



## A LEGAL RESOURCE CENTRE FOR PERSONS WITH DISABILITIES

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Via E-mail Christine.Hughes@css.gov.on.ca and regular mail

December 13, 2004

Christine Hughes  
Manager, Policy Coordination  
Developmental Services Branch  
Ministry of Community and Social Services  
56 Wellesley Street West, 12<sup>th</sup> Floor  
Toronto, ON M7A 1E9

Dear Ms Hughes:

**Re: Discussion Paper Feedback: Transforming Services in Ontario for People who have a Developmental Disability**

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Please find enclosed ARCH's submission in response to the discussion paper "Transforming Services in Ontario for People who have a Developmental Disability".

I would like to thank you for extending the deadline for accepting our submission. This assisted us to prepare a more complete response.

If you have any questions or would like to discuss the submission, please feel free to contact me or Phyllis Gordon, Executive Director of ARCH.

Yours very truly,

Lana Kerzner  
Staff Lawyer

Enclosure

cc: Myra Wiener, Director, Developmental Services Branch, Ministry of Community and Social Services, Myra.Wiener@css.gov.on.ca

**Submission of ARCH: A Legal Resource Centre for Persons with  
Disabilities**

**To the Developmental Services Branch of the Ministry of  
Community and social Services**

**Discussion Paper Feedback: Transforming Services in Ontario for  
People who have a Developmental Disability**

**December 13, 2004**

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## Preface

ARCH congratulates the Ministry of Community and Social Services (Ministry) for this initiative which aims to effectively address the needs of adults who have a developmental disability. The creation of a developmental services system that is based on fundamental values of full citizenship is long overdue.

ARCH is encouraged by the activities the Ministry has already undertaken to achieve its goal. The Preliminary Discussion Paper developed by the Partnership Table raises very important issues. The principles it sets out are excellent guides to the design of a fair and responsive system. The forums on specialized resources and residential options provided a needed opportunity to canvass a broad range of research, experience and options. We urge the Ministry to continue to obtain broad feedback from stakeholders at all stages of the review process. In particular, it is crucial that the reform reflect the perspectives of those being served, that is, persons who have a developmental disability.<sup>1</sup>

In this submission ARCH focuses on legal issues that are, in our view, essential considerations for this review. We hope this will be useful to the consultation process and to the formulation of the draft plan. Given our emphasis on legal matters, we do not directly respond to the questions posed in “Transforming Services in Ontario for People who have a Developmental Disability”.

ARCH is well aware that there is not a consensus on the resolution of the issues that need to be addressed. ARCH hopes that the Ministry plan for developmental services will reflect this diversity of views and needs and provide a broad approach which meets the range of needs and preferences rather than a more narrowly

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<sup>1</sup>In this submission ARCH refers to “developmental” disability, as this is the language in the Preliminary Discussion Paper. We note that there is a difference of views in the community regarding the most appropriate language and suggest that the review canvass this issue.

focused “one size fits all” solution. The latter approach will ultimately leave many people unserved.

## **About ARCH**

ARCH is an Ontario-based not-for-profit legal clinic that is dedicated to defending and advancing the equality rights of persons with disabilities, regardless of the nature of the disability. ARCH provides a telephone summary advice and referral service to Ontarians with disabilities. ARCH represents individuals as well as provincial and national disability organizations in test case litigation at all levels of tribunals and courts. We provide education to persons with disabilities and to their advocates and families on disability rights and to the legal profession about disability law. We make submissions to governments on matters of policy and law reform. ARCH maintains an informative web site on disability law. ARCH is governed by a volunteer board of directors, a majority of whom are persons with disabilities.

## **ARCH’s Experience with Persons who have a Developmental Disability**

ARCH regularly hears concerns about the delivery of supports and services to persons who have a developmental disability. Our experience with these issues is broad and is based on our contacts with persons with disabilities themselves, their families and support people, advocates and community groups. ARCH staff have provided advice as part of our summary advice and referral service to individuals who have a developmental disability, have represented clients in relevant litigation<sup>2</sup>, have engaged in discussions of these issues with consumer and

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<sup>2</sup> ARCH has recently litigated two cases relevant to this review. We were co-counsel in *Nieberg (Litigation guardian of) v. Ontario (Minister of Community Family and Children’s Services)*, [2004] O.J. No. 1135 (QL) which considered the delivery of services under the *Child and Family Services Act*, R.S.O. 1990, c. C.11. ARCH is counsel to People First of Canada and the Canadian Association of Community Living in the appeal before the Supreme Court of Canada of the Nova Scotia Court of Appeal decision of *Nova Scotia (Minister of Mealth) v. J.J.*, 2003 NSCA 71. This case, which was argued on November 4, 2004, before the Supreme Court, considered the interpretation of the *Adult Protection Act*, R.S.N.S. 1989, c. 2 of Nova Scotia.

advocacy groups and have conducted legal and non-legal research on supports and services for persons who have a developmental disability.

## **Overview**

ARCH is concerned that without prompt attention to the inadequacies of the developmental services system a crisis will occur. It was not long ago that Stephanie Jobin's life was lost from injuries suffered as a result of restraints that were imposed on her in a group home. Following this horrific event, and subsequent Coroner's inquest and recommendations of the Coroner's jury, there were substantial additions to the Regulations to the *Developmental Services Act* setting out detailed rules governing physical restraints. ARCH urges the Ministry to act now to take steps to evaluate and amend the statutory framework governing developmental services. We urge the Ministry to be proactive in anticipating and preventing injustice and abuse rather than wait until yet another crisis provides impetus for change.

While some individuals who have developmental disabilities are content with the supports and services they receive, the vast majority are not. There is not one specific problem or complaint. Rather, a number of concerns arise in many aspects of program and service delivery.

It is ARCH's view that these problems, and many others that have been identified during the consultation, arise, in part, from the absence of a clear statutory framework for developmental services. The *Developmental Services Act* (DSA) authorizes the establishment, operation and maintenance of facilities and the provision of services and assistance upon such terms and conditions as the Minister sees fit. (s. 2(1)). Section 2(2) provides for the Minister to purchase such services. In contrast to health and education statutes, the DSA is a very brief statute. While there are some details in the regulations to the DSA (Regulations), the detailed workings of the various programs are for the most part ad hoc and not public knowledge.

Some resulting fundamental concerns are as follows:

1. **Citizenship.** Citizenship needs to be addressed directly and must address rights and fair processes.
2. **Appeals.** The lack of a complaints or appeal procedure needs to be addressed.
3. **Abuse.** Abuse is an issue that must be acknowledged and addressed directly.
4. **Capacity and Autonomy.** There is no statutory recognition of the fundamental right of autonomy and self-determination of persons who have a developmental disability in the administration of programs and services.
5. **Residential Tenancies and Group Homes.** Tenancy issues, especially in the context of group homes, must be reviewed.
6. **Education of all Stakeholders.** There is a critical lack of information about programs and services.
7. **Co-ordination between Ministries and Government Departments.** There is a need for collaboration between the various ministries and government departments that deliver services to and/or have an impact upon persons who have a developmental disability.
8. **Transition Planning.** Concrete plans for action to address life transitions need to be implemented.

ARCH submits that the Ministry must address each of these issues in order to gain the community's confidence and to achieve the Vision of full participation set out on page 8 of the Preliminary Discussion Paper. In this submission we identify some of the statutory gaps that are problematic and make some recommendations. This is not, however, a comprehensive proposal for statutory reform. Rather, it is our hope to identify areas for further deliberation and suggestions for discussion, to make the achievement of the Vision more likely. Each of these topics is addressed below.

## **1. Citizenship**

Underpinning this submission is our belief that full citizenship for persons who have a developmental disability means entitlement to the same rights that are enjoyed by persons who do not have a developmental disability. The new plan for services delivery must ensure that rights provided for in other contexts are not overlooked or discounted for persons who have a developmental disability.

It is our experience that providers of services to persons who have a developmental disability do not often appreciate that, generally speaking, all people are entitled to the same legal rights, protections and benefits, regardless of whether one has a developmental disability. Thus, (and with reference to the problems we most frequently encounter at ARCH) persons who have a developmental disability have the right to be free of discrimination or harassment, are entitled to privacy, have tenancy protections and are subject to the personal decision-making rules of the province. It needs to be better understood that laws of general application, such as Ontario's *Human Rights Code*, the *Tenant Protection Act*, the various pieces of legislation covering privacy of information, the *Health Care Consent Act* and the *Substitute Decisions Act* apply to all Ontarians, unless there is a specific exception.

### **Recommendation 1**

*ARCH recommends that the Ministry ensure that it and the agencies from which it purchases services are aware of laws of general application and how they pertain to the provision of funding and services to persons who have a developmental disability.*

We believe that the Ministry and stakeholders to this review share a common belief that fairness is an essential component of full citizenship. It is important to note that, for the Ministry, fairness is also a legal duty. The courts have held that

there is a duty of procedural fairness on the part of public authorities when they make decisions affecting rights, privileges or interests of an individual. Recently, this principle was upheld by the Ontario Divisional Court in the context of funding for children who have a developmental disability.<sup>3</sup>

## **Recommendation 2**

*ARCH recommends that the Ministry ensure that its decision-making processes and administration of programs are guided by the standard of procedural fairness that is articulated in the jurisprudence. This includes ensuring the articulation of objective criteria for the decision-making process, ensuring applicants are made aware of the criteria, providing detailed reasons for all decisions about funding and services, and providing an opportunity to address objections.*

The Vision of full participation and citizenship requires that the dignity and well-being of persons who have a developmental disability be respected. It is our view that some substantive rights need to be enshrined in law in order to ensure this occurs. At a minimum, these rights include the right to:

- live free from discrimination, harassment and abuse
- be informed of programs and services and the protocols, policies and complaint procedures that govern them
- enjoy personal privacy, including expectations of daily living such as the freedom to close one's door, to have private telephone conversations, receive unopened mail and select personal possessions
- a healthy, clean physical environment
- a nourishing diet, exercise and access to health care
- have personal relationships
- have personal decisions respected

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<sup>3</sup> *Nieberg (Litigation guardian of) v. Ontario (Minister of Community Family and Children's Services)*, [2004] O.J. No. 1135 at para. 24 (QL).



Rights have been enshrined elsewhere in Ontario laws, notably in the Bills of Rights found in the *Long-Term Care Act*, the *Nursing Homes Act*, the *Homes for the Aged and Rest Homes Act* and the *Charitable Institutions Act*. We do not recommend a wholesale adoption of any of these, and note that some are overly wordy and complex. Rather, specific rights relevant to persons who have a developmental disability in the context of a new or reformed developmental services regime should be identified. They need to be presented in plain language.

### **Recommendation 3**

*ARCH recommends that the reform of developmental services in Ontario include statutory provision for substantive rights for persons who have a developmental disability with respect to the funding and services they receive. Further, we recommend that stakeholders be consulted regarding the rights we have set out above, as well as asked to identify what other substantive rights they believe are important. Stakeholder views on the best form for enshrining these rights should be requested.*

## **2. Appeals**

Ministry program administrators, Ministry partners charged with the administration of program or services funding, and local service provision agencies regularly make decisions that affect the lives of persons who have a developmental disability. These decisions include whether to provide funding, how much funding to grant, whether the funding is transportable, and, whether to permit or deny a placement in a group home, a transfer request or a special service.

One cannot underestimate the enormous impact of these decisions. Decisions to refuse services from a group home, require a transfer to another group home, deny services altogether or provide insufficient funding through programs such as

SSAH are momentous in many circumstances. The result is that individuals may be left without the vital services they need, such as a group home placement, care at home, or respite. Without these the individual with the disability as well as their family or support persons live in constant exhaustion and stress from having to fill the gap with less satisfactory and more expensive alternatives or go without services altogether. In addition, many callers to ARCH articulate frustration, a sense of vulnerability and powerlessness because they have had no say in the decision and no route to appeal it. They are often shocked that there is no remedy or appeal, short of bringing a costly judicial review of the denial.

It is also significant that in the context of other governmental services, appeals do exist. For example, the *Education Act* provides for appeals of a placement decision, and ultimately, a hearing at the Special Education Tribunal (SET). Similarly, the Health Services Appeal and Review Board (HSARB) reviews many categories of health-related decisions, including decisions of the Ontario Health Insurance Plan, decisions of agencies under the *Long-Term Care Act* and decisions with respect to licensing under the *Nursing Homes Act*. The Social Benefits Tribunal (SBT) reviews decisions made under the *Ontario Disability Support Program Act* and *Ontario Works Act*. In our view, the lack of a similar approach in the *DSA* reflects an out of date and paternalistic approach to persons who have a developmental disability. We expect that now-rejected myths led to a system without any statutory appeal process. In order to give effect to the Vision for this review, it is essential to rethink this omission.<sup>4</sup>

ARCH submits that it is imperative that an amended *DSA* contain clear provisions that enable persons who have a developmental disability or their families (in proscribed situations) to raise concerns, make complaints regarding funding and services and appeal decisions with which they are not satisfied. We suggest the following at a minimum:

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<sup>4</sup> While there are currently some very limited appeal processes, such as those relating to Special Services at Home contained in the Special Services at Home Program Guidelines, these are not statutorily mandated. To our knowledge the majority of the Ministry's programs and services do not have any complaint or appeal routes.

- The legal framework and processes must be easy to follow and accessible to people so they do not feel the need to hire a lawyer.
- As persons with disabilities are particularly vulnerable in the context of service delivery, there must be a right to complain or appeal without reprisal.<sup>5</sup>
- Mechanisms about to whom, in what time frame and how to complain about quality of service must be defined in the statute or by regulation.
- Mechanisms about to whom, in what time frame and how to appeal a denial of services and funding or the amount of funding must be defined in the statute or by regulation.
- Notice of complaints and appeals procedures must be provided upon the denial of a funding or service application and be posted in locations where services are delivered.
- Clarification of the appointment of and role of substitute decision-makers and advocates must be provided.

#### **Recommendation 4**

*That the Ministry include in its draft plan to transform services a detailed proposal for a statutory complaints and appeals process for all developmental services and to consult with stakeholders about issues relevant to complaints and appeals and ideas to make these processes fully accessible to persons who have a developmental disability.*

As with other public services, there should also be an independent and specialized appeals tribunal for review of developmental services decisions. We recommend that this tribunal be modelled on existing tribunals such as the HSARB, the SET or the SBT.

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<sup>5</sup> Provisions of this kind are not new to Ontario law and can be found in both the *Long-Term Care Act, 1994*, S.O. 1994, c. 26 at s. 3(1)7 and Ontario's *Human Rights Code*, R.S.O. 1990, c. H. 19 at s.8.

## **Recommendation 5**

*That the Ministry include in its draft plan to transform services a detailed proposal for an independent and specialized appeals tribunal and to consult with stakeholders about its composition, the scope of its mandate, and ideas to make it fully accessible to persons who have a developmental disability.*

### **3. Abuse**

The experience of abuse is an unfortunate reality for many people who have a developmental disability. It has been estimated that over the course of their lifetimes, people who have a developmental disability are at least one and a half to two times more likely to be victims of abuse than people who do not have disabilities.<sup>6</sup>

Abuse occurs in a host of settings and there are a wide range of people who engage in abusive behaviour, such as caregivers (including family members), other residents in residential settings and professionals. Abuse also takes many forms, including physical, sexual and emotional abuse as well as neglect. Abuse is often a crime, but can be addressed through a number of other legal avenues as well.<sup>7</sup>

Because of the severity and prevalence of abuse it is imperative that the statutory framework address situations of abuse which occur in the context of services and programs for persons who have a developmental disability. In particular, the abuse experienced by persons who have a developmental disability must be

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<sup>6</sup> Kristine Ericson, Barry Isaacs & Nitza Perlman, "Enhancing Communication with Persons with Developmental Disabilities: The Special Case of Interviewing Victim-Witnesses of Sexual Abuse" in Ivan Brown & Marie Percy, eds., *Developmental Disabilities in Ontario*, 2<sup>nd</sup> ed. (Ontario: Ontario Association on Developmental Disabilities, 2003) at 465.

<sup>7</sup> For example, civil actions, applications to the Criminal Injuries Compensation Board for compensation, investigations by the Office of the Public Guardian and Trustee and complaints to the Ontario Human Rights Commission and to health professional colleges.

addressed directly. This is to be separate from any policies that exist to deal with concerns regarding the potential for abuse of those who provide the services, such as staff members.

There should be a comprehensive scheme to address abuse, which could include the following:

- duties of both the Ministry and service providers in the context of abuse
- duties relating to preventing, recognizing and addressing abuse
- duties relating to educating Ministry staff, service providers and persons with disabilities about abuse
- remedies for abuse
- detailed policies regarding abuse should be required, and there should be a requirement that all stakeholders be notified about the policies and be provided with a copy
- process for investigations of abuse
- reporting obligations relating to abuse

## **Recommendation 6**

*ARCH recommends that the reform of developmental services in Ontario include comprehensive statutory provisions relating to abuse of persons who have a developmental disability. We recommend that stakeholders be consulted regarding the issues we have set out above, as well as be asked to identify other issues to be dealt with and the appropriate manner of doing so.*

## **4. Capacity and Autonomy**

### **Legal Capacity in the context of Persons who have a Developmental Disability**

Issues of capacity have posed challenges to the legal profession, as well as health professionals and philosophers, for years. There are a wide range of contexts in which issues of capacity arise in the lives of persons who have a developmental disability. These include decisions regarding:

- health care
- managing money and other property
- paying bills
- all aspects of various government benefits such as Ontario Disability Support Program (ODSP) payments and Special Services at Home (SSAH) funding
- where to live
- group home living arrangements

Considerations of capacity are bound to arise in the context of persons who have a developmental disability. This is certainly not the case for all recipients of services or funding but as situations where capacity are at issue are common, they must be addressed.

Adults who are mentally capable are entitled to make decisions for themselves. As a starting point, we presume that persons with disabilities are also mentally capable. This does not mean that this is true in all cases, but that all interactions with persons who have a developmental disability assume mental capacity to conduct one's affairs unless there is proof to the contrary. This presumption is fundamental to protecting an individual's autonomy, independence and ability to control one's own life. In other words, when individuals are not allowed to make choices for themselves and someone else does this on their behalf, they no longer have control over what will happen in their lives. In law, another person (often referred to as a substitute decision maker) should only make decisions for an individual when that person is incapable of doing so or in some circumstances when he or she is mentally capable and chooses that another person do so.

Families and support people also play an important role in the decision-making process of persons who have a developmental disability. This role changes depending on the individual's level of capacity and wishes. For example, in some circumstances individuals will make decisions for themselves but wish family members or other support people to assist them in doing so. In cases of

incapacity, family members or support people may become the legal substitute decision maker.

In law, there is no single test or definition for mental capacity. A commonly accepted definition of mental capacity is:

To be 'mentally capable' means that a person must have the ability to understand information relevant to making a decision and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of decision.<sup>8</sup>

Whether an individual is mentally capable depends on the type of decision to be made. In law, individuals can be capable of making some types of decisions but not others.

For example, an individual who has a developmental disability may have very strong preferences about where she wishes to live and have well thought out reasons for so choosing in the context of the implications that the decision would entail. She may wish to live in a particular residence because her friends live there and she likes the neighbouring park and the proximity to her family. She may chose this instead of living with her parents where she misses the companionship of her contemporaries. At the same time, she may not be mentally capable of making health care decisions. She may not have the capacity to make a decision about major risky surgery. This decision would require an understanding of her current health status and the complexities of the procedure, the particular risks and benefits and the impact on her life.

There are many different pieces of legislation and court decisions in Ontario that address capacity. They each articulate tests for capacity in different contexts.<sup>9</sup> The most significant pieces of legislation in Ontario that address consent and capacity are the *Substitute Decisions Act, 1992* and the *Health Care Consent Act, 1996*. The *Substitute Decisions Act* contains laws about who can make decisions

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<sup>8</sup> George T. Monticone, ed., *Long-Term Care Facilities in Ontario: The Advocate's Manual*, 3<sup>rd</sup> ed. (Toronto: Advocacy Centre for the Elderly, 2004) at 7.7.

<sup>9</sup> These contexts include capacity to make a power of attorney for personal care, capacity to make a continuing power of attorney for property, capacity to make a will and capacity to make health care decisions.

about property and personal care (including health care, food, housing and safety) when an individual is not mentally capable of making his or her own decisions. It sets out processes for ways in which substitute decision makers may legally make decisions for the incapable person. This differs depending on the type of decision. Additionally, the *Health Care Consent Act* specifically covers decisions about treatment. The Office of the Public Guardian and Trustee investigates reports of serious abuse or neglect of persons who are incapable and in some circumstances acts as a last resort substitute decision maker.

### **Capacity and Reform of Developmental Services**

Considerations of mental capacity and autonomous decision-making are not addressed in the *DSA* and Regulations or in the Ministry's policies. Similarly, these issues do not appear to be addressed in the administration of programs and services.

Developmental services must be provided through a lens that promotes autonomous decision-making. Persons who have a developmental disability should be presumed to possess the requisite mental capacity in all respects unless there is proof to the contrary.

In certain statutes where diminished capacity is likely to arise, there is an explicit recognition of presumed capacity. This prevents the all too frequent occurrence of treating an individual as though he or she is incapable solely on the basis that they have a developmental disability. Both the *Health Care Consent Act* and the *Substitute Decisions Act* contain sections which state that individuals are presumed to be capable. People are entitled to rely on this presumption unless there are reasonable grounds to believe that the person is incapable.<sup>10</sup>

The *DSA* does not include similar provisions. Indeed, it does not even seem to recognize the issue. Section 7 of the *DSA* allows a person to apply for admission to a facility or for assistance or services *on behalf of* a person whom he or she

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<sup>10</sup> *Health Care Consent Act, 1996, section 4(2) and (3); Substitute Decisions Act, 1992, section 2*



*believes* has a developmental disability. This is the case regardless of whether or not the person who has the developmental disability is mentally capable. This could mean that someone other than the person with the disability is allowed to make choices about that person's life even when the individual may be fully capable of making his or her own choice.

Another problematic example is with Special Services at Home (SSAH). Under this program, in order to be eligible for funding through SSAH the adult who has the disability must live at home with his or her family. This criterion does not respect the individual's right to make choices about his or her life. In fact, it acts as a disincentive to independence as people may feel a necessity to live at home because of the availability of funding if they do so.

### **Recommendation 7**

*ARCH recommends that the Ministry evaluate its governing legislation, policies, programs and services in the context of their impact on the autonomy of persons who have a developmental disability. The Ministry should initiate reforms to ensure that persons who have a developmental disability are able to make choices for themselves when they are mentally capable of so doing. There should be an appropriate legal process for appointing a substitute decision maker for situations where the individual does not have the requisite capacity. The role of support, through family members, other support people and support circles, should be respected and be part of this scheme.*

Some questions that we recommend that the Ministry to consider are as follows:

- What should the test of capacity be in the context of developmental services?
- How should the test of capacity be worded?
- How should capacity be assessed or determined?
- What process should exist to allow individuals to challenge decisions that they are not capable?
- How do current Ontario laws dealing with capacity apply to developmental services?

## 5. Residential Tenancies and Group Homes

ARCH hears desperate concerns from consumers and their families about tenancy problems in the context of their receipt of services, most notably in group homes. We hear concerns about services being withdrawn, people being told that they must transfer to another group home or that they cannot be accommodated in a group home altogether. It is our belief that these decisions are being made without reference to existing residential tenancy laws and in an informal and ad hoc way.

These decisions have a profound effect on the lives of the persons to whom they apply. Being told where one must live and with whom, or that there will be no supported shelter altogether affects a person's ability to participate in the social and cultural community of their choice. Frequently, placements are made with individuals with whom one is not compatible and in locations geographically far away from family, friends and familiar surroundings. All too often in this context, the health and well being of the person who has a developmental disability deteriorates and they become lonely and unhappy.

It is essential that this review investigate how various laws of general application play out in the developmental services context. Of particular importance is the applicability of the *Tenant Protection Act* in the context of group homes. In this submission we do not focus on tenancy issues, other than to point out that this is a complex area of the law that needs concerted review and harmonization.<sup>11</sup> We also submit that the tenancy rights of persons who have a developmental disability be maintained and, where feasible, enhanced.

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<sup>11</sup> ARCH made submissions to the Residential Tenancy Reform Consultation undertaken by the Ministry of Municipal Affairs and Housing in 2004. These are posted on our website at [www.archlegalclinic.ca/aboutARCH/lawReform/A73\\_2004\\_002928/index.asp](http://www.archlegalclinic.ca/aboutARCH/lawReform/A73_2004_002928/index.asp)

## **Recommendation 8**

*ARCH recommends that the review examine the obligations of service providers and the rights of persons living in group homes in the context of the Tenant Protection Act and any other relevant laws and ensure that harmonization with any reforms to be instituted, always with the goal of preserving existing tenancy rights and enhancing them where feasible.*

### **6. Education of all stakeholders**

There is a glaring absence of knowledge among all stakeholders regarding the existence of the various supports and services for persons who have a developmental disability, what the programs offer, how applications are to be made, what laws and applicable policies govern them and so on. It is ARCH's belief that a significant explanation as to why in many instances people do not have the support and services they need is because they are not aware of the array of options available. They often cannot obtain effective assistance from advocates or lawyers, who are also unable to obtain this information. Detailed information about programs and services are not available on the Ministry's web site or through other sources such as written materials (e.g. pamphlets). To our knowledge there is no point of contact in the Ministry for the public to obtain such information.

There is a pressing need for the Ministry to take such initiatives as are necessary to ensure that information about developmental services is available and easily accessible to all stakeholders. This could take various forms such as improvements to the Ministry web site, clearly worded pamphlets, the provision of information sessions and the creation of an access point of contact in the Ministry for people to obtain information on all aspects of developmental services.

## **Recommendation 9**

*The Ministry should commit to launching a number of initiatives to inform all stakeholders about developmental services programs. Further, the Ministry should canvass options with stakeholders to determine what information they need and the most effective mode of delivery.*

## **7. Co-ordination between Ministries and Government Departments that Provide Services and Funding to Persons who have a Developmental Disability**

ARCH recognizes that while it is the Ministry of Community and Social Services that has taken the initiative to transform developmental services, there are other ministries and government departments as well that provide services and funding to persons who have a developmental disability. The Ministry of Children and Youth Services funds services and supports to children who have a developmental disability and their families, the Ministry of Health and Long-Term Care provides health care and attendant services to persons who have disabilities and the Ministry of Education provides education programs and services for children who have disabilities. Additionally, there are various Federal government and municipal government departments and programs which serve persons who have a developmental disability. There are other Ministries whose activities impact upon persons who have a developmental disability such as the Ministry of Municipal Affairs and Housing with respect to the residential settings in which they live.

ARCH believes that co-ordination between the various government departments is an important step to achieve the Province's vision of a fair and sustainable developmental services system. Such co-ordination will work towards ensuring that programs will be delivered efficiently and that gaps and inequities in service delivery will be remedied.

Additionally, the Government should create a single point of access for persons who have a developmental disability, their families and members of the public to

obtain information about all existing programs and services regardless of which Ministry or department is responsible. It is ARCH's experience that very few people, even those who are well-resourced and active advocates, have knowledge of the range of programs and services and where information can be obtained. It is ARCH's belief that this lack of knowledge is a significant barrier to the receipt of supports that people need.

### **Recommendation 10**

*ARCH recommends that the Ministry of Community and Social Services work in collaboration with all other government departments in the provision of supports and services to persons who have a developmental disability and in the dissemination of information relating to all such programs. ARCH recommends that a single point of access be created to co-ordinate programs and provide information. Such collaborative activities must be on-going.*

### **8. Transition Planning**

The Ministry is well-aware that specific attention must be given to various transitions in the lives of persons who have a developmental disability. Some transitions will always be a reality (and have been documented in the Preliminary Discussion Paper at page 16) such as the transition into and out of the school system, the transition into senior years and the transition that occurs when parents and other support persons pass away. These are times when there is usually a change in the types of programs and services which are available. People who contact ARCH often go without much needed services and funding as they are unaware of what is available, who to contact for information and how to apply for such programs.

Additionally, a significant point of transition resulting from the Ministry's current initiative will occur as the three remaining institutions for adults who have a developmental disability are closed. Some concerns about the impact on the lives

of people who have been living in these institutions have been canvassed in the forums hosted by the Ministry. ARCH echoes concerns such as the loss of important social and community connections and supports to name a few. In this regard, ARCH is not aware of any specific plans of the Ministry to address potential problems raised by closure of the institutions and to ensure that people will receive the supports they need to live successfully in the community and that their particular needs and preferences will be respected.

### **Recommendation 11**

*ARCH recommends that the Ministry develop concrete plans which ensure that such transitions are responsive to the needs of individuals who have a developmental disability. ARCH recommends that special programs and supports are established to serve people during life transitions, which may include skills training and provision of information about available programs. To this end, ARCH recommends that the Ministry continue to consult with stakeholders in fashioning strategies and solutions for addressing transition planning.*

### **Summary of Recommendations**

1. ARCH recommends that the Ministry ensure that it and the agencies from which it purchases services are aware of laws of general application and how they pertain to the provision of funding and services to persons who have a developmental disability.
2. ARCH recommends that the Ministry ensure that its decision-making processes and administration of programs are guided by the standard of procedural fairness that is articulated in the jurisprudence. This includes ensuring the articulation of objective criteria for the decision-making process, ensuring applicants are made aware of the criteria, providing detailed reasons for all decisions about funding and services, and providing an opportunity to address objections.

3. ARCH recommends that the reform of developmental services in Ontario include statutory provision for substantive rights for persons who have a developmental disability with respect to the funding and services they receive. Further, we recommend that stakeholders be consulted regarding the rights we have set out above, as well as asked to identify what other substantive rights they believe are important. Stakeholder views on the best form for enshrining these rights should be requested.
4. That the Ministry include in its draft plan to transform services a detailed proposal for a statutory complaints and appeals process for all developmental services *and* to consult with stakeholders about issues relevant to complaints and appeals and ideas to make these processes fully accessible to persons who have a developmental disability.
5. That the Ministry include in its draft plan to transform services a detailed proposal for an independent and specialized appeals tribunal and to consult with stakeholders about its composition, the scope of its mandate, and ideas to make it fully accessible to persons who have a developmental disability.
6. ARCH recommends that the reform of developmental services in Ontario include comprehensive statutory provisions relating to abuse of persons who have a developmental disability. We recommend that stakeholders be consulted regarding the issues we have set out above, as well as be asked to identify other issues to be dealt with and the appropriate manner of doing so.
7. ARCH recommends that the Ministry evaluate its governing legislation, policies, programs and services in the context of their impact on the autonomy of persons who have a developmental disability. The Ministry should initiate reforms to ensure that persons who have a developmental disability are able to make choices for themselves when they are mentally capable of so doing. There should be an appropriate legal process for appointing a substitute decision maker for situations where the individual does not have the requisite capacity. The role of support, through family members, other support people and support circles, should be respected and be part of this scheme.
8. ARCH recommends that the review examine the obligations of service providers and the rights of persons living in group homes in the context of the

Tenant Protection Act and any other relevant laws and ensure that harmonization with any reforms to be instituted, always with the goal of preserving existing tenancy rights and enhancing them where feasible.

9. The Ministry should commit to launching a number of initiatives to inform all stakeholders about developmental services programs. Further, the Ministry should canvass options with stakeholders to determine what information they need and the most effective mode of delivery.
10. ARCH recommends that the Ministry of Community and Social Services work in collaboration with all other government departments in the provision of supports and services to persons who have a developmental disability and in the dissemination of information relating to all such programs. ARCH recommends that a single point of access be created to co-ordinate programs and provide information. Such collaborative activities must be on-going.
11. ARCH recommends that the Ministry develop concrete plans which ensure that such transitions are responsive to the needs of individuals who have a developmental disability. ARCH recommends that special programs and supports are established to serve people during life transitions, which may include skills training and provision of information about available programs. To this end, ARCH recommends that the Ministry continue to consult with stakeholders in fashioning strategies and solutions for addressing transition planning.