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COMMISSION DU DROIT DE L'ONTARIO

**Enforcing the Rights of People with Disabilities in
Ontario's Developmental Services System**

FINAL RESEARCH PAPER

**Prepared for the Law Commission of Ontario's
The Law as it Affects Persons with Disabilities**

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I. INTRODUCTION

In 2008 Ontario passed new legislation, entitled the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (“*Social Inclusion Act*”). The *Social Inclusion Act* is intended to shift Ontario’s developmental services sector away from institutionalized care and towards a system of services and supports that will enable people with intellectual disabilities to exercise more independence, have greater decision-making power over their day-to-day lives, and ultimately live as full citizens in communities of their choosing. The Act is coming into effect in various stages, from July 1, 2010 until July 1, 2011, when it will replace the 36-year old *Developmental Services Act*.

This report discusses the impact that the *Social Inclusion Act* will have on people with intellectual disabilities who receive publicly-funded services and supports from the government of Ontario. The report asserts that there are significant limitations to the new legislation that will prevent it from achieving its much-needed goal of transforming Ontario’s developmental services sector. Two of these limitations are: the absence in the legislation of rights for people with intellectual disabilities when they receive developmental services and supports; and the lack of robust mechanisms to enforce such rights. In this context, the rights referred to are those that relate to the day-to-day lives of people with intellectual disabilities and the specific developmental services and supports they receive. Throughout this report we refer to these rights as “service rights” to denote this meaning and to distinguish them from the fundamental rights,

freedoms and protections provided for in the *Canadian Charter of Rights and Freedoms*, federal, provincial and territorial human rights codes, and other legislation.

Employing a rights-based approach, this report explores the kinds of enforcement mechanisms that are needed in Ontario's developmental services sector in order to ensure that people with intellectual disabilities are treated with respect and dignity, have more choice and control over the services they receive, and are supported to live as equal citizens in society.

The report begins with a very brief history of the various approaches that Ontario has taken to the provision of services and supports to people with intellectual disabilities, including the approach that is taken in the *Social Inclusion Act*. A description of some of the significant challenges facing people with intellectual disabilities follows. The next section of the report develops and describes a human rights-based approach to enforcement mechanisms in the developmental services sector. Section IV outlines enforcement mechanisms used in developmental services systems in selected jurisdictions outside of Ontario. The report concludes by proposing four key initiatives that should be implemented to enforce the rights of people with intellectual disabilities in Ontario's developmental services system.

A. About ARCH Disability Law Centre

ARCH Disability Law Centre ("ARCH") is a specialty community legal clinic dedicated to advancing the equality rights of people with disabilities. ARCH

provides legal services to help Ontarians with disabilities live with dignity and participate fully in our communities. ARCH provides free and confidential legal advice and information to people with disabilities in Ontario. We provide legal representation to people with disabilities whose cases fall within our priority areas of work and who meet Legal Aid Ontario's financial eligibility guidelines. We work with Ontarians with disabilities and the disability community on community development, law reform and policy initiatives. We also provide public legal education to people with disabilities and continuing legal education to the legal community.

ARCH has extensive experience working with people who have intellectual disabilities. This experience is broad and is based on our contacts with people with disabilities themselves, their families and support people, advocates and community organizations. ARCH regularly hears concerns about the delivery of supports and services to people with intellectual disabilities, and we provide legal information and advice on these issues. ARCH has represented clients in litigation dealing with developmental services issues. We have engaged in discussions of these issues with consumer and advocacy groups, and have conducted legal and non-legal research on supports and services for people with intellectual disabilities.

ARCH has been actively engaged in law reform initiatives related to the *Social Inclusion Act*. In 2008, we made written and oral submissions to the Standing Committee on Social Policy regarding Bill 77, the predecessor to the *Social Inclusion Act*. More recently, we made written submissions to the Ministry

of Community and Social Services regarding draft regulations under the *Social Inclusion Act*, and met with the Ministry regarding specific issues related to services for people with intellectual disabilities.

B. Terminology

This paper uses the term ‘developmental services’ or ‘developmental service systems’ to refer to government-funded services and supports provided to people with disabilities. The terms ‘people with disabilities’, ‘people with intellectual disabilities’, or ‘people who have been labeled with an intellectual disability’ are used when referring to people with disabilities who are recipients of these services. We note that there are various views regarding the most appropriate language and we defer to members of the community and people with disabilities themselves regarding appropriate terminology.

C. Methodology

The methodology for this report was comprised of two phases: (1) a literature review; and (2) consultations with stakeholders.

1. Literature Review

We conducted a review of the literature on human rights-based approaches and the literature on enforcement mechanisms used in developmental services systems outside of Ontario. We examined the following:

- Academic articles;

- Government reports;
- National and international legislation;
- Policies and procedures; and,
- Web-based materials.

The literature on human rights-based approaches, and international and national legislation were analyzed and used to develop principles of a human rights-based approach to enforcement.

The literature on enforcement mechanisms outside of Ontario was synthesized and used to analyze the various approaches to enforcement in the context of developmental services. We examined four Canadian provinces: Alberta, British Columbia, New Brunswick and Quebec. Outside of Canada we examined the Australian province of Victoria, the United Kingdom, California and Texas. We chose these jurisdictions because they speak and write in English, allowing us to access available literature; they vary in size, both in terms of population and geography; and they have interesting or noteworthy approaches to enforcement or the delivery of developmental services. The purpose of this analysis was to gain insight into the laws and practices in jurisdictions beyond Ontario, and use this insight to inform the enforcement mechanisms we propose for Ontario. Due to the time constraints of the project, our analysis was not exhaustive. It is fair to say that there is likely a gap between what is described in the report and what actually happens in practice in other jurisdictions, as is our experience in Ontario.

2. Consultations with Stakeholders

In the second phase of the research, we consulted with a range of stakeholders to obtain their thoughts on our findings and proposals. The emphasis for our consultations was speaking to people with intellectual disabilities in Ontario, as this is the community who will be impacted by the recommendations in our report. We are also mindful that the voices of people with intellectual disabilities are rarely heard when governments create and enforce developmental services systems. In the report, we use the term ‘stakeholders with disabilities’ to refer to people with intellectual disabilities who receive or are familiar with Ontario’s developmental services system and with whom we consulted.

During consultations with stakeholders with disabilities, we presented our findings and proposals and solicited feedback regarding the specific enforcement mechanisms being considered; the extent to which these mechanisms would address some of the key challenges that people with disabilities face in the developmental services sector; and, the potential for such mechanisms to have a positive impact on the lives of people who receive developmental services.

All of the consultations with people with disabilities were conducted by in-person meetings. We obtained consent from stakeholders for their participation in the consultations and for the use of information gathered at the consultations in this report. Plain language was used during all the consultations, and most of the consultations were facilitated by advisors or facilitators who were known to the group. At several of the consultation meetings, support staff were present to

assist stakeholders. To ensure that stakeholders would not suffer repercussions from discussing their opinions, experiences and concerns, we provided opportunities for them to ask support staff to leave the meetings and we informed them that there was no obligation to participate in the consultations.

We also consulted with developmental service providers, advocates for people with intellectual disabilities, administrators and employees of government enforcement agencies. Some of these stakeholders were located in Ontario and others were located in the jurisdictions we surveyed outside of Ontario. Most of these consultations were conducted by telephone. They were used to gather a practical, “on the ground” understanding of enforcement mechanisms in other jurisdictions; learn about enforcement strategies that worked or failed; and obtain stakeholders’ thoughts on our findings and proposals.

The feedback and information received from stakeholders was invaluable and certainly informed our recommendations in this report. The responses, opinions and information gained from the consultations are reflected throughout the report. A list of those who participated in the consultations can be found in Appendix 1. However, due to the time constraints of the project, we did not consult with nearly as many stakeholders as we would have liked.

II. CONTEXT

Public policies, social programs and the laws that govern them often reflect the dominant approach of the era in which they are developed.¹ The values underlying the *Social Inclusion Act* and its accompanying draft regulations

express a particular perspective on disability issues or models of disability. The same is true for the legislation and policies that preceded the Act. In this section, we provide a brief history of the various approaches to providing services and supports to people with intellectual disabilities that have been employed in Ontario. This historical perspective provides important context for our argument that service rights and mechanisms to enforce those rights must be included in the *Social Inclusion Act* framework. In addition, an historical understanding of the relationship between governments, service providers and people with intellectual disabilities informs the kinds of enforcement mechanisms that we propose later in the report.

A. Brief History of Ontario’s Approach to Providing Services and Supports to People with Intellectual Disabilities

1. The Pre-Institution Era

Prior to the introduction of institutions, there were virtually no government policies, services or supports specifically for people with intellectual disabilities in Ontario. People with intellectual disabilities and their families were viewed as objects of pity or charity. Typically, families were required to care for their child or adult family member at home. If families were unable to provide for all the needs of their loved-ones, communal support networks represented by friends and neighbours offered assistance. Local government councils could also be petitioned for financial aid.² People with intellectual disabilities who were left on their own often ended up in prisons, where conditions were crowded and

unsanitary, and where some people with disabilities were treated worse than convicted criminals.³

Society's treatment of people with intellectual disabilities can be captured by the common terminologies that were used to describe them, including "imbeciles", "idiots", the "feeble-minded" and "morons".⁴ The medical community restricted its examination of people with intellectual disabilities to the "degree of idiocy" suffered by the individual.⁵ This language illustrates that people with intellectual disabilities were considered different than "normal" people, consequently it was acceptable to treat them differently. Such treatment was almost always accompanied by stereotypes about abilities (or lack thereof), and in particular, the assumption that people with disabilities were unable to lead independent lives.⁶

2. Institutionalized Care for People with Intellectual Disabilities

In 1839, Upper Canada passed legislation to formally permit the establishment of provincially funded institutions, entitled *An Act to Authorize the Erection of an Asylum within this Province for the Reception of Insane or Lunatic Persons*.⁷ In 1876, Ontario opened its first large institution, the Ontario Asylum for Idiots, in Orillia.⁸

Initially, the concept of institutions was based on the notion that there was a better way to assist people with intellectual disabilities. Institutions were conceived as boarding houses, where people could go for short periods of time (typically no longer than five years), and be taught skills that would assist them to

integrate back into the community and live independently.⁹ Alternatively, institutions, like large hospitals, were places where people could go to have their disability “fixed”, as promoted by the medical model of disability. The medical model viewed disability as an abnormality or flaw that was located in the individual and sometimes could be treated or cured. Doctors urged parents to place their children in institutions, where they would be with “people like themselves”, who would better understand them, and be happier not having to face the difficulties of living in society. Institutions were paternalistically seen as places that would protect people with intellectual disabilities from the unintended consequences of industrialization, such as poverty, crime, poor working conditions, lack of adequate housing, disease and poor hygienic conditions.¹⁰ It was felt that people with intellectual disabilities would be well cared for and protected. Given the paucity of services and supports available to people with disabilities and their families, publicly-funded institutions were often the only choice.

There were also less humanitarian reasons for the development of institutions. Eugenicists believed that people with intellectual disabilities, among others, contributed to social problems and unrest, and therefore should be isolated and eliminated from the general population. People with intellectual disabilities were blamed for social problems such as poverty, prostitution and the existence of slums. Tragically, many Canadians with intellectual disabilities were subject to forced birth control and sterilization.¹¹ Ontario was not immune from the influence of the eugenics movement. It is likely that forced sterilizations

occurred, and there is evidence that people with intellectual disabilities were often placed in institutions during their child-bearing years, where men and women were segregated from one another.¹² Films produced by people with intellectual disabilities document the devastating effects of the eugenics movement. Not only were people with intellectual disabilities denied the basic human rights and freedoms of bearing children and having sexual relationships, they were also subjected to medical procedures without their knowledge or consent. Many people did not discover that they had been victims of the eugenics movement until decades after their release from institutions.¹³

Conditions in institutions were often appalling. 'Inmates' lived in dormitories with tens or hundreds of others, with no curtains on the windows and no privacy between beds. The doors were locked from the outside, and abuse among the inmates themselves was not uncommon. Typically there were no protections and no involvement from the staff at night.¹⁴ Bathrooms afforded no privacy either; rows of open stalls without walls or doors were common.¹⁵ People with intellectual disabilities were often forced to work without pay. Some 'inmates' even performed the same kinds of jobs that staff members were paid to do, such as work in the kitchen or hospital, or feeding other patients.¹⁶ Documentaries by people with intellectual disabilities have exposed the lack of stimulation, fear of punishment and degrading treatment that characterized institutional life.¹⁷

Sexual, physical and emotional abuse of people with disabilities by staff were rampant in institutions. However, many who suffered abuse did not report it, as there was no way to do so. It is unlikely that abuse would have been reported

even if there had been reporting mechanisms in place. 'Inmates' were extremely reluctant to speak out about the abuse they experienced for fear of punishment or negative repercussions.¹⁸

Institutions were deliberately built away from cities. Living in rural areas was justified as a way to provide fresh air and open spaces that would contribute to the over-all health and well-being of people with disabilities.¹⁹ Today, it is recognized that building institutions far from cities served to segregate people with intellectual disabilities from society. Social isolation made it extremely difficult for 'inmates' to maintain relationships with family or friends, and meant that abuse and control of 'inmates' by institutional staff could not be threatened or exposed. At times parents were told that their son's or daughter's stay in an institution would be temporary, only to discover that their son or daughter could not be released without consent of a psychiatrist.²⁰ Locating institutions in rural areas also made it difficult for 'inmates' to escape. Those who did attempt escape were often caught, returned to the institution, and punished by being stripped of their clothing, soaked in cold water, or placed in a cell without heat or blankets.²¹

Unfortunately, the lack of developmental services and supports outside of institutions often meant that large institutions like the Ontario Asylum for Idiots continued to grow. Although its initial capacity was 150, demand exceeded this number and additional land was purchased to expand the facility. In 1961, Huronia Regional Centre, as the Ontario Asylum was renamed, housed 2,800 people with intellectual disabilities.²² Huronia Regional Centre was not the only

large institution run by the province of Ontario. In the 1970s, at the height of the institutional era, there were approximately 30 large and small institutions for people with intellectual disabilities in Ontario.²³

There were several reasons for continued demand for space in institutions. There was a fear that people with disabilities were living longer lives. The greater the number of people with intellectual disabilities, the greater the threat to society would be, hence they needed to be removed from society and placed in institutions.²⁴ Alternatively, some parents were convinced by the medical community that institutionalizing their son or daughter would be beneficial to the child and the rest of the family. Institutionalizing a child meant that the costs and responsibility of caring for him or her would be transferred to the state instead of being borne by the family. Because an intellectual disability was seen as a medical condition, it made sense to place a person in a specialized facility. Indeed, many of the institutions changed their names from asylums to hospitals to signify this approach, and many were staffed by health care practitioners.²⁵ People with intellectual disabilities were no longer called 'inmates', but were now 'patients', further entrenching the medical model of disability. Typically, living in an institution meant trading control over one's own life and decisions for lifelong "care".

Institutions were eventually exposed as places of extreme cruelty, abuse and inhumane treatment, and consequently began being shut down, with the last large institution in Ontario closing on March 31, 2009. Several factors contributed to the closure of large institutions, including lack of funding, insufficient

demonstration of rehabilitation, recognition that drugs were being overused to control behaviour, gradual social acceptance that people with disabilities were not dangerous or deviant, and the application of values of equality and human rights to disability issues. Public awareness of the extremely poor living conditions within institutions also played a role. Perhaps most significantly, the adoption of community living as a philosophy offered an alternative to institutionalized care. Supporters of community living tirelessly drew attention to the atrocious conditions in institutions, and demonstrated that people with intellectual disabilities could live and participate in the community with appropriate services and supports.²⁶

3. The Developmental Services Act

In 1974 Ontario passed the *Developmental Services Act*. The Act still governs services for people with intellectual disabilities today. Generally, the Ministry of Community and Social Services, the ministry responsible for the *Developmental Services Act*, does not provide any direct services or supports, but rather provides funding, policy direction and oversight to community-based agencies, which in turn provide direct services to people with disabilities and/or their families.²⁷ Regulation 272 pursuant to the Act governs the operation of group homes and other living environments.²⁸

During the era in which the *Developmental Services Act* was introduced, the social model of disability gained support from the community living movement, as well as other equity-seeking groups, such as those who

experienced racism, sexism, and homophobia.²⁹ Unlike the medical model and eugenics movement, the social model does not view disability simply as a deficit or flaw inherent in the individual. The social model focuses attention on the physical and social conditions that erect barriers and prevent people with disabilities from accessing goods, services, rights and entitlements, and the lack of adequate supports to enable people with disabilities to be fully included in society.

The *Developmental Services Act* made some attempts to respond to the social model of disability. For example, the Act provided for public funding of community-based services and supports for people with intellectual disabilities.³⁰ Such services include group homes, individual living arrangements in which people with disabilities received support services, sheltered workshops, day programs and life skills training programs. The funding of community-based services acknowledged that many people with intellectual disabilities can live and participate in their communities with appropriate support. The Act also acknowledged that many people with intellectual disabilities live at home and require supports in that setting.³¹

Despite these attempts, the *Developmental Services Act* fails to realize or acknowledge some of the most important tenets of the community living movement, including full participation, inclusion in society, equality, acceptance and citizenship for people with intellectual disabilities.³² Equally, the Act fails to realize the vision of the People First movement, which is the promotion of equality, and the ability of all people with intellectual disabilities to exercise

autonomy, make life decisions, and self-advocate.³³ Practically, the developmental services provided for under the Act often constrain rather than promote inclusion for people with intellectual disabilities. Many of the funding programs pursuant to the Act include strict eligibility criteria, a cumbersome application process, long wait lists, and inadequate funding. In addition, the Act does not provide for robust enforcement mechanisms that people with disabilities can access if they have complaints or concerns about funding or services. Often, barriers are created due to limited collaboration or co-ordination between the Ministry of Community and Social Services and other government ministries with which people with intellectual disabilities may interact.³⁴

A stark example of the failure of the *Developmental Services Act* to truly enable people with intellectual disabilities to be included in society is the fact that under the Act, large institutions continued to exist and be operated by the province of Ontario. These institutions were funded to provide supervised residential programs as well as day and leisure programs for people who required specialized care. As a result, people with intellectual disabilities continued to be segregated from society and be victims of abuse and degrading treatment. Such institutions were in operation until March 31, 2009, when the last large institution in Ontario was closed.³⁵

4. Deinstitutionalization and the Social Inclusion Act

In 2008, Ontario passed the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*. Until very recently the

government had not set a proclamation date for the Act, and it was unknown when the Act would come into effect. Various proclamation dates have now been set, and the Act is coming into effect in three stages, from July 1, 2010 until July 1, 2011. On July 1, 2011 the Act will replace the 36-year old *Developmental Services Act*.³⁶

The Act marks a shift in the developmental services sector away from institutionalized care and towards a system of services and supports that are intended to enable people with intellectual disabilities to live and participate fully in communities of their choosing. This represents a paradigm shift from professional, controlled services in segregated institutions to services that underpin community participation.³⁷ As part of its strategy to transform the way in which publicly-funded services are delivered to people with intellectual disabilities, the Ministry of Community and Social Services promises that this new legislation will build a modern, fair and sustainable developmental services system that will give people with intellectual disabilities more independence and choice and foster their full inclusion in society.³⁸ Indeed, this objective is reflected in the title of the Act.

The focus of the *Social Inclusion Act* is on the delivery of community-based developmental services and supports and the provision of direct funding to enable people with disabilities and/or their families to purchase and direct services and supports of their choosing. Under the Act people with disabilities will either receive developmental services through community-based agencies, purchase services with direct funding, or utilize a combination of these methods.

The Act sets out a variety of residential settings for people with intellectual disabilities, including group homes in which several people with intellectual disabilities live and receive live-in support from a service provider; host family residences, in which people with disabilities live with a host family who provides support to them; and supported independent living residences, in which people with disabilities live independently with supports as needed.³⁹ The kinds of services and supports that people may receive under the Act include support for activities of daily living, such as making meals, getting dressed, personal hygiene, managing money and using transportation; supports for community participation, such as work, volunteer or social activities; and professional services, such as those of a psychologist, social worker or speech language pathologist.⁴⁰ In addition, people are also eligible to receive person-directed planning, which assists a person to identify a life-plan and the services and supports needed to implement the plan.⁴¹

The Act makes some positive changes to the developmental services sector, such as eliminating the operation of large institutions, providing for direct funding to enable people with disabilities and/or their families to exercise more choice and control over the services they receive, and funding person-directed planning to assist people with disabilities to create life-plans. However, the Act fails to truly transform the developmental services sector, and instead maintains a system of services that reflects elements of both the medical and social models of disability. For example, the Act defines developmental disabilities as, “prescribed significant limitations in cognitive functioning and adaptive functioning

that originated before the person was 18, are likely to be life-long in nature, and affect major areas of life activity.”⁴² In order to be eligible for services or funding under the Act, a person must demonstrate that she or he meets this definition by providing an assessment from a pre-determined list of medical and health care professionals.⁴³ As a result, the medical model continues to dominate the legal definition of intellectual disability, and the power to determine who is eligible to receive services or funding remains in the hands of medical professionals.

Another troubling example is the manner in which the Act treats the basic principle that each person is entitled to make his or her own life decisions. Several provisions of one of the draft regulations pursuant to the Act permit service providers to share information about an individual’s service plan, any allegations of abuse, or plans concerning restraints with the individual themselves or a person acting on the individual’s behalf.⁴⁴ The service provider does not need permission from the person with the disability before sharing this information with a third party, and consequently, these provisions may remove some autonomy and decision-making power from people who receive developmental services. Underlying these provisions are the discriminatory assumptions that all people with intellectual disabilities cannot understand information on their own; that they are not able to recognize when they may need assistance or support; and that others may be in a better position to determine what is in their best interests.

Perhaps most troubling is the fact that the Act fails to include any rights whatsoever for people with disabilities when they receive developmental services and supports. A system that truly supports the full participation, dignity and

citizenship of people with intellectual disabilities must enshrine substantive rights in legislation. The provision of rights, as well as mechanisms to enforce those rights, would enable people with disabilities to become active consumers of services that are accountable to them, rather than remaining passive recipients of care. The inclusion of rights in the *Social Inclusion Act* framework is necessary for true transformation of the developmental services sector.

B. Enforcement Mechanisms under the *Social Inclusion Act*

Incorporating rights for people with intellectual disabilities in the *Social Inclusion Act* framework is one means of ensuring that services are appropriate and spending is accountable. However, rather than utilizing this approach, the *Social Inclusion Act* and accompanying regulations establish minimum standards with which service providers and community agencies that administer funding or process applications must comply to ensure quality assurance.⁴⁵ Enforcement of these minimum standards occurs predominantly via government oversight, through mandatory reporting requirements, inspections, orders and government take-overs of agencies.

The minimum standards with which agencies must comply will be determined by a regulation on quality assurance measures, and possibly by other regulations and policy directives.⁴⁶ To date, the government of Ontario has not yet passed this regulation, but has released a *Draft Regulation on Quality Assurance Measures* (“*Draft Regulation*”). The *Draft Regulation* stipulates that every service agency must address the promotion of social inclusion, individual

choice and independence; the development of individual support plans; management of and assistance with finances; health promotion; abuse prevention and reporting; confidentiality and privacy; and a variety of safety issues.⁴⁷ Service providers must create policies and procedures to address most of these items and in some cases must review these policies and procedures with people who receive services.⁴⁸

Service providers are required to report to the Minister of Community and Social Services when requested to do so, or when required to do so by regulation.⁴⁹ To date, neither of the draft regulations that the government has released stipulate reporting requirements.

Directors appointed by the Minister of Community and Social Services may appoint inspectors who may carry out inspections to determine whether a service agency, application entity or funding entity is complying with the minimum standards set out in the Act, regulations and policy directives.⁵⁰ Inspectors may require the production of relevant documents, question any person present regarding the inspection, and examine the condition of the premises and its equipment. Inspectors may be accompanied by experts to assist in the conduct of the inspection.⁵¹

Directors may order service providers and community agencies that administer funding or process applications to comply with the Act, regulations and policy directives. Orders may require agencies either to do or refrain from doing anything to achieve compliance, or to submit and implement a plan for achieving compliance within a specified period of time. Prior to issuing an order,

the Director must give the agency notice, and the agency has the right to make submissions to the Director regarding the proposed order. Failure to comply with an order triggers possible termination of a funding agreement or revocation of an agency's designated power to administer funds or process applications.⁵²

Upon notice to an agency, the Minister may appoint a person to take over and manage the affairs of the agency with respect to services and supports for people with intellectual disabilities. Grounds for such a take-over include misappropriation of funding, gross negligence in the management of funding, or providing services in a manner that constitutes an immediate threat to the health, safety or well-being of people with intellectual disabilities. Service providers that receive notice of the appointment of a manager are entitled to request a review of this order.⁵³ Managers have all the powers of the agency's board of directors, and may immediately occupy and operate the agency. Without the consent of the agency, managers cannot occupy or operate agencies for more than two years.⁵⁴

Section 26 of the Act requires service agencies to have written procedures for initiating complaints to the agency and for how the agency will deal with such complaints. Section 26 also requires service agencies to ensure that these written procedures comply with the regulations. Section 38(p) of the Act provides that the Lieutenant Governor in Council may make regulations governing practices and procedures relating to complaints processes, however as of the date of this paper, no such regulations have been released.

Although the *Social Inclusion Act* is not yet in effect, many Ontario service providers have complaints procedures already in place. Often, people who wish

to make complaints will be encouraged to raise their concern with the individual support person against whom the complaint lies. If this does not resolve the issue, the person may make the complaint to the worker's manager or supervisor. If the complaint remains unresolved, the next step is usually to address the complaint to the executive director or Board of Directors.

C. Challenges Specific to the Developmental Services Sector

The shift away from a medical model to a social model of disability has brought with it a growing recognition that people with intellectual disabilities are entitled to live in communities of their choosing, participate as equal citizens in community life, and receive services that support community living for the greatest number of people possible. Despite this recognition, there continue to be barriers that impede the realization of these entitlements. Two such barriers include discriminatory attitudes towards people with disabilities and difficulty establishing a culture in which service providers and community members respect the right of people with disabilities to self-determination.⁵⁵

1. Barriers to Autonomous Decision-Making

Inclusion: being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport and go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.⁵⁶

Some of the most significant barriers to the realization of full inclusion and citizenship for persons with intellectual disabilities are the pervasive negative

stereotypes and discriminatory attitudes they face. People with intellectual disabilities continue to be seen as objects of pity, who need care or protection. They are not considered adults who are fully capable of living independently and making their own choices about every-day matters in their lives.

Stakeholders with disabilities repeatedly told us that they knew they had the right to make their own choices about how to live their lives, but others stood in their way of doing so. Stakeholders identified every-day decisions that persons with intellectual disabilities are often prevented from exercising, such as having choice over where to live and with whom; what to eat; where to go on social or other outings; how to spend their time; and who their support worker should be. Choices like these are critical to independence and self-determination, yet they are being denied to people with intellectual disabilities on a daily basis. Instead of having choice over what to eat, some people with disabilities are forced to eat whatever is cooked for them or the same meal every day for years. Instead of having choice over where to go on outings, some people with disabilities are not permitted to go anywhere unsupervised because it is considered unsafe. Instead of choosing how to spend their free time, some people with disabilities are forced to participate in day programs they dislike because it is more convenient for staff to have everyone in the same place. And instead of choosing a support worker with whom they feel comfortable and safe, collective agreements and organizational bureaucracy force many people with disabilities to be supported by a worker who is assigned to them.

Often the denial of such entitlements occurs not because service providers, family members and others are ill-intentioned, but because there remain paternalistic attitudes towards people with disabilities, leading to persons with disabilities being treated like children rather than adults. Too often service providers, family members, guardians and others who want to help those with intellectual disabilities believe they know what is best for the person, and do not allow the person to make his or her own choices or fail to consult with the person when making a decision on his or her behalf. Denying people the right to make their own life choices usurps independent decision-making. People with disabilities are denied the opportunity to gain decision-making skills, make mistakes and learn from those mistakes, learn self-advocacy skills, and assert their rights.⁵⁷

Linked with the removal of autonomy over one's life choices is the issue of decision-making capacity. Service providers, family members, advocates, administrative tribunals and others may assume that a person lacks capacity to make his or her own decisions based solely on the fact that he or she has an intellectual disability, requires support, or receives developmental services. Such an approach is evident in provisions of the *Social Inclusion Act*, which assign decision-making power in particular circumstances to the individual or a person acting on their behalf.

In law, there is a presumption that adults are capable of making their own life decisions.⁵⁸ Capacity is both issue-specific and dynamic. A person can be capable to make one kind of decision, but not another. A person may not be

capable at one point in time, but may become capable at another point in time. It is important that families, support workers, group home staff, medical practitioners and others receive specific training on the law regarding capacity. Such training would assist in reducing the number of situations in which others make decisions for people with intellectual disabilities, thereby addressing one of the barriers to autonomous decision-making.

In addition to training on the law regarding capacity, people must also be trained to experiment with, and use, alternate forms of communication. Far too often, people who are non-verbal are assumed to lack capacity simply because they do not speak. However, research has demonstrated that using creative ways to communicate with a person with an intellectual disability can enable the person to make independent and autonomous decisions.⁵⁹ Employing creative and alternate forms of communication builds capacity and skills, and allows information to be communicated to the person with an intellectual disability to assist him or her in making his or her own decisions.⁶⁰

2. Fear of Abuse, Retaliation and Reprisal

Due to the nature of the services and supports that some people require and the environments in which these services are delivered, many people with disabilities fear being abused, threatened or retaliated against if they raise concerns or make complaints about services. Depending on their needs, some people with intellectual disabilities rely on developmental services and supports for assistance with daily activities such as eating, dressing, bathing, toileting,

managing finances, using public transportation or navigating complex bureaucracies of social assistance systems. This dependence leaves people with disabilities vulnerable; they must work hard to maintain good relationships with support workers, family members and others on whom they rely in order to ensure that they continue to receive support and their basic needs are met. Making a complaint about a support worker or raising a concern about services may threaten or sever these relationships, and this can have disastrous impacts for the person with the disability.⁶¹

Indeed, fear of retaliation or reprisal was cited by stakeholders with disabilities as a significant barrier preventing people from raising concerns or making complaints about developmental services. Stakeholders described situations in which people with disabilities who made complaints were reprimanded or harmed by their support worker. In other cases support workers threatened to cut off a person's Ontario Disability Support Program benefits or removed privileges like watching television or attending outings. Stakeholders noted that when a culture of reprisal exists, people will be reluctant to raise concerns even if they themselves have not been the victim of a reprisal or retaliation.

Another barrier raised by stakeholders with disabilities was a culture of impunity that exists within some service agencies. Several stakeholders who had made complaints about services or a particular support worker stated that their complaint was not addressed by the service provider and no changes were made. Failure to appropriately address complaints can create a culture of

impunity, leaving people with disabilities even more vulnerable to mistreatment. Another problematic practice that stakeholders cited was a tendency for service providers to require people to raise their complaints with the particular support worker or individual against whom the complaint was directed. Again, fear of jeopardizing the relationship or suffering reprisal means that many people with disabilities remain silent. Some people with disabilities will require assistance from their support worker to complete a written complaint form. In some cases stakeholders reported that support workers refused to complete the complaint form, while in other cases people with disabilities did not feel comfortable asking workers to perform this task. Many people with intellectual disabilities will require support and assistance to make a complaint or raise a concern about services. It is clear, however, that this support must be independent from the service provider in order to be useful.

3. Need for Appropriate Supports

In order for services and supports to be effective, they must be individually tailored to meet the specific needs of each person with a disability. This cannot be a case of one size fits all, given the broad diversity of abilities and needs among people with intellectual disabilities. For example, some people with intellectual disabilities do not speak. They may use Bliss Boards or electronic equipment to communicate. Service providers and others who interact with the person must know how to use these kinds of alternate communication devices in order to be able to provide appropriate services and supports. For some people

with intellectual disabilities who do not speak, sometimes what is required of a support person is careful listening to sounds and spending time learning the cues and communication techniques that the individual employs. Indeed, new technologies are being introduced every day, which can strengthen the capacity for communication with people with disabilities who are non-verbal.⁶² Like services, enforcement mechanisms must be designed to take into account the need for appropriate supports in order to be effective.

One of the major challenges in providing appropriate services and supports is funding. Government fiscal policies are fickle, and often change when governments do. Even if a new government is elected, there is certainly no guarantee that a prior government's policies will be changed or implemented. This raises the issue of equality of services available to people with intellectual disabilities, and whether there should be an entitlement to developmental supports and services.⁶³ Such an entitlement would help to make community living a reality and not a chimera.

4. Absence of Enforceable Rights

As discussed earlier, the *Social Inclusion Act* and accompanying draft regulations do not establish any substantive rights for people with intellectual disabilities when they receive developmental services. Stakeholders with disabilities consistently stated that the government's failure to include rights in the *Social Inclusion Act* is one of the legislation's most significant shortcomings. Without fail, stakeholders expressed the desire to exercise greater autonomy and

control over their lives. However in order to know what choices they can make, they must know what choices they have a right to make. Currently, there are no federal or provincial laws that address this issue or provide rights for people with intellectual disabilities when they receive developmental services and supports.

Including rights in the *Social Inclusion Act* framework is important for several reasons. Symbolically, it demonstrates that the humanity and dignity of people with intellectual disabilities is not merely recognized in words, but in substantive rights that people can use to improve the quality of their daily lives. Practically, including rights in the legislation is the first step towards creating a culture of rights within the developmental services sector, thereby increasing the possibility that people with disabilities will have more autonomy, control and self-determination over their lives. Moreover, the first step to enforcing service rights is to enshrine them in legislation. Another compelling reason for the inclusion of rights in the legislation is to ensure that people with disabilities and service providers have similar expectations and standards. Currently, there are service providers across Ontario who have recognized the need to create rights for people who receive developmental services, and who have taken the initiative to develop statements, charters or bills of rights that apply to the services they provide. Some service providers have worked with people with intellectual disabilities to develop these rights documents.⁶⁴ While these efforts are laudable, they are not a substitute for including rights in legislation. The voluntary adoption of rights statements by some service providers means that the practice is not uniform across the province. As a result, some people with disabilities benefit

from having service rights, while others do not. This is hardly fair or consistent with recognizing the inherent dignity of all people with disabilities. Adopting rights in legislation would ensure that these rights apply to everyone who receives developmental services, regardless of which agency or support worker provides the service. Similarly, there is no uniformity in the ways in which these rights are enforced. Some service providers have detailed complaint procedures with built in supports, while others do not. Equally, the kinds of rights that are provided through these initiatives vary from one service provider to another. Donato Tarulli, Christine Tardif, Dorothy Griffiths, *et. al.* explain that:

In the absence of clear guidelines for service providers regarding individual rights, each service staff member becomes, de facto, a policy maker. Under such circumstances, clearly, the rights of individuals would be inconsistently understood, and measures to protect them inconsistently applied. In short, certain rights might be respected at certain times and at other times restricted, depending on which staff member was at hand. Understandably, the spectre of this type of inconsistent treatment creates an environment in which it is very difficult for people to become empowered to take responsibility for their own lives.⁶⁵

The inclusion of rights in legislation would provide a degree of uniformity that is presently lacking in the developmental services sector.

Some claim that there is no need to include rights in the *Social Inclusion Act* because people with disabilities already have rights under the *Canadian Charter of Rights and Freedoms* (“*Charter*”) and Ontario’s *Human Rights Code*. This claim is misguided. While the *Charter* and the *Human Rights Code* guarantee fundamental rights, freedoms and protection from discrimination to all, including people with intellectual disabilities, they do not address the unique needs and circumstances of people with intellectual disabilities when they receive developmental services and supports. For example, one of ARCH’s

clients reported that she was having problems in the group home where she lived. She had been isolated from her peers and her family expressed concern that she was being overly medicated, as she was no longer able to participate in family activities that she once enjoyed. She developed kidney stones from her medication. Since moving into the group home, she had gained a significant amount of weight, was generally unwell, and was forced to wear diapers. While the *Charter* and the *Human Rights Code* would protect this woman from discrimination, neither law addresses the specific concerns she had about living in her group home. Neither law provides her with rights related to the quality and types of services and supports she needed or was entitled to. Therefore, neither the *Charter* nor the *Human Rights Code* provide legal protections applicable to this woman's situation and neither law provides a mechanism for her to have her concerns addressed.

Rights must be tailored to the unique circumstances of the developmental services sector. The purpose of this paper is not to explore or propose the content of a set of rights. However, at minimum, developmental service rights should include:

- Right to live free from discrimination, harassment, abuse and neglect;
- Right to be provided services and supports in a manner that recognizes the person's individuality and responds to the person's needs and preferences, including preferences based on ethnic, spiritual, linguistic, familial, gender and cultural factors;

- Freedom of choice regarding activities of daily living, including decisions about food, clothing, personal appearance and participation in activities;
- Right to be informed in writing (or other accessible method) of programs and services and the laws, policies and complaint procedures that govern them;
- Freedom of choice regarding which services and supports to access;
- Right to enjoy personal privacy, including expectations of daily living such as the right to have private telephone conversations and the right to receive visitors of the person's choosing;
- Right to be free from confinement or restraint, except as provided for by the Act and regulations;
- Right to have personal decisions respected;
- Right to receive information about these rights in plain language and an accessible format;
- Right to raise concerns or recommend changes and complain about services and supports without interference, fear of reprisal or retaliation;
- Right to effective ways to enforce these rights, and a right to receive information about these enforcement mechanisms;
- Right to access or be referred to advocacy support services or legal services for appropriate representation;

Including rights in legislation is a necessary step, without which it is not possible to create robust enforcement mechanisms that ensure that developmental services are accountable to all recipients.

III. DEVELOPING A HUMAN RIGHTS-BASED APPROACH TO ENFORCEMENT MECHANISMS IN THE DEVELOPMENTAL SERVICES SECTOR

Enshrining service rights for people with intellectual disabilities in legislation is a vital step in transforming the developmental services sector. However rights alone are not enough. People with disabilities must have appropriate tools to enable them to enforce those rights. In this section we describe a human rights-based approach to enforcement mechanisms in the developmental services sector. A human rights-based (“HRB”) approach provides a theoretical framework and practical guidance for establishing enforcement mechanisms in the developmental services sector. An HRB approach is predicated on the existence of rights, but goes beyond merely enshrining rights in legislation or policy. An HRB approach focuses on human rights principles and uses those principles to guide the development and implementation of systems, programs and mechanisms. This section begins with a discussion of the transformative potential that an HRB approach offers. Next we outline various legal sources for this approach, and conclude by proposing four principles of an HRB approach to developing enforcement mechanisms.

A. Why a Human Rights-based Approach?

A human rights approach to disability is empowering. Unlike approaches that view disability as a form of individual pathology, a human rights approach views disability as “normal” variations in the human condition, and posits that disabling experiences exist when social and environmental conditions fail to include these inherent variations. An HRB approach insists that people with disabilities, like all others, are entitled to enjoy all human rights. As a result, governments must take measures to create inclusive societies in which people with disabilities are welcomed, accommodated, and enabled to live as full citizens.⁶⁶

An HRB approach enables people with disabilities to conceive of themselves as rights-bearers, and positions them as active claimants of rights in relation to government and service providers. According to Christopher Jochnick:

The real potential of human rights lies in its ability to change the way people perceive themselves vis-à-vis the government and other actors. A rights framework provides a mechanism for reanalyzing and renaming ‘problems’ as ‘violations’, and, as such, something that need not and should not be tolerated.⁶⁷

An HRB approach treats people not as passive recipients of goods and services but as active participants in services that affect their well-being. As participants in the developmental services sector, people with disabilities are entitled to voice their concerns and hold service providers accountable when their rights are not respected. Alicia Ely Yamin notes that:

...what a rights-based approach... uniquely adds...lies precisely in the definition of relationships between rights-holders and duty-bearers, which permits the creation of a framework for and mechanisms of accountability, including effective recourse in the event of violations.⁶⁸

Adopting such an approach has significant implications, both philosophically and practically.⁶⁹ Philosophically, an HRB approach can address the history of segregation, abuse, discrimination and oppression that people with intellectual disabilities have suffered, in part, because they were seen as passive, in need of care, and in need of others to determine their best interests. As Thomas Pogge has stated, by adopting a human rights approach those who are disadvantaged will no longer be seen as “shrunk wretches begging for our help”, but rather as “persons with dignity who are claiming what is theirs by right.”⁷⁰ In a human rights framework fundamental rights and protections are provided without qualification or exception, on the basis of universal human dignity and entitlement to equality. It is this universal, non-judgmental aspect of an HRB approach that is particularly responsive to the historical segregation, social isolation and lack of self-determination that has characterized services for people with intellectual disabilities.⁷¹

Practically, adopting an HRB approach can lead to changes in the nature of the roles and relationships that various actors play within the service delivery system. Under the *Social Inclusion Act* people with disabilities are generally viewed as passive recipients of services. The Act assigns very few roles or responsibilities to people with disabilities, other than some limited decision-making roles, the majority of which can be removed from the person and performed by others. As discussed earlier, service rights for people with disabilities are absent altogether from the Act. In contrast, the Act assigns large and important roles and responsibilities to service providers to ensure that

minimum standards and quality assurance mechanisms are in place. The service delivery system envisioned by the legislation is, therefore, largely a relationship between government and service providers. People with disabilities are not part of this system, except to the extent that they receive services. In contrast, an HRB approach orients people with disabilities as bearers of rights who necessarily are active participants in the system of services and supports delivered by government and service providers. One way in which people with disabilities can become active participants in the developmental services system is by exercising and enforcing their service rights. Effective mechanisms of enforcement and redress are a hallmark of an HRB approach to services.

Providing a means by which people can actively seek redress when their service rights are challenged is one way in which a developmental services system that is based on human rights principles can enable people with disabilities to participate in the service delivery system. Utilizing an HRB approach, people with disabilities can be transformed from passive recipients of services into active participants. This makes an HRB approach particularly relevant in the current context of transformation of Ontario's developmental services system, as it can assist in shaping this transformation.

Under the *Social Inclusion Act* people with intellectual disabilities have very little control or power over funding decisions or the types and amount of services and supports to which they are entitled. This is another example of the passive, dependent role that people with disabilities occupy in the developmental services sector. According to Tanya D. Whitehead and Joseph B. Hughey, a

service delivery system that maintains this passive role will not be able to truly improve the lives of people with intellectual disabilities:

... it is becoming clear that real choice means real options, control of the process of decision making, and control of the resources would move from the system's control to the person's control. If a shift in control of this type should occur, it would have profound implications for the relationship between support people, the organization of services and supports, and the people with disabilities who use those services on a day to day basis.⁷²

A system that includes people with disabilities will ultimately deliver services that better meet the needs of recipients and will do so in a manner that is more accountable to them.

Another practical implication of adopting an HRB approach is that it can contribute to ensuring that services are designed and delivered in a manner that respects recipients' rights. Services that do not pay attention to rights may unintentionally result in future rights violations.⁷³ For example, failing to respect a person's capacity to make their own decisions regarding services by allowing a third party to make those decisions may lead to violations of the person's right to privacy. Implementing an HRB approach ensures that there is a focus on respecting the rights of people with disabilities, contributing to safeguards that will prevent future rights violations.

Despite these promising philosophical and practical implications, critics of the HRB approach have asserted that for rights to positively impact the lives of people with disabilities, circumstances and supports must be in place to enable people with disabilities to be included in society. Damon A. Young and Ruth Quibell point out that such circumstance often do not exist, leaving many people with intellectual disabilities absent from community life and the promise of

inclusion elusive.⁷⁴ Moreover, the onus to create inclusive circumstances and provide rights to people with disabilities often rests with government, advocates, guardians, parents and service providers. The promise of inclusion, therefore, depends on these actors to implement their commitments and responsibilities.⁷⁵

Young and Quibell further point out that enforcement mechanisms that accompany rights tend to be engaged only after a rights violation has occurred. They assert that obtaining an after-the-fact remedy is not an effective basis for facilitating just outcomes. On the other hand, Terry Carney writes that the very services that are provided to people with intellectual disabilities, as well as the attitudes and beliefs of service providers, are key factors that contribute to the denial of rights. Therefore meaningful change can only occur if discriminatory and disempowering attitudes and beliefs are addressed in a proactive way, before rights violations occur.⁷⁶

Other critics draw attention to the issue of rights education, noting that rights are useless if people are unable to understand them.⁷⁷ Moreover, enforcing one's rights depends on individual agency and capacity. For people with disabilities who cannot exercise legal capacity, rights are ineffective as tools of empowerment.⁷⁸

Rather than discounting the use of an HRB approach altogether, these critiques present important questions that must be considered when designing and implementing enforcement mechanisms in the developmental services sector. One of the goals of the provision of legislatively enshrined service rights and accompanying enforcement mechanisms is to imbue the developmental

services sector with a culture of awareness and respect for the rights of people with disabilities. The importance of changing attitudes and beliefs of service providers points to the need for education about rights for these workers. Therefore, while the infusion of rights into this sector must be focused on people with disabilities, service providers, administrators, workers, family members and others who support people with disabilities must also be sensitized to rights issues. A culture of rights would address critiques concerning the need to change service providers' attitudes and beliefs, and the after-the-fact nature of enforcement mechanisms.

Employing an HRB approach to developmental services is only one tool for improving the lives of people with intellectual disabilities. Critiques concerning the need for government and other actors to put in place inclusive circumstances and opportunities points to the importance of continuing to use other tools, such as lobbying, coalition-building and law reform initiatives to ensure that people with disabilities are enabled to live as full citizens in their communities. Concerns related to the need for capacity to exercise one's rights points to the importance of designing enforcement mechanisms that are responsive to the unique ways in which people with intellectual disabilities understand information and express themselves. This includes the provision of supports needed to enable people with intellectual disabilities to exercise their legal capacity.⁷⁹ Finally, critiques concerning the way rights are described point to the importance of articulating and presenting rights education in a manner that is accessible and understandable to people with intellectual disabilities.

B. Legal Sources of a Human Rights-based Approach

1. The UN Convention on the Rights of Persons with Disabilities

On December 13, 2006 the United Nations adopted the *Convention on the Rights of Persons with Disabilities* (“*CRPD*”) and its *Optional Protocol*.⁸⁰ The *CRPD* opened for signature on March 30, 2007, receiving the highest number of signatories to a UN convention in history on its opening day. The treaty came into force on May 3, 2008.⁸¹

Building on a significant body of international treaties, conferences and programs that have recognized rights for people with disabilities, the *CRPD* provides a framework of goals and obligations for States Parties.⁸² The purpose of the treaty is to promote respect for the dignity of people with disabilities and promote, protect and ensure the full and equal enjoyment of all human rights and freedoms by people with disabilities.⁸³ The *CRPD* has been characterized as a landmark document that marks a paradigm shift in attitudes and approaches to people with disabilities; no longer are people with disabilities viewed as objects of pity and charity, but rather as holders of fundamental rights and freedoms.⁸⁴ However, in international law, and in Canada and many other democratic countries, people with disabilities have long been viewed as bearers of rights. Thus the significance of the *CRPD* is not that it takes a novel approach to disability, but rather that it officially entrenches a rights-based approach in a multi-lateral, legally-binding international instrument. Moreover, a large number of states and civil society actors participated in the development and negotiation of

the treaty, lending it a degree of authenticity and credibility. The *CRPD*, therefore, constitutes a significant global commitment to a human rights framework for people with disabilities.⁸⁵

The *CRPD* articulates a number of general principles, including:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Equality of opportunity; and
- Accessibility.⁸⁶

These principles are intended to guide the interpretation and implementation of the specific legal obligations provided for in the *CRPD*. As general principles, they also represent the values and standards that underlie the rights-based paradigm articulated in the treaty.

Many of the specific obligations in the *CRPD* provide for rights and freedoms that are significant for people with intellectual disabilities, such as the right to life, the right to respect for privacy, freedom from exploitation, violence and abuse, and the right to inclusive education. Article 19 is of particular significance, as it provides for the right to live and be included in the community, and have access to community supports. Article 19 declares that:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.⁸⁷

Debates surrounding the development of the *CRPD*, and article 19 in particular, provide insight into the meaning of community living as envisioned by Canada, other country delegations, and non-governmental organizations (“NGOs”) that participated in the drafting of the treaty.⁸⁸ During the seventh session of debates it was agreed that article 19 was intended to capture the right of people with disabilities to freely choose to live in the community, a right that is closely related to principles of self-determination and autonomy. Article 19 was intended to protect this right and prevent isolation or segregation of people with disabilities.⁸⁹ This conception of community living reflects a human rights perspective; people with disabilities are entitled to live and receive services and supports in the community because all human beings develop their identities within social contexts and have rights to work, study, participate in community events, and spend time with family and friends.⁹⁰

As a treaty that articulates a rights-based approach to disability issues, the *CRPD* provides an authoritative source for the development of such an approach in the context of developmental services. In particular, the general principles set out in article 3 and the values evident in article 19 can be drawn upon to develop this approach in the context of Ontario’s developmental services sector.

Canada signed the *CRPD* on March 30, 2007 and ratified it on March 11, 2010.⁹¹ By ratifying the *CRPD*, Canada bound itself to the treaty and assumed the responsibility of ensuring that its obligations under the treaty are respected.⁹² Ratification of the *CRPD* was, therefore, a significant step in confirming Canada's commitment to the principles and obligations set out in the treaty, including the general principles underlying the rights-based paradigm articulated therein. In particular, ratification demonstrates Canada's commitment to the right of people with disabilities to live independently, access appropriate supports, and be included in the community.

In Canada the usual method of implementing international human rights treaties is to rely on existing Canadian legislation and policies.⁹³ Often Canada ratifies international human rights treaties after it has determined that existing federal, provincial and territorial legislation, policies and programs conform and comply with the principles and obligations set out in the international treaty. Before ratifying a treaty the federal government seeks formal support from the provinces and territories. Typically, no new legislation is enacted to specifically implement the treaty into Canadian domestic law. In circumstances where new federal, provincial or territorial legislation is required, such new legislation will be passed prior to ratification.⁹⁴

Assuming that this usual method is the approach being taken with respect to the *CRPD*, which it appears to be,⁹⁵ it is significant, as it signals Canada's position that the *CRPD* was ratified on the basis that existing Canadian law and policy conforms to and complies with the treaty. This includes law and policy

regarding services for people with intellectual disabilities, indicating that the Canadian government's view is that these laws and policies are already consistent with article 19 and the general principles and HRB approach evident in the *CRPD*. If it is presumed that Canadian domestic law complies with the *CRPD*, it follows that domestic law should be interpreted and implemented in accordance with the international obligations contained in the treaty.⁹⁶ In the developmental services context, this implies that relevant provincial legislation, such as the *Social Inclusion Act*, should be interpreted and applied in a manner that is consistent with the general principles articulated in article 3 and the obligations provided for in article 19.⁹⁷ Canada's ratification of the *CRPD*, therefore, provides additional rationale for the adoption of a human rights-based approach in the developmental services sector. Implementing such an approach would be consistent with Canada's obligations, following ratification, to ensure that domestic legislation and policy comply with the *CRPD*.

2. Principles of Canadian Human Rights Law

Canadian equality rights and anti-discrimination law reflect similar principles as those provided for in article 3 of the *CRPD*. Section 15(1) of the *Canadian Charter of Rights and Freedoms*, also referred to as the equality rights provision, states that every individual is equal before and under the law and has the right to equal protection and benefit of the law without discrimination based on mental or physical disability.⁹⁸ Federal, provincial and territorial human rights codes prohibit discrimination on the basis of disability in certain prescribed areas

of social life. Section 1 of Ontario's *Human Rights Code* ("Code") provides that every person has a right to equal treatment with respect to services, goods and facilities, without discrimination because of disability.⁹⁹ Underlying the *Charter's* equality rights provision and the *Code's* prohibition against discrimination are the values of inclusion, accessibility, independence and dignity for people with disabilities. Each of these values will be discussed below.

Charter jurisprudence has explained that inclusion in society is an important value underlying the equality guarantee in section 15(1) because much of the historical discrimination and disadvantage that people with disabilities have suffered has resulted from their exclusion from society. In *Eldridge v. British Columbia (Attorney General)* the Supreme Court of Canada recognized the historical disadvantage that people with disabilities have experienced:

It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions; ... This historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the "equal concern, respect and consideration" that s. 15(1) of the *Charter* demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms; ... One consequence of these attitudes is the persistent social and economic disadvantage faced by the disabled. ...¹⁰⁰

As a result, discrimination against people with disabilities has been described as the creation of barriers or the failure to accommodate the needs of a person with a disability resulting in the person being prevented from participating in society and the perpetuation of historical disadvantage. Full, effective and meaningful participation in society is, thus, recognized as a fundamental goal of equality for

people with disabilities.¹⁰¹ As the Supreme Court of Canada stated in *Eaton v.*

Brant County Board of Education:

Exclusion from the mainstream of society results from the construction of a society based solely on “mainstream” attributes to which disabled persons will never be able to gain access. ...it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not result in the relegation and banishment of disabled persons from participation, which results in discrimination against them. ... It is recognition of the actual characteristics, and reasonable accommodation of these characteristics which is the central purpose of s. 15(1) in relation to disability.¹⁰²

Similarly, the Ontario Human Rights Commission has cited inclusion in society as a key principle and goal underlying the *Code*'s prohibition against discrimination:

... our society should be structured and designed for inclusiveness. This principle, which is sometimes referred to as integration, emphasizes barrier-free design and equal participation of persons with varying levels of ability. ... Inclusive design and integration are also preferable to “modification of rules” or “barrier removal,” terms that, although popular, assume that the *status quo* (usually designed by able-bodied persons) simply needs an adjustment to render it acceptable. In fact, inclusive design may involve an entirely different approach. It is based on positive steps needed to ensure equal participation for those who have experienced historical disadvantage and exclusion from society's benefits.¹⁰³

Related to the concept of inclusion for people with disabilities are the principles of accessibility and independence. Accessibility refers to the extent to which a good, service, program, process, or other thing is usable by people with disabilities. Independence is the extent to which people with disabilities must depend on others to access goods, services, programs, processes and other aspects of social life. Enhancing accessibility and independence is one way to enable people with disabilities to participate more fully in Canadian society, on an equal basis as people without disabilities. The Ontario Human Rights Commission has stated that for people with disabilities section 1 of the *Code*

includes the right to accessible workplaces, public transit, health services, restaurants, shops and housing.¹⁰⁴

Accommodation is seen as a way to enhance accessibility and remove barriers that impede full participation. Canadian human rights law recognizes the relationship of accommodation to equality and non-discrimination, and therefore imposes upon government actors and private sector employers, service providers, landlords and others a duty to accommodate people with disabilities. Under section 15(1) of the *Charter* this duty is subject to section 1 defenses, while under provincial and federal human rights statutes this duty extends to the point of undue hardship. Accommodation mandates that steps be taken to facilitate the participation of people with disabilities in all aspects of community life. In *Council of Canadians with Disabilities v. VIA Rail* the Supreme Court of Canada stated that accessibility and independence are two objectives of accommodation:

To redress discriminatory exclusions, human rights law favours approaches that encourage, rather than fetter, independence and access. This means an approach that, to the extent structurally, economically and otherwise reasonably possible, seeks to minimize or eliminate the disadvantages created by disabilities. It is a concept known as reasonable accommodation.¹⁰⁵

Ontario's Human Rights Commission has commented that:

Privacy, confidentiality, comfort, autonomy, individuality and self-esteem are important factors as well to show whether an accommodation maximizes integration and promotes full participation in society.¹⁰⁶

Accommodation is, therefore, a way in which the principles of accessibility and independence can be promoted and realized for people with disabilities.

Respect for human dignity is a core principle underlying section 15(1) of the *Charter* and section 1 of the *Code*. Dignity requires respect for the intrinsic value of each person's unique capabilities.¹⁰⁷ Accommodation must be provided

in a manner that most respects the dignity and individuality of the person with the disability. According to the Ontario Human Rights Commission, dignity is an essential consideration when determining whether discrimination on the basis of disability has occurred:

Dignity includes consideration of how accommodation is provided and the individual's own participation in the process. ... Human dignity encompasses individual self-respect and self-worth. It is concerned with physical and psychological integrity and empowerment. It is harmed when people are marginalized, stigmatized, ignored or devalued.¹⁰⁸

The Supreme Court of Canada has recognized that the purpose of section 15(1) of the *Charter* is to prevent violations of human dignity and freedom that occur through the imposition of disadvantage, stereotyping or prejudice, and to promote a society in which all persons enjoy equal recognition at law as human beings and members of Canadian society. Prior to the Supreme Court of Canada's 2008 decision in *R. v. Kapp*, dignity was an element of the legal test that courts applied when determining whether a government action or law had violated section 15(1) of the *Charter*. In *Kapp* the Supreme Court recognized the practical difficulties associated with utilizing an abstract concept like human dignity as a legal test, noting that it was confusing, difficult to apply, had resulted in additional burdens being placed on claimants of equality rights, and had led to formalistic analyses of equality.¹⁰⁹ Therefore following *Kapp*, a dignity analysis is, arguably, no longer part of the legal test under section 15(1). Nevertheless, dignity remains a key principle underlying the *Charter's* equality provision. In *Kapp* the Supreme Court made the following instructive comment:

There can be no doubt that human dignity is an essential value underlying the s. 15 equality guarantee. In fact, the protection of all of the rights guaranteed by the *Charter* has as its lodestar the promotion of human dignity. As Dickson C.J. said

in *R. v. Oakes* ...: The Court must be guided by the values and principles essential to a free and democratic society which I believe embody, to name but a few, respect for the inherent dignity of the human person ...¹¹⁰

Dignity, thus, remains a foundational principle that informs Canadian human rights law.

There is a wealth of jurisprudence interpreting section 15(1) of the *Charter* and section 1 of the *Code*. The values and principles inherent in those legal provisions are, therefore, well developed in law. On the other hand, section 7 of the *Charter* is still in its infancy insofar as claims of social justice are concerned. Nevertheless section 7 has potential to be used to support disability rights claims.¹¹¹ Section 7 provides that everyone has the right to life, liberty and security of the person. These fundamental rights can be interfered with only in accordance with principles of fundamental justice.¹¹² The *CRPD* offers a way of discerning the principles underlying section 7 that are relevant to disability rights claims. If section 7 is interpreted in accordance with articles 3 and 19 of the *CRPD*, section 7 can be said to incorporate the principles of accessibility, inclusion and personal autonomy to make life choices. Article 19 speaks to liberty by its insistence that people with disabilities be afforded the right to choose their place of residence, and have access to a range of supports to enable them to live in the community without being isolated or segregated. Section 7 can also be said to incorporate the principle of dignity since exercising choice over where one lives and being free from social isolation will contribute to self-respect and self-worth for people with disabilities.

Canadian human rights law thus reflects similar principles as those set out in the *CRPD*, including full and effective participation in society; accessibility and

independence; and respect for the inherent dignity of people with disabilities.

These values are inherent in the *Charter's* equality provision and in the protection from discrimination afforded by provincial, territorial and federal human rights statutes.

C. Principles of a Human Rights-based Approach to Enforcing Service Rights

The goals of a human rights-based approach are to develop a culture of rights in the developmental services sector; empower people with disabilities to be active participants and consumers of services; and provide ways in which services are accountable to the people who receive them. Drawing on the principles set out in the *CRPD* and in Canadian human rights law, the following four principles form the foundation of an HRB approach to enforcing service rights:

- Accountability;
- Accessibility;
- Participation; and
- Independence

Most of these principles are common to the *CRPD* and Canadian human rights law, demonstrating that they reflect international and domestic human rights values and making them suitable, relevant principles to guide the development of a human rights-based approach to enforcement. Accountability is the one principle that does not appear in the *CRPD* or Canadian human rights law. Nevertheless accountability is included here as it appears in the literature as

a key element associated with a human rights-based approach. Accountability is also a principle that is logically required for any enforcement scheme.

1. Accountability

Accountability is a fundamental principle in an HRB approach. The United Nations has called accountability “the *raison d’être* of the rights-based approach...”¹¹³ Yamin and other authors have argued that a human rights framework establishes that all people, by virtue of being human, have a claim for redress when they are treated unfairly.¹¹⁴ “Accountability”, she writes, “is a central feature of any rights-based approach ... because it converts passive beneficiaries into claims-holders and identifies states and other actors as duty-bearers that can be held responsible for their discharge of legal, and not merely moral, obligations.”¹¹⁵ Within a rights-based approach accountability means holding duty-bearers responsible for fulfilling their obligation to promote and respect rights.¹¹⁶ Enshrining rights in legislation does not magically resolve conflicts or transform people with disabilities into active participants in the developmental services system. Government and service providers must be accountable for ensuring that those rights are promoted and respected.

Applied to the developmental services context, accountability requires the development and implementation of effective enforcement mechanisms to empower and enable people with intellectual disabilities to hold government and service providers responsible when rights are not respected.

2. Accessibility

Accessibility is one of the general principles listed in article 3 of the *CRPD*. It is also one of the foundational principles reflected in Canadian human rights law, and is closely related to equality and non-discrimination for people with disabilities. Ensuring that services, programs and other elements of society are designed to be usable by people with disabilities, or that accommodations are made to enable people with disabilities to access society are ways to remove discriminatory barriers and enhance equal participation. Drawing on the *CRPD* framework and Canadian human rights law, accessibility must be a central principle underlying an HRB approach to enforcement.

Applied to the developmental services context, accessibility requires that people with disabilities know about their service rights and the various mechanisms available to enforce those rights. Furthermore, the principle requires enforcement mechanisms to be designed so that people with disabilities can access and utilize them effectively. Enforcement mechanisms must be designed so that appropriate accommodations and supports are available. Enforcement mechanisms must be tailored to the unique needs of people with intellectual disabilities and particular circumstances of the developmental services sector. Mechanisms that are overly complex, legalistic or otherwise inaccessible would create barriers and prevent people with disabilities from using them, ultimately undercutting the principle of accessibility and the very purpose for which the enforcement mechanism was created.

3. Participation and Independence

Full, effective and meaningful participation is a key principle that appears in international and domestic law. Participation and inclusion in society is one of the general principles referred to in article 3 of the *CRPD*. It is also reflected in Canadian human rights law as a fundamental goal of equality rights and the protection from discrimination for people with disabilities.

The principle of participation requires that people with disabilities are integrated into society, participating actively in the formulation and implementation of policies, services and supports that directly affect them. Participation requires that people with intellectual disabilities be consulted with and involved in the development and implementation of enforcement mechanisms in the developmental services sector.¹¹⁷

Self-advocacy is viewed by many disability scholars and stakeholders with disabilities as one of the primary tools for advancing the participation of people with intellectual disabilities in developmental service systems. Self-advocacy must, therefore, play a significant role in enforcement schemes.¹¹⁸ Self-advocacy provides knowledge, skills and partnerships to enable and encourage people with intellectual disabilities to advocate for their beliefs, express their needs and make decisions about their lives. Self-advocacy necessarily includes education about rights and developing skills to enable a person to articulate their needs, feelings and beliefs. Often, self-advocacy also includes developing connections and partnerships with others who are similarly-situated and/ or with already-established advocacy groups led by and for people with intellectual disabilities.¹¹⁹

Becoming a member of a self-advocacy group has been described as becoming part of a social rights movement, whose purpose is to achieve group and personal goals and fight discrimination. Each self-advocacy group determines its own goals; some focus on training all members to be self-determined self-advocates; others focus on systemic issues of discrimination against people with intellectual disabilities; and others are primarily social groups.¹²⁰

People First is a well-known international self-advocacy movement for people with intellectual disabilities. In Canada, People First has a national chapter, provincial and territorial chapters, and local community chapters.¹²¹ The goals of People First of Canada are to promote equality for all people who have been labeled with an intellectual disability; enable people with disabilities to speak for themselves and make their own decisions; and teach the community about the movement and issues that affect people who have been labeled with an intellectual disability. Peter Park, Althea Monteiro, and Bruce Kappel describe People First groups as:

...made up of people who have been labeled (with a developmental or intellectual disability). The groups are run and controlled by people who have been labeled. ...People First members are ... called 'self-advocates'. Self-advocates are people who speak up for themselves. They know their rights. They stand up for their rights. Self-advocates speak up about issues that are important to them and other people who have been labeled.¹²²

Self-advocacy can reduce people with intellectual disabilities' dependence on service providers, family members and others to ensure that supports are appropriate and adequate. Self-advocacy can also enable people with intellectual disabilities to gain new skills, confidence and the ability to identify concerns and take action. As a result, this form of participation in the developmental services

system can actualize the principle of independence for some people with disabilities.

D. Conclusions

Adopting a human rights-based approach has transformative potential for Ontario's developmental services sector. Philosophically an HRB approach can help to address the historical discrimination and segregation that people with disabilities have endured. Practically, the implementation of such an approach can change the role assigned to people with disabilities in the service delivery system, and ultimately create services that are more responsive to the needs of people with disabilities and accountable to them.

The *Convention on the Rights of People with Disabilities* constitutes a significant global commitment to a human rights framework for people with disabilities, and provides an authoritative source for informing an HRB approach. Canadian human rights law provides another authoritative source, and articulates similar principles as those enumerated in article 3 of the *CRPD*. Drawing on these sources, we propose that the principles of accountability, accessibility, participation and independence are important foundational elements of an HRB approach to enforcing service rights. Underlying each of these principles is the value of respect for human dignity. These principles do not stand alone, but are interrelated with one another, and as a group should guide the development and implementation of mechanisms to enable people with disabilities to enforce their rights in the developmental services sector.

IV. SELECTED ENFORCEMENT MECHANISMS IN OTHER JURISDICTIONS

This section of the paper provides an overview of enforcement mechanisms utilized in government-funded developmental services systems in selected national and international jurisdictions. Within Canada, we examined four provinces: Alberta, British Columbia, New Brunswick and Quebec. Outside Canada, we examined selected provinces or states in Australia, the United States and the United Kingdom.

The purpose of this section is to facilitate a basic understanding of the enforcement mechanisms available in other jurisdictions in order to determine innovative approaches to enforcement that could potentially influence or be replicated or adapted in Ontario. This is not an exhaustive review or analysis of the laws and practices in these jurisdictions, as such a review is beyond the scope of this paper. For accuracy, we use the terminology employed in each jurisdiction.

A. Alberta

1. Government Inspections and Oversight of Developmental Services

Alberta's Ministry of Seniors and Community Supports administers the Persons with Development Disabilities ("PDD") Program, the focus of which is to support the community inclusion and independence of adults with intellectual disabilities.¹²³ The PDD Program funds, monitors and evaluates the provision of specific services for adults with intellectual disabilities, including community

living supports, employment supports, community access supports to promote participation in society, and specialized community supports.¹²⁴ These services supplement the support of family, friends and community members and assist the individual in living as independently as possible in the community.¹²⁵

Six regional PDD Community Boards work with individuals, their representatives and families, and service providers to deliver services throughout Alberta. Their purpose is to manage the provision of services, determine community priorities, assess the service needs of the region, and work with local agencies to provide services.¹²⁶ The Community Boards are agents of the Crown and are overseen and evaluated by the Ministry of Seniors and Community Supports.

The PDD Program is governed by the *Persons with Developmental Disabilities Community Governance Act*.¹²⁷ The Act contains a preamble which states that statutory programs, resources and services are, “best provided to adults with developmental disabilities in a manner that acknowledges responsibility to the community and accountability to the Government through the Minister.”¹²⁸ The Act states that the role of the Minister includes evaluating results with respect to services for adults with developmental disabilities, setting standards for the provision of services, and monitoring and assessing the Community Boards.¹²⁹ Community Boards are required under the Act to manage the provision of services to adults with developmental disabilities in a way that is responsive to the needs of those adults.¹³⁰

The Act also sets out inspection powers. An inspector can be appointed by the Minister or the Community Board, or can be a member of the Community Board itself.¹³¹ The inspector is authorized to ensure compliance with the Act by entering premises, requiring the production of documents or records in the possession of the Board or service provider, copying those records, and inspecting and taking samples of any material, food, medication or equipment being used in the provision of services to adults with developmental disabilities. An inspector cannot exercise any of these powers without obtaining the permission of the service provider.¹³²

The Minister may appoint someone to conduct an inquiry in respect of services for which funding is allocated by a Community Board, or in respect of how the Community Board carries out its activities under the Act.¹³³ For these purposes, the person appointed to conduct the inquiry has all of the powers, privileges and immunities of a commissioner under the *Public Inquiries Act*.

2. Accreditation of Service Providers

The Alberta Council of Disability Services, a representative organization for 130 agencies that provide services to people with intellectual disabilities, offers accreditation to service providers that meet the criteria and standards outlined in a document entitled *Creating Excellence Together*.¹³⁴ Under the agreement that governs the relationship between service providers, Community Boards and the PDD Program, service providers must comply with these standards or another recognized accreditation process.¹³⁵ The extent to which a

service provider has complied with these criteria is measured through an on-site visit conducted by the Council of Disability Services. Two levels of accreditation are possible: primary and advanced. Both levels address issues such as whether people who receive developmental services are supported to make decisions about every-day matters; are treated with dignity and respect; have strong, positive relationships; are included in the community; are supported to take care of their health; are free from abuse; and are able to access fair, equitable and reasonable dispute resolution processes.¹³⁶

3. Complaints and Appeal Mechanisms

The PDD Program emphasizes that disputes are to be resolved at the service provider, Community Board or regional level wherever possible. Individuals who have concerns or complaints about decisions made regarding their services can file an appeal using the service providers' appeal process. The Community Board is responsible for ensuring that the appellant is given adequate access to dispute resolution and appeal processes.¹³⁷

The PDD Program has an appeal process that individuals who receive services can use when they are unhappy with decisions of a Community Board or PDD staff member that affect them. The appeal process is independent from the program itself. Decisions that are not subject to appeal are those that affect contractual arrangements such as decisions to enter into, amend or terminate a contract with a service provider. Reductions or suspensions of services, or disagreements concerning the level of services being provided can be

appealed.¹³⁸ A person files an appeal using the Notice of Appeal form, which must be completed and submitted to the Appeal Secretariat within 30 days of receiving the decision that is the subject of the appeal. The Secretariat contacts the person who filed the appeal to discuss the concern, and may refer the matter for dispute resolution or mediation. Dispute resolution is voluntary and entails referring the appeal to the CEO of the relevant Community Board, who may investigate the appeal. Likewise, mediation is voluntary and is generally pursued when dispute resolution has not been successful.¹³⁹ The majority of complaints made to the appeal process are resolved through the mediation process. The PDD program may also refer individuals who require support to the Alberta Association for Community Living.¹⁴⁰

If an appeal is not resolved within 45 days, a hearing is scheduled. The hearing is conducted by an Appeal Panel, established under section 15 of the Act, and made up of up to three individuals from the eight PDD Appeal Panel Members who have been appointed by the Minister. Prior to the hearing each party submits written information about the appeal. At the hearing the appellant and the Community Board are provided with an opportunity to present their case and question the other party. The Appeal Panel may also question either party. The rules of evidence that apply to judicial hearings do not apply to hearings before the Appeal Panel, and the panel must consider any evidence that is, in its opinion, reliable and relevant to the matter being heard and weigh it accordingly.¹⁴¹ The Appeal Panel renders its decision in writing, generally within one month of the hearing. The panel can change, agree with or reverse the

decision that is the subject of the appeal. Decisions of the Appeal Panel are final. Previous decisions of the panel do not establish binding precedents and the panel generally does not award costs.¹⁴²

The PDD program also monitors complaints it receives using a dispute-tracking system. This allows the program to oversee agencies that receive many complaints, and work with service providers to develop training, policies and plans to address systemic problems.¹⁴³

4. Inspections and Complaints for Supportive Living Accommodations

The *Supportive Living Accommodation Licensing Act* (“*SLALA*”) applies to supportive living accommodation that is provided to 4 or more adults who are not related to the operator, and where the operator provides for services related to safety, housekeeping or meals. This includes residential facilities such as group homes, although the Act does not specifically state this.¹⁴⁴ The *SLALA* sets out a framework for the reporting, investigation, and resolution of complaints using a variety of positions designated by the Minister, including directors, inspectors, complaints officers, and investigators. While inspections are conducted by inspectors at the request of the director, complaints officers and investigators become involved as part of the complaints process set out in the Act.

At the request of the director, the inspector may exercise a number of powers in order to ensure compliance with the *SLALA*, its regulations, an order issued under the Act, or a condition of a licence. These include the power to enter the supportive living accommodation at any reasonable hour and inspect it,

to require the production of records and documents that pertain to the supportive living accommodation and examine and copy them, to inspect and take samples of material, food, and equipment used in the supportive living accommodation, to perform tests, take photographs or make recordings, and to interview the operator of the supportive living accommodation.¹⁴⁵ The inspector can only exercise these powers with the permission of the operator of the supportive living accommodation, but the inspector can only enter a resident's unit with the permission of the resident or the resident's legal representative.¹⁴⁶ The results of the inspection must be reported to the director, and the operator of the supportive living accommodation.¹⁴⁷ After inspection, if the director is of the opinion that the *SLALA*, its regulations, an order issued thereunder, or a condition of the license has not been complied with, s/he may issue an order requiring the operator to take action within specified time limits, issue a stop order, or cancel the licence issued to the operator. The director may require any order to be posted in a prominent place in the supportive living accommodation.¹⁴⁸

The Minister may also appoint complaints officers who have the same powers as inspectors and investigators.¹⁴⁹ The role of the complaints officer differs from that of an inspector; whereas the inspector conducts inspections upon request by the director, the complaints officer becomes involved once a complaint has been made to him or her about the failure of an operator to comply with the *SLALA*, regulations, an order, or a condition of the license.¹⁵⁰ The complaints officer reviews the complaint to determine if an investigation is necessary by making inquiries or attempting to resolve the complaint through

mediation or conciliation.¹⁵¹ If an investigation is necessary, the complaints officer can refer the complaint to an investigator.¹⁵² The complaints officer must inform the complainant, if known, of any decision he or she makes not to refer the complaint to an investigator, and this decision can be appealed to the director.¹⁵³

Investigators are also designated by the Minister.¹⁵⁴ The investigator becomes involved once a complaint is referred by the complaints officer, and has the same powers as an inspector for the purposes of making an investigation.¹⁵⁵ The investigator must inform the operator and the director of the results of the investigation, and the director must then notify the complainant, if known, and the operator of the results of the investigation, including whether or not the complaint was found to be substantiated.¹⁵⁶ If after the investigation the director deems that the *SLALA*, accompanying regulations, an order issued thereunder, or a condition of the license has not been complied with, the director may order the operator to take measures within a specified time, issue a stop order, or cancel the license, and these directions must be made in writing.¹⁵⁷

Pursuant to section 16(2), a stop order can require the operator to cease the contravention specified in the order, stop any activity occurring at a supportive living accommodation, or stop operating the supportive living accommodation altogether. If the operator fails to comply with the stop order, the director may make an application to the Court of Queen's Bench for an order requiring compliance.¹⁵⁸ Section 22(1) further sets out that a person who fails to comply with an order is guilty of an offence and is liable to a fine of not more than

\$100,000, or in the case of a continuing offence, to a further fine to a maximum of \$1000 per day for each day that the failure continues.¹⁵⁹

B. British Columbia

In British Columbia, the delivery of services to people with intellectual disabilities falls under the responsibility of Community Living British Columbia (“CLBC”).¹⁶⁰ CLBC was designated a Crown agency under the provincial government’s Crown Agency Secretariat on July 1, 2005.¹⁶¹ As a Crown agency, CLBC is responsible to the provincial government. In particular, CLBC is responsible for developing broad services, funding, and capital plans for both vocational and residential supports for people with intellectual disabilities in British Columbia, and submitting these plans to the provincial government.¹⁶²

CLBC has a complex organizational structure, shown in Figure 1 below. Familiarity with this structure assists in understanding how CLBC’s various enforcement mechanisms operate.

Figure 1

¹⁶³

Community Councils are established in each of CLBC's four regions: Coast, Interior, North, and Vancouver Island.¹⁶⁴ The purpose of these Councils is to ensure that the communities served by CLBC are able to engage meaningfully in decisions about how services are delivered.¹⁶⁵

CLBC has a Board of Directors, which is appointed by the Minister of Housing and Social Development.¹⁶⁶ Because CLBC is a Crown agency, the Board of Directors has a fiduciary duty to its stakeholders, and is responsible for supervising CLBC management and overseeing the conduct of the organization's business.¹⁶⁷ Its primary responsibility is to guide CLBC's short-term and long-term goals, "consistent with the Board's responsibility to the government and the stakeholders."¹⁶⁸

Under the *Community Living Authority Act*, the Board of Directors is required to have an Advisory Committee.¹⁶⁹ The Advisory Committee consists of one member from each of the Community Councils, and meets four times per year. The Advisory Committee assists the Board of Directors by providing it with information and advice. To this end, the Committee serves as a go-between for the Community Councils and the Board of Directors. The Advisory Committee relays the concerns of the Community Councils to the Board, and makes recommendations on how CLBC policies and practices can be improved in the interests of those who receive services from CLBC.¹⁷⁰ The Advisory Committee

also provides feedback to the Board from self-advocates and families about how the service delivery system is functioning.¹⁷¹

Two safeguards are employed by CLBC to ensure that services are focused on and responsive to the needs of the individuals receiving them. One safeguard is an external quality service review that addresses complaints about services and the other is the Advocate for Service Quality, who assists in situations where the person's concerns may not have been resolved satisfactorily with CLBC.¹⁷² An additional mechanism that pertains to service quality is the complaints resolution process.

1. Complaints Resolution Process

CLBC's Complaints Resolution Policy sets out a process by which complaints about services can be made. A complaint can be initiated by an individual, youth, family member or other person if that person is dissatisfied with a service provided by CLBC, disagrees with a decision made by a CLBC staff member, or believe they have not been treated fairly or respectfully.¹⁷³

The policy stipulates that each contracted service provider must have a complaints processing and resolution system for situations where an individual takes the complaint directly to the service provider, which is encouraged.¹⁷⁴ Complaints or concerns should initially be raised with the staff member with whom the individual works, in the hopes that the complaint will be resolved in a timely manner before becoming a serious problem. CLBC recommends this as

the first step, even if the individual's complaint relates to unfair or disrespectful treatment by that particular staff person.¹⁷⁵

If the individual is not satisfied with the outcome of addressing the issue directly with the staff member, or if for some reason the individual or family member does not wish to raise the complaint with the service provider, it can be discussed with CLBC staff or submitted as a complaint through the CLBC complaints process. A Complaints Resolution Form is available at CLBC offices and on the CLBC website. A complaint can be made by the individual, a family member, advocate, support network member or service provider. CLBC staff respond to the complaint within 48 hours, and will make every effort to address the complaint within 30 days.¹⁷⁶ The complaint is sent to a Quality Service Manager or to a Community Planning and Development Manager.¹⁷⁷ When either of those managers receives a complaint, s/he transmits the complaint to the staff involved and provides advice or options as to how the complaint can be resolved. Alternatively, the manager contacts the person making the complaint within ten business days to discuss the issue and determine how to address or resolve it.¹⁷⁸ The manager advises the complainant of the outcome of the review, the decision, and the reasons for the decision. The manager then forwards the complaint to the Director of Regional Operations who may, "consult with a broader range of colleagues to assess similar complaints, precedents and potential options for resolution."¹⁷⁹ The Director must also forward the complaint to the Director of Quality Assurance as required or requested.¹⁸⁰

If the complainant is not satisfied with the response, s/he may ask the Director of Regional Operations to review the complaint. Another alternative is to have the Director of Quality Assurance review the complaint and assist in resolving the concern.

If the complaint remains unresolved and all local or regional complaints processes have been exhausted, the Complaints Resolution Policy suggests that the manager refer the matter to the Director of Quality Assurance.¹⁸¹ The Director cannot override decisions made at the local or regional level, but may suggest alternative approaches to the resolution of the complaint. The main purpose of the Director of Quality Assurance is an almost ombuds-like role, “to determine whether the process followed has been clear and accessible for individuals, youth, and families, to identify potential areas for either resolution or further discussion and to provide support as required.”¹⁸² However, the policy does permit the Director to carry out an independent practice review if the issues arising from the complaint are complex, or there is something to be gained from the participation of an independent third party.¹⁸³

If, having exhausted this process, the complainant is not satisfied with either the outcome or the process by which the outcome was achieved, the complaint will be forwarded to the CEO, who has final decision-making authority.¹⁸⁴ The CEO must review the decision and the information relied upon in making the decision, send the complainant a final decision with reasons, and advise the complainant of external complaint processes, such as through the

provincial Ombudsman or the Advocate for Service Quality for People with Developmental Disabilities.¹⁸⁵

At any time in this process, the complainant is permitted to take the complaint to an external body such as the Advocate for Service Quality or the Ombudsman of British Columbia.¹⁸⁶ Despite the existence of this multi-layered complaint process the majority of people address their complaints with service providers at the local level, rather than using the complaints process.¹⁸⁷

CLBC is required by the Complaints Resolution Policy to keep records of all complaints and the outcomes in order to improve services, policies and the training of CLBC staff.¹⁸⁸ This may include revisions to policies and procedures, responding to individuals, youth and families, changes to practice or in-depth review of potentially systemic issues.¹⁸⁹ This indicates that the complaints resolution process is not intended merely to address individual complaints, but to identify and address systemic problems as well.

The policy states that the complaints process should be accessible and consistent, with a person-centred, rights-based approach. The intention is that the concerns and interests of the affected individual will guide the complaints resolution process, and that the individual will be supported to participate fully in the process so that their independent views will be heard, respected and considered.¹⁹⁰ The policy also states that the person making the complaint has the right to have an advocate, family member, or friend support him or her throughout the complaints resolution process. One way in which the complaints process is accessible is via ensuring that information about the process is widely

available and easy to understand. When CLBC staff at any location receive a complaint, their role is to, "...ensure that the views of the person making a complaint are fully heard and wherever possible an acceptable resolution is found for the person and CLBC."¹⁹¹

2. External Review Procedures

CLBC's External Review is a formal safeguard, the purpose of which is to have a neutral third party investigate situations that arise in the course of service delivery, with the goal of enhancing accountability, service quality, and the competency of service providers.¹⁹² The External Review is governed by an External Reviews Policy.

The external reviewer may be a person or organization. The person or organization must be independent and performs its duties under contract to CLBC.¹⁹³ The external reviewer may provide a myriad of services, including consultation; problem-solving and conflict resolution; quality assurance; and debriefing affected individuals and their families, affected services providers, and CLBC staff.¹⁹⁴

There are three kinds of External Reviews: serious incident review, quality service review, and instructional review. A Quality Service Review is triggered when between one and three incidents occur that raise concerns that there is a risk that an individual's rights will be infringed upon. These incidents may include a substantial change in services, a complaint by the individual after the CLBC

complaints process has been exhausted, or ongoing health and safety concerns.¹⁹⁵

The Quality Service Review is “an in-depth audit of specific or overall services that a service provider is performing.”¹⁹⁶ It is instigated by CLBC as needed, “or as part of on-going evaluation of service provider conformance with CLBC mission, values, and contract expectations, including standards.”¹⁹⁷

The External Review Policy emphasizes that the full participation of everyone involved is essential to an effective External Review, especially the person who is receiving services.¹⁹⁸ The process is instructional and educational, not penalty-driven. The policy encourages CLBC staff to ensure that the review is transparent so that those involved can communicate openly and experience minimal anxiety. The process is intended to foster willingness to learn and change, and should respect the dignity and value of those involved in the review, especially the individuals who receive services.¹⁹⁹ The policy considers the actions that may be taken by CLBC after an External Review has been carried out; these actions include changing the service provider, modifying the service contract, terminating the service contract, or amending CLBC’s policies and practices.²⁰⁰ The policy also states that CLBC use the results and recommendations that arise from the External Review to educate service providers and other stakeholders in order to maximize the utility of the review.²⁰¹ This indicates that like the complaints resolution process, there is a systemic dimension to the External Review.

3. Advocate for Service Quality

The Advocate for Service Quality (“Advocate”) is appointed by, and reports to the Minister of Housing and Social Development, but does not work directly for the provincial government.²⁰² The Advocate’s role is to assist adults with intellectual disabilities in receiving good quality services from the Ministry of Housing and Social Development, CLBC, and other provincial ministries or service agencies.²⁰³ The Advocate works collaboratively with CLBC and several provincial government ministries, but is independent from them.²⁰⁴

A person with an intellectual disability can call the Advocate and request assistance to resolve complaints about situations in which the person does not like the services she or he is getting, feels she or he is not being treated fairly or respectfully, or does not agree with a decision made on his or her behalf.²⁰⁵ The Advocate provides a means by which complaints about government ministries, crown agencies, or service providers can be heard and responded to, and is also able to review service providers’ processes and carry out impartial reviews on request.²⁰⁶ The Advocate does not make binding decisions.²⁰⁷

An additional element of the Advocate’s role is to encourage and assist adults with intellectual disabilities to advocate on their own behalf.²⁰⁸ The Advocate’s pamphlet states, “The philosophy of the office is to assist people to advocate for themselves, to support their ability to ‘work through the system,’ to encourage the participation of those involved in decision-making and to promote problem-solving and resolution at the local level.”²⁰⁹

4. Accreditation of Service Providers

According to CLBC the majority of service providers in British Columbia are accredited by the Council on Rehabilitation Facilities (“CARF”), an independent, non-profit organization that provides accreditation to health and human service providers.²¹⁰ In order to be accredited, service providers must have statements or policies concerning recipients’ rights, education programs or materials about rights, and complaint procedures or policies. Posters or other material about recipients’ rights must be displayed in the service provider’s agency or residential facility. CLBC itself is in the process of becoming accredited by CARF. As part of this process CLBC is developing a bill of rights as well as a rights handbook for service providers. These materials will be available in pictorial and plain language formats.²¹¹

C. New Brunswick

1. Monitoring and Complaints Procedures for Adult Residential Facilities

The New Brunswick Department of Social Development established *Standards and Procedures for Adult Residential Facilities* (“Standards and Procedures”) in 2009. The Standards and Procedures apply to residential facilities that offer long-term care services as defined under the *Family Services Act*, and are intended to guide Department of Social Development staff, board members, operators, and the staff of residential facilities.²¹²

The Standards and Procedures state that the approach to service delivery is client-focused, to ensure that the dignity of the person is recognized and respected.²¹³ The Standards and Procedures discuss quality assurance as one of the principles upon which service delivery is based; long-term care residential facilities are monitored regularly to enhance accountability, effectiveness and efficiency in the planning and delivery of these services.²¹⁴ The Standards and Procedures also require operators of residential facilities to ensure that a sufficient level of services is provided to residents, and that these services are held to a high standard.²¹⁵

The Standards and Procedures recommend that operators of residential facilities should:

- establish and follow a regular written procedure for hearing the concerns and complaints of residents;
- explain the procedure for hearing concerns in a clear and simple manner, and indicate that these concerns or complaints can be expressed without fear of retaliation;
- make the procedure accessible to the residents and their relatives or advocates;
- inform staff when they are hired and thereafter at regular staff meetings of written procedures for addressing concerns of residents;
- record resident concerns in a daybook;
- investigate the concerns expressed by residents, their relatives or their advocates; and

- record the outcome of the investigations in the daybook.²¹⁶

The Standards and Procedures state that operators must inform residents upon their arrival at the residential facility of the process for making and hearing complaints.²¹⁷

The Standard also sets out a list of residents' rights, which are based on the requirement, in accordance with *Regulation 83-77* under the *Family Services Act*, that operators run the facility in a manner that maintains the spirit, dignity and individuality of the residents.²¹⁸ Among the rights recognized are the right to be free from mental and physical abuse; to be treated with courtesy and respect, in a way that recognizes dignity and individuality; to be sheltered, fed, clothed, groomed and cared for in a way that is consistent with the resident's needs; to be told who is responsible for and who is providing the resident's direct care; to be permitted to exercise rights of citizenship, and raise concerns or recommend changes in policies and services on behalf of oneself and others, without fear of discrimination, coercion, reprisal, or interference; and to be informed in writing of the laws, rules, and policies that govern the operation of the home and the procedure for lodging complaints.²¹⁹

D. Quebec

Quebec's health and social services system is governed by some 30 statutes which establish a three-tiered governance structure.²²⁰ The Ministère de la santé et des services sociaux oversees, regulates and coordinates the entire system and formulates objectives, policies and priorities for the regions. In turn,

regional service agencies are in charge of implementing and coordinating health and social services in their region. Finally, five types of institutions provide health and social services on a local level: local community service centres, hospitals, child and youth protection centres, residential and long-term care centres, and rehabilitation centres.

Individual institutions are overseen by a Health and Social Services Centre (“CSSS”), which closely monitors the needs of the population it serves.²²¹ The mission of the CSSS is to ensure the accessibility, continuity and quality of service provided by the institutions under its purview.

Each institution’s Board of Directors must establish by-laws outlining a formal complaint examination procedure.²²² In addition each institution has a Users’ Committee, which exists to ensure that consumers of the services are afforded all their rights under the law and are treated with respect and dignity.

1. Complaints Commissioner

A Service Quality and Complaints Commissioner (“Commissioner”) is appointed and trained to consider user complaints. If a consumer of the service is unhappy with the quality or level of service he or she is receiving, the first step is to discuss the issue with the caregiver, the staff, a professional or the head of the service centre.²²³ If this approach fails to resolve the situation in a satisfactory manner, the consumer can register a complaint with the Commissioner. Complaints can also be registered by any person who acts as an authorized legal representative of the individual who is receiving the services.²²⁴ This can be

done in person, over the phone, or in writing, and if the person needs help in registering a complaint, the Commissioner and the Users' Committee are available to assist. Once the complaint is made, the Commissioner must acknowledge receipt within five days.²²⁵

Subsequently, the Commissioner has 45 days during which to investigate the complaint and contact all relevant parties.²²⁶ In practice, Commissioners do not always conduct investigations, as they may be able to resolve complaints by facilitating discussion between the parties.²²⁷ At the conclusion of the investigation, the Commissioner must report his or her findings to the person who has made the complaint. If the complaint was made in writing, the decision must be delivered in writing.²²⁸ The Commissioner's findings and recommendations are reported to the service agency's Board of Directors. While not binding, the Commissioner's recommendations are typically treated seriously and are implemented.²²⁹

Should the Commissioner deliver a decision that is unsatisfactory to the complainant or fail to deliver a decision within 45 days, a further complaint lies with the Ombudsman.²³⁰

2. Ombudsman

An Act Respecting the Health and Social Services Ombudsman ("Ombudsman Act") empowers an appointed ombudsman to examine the conclusions reached by the Complaints Commissioner, and allows for an inquiry to be held as part of the investigation.²³¹ To further that goal, the ombudsman

must establish a complaint examination procedure, the specific contents of which are mandated by article 10 of the *Ombudsman Act*. The ombudsman is appointed by the National Assembly of Quebec and is accountable only to them. He or she is, therefore, independent.²³²

At the conclusion of the investigation, if the ombudsman believes that an error or injustice was committed, he or she will transmit recommendations to the government ministry, agency or institution so that it can remedy the situation. That institution or agency then has 30 days to inform the ombudsman and the complainant, in writing, of the actions that it is taking, if any.²³³ The ombudsman does not have the authority to impose any remedy. However, according to the Office of the Quebec Ombudsman, in 2008-2009, 99% of its recommendations were accepted regardless of the fact that the ombudsman has no powers of enforcement.²³⁴

3. Users' Committees

Each service provider has a Users' Committee associated with it. Users' Committees host social and educational events; promote ways to improve quality of life; support consumers of services if they need to file a complaint; and ensure that consumers are represented on the agency's Board of Directors.²³⁵ Most Users' Committees are elected by consumers of services, and those who serve on the Committees receive orientation or training upon their election. Committees are typically comprised of a majority of consumers, but also include parents or legal guardians of consumers. Users' Committees receive funding directly from

the operating budget of the service provider with which they are associated. They are accountable only to the service provider's Board of Directors. Users' Committees assist and support consumers who wish to make complaints to the Complaints Commissioner by explaining the complaints process; helping the consumer to make the complaint in writing; accompanying and assisting the consumer at any meetings; and advocating on the consumers' behalf. Committees are also responsible for monitoring the needs of all of the agency's consumers and conducting systemic advocacy on their behalf, including making reports to the Board of Directors.²³⁶

E. Australia: Victoria

On January 1, 2009, the National Disability Agreement ("NDA") came into effect. The NDA was signed by the Australian government as well as individual State and Territory governments, with a view to improving and increasing services for people with disabilities, their families and carers. The NDA Reform Agenda specifically concentrates on introducing national tools to identify service benchmarks, plan for changing needs, identify people at risk and work towards program and service delivery consistency across jurisdictions. The NDA sets out several priority areas, one of which is the development of Quality Improvement Systems based on Disability Standards. By mid-2010, a National Disability Quality Framework with a National Quality Assurance system will be developed, thus introducing a national approach to quality assurance respecting disability services.

Australian states and territories are responsible for the provision of specialized disability services. On July 1, 2007, Victoria introduced the *Disability Act 2006 (Vic.)* (“DA”), replacing the *Intellectually Disabled Persons’ Services Act 1986 (Vic.)* and the *Disability Services Act 1991 (Vic.)*. The DA provides a detailed framework for the provision of disability services and an improved complaint and review system. Some of the key stated objectives of the DA are to:

- promote and protect the rights of persons accessing disability services;
- support the provision of high quality disability services; and,
- make disability service providers accountable to persons accessing those disability services.²³⁷

1. Monitoring of Quality Assurance

Victoria has developed the Quality Framework for Disability Services (“Framework”) as a means of monitoring, measuring and managing the quality of disability service providers. The Framework also supports the implementation of standards for disability services that apply to both public and private sectors. The DA states that the Minister must determine service standards to be met by disability service providers when providing disability services under the DA.²³⁸ The standards must be published in the Government Gazette. Moreover, performance measures in relation to the standards must be specified.

The DA creates an offence for disability service providers who fail to comply with the stated standards.²³⁹ Sections 101-103 of the DA grant power to

the Secretary to appoint an administrator in cases where a disability provider has failed to provide efficient or effective service or has failed to fulfill the requirements of its service agreement. Specific triggering points for the appointment of an administrator are outlined in the *DA*, as are provisions that regulate the appointment and the powers and duties associated with the administrator's role. The *DA* also imposes additional requirements on administrators appointed to disability services that provide residential services to persons with disabilities.²⁴⁰

2. Complaints to Service Providers

One of the goals of the *DA* when it was enacted was to build a strong complaint and review system. To that end, the *DA* has set out several complaint and appeal processes.

The *DA* requires that all disability service providers have an effective system for dealing with complaints made by consumers of their services.²⁴¹ This system must be confidential, visible and accessible to consumers. Under section 89, disability service providers are responsible for ensuring that consumers of their services know how internal complaints can be made. Disability service providers must keep track of the numbers of complaints received on an annual basis as well as how those complaints were addressed.²⁴² This information is then reported to the Disability Services Commissioner.

To ensure that consumers who make an internal complaint do not face repercussions for doing so, section 106 of the *DA* states that a disability service

provider must take all reasonable steps to ensure that a person using the services is not adversely affected by making a complaint.

3. Complaints to the Disability Services Commissioner

The Disability Services Commissioner (“Commissioner”) is independent from government and is responsible for overseeing the quality of services delivered by disability service providers. The *DA* establishes the Commissioner and outlines his or her functions and powers in sections 14-19. The main functions of the Commissioner, as they relate to the complaints process are to:

- investigate complaints relating to the provision of disability services;
- identify causes of complaints and create ways to diminish or remove them;
- maintain records of complaints and publish such information;
- refer issues to the Disability Services Board; and,
- provide training for disability service providers on how to prevent and resolve complaints.²⁴³

The Commissioner’s work is guided by the values of rights, respect and fairness; rights refers to the right of people with disabilities to receive quality services that support their quality of life and to make complaints about services; respect refers to taking all complaints seriously, maintaining confidentiality, and treating all parties with dignity, sensitivity and courtesy; and fairness refers to resolving complaints through a fair process, which includes taking an objective and unbiased approach to complaints, ensuring that there are no conflicts of

interest, and making decisions based on verified information. The Commissioner's work is also guided by the principles of accessibility, accountability, excellence and taking a person-centred approach, which are meant to ensure that the Commissioner's work is consistent with the *DA*, Australian human rights legislation, and the *CRPD*.²⁴⁴

The rules and procedure for making complaints to the Commissioner are set out in sections 107-128 of the *DA*. Any person can make a complaint to the Commissioner, orally, in writing, or by other appropriate means given the person's circumstances.²⁴⁵ In turn, the *DA* bestows upon the Commissioner broad and flexible discretion to entertain a variety of complaints that arise regarding the provision of disability services.

Once a complaint has been received, the Commissioner has 28 days to assess the complaint and decide whether it is reasonable. Sections 114 and 115 outline some examples where it may be appropriate for a Commissioner to decline to consider a complaint. For example, the complaint may not comply with the requirements for making a complaint under the *DA*, or is frivolous, vexatious or lacking in substance. Complaints relating to incidents that occurred more than a year ago and which have no good reason for the delay in bringing the complaint may also be declined. In the event that the Commissioner declines to consider a complaint, written notice must be given within 14 days to the person who made the complaint. Likewise, if the Commissioner decides to consider the complaint, written notice must be provided within 14 days to the disability service provider.²⁴⁶

Section 116 mandates conciliation in cases where the complaint is suitable for such a procedure. The procedure is analogous to the Canadian concept of mediation, and involves the Commissioner facilitating discussions between the disability service provider and the complainant and, if possible, assisting the parties to reach a resolution.

The *DA* empowers the Commissioner to investigate complaints that are not suitable for conciliation or when conciliation was attempted unsuccessfully.²⁴⁷ The investigative powers of the Commissioner may be broad, as the *DA* grants discretion to the Commissioner to determine what procedure to follow. The Commissioner is not bound by the rules of evidence, but is bound by rules of natural justice and is required to use minimal formality and technicality in the investigation. If the Commissioner decides that the complaint is justified, he or she has 14 days to notify both parties, in writing, of the decision, the reasons for the decision and the actions that must be taken as a consequence of the decision. This triggers a 45-day period during which the disability service provider must send a report to the Commissioner outlining the actions which it has taken with respect to the complaint.

4. Oversight by the Disability Services Board

In conjunction with the Commissioner, the *DA* establishes the Disability Services Board, whose role is to provide advice to the Commissioner and to generally oversee the complaints system. The functions of the Board include providing expertise, guidance and advice to the Commissioner, referring matters

to the Commissioner for inquiry and advising the Minister on the disability complaints system and on issues referred to the Board by the Commissioner.²⁴⁸

5. Appeals to a Tribunal

Under various sections of the *DA*, the Victorian Civil and Administrative Tribunal has jurisdiction to review a wide range of decisions made by disability service providers. This permits consumers of a disability service provider to go to the tribunal directly, if their complaint falls within the ambit of one of the enumerated decisions. For example, the tribunal can become involved where the disability service provider decides to reduce the services provided as part of the residential fee a consumer pays. Reduction of services includes a reduction in the level or range of services, or a termination of services.²⁴⁹ Section 70(1) of the *DA* states that if service items are reduced, the service provider must also reduce the amount of the residential fee by an amount that is agreed upon by both the service provider and the resident. If agreement cannot be reached, the service provider or the resident can apply to the tribunal to make a determination of the appropriate amount.²⁵⁰ Under section 82 of the *DA*, a resident may also apply to the tribunal for a review of a notice to vacate.²⁵¹ The tribunal will then determine whether or not the notice is valid.²⁵²

F. United Kingdom

The *Care Standards Act 2000* (“CSA”) established the National Care Standards Commission. The National Care Standards Commission was a non-

governmental public body that regulated social and health care services on a national level, displacing the earlier local council system. As of April 1, 2010, the National Care Standards Commission has been replaced by the Care Quality Commission (“CQ Commission”), which has exclusive responsibility for the inspection, monitoring and regulation of health and social care. The Compliance Guideline Criteria are standards that the CQ Commission must consider when making decisions regarding service providers. These criteria contain essential standards of quality and safety, consisting of 28 Regulations and associated Outcomes that are set out in the *Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 (“HSCA Regulations”)* and the *Care Quality Commission (Registration) Regulations 2009*.

1. Monitoring by the Quality Care Commission

Under its regulatory umbrella, the CQ Commission continually monitors service providers to ensure that they comply with essential standards of quality and safety. The CQ Commission is still brand new, but will have quality assurance mechanisms in place to monitor consistency. Additionally, it will assign a Quality and Risk Profile to each registered service provider. Non-compliance will be addressed by a variety of actions including warning notices, imposition or variation of conditions, suspension of registration to provide certain services, fines, prosecution or cancellation of registration.²⁵³

Quality assurance is provided under Regulation 10 and Outcome 16. Regulation 10(1) imposes on service providers the requirement to regularly

assess and monitor the quality of services provided and identify, assess and manage risks. To ensure that this goal is met, the service provider must seek out professional advice and consider, among other things, the views expressed by its consumers (including complaints), appropriate professional and expert advice, as well as reports and reviews prepared by the CQ Commission from time to time.²⁵⁴

2. Complaints to Service Agencies

Pursuant to Regulation 19 agencies are responsible for having effective complaints systems in place for identifying, receiving, handling and responding appropriately to complaints and comments made by consumers of the service or their representatives.²⁵⁵ Additionally, the agency must assist consumers and their representatives with bringing forth the complaint if necessary and ensure that all complaints are fully investigated and resolved as much as is reasonably practicable.²⁵⁶ Finally, all complaints and agency responses to them must be reported to the CQ Commission.²⁵⁷

3. Self-Advocacy

Self-advocacy is promoted under Regulation 17 of the *HSCA*. The Regulation states that service providers must, as much as is reasonably practicable, make arrangements to encourage their consumers and representatives to understand the choices available to them with respect to services, assist them to express their views, provide opportunities for them to

manage their own care or treatment and provide appropriate opportunities, encouragement and support to them with respect to promoting autonomy, independence and community involvement.²⁵⁸

4. Appeals to Ombudsmen or Adjudication Service

Under Outcome 17, which addresses complaints that can be made pursuant to Regulation 19 of the *HSCA*, consumers of a service agency must be informed that they can rely on the National Health Service complaint process in any circumstance where their care, treatment and support was funded by the National Health Service.²⁵⁹ This is the case even if the service was not delivered at a National Health Service facility.

Additionally, consumers who are not satisfied with the findings or outcome of the response to their complaint must be advised of their right to refer the matter to the Health Service Ombudsman, the Local Government Ombudsman or the Independent Sector Complaints Adjudication Service, depending on the type of complaint in question.

The Local Government Ombudsman (LGO) receives complaints about local councils and some other authorities, and its services are free.²⁶⁰ There are three LGOs in England who are appointed by the Queen. The LGO website makes it clear that its role is not to be a consumer champion, but rather is to examine complaints in an impartial and independent manner.²⁶¹ Decisions of an LGO are final and not subject to appeal, but can be taken to the High Court on the ground that there is a legal flaw in the LGO's reasoning for the decision.²⁶² If

people are not satisfied with the final answer that they receive from a council in response to a complaint, the person may submit a complaint to an LGO within 12 months by telephone or by filling out the online complaint form.²⁶³ In some cases, complaints are allocated to an investigator who may make decisions on the Ombudsman's behalf.²⁶⁴ Before a complaint is investigated, the LGO must first determine whether it has legal authority to consider the complaint. Typically, the LGO will provide the complainant with an opportunity to comment on this issue before making a final decision, unless it is obvious that the complaint cannot be considered.²⁶⁵ Once the LGO has made a final decision, it will write to the complainant and explain its reasons for the decision.²⁶⁶ There are four different outcomes that may result from the LGO's involvement. The LGO may find that there was no fault on the part of the council, or that even if the council is at fault, the effect on the complainant is not serious enough to continue investigating the complaint.²⁶⁷ If the complaint is sufficiently serious, the LGO may suggest how the complaint can be resolved in hopes of achieving a settlement between the council and the complainant.²⁶⁸ A formal written report by the LGO is the fourth possible outcome, if the council does not agree to the proposed settlement or if the LGO thinks that the issue is of interest to the public.²⁶⁹ The report may contain recommendations as to how the council should address the issues raised by the complaint, but councils are not obligated to implement these recommendations.²⁷⁰

G. United States: California

In 1977, California passed the *Lanterman Developmental Disabilities Act* (AB 846) (“*Lanterman Act*”) as part of California’s *Welfare and Institutions Code*.²⁷¹ The Act sets out the rights and responsibilities of people with intellectual disabilities. In 2003, the Act was amended to expand its reach, and it now applies to anyone who is experiencing significant functional limitations in “three or more ... areas of major life activity.”²⁷²

The *Lanterman Act* establishes a regulated network for the planning, provision and co-ordination of services for people with disabilities. To that end, it charges the state’s network of regional centers with advocacy for, and protection of the rights of people who fall within its ambit. Section 4620 states:

In order for the state to carry out many of its responsibilities as established in this division, the state shall contract with appropriate agencies to provide fixed points of contact in the community for persons with developmental disabilities and their families, to the end that these persons may have access to the services and supports best suited to them throughout their lifetime. It is the intent of the Legislature in enacting this division that the network of regional centers for persons with developmental disabilities and their families be accessible to every family in need of regional center services. It is the further intent of the Legislature that the design and activities of regional centers reflect a strong commitment to the delivery of direct service coordination and that all other operational expenditures of regional centers are necessary to support and enhance the delivery of direct service coordination and services and supports identified in individual program plans.

The Legislature finds that the service provided to individuals and their families by regional centers is of such a special and unique nature that it cannot be satisfactorily provided by state agencies. Therefore, private nonprofit community agencies shall be utilized by the state for the purpose of operating regional centers.²⁷³

The various responsibilities of a regional center are outlined in Article 2 of Chapter 5 of Division 4.5 of the *Lanterman Act*. They include, among other

things, assurance control respecting the quality and effectiveness of services and supports that are provided to the consumer. Moreover, some regional centers may, pursuant to subsection 4512(b) of the *Lanterman Act*, provide self-advocacy training, facilitation, and peer advocates to people with disabilities.

Article 4502 of Chapter 1 of Division 4.5 establishes a set of rights for people with intellectual disabilities. These include the right to treatment and supports that protect the personal liberty of the person in the least restrictive environment; the right to dignity, privacy and humane care; the right to social interaction and participation in community activities; the right to physical exercise and recreational opportunities; the right to be free from harm, unnecessary physical restraint, isolation, excessive medication, abuse or neglect; the right to make choices about where and with whom to live, how to spend one's time, and program planning and implementation; and other rights. The Act requires service providers to give consumers opportunities to make decisions about daily life as well as the information needed to make those decisions.²⁷⁴

1. Oversight by the State Council on Developmental Disabilities

The *Lanterman Act* establishes the State Council on Developmental Disabilities ("SCDD") in Chapter 2 of Division 4.5. The SCDD is funded by the government and functions as an independent state agency made up of people from diverse socioeconomic, ethnic and geographic backgrounds. The SCDD in turn funds 13 Area Boards that act as regional bodies to ensure that local needs and priorities are being addressed. Area Boards are on the front lines of service

delivery in that they provide public education, outreach and encourage individuals to start and set up self-advocacy organizations.

The primary function of the SCDD is to create and monitor a State Plan, which establishes goals and objectives for improving the service system in California. The State Plan focuses on areas that must be enhanced and services that are currently lacking. The State Plan aids the SCDD in making recommendations and providing advice and guidance to the California government and legislature.

2. Self-Advocacy

Built into California's legislative scheme is the recognition that people with disabilities should be able to advocate for their own rights. To that end, Area Boards both encourage people with disabilities to start advocacy groups and help to establish such groups.²⁷⁵ Area Boards also have a mandate to provide education to people with intellectual about rights and complaint procedures.²⁷⁶ Moreover, regional centers may, but are not required to, offer self-advocacy training, facilitation and peer advocates.²⁷⁷ To further this goal, the regional center may hire facilitators, sponsor conferences held by self-advocacy groups and cover the expenses of transportation to meetings.

In addition to the assistance provided by Area Boards and regional centers, there are a number of organizations in California that promote and support self-advocacy. These include People First and Disability Rights California, whose Developmental Disabilities Peer/Self-Advocacy Unit exists

specifically to provide support, education, outreach and training to self-advocates. Through this program people with intellectual disabilities share their experiences; become better informed about their legal, service and human rights; and learn how to protect themselves and exercise their rights.²⁷⁸

3. Appeals to Regional Centres

Individuals who have complaints about the delivery or quality of their services may appeal, depending on whether their dispute is with the regional center or with the service provider.

The *Lanterman Act* sets up a formal appeal procedure that is engaged when an individual disagrees with a decision made by a regional center - affecting his or her eligibility or services. The individual's legal guardian, conservator or representative, or in the case of a minor, the person with legal custody, can also appeal the decision of a regional center.²⁷⁹ In either case, complaints encompass decisions that deny services, stop services, change services or decrease the level of services received.²⁸⁰

The regional center must provide written notice of a denial of or change to service.²⁸¹ The contents of the notice are strictly mandated and include what the regional center will do, why and when they are doing it and the law, rule or policy that enables their decision. Moreover, the notice must include information regarding the appeal procedure, such as deadlines for filing, access to the regional center's records and where to seek advocacy help.

The legislation itself dictates the deadlines for filing, as well as the means by which a consumer can have his or her services continued while the appeal process is pending.²⁸² Recognizing California's ethnic diversity and high immigration levels, the *Lanterman Act* also requires that all regional center notices must be in the language that the consumer or his or her authorized representative can understand.²⁸³ This places the onus on the consumer or the authorized representative to inform the service coordinator that notices in a language other than English are required.

The first step in the appeal process is to request a hearing. The regional center must acknowledge this request by sending a notice and providing the person who made the request with a fair hearing request form.²⁸⁴ The regional center also has the duty to help with completing the form, if required.²⁸⁵ The complainant may request an informal meeting with the regional centre, may request mediation, or may refuse these options.²⁸⁶ If the appeal goes to a hearing, it is heard before an administrative law hearing officer within 50 days of the regional center having received the request for a hearing. The hearing officer, in turn, must make a decision within ten business days of the end of the hearing.²⁸⁷ Should the complainant disagree with the hearing decision, a further appeal lies with the superior court. A Writ of Administrative Mandamus must be filed within 90 days of the initial hearing's decision.²⁸⁸

4. Complaints to Service Providers

Subsection 4705(a) of the *Lanterman Act* states that as a condition of receiving state funding, every service agency must have a written internal grievance procedure.²⁸⁹ Consequently, the starting point for addressing disagreements with a service provider is obtaining a copy of the grievance procedure. Moreover, all such service agencies must also adopt and state in writing, in English and any other language appropriate to the needs of the consumers of the particular agency, a mediation and fair hearing procedure.²⁹⁰ Copies of the procedure and the relevant provisions of the *Lanterman Act* must be posted on service agency's premises.

A consumer of the agency's services can also make a complaint to the service provider's licensing agency.²⁹¹ A licensing agency is charged with ensuring that licensed service providers comply with federal and state laws and regulations. Most health care service providers are licensed by the Department of Health Care Services while most community and residential care providers are licensed by the Department of Social Services. Consumers can get help with respect to their complaints to licensing agencies from an Area Board.

H. United States: Texas

In Texas, the provision of disability services falls within the purview of the Health and Human Services Commission. This commission is further organized into five state agencies, two of which are particularly relevant to this paper. The Department of Assistive and Rehabilitative Services ("DARS") works in

partnership with Texans with disabilities to assist them with independent living, improve their quality of life and help them achieve their goals. The Department of Aging and Disability Services (“DADS”), has been in operation since September 1, 2004, and administers long-term services for people who are ageing and who have cognitive and physical disabilities. DADS is also in charge of licensing and regulating service providers who deliver services within its mandate.

1. DARS Service Standards and Complaints

DARS publishes DRS Standards for Providers and places the onus on individual service providers to comply with the most recent Standards.²⁹²

Generally, all service providers are monitored continuously by DARS field staff.²⁹³ The Standards relating to the monitoring process enable periodic on-site monitoring (both scheduled and otherwise), outline typical monitoring visits and records reviews, and set out reporting guidelines regarding monitoring results. Each service provider is required to establish a grievance procedure and a Client Assistance Program.²⁹⁴ The grievance procedure must be distributed and explained to both consumers and staff of the service provider.

2. DADS Service Standards and Complaints

Any long-term care facility or agency that meets the definition of a nursing home, assisted living facility, adult day care facility, privately owned Intermediate Care Facility for Persons with Mental Retardation or Home and Community Support Services must be licensed in the State of Texas. If the agency receives

funding under the Medicare and/or Medicaid programs, it also must comply with regulations under Titles XVIII and/or XIX of the *Social Security Act*. DADS itself is responsible for licensing such agencies, investigating complaints and provider self-reported incidents, and monitoring facilities that fall out of compliance with the regulations.

Complaints that are made by certified or licensed providers of disability services are handled by the Consumer Rights and Services office of DADS. In order to better serve its consumers, the Consumer Rights and Services office is split into two units: Consumer Rights and Complaint Intake.

The Consumer Rights Unit specializes in a number of specific types of complaints, including the Home and Community-based Services program, the Texas Home Living program, mental retardation authorities, and rights and issues affecting people with intellectual disabilities.²⁹⁵ The Complaint Intake unit is charged with providing information about long-term care services and community-based programs under DADS. It also processes complaints relating to state supported or assisted or intermediate care living facilities, adult day cares, home health agencies, hospices and personal assistance service providers. All complaints are tracked by the intake tracking system, and any investigations are conducted by Regulatory Services according to state and federal rules and regulations.²⁹⁶ Following an investigation, it is the duty of the Regulatory Services to notify the person who made the complaint of their findings. The notice can be provided in writing or by telephone.²⁹⁷

3. Appeal Mechanisms under DARS and DADS

Since DARS and DADS both operate within the Health and Human Services Commission and are required to provide the right to a fair hearing, formal appeals in both cases will be directed to the Appeals Division of the Commission. The appeals process and the administrative hearing will be conducted by the Fair and Fraud Hearings section of the Appeals Division.

The Health and Human Services Commission follows the notice requirements and administrative hearing procedures set out in the *Texas Administrative Code* (“TAC”) and any other appropriate state or federal law or regulations, depending on the program in question. Section 357.11 of the TAC requires that a service provider must provide notice to the consumer when it decides to deny or reduce services or eligibility. The provision also sets out the contents of the notice, which include the right to a fair hearing, how to request an appeal, the right to representation (legal or otherwise), the availability of community legal services and any explanation of how the services may continue while the legal process is ongoing. The right to a fair hearing as well as the deadline for requesting a hearing are set out in subsection 357.3(b).

Pursuant to the TAC, Spanish interpreters are provided automatically,²⁹⁸ while every effort is made to provide interpreters of other languages, including sign language.²⁹⁹ Subsection 357.21(c) also establishes a mechanism for making a complaint with respect to the quality of interpretation service provided.

Appeal requests must be completed within 90 days of the request date.³⁰⁰ If the complainant is not satisfied with the outcome of the appeal hearing, she or

he may request an administrative review of the decision. The request for review must be made within 30 days of the hearing decision. The request is forwarded to the Health and Human Services Legal Division, which designates a Health and Human Services lawyer to handle the review. The *TAC* outlines the administrative and judicial review process in sections 357.701-703.

I. Conclusions

Like Ontario, several of the jurisdictions surveyed employ government oversight and monitoring mechanisms to ensure quality of services. For example, Alberta's legislation sets out robust inspection and inquiry powers by government-appointed inspectors. Under the *Disability Act* in Victoria service providers must comply with quality standards and the government can appoint administrators in cases where a service provider fails to meet these standards. Interestingly, all the jurisdictions surveyed employed complaint and/or appeal mechanisms as an important element of their service delivery systems. While Ontario's *Social Inclusion Act* requires service agencies to establish complaints procedures, the legislation does not stipulate details about how the process should function or what principles should underpin these procedures. In contrast, many of the jurisdictions surveyed include very detailed requirements for complaints and appeals processes in their respective legislation and policies. British Columbia's Complaint Resolution Policy and the appeal procedures under California's *Lanterman Act* are two examples. This suggests that robust complaint and appeal mechanisms are an important element of enforcement in

every developmental services system, including those in which government oversight and monitoring are emphasized.

Several of the jurisdictions surveyed have employed elements of a rights-based approach when designing service delivery systems and enforcement mechanisms. California's *Lanterman Act*, for example, provides for rights for people with intellectual disabilities in the legislation itself. It also recognizes that people with disabilities should be able to advocate on their own behalves, and permits regional centres and Area Boards to provide self-advocacy training and peer support to those who wish to learn about their rights or make complaints about services. Several of the principles guiding the Australian Disability Rights Commissioner can be linked to a human rights-based approach, including the principles of accessibility, accountability, respect for rights and taking a person-centered approach. In British Columbia, CLBC's Complaints Resolution Policy requires complaint procedures to be accessible and consistent with a person-centered, rights-based approach. Notably, CLBC used the UN *Convention on the Rights of the Child* as a reference for its policy.³⁰¹ The use of elements of a human rights-based approach in Canadian and international jurisdictions demonstrates the utility and practical applicability of this approach for developmental services.

Of note is the fact that self-advocacy is recognized as an important element of enforcement in several of the jurisdictions surveyed. In Quebec, Users Committees' provide peer support to assist consumers to understand complaints procedures and make complaints about services. They also assist in

bringing systemic concerns to the attention of a service provider's Board of Directors. Under California's legislative scheme, Area Boards encourage and assist in the establishment of self-advocacy initiatives, and a number of self-advocacy organizations exist. Self-advocacy is also promoted in the UK, where service providers are legislatively required to make reasonable arrangements to assist people with disabilities to express their views, manage their own care, and support and promote their autonomy, independence and community involvement. While a number of self-advocacy organizations and initiatives exist in Ontario, few (if any) have a specific mandate to support people to understand their rights in the developmental services sector, gain advocacy skills, or bring forward complaints and concerns regarding service rights violations. The official incorporation of self-advocacy initiatives into enforcement mechanisms in Canada and abroad demonstrates that these initiatives are feasible, valuable elements of a robust developmental services system.

V. ENFORCING RIGHTS IN ONTARIO'S DEVELOPMENTAL SERVICES SECTOR: KEY COMPONENTS

Applying the four principles of a human rights-based approach, and drawing on ARCH's experience, the input of people with disabilities and other stakeholders, ARCH is of the view that the following are key elements that must be part of a scheme to enforce the service rights of people with intellectual disabilities who receive government-funded services and supports:

- **Rights Education:** People with intellectual disabilities must be educated about their rights when receiving developmental services, as well as their rights more generally. A rights curriculum must be created to provide education about service rights, education about other rights and related legal issues; training on identifying situations in which rights are threatened; and what actions can be taken. While rights education initiatives should be primarily targeted to people with disabilities, service providers, administrators, support staff, and family members must also receive rights education.
- **Complaint Mechanisms:** The *Social Inclusion Act* requires service providers to establish complaint procedures, but does not specify any details about these procedures. Given the importance of ensuring that an appropriate, accessible complaint mechanism exists for every service provider, the *Social Inclusion Act* framework must be amended to include more detailed provisions regarding complaint mechanisms, including provisions to ensure that these mechanisms will be accessible for people with intellectual disabilities.
- **Appeals to an Independent Administrative Body:** The principle of accountability requires that people with disabilities have recourse to an independent administrative body if they are not satisfied with the service provider's response to the complaint. The *Social Inclusion Act*

framework should be amended to include the designation of a newly constituted, independent administrative body and a process to receive appeals from complaints filed with service providers. The appeal body's processes and procedures must be accessible to people with intellectual disabilities. In addition to adjudicating individual appeals, the appeal body must create a process for annually reviewing appeals to discern trends and issues needing broader attention by the Ministry of Community and Social Services.

- **Peer Advocacy Committees:** Self-advocacy is a vital component of a system of enforcement for the developmental services sector. Self-advocacy is a means to implement the principle of participation by empowering people with disabilities, increasing self-confidence, enabling greater autonomy in decision-making, and providing the supports necessary to enable people to make complaints or raise concerns about services. Peer Advocacy Committees composed of people who receive developmental services must be created for geographic regions throughout Ontario. Within their geographic regions, Committees would conduct rights education activities; support recipients of services to raise concerns and access complaint and appeal mechanisms; and meet annually with the Ministry of Community and Social Services to report on systemic concerns and identify issues that require the Ministry's attention.

A. Rights Education

Stakeholders with disabilities reported that many people who receive developmental services do not know that they have legal rights or that they are entitled to service rights such as respect for privacy and the right to make individual choices. Moreover, stakeholders reported that the culture of many group homes and support services is such that most aspects of people's lives are controlled by service providers, family members, guardians and others. People with disabilities are told what to do, when, and with whom. This culture of control and absence of independent choice contribute to a lack of awareness about rights, a sense that there are no other options, and a culture in which making complaints or raising concerns about services is not possible.

Stakeholders with disabilities uniformly stated that it is necessary to educate people with intellectual disabilities about their rights. Some linked education about rights with issues of dignity, stating that rights education was important because people with disabilities are people first. Others felt that rights education was a way to empower people with disabilities - if people know about their rights they would be better able to exercise independence, have privacy and make choices about their day-to-day lives. Several stakeholders spoke of personal experiences in which learning about their rights and gaining advocacy skills had enabled them to gain self-confidence and improve their lives by making their own choices and advocating for their entitlements. Thus, rights education was seen by stakeholders with disabilities as an important way to achieve the goals of a human rights-based approach, namely to develop a culture of rights in

the developmental services sector and empower people with disabilities to be active participants and consumers of services.

Stakeholders who work in the developmental services sector echoed the sentiments of stakeholders with disabilities regarding the need for rights education. They highlighted the need for concerted rights education efforts and advocacy skills training. It was suggested that these activities must be provided on an on-going basis.³⁰² One service provider noted that from an ethical point of view it was not acceptable to provide people with service rights without any training or support to express and enforce those rights.³⁰³

The concept of rights education is supported by the human rights principle of accessibility. In order to access enforcement mechanisms, people with disabilities must know about their service rights and the various mechanisms available to enforce those rights. Armed with information, people with disabilities will be in a better position to exercise and enforce their rights.

Rights education would be facilitated by the creation of a general rights curriculum. Orienting people with disabilities to the *Social Inclusion Act* and their service rights is only one component of the content of this curriculum. The curriculum must also include training on identifying and recognizing situations in which rights are being threatened or violated. Equally, the curriculum must include training on self-advocacy skills and what actions can be taken when rights are threatened or violated. This could include training and information on service providers' complaints procedures and other enforcement mechanisms. Legal information about issues related to service rights should be built into the

curriculum; this may include information about human rights, informed consent, substitute decision-making, privacy rights and other legal issues.

People with disabilities must be educated about their service rights as well as other, more general rights, such as the right to be free from discrimination, the right to equality before the law, and the right to vote. Education about general rights is important so that people with disabilities may exercise the rights and responsibilities of citizenship; become aware of legal protections that exist outside the developmental services sphere; and participate in broader society. Many of the stakeholders with disabilities who participated in the consultations were aware of their general and service rights, however there was some confusion about which rights applied in which context. This points to the need for clarity when designing educational curricula so that people with disabilities are provided with legally accurate rights information.

Critiques concerning rights education point to the importance of articulating and presenting rights information in a manner that is accessible and understandable to people with intellectual disabilities. This was a concern echoed consistently by stakeholders with disabilities. Stakeholders stated that rights information must be presented in plain language. The use of pictograms and cartoons was also suggested. Equally, attention must be paid to ensuring that the manner in which rights education is delivered is accessible to people with intellectual disabilities. It is unlikely that listening to a lecture of several hours will be an effective means of transmitting the information. Creative means of delivering the rights curriculum are necessary, such as role play scenarios,

storytelling, games, videos and small group discussions.³⁰⁴ Activities that simulate everyday, real-life situations are more likely to enable people with intellectual disabilities to apply the knowledge and skills they learn to their everyday lives. Rather than providing one educational session, several short sessions may be more effective. Educational activities that are interactive and incorporate audio, video and other technology may be especially engaging and effective.³⁰⁵ In addition, rights education must be ongoing to facilitate a culture of rights awareness and ensure that people have opportunities to ask questions and obtain clarification about rights issues.

Critics of rights assert that providing legislatively enshrined service rights and accompanying enforcement mechanisms are unlikely to imbue the developmental services sector with a culture of rights awareness and respect unless the attitudes and beliefs of service providers are changed. Similar concerns were voiced by stakeholders with disabilities, who suggested that support workers must also receive rights education. Stakeholders also noted that some family members can be a source of valuable support, while others perpetuate or collude in rights violations. ARCH is of the view that given the wide-ranging lack of knowledge about service rights among people with disabilities, and the importance of rights education to the empowerment of people with disabilities, efforts to infuse rights into this sector must be focused on people with disabilities. However, recognizing that a change in culture depends on all participants in the sector, service providers, administrators, workers, family members and others who support people with disabilities must also be educated

about and sensitized to rights issues. It must also be noted that a change in organizational and sectoral culture will not happen quickly. One service provider reported that rights issues only began to be raised by people with disabilities and support workers several years after management began a process of rights education.³⁰⁶

When asked who should provide rights education, stakeholders with disabilities overwhelmingly stated that it would be most effective if self-advocates, people with intellectual disabilities who either receive or are familiar with developmental services, provided the education. Stakeholders felt that people with intellectual disabilities were more likely to trust self-advocates because they were viewed as peers, rather than outsiders. Trust was considered to be one of the most important elements to the success of rights education and enforcement. Stakeholders expressed concern that people may be reluctant to participate in rights education, ask questions or discuss rights violations if educational sessions were led by someone other than a self-advocate. Such reluctance would likely be due to dependence on support workers and fear of negative consequences or possible reprisals if concerns about services or rights violations were raised. ARCH recommends that the rights education curriculum be developed in consultation and partnership with people with intellectual disabilities and consumer-led self-advocacy organizations such as People First. Self-advocates should be supported to deliver the curriculum to people with disabilities. This can be done via Peer Advocacy Committees, which will be described later in this section.

ARCH is of the view that rights education should be mandatory for people who receive developmental services and those who work in the developmental services system. For people with disabilities, rights education must be done in the absence of service providers, and in a manner that ensures confidentiality. These elements may assist in protecting people with disabilities from reprisals, as support workers would not know when rights education was received or what concerns may have been raised, and by whom, during educational sessions.

B. Complaint Mechanisms

The majority of stakeholders with disabilities agreed that complaint mechanisms, formalized processes by which people with disabilities can raise concerns with service providers and receive a response, are important accountability measures. The human rights principle of accessibility requires that complaint mechanisms be designed to ensure that people with disabilities can access and utilize them effectively. Complaints procedures that are overly complex, legalistic or otherwise inaccessible would create barriers that prevent people with disabilities from using them, ultimately undercutting the principle of accessibility and the very purpose for which the complaint mechanism was created.

The *Social Inclusion Act* requires service providers to establish complaint procedures, however the Act and draft regulations do not set out any details with respect to such procedures. Like other jurisdictions, many Ontario service providers currently have complaints procedures or complaints policies, however

these mechanisms vary from one provider to another. Stakeholders with disabilities who participated in consultations were of the view that some agencies have effective complaint mechanisms, while other agencies do not have such mechanisms or people are not aware of their existence. Of those service providers who have complaint mechanisms, many require or prefer that the complaint initially be made to the staff person who works with the person with the disability. Stakeholders noted that this presented a barrier because often the complaint or concern related directly to that worker, and people felt uncomfortable or feared complaining to that individual.

Given the importance of ensuring that an appropriate, accessible complaint mechanism exists for every service provider in Ontario, ARCH recommends that the *Social Inclusion Act* framework include more detailed provisions regarding complaint mechanisms. These provisions could be incorporated into the legislative framework via an amendment to the Act or, the enactment of regulations pursuant to s. 38(p) of the Act. Such provisions should require service providers to create policies and procedures and establish a formal complaint mechanism that people can access when they wish to raise concerns, recommend changes or complain about the services and supports they receive. Complaint mechanisms must include, at minimum, information on how the complaint can be made and to whom it should be directed; what efforts the service provider will undertake to address and resolve the complaint; procedures for written notification regarding the actions to be taken to address the complaint; timeframes within which the agency will respond to the complaint

and take action to address and resolve the complaint; a requirement that the service provider provide information on advocacy resources that the person can choose to access if she or he wants support to make the complaint; and information on what steps the person can take if she or he is not satisfied with the service provider's response to the complaint. This should include information about various levels of review within the agency, as well as information about appeal mechanisms. The complaint mechanism should not require complaints to be made initially to the person's primary support worker. Instead, complaint mechanisms should offer various points of entry.

Consistent with the principle of accessibility, complaint mechanisms must be accessible and useable by people with intellectual disabilities. Legislative provisions should require service providers to ensure that people with disabilities be informed about the complaint mechanism in a language and manner that is meaningful to them. This would include the use of plain language, pictograms and other accessible means. People should be informed of the availability of such mechanisms when they begin receiving services and annually thereafter. Moreover, complaint forms and other administrative components of complaint mechanisms must be written in accessible language, and not be overly lengthy or complex.

Complaint mechanisms must be designed so that appropriate accommodations and supports are available. Complaint policies or procedures should state that the person making the complaint has the right to have an advocate, family member, or friend support him or her throughout the complaint

process. People with disabilities may also choose to receive support through Peer Advocacy Committees.

As discussed earlier, a significant barrier that prevents people with intellectual disabilities from utilizing complaint mechanisms is fear of reprisal. To combat this barrier, complaint mechanisms must build in safeguards to ensure that people who make complaints are not subject to retaliation, reprisal or threats. The *Social Inclusion Act* framework must include a provision prohibiting such actions. In addition, it is hoped that rights education combined with voluntary monitoring on the part of Peer Advocacy Committees (as described later in this section) would reduce the incidence and fear of reprisals, and contribute to the creation of a culture of rights.

The primary function of complaint mechanisms is to address the individual concerns of people who receive services, however complaint mechanisms should also be used to uncover and address systemic issues. ARCH recommends that the *Social Inclusion Act* framework require service providers to develop policies and procedures for reviewing all complaints to determine trends, areas needing performance improvement and actions to be taken. Service providers must be required to keep records of all complaints received and their outcomes. These records should be reviewed annually, and recommendations should be made for service improvement, revisions to policies and procedures, changes in practice, informing the training of staff, and investigation of systemic concerns.

C. Appeals to an Independent Administrative Body

The creation of complaint mechanisms to enable people with disabilities to raise rights-related concerns with service providers is important, but it is not sufficient. The human rights principle of accountability requires that people with disabilities must have recourse to an independent adjudicative body if they are not satisfied with the service provider's response to the complaint.

ARCH recommends that the *Social Inclusion Act* framework be amended to include the designation of an independent administrative body and a process to receive appeals from complaints filed with service providers. The administrative body would be a newly-constituted complaint appeals and review body made up of members who have expertise or experience in the developmental services sector; knowledge of relevant legislation including the *Social Inclusion Act* and accompanying regulations; and knowledge of relevant administrative law principles including natural justice, fairness and due process. The appeal body would have fairly broad remedial powers to dismiss appeals, make orders requiring service providers to remedy rights violations, or take appropriate actions within specified periods of time. The appeal body may also require investigative powers to ensure that it has access to sufficient information to make a fair decision, and that it can verify information received from the parties.

Parties to an appeal would likely be the person or people who made the original complaint and the service provider. Elements of the appeal process would include a timeframe within which the appeal body would conduct mediation

or dispute resolution or begin a hearing after it receives the appeal, and a prompt timeframe within which a decision would be rendered and the parties notified. Legislation establishing the appeal mechanism must strictly prohibit any threats, reprisals or retaliation against a person who exercises their right to appeal.³⁰⁷

The appeal board should create a process for annually reviewing appeals to determine trends and areas needing performance improvement and/or greater enforcement action. Such information could be delivered to the Ministry of Community and Social Services via an annual report. This would be a valuable function of the appeal body, as it may assist in addressing systemic concerns in a proactive manner.

Of utmost importance when designing the appeal body's process is the need to ensure that the process is accessible to people with intellectual disabilities. A formal, legalistic process is not likely to achieve this objective. Rather, the appeal body's process must be simplified, fairly flexible and must incorporate accessibility features that enable people with intellectual disabilities to readily participate in the process. This may include, for example, creating appeal forms and instructions about the process that are in plain language, pictograms or other accessible format. Appeal body members must have an understanding of their obligation to accommodate people with disabilities during the appeal process, and must receive practical training to enable them to fulfill this obligation. Procedures must include non-adversarial options for resolution of the appeal, such as informal meetings and facilitated mediation. Procedural barriers that may prevent people from participating, such as requirements to draft

and file large numbers of documents, adhere to tight deadlines, or present complex legal arguments, must be modified. Similarly, attention must be paid to ensure that procedural requirements regarding mental capacity do not create undue barriers that prevent people from participating in the process.³⁰⁸ People with disabilities may want or need the assistance of legal counsel or a lay advocate during the appeal process, and the appeal body may be able to provide appropriate referrals. Equally, people should be entitled to have an advocate, family member, or friend support them throughout the appeal process.

D. Peer Advocacy Committees

Self-advocacy has been defined by people with disabilities as:

...learning to speak assertively for yourself, learning to make decisions and solve problems on your own, and learning, practicing and implementing the rights and responsibilities of citizenship.³⁰⁹

According to Tim Stainton, three elements are necessary for self-advocacy to be effective. There must be a clear recognition of the individual's right to decide for themselves; individuals must be given the support and information necessary to make informed decisions; and alternate forms of communication must be recognized and supported.³¹⁰

As discussed earlier, the literature on human rights-based approaches views self-advocacy as a primary means by which people with disabilities can become active participants in service systems. Self-advocacy provides knowledge, skills and partnerships to enable and support people with intellectual disabilities to advocate for their beliefs, express their needs and make decisions about their lives. Stakeholders with disabilities were strongly in favour of self-

advocacy as a tool for enforcement. They echoed the findings in the literature, reporting that from personal experiences and their observations of others, self-advocacy was a means to empower people with disabilities, increase self-confidence, enable greater autonomy in decision-making, and provide support to make complaints or raise concerns about services. Making self-advocacy part of an enforcement system in the developmental services sector is, therefore, a way to implement the principle of participation.

ARCH recommends that a Peer Advocacy Committee be created for each geographic region in the province. Each committee would be comprised of members, all of whom receive services or funding from one or more of the service providers in that geographic region. Committees would be responsible for working with people with disabilities and service providers in their geographic region.

Committees would have three primary roles. First, they would be responsible for conducting rights education activities with people who receive services in their geographic area. Committee members would receive training on the content of the rights education curriculum and methodologies for delivering the information in an accessible manner. Rights education would include information regarding enforcement of rights, including how to make a complaint or conduct an appeal. Second, committee members would be available to support individuals to make complaints and access established complaint and appeal mechanisms. This may include providing information about available complaint and appeal mechanisms; assisting with the identification of situations

in which service rights have been threatened or violated and it is appropriate to make a complaint; assisting with the completion of administrative requirements such as filling out complaint forms; supporting the characterization of the complaint and identification of which service rights were threatened or violated; and connecting the person with advocacy or support resources if necessary. Such support would be provided at the request of the individual and in a confidential manner. The committees' final role would be to meet annually with the Ministry of Community and Social Services to report on systemic concerns and assist in identifying issues that could be addressed by the Ministry.

Stakeholders with disabilities generally felt that supporting people to access enforcement mechanisms was best done through Peer Advocacy Committees, rather than through external advocacy resources, such as an ombudsperson or designated advocate. Trust was cited as a very important consideration when deciding whether to make a complaint or seek assistance in doing so. Members of Peer Advocacy Committees were viewed as people who could be trusted much more readily than external advocates because of their status as fellow service recipients and members of the disability community. One stakeholder stated that members of Peer Advocacy Committees would feel more like family and would speak the same language as those they support, as opposed to outsiders who don't use plain language and tend to make people who receive developmental services nervous. As members of the community of people with disabilities who receive developmental services, committee members would be present in the day-to-day lives of those they would support. This

visibility and familiarity would enable people to have relationships with members, develop trust, and feel much more comfortable relying on members for support when enforcing their rights. As a result, Peer Advocacy Committee members would be called upon more often, making them likely to be more effective at supporting and enabling people with disabilities to raise concerns and make complaints than external advocates.

The visibility and familiarity of Peer Advocacy Committees within the community of people who receive developmental services may also help to address some of the unique needs of people with intellectual disabilities who do not speak or appear to have very limited understanding of their rights. Members of the Peer Advocacy Committee who have long-term relationships with such individuals may be better able to communicate with them, interpret their communication and understand when they are distressed or upset. This would enable Peer Advocacy Committees to deliver rights education in a manner that is tailored to the particular communication style and needs of people who may otherwise not receive or benefit from such education. Peer Advocacy Committee members may also be able to identify potential situations in which the person's rights have been threatened or violated, and offer their support. This kind of proactive approach to advocacy support cannot be offered by external advocates who are unfamiliar with the personality, unique communication needs, and day-to-day lives of people with intellectual disabilities.

The presence of Peer Advocacy Committee members in the community may also assist in reducing fear of reprisals or retaliation, which is one of the

primary barriers to making complaints regarding service rights. Committee members who have assisted an individual to bring forward a complaint will be aware of the nature of the complaint and the parties involved. The committee member will also be familiar with the day-to-day functioning of a group home or service provider and the nature of the relationship between the complainant and their support workers. As a result, the committee member will be in a position to monitor this relationship and become aware of any threats, reprisals or retaliation the complainant is subject to, either through his or her own observation or through conversations with the complainant. In consultation with the complainant, the committee member may then assist in engaging the Peer Advocacy Committee to address such reprisals or retaliation. Committee members may be reluctant to take on such a role due to their own fears of retaliation. As a result, monitoring of retaliation and reprisal should be done at the discretion and option of the individual committee member or Peer Advocacy Committee. This should not be one of the roles officially required of Peer Advocacy Committees.

It is vital for Peer Advocacy Committees to be supported in their work by independent facilitators or advisors. The concept of self-advocacy groups being supported by facilitators and advisors is not new. Facilitators have successfully supported self-advocacy groups for decades, and play a key role in Canadian consumer-led self-advocacy organizations, such as People First. The role of the facilitator is to ensure that committee members are appropriately supported to fulfill their roles. This could include ensuring that members receive appropriate training; coordinating and arranging for meetings and other administrative tasks;

providing plain language interpretation during meetings with government or service providers; and locating additional supports that committees may require such as legal aid services or media contacts.³¹¹ Facilitators do not make decisions for committee members or provide advocacy support instead of committee members. Rather, they are skilled at assisting committee members to acquire the skills and knowledge needed to fulfill their role. Facilitators are committed to empowerment, and assist the committee while respecting the dignity and self-determination of individual committee members.³¹² Similar to facilitators, advisors do not make decisions for committee members. Advisors provide guidance and advice in their area of expertise and help committee members to understand the pros, cons and implications of decisions. Often a self-advocacy group will have several advisors.

Stakeholders emphasized the importance of ensuring that Peer Advocacy Committees are completely independent from service agencies and government. This is vital in order to ensure that Peer Advocacy Committees are able to fulfill their roles, without being restricted due to conflicts of interest, accountability to a service provider's Board of Directors, conditions tied to funding, or simply what others decide may be the best course of action. The importance of independence was highlighted, as several stakeholders spoke of personal experiences in which they were asked to participate in a service provider's initiative or provide the perspective of people with intellectual disabilities, only to have their contributions ignored, have very little input into decision-making, and feel as if they had served a tokenistic role. Interestingly, the importance of independence was echoed by

stakeholders in Quebec who are familiar with the role of Users' Committees in that province.³¹³

The principle of independence applies to facilitators and advisors as well. Peer Advocacy Committees must receive government funding to employ facilitators and advisors. Facilitators and advisors must be recognized as employees of Peer Advocacy Committees, not as employees of government or service providers. Peer Advocacy Committees must be able to interview and hire facilitators and advisors of their choosing, evaluate their performance, and terminate those who do not fulfill their roles appropriately. Committee members would also be responsible for orienting and training their facilitators and advisors.³¹⁴

It must be noted that a number of Ontario service providers presently have self-advocate committees that are associated with the agency. The role that these committees play varies from agency to agency, but can include providing information to the Board of Directors about policies and issues that affect people with intellectual disabilities; working on specific issues that arise associated with the rights, needs and interests of people with intellectual disabilities; and playing a role in decisions made by the agency that affect people with intellectual disabilities.³¹⁵ These self-advocate committees serve a vital role in empowering people with intellectual disabilities and enabling them to participate in the provision of developmental services. However, this is distinct from the Peer Advocacy Committees proposed in this report. If implemented, Peer Advocacy Committees would have a specific mandate to provide on-going rights education,

assistance with complaints, systemic advice to the government and voluntary monitoring. Self-advocate committees may conduct some of these activities from time to time, but do not have a mandate to do so in a concerted, on-going manner. In addition, Peer Advocacy Committees must be independent from government and service providers, while existing self-advocate committees are associated with a service provider or agency. Self-advocate committees are also distinct from consumer-driven organizations such as People First. Given the existence of self-advocate committees and People First groups, it will be important to name the Peer Advocacy Committees in a way that recognizes the distinctions between these groups. If Peer Advocacy Committees are implemented in Ontario, ARCH recommends that consultations be held with the community of people with intellectual disabilities regarding appropriate terminology. Consultation would also be able to identify existing networks and structures within the community that could participate in the development and implementation of Peer Advocacy Committees.

E. Conclusions

Based on the human rights principles of accountability, accessibility, participation and independence, each of the recommended mechanisms is an important part of a scheme to enforce the service rights of people with intellectual disabilities. To have maximum impact, it is necessary to implement all of the mechanisms, as they can work together to address some of the unique challenges in the developmental services sector. For example, rights education

for people with disabilities, service providers, support workers and family members will contribute to a culture of rights, thereby reducing the incidence of reprisals or retaliation when people with disabilities make complaints or raise concerns. Rights education alone, however, will certainly not ensure complete security from reprisals. The potential for reducing the incidence and fear of reprisals will be greatly enhanced if rights education is combined with voluntary monitoring that Peer Advocacy Committees may choose to undertake. Similarly, complaint mechanisms provide a vehicle for individuals to raise concerns about service rights, however without the support of a Peer Advocacy Committee, many complaints may not be made due to fear or lack of awareness about the process. Having a mechanism to make complaints to service providers is important, but without an independent appeal process complaints may not be effective. It is important to note that each of the recommended enforcement mechanisms incorporate an element of systemic oversight, advocacy or enforcement. Together, the recommended enforcement mechanisms can ensure that common concerns or rights violations are addressed on a systemic basis, in a proactive manner.

VI. CONCLUSION

This report proposes that, despite the limitations of the *Social Inclusion Act*, the Ontario government's promise that this legislation will give people with intellectual disabilities more independence, choice and foster their full inclusion in society is a promise that can be realized. True transformation of Ontario's

developmental services system is possible. Two of the key ingredients that are necessary to achieve this transformation are: the inclusion of service rights for people with disabilities in the *Social Inclusion Act* framework; and the creation of robust mechanisms that will enable people with disabilities to realize and enforce their rights.

Adopting a human rights-based approach has transformative potential for Ontario's developmental services sector. Philosophically a human rights-based approach can help to address the historical discrimination and segregation that people with disabilities have endured as a result of previous government policies. Practically, the implementation of such an approach can result in the creation of services that are more responsive to the needs of people with intellectual disabilities; address some of the challenges that prevent people with intellectual disabilities from exercising self-determination; and, include greater accountability.

Applying the principles of a human rights-based approach, and drawing on ARCH's experience, the input of people with disabilities and other stakeholders, ARCH proposes that there are four key elements that must be part of a scheme to enforce the rights of people with intellectual disabilities who receive developmental services and supports:

- Rights education for people with disabilities, service providers, support workers, family members and other stakeholders;
- Amendment of the *Social Inclusion Act* framework to include more detailed provisions regarding complaint mechanisms, including

provisions to ensure that these mechanisms will be accessible for people with intellectual disabilities;

- Designation in the *Social Inclusion Act* framework of an independent administrative body and a process to receive and resolve appeals from complaints; and,
- The creation of Peer Advocacy Committees, who would be charged with conducting rights education activities, supporting recipients of services to use complaint and appeal mechanisms, and meeting annually with the Ministry of Community and Social Services to report on systemic concerns.

Implementation of these four proposals is achievable. Experiences from jurisdictions outside Ontario demonstrate that rights education initiatives, robust complaint and appeal mechanisms, and the creation of self-advocacy networks are feasible, valuable elements of a strong developmental services system. Many consumer-run organizations of people with intellectual disabilities already exist to support the realization of greater rights in the developmental services sector. In addition, several service providers throughout Ontario have acknowledged the need for greater rights awareness and enforcement, and have taken the initiative to develop a variety of rights documents, curricula and enforcement mechanisms. Thus, momentum for the implementation of the four proposals currently exists within the developmental services sector. It must also be noted that Ontario is fortunate to have an active, diverse community of stakeholders in the developmental services sector, many of whom could be consulted with to

participate in the formulation and implementation of these proposals.

Opportunities exist for the government to partner with people with intellectual disabilities, service providers and disability advocacy organizations to facilitate implementation.

ARCH hopes that the research and recommendations included in this report will be given serious review and consideration. Adopting a new approach to developmental services and incorporating the proposals in this report will enable people with intellectual disabilities to become empowered and to gain more independence and choice in their day-to-day lives.

APPENDIX 1: List of Participants in Consultations

Alberta PDD Program Edmonton Region Community Board

Anonymous

California Area Board VII

Community Living British Columbia

Community Living Welland Pelham and Brock University 3 Rs Project: Rights, Respect & Responsibility

Council of Community Living Ontario

Greater Moncton Association for Community Living

People First of Lanark County

People First New Brunswick

People First of Ontario

Quebec Service Quality and Complaints Commissioner

West Montreal Rehabilitation Centre

VII. ENDNOTES

¹ Tanya D. Whitehead and Joseph B. Hughey, *Exploring Self-Advocacy From A Social Power Perspective* (New York: Nova Science Publishers, Inc., 2004) at 5. Whitehead and Hughey assert that public policies and laws reflect dominant worldviews, even though the underlying values may not be known by the people designing and implementing the policies and programs.

² Edgar-Andre Montigny, *Foisted Upon the Government? State Responsibilities, Family Obligations and the Care of the Dependent Aged in Late Nineteenth-Century Ontario* (Montreal & Kingston: McGill-Queen's University Press, 1997) at 63-65.

³ Ivan Brown and Maire Percy, *Developmental Disabilities in Ontario* (Canada: Ontario Association on Developmental Disabilities, 2003) at 3.

⁴ Ontario Ministry of Community and Social Services, "The Words We Used: 1850s-1940s", online: Ontario Ministry of Community and Social Services History of Developmental Services <http://www.mcscs.gov.on.ca/en/dshistory/language/1850s_1940s.aspx> (last accessed: May 26, 2010) [The Words We Used].

⁵ The Words We Used, note 4.

⁶ The Words We Used, note 4.

⁷ Ontario Ministry of Community and Social Services, "The Constitutional Act of 1791", online: Ontario Ministry of Community and Social Services History of Developmental Services <http://www.mcscs.gov.on.ca/en/dshistory/reasons/constitutional_act.aspx> (last accessed: May 26, 2010) [The Constitutional Act of 1791].

⁸ Brown and Percy, note 3 at 6.

⁹ The Label Game, "Housing: Communities and Institutions", online: The Label Game <<http://www.labelgame.org/housing.html#five>> (last accessed: May 25, 2010); Brown and Percy, note 3 at 2-3.

¹⁰ Ivan Brown, "The Time is Right for Closing Institutions" (2004) 11:2 *Journal on Developmental Disabilities* vii at viii.

¹¹ Brown and Percy, note 3 at 7 and 11.

¹² Brown and Percy, note 3 at 11.

¹³ One such documentary is *The Freedom Tour*, a brave and often chilling documentary about institutionalization by 16 members of People First Canada. The goal of the film was to portray the lives lived and lost in institutions in order to bring them to an end. People First of Canada, "The Freedom Tour", DVD: (Canada: National Film Board's Filmmakers Assistance Program and Human Resources and Skills Development Canada, 2008) [The Freedom Tour].

¹⁴ *The Freedom Tour*, note 13.

¹⁵ *The Freedom Tour*, note 13.

¹⁶ The Freedom Tour, note 13.

¹⁷ The Freedom Tour, note 13.

¹⁸ The Freedom Tour, note 13.

¹⁹ Brown, note 10 at ix.

²⁰ The Freedom Tour, note 13.

²¹ The Freedom Tour, note 13.

²² Brown and Percy, note 3 at 7.

²³ Brown and Percy, note 3 at 8-9.

²⁴ Brown and Percy, note 3 at 11.

²⁵ Brown and Percy, note 3 at 12.

²⁶ Brown and Percy, note 3 at 36-37, 45.

²⁷ Tess C. Sheldon, "Programs and Services for Persons with Intellectual Disabilities" (November 2003), online: ARCH Disability Law Centre <http://www.archdisabilitylaw.ca/sites/all/files/08_intellectualDisabilities.pdf> provides additional details regarding the framework of services provided for under the *Developmental Services Act*.

²⁸ *Developmental Services Act*, R.R.O. 1990, Reg. 272.

²⁹ Brown and Percy, note 3 at 33-34.

³⁰ *Developmental Services Act*, R.S.O. 1990, c. D.11, s. 2(2).

³¹ Sheldon, note 27 at 2-3.

³² Community Living Ontario, "Mission, Vision & Goals", online: Community Living Ontario <<http://www.communitylivingontario.ca/about-us/mission-vision-goals> website – mission and values> (last accessed: 28 June 2010).

³³ People First of Ontario, "The Goals of People First of Ontario". online: People First of Ontario <<http://www.peoplefirstontario.com/>> (last accessed: 28 June 2010).

³⁴ Lana Kerzner and Phyllis Gordon, "Discussion Paper Feedback: Transforming Services in Ontario for People who have a Developmental Disability" (December 2004) at 5, online: ARCH Disability Law Centre <http://www.archdisabilitylaw.ca/sites/all/files/Developmental_Services.pdf> (last accessed: 21 May 2010).

³⁵ Ontario Ministry of Community and Social Services, "The Evolution of Government Policy and Legislation: 2000 and Beyond", online: Ontario Ministry of Community and Social Services History of Developmental Services

<http://www.mcass.gov.on.ca/en/dshistory/legislation/2000s_beyond.aspx> (last accessed: 26 June 2010).

³⁶ *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, S.O. 2008, c.14 [Social Inclusion Act].

³⁷ Karen R. Fisher, Sarah Parker and Christiane Purcal, "Measuring the Effectiveness of New Approaches to Housing Support Policy for Persons with Disabilities" (2009) 68:3 *The Australian Journal of Public Administration* 319 at 320.

³⁸ Ontario, Legislative Assembly, *Official Reports of Debates (Hansard)* 47 (May 26, 2008) at 2042–2043 (Hon. Steve Peters).

³⁹ *Social Inclusion Act*, note 36 at s. 4.

⁴⁰ *Social Inclusion Act*, note 36 at s. 4.

⁴¹ *Social Inclusion Act*, note 36 at s. 4.

⁴² *Social Inclusion Act*, note 36 at s. 3.

⁴³ *Social Inclusion Act*, note 36 at s. 14.

⁴⁴ *Services and Supports to Promote The Social Inclusion of Persons With Developmental Disabilities Act, 2008: Quality Assurance Measures* at ss. 5(1)2, 9, and 18(4)(e) [Draft Regulation on Quality Assurance].

⁴⁵ *Social Inclusion Act*, note 36 at s. 24.

⁴⁶ The *Social Inclusion Act* empowers the Ministry of Community and Social Services to make regulations regarding reviewing determinations of eligibility for services, quality assurance measures, reporting requirements to the Minister and the maintenance of financial records. The Lieutenant Governor in Council may make regulations regarding definitions in the *Social Inclusion Act*, funding agreements between the Minister and service agencies, direct funding, reviews of orders regarding quality assurance measures, composition and operation of service agencies, services provided by service agencies, training for staff and volunteers of service agencies, practices and procedures related to complaints received from people with disabilities, and other matters. Directors appointed by the Minister may issue policy directives regarding performance standards and measures for service agencies, procedures to be followed by application entities when determining eligibility for services and administering direct funding, and other matters. See *Social Inclusion Act*, note 36 at ss. 7, 37 and 38.

⁴⁷ *Draft Regulation on Quality Assurance*, note 44 at s. 3(1).

⁴⁸ For example, the *Draft Regulation on Quality Assurance* requires service providers to create a mission statement that promotes social inclusion and individualized approaches to meeting the needs of people with intellectual disabilities. This mission statement must be reviewed with people who receive services and supports and their families when they begin receiving services. See *Draft Regulation on Quality Assurance*, note 44 at s. 4(1).

⁴⁹ *Social Inclusion Act*, note 36 at s. 25.

⁵⁰ *Social Inclusion Act*, note 36 at ss. 27-28.

⁵¹ *Social Inclusion Act*, note 36 at s. 28(6).

⁵² *Social Inclusion Act*, note 36 at s. 30(7).

⁵³ *Social Inclusion Act*, note 36 at s. 31.

⁵⁴ *Social Inclusion Act*, note 36 at ss. 32-33.

⁵⁵ Whitehead and Hughey, note 1 at 20.

⁵⁶ M. Wullink, H. Widdershoven, L. van Schrojenstein, J. Metsemakers, and G.-J. Dinant, "Autonomy in relation to health among people with an intellectual disability: a literature review" (2009) 53:9 *Journal of Intellectual Disability Research* 816 at 816.

⁵⁷ Tim Stainton, "Can Advocacy Eliminate Abuse? Critical Components of an Effective Advocacy System" in Disability-Life-Dignity and Montreal Consortium for Human Rights Advocacy Training, McGill University, School of Social Work, *Speaking Out Against Abuse in Institutions: Advocating for the Rights of People with Disabilities: Conference Proceedings, December 1, 1995* (North York, Ontario: The Roeher Institute, 1997) at 96 [Speaking Out].

⁵⁸ *Kacan v. Ontario Public Service Employees Union*, 2010 HRTO 795 (CanLII) at para. 16.

⁵⁹ The Freedom Tour, note 13; Christina Doody, "Multi-element behaviour support as a model for the delivery of a human rights based approach for working with people with intellectual disabilities and behaviours that challenge" (2009) *British Journal of Learning Disabilities* 293 at 293.

⁶⁰ Doody, note 59 at 297.

⁶¹ Stanley S. Herr and Germain Weber, "Prospects for Ensuring Rights, Quality Supports, and a Good Old Age" in Stanley S. Herr and Germain Weber, eds., *Aging, Rights and Quality of Life: Prospects for Older People with Developmental Disabilities* (Baltimore, Maryland: Paul H. Brookes Publishing Co., 1999) 343 at 346.

⁶² Leanne Dowse, "'Some people are never going to be able to do that': Challenges for people with intellectual disability in the 21st century" (2009) 24:5 *Disability and Society* 571 at 572.

⁶³ Brown and Percy, note 3 at 52.

⁶⁴ Dorothy M. Griffiths, Frances Owen, Leanne Gosse, Karen Stoner, Christine Y. Tardif, Shelley Watson, Carol Sales and Barbara Vyrostopko, "Human Rights and Persons with Intellectual Disabilities: An Action-Research Approach for Community-Based Organizational Self-Evaluation" (2003) 10:2 *Journal on Developmental Disabilities* 25.

⁶⁵ Donato Tarulli, Christine Y. Tardif, Dorothy Griffiths, Frances Owen, Glenys McQueen-Fuentes, Maurice A. Feldman, Carol Sales, and Karen Stoner, "Human Rights and Persons with Intellectual Disabilities: Historical, Pedagogical, and Philosophical Considerations" (Fall 2004) 5 *Encounters on Education* 161 at 165-166.

⁶⁶ Marcia Rioux and Anne Carbert, "Human Rights and Disability: The International Context" (2003) 10:2 *Journal on Developmental Disabilities* 1 at 11.

⁶⁷ Christopher Jochnick, "Confronting the Impunity of Non-State Actors: New Fields for the Promotion of Human Rights" (1999) 21:1 *Human Rights Quarterly* 56 at 59.

⁶⁸ Alicia Ely Yamin, "Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care" (2008) 10:1 *Health and Human Rights* 45 at 49.

⁶⁹ While not elaborated on in this paper, a significant implication of a human rights-based approach is the securing of entitlements for social and economic integration. To date disability policies have been largely reactive and focused on meeting the special needs of a distinct minority group. Human rights frameworks "normalize" disability issues, thereby moving them into wider debates about social policy and human development. This move may lead to a sustained development of equality in all areas of social life, not only with respect to disability issues. See Patricia Noonan Walsh, "Keynote Review: Human rights, development and disability" (2003) 2:1 *Journal of Law and Equality* 1; Jerome E. Bickenbach, "Disability and Equality" (2003) 2:1 *Journal of Law and Equality* 7.

⁷⁰ Thomas Pogge (ed.), *Freedom from Poverty as a Human Right: Who Owes What to the Very Poor?* (New York: Oxford University Press and UNESCO, 2007) at 4.

⁷¹ Lawrence O. Gostin, "Beyond Moral Claims: A Human Rights Approach in Mental Health" (2001) 10 *Cambridge Quarterly of Healthcare Ethics* 264 at 264.

⁷² Whitehead and Hughey, note 1 at 17.

⁷³ Sussannah Mayhew, Megal Douthwaite and Michael Hammer, "Balancing Protection and Pragmatism: A Framework for NGO Accountability in Rights-Based Approaches" (2006) 9:2 *Health and Human Rights* 180 at 183.

⁷⁴ Damon A. Young and Ruth Quibell, "Why Rights are Never Enough: Rights, Intellectual Disability and Understanding" (2000) 15:5 *Disability and Society* 747 at 749-751.

⁷⁵ Young and Quibell, note 74 at 749-751.

⁷⁶ Terry Carney, "'Righting' Wrongs for the Aged: a Bill of Rights?" (2008) 16:2 *Australian Journal on Ageing* 73 at 76.

⁷⁷ Carney, note 76 at 76-77.

⁷⁸ Young and Quibell, note 74 at 753; Dowse, note 62 at 577-578 provides another critique of empowerment, arguing that it focuses on acquiring skills and accessing resources and is in danger of becoming just another intervention used by service providers.

⁷⁹ Such supports may include disability accommodations and/or supported-decision making.

⁸⁰ *Convention on the Rights of Persons with Disabilities*, UN GAOR, 61st Sess., 76th Mtg., UN Doc. GA/10554 (2006), online: United Nations Enable

<<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>> (last accessed: 25 June 2010) [CRPD]; United Nations General Assembly, News Release/Communiqué, “General Assembly Adopts Groundbreaking Convention, Optional Protocol on rights of Persons with Disabilities” (13 December 2006), online: United Nations <<http://www.un.org/News/Press/docs/2006/ga10554.doc.htm>> (last accessed: 21 May 2010).

⁸¹ United Nations Enable, “Timeline of Convention Events”, online: United Nations Enable <<http://www.un.org/disabilities/default.asp?navid=22&pid=153>> (last accessed: 21 May 2010).

⁸² Some examples of international instruments that have provided for rights for people with disabilities include the *World Programme of Action Concerning Disabled Persons*, the *Inter-American Convention on the Elimination of All Forms of Discrimination against People with Disabilities*, and the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. There have also been international instruments dealing specifically with the rights of people with intellectual disabilities, such as the *Montreal Declaration on Intellectual Disabilities*. For a detailed history of the development of a rights-based approach to disability at international level, see Rioux and Carbert, note 66 at 1-13; see also Marcia H. Rioux, Bengt Lindqvist and Anne Carbert, “International Human Rights and Intellectual Disability” (2006) *Intellectual and Developmental Disabilities: International Edition* 59 at 59-67.

⁸³ CRPD, note 80 at art. 1.

⁸⁴ Office of the United Nations High Commissioner for Human Rights, “General Assembly Ad Hoc Committee, 8th Session: Statement by Louise Arbour, UN High Commissioner for Human Rights” (5 December 2006), online: United Nations High Commissioner for Human Rights <<http://www2.ohchr.org/English/issues/disability/docs/statementhcdec06.doc>> (last accessed: 21 May 2010); Tony Ward and Claire Stewart, “Putting Human Rights into Practice with People with Intellectual Disability” (2008) 20:3 *Journal of Developmental and Physical Disabilities* 297 at 305.

⁸⁵ Jonathan Kenneth Burns, “Mental Health and Inequity: A Human Rights Approach to Inequity, Discrimination and Mental Disability” (2009) 11:2 *Critical Concepts* 19 at 20.

⁸⁶ CRPD, note 80 at art. 3.

⁸⁷ CRPD, note 80 at art. 19.

⁸⁸ By General Assembly resolution 56/168, the United Nations established the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities. This Committee was charged with drafting what became the CRPD. The resolution also invited states and non-governmental organizations that were not members of the Committee to make submissions on the Committee’s work. *Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities*, GA Res. 56/168, UN GAOR, 56th Sess., UN Doc. A/56/PV.88 (2001), online: United Nations <<http://www.un.org/esa/socdev/enable/disA56168e1.htm>> (last accessed: 21 May 2010).

⁸⁹ Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 7th Sess., vol. 8, no. 5, Daily summary of discussion at the seventh session, UN Convention on the Human Rights of People with Disabilities (2006), online: United Nations Enable <<http://www.un.org/esa/socdev/enable/rights/ahc7sum20jan.htm>> (last accessed: 21 May 2010).

⁹⁰ Alicia Ely Yamin and Eric Rosenthal, "Out of the Shadows: Using Human Rights Approaches to Secure Dignity and Well-being for People with Mental Disabilities" (2005) 2:4 Public Library of Science 296 at 296-298.

⁹¹ United Nations Treaty Collection, "Convention on the Rights of Persons with Disabilities" (13 December 2006), online: United Nations Treaty Collection <http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec> (last accessed: 21 May 2010). Canada made the following declaration and reservation upon ratification: Canada recognises that persons with disabilities are presumed to have legal capacity on an equal basis with others in all aspects of their lives. Canada declares its understanding that Article 12 permits supported and substitute decision-making arrangements in appropriate circumstances and in accordance with the law. To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards. With respect to Article 12 (4), Canada reserves the right not to subject all such measures to regular review by an independent authority, where such measures are already subject to review or appeal. Canada interprets Article 33 (2) as accommodating the situation of federal states where the implementation of the Convention will occur at more than one level of government and through a variety of mechanisms, including existing ones.

⁹² Armand de Mestral and Evan Fox-Decent, "Rethinking the Relationship Between International and Domestic Law" (2008) 53 McGill L.J. 573 at para. 48.

⁹³ Canada employs a "dualist" model, meaning that once a treaty has been signed and ratified by the federal executive it still requires incorporation into domestic law to be enforceable at the national level. Due to the nature of Canadian federalism, responsibility for implementing the *CRPD* falls to both the federal and provincial/territorial governments. The federal government can legislate to implement the *CRPD* in areas that fall within federal jurisdiction, but cannot do so in areas within provincial/territorial jurisdiction. Human rights obligations with respect to education fall squarely within provincial and territorial jurisdiction. It is, therefore, provincial and territorial governments that have the legal authority to create new laws or policies to implement the obligations relating to education as set out in the *CRPD*.

⁹⁴ de Mestral, note 92 at paras. 48-49; see also Canada, Parliament, "Canada's Approach to the Treaty-Making Process" by Laura Barnett, Legal and Legislative Affairs Division, PRB 08-45E (24 November 2008).

⁹⁵ Several clues point to the conclusion that this is the approach being taken by the Canadian government to implementation of the *CRPD*. Between signing the *CRPD* in March 2007 and ratifying it two years later, the federal government sought the views of the provinces and territories on the extent to which provincial and territorial laws conform to the treaty. Upon ratifying the *CRPD* the federal government announced that it had done so with the full support of the provincial and territorial governments. To date, no new legislation has been enacted to implement the *CRPD* into Canadian domestic law. Rob Nicholson, Minister of Justice and Attorney General of Canada, stated that upon ratification, the *CRPD* will complement domestic laws, implying that the enactment of new legislation is unlikely. See: Foreign Affairs and International Trade Canada, News Release, No. 368, "Government of Canada Tables Convention on Rights of Persons with Disabilities" (3 December 2009), online: Foreign Affairs and International Trade Canada <<http://www.international.gc.ca/media/aff/news-communicues/2009/368.aspx?lang=eng>> (last accessed: 21 May 2010); Foreign Affairs and International Trade Canada, News Release, No. 99, "Canada Ratifies UN Convention on the Rights of Persons with Disabilities" (11 March 2010), online: Foreign Affairs and International

Trade Canada <<http://www.international.gc.ca/media/aff/news-communiqués/2010/99.aspx?lang=eng>> (last accessed: 21 May 2010).

⁹⁶ Elisabeth Eid and Hoori Hamboyan, “Implementation by Canada of its International Human Rights Treaty Obligations: Making Sense out of the Nonsensical” in Oonagh E. Fitzgerald et al. eds., *The Globalized Rule of Law: Relationships between International and Domestic Law* (Toronto: Irwin Law, 2006) at ch. 13.

⁹⁷ The fact that the provision of developmental services falls within provincial and territorial jurisdiction does not detract from this implication, since the federal government ratified the *CRPD* after consulting with and receiving full support from provincial and territorial governments.

⁹⁸ *Canadian Charter of Rights and Freedoms*, s. 15, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11 [*Charter*].

⁹⁹ *Human Rights Code*, R.S.O. 1990, c. H.19, s. 1.

¹⁰⁰ *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624 [*Eldridge*] at para. 56.

¹⁰¹ M. David Lepofsky, “Discussion: The Charter’s Guarantee of Equality to People with Disabilities - How Well is it Working?” (1998) 16 Windsor Year Book of Access to Justice 155 at 171-172.

¹⁰² *Eaton v. Brant County Board of Education*, [1997] 1 S.C.R. 241 [*Eaton*] at para. 67.

¹⁰³ Ontario Human Rights Commission, “Policy and guidelines on disability and the duty to accommodate” (23 November 200, revised December 2009) at 4, online: Ontario Human Rights Commission <<http://www.ohrc.on.ca/en/resources/Policies/PolicyDisAccom2/pdf>> (last accessed: 29 June 2010) [OHRC Policy and guidelines].

¹⁰⁴ OHRC Policy and guidelines, note 103.

¹⁰⁵ *Council of Canadians with Disabilities v. VIA Rail Canada Inc.*, [2007] 1 S.C.R. 650, 2007 SCC 15 at para. 110.

¹⁰⁶ OHRC Policy and guidelines, note 103 at 10.

¹⁰⁷ *Eaton*, note 102 at paras. 66-67; *Eldridge*, note 100 at para. 65; *Nova Scotia (Workers’ Compensation Board) v. Martin*; *Nova Scotia (Workers’ Compensation Board) v. Laseur*, [2003] 2 S.C.R. 504, 2003 SCC 54 at paras. 89 and 93.

¹⁰⁸ OHRC Policy and guidelines, note 103 at 10.

¹⁰⁹ *R. v. Kapp*, [2008] 2 S.C.R. 483, 2008 SCC 41 at para. 21.

¹¹⁰ *Kapp*, note 109 at paras. 21-23.

¹¹¹ For a detailed discussion of the potential for s. 7 to be used to advance claims of social justice, see James R. Hendry, “Section 7 and Social Justice” (Paper presented to the Ontario Bar Association 8th Annual *Charter* Conference, 18 September 2009).

¹¹² *Charter*, note 98 at s. 7.

¹¹³ United Nations Office of the High Commissioner for Human Rights, *Claiming the Millenium Development Goals: A Human Rights Approach* (New York: United Nations, 2008) at 15, online: <http://www.ohchr.org/Documents/Publications/Claiming_MDGs_en.pdf> (last accessed: 29 June 2010).

¹¹⁴ Alicia Ely Yamin, "Shades of Dignity: Exploring the Demands of Equality in Applying Human Rights Frameworks to Health" (2009) 11:2 *Health and Human Rights* 1 at 14.

¹¹⁵ Alicia Ely Yamin, "Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health" (2008) 10:2 *Health and Human Rights* 1 at 1.

¹¹⁶ Mayhew, Douthwaite and Hammer, note 73 at 181.

¹¹⁷ Paul Hunt and Judith Mesquita, "Mental Disabilities and the Human Right to the Highest Attainable Standard of Health" (2006) 28:2 *Human Rights Quarterly* 332 at 350-351.

¹¹⁸ Herr and Weber, note 61 at 354 and 359; Burns, note 85 at 25. Burns writes that it has been repeatedly demonstrated that "user-led" advocacy regarding legal reform, service development, and social transformation has been very effective in ending discrimination and stigmatization and achieving human rights for specific minority communities.

¹¹⁹ Herr and Weber, note 61 at 360.

¹²⁰ Whitehead and Hughey, note 1 at 16-17; Peter Park, Althea Monteiro and Bruce Kappel, "People First: The History and The Dream" in Deborah Stienstra and Aileen Wight-Felske, eds., *Making Equality: History of Advocacy and Persons with Disabilities in Canada* (Concord: Captus Press Inc., 2003) 183 at 184.

¹²¹ Park, Monteiro and Kappel, note 120 at 184. For a more detailed history of the People First movement see 186-187.

¹²² Park, Monteiro and Kappel, note 120 at 184.

¹²³ Alberta Ministry of Seniors and Community Supports, "Persons with Developmental Disabilities", online: Alberta Ministry of Seniors and Community Supports <<http://www.seniors.alberta.ca/PDD/>> (last accessed: 9 April 2010).

¹²⁴ Alberta Ministry of Seniors and Community Supports, "Persons with Developmental Disabilities: Overview", online: Alberta Ministry of Seniors and Community Supports <<http://www.seniors.alberta.ca/PDD/overview.asp>> (last accessed: 9 April 2010) [Alberta Persons with Developmental Disabilities Overview].

¹²⁵ Alberta Persons with Developmental Disabilities Overview, note 124.

¹²⁶ Alberta Ministry of Seniors and Community Supports, "PDD Quick Fact Sheet", online: Alberta Ministry of Seniors and Community Supports <<http://www.seniors.alberta.ca/PDD/FactSheets/QuickFacts.asp>> (last accessed 9 April 2010).

- ¹²⁷ *Persons with Developmental Disabilities Community Governance Act*, R.S.A. 2000, c. P-8 [PDD Community Governance Act].
- ¹²⁸ *PDD Community Governance Act*, note 127 at preamble.
- ¹²⁹ *PDD Community Governance Act*, note 127 at ss. 9(1)(a), (b), and (k).
- ¹³⁰ *PDD Community Governance Act*, note 127 at ss. 11(e).
- ¹³¹ *PDD Community Governance Act*, note 127 at ss. 16(1).
- ¹³² *PDD Community Governance Act*, note 127 at ss. 16(2) and (3).
- ¹³³ *PDD Community Governance Act*, note 127 at ss. 17(1).
- ¹³⁴ Alberta Council of Disability Services, online: <www.acds.ca> (last accessed: 29 June 2010).
- ¹³⁵ Alberta Ministry of Seniors and Community Supports, *Persons with Developmental Disabilities Program: Operational Program Policy, Community Inclusion Supports Framework*, (3 January 2007) at Section 06 - Page 1, online: Alberta Ministry of Seniors and Community Supports <<http://www.seniors.alberta.ca/pdd/policies/CISF.pdf>> (last accessed: 29 June 2010).
- ¹³⁶ Alberta Council of Disability Services, *Creating Excellence Together: Accreditation Level 1 Standards and Accreditation Level 2 Standards* (September 2008), online: Alberta Council of Disability Services <http://www.acds.ca/PDFS/CET%20Level%201%20and%202/CET_Levels_1_2_StdS_2008.pdf> (last accessed: 29 June 2010).
- ¹³⁷ Alberta Ministry of Seniors and Community Supports, "Guide to the Persons with Developmental Disabilities (PDD) Appeal Process", online: Alberta Ministry of Seniors and Community Supports <<http://www.seniors.alberta.ca/pdd/appeals/AppealGuide.pdf>> (last accessed: 9 April 2010).
- ¹³⁸ Interview of Alberta PDD Program Edmonton Region Community Board (31 May 2010).
- ¹³⁹ Alberta Ministry of Seniors and Community Supports, "Guide to the Persons with Developmental Disabilities (PDD) Appeals Process: *Persons with Developmental Disabilities Community Governance Act, Section 4(2) and 15(3)*" at 20 and 24, online: Alberta Ministry of Seniors and Community Supports <<http://www.seniors.alberta.ca/PDD/appeals/appealguide.pdf>> (last accessed: 9 April 2010) [Alberta – PDD Regulation and Appeals Guide].
- ¹⁴⁰ Interview of Alberta PDD Program Edmonton Region Community Board (2 June 2010) [Interview of Alberta PDD Program – 2 June 2010].
- ¹⁴¹ *Persons with Developmental Disabilities Community Governance (Ministerial) Regulation*, Alta. Reg. 181/2006; Alberta – PDD Regulation and Appeals Guide, note 139.
- ¹⁴² Alberta – PDD Regulation and Appeals Guide, note 139.
- ¹⁴³ Interview of Alberta PDD Program – 2 June 2010, note 140.

¹⁴⁴ *Supportive Living Accommodation Licensing Act*, S.A., 2009, c. S-23.5 at s. 2(1) [SLALA]. This Act applies to supportive living accommodation provided by an operator where (a) the supportive living accommodation is provided to 4 or more adults who are not related to the operator, (b) the operator provides or arranges for services related safety and security for the persons referred to in clause (a) in accordance with the standards set out or adopted in the regulations, and (c) the operator provides, offers or arranges for (i) at least one meal per day, or (ii) housekeeping services, for the persons referred to in clause (a). Section 1 of the Act defines “supportive living accommodation” as building or units in buildings that are intended for permanent residential living where an operator also provides or arranges for services in order to assist residents to live as independently as possible. See also Interview of Alberta PDD Program – 2 June 2010, note 140.

¹⁴⁵ SLALA, note 144 at ss. 7(1)(a)-(e).

¹⁴⁶ SLALA, note 144 at ss. 7(1) and (2).

¹⁴⁷ SLALA, note 144 at s. 7(9).

¹⁴⁸ SLALA, note 144 at ss. 8(1)-(2).

¹⁴⁹ SLALA, note 144 at s. 9(1)-(2).

¹⁵⁰ SLALA, note 144 at s. 10(1).

¹⁵¹ SLALA, note 144 at s. 10(2)(a)(i)-(ii).

¹⁵² SLALA, note 144 at s. 10(2)(b). Subsection 10(3) states that a complaints officer may refuse to refer a complaint to an investigator if the complaint is frivolous or vexatious or the complaints officer resolves the complaint.

¹⁵³ SLALA, note 144 at ss. 10(4)-(5).

¹⁵⁴ SLALA, note 144 at s. 11.

¹⁵⁵ SLALA, note 144 at s. 12(1).

¹⁵⁶ SLALA, note 144 at ss. 12(2)-(3).

¹⁵⁷ SLALA, note 144 at ss. 12(4)(a)-(c). Pursuant to s. 12(5), the director can require an order issued under subsection 4(a) to be posted in a prominent place in the supportive living accommodation.

¹⁵⁸ SLALA, note 144 at s. 17(1).

¹⁵⁹ SLALA, note 144 at s. 22(1).

¹⁶⁰ *Community Living Authority Act*, S.B.C. 2004, c. 60 [Community Living Authority Act].

¹⁶¹ Community Living British Columbia, “Who We Are: History”, online: Community Living British Columbia <http://www.communitylivingbc.ca/who_we_are/history.htm> (last accessed: 14 May 2010).

¹⁶² *Community Living Authority Act*, note 160 at ss. 11-12.

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¹⁸¹ CLBC Complaints Resolution Policy, note 173 at 5.

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¹⁸⁴ CLBC Complaints Resolution Policy, note 173 at 5.

¹⁸⁵ CLBC Complaints Resolution Policy, note 173 at 6.

¹⁸⁶ CLBC Complaints Resolution Policy, note 173 at 6.

¹⁸⁷ Interview of Community Living British Columbia (10 June 2010) [Interview of CLBC].

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- ²¹⁵ NB Standards and Procedures for Adult Residential Facilities, note 212 at s. 2.20.
- ²¹⁶ NB Standards and Procedures for Adult Residential Facilities, note 212 at s. 2.21. The Standards and Procedures at section 5.4 also require operators of residential facilities to develop programs that recognize the individuality of each resident, and that assist residents in attaining and maintaining an optimal personal level of functioning, self-care and independence. Operators

are also required to develop programs that enhance inclusion and autonomous decision-making for residents.

²¹⁷ NB Standards and Procedures for Adult Residential Facilities, note 212 at s. 6.1.

²¹⁸ NB Standards and Procedures for Adult Residential Facilities, note 212 at s. 6.2.

²¹⁹ NB Standards and Procedures for Adult Residential Facilities, note 212 at 6.2.

²²⁰ See generally, Gouvernement du Québec, “Focus on the Québec Health and Social Services System” at 50-51, online: Gouvernement du Québec <<http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2009/09-731-01A.pdf>> (last accessed: 18 May 2010) [Focus on Quebec Health and Social Services System].

²²¹ Focus on Quebec Health and Social Services System, note 220.

²²² *An act respecting health and social services*, R.S.Q. c. S-4.2 at s. 29 [*Act respecting health and social services*].

²²³ West Montreal Readaptation Centre, “What to do if you are dissatisfied with a service?” online: West Montreal Readaptation Centre <<http://crom-wmrc.ca/complaints-and-service-quality.html>> (last accessed: 6 May 2010).

²²⁴ *Act respecting health and social services*, note 222 at s. 12.

²²⁵ *Act respecting health and social services*, note 222 at s. 33(3).

²²⁶ *Act respecting health and social services*, note 222 at s. 33(6).

²²⁷ Interview of Quebec Service Quality and Complaints Commissioner (3 June 2010) [Interview of Service Quality and Complaints Commissioner].

²²⁸ Otherwise, the decision may be transmitted verbally. See *Act respecting health and social services*, note 222 at s. 33(6).

²²⁹ Interview of Service Quality and Complaints Commissioner, note 227.

²³⁰ Likewise, if the institution in question does not follow up with the recommendations of the Commissioner, a complaint lies with the Ombudsman.

²³¹ *An act respecting the health and social services ombudsman*, R.S.Q., c. P-31.1 at ss. 8-9 [*Ombudsman Act*].

²³² Le Protecteur du citoyen, “Mandate” online: Le Protecteur du citoyen <<http://www.protecteurducitoyen.qc.ca/en/the-quebec-ombudsman/mandate/index.html>> (last accessed: 17 May 2010) [Le Protecteur du citoyen - Mandate].

²³³ *Ombudsman Act*, note 231 at s. 15.

²³⁴ Le Protecteur du citoyen – Mandate, note 232.

- ²³⁵ *Act respecting health and social services*, note 222 at s. 212.
- ²³⁶ Interview of West Montreal Rehabilitation Centre (4 June 2010) [Interview of West Montreal Rehabilitation Centre].
- ²³⁷ *Disability Act 2006* (Vic.), ss. 4(d)-(f).
- ²³⁸ *Disability Act 2006* (Vic.), note 237 at s. 97.
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- ²⁴⁰ *Disability Act 2006* (Vic.), note 237 at s. 103.
- ²⁴¹ *Disability Act 2006* (Vic.), note 237 at s. 104.
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- ²⁴³ *Disability Act 2006* (Vic.), note 237 at s. 16.
- ²⁴⁴ Office of the Disability Services Commission, *Good practice guide and self audit tool: Developing an effective person centred complaints management culture and system* (Victoria, Australia: 2009) at 4, online: Office of the Disability Services Commission <http://www.odsc.vic.gov.au/downloads/good_practice_guide_introduction.pdf> (last accessed: 29 June 2010).
- ²⁴⁵ *Disability Act 2006* (Vic.), note 237 at s. 111(1).
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- ²⁴⁷ *Disability Act 2006* (Vic.), note 237 at ss. 118-120.
- ²⁴⁸ *Disability Act 2006* (Vic.), note 237 at s. 22.
- ²⁴⁹ *Disability Act 2006* (Vic.), note 237 at ss. 70(4)(a)-(b) and 71(1).
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- ²⁵¹ *Disability Act 2006* (Vic.), note 237 at s. 82(1).
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- ²⁵³ Care Quality Commission, "How we will monitor compliance," online: Care Quality Commission <<http://www.cqc.org.uk/guidanceforprofessionals/introductiontoregistration/howthenewregistrationssystemworks/howwewillmonitorcompliance.cfm>> (last accessed: 12 May 2010).
- ²⁵⁴ *Health and Social Care Act 2008* (Regulated Activities) Regulations 2010 reg. 10(2) [*Health and Social Care Act Regulation*].
- ²⁵⁵ *Health and Social Care Act Regulation*, note 254 at reg. 19(1).

- ²⁵⁶ *Health and Social Care Act Regulation*, note 254 at reg. 19(2).
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- ²⁵⁹ Care Quality Commission, “Guidance about compliance”, at 153, online: Care Quality Commission <http://www.cqc.org.uk/_db/_documents/Essential_standards_of_quality_and_safety_FINAL_081209.pdf> (last accessed: 13 May 2010).
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- ²⁸³ *Lanterman Act*, note 272 at s. 4701(n).
- ²⁸⁴ *Lanterman Act*, note 272 at ss. 4710.6(a)-(c).
- ²⁸⁵ *Lanterman Act*, note 272 at ss. 4710.5(b) and (c).
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²⁹⁸ *Texas Administrative Code*, T.A.C. (1999) at ss. 357.1(11) and 357.21(a)(b) [*Texas Administrative Code*].

²⁹⁹ *Texas Administrative Code*, note 298 at s. 357.21(b).

³⁰⁰ This means the hearing must be scheduled and conducted and a decision must be issued. See *Texas Administrative Code*, note 298 at s. 357.23(a)(2).

³⁰¹ CLBC Complaints Resolution Policy, note 173 at 7.

³⁰² Interview of West Montreal Rehabilitation Centre, note 236; Interview of the Greater Moncton Association for Community Living (11 June 2010).

³⁰³ Interview of the Community Living Welland Pelham and Brock University 3 Rs Project (17 June 2010) [Interview of 3 Rs Project].

³⁰⁴ One service provider noted that a combination of group training, online training and games was found to be the most effective method of delivering rights education to people with intellectual disabilities in a group home setting. Interview of 3 Rs Project, note 303.

³⁰⁵ Tarulli, Tardif, Griffiths and Owen, note 65 at 167-170.

³⁰⁶ Interview of 3 Rs Project, note 303.

³⁰⁷ Provisions of this kind can be found in many Ontario statutes, including the *Long Term Care Act, 1994*, S.O. 1994, c.26, s. 3(1)7, the *Long-Term Care Homes Act, 2007*, S.O. 2007, c. 8, s. 26, and Ontario’s *Human Rights Code*, R.S.O. 1990, c. H. 19 at s. 8.

³⁰⁸ For a more detailed analysis of procedure barriers with respect to capacity, as well as suggestions for reform, see Tess C. Sheldon, “Access to Administrative Justice for Persons with Disabilities: Addressing the Capacity of Parties Before Ontario’s Administrative Tribunals” (December 2009), online: ARCH Disability Law Centre <<http://www.archdisabilitylaw.ca/?q=addressing-capacity-parties-ontario%E2%80%99s-administrative-tribunals-respecting-autonomy-protecting-fairne>>.

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APPENDIX 2: List of Acronyms

Advocate	Advocate for Service Quality (British Columbia)
Board	Disability Services Board (Australia)
CEO	Chief Executive Officer
CLBC	Community Living British Columbia
Commissioner	Service Quality and Complaints Commissioner (Quebec)
Commissioner	Disability Services Commissioner (Australia)
<i>CRPD</i>	<i>Convention on the Rights of Persons with Disabilities</i>
CSA	<i>Care Standards Act 2000</i> (UK)
CSSS	Health and Social Services Centre (Quebec)
CQ Commission	Care Quality Commission (UK)
<i>DA</i>	<i>Disability Act 2006 (Vic.)</i> (Australia)
DADS	Department of Aging and Disability Services (US: Texas)
DARS	Department of Assistive and Rehabilitative Services (US: Texas)
<i>Draft Regulation</i>	<i>Draft Regulation on Quality Assurance Measures</i> (Ontario)
HRB Approach	Human Rights-based Approach
<i>HSCA Regulations</i>	<i>Health and Social Care Act 2008 (Regulated Activities) Regulations 2010</i> (UK)

<i>Lanterman Act</i>	<i>Lanterman Developmental Disabilities Act (US: California)</i>
LGO	Local Government Ombudsman (UK)
NDA	National Disability Agreement (Australia)
NGO	Non-governmental Organization
<i>Ombudsman Act</i>	<i>An act respecting the health and social services ombudsman (Quebec)</i>
PDD Program	Persons with Developmental Disabilities Program (Alberta)
SCDD	State Council on Developmental Disabilities (US: California)
<i>Social Inclusion Act</i>	<i>Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (Ontario)</i>
Standards and Procedures	<i>Standards and Procedures for Adult Residential Facilities (New Brunswick)</i>
TAC	<i>Texas Administrative Code (US: Texas)</i>