



Citizens With Disabilities – Ontario

www.cwdo.org

“Together We Are Stronger”

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Comments on the College of Physicians and Surgeons of Ontario’s Draft Policy

“Planning for and Providing Quality End-Of-Life Care”

Introduction

Citizens With Disabilities – Ontario (CWDO) is committed to the rights of all persons to participate fully in the civil, cultural, economic, political and social life of our communities. CWDO actively promotes the rights, freedoms and responsibilities of persons with disabilities through community development, social action, and member support and referral. Our primary activity is public education and awareness about the social and physical barriers that prevent the full inclusion of persons with disabilities in Ontario. Our members have a variety of types of disability – mobility, vision, hearing, mental health, learning and developmental disabilities. People with disabilities represent about 15% of Ontario's population and are protected from discrimination under the Ontario Human Rights Code.

We recognize that physicians and surgeons interact with a wide range of diverse Ontarians in providing advice, offering their skills, and communicating about the range of options available for treatment. Few situations could require more sensitivity than planning and discussions about end-of-life care. To exercise sensitivity in its truest sense, physicians and surgeons need to be aware of their own biases against disability and how these biases might manifest in terms of the options that are presented to individuals and their decision-makers.

We understand that the intention is to provide better guidance to physicians in a climate of competing values when emotions may be elevated. CWDO has identified key areas outlined below where we feel this policy could be strengthened to better protect vulnerable people with disabilities from those who may wrongly assume that treatment is futile, that their expressed wish or request to hasten death is reasonable, or that their quality of life will be low or nonexistent.

CWDO has thoughtfully considered the range of views on end-of-life care, and recently developed a resolution on assisted suicide. This provides a context for our feedback on the College of Physicians and Surgeons of Ontario's draft policy, "Planning for and Providing Quality End-of-Life Care."

CWDO Resolution on Assisted Suicide

Whereas; Citizens with Disabilities Ontario believes that all human beings have value and endless potential and that persons with disabilities have the right to live their lives without fear of being euthanized simply because they are persons with disabilities; and

Whereas; persons with disabilities have the full protection of all the laws and access to the justice system as any other citizens or resident of Canada has at their disposal;

Therefore; be it resolved that CWDO supports and affirms the current position held by the Council of Canadians with Disabilities that the Federal Government make no changes to the Criminal Code of Canada or any other legislation to allow assisted suicide, so-called mercy killing to be legalized in any form or in any jurisdiction within Canada;

Be it further resolved; that CWDO believes killing people with disabilities simply because they are disabled is and should be treated as a hate crime and a crime against humanity. Individuals convicted of such crimes should receive the maximum sentence allowed for by Canadian law, with no exceptions. (November 16, 2014)

General Comments:

Given the February 6, 2015 decision of the Supreme Court to strike down the illegality of physician-assisted suicide, our comments to you are more urgent than ever. We attach for your consideration the analysis of the [Council of Canadians with Disabilities](#) on this legislation and urge you to pay special attention to the cautions and safeguards that need to be considered in order to protect people with disabilities from becoming targeted for assisted suicide. What safeguards could the College of Physicians and Surgeons of Ontario put in place to ensure people with disabilities need not fear that they will be pressured, steered or encouraged to request assist suicide when the real issues might be poverty, isolation, lack of access to medical and community supports?

CWDO strongly recommends that the term patient does not necessarily reflect all persons with disabilities that require medical professionals are sick to deal with their individual needs related to individual disabilities. The term patient often refers to someone requiring medical assistance. Some people with disabilities require medical professionals to deal with accommodation issues or assistance with service providers. In these particular cases, the individual with a disability is not necessarily sick or requiring medical attention but may simply asking for support to deal with accommodation issues related to the disability. This distinction should be noted in the policy.

CWDO recommends that the College of Physicians and Surgeons of Ontario support the creation of a Healthcare Standard under the Accessibility for Ontarians with Disabilities Act, and that this Standard include a Patient's Bill of Rights to deal with accessibility and disability issues.

CWDO and other disability advocates across the province have been developing legislation regarding attendant support services. Please see Appendix 1 for a copy of the draft legislation. CWDO would be pleased if the College of Physicians and Surgeons of Ontario would support this proposed legislation.

CWDO shares and supports comments under the Introduction Section

(line 3). However, CWDO notes that the Introduction Section does not mention or indicate current legislative rights for patients that exist under the:

1. Long-Term Care Homes Act, 2007
2. Home Care and Community Services Act, 1994

CWDO believes the policy document should have a section regarding current legislative and regulatory requirements for physicians, surgeons, other medical professionals and patients. The list should also include requirements and responsibilities under the Local Health System Integration Act of 2006.

Under the Principles Section (line 18) CWDO recommends that Draft Principle 3 (LINE 26) also state that in the interest of resolving conflicts, patients and medical personnel can develop individual accommodation plans to address needs regarding accessibility requirements to a medical office or other facilities.

Under the Purpose Section (line 33) CWDO recommends this section be moved up to the front of policy to ensure that the purpose is clear and sets the proper tone for the document.

CWDO believes that the policy should include a section regarding access and requirements for all 14 Ontario Health Integration Networks. Physicians, Surgeons, other medical professionals and patients should have access to their local (LHINs). Furthermore, the policy should reflect the current governance and funding structure of the health care system in Ontario.

CWDO strongly supports the College of Physicians and Surgeons in its approach to patient dignity and access to care.

line 88 – “Avoiding the unnecessary prolongation of dying, especially when there is little hope for meaningful recovery”

- CWDO is concerned with the use of the term "meaningful recovery" since nondisabled people frequently have a skewed or biased perspective, in determining quality of life issues for people

with disabilities. What may not seem to be meaningful recovery to a medical practitioner could be very meaningful to the person with a disability.

Given the recent decision of the Supreme Court to strike down the legality of physician-assisted suicide, it is critical that the College of Physicians and Surgeons of Ontario develop very clear guidelines, **in consultation with people who have lived with disabilities all of their lives**, as well as those who acquire disabilities later in life through illness or injury. Some people with disabilities will now live in fear of being "encouraged" to request suicide as a health option, on the erroneous assumption that all people with disabilities feel the same way about the quality of their lives.

This is not an idle fear. In a fiscal environment where healthcare costs have been growing year over year and still unable to keep up with demand, the pressure on people with disabilities to request suicide will grow exponentially. Indeed, it may become the option of "choice" when palliative care, home care, and other forms of therapy or medical redress are unavailable.

We believe it would be discriminatory to encourage people with disabilities to request suicide when our response to people who do not have disabilities is exactly the opposite when they voice suicidal ideation.

line 98 – "Preserving dignity, being treated with respect and compassion, and being treated in a manner that affirms the whole person"

- CWDO supports this type of statement and urges the College to encourage physicians and surgeons to broaden their perspective regarding persons with disabilities so that they truly can understand what "the whole person" could mean for someone with a disability.
- CWDO urges the College to include a requirement for sensitivity training for physicians and surgeons on a regular, recurring basis, over and above the customer service training required by the

Accessibility for Ontarians with Disabilities Act's Accessibility Standards for Customer Service regulation. This sensitivity training would go a long way to ensuring the needs of people with disabilities were understood and would help to provide a more realistic perspective of the quality of life of the many people who live with disabilities.

lines 108-125 – Communication

- CWDO supports direction to physicians and surgeons for effective and compassionate communication. Mention should be made that people will have a variety of ways of communicating that are equally valid, including the use of augmentative communication, gestures, sign language, eye movement, vocalization, facial expression, and so on. The policy should not assume that everyone is able to communicate verbally.

Lines 175-178 "Physicians are advised that in the context of end-of-life care the capacity to consent to treatment may be affected by a number of health conditions. As such and given that capacity may fluctuate, physicians are advised to exercise caution regarding the presumption of capacity and to reassess capacity as appropriate."

- Because persons with disabilities are vulnerable to being presumed less capable than they really are, CWDO would rather that the policy advises physicians and surgeons to exercise caution regarding the presumption of *incapacity* and to reassess incapacity as appropriate. This gives people with disabilities better assurance that they will first be presumed to be competent.

Line 215 – 251 Life-Saving and Life Sustaining Treatment

- CWDO supports the policy directive that consent must be obtained prior to withdrawing life-sustaining treatment, or before issuing a "do not resuscitate" order.

Line 228-235 "Physicians are advised that patients and substitute decision makers may assess the proposed treatment options differently than the physician as they may consider, for example, whether the treatment prolongs life even if there is no clinical benefit.

Physicians may wish to propose life-sustaining treatment on a trial basis while being clear regarding the outcomes that would need to be achieved to warrant the continuation of treatment and outcomes that would warrant the discontinuation of treatment. This allows for the exploration of a potentially positive outcome while building consensus regarding the circumstances in which life-sustaining treatment will be withdrawn.”

- CWDO believes this aspect of the policy may give physicians and surgeons the right to trump the expressed consent of an individual or decision maker to provide life-saving or life-sustaining treatment.
- CWDO recognizes that a physician or surgeon cannot possibly approach this decision from a neutral or unbiased position and that there is potential jeopardy to someone with a disability – even a mild disability – that treatment may not be provided. Historically, for example, treatment has refused for infants with spina bifida, Down syndrome and other disabilities on the basis that it was futile or the child would have a poor outcome or quality of life. CWDO does not support any aspect of this policy which even subtly gives physicians or surgeons an option to make judgments about the quality of life of a person with a disability or their decision maker.

The recent decision of the Supreme Court to strike down the illegality of physician-assisted suicide, makes the existence of a “grievous and irremediable medical condition”, rather than a terminal illness, one of the two primary criteria – this potentially means that all persons with a serious disability in Canada can access Assisted Suicide. This degree of permissiveness does not exist anywhere else in the world. Therefore, it is especially important that physicians and surgeons do not make the withholding of care an option.

Line 310- 312 "a patient's wish or request to hasten death may be a genuine expression of a desire to hasten their death, but it may also be motivated by an underlying and treatable conditions such as depression, psychological suffering, unbearable pain or unmet care

needs.”

- CWDO is pleased that the policy recognizes that a person's expressed wish or request to hasten death may be motivated by underlying and treatable conditions, including unmet care needs.

Line 315-322 - "Physicians must respond to these wishes and requests in a sensitive manner. Because these expressions may be motivated by an issue that can be treated or addressed, physicians must be prepared to engage patients in a discussion to seek to understand the motivation for their expression and to resolve any underlying issues that can be treated or otherwise addressed. This may include providing more effective treatment, improving pain management strategies, providing or referring the patient for psychological counselling, seeking specialist support, and involving other professionals in the patient's care (e.g., chaplaincy support, social workers, grief counselling, etc.)

- CWDO supports the policy placing onus on physicians and surgeons to address underlining causes for wishes or requests to hasten death.

CWDO recently has made comments on Ontario's review of the accessibility for Ontarians with Disabilities Act. CWDO along with other disability organizations have made recommendations regarding. We would like to share our comments with the College for your information and consideration.

Proposed Standard regarding Healthcare

CWDO is recommending that the provincial government enact draft legislation entitled The Consumer Attendant Support Services Protection Act. A copy of the draft legislation is attached to this submission. We believe the proposed legislation should make up part of the proposed Accessibility Healthcare Standard.

CWDO is also recommending the provincial government make amendments to the 14 Local Health Integration Networks across Ontario. Specifically, CWDO is recommending that Section 7 of the Local Health System Integration Act, 2006 be amended to allow for the

creation of Accessibility Advisory Committees for each Network. These committees once established will be comprised of persons with disabilities living in the community for which the Network has responsibility to provide health care and other support services. The committees will advise the Board of Directors on issues related to accessibility issues, attendant support services and home care.

CWDO recommends that all hospitals and other healthcare facilities as identified under the Health and Long-Term Care Act purchase patient lifts and other adaptive equipment for patients with disabilities. Furthermore, hospitals and other healthcare facilities must purchase this equipment by January 1, 2016. CWDO also recommends that all hospitals and other healthcare facilities go through a consultative process with persons with disabilities when purchasing adaptive equipment for patient use.

CWDO recommends all hospitals and healthcare facilities develop a patient and family consultation and complaints process that will allow persons with disabilities as patients to exercise more control over their healthcare needs and address specific concerns.

CWDO recommends that hospitals and other healthcare facilities review the training for staff every six months. Training plans and policies should emphasize sensitivity towards patients with disabilities. CWDO also recommends training manuals should be available in alternative formats for the review of patients with disabilities. Training manuals should also be written in plain language.

CWDO recommends that all hospitals and other healthcare facilities undergo an accessibility access review to ensure their facilities are physically accessible for all patients with disabilities.

CWDO recommends that Ontario's healthcare include massage and physiotherapy and dental benefits for persons with disabilities. We specifically recommend that this be considered for persons with disabilities earning less than \$50,000 a year and for every Ontarian on the Ontario Disability Support Program.

CWDO recommends that Developmental Service Workers be

specifically trained regarding sensitivity towards persons with disabilities. Furthermore, Developmental Service Workers should assist persons with disabilities to develop individual accessibility plans to help promote education and training, legal rights, knowledge and employment training.

Conclusion

Citizens With Disabilities – Ontario applauds the efforts of the College of Physicians and Surgeons of Ontario to articulate clear and sensitive policies governing the planning and provision of quality end-of-life care. We recognize this will now be more complex, given the recent decision of the Supreme Court of Canada to strike the illegality of physician-assisted suicide. Because of this complexity, it is vital to consult with a wide range of people with disabilities having a wide range of experiences living with their disabilities.

We urge the College to adopt a policy which has at its core a respect for the life, dignity, worth and independence of people with disabilities and maintains a first assumption of competence.

Please do not hesitate to contact our organization if any further information or clarification of our recommendations is desired.

Sincerely,

Attachments:

- Proposed draft legislation: **The Consumer Attendant Support Services Protection Act**
- CWDO Submission on the AODA 2014 Final June 11, 2014
- CCD-CACL Carter - Friday Release - Final
- CCD Commentary on SCC Assisted Suicide Judgment in Carter v. Canada - Key Concerns

Consumer Attendant Support Services Protection Act

Explanatory Note:

The Consumer Attendant Support Services Protection Act will amend the *Home Care and Community Services Act, 1994*

The purpose of this legislation is to ensure that Consumers of attendant support services are protected and have the right to be involved with decisions regarding their own attendant support services. Consumers need to be directly involved in how policies and procedures are developed with the Service Providers, which provide attendant support services for them.

The people of Ontario support the right of persons of all ages with disabilities to enjoy equal opportunity and to participate fully in the life of the Province. Also, this legislation recognizes and understands that persons with disabilities are to be treated equally and without discrimination in accordance with the *Human Rights Code* of Ontario.

The Government of Ontario is committed to working with persons with disabilities and attendant support services providers to build on what has already been achieved by ensuring that all persons with disabilities have the opportunity to participate in the day-to-day operations and policy development of their attendant support services.

Section 1 establishes definitions.

Section 2 provides for rights and obligations of Consumers and attendant support services.

Section 3 provides for the creation of a Consumer Advocate Office. This agency will advocate on behalf of all Consumers who receive attendant support services within Ontario.

Section 4 outlines governance obligations for attendant support services within Ontario.

Section 5 outlines the Executive Director's role with the Board of Directors of all providers of attendant support services within Ontario.

Section 6 establishes regulation making authority for the Minister under the Act.

Section 7 establishes the Solutions Committee to address wait times and emergency shelter attendant support services for persons with disabilities who require attendant support services.

Section 8 sets out obligations after Royal Assent.

Draft regulations follow Section 7 and pertain to specific areas of attendant support services. Draft regulations are as follows:

Funding for Consumer Advocate Office

Wait Times and emergency shelter for Potential Consumers to Receive Attendant Support Services

Dispute Resolution Process

Section 1

Definitions:

1.1 Service Provider is an organization receiving provincial funding to provide attendant support services to persons living in their own homes whether or not these homes are rented, owned, cooperatively, communally shared or with family members within Ontario.

1.2 Board of Directors is the governing body for the attendant support services provider recognized by the Ministry of Health and Long-Term Care (or other ministries) for funding purposes. They are accountable to the Ministry for operating within the established policies and procedures for attendant support services within Ontario.

1.3 Executive Director is the individual who is responsible for the overall day-to-day operations of a Service Provider, and who reports to the Board of Directors.

1.4 Attendant is a person who is paid or volunteers to provide personal attendant support services to a Consumer on behalf of a Service Provider.

1.5 Provincial cross-disability non-profit advocacy organization will be responsible for hiring adequate staff to operate the Consumer Advocate Office. The Provincial cross-disability non-profit advocacy organization will be selected by a tendering process to operate the Consumer Advocate Office.

1.6 The Consumer Advocate Office advocates for the Consumer during disputes with their Service Provider. The Consumer Advocate Office provides advice and recommendations to Consumers on how to deal with disputes between themselves, Attendants and their Service Provider.

1.7 A Consumer is the person who receives attendant support services from a Service Provider within Ontario . For the purpose of this legislation, receiving services from a specific Service Provider does not constitute a conflict of interest in serving on the Board of Directors of that Service Provider.

1.8 A Potential Consumer is a person who is eligible to receive attendant support services from a Service Provider within Ontario, but has not chosen an organization to provide these services.

1.9 Community Care Access Centre (CCAC) is the provincial government organization currently evaluating and qualifying a potential Consumer's need for attendant support services. They form contractual relations with regional Service Providers to provide attendant support services to the Consumer in accordance to CCAC assessment evaluations, for time and care tasks.

1.10: Attendant Support Services include personal care and light home care services. These are services that affect the Consumer's well being in acquiring or maintaining personal health, and their independent living goals, which promote their autonomy and inclusion in society.

Section 2

Rights and Obligations:

2.1 Every Consumer has the right to control how their attendant support services are provided to them.

2.1.1 Every Consumer has the right to declare the type and level of support required to meet their independent living goals, and promote their autonomy and inclusion in society.

2.1.2 Every Consumer has the right to assist in the selection and evaluation of Attendants who will be providing services in the Consumer's home.

2.1.3. Every Consumer has the right to report concerns to the Service Provider. Consumers have a right to expect these concerns to be responded to in a timely manner, and in a way that effectively works to resolve the issue. The Minister shall establish in consultation with Service Providers and the Consumer Advocate Office a regulation to spell out specific time frames and obligations to formulate an effective resolution process.

2.2 Every Consumer may participate in a training session designed to resolve conflicts between them, their Service Provider and Attendants.

2.3 Service Providers are obligated to ensure that any corrective measures taken by them, which may impact a Consumer, has a fair process that allows the Consumer the opportunity to appeal decisions that impact their services.

2.3.1 Every Service Provider will develop policies and procedures to deal with disputes between Consumers and Attendants. The Service Provider's Board of Directors will approve these procedures.

2.3.2. All Service Providers must adopt these procedures within 30 days of this legislation receiving Royal Assent.

2.4 Every Attendant hired by a Service Provider must be trained in conflict resolution. The Minister shall establish in consultation with Service Providers and the Consumer Advocate Office a regulation that will establish Ontario guidelines for staff to be trained in conflict resolution procedures.

2.4.1 Under this legislation no Attendant will be allowed to deliver services to any Consumer without supervision unless this training is completed to the satisfaction of the Service Provider and the Consumer Advocate Office Representative.

2.4.2 Service Providers are required under this legislation to fund training in conflict resolution for Consumers and Attendants.

2.4.2.1 Service Providers may share the cost of such training programs with other Service Providers. All Organizations involved in joint training programs must have the approval of each individual organization's Board of Directors.

2.5 Once CCAC has qualified the Consumer's eligibility, the Consumer then has complete control to direct their attendant support services with the Service Provider until their eligibility changes.

Section 3

Consumer Advocate Office:

3.1 The Consumer Advocate Office will be established on the day that this legislation receives royal assent.

3.2 A Provincial cross-disability non-profit advocacy organization will have the responsibility under this legislation to hire appropriate staff to manage the Consumer Advocate Office.

3.2.1 Service Providers will have the right to be involved with the hiring of staff for the Consumer Advocate Office.

3.2.1.1 Despite the previous subsection the Provincial cross-disability non-profit advocacy organization will have the ultimate responsibility for staffing this agency.

3.3 All Service Providers equally under regulation will provide funding for the office. The Minister shall establish in consultation with Service Providers and the Consumer Advocate Office a regulation that will establish Ontario guidelines regarding sustainable funding on an annual basis.

3.4 The Ministry of Health and Long-Term Care will seek out a provincial body that has the following characteristics to operate the Consumer Advocate Office:

Incorporated organization
Cross disability membership throughout Ontario
Non-profit advocacy capabilities

Section 4

Governance:

4.1 Every Service Provider must have a Board of Directors elected through a democratic process by the membership of the organization.

4.1.1 All Consumers who receive services from the Service Provider are automatically members of the organization with associated rights and privileges.

4.2 The Board of Directors for the Service Provider shall make every effort on an annual basis to recruit Consumers receiving attendant support services to serve on the Board.

4.2.1 This effort may include remuneration for expenses, provision of attendant support services to participate on the Board and per diems.

4.2.2 Service Provider by-laws must direct that the majority of Board Members must be Consumers receiving attendant support services from a Service Provider.

4.2.3 Despite any existing By-law of any Service Provider, Consumers must be represented on the Board of Directors.

4.3 No Board of Directors may operate legally under this legislation without representation from the Consumer population of their own Organization.

4.4 If a Service Provider cannot find Consumers willing to serve on the Board of Directors, the Service Provider must inform the Minister of Health and Long-term Care in writing detailing the search process used to contact Consumers regarding membership on the Board of Directors. If the Minister is satisfied that the Service Provider has attempted to ensure Consumer membership on the Board of Directors, the Service Provider will be allowed to operate for one year without Consumer participation on the Board.

4.4.1 Service Providers may also seek out disability organizations to augment their boards with appropriate members of persons with disabilities.

4.5 Service Providers that do not have Consumers on the Board must annually seek them out to ensure proper representation on the Board of Directors.

Section 5

Executive Director

5.1 Despite any existing By-law of any Service Provider, the Executive Director is not eligible to be a Board Member in any capacity.

5.2 Executive Directors may be present at all Board meetings or subcommittee meetings. They are not eligible to vote on any matter for Board consideration.

5.3 Despite Section 5.2 the Executive Director of a Service Provider may not be present during discussions at the Board regarding his/her performance, compensation or employment status unless invited by the Board.

Section 6

6.1 The Minister shall establish regulations for specific purposes under this legislation.

Section 7

7.1 The Ministry of Health and Long-Term Care will establish a Wait Times and Emergency Shelter Solutions Committee on the day the legislation receives royal assent to examine wait times and emergency shelter support for individuals seeking attendant support services.

7.1.1 The committee will be established by regulation under this legislation.

7.2 The committee established will provide a draft report to the Minister within six months.

7.2.1 The committee will be made up of Consumers, Potential Consumers, a member of the Consumer Advocate Office and Service Providers.

Section 8

Royal Assent:

8.1 This Act comes into force on the day it receives third reading approval in the Ontario Legislature.

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Draft Regulation: Funding for Consumer Advocate Office

1.1 All Service Providers as defined in Section 1 shall dedicate ten per cent of their annual budgets to create the Consumer Advocate Office as defined in Section 3. The Consumer Advocate Office's Budget will be reviewed every two years to ensure that adequate long-term funding is secure for the Office to conduct its work.

1.2 Service Providers may not decrease operational budgets to fund the Consumer Advocate Office.

1.3 Service Providers must hand over their dedicated funds to the Consumer Advocate Office on the day the legislation receives royal assent.

1.3.1 The Consumer Advocate Office will report any Service Provider that does not provide these funds in accordance with this regulation to the Ministry.

1.3.2 The Ministry will immediately transfer the appropriate funds to the Consumer Advocate Office and deduct that amount from the Service Provider's Provincial grant allocation.

1.3.3 After Royal Assent the Ministry will allocate ten percent of the next year's Provincial grant allocation to be paid to the Provincial cross-disability non-profit advocacy organization directly. The Ministry will continue to be responsible for financing the Provincial cross-disability non-profit advocacy organization directly.

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Draft Regulation: Wait Times and Emergency Shelter Solutions Committee for Consumers and Potential Consumers to Receive Attendant Support Services and Emergency Attendant Support when Necessary

1. Pursuant to section 7 of the legislation the Minister shall appoint a committee made up of:
 1. Representatives of the Consumer Advocate Office
 2. Representatives from all Service Providers
 3. Representatives from Consumers and Potential Consumers
 4. The Consumer Advocate Office in consultation with all representatives and the Minister will appoint the Chair of the committee.
 5. Committee membership will be voluntary and appointed by Minister's Order.

1.2 The primary mandate of the committee will be to examine attendant support services in Ontario and recommend options to the government on how to best service Consumers and potential Consumers to ensure they have access to this community resource.

1.3 The committee will be given a broad mandate to examine all aspects of attendant support services.

1.4 The committee will also examine attendant support services provided to individuals seeking emergency shelter.

1.4.1 The committee has the authority under this regulation to invite any individual organization to address the committee.

1.4.2 Any individual or organization has the right to address the committee.

1.5 Pursuant to section 7.2 the committee will present a draft report of their findings to the Minister for review within six months of the committee be established.

1.6 The draft report will have a timetable and a work plan outlining the final report.

1.7 The committee will also provide an action plan on attendant support services for the Minister's consideration.

1.8 The committee will establish guidelines and best practices for attendant support services.

Draft Regulation: Dispute Resolution Process

1. Pursuant to Section 2.3.1 all Service Providers within Ontario will develop and approve a comprehensive dispute resolution mechanism.

1.2 Each Service Provider must develop their own dispute resolution mechanism to deal with issues and conflicts between Consumers and Attendants.

1.2.1 Each Service Provider must provide for the following within their dispute resolution mechanism:

1. Consumer participation throughout the process.
2. Consumer Advocacy Office participation throughout the process. The Office must be given the authority to question Attendants and other staff regarding disputes involving Consumers.
3. Once the process is finalized and approved by the Board of Directors, the Service Provider must communicate this dispute resolution mechanism to all Consumers and send a copy to the Consumer Advocacy Office.
4. When a Consumer is sent a notice from the Service Provider warning that their services are being terminated the Consumer shall be able to direct that the Consumer Advocate Office investigate. No termination of services can come into effect until the Office has investigated the directive of termination.

1.3 Service Providers must have approved dispute resolution mechanisms in place seven days after the Act receives Royal Assent.

1.4 Failure to comply with section 1.3 of this regulation will result in the Ministry of Health and Long-Term Care in conjunction with the Provincial cross-disability non-profit advocacy organization developing a dispute resolution process to be imposed on the Service Provider

1.5 Continued failure to comply will result in the Ministry of Health and Long - Term Care sending an official letter to the Service Provider that further non-compliance will result in the Minister seeking out another Service Provider, and suspending all operations of the current Service Provider. The suspension will not come into effect until another Service Provider is appointed. If no Service Provider volunteers to come forward and accept this responsibility, the Minister will appoint a Service Provider within one month of official notice of the previous Service Provider's termination to take on this role.

1.6 This Regulation if passed will amend Sections 39 to 48 in the Home Care and Community Services Act



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June 11, 2014

Citizens with Disabilities – Ontario (CWDO) is committed to the rights of all persons to participate fully in the civil, cultural, economic, political and social life of their communities. We have over 2000 members in almost every electoral district in Ontario.

CWDO is pleased to submit the following position paper outlining our recommendations regarding the Accessibility for Ontarians with Disabilities Act. In developing this paper, we have reached out to our membership to seek their input and advice regarding recommendations that we believe will make improvements to the current legislation, standards, regulations and proposed new standards to help meet the goals of an Ontario to be accessible by 2025.

We look forward to your final report to the government and trust that our suggestions and recommendations will form a strong basis for your recommendations to the provincial government.

Please let us know if you would like to meet over the summer to discuss any of our recommendations.

Attachment



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Citizens with Disabilities Ontario Accessibility for Ontarians with Disabilities Act (AODA), 2005

Submission Paper

May 30, 2014

Introduction

Citizens with Disabilities – Ontario (CWDO) is committed to the rights of all persons to participate fully in the civil, cultural, economic, political and social life of their communities, we are pleased to submit the following Position Paper regarding CWDO’s views and recommendations regarding the Accessibility for Ontarians with Disabilities Act.

We will be providing comments on the legislation, regulations and proposing new accessibility standards for the Government of Ontario to consider. These comments were informed by a general membership survey undertaken by CWDO between February and May, 2014, as well as a “town hall” with our members held online March 25, 2014.

Background

The Government of Ontario has stated that the purpose of the AODA, its regulations and standards, is to ensure that Ontario is fully accessible by the year 2025. We commend the current government for continuing to support this initiative. We also believe that, as an organization dedicated to assisting people with disabilities, we must continually engage all sectors of society regarding accessibility issues. Having such legislation provides a vehicle for those discussions.

We would also like to commend the current government for placing the Accessibility Directorate of Ontario (the Directorate) with the Ministry of Economic Development, Trade and Employment. This change will allow the Directorate to focus on the most important issue to our membership – access to employment opportunities. In a recent survey conducted by CWDO, our members stated overwhelmingly that employment is the number one issue they face as Ontarians with disabilities.

Recommendations Regarding the AODA

Accessibility Advisory Committees

Section 29 of the AODA establishes the authority for municipalities with a population of 10,000 or greater to convene an Accessibility Advisory Committee. CWDO would like to make the following proposed amendments:

1. That the Advisory Committees be chaired by a person with a disability, provided an individual can be persuaded to take on the position.
2. That despite subsection (5) the Advisory Committees will have the ability to set their own agenda, review and make comments to municipal councils on any municipal matter related to accessibility issues or the removal of barriers for people with disabilities within the municipality.
3. That the Advisory Committees be granted the legislative authority to contact the provincial government regarding barriers at the municipal level that are not being addressed by municipal councils.

AODA Reporting and Enforcement Mechanism

CWDO recommends that the legislation be amended to allow for a proper reporting and enforcement mechanism so that Ontarians with disabilities or visitors with disabilities can report barriers or difficulties directly to the

Directorate. CWDO recommends that proper enforcement procedures be implemented within the legislation to ensure compliance with the legislation, current standards and future standards.

Recommendations regarding the Customer Service Standard

CWDO recommends that Section 4 (use of service animals and support persons) under the Accessibility Standards for Customer Service Regulation be amended to require that every designated public sector organization and every other provider of goods or services establish a physical assistance policy to support consumers with disabilities. If a consumer with a disability requests physical assistance, the obligated organization will provide such services. Furthermore, the policy will be reviewed annually. We further recommend that if this policy is put in place, the obligated organization, provided they act in good faith, shall be exempt from any legal liability.

CWDO recommends that the Customer Service Standard be amended to set a clear timeline for compliance for new public or private sector organizations that have 20 or more employees. The current Customer Service Standard does not set forth any timeline for new organizations. We believe there should be a direct link to this standard when someone is searching for how to start a business in Ontario or if they wish to visit one of the Small Business Enterprise Centres and community-based provider locations across Ontario.

Recommendations regarding training under Section 6 (3)

CWDO recommends the term "as soon as practicable" under this subsection be changed to "six months".

We believe that the phrase in the current regulation is too general and does not allow for specific compliance dates to be met.

Recommendations regarding the Employment Standard under the Integrated Accessibility Regulation

In order to address the primary concern expressed by CWDO members related to employment, CWDO recommends that the ministries of Economic Development, Trade and Employment; Labour; Health and Long-Term Care and Community and Social Services work together to develop policies and a funding mechanism which would allow Ontarians with severe disabilities the opportunity to work with the proper accommodations available to them. For example, funding should be made available to allow attendant support services to employees with

disabilities so they can keep their jobs. We further recommend that this funding model be made available to all sectors.

CWDO recommends that the government of Ontario establish the “**Ontario Accessibility Employment Centre**”. This organization will assist all Ontarians with disabilities who are seeking employment opportunities. The organization will be established to provide the following services:

1. Assistance with the development of resumes and other job related materials for all Ontarians with disabilities who are looking for employment opportunities.
2. Work with employers to ensure that job advertisements are provided in alternative formats.
3. Develop a database of Ontarians with disabilities seeking employment, listing their skills and qualifications. This database will allow employers to seek out potential candidates with disabilities.
4. Develop training and technical courses for Ontarians with disabilities, in collaboration with employers in the public and private sectors.

CWDO further recommends that provisions for this Ontario Accessibility Employment Centre be added to the current Employment Standard under the Integrated Accessibility Regulation.

CWDO recommends that persons with disabilities seeking employment opportunities should be eligible for any existing employment program offered by the Ontario Government regardless of age, educational experience or access to financial assistance (e.g., Ontario Disability Support Program).

CWDO recommends that all universities and colleges develop mentorship programs specifically designed for persons with disabilities in order to assist with the transition from school to work, and that they work with the public sector, broader public sector, and private sector to deliver mentoring programs. CWDO recommends that these mentorship provisions come into force for all obligated organizations by January 1, 2016.

Recommendations regarding the Information and Communications Standard under the Integrated Accessibility Regulation

Under Section 12 (Accessible Formats and Communication Supports) of the Standard the term "in a timely manner" is used. CWDO recommends that this term be specifically defined. Under Section 13, the term "as soon as practicable"

is also too general. CWDO recommends that this term be defined as well. Both terms listed above are too general and potentially lead to confusion and misinterpretation.

Recommendations regarding the Transportation Standards under the Integrated Accessibility Regulation

Under Section 35 (Non-functioning Accessible Equipment) the term "reasonable steps" is used to describe the steps transportation providers will use to communicate non-functioning accessible equipment. Once again, CWDO recommends clarification regarding this term. CWDO recommends that terms as described above need to be clarified specifically in each of the standards to avoid misunderstandings and misrepresentations.

Recommendations for the Built Environment Accessibility Standard under the Integrated Accessibility Regulation

With regard to Accessibility Reports under Section 86.1, CWDO recommends that all public-sector organizations report annually instead of a two-year term.

CWDO recommends that apartments and condominiums establish security features (security guards and video surveillance) to help protect persons with disabilities.

CWDO recommends that homebuilders set aside a minimum 30% of new homes to be bungalows.

CWDO recommends that private dwellings be required to retrofit to current Building Code standards if they are undergoing extensive renovations that change the access to the dwelling.

CWDO recommends that high-rise apartment units and condominiums be required to have accessible balconies and washroom facilities, as currently prescribed in the Ontario Building Code, as well as other amenities be made accessible, such as parking, laundry, and common spaces. CWDO recommends that Home owners and Business owners receive provincial tax credit to retrofit buildings or dwellings.

Proposed New Accessibility Standards

CWDO supports the AODA Alliance's recommendation to create three new accessibility standards for education, housing and health care. In addition, CWDO recommends that an Accessible Elections Standard be created.

Proposed New Standard Regarding Accessible Health Care

CWDO recommends that the government enact legislation entitled *The Consumer Attendant Support Services Protection Act*. A copy of the draft legislation and other materials are attached to this submission. We believe the proposed legislation should make up part of the proposed Accessibility Health Care Standard.

CWDO recommends that the government make amendments to the 14 Local Health Integration Networks (LHINs) across Ontario. Specifically, CWDO recommends that Section 7 of the *Local Health System Integration Act, 2006* be amended to allow for the creation of Accessibility Advisory Committees for each Network. These committees, once established, will be comprised of persons with disabilities living in the community for which the LHIN has responsibility to provide health care and other support services. The committees will advise the LHIN Boards of Directors on issues related to accessibility issues, attendant support services and home care.

CWDO recommends that all hospitals and other healthcare facilities as identified under the *Health and Long-Term Care Act* purchase lifts and other adaptive equipment for patients with disabilities. Furthermore, hospitals and other health care facilities must purchase this equipment by January 1, 2015. CWDO recommends that all hospitals and other health care facilities go through a consultative process with persons with disabilities when purchasing adaptive equipment for patient use.

CWDO recommends all hospitals and health care facilities develop a patient and family consultation and complaints process that will allow persons with disabilities, as patients, to exercise more control over their health care needs and address specific concerns.

CWDO recommends that hospitals and other health care facilities review the training for staff every six months. Training plans and policies should emphasize

sensitivity toward patients with disabilities. CWDO recommends that training manuals be available in alternative formats for the review of patients with disabilities. Training manuals should also be written in plain language.

CWDO recommends that all hospitals and other health care facilities undergo an accessibility access review to ensure their facilities are physically accessible for all patients and visitors with disabilities.

CWDO recommends that Ontario's health care coverage include massage therapy and dental benefits for persons with disabilities. We specifically recommend that this be considered for persons with disabilities earning less than \$50,000 a year and for every Ontarian on the Ontario Disability Support Program.

CWDO recommends that Developmental Service Workers and Personal Support Workers be specifically trained regarding sensitivity toward persons with disabilities. Furthermore, Developmental Service Workers should assist persons with disabilities to develop individual accessibility plans to help promote education and training, legal rights knowledge and employment training.

Proposed New Standard Regarding Accessible Education

CWDO recommends that specialized schools, such as Sunnyview Public School in the City of Toronto, be required to institute the same curriculum testing that occurs across Ontario for students in other elementary and secondary schools.

We believe that, in order to meet employment objectives, persons with disabilities must have access to higher levels of education. This requires sound knowledge of reading, writing and mathematics. Some specialized schools are currently exempt from providing these standardized tests. Students with disabilities, if not exposed to equal levels of testing in reading, writing and mathematics will not be able to compete in the highly competitive Ontario job market. Once graduated, persons with disabilities who have not been exposed to this testing will likely find low income work or be forced on to the Ontario Disability Support Program. CWDO believes education is key to enabling persons with disabilities to be full members of society.

CWDO believes that Ontarians with Disabilities should have access to postsecondary education. We therefore recommend that all universities and colleges across Ontario establish enrolment thresholds for students with disabilities seeking postsecondary education. We further recommend that students with disabilities that require financial assistance to attend university or

college be given access to grants so they can attend the institution of their choice.

CWDO recommends that all postsecondary institutions develop employment action plans for students with disabilities nearing graduation. The individual action plan for a student with a disability would allow the institution to work with the student to connect with possible employers.

CWDO recommends that all teachers receive training regarding all forms of disability – specifically, the impact a disability has on a student’s ability to learn, grow and achieve.

CWDO recommends that the Ontario curriculum be changed to allow for sensitivity training for all students regarding disability issues.

CWDO recommends that schools for students who are deaf and/or visually impaired be properly funded to allow those students who attend these specialized schools every opportunity to succeed. The students should also have the right to develop individual education plans that will allow them to access postsecondary educational opportunities or the workforce.

CWDO recommends that an amendment be made to the Schedule under the *University Foundations Act, 1992* to create a specialized University for deaf students and other students who wish to use sign language as their primary communication method. This University, once established, will teach all courses using American Sign Language/langue des signes québécoise as the primary communication and education method. Alternately, CWDO recommends that grants be provided to Ontario students who wish to attend Gallaudet University in Washington, USA.

Proposed New Standard Regarding Accessible Elections

CWDO recommends the establishment of an Accessible Elections Standard designed to make provincial and municipal elections more accessible to persons with disabilities. Specific recommendations would include amendments to the *Elections Act* and *Municipal Elections Act* which would require both the province and all municipalities to allow for alternate voting methods for any person with a disability eligible to vote as described in these two pieces of legislation.

Specifically, CWDO recommends amendments to the *Elections Act* section 34 (Form of ballot) by allowing individual electors with disabilities to request alternative voting methods. These methods include but are not limited to:

1. vote by mail
2. Internet voting
3. telephone voting
4. mobile polling places

CWDO also recommends that eligible voters with disabilities for municipal elections be permitted to request alternative voting methods for the purpose of participating in municipal elections. These methods include but are not limited to:

1. vote by mail
2. internet voting
3. telephone voting
4. mobile polling places

CWDO is specifically recommending that the *Municipal Elections Act*, section 41 (2) (Rules for ballots) be amended to permit ballots to be accessible through the alternative voting methods previously mentioned above. We also believe amendments need to be made to Ontario Regulation 101/97 to allow a Deputy Returning Officer the authority to accept a ballot that has been submitted by a person with a disability using alternative voting methods.

Candidates with Disabilities

CWDO recommends that all provincial political parties and all municipalities develop information guides to promote the involvement of persons with disabilities to become candidates in these elections for the Provincial Legislature; Municipal Councils and School Boards. This recommendation is not unusual, for example; the Federation of Canadian Municipalities has developed a set of [strategies to increase the number of women on municipal councils](#) across Canada. CWDO believes that a similar strategy to assist candidates with disabilities is necessary to help improve the political involvement of persons with disabilities in the election process.

Recommendation Regarding Other Legislation

CWDO recommends that the Government make legislative changes to the *Condominium Act* specifically, Section 93 (Reserve fund) and Ontario Regulation 48/01, in order to allow the reserve fund to be used for accessibility purposes in a condominium. For example, the fund could be used to purchase accessible, automatic doors and other accessible features like ramps and specialized lighting for people with vision impairments.

CWDO recommends that the provincial government, under the authority of the Ministry of Community and Social Services, review the Ontario Disability Support Program. The purpose of the review will be to ensure that persons with disabilities utilizing the Program will have a liveable financial supplement and provide those individuals with education and employment opportunities and support. These supports, if implemented, would have the potential to help people become financially self-sufficient, and reduce the number of people relying on ODSP.

CWDO believes many individuals with disabilities can work or participate in educational activities and that ODSP should only be used for temporary issues or for persons with disabilities that are unable to enter the workforce.

Attachments

Appendices

Appendix 1: Consumer Attendant Support Services Protection Act

Appendix 2: Information Note: Attendant Support Services in Ontario

Appendix 1

Consumer Attendant Support Services Protection Act

Explanatory Note:

The Consumer Attendant Support Services Protection Act will amend the *Home Care and Community Services Act, 1994*

The purpose of this legislation is to ensure that Consumers of attendant support services are protected and have the right to be involved with decisions regarding their own attendant support services. Consumers need to be directly involved in how policies and procedures are developed with the Service Providers, which provide attendant support services for them.

The people of Ontario support the right of persons of all ages with disabilities to enjoy equal opportunity and to participate fully in the life of the Province. Also, this legislation recognizes and understands that persons with disabilities are to be treated equally and without discrimination in accordance with the *Human Rights Code* of Ontario.

The Government of Ontario is committed to working with persons with disabilities and attendant support services providers to build on what has already been achieved by ensuring that all persons with disabilities have the opportunity to participate in the day-to-day operations and policy development of their attendant support services.

Section 1 establishes definitions.

Section 2 provides for rights and obligations of Consumers and attendant support services.

Section 3 provides for the creation of a Consumer Advocate Office. This agency will advocate on behalf of all Consumers who receive attendant support services within Ontario.

Section 4 outlines governance obligations for attendant support services within Ontario.

Section 5 outlines the Executive Director's role with the Board of Directors of all providers of attendant support services within Ontario.

Section 6 establishes regulation making authority for the Minister under the Act.

Section 7 establishes the Solutions Committee to address wait times and emergency shelter attendant support services for persons with disabilities who require attendant support services.

Section 8 sets out obligations after Royal Assent.

Draft regulations follow Section 7 and pertain to specific areas of attendant support services. Draft regulations are as follows:

- Funding for Consumer Advocate Office
- Wait Times and emergency shelter for Potential Consumers to Receive Attendant Support Services
- Dispute Resolution Process

Section 1

Definitions:

1.1 Service Provider is an organization receiving provincial funding to provide attendant support services to persons living in their own homes whether or not these homes are rented, owned, cooperatively, communally shared or with family members within Ontario.

1.2 Board of Directors is the governing body for the attendant support services provider recognized by the Ministry of Health and Long-Term Care (or other ministries) for funding purposes. They are accountable to the Ministry for operating within the established policies and procedures for attendant support services within Ontario.

1.3 Executive Director is the individual who is responsible for the overall day-to-day operations of a Service Provider, and who reports to the Board of Directors.

1.4 Attendant is a person who is paid or volunteers to provide personal attendant support services to a Consumer on behalf of a Service Provider.

1.5 Provincial cross-disability non-profit advocacy organization will be responsible for hiring adequate staff to operate the Consumer Advocate Office. The Provincial cross-disability non-profit advocacy organization will be selected by a tendering process to operate the Consumer Advocate Office.

1.6 The Consumer Advocate Office advocates for the Consumer during disputes with their Service Provider. The Consumer Advocate Office provides advice and recommendations to Consumers on how to deal with disputes between themselves, Attendants and their Service Provider.

1.7 A Consumer is the person who receives attendant support services from a Service Provider within Ontario . For the purpose of this legislation, receiving services from a specific Service Provider does not constitute a conflict of interest in serving on the Board of Directors of that Service Provider.

1.8 A Potential Consumer is a person who is eligible to receive attendant support services from a Service Provider within Ontario, but has not chosen an organization to provide these services.

1.9 Community Care Access Centre (CCAC) is the provincial government organization currently evaluating and qualifying a potential Consumer's need for attendant support services. They form contractual relations with regional Service Providers to provide attendant support services to the Consumer in accordance to CCAC assessment evaluations, for time and care tasks.

1.10: Attendant Support Services include personal care and light home care services. These are services that affect the Consumer's well being in acquiring or maintaining personal health, and their independent living goals, which promote their autonomy and inclusion in society.

Section 2

Rights and Obligations:

2.1 Every Consumer has the right to control how their attendant support services are provided to them.

2.1.1 Every Consumer has the right to declare the type and level of support required to meet their independent living goals, and promote their autonomy and inclusion in society.

2.1.2 Every Consumer has the right to assist in the selection and evaluation of Attendants who will be providing services in the Consumer's home.

2.1.3. Every Consumer has the right to report concerns to the Service Provider. Consumers have a right to expect these concerns to be responded to in a timely manner, and in a way that effectively works to resolve the issue. The Minister shall establish in consultation with Service Providers and the Consumer Advocate Office a regulation to spell out specific time frames and obligations to formulate an effective resolution process.

2.2 Every Consumer may participate in a training session designed to resolve conflicts between them, their Service Provider and Attendants.

2.3 Service Providers are obligated to ensure that any corrective measures taken by them, which may impact a Consumer, has a fair process that allows the Consumer the opportunity to appeal decisions that impact their services.

2.3.1 Every Service Provider will develop policies and procedures to deal with disputes between Consumers and Attendants. The Service Provider's Board of Directors will approve these procedures.

2.3.2. All Service Providers must adopt these procedures within 30 days of this legislation receiving Royal Assent.

2.4 Every Attendant hired by a Service Provider must be trained in conflict resolution. The Minister shall establish in consultation with Service Providers and the Consumer Advocate Office a regulation that will establish Ontario guidelines for staff to be trained in conflict resolution procedures.

2.4.1 Under this legislation no Attendant will be allowed to deliver services to any Consumer without supervision unless this training is completed to the satisfaction of the Service Provider and the Consumer Advocate Office Representative.

2.4.2 Service Providers are required under this legislation to fund training in conflict resolution for Consumers and Attendants.

2.4.2.1 Service Providers may share the cost of such training programs with other Service Providers. All Organizations involved in joint training programs must have the approval of each individual organization's Board of Directors.

2.5 Once CCAC has qualified the Consumer's eligibility, the Consumer then has complete control to direct their attendant support services with the Service Provider until their eligibility changes.

Section 3

Consumer Advocate Office:

3.1 The Consumer Advocate Office will be established on the day that this legislation receives royal assent.

3.2 A Provincial cross-disability non-profit advocacy organization will have the responsibility under this legislation to hire appropriate staff to manage the Consumer Advocate Office.

3.2.1 Service Providers will have the right to be involved with the hiring of staff for the Consumer Advocate Office.

3.2.1.1 Despite the previous subsection the Provincial cross-disability non-profit advocacy organization will have the ultimate responsibility for staffing this agency.

3.3 All Service Providers equally under regulation will provide funding for the office. The Minister shall establish in consultation with Service Providers and the Consumer Advocate Office a regulation that will establish Ontario guidelines regarding sustainable funding on an annual basis.

3.4 The Ministry of Health and Long-Term Care will seek out a provincial body that has the following characteristics to operate the Consumer Advocate Office:

Incorporated organization

Cross disability membership throughout Ontario

Non-profit advocacy capabilities

Section 4

Governance:

4.1 Every Service Provider must have a Board of Directors elected through a democratic process by the membership of the organization.

4.1.1 All Consumers who receive services from the Service Provider are automatically members of the organization with associated rights and privileges.

4.2 The Board of Directors for the Service Provider shall make every effort on an annual basis to recruit Consumers receiving attendant support services to serve on the Board.

4.2.1 This effort may include remuneration for expenses, provision of attendant support services to participate on the Board and per diems.

4.2.2 Service Provider by-laws must direct that the majority of Board Members must be Consumers receiving attendant support services from a Service Provider.

4.2.3 Despite any existing By-law of any Service Provider, Consumers must be represented on the Board of Directors.

4.3 No Board of Directors may operate legally under this legislation without representation from the Consumer population of their own Organization.

4.4 If a Service Provider cannot find Consumers willing to serve on the Board of Directors, the Service Provider must inform the Minister of Health and Long-term Care in writing detailing the search process used to contact Consumers regarding membership on the Board of Directors. If the Minister is satisfied that the Service Provider has attempted to ensure Consumer membership on the Board of Directors, the Service Provider will be allowed to operate for one year without Consumer participation on the Board.

4.4.1 Service Providers may also seek out disability organizations to augment their boards with appropriate members of persons with disabilities.

4.5 Service Providers that do not have Consumers on the Board must annually seek them out to ensure proper representation on the Board of Directors.

Section 5

Executive Director

5.1 Despite any existing By-law of any Service Provider, the Executive Director is not eligible to be a Board Member in any capacity.

5.2 Executive Directors may be present at all Board meetings or subcommittee meetings. They are not eligible to vote on any matter for Board consideration.

5.3 Despite Section 5.2 the Executive Director of a Service Provider may not be present during discussions at the Board regarding his/her performance, compensation or employment status unless invited by the Board.

Section 6

6.1 The Minister shall establish regulations for specific purposes under this legislation.

Section 7

7.1 The Ministry of Health and Long-Term Care will establish a Wait Times and Emergency Shelter Solutions Committee on the day the legislation receives royal assent to examine wait times and emergency shelter support for individuals seeking attendant support services.

7.1.1 The committee will be established by regulation under this legislation.

7.2 The committee established will provide a draft report to the Minister within six months.

7.2.1 The committee will be made up of Consumers, Potential Consumers, a member of the Consumer Advocate Office and Service Providers.

Section 8

Royal Assent:

8.1 This Act comes into force on the day it receives third reading approval in the Ontario Legislature.

Draft Regulation: Funding for Consumer Advocate Office

1.1 All Service Providers as defined in Section 1 shall dedicate ten per cent of their annual budgets to create the Consumer Advocate Office as defined in Section 3. The Consumer Advocate Office's Budget will be reviewed every two years to ensure that adequate long-term funding is secure for the Office to conduct its work.

1.2 Service Providers may not decrease operational budgets to fund the Consumer Advocate Office.

1.3 Service Providers must hand over their dedicated funds to the Consumer Advocate Office on the day the legislation receives royal assent.

1.3.1 The Consumer Advocate Office will report any Service Provider that does not provide these funds in accordance with this regulation to the Ministry.

1.3.2 The Ministry will immediately transfer the appropriate funds to the Consumer Advocate Office and deduct that amount from the Service Provider's Provincial grant allocation.

1.3.3 After Royal Assent the Ministry will allocate ten percent of the next year's Provincial grant allocation to be paid to the Provincial cross-disability non-profit advocacy organization directly. The Ministry will continue to be responsible for financing the Provincial cross-disability non-profit advocacy organization directly.

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Draft Regulation: Wait Times and Emergency Shelter Solutions Committee for Consumers and Potential Consumers to Receive Attendant Support Services and Emergency Attendant Support when Necessary

1. Pursuant to section 7 of the legislation the Minister shall appoint a committee made up of:
 1. Representatives of the Consumer Advocate Office
 2. Representatives from all Service Providers
 3. Representatives from Consumers and Potential Consumers
 4. The Consumer Advocate Office in consultation with all representatives and the Minister will appoint the Chair of the committee.
 5. Committee membership will be voluntary and appointed by Minister's Order.

1.2 The primary mandate of the committee will be to examine attendant support services in Ontario and recommend options to the government on how to best service Consumers and potential Consumers to ensure they have access to this community resource.

1.3 The committee will be given a broad mandate to examine all aspects of attendant support services.

1.4 The committee will also examine attendant support services provided to individuals seeking emergency shelter.

1.4.1 The committee has the authority under this regulation to invite any individual organization to address the committee.

1.4.2 Any individual or organization has the right to address the committee.

1.5 Pursuant to section 7.2 the committee will present a draft report of their findings to the Minister for review within six months of the committee be established.

1.6 The draft report will have a timetable and a work plan outlining the final report.

1.7 The committee will also provide an action plan on attendant support services for the Minister's consideration.

1.8 The committee will establish guidelines and best practices for attendant support services.

Draft Regulation: Dispute Resolution Process

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1. Pursuant to Section 2.3.1 all Service Providers within Ontario will develop and approve a comprehensive dispute resolution mechanism.

1.2 Each Service Provider must develop their own dispute resolution mechanism to deal with issues and conflicts between Consumers and Attendants.

1.2.1 Each Service Provider must provide for the following within their dispute resolution mechanism:

1. Consumer participation throughout the process.
2. Consumer Advocacy Office participation throughout the process. The Office must be given the authority to question Attendants and other staff regarding disputes involving Consumers.
3. Once the process is finalized and approved by the Board of Directors, the Service Provider must communicate this dispute resolution mechanism to all Consumers and send a copy to the Consumer Advocacy Office.
4. When a Consumer is sent a notice from the Service Provider warning that their services are being terminated the Consumer shall be able to direct that the Consumer Advocate Office investigate. No termination of services can come into effect until the Office has investigated the directive of termination.

1.3 Service Providers must have approved dispute resolution mechanisms in place seven days after the Act receives Royal Assent.

1.4 Failure to comply with section 1.3 of this regulation will result in the Ministry of Health and Long-Term Care in conjunction with the Provincial cross-disability non-profit advocacy organization developing a dispute resolution process to be imposed on the Service Provider

1.5 Continued failure to comply will result in the Ministry of Health and Long - Term Care sending an official letter to the Service Provider that further non-compliance will result in the Minister seeking out another Service Provider, and suspending all operations of the current Service Provider. The suspension will not come into effect until another Service Provider is appointed. If no Service Provider volunteers to come forward and accept this responsibility, the Minister will appoint a Service Provider within one month of official notice of the previous Service Provider's termination to take on this role.

1.6 This Regulation if passed will amend Sections 39 to 48 in the Home Care and Community Services Act

Appendix 2

Information Note Attendant Support Services in Ontario

Consumer Attendant Support Services Protection Act:

- If adopted, the proposed legislation will give equal voice to consumers and service providers.
- The proposed legislation will safeguard consumers, attendants and service providers.
- Current legislative authority comes under the *Home Care and Community Services Act, 1994*.

If adopted the proposed legislation will do the following:

1. Create a Consumer Advocate Office
2. Establish a new Governance Structure for Service Provider Boards
3. Address Consumers' Long Waiting Times for Attendant Services
4. Provide for a Dispute Resolution Process

Achievements to date:

- Met with Sylvia Jones MPP for Dufferin-Caledon, summer of 2008
- Meeting with the Abuse Prevention Working Group, 2008.
- Interview on Rogers TV, spring of 2008
- Wrote every MPP, spring of 2009; 2010 and 2012
- Wrote every Community Care Access Centre, spring of 2008 (no response from any CCAC)
- Wrote every Local Health Integration Network, spring of 2008 (no response from any LHIN to date)

Background:

- There are three primary agencies that deal with attendant support services in Ontario (Local Health Integration Networks, Community Care Access Centres and Attendant Support Services Providers).

- Local Health Integration Networks (LHINs) created by the Ontario government in March 2006, 14 not-for-profit corporations who work with local health providers and community members to determine the health service priorities. Local Health Integration Networks (LHINs), integrate and fund local health services, including: Hospitals; Community Care Access Centres; Community Support Services; Long-term Care; Mental Health and Addictions Services and Community Health Centres.
- Community Care Access Centres (CCACs) are comprised of 14 local CCAC organizations across the province to manage local care. Funded and legislated by the Ontario Ministry of Health and Long-Term Care through the corresponding LHINs. Services include: Attendant Service Providers, home care, long-term care destinations, and other community services.
- Attendant Support Services Providers are non-profit organizations that provide assistance with the activities of daily living to people with physical disabilities. These services include assistance with bathing, dressing, personal care, cooking, shopping, housekeeping and laundry, as well as escorting and assisting consumers when they pursue activities away from home.

Potential policy gaps

- The current Legislation does not ensure that consumers have equal access to advocacy groups or representation during disputes.
- The proposed legislation offers a potential opportunity to resolve issues related to wait times for people with disabilities who require attendant support services.
- Proposed legislation also ensures accountability and accessibility for persons with disabilities to control their own support services.
- The proposed Consumer Advocacy Office will ensure that all parties can resolve disputes within a Service Provider.

February 8, 2015



**Council of Canadians
with Disabilities**
A VOICE OF OUR OWN

**Conseil des Canadiens
avec déficiences**
CETTE VOIX QUI EST LA NOTRE



**Canadian Association
for Community Living**
Association canadienne pour
l'intégration communautaire

Diversity includes. On se ressemble.

FOR IMMEDIATE RELEASE

Toronto and Winnipeg: February 6, 2015

Assisted Suicide Decision Changes Landscape, Makes Disability a Defining Issue

Today's decision of the Supreme Court fundamentally alters end-of-life for all Canadians. The Council of Canadians with Disabilities (CCD) and the Canadian Association for Community Living (CACL) are profoundly disappointed by today's ruling and extremely concerned about the implications of the ruling.

An immensely important discussion must now begin with Canadians and politicians at all levels, with civil society, health professions and the legal community. We start from the premise that the lives of Canadians with disabilities are worthy of the utmost respect. Such respect, regrettably, cannot be taken for granted.

To begin this critical discussion, we offer the following questions, reflections and commitments:

1. As we each near the end of our lives, at the time when we are likely to be most vulnerable to despair and fear, we have now lost the protection of the Criminal Code. Where shall we now find that protection? CCD and CACL caution that our collective response to this question must go far beyond the technical exercise of so-called "safeguards".
2. In the final stages of a terminal illness, at the time when grief and fear may be most powerfully present in our lives, Canadians must now decide for themselves whether life is worth living. Among them are the most vulnerable Canadians, those who are dependent on others, and who are relegated to the margins of social and economic participation. We must not allow them to be diminished again in the coming discussions about their own end of life options.
3. At the time when our physical powers fail us, every Canadian will now be obliged to calculate how much love and support is too much to ask of others. How shall we ensure that the needs of the dying are not by default secondary to the well-being of the living?
4. As we contemplate the changes about to unfold in the wake of this decision, our elected officials must take notice of the pressing questions that are of urgent concern to Canadians with disabilities. To what extent do conditions of poverty, exclusion and lack of support actually restrict autonomy, and erode the human will to live among dependent Canadians? Will our governments stand firm in maintaining and expanding home care

services and supports for community/independent living? Will our national commitment to suicide prevention extend to persons with disabilities and degenerative conditions? Most critically, will access to palliative care become a universally available health care service to provide needed support and choice at the end of life?

What happens now? In the days ahead, members of CCD and CACL will review the judgment in detail, seeking to grasp its full implication and to comprehend the Court's dramatic departure from a legal precedent established 22 years ago in *Rodriguez v British Columbia*. And in the months and years to come, we will redouble our efforts to secure conditions of equal respect and robust citizenship for all Canadians with disabilities. The stakes are higher now than ever before.

Debate leading up to this legal decision has too often been polarized and divisive. CCD and CACL know that Canadians wish to be compassionate. CCD and CACL are resolved to work creatively and in good faith to build solidarity among justice seeking communities as we embark upon the journey invoked by today's Court's ruling.

There are difficult days ahead. The Canadian disability movement remains united in our claim that the lives of people with disabilities matter. We speak with one voice in our condemnation of all forms of discrimination and abuse. We affirm together our entitlement to live good lives in places and conditions of our choosing. Consistent with our long history of fearless and principled advocacy, we now join with fellow citizens across the full spectrum of views on end-of-life in an urgent call for universal, unencumbered access to the highest possible standard of palliative care in Canada.

In the dialogue to come, we urge respect, openness and assurance that Canadians with disabilities and our representative organizations can fully participate, in full confidence that our experience, voices and knowledge are valued. We seek wise decisions guided by the values of diversity and inclusion that define us and underpin our Canadian society.

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For the CCD/CACL Factum to the Supreme Court of Canada see
<http://ccdonline.ca/media/humanrights/carter-factum-ccd-cacl-14-08-28.pdf>

CCD and CACL representatives will be available for comment following the Supreme Court decision Friday:

Commentary on SCC Assisted Suicide Judgment in Carter v. Canada - Key Concerns

Related Documents

February 6, 2015

[Assisted Suicide Decision Changes Landscape, Makes Disability a Defining Issue](#)

February 4, 2015

[What's At Stake in Friday's Supreme Court Decision on Assisted Suicide](#)

October 14, 2014

["Canadians Should not be Provided Public Support to Kill Themselves"](#)

[More on Ending of Life Ethics](#)

FOR IMMEDIATE RELEASE
Toronto and Winnipeg: February 6, 2015

Commentary on SCC Assisted Suicide Judgment in Carter v. Canada – Key Concerns

1. The judgment creates the potential for the most permissive and least restrictive criteria for assisted suicide in the world, putting persons with disabilities at serious risk.
2. CCD and CACL are disappointed that the views of people with disabilities in Canada, as shared by the leading disability advocacy groups around the world, were disregarded by the Court.
3. The Court did not impose a requirement of terminal illness, as is required in the states of Washington and Oregon.
4. The judgment permits assisted suicide on the basis of psychological suffering. This places people with serious mental and emotional disabilities at risk, as well as people who have not yet come to grips with their disability.
5. The judgment allows people to decline palliative and other care that would alleviate their suffering, and imposes an obligation on the state to provide Assisted Suicide, but not palliative care.

6. The Court has focused on striking the law using two potentially expansive criteria –in doing so, it paid no attention to ensuring Assisted Suicide is limited to a small number.

7. The judgment makes the existence of a “grievous and irremediable medical condition” , rather than a terminal illness, one of the two primary criteria – this potentially means that all persons with a serious disability in Canada can access Assisted Suicide. This degree of permissiveness does not exist anywhere else in the world.

8. The second criteria, “intolerable suffering,” is completely subjective and will make it difficult to review decisions of doctors like Dr. Kevorkian who felt the existence of a disability was intolerable.

9. Numbers are revealing – in Belgium, the number of Assisted Suicide deaths has increased an average of 47.77% annually since 2003, and in the Netherlands it has increased 64.13% since 1995, with no end in sight to this increase.

10. Parliament can and should act to place crucial safeguards on the Court’s judgment to limit access to assisted suicide.

11. CCD and CACL call on Parliament to show national leadership on the issues of palliative and long-term care to reduce the number of people who will choose assisted suicide out of desperation because they do not have access to support systems to ease their end of life.