this study evaluates the services provided through such legislation in supporting young adults who choose to live independently.

Project Description: We will be interviewing a cross-section of people drawn from community service agencies involved in policy development and service provision in the area of developmental disabilities. The project's core objectives are to evaluate Ontario's disability policies with regards to:

- The issues that individuals with disabilities face on a day to day basis.
- The role of community care in supporting people with different disabilities.
- The role of government and/or supports in supporting young adults in their choice to live independently.

The questions in this interview will take approximately 45 minutes to answer. Some of the questions that you might be asked include: What would you identify as the most fundamental changes to have occurred in the policy and service fields relating to disability since the implementation of the Ontario Disability Supports Program? And what role has your organization played in shaping services for individuals with developmental disabilities in the greater Toronto area?

What is Experimental in this Study: The same questions will be asked to all respondents. The only experimental aspect of this study is to gather information for the purpose of analysis.

Risks or Discomforts: Participation in this research is of minimum risk for the interview participants as well as their organizations. Participating agencies may fear legal repercussions by inadvertently discussing clients and breaching their own separate confidentiality agreements. They also may fear losing funding as a result of criticizing the legislation during the interview process. If some questions make you feel uncomfortable, please stop me. Please remember, you can stop the interview at any time, and for any reason. If you think that the information is too personal you may refuse to answer that question or end the interview. If this happens, the material will be destroyed at your request.

Benefits of the Study: The present study may benefit young adults living with disabilities by identifying certain gaps in services which fall under the current disability legislation, that may hinder an individual's ability to live independently, enlightening future policies. In any study, benefit can never be guaranteed.

Confidentiality: Your participation in this study is strictly confidential. The interview, and tapes/notes/transcripts derived from it, will be used for research purposes only. Findings will be published in report, article, or book form, or presented at public meetings (such as the Canadian Political Science Annual Meeting, or the International Political Science Association Meeting). However, the identities of respondents will not be disclosed or revealed in any way. Interview tapes/notes/transcripts will be retained in a secure place and destroyed once the thesis is completed.

Costs and/or Compensation for Participation: There will be no costs incurred to yourself or your organization for participating in this study.

Incentives to Participate: You will not be paid to participate in this study. However, you will have the opportunity to have access to the general results of the study when available.

Voluntary Nature of Participation: Your participation is strictly voluntary and you may end the interview at any time or refuse to answer particular questions. You may also choose not to have the interview audio-taped. You will be asked again at the end of the interview whether or not you still consent to these terms of consent. Your participation will not have any effect on your future relationship with Ryerson University, agency clients or your funding arrangements with other institutions.

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

Jessica Chicoine, B.Sc., M.A. (Candidate)
Email: _____
Telephone: _____

Janet Lum, PhD
Email: jlum@ryerson.ca
Telephone: (416) 979-5000, x 7045

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

Research Ethics Board
C/o Office of the Associate Vice President, Academic
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

By signing this consent agreement you are not giving up any of your legal rights.

I agree to be audio-taped for this interview for the purpose of assisting in note taking.

Name of Participant (please print)

Signature of Participant

Date

Signature of Researcher

Date

Signature of Witness (if applicable)

Date

I do not wish to be audio-taped for this interview but agree to continue with the interview with note-taking.

Name of Participant (please print)

Signature of Participant

Date

Signature of Researcher

Date

Signature of Witness (if applicable)

Date

Appendix D

Interview Questionnaire

Remind participant of the goals of the study:

The study explores the impact of Ontario's current disability policies, the Ontario Disability Supports Program (ODSP, 1997), the Ontarians with Disabilities Act (AODA, 2001), and the Accessibility for Ontarians with Disabilities Act (AODA, 2005) on individuals with a developmental disability. In particular this study evaluates the services provided through such legislation in supporting young adults who choose to live independently.

The project's core objectives are to evaluate Ontario's disability policies with regards to:

- The issues that individuals with disabilities face on a day to day basis.
- The role of community care in supporting people with different disabilities.
- The role of government and/or supports in supporting young adults in their choice to live independently.

Part A: Disability legislation and supports

- 1) What would you identify as the most fundamental changes to have occurred in the policy and service fields relating to disability since the implementation of the Ontario Disability Supports Program?
 - a. Since the Ontarians with Disabilities Act (2001) was passed?
 - b. Since the Accessibility for Ontarians with Disabilities Act (2005) was passed?
- 2) What supports are available to young people with disabilities?
- 3) Which services fall through the legislative cracks?

Part B: Independent Living

The current definition of independent living suggests that individuals should have the right to live with dignity in their chosen community, participate in all aspects of their life; and control and make decisions about their own lives. Given this definition,

- 4) How are individuals with disabilities supporting themselves?
- 5) Do you think there are any barriers to independent living as a result of current provincial legislation? If yes, please provide some examples.

Part C: Access to Services

It is perceived that individuals with certain kinds of disabilities have an easier time gaining access to services.

- 6) In your work experience have you noted differences in accessibility that may depend on disability type?

Historically speaking, individuals with more obvious, identifiable disabilities have been well cared for in our health system, for example individuals who require a wheelchair for mobility. On the other hand, individuals with cognitive disabilities, such as dementia in young people have had difficulty receiving treatment and in the past the solution was institutionalization.

- 6) Do you think individuals with cognitive disabilities have more difficulty accessing services?

Nowadays cognitive disabilities are widely recognized as valid disabilities. For instance, the Ontarians with Disabilities Act's (2001) definition of disability includes this category of disability which is composed of disabilities like dementia, severe depression and intellectual disabilities. There still are certain conditions however, which remain to be recognized as disabilities and there appears to be a negative stigma attached to them.

Provide examples as needed

- 7) Do you think the socially contested nature of some of these disabilities affect an individual's access to supports?

Part D: Concluding Remarks:

- 8) Would you like to raise any other issues that have not emerged from the questions of this interview?
- 9) Are there any questions that you would have liked to have been asked?
- 10) Do you still consent to the terms outlined in the letter of consent?

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