

**Written Submissions of
ARCH Disability Law Centre**

Based on ARCH's Community Consults,

RE: *Carter v Canada*

Prepared for the

**Provincial-Territorial Expert Advisory Group on Physician-
Assisted Dying (Dr. Jennifer Gibson and Maureen Taylor, co-
chairs)**

by

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INTRODUCTION

ARCH Disability Law Centre is pleased to offer submissions on physician-assisted dying (PAD) to the Federal External Panel on Options for a Legislative Response to *Carter v Canada* (the Panel). We feel it is essential that the Panel hear from the communities of persons with disabilities. ARCH has made every effort to present the opinions, concerns and suggestions of persons with disabilities regarding physician assisted dying. We have also encouraged groups and individuals to present their views to the Panel themselves using the Panel's survey mechanism.

ABOUT ARCH

ARCH Disability Law Centre (ARCH) is a specialty legal clinic with a provincial mandate dedicated to advancing the equality rights of persons with disabilities. ARCH provides legal services to help Ontarians with disabilities live with dignity

and participate fully in our communities. ARCH provides free and confidential legal advice and information to people with disabilities in Ontario. We provide direct legal representation, conduct law reform activities and participate in policy and community development work. We also deliver public legal education to people with disabilities and continuing legal education to the legal community. For more information, visit ARCH's website at www.archdisabilitylaw.ca.

ARCH'S CONSULTATIONS ON PHYSICIAN-ASSISTED DYING

The issue of physician-assisted dying has provoked a wide range of responses from the various segments of the communities of persons with disabilities in Ontario. ARCH has gone to great effort to canvas community opinions on this issue using the means listed below.

a) Access Awareness Event – Law Society of Upper Canada (June 2015)

Every June, ARCH, in conjunction with the Law Society of Upper Canada, holds a free Access Awareness event open to the public and members of the legal profession. On June 6th, 2015, ARCH used this event to present a forum on the *Carter* decision and physician assisted dying. The goal was to explain the decision to the public. Our panels included persons with expertise in law, disability and biomedical ethics as well as persons with lived experience. The key panel consisted of the following members:

- 1) Kerry Bowman, a medical ethicist at the University of Toronto;
- 2) Michelle Gardiner, a person with a physical disability and a member of Canadians with Disabilities – Ontario; and
- 3) Michael Bach, Executive Vice-President of the Canadian Association for Community Living.

The forum offered members of the public an opportunity to question the experts and express their own concerns about how the implementation of a physician assisted dying regime could affect their lives.

About 100 persons, many of them persons with disabilities, attended the Access Awareness event in person, while another 100 attended via live webcast. Persons viewing by webcast were able to submit on-line questions to the panelists. To view a video of the Access Awareness Event please visit:

<http://www.lawsocietygazette.ca/event/access-awareness-event-the-carter-decision/>

b) Community Partners Consultation (Oct. 1, 2015)

ARCH also sought to gather more focussed comments. On October 1st, 2015 we invited our “community partners” (representatives from various community agencies working with persons with disabilities) to present their views on physician assisted dying, outline the key concerns of their communities and offer their opinions as to what safeguards and protections should be incorporated into any physician assisted dying regime. The agencies in attendance presented views and comments from the populations of persons with physical, sensory, degenerative and intellectual disabilities.

If an agency was unable to attend our consultation, we offered each the opportunity to either send us their comments in writing or schedule a phone call to express their views. Participants included:

- Advocacy Centre for the Elderly
- Alliance for Equality of Blind Canadians
- Canadian Hard of Hearing Association

- Citizens with Disabilities – Ontario
- Council for Canadians with Disabilities
- Communication Disabilities Access Canada
- Easter Seals Canada
- Family Alliance Ontario
- Huntington’s Society
- Ontario Federation for Cerebral Palsy

These groups represent a large population of persons with a wide range of disabilities, including physical disabilities, sensory disabilities and intellectual disabilities. A number of the groups who attended our consultation had also consulted with their own members. They were able to offer responses to our questions that reflected the results of their own community consultations on the issue of physician assisted dying. For example Citizens with Disabilities – Ontario conducted a survey of their own members.

It was our goal to supplement the more general perspectives gathered through our community partners consultation by conducting specialized focus groups. Our aim was to explore the views of particularly vulnerable groups in more detail. We specifically identified persons with disabilities that would not, in and of themselves, be likely lead to terminal conditions. This included persons with mental health disabilities and persons with intellectual disabilities. We felt it was essential to canvas the opinions of these populations since persons with non-terminal conditions could be even more vulnerable in relation to PAD if their unique circumstances are not taken into consideration.

While we were able to conduct a focus group with persons with mental health disabilities (see especially section B-1(e) to (i) and 2(f), below), time did not permit us to conduct focus groups with persons with intellectual disabilities. Information from this community was gathered during our more general consultations, and when Michael Bach spoke about the concerns of persons with

intellectual disabilities during our Access Awareness Event. This information is blended into the substance of our comments. A more targeted focus group discussion would have allowed us to explore the opinions about of persons with intellectual disabilities in a more sophisticated manner. Both these populations require specialized individualized forms of accommodation. We feel more information is required to understand how to provide effective accommodation to these individuals during a PAD process.

ARCH urges the Advisory Group to canvas the views of both the population of persons with intellectual disabilities and the community of persons with mental health disabilities in greater detail to obtain a more fulsome understanding of the impact PAD may have upon these communities, whose populations include a number of particularly vulnerable persons.

ARCH is willing to assist with further consultation of these communities.

c) Focus Group (Mental Health Disabilities)(Oct. 23, 2015)

ARCH held a smaller “focus group” consultation with persons with mental health disabilities. We felt that this community required a more targeted consultation since their perspectives may not have been canvassed when it was assumed physician-assisted dying would apply to only persons with terminal conditions. We met with individuals with lived experience and who also provided counselling and support to other members of the community of persons with mental health disabilities. In this way, we attempted to capture the views of individuals who had a personal stake in PAD legislation who could also relay the views and comments of the larger population of persons with whom they work on a daily basis.

d) Summary re: Sources of Information

ARCH’s submissions offer an overview of the various comments we received from members of the public during the Access Awareness Event as well as the

comments, concerns and suggestions received during our community partners' consultation and our smaller focus group meeting. While there remains a wide range of opinions on all aspects of physician assisted dying within the communities of persons with disabilities, we are confident that our submissions reflect many key concerns, ideas and aspirations of these diverse organizations and communities.

We have organized our comments according to the issues identified in Section 3 of the Panel's mandate.

- a) Different forms of physician-assisted dying;
- b) Eligibility criteria and definition of key terms;
- c) Risks to individuals and society associated with physician-assisted dying;
and
- d) Safeguards to address risks and procedures for assessing requests for assistance in dying and the protection of physician's freedom of conscience.

While we have made every effort to organize our materials in a coherent fashion, it was not our goal to impose any specific organization or legal analysis as we received community members' responses. We have identified areas of consensus where there appeared to be consensus. Our aim, however, was to present the full range of opinions and concerns expressed by community members, although these comments do not necessarily represent the views of ARCH. Where comments were relevant to more than one topic of discussion, we have included them in all relevant segments of our submissions. We felt the risk of being repetitive was outweighed by the risk of relevant information being omitted.

ARCH'S SUBMISSIONS

A. DIFFERENT FORMS OF PHYSICIAN ASSISTED DYING (Assisted suicide and voluntary euthanasia)

When consulting with our community partners, people were already familiar with the content of *Carter v Canada* and consequently, our discussions focused on physician-assisted dying (PAD) as a broad concept.

At both our Access Awareness event in June and our community partners' consultation in October we took time to explain what the Supreme Court said in *Carter* and it was made clear that the decision was not meant to apply to persons who were deemed to be legally "incapable" to make such a decision and therefore, as far as the Court stated, physician assisted dying was not an option that would be open to persons with a substitute decision maker for medical or personal care decisions.

We did not delineate between assisted suicide and voluntary euthanasia, terms which were contentious and, in the case of euthanasia, abhorrent to many of our community partners. Please see the definitions section below (section B-2) for details.

B. ELIGIBILITY CRITERIA AND DEFINITION OF KEY TERMS

1. Eligibility

When asked who should be able to access the PAD "option," our community partners were somewhat divided on eligibility criteria.

a) Vulnerability and Eligibility

While individuals commented that they wanted to have the "PAD" option available to them if they were faced with a "grievous and irremediable condition

that made their life intolerable,” they were concerned about how PAD might be applied to other persons deemed to be more vulnerable. As one participant stated:

I personally would want the choice, but I have concerns about when that choice should be open [to others]

Factors Contributing to Vulnerability

In general, participants felt that the concept of “vulnerability” should be incorporated into any assessment of who is eligible to accept or pursue PAD. There was no clear consensus on exactly how to define vulnerability. Comments focused on the degree to which a person may choose to accept PAD for reasons other than their own personal medical or physical condition.

In that regard many comments focused on vulnerability related to a lack of support services or adequate palliative care, a lack of family support or the belief that funding shortfalls render long-term care “intolerable.” There was a clear consensus that all Canadians could be vulnerable if they are led to choose the PAD option merely because they have no safe, viable alternative options. In this vein a lack of palliative care, limited home support, fears about the low quality of care in nursing homes and the high cost of private care were all mentioned as adding to the potential vulnerability of persons who may be eligible to accept PAD.

It is worth noting that 80% of respondents to the Citizens with Disabilities – Ontario (CWDO) survey on PAD indicated that living in a nursing home where life has become tedious or oppressive would be a reason to pursue PAD, while 60% felt that living in difficulty because needed supports and services are not available would justify seeking PAD. Other responses indicated that a majority of people fear that a loved one would pursue PAD if they did not have access to

sufficient community supports and did not want to impose on their family.¹ Community partners were clear that additional support was needed.

There was some agreement that whatever process was created for PAD, any person found eligible to pursue that option should have that determination supported by a second opinion from a qualified health care professional. There was less agreement about whether the key issue to confirm should be the person's medical condition, their capacity to make a decision, or whether their consent was freely given and fully informed. The majority of our community partners focused on the issue of freely obtained consent, from a person who meets the legal definition of capacity and has a "grievous and irremedial condition" is at issue.

b) Level of Capacity Required to Accept PAD

There was some consensus among our community partners around the following points:

- Individuals should be able to access the PAD option independently; and
- Individuals accessing the PAD option must have the decision-making capacity to make this decision and give clear consent.

There was no clear consensus about what level of capacity must be present for a person to be able to choose the PAD option. Some felt that the "understand and appreciate" standard currently applied to determine capacity in most other decision-making realms (both in Ontario and elsewhere) may not be sufficient to assess a person's ability to make a decision as serious and final as choosing physician-assisted death. It was suggested by some that a higher standard should be applied and that people should have to demonstrate their capacity to accept the PAD option rather than being assumed to be capable.

¹ CWDO Member Survey on Physician-Assisted Dying (results as of September 30, 2015) at 4, 5.

Other participants argued that equity demanded that the same presumptions, standards and tests that apply to other assessments of decision-making capacity be applied to decisions related to PAD. Although accessing PAD may imply more obvious and serious consequences than some other decisions, it was felt that applying a higher standard to determinations of capacity would create unnecessary barriers to accessing PAD and would discriminate against some persons with disabilities contrary to various human rights codes and the Charter.

c) Capacity and Consent for Physician-Assisted Death

Community partners also referred to issues of consent and the requirement that consent be given freely without coercion and that consent be fully informed. Although consent and capacity are clearly linked, participants were just as concerned about proving a person was free from undue influence as they were about a formal assessment of capacity.

A few participants noted that a doctor or other professional assisting a person to pursue PAD should be required to report any concerns they may have about a person's capacity to accept physician-assisted death. They should further report any reason (if it exists) to believe a person was being influenced or pressured to continue with a PAD process.

d) Persons with Intellectual Disabilities and Supported Decision Making

There were concerns about how PAD would apply to persons with intellectual disabilities. A number of persons within this community make decisions with support. This means that a trusted friend or relative who knows the person well helps them understand information provided to them. This support person helps to communicate their wishes to others, if required. The assumption is that the support person only offers support and does not make the decision for the persons with the intellectual disability. In many instances, individuals are accepted as being capable to make decisions with this support. There was some discussion about whether a person who requires support to make a decision

could be considered capable to accept PAD. There were also concerns that a support person could influence the decision being made.

At the same time, if a person requires accommodation to overcome barriers related to their disability, they are legally entitled to this accommodation even if it is applied to decision-making. Many felt that rejecting the validity of a form of accommodation employed by some persons with disabilities could be discriminatory and contrary to the Charter. Supported decision-making has been endorsed by the United Nations as a valid form of accommodation for persons with capacity issues.²

There was a degree of consensus that any finding that a person is capable (or not capable) to pursue the PAD option be supported by a second opinion. However, it appears that many people conflated capacity with consent and their key concern was confirming that a person consents to pursue PAD, that they are fully informed about PAD and its consequences, and they are free from undue influence.

e) Challenges of Making a Decision while in Pain or Under Stress

There were concerns that even if a person was technically “capable” to accept PAD, persons in intolerable pain dealing with a highly stressful life situation may not be best positioned to decide if PAD is the right option for them. People noted that pain can be overwhelming; even short bouts of intense pain can make life intolerable. Under such circumstances it may be impossible for a person to reasonably consider alternatives or accept that their pain may not be permanent. Even being diagnosed with a terminal condition does not always mean that there is no hope of recovery. As one participant shared with the group:

² See *The United Nations Convention on the Rights of Persons with Disabilities*, UNCRPD A/RES/61/106 (13 December 2006) at Article 12, online: <<http://www.un.org/disabilities/convention/signature.shtml>>.

When is something determined [to be] terminal? I was terminal ten years ago, and in lots of pain during treatment, and sometimes you want to die. At that point in time, who is making that decision?

The group felt that processing a PAD request should involve a series of steps during which a person's situation can be re-evaluated, information is provided about alternatives, and the individual is offered a chance to re-consider their options or confirm their decision to pursue physician-assisted death.

Some participants were concerned that when pain was combined with certain disabilities, such as intellectual disabilities, there may be an even higher risk that the person would be denied access to PAD based upon assumptions about that person's capacity to accept PAD.

Participants in our Community Partners' consultation were given copies of Quebec's Bill 52, *An act respecting end of life care*, to review.³ Most participants felt that any new Federal or provincial legislation dealing with PAD should, at the very least, include steps similar to those outlined in section 28 of Bill 52.

f) Non-Terminal Conditions

There were serious concerns about extending the PAD option to persons who do not have a terminal condition.

Our community partners were concerned that people with recurring mental health disabilities might find their disability makes their conditions of life intolerable for certain periods of time. During a crisis period some might choose to access PAD even though it is very possible that the crisis might pass and their life may become tolerable again. Many individuals experiencing a mental health-related crisis might not, according to current standards, have the decision-making capacity required to accept the PAD option. In many cases, however, a mental

³ 2013, online: < <http://www.assnat.qc.ca/en/travaux-parlementaires/projets-loi/projet-loi-52-40-1.html>>.

health crisis may not affect a person's legal capability to choose PAD. It is also very possible that a person with a serious episodic mental health disability may, during a period of good health and lucidity, decide that they are not willing to tolerate another period of mental health crisis, and chose instead seek PAD while they are capable to make that decision.

Our community partners (people who did not identify as having a mental health disability) felt that in cases of non-terminal conditions, some extra or specific protections may be required to ensure that a short term "intolerable condition of life" or episodic disability did not lead people to accept PAD prematurely or for the wrong reasons.

g) Specific Concerns I: Feedback from our Focus Group on Mental Health Disabilities and PAD

The conversation about PAD was more complex and nuanced in our focus group on mental health disabilities. It was clear that the population of persons with mental health disabilities is divided on PAD.

One segment of the population is deeply concerned about the impact PAD will have on a vulnerable population. It is felt that in relation to PAD, mental illness is distinct from other illnesses, disabilities and terminal conditions; therefore, it is necessary for any legislation dealing with PAD to treat mental health disabilities differently. It was "strongly recommended" that persons with a non-terminal illness or mental health disability should have to follow a different process to access PAD than persons with terminal conditions; a process with greater emphasis on rehabilitation, counselling, the provision of supports and the remediation of social conditions that could lead to the conditions of life becoming intolerable, such as homelessness, social isolation or lack of treatment options.

At the same time there is a strong sentiment in the community that PAD is about offering choice and self determination to a vulnerable population. Basic equality demands that persons with mental health disabilities should be offered access to

PAD on the same basis as other persons; no extra steps or restrictions should be required. Mental health disabilities, it was argued, can make life seem intolerable. Therefore, persons with mental health disabilities should have the option of accessing PAD, as other persons who find their conditions of life intolerable, even if their condition is not terminal. One participant recalled another psychiatric survivor's experience, repeating their words:

I was literally dying and so depressed that I didn't eat for a month; I could not get food; I could not afford food. Is that intolerable or terminal?

It was also noted that if a person feels that ending their life is their only option, they will find a way to accomplish their goal even if barred by legislation from PAD. In such situations, people may not succeed in ending their life, but may only make their overall condition of life even more challenging. Being able to work with professionals would, in such circumstances, at least reduce the overall negative consequences. As one participant noted:

[I know] two people who were both unsuccessful ending their lives and wound up with physical disabilities. If they knew they had the option of PAD, they would rather have a professional do it.

Even those persons who support access to PAD for persons with non-terminal mental health disabilities accepted that access should be limited to persons who have determined that no other existing options will ameliorate their "intolerable" conditions of life. There was agreement that PAD should not be offered as an alternative to providing support, counselling and social services to vulnerable and marginalized persons. In fact, there was consensus that the availability of PAD would increase the government's obligation to ensure that proper treatment and social supports are available in the community for all who require them.

It was noted that it would set a dangerous and disturbing precedent to allow people with mental health disabilities to access PAD without greatly improving the services and supports available to them. To the extent that a person's

intolerable conditions of life are caused by inadequate public services and supports, it would be immoral for the state to offer PAD to a person before ensuring that services and supports are well funded, supplied, and diversified.

Whether accurate or not, more than a few persons with mental health disabilities have expressed concerns that PAD may be seen as a form of “eugenics” – a way to reduce the costs accrued by providing services to persons seen as having little or no value to society by “getting rid of” them. This is a view the government will have to work hard to dispel.

h) Specific Concerns II: Should Mental Health Disabilities Be Governed by a Different Process?

Amongst individuals with mental health disabilities, there was some division on whether or not there should be separate eligibility criteria for individuals with non-terminal conditions compared to those with terminal illnesses. Some community members strongly believe that mental health disabilities should be treated equally to other disabilities, and follow the same process. They assert that there is already a stigma against mental health disabilities, and that people with mental health disabilities often are denied control over their own bodies by healthcare professionals. Nevertheless, one of our participants stated the following:

I would be strongly in favour of different criteria; I understand where [name omitted]'s comments about the community are consistent with what I've heard. Within the survivor community, there's more support for this issue. Part of it relates to the amount of control the system, psychiatrists and others have had with decisions over individual's bodies. It plays into an argument that I don't want people telling me what I can do with my body. If I don't want to live, that should be my right, as it's allowed to other groups.

Part of the problem around euthanasia [assisted dying] in general is we tend to clump disability with disease; I know you can't neatly separate the issues, but the circumstances that someone who's terminally ill is in are different from the circumstances of someone who's lived with a disability their whole life. I'm sympathetic to someone who wishes to have control over the way they want to die, particularly when they know they will die soon, but these are two different issues, and the reasons for choosing – the circumstances – are different...

i) Further Information Required

At the very least many persons wish to see the issue of applying PAD to persons with non-terminal illness studied in greater detail before any process is open to persons with non-terminal episodic conditions or conditions that are not likely, in themselves, to result in physical illness or death. At the moment, it is not clear that the potential impact of PAD on the community of persons with mental health disabilities is understood fully enough to allow effective and safe legislation to be crafted.

j) Overlapping Disabilities

In circumstances where individuals have overlapping disabilities, our community partners were concerned about how those disabilities would be characterized and prioritized by healthcare providers and other individuals involved in the PAD process. There was great concern that, for example, a person with a mental health disability who receives another diagnosis (*e.g.* a terminal illness) would be denied PAD because of assumptions about their reasons for wishing to access this option. In one specific example, community partners referred to an individual whose unsuccessful attempt at suicide left them with a physical disability which, in their view, reduced their quality of life. In this example, there are two issues in particular: firstly, it begs the question of when (and whether) the individual will be able to access PAD if they wish to do so in their current circumstances, and secondly, it highlights the risks to people with mental health disabilities should the stigma against them prevent their access to physician-assisted dying. In contrast, our community partners were also concerned that a person with a terminal diagnosis and a mental health disability, for example, may be offered PAD on the basis of their terminal diagnosis, without adequate consideration and treatment options being presented to address their mental health disability. These are concerns which our community partners hope the legislation might address.

k) ARCH's Concerns about Using Determinations of Capacity to Access PAD

As the above comments reveal, the interaction of capacity issues, decision-making autonomy and risk reduction is a complex area. A PAD process that relied on assessments of a person's decision-making capacity to determine eligibility would not be inconsistent with most existing provincial capacity regimes. Similarly, the idea that a higher threshold may apply to determinations of capacity to make one type of decision compared to the capacity required to make another type of decision is not inconsistent with many current provincial regimes. Therefore it should be possible to create a PAD process that requires a certain level of "capacity" to make the decision to pursue PAD and imposed a higher or different standard of decision-making capacity than that required for other types of decisions.

Having a system that imposed a higher standard upon persons with particular types of disabilities would be more problematic. Setting different standards for different types of decisions where the same standard applies to all persons making that same type of decision is one thing. It is incredibly problematic to impose different standards on different people making the same decision, based upon the specific disability the people have. Such a system would be open to attack, as it would arguably discriminate on the basis of disability, contrary to the Charter and provincial human rights codes.

An even more serious problem is that any regime that depends upon findings of capacity to determine eligibility may quickly become out of date and at odds with international trends in the areas of capacity and decision-making rights. While many of ARCH's community partners made comments based upon their understanding of Ontario's and Canada's current capacity and decision-making regimes, Canada's current systems for determining capacity are no longer consistent with international trends and is considered outdated by UN standards. While ARCH respects the views of our community, we feel obliged to highlight

emerging trends and new approaches to capacity and decision-making outside of Canada.

The United Nations Convention on the Rights of Persons with Disabilities, Article 12, puts into question the very use of determinations of capacity (or incapacity) to remove a person's ability to make certain decisions. *United Nations Comment No 1 (2014) Article 12: "Equal Recognition before the Law, the Committee on the Rights of Persons with Disabilities (Committee),"* states that a person's legal capacity to make decisions should never be removed.⁴ Historically, the denial of legal capacity to persons with disabilities has led to a deprivation of many of their fundamental rights. The committee found that imposing substitute decision-making upon a person is a rights violation and that all substitute decision regimes should be replaced with *supported* decision making. This requires the provision of supported decision-making alternatives to all persons who require support to make decisions. Capacity assessments are to be used to determine what level of support a person requires to make decisions, not to remove a person's ability to make decisions for themselves.

While Canada has signed and ratified the UN Convention, Canada has reserved the right to maintain guardianship and substitute decision making regimes. This means that a PAD system that relied on a traditional system of using capacity assessments to determine capacity and imposing substitute decision makers on those persons found to lack capacity could exist in Canada. Nevertheless, whether in the short-term or the long term, any PAD system is going to have to take into consideration international trends in capacity law. The government will have to consider whether it is justifiable to use findings of incapacity to remove a person's access to the PAD option. Consideration will also have to be given as to whether a person using the assistance of a supported decision maker could be found capable to pursue the PAD option.

⁴ For more detail, see the comment online at: <<http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>>.

Clearly PAD highlights two competing goals: protecting and promoting autonomy, and ensuring the safety of potentially vulnerable adults. These challenges become particularly apparent in the context of applying PAD to persons with mental health disabilities and persons with intellectual disabilities. The challenge is to find a way for both these goals to be achieved. Certainly in ARCH's opinion, if one goal must dominate, promoting and protecting autonomy should always take priority even if promoting autonomy may create certain risks or complications.

2. Terminology

Some of the following key terms were discussed at length by community partners:

a) Capacity (and vulnerability)

Most of our community partners were concerned about the definition for capacity. This definition should be extremely clear and in plain language to facilitate understanding. As mentioned above, there were some concerns that different standards of capacity may have to be applied to decisions to accept PAD than are currently used to determine capacity to make financial or personal care decisions.

At the same time, participants were concerned that a person's perceived 'vulnerability' may be used against them to argue that their vulnerability renders them incapable of making the decision to pursue PAD. Many of our community members realize that they would likely be considered "vulnerable" persons; given that many of them live with fragile health, experience social isolation and economic marginalization and rely on support services and assistive devices. Our community partners expressed some concern that many people with disabilities would be misconstrued as inherently "vulnerable" because of social stigma and bias. Thus, the term "vulnerable" should also be clearly described in any relevant legislation to prevent the term from being applied to too wide a

range of persons or being applied without any proper investigation into the actual circumstances of the individuals in question.

b) Grievous and Irremedial (Pain)

Our community partners agreed that pain, both mental and/or physical, can be a driving force in people's judgment of quality of life, and should likely be the basis for defining a "grievous and irremedial condition." Our community partners agreed that severe, chronic, and ongoing pain that cannot be measured (or potentially managed) by medical means could be a ground for access to the PAD option, and should be discussed in the context of the legislation.

Our community partners also concluded that the lack of independent living options, and other external factors could potentially be considered "grievous and irremedial" under our current system. Waitlists, minimal homecare, and minimal checks on quality of service are all factors contributing to a lower quality of life for some individuals. Without appropriate measures to preserve independence, participation in the community, and accessibility, some individuals might find their lived experience oppressive. Consequently, these barriers may lead some individuals to believe that their disability or illness was having an impact upon their quality of life, when in fact the issue arises from social and structural barriers.

When considering this standard, the communities represented agreed that "grievous and irremedial" should be defined using a subjective, not an objective, scale; in spite of this, there was some concern that by concluding that a person's illness is "grievous and irremedial," particularly when it is a recent diagnosis, might lead individuals to consider assisted PAD too quickly, before giving adequate thought to alternatives.

The participants were divided on whether a "waiting" period should be imposed on persons seeking PAD. Such a restriction on access might benefit those people whose conditions may improve or stabilize over time. However, there was

a fear that for people living in extreme pain, a waiting period could simply impose unnecessary suffering and anxiety, particularly in cases where it was already clear that no other viable options remained.

c) Assisted Dying, Assisted Suicide, Euthanasia, Dying With Dignity

Our community partners were divided in their preference for the term “assisted dying” compared with “assisted suicide.” For some, they appreciated the amount of agency and individual control that the term “suicide” implies. Others felt that “suicide” was a negative term, making the PAD option sound undesirable. There was some disagreement about whether or not this negative connotation was, in fact, a bad thing; a few of our community partners wanted those accessing this option to be discouraged by the negative implications of “suicide.”

There was also debate about whether the term “death” or “dying” was more appropriate. Many commented that “physician-assisted dying” already exists in the sense of palliative care or home support options that help a person through the dying process. It was felt that “physician-assisted death” implied an event rather than a process and that this may be more accurate given that PAD is meant to bring the dying process to a quick end. Despite these comments, no one expressed a strong opinion either way and no one suggested that either term was offensive.

Our community consults with persons with mental health disabilities involved a similar debate on dying v suicide as a preferred term. Although there was concern about stigmatizing people who choose PAD by using the term suicide, dying was viewed by some as euphemistic, too soft, and an inaccurate description given the amount of agency the individual has when choosing PAD. Others felt that, since physician-assisted dying is a process, PAD is a preferable term. Should suicide be the chosen term, community partners preferred **death/dying by suicide** or **successfully ended their life** to committing/committed suicide; otherwise, there have been limited discussions around this language within the community.

In spite of the division on assisted dying vs. assisted suicide, or assisted dying v. assisted death, our community partners were unanimously strongly opposed to the terms “dying with dignity,” “peaceful departure,” and “euthanasia.” Dying with dignity suggested to many participants that individuals with a disability had less dignity than others; when discussing individuals diagnosed with a degenerative disease who subsequently acquired a disability, this was a particular concern. Using such terms could potentially devalue the lives of those with disabilities, and would heighten the stigma and fear already associated with being a person with a disability amongst communities of people without disabilities.

“Euthanasia” is also particularly abhorrent to individuals with a disability. Historically, the term was too often used to justify the deaths of many individuals diagnosed with a disability. Some community members are concerned that attaching this term to a modern assisted dying program could imply that this process is performing a “social good,” in the same way that social eugenics and sterilization programs in early 20th century Canada claimed to “protect” society. Using the term could also suggest that for those living with a disability, death is preferable to accommodation – a statement that was forcefully challenged by all present.

However, there was some limited support for the term “euthanasia,” given some individuals’ personal circumstances and wishes for themselves and their family members. Nevertheless, most partners found terms that implied a peaceful, passive choice to be incompatible with their own beliefs about PAD. Most felt that euthanasia was an offensive term, recalling historical eugenics movements.

d) Assisted Dying as a “Service,” Option, Regime, etc.

Our community partners felt strongly that the term “service” was loaded with additional meanings and implications, and was as problematic as the term “euthanasia.” As such, when making reference to administering medication with the object of ending a person’s life, our community partners generally preferred the term “option,” or “request,” wherein users are “accessing this option.” While

the communities did not reach a consensus on preferred language, it was highly important that the term used be as neutral as possible.

e) Suicide vs Dying: Concerns about Insurance Claims

Our community partners were universally concerned that use of the term “assisted suicide” could prevent individuals with an otherwise terminal condition from accessing insurance policies that deny claims on the basis of a suicide. This was even more of a concern for persons who do not have a terminal condition. This was a concern which needs to be addressed, and accounted for, when defining terms within the legislation to prevent inequitable treatment by insurance companies.

f) Preferred Terminology for People with Mental Health Disabilities

Based on our discussions with community partners and community members, there is no consensus on the preferred terminology for persons with Mental Health Disabilities. However, the set of preferred language may include: mental health disability, consumer, survivor, peer, client, patient.

Community members were generally opposed to the use of “mental illness” as a term. This language is generally stigmatizing, and tends to place mental health underneath the same umbrella that captures physical illness. Our community partners felt that it was important to distinguish between the two.

C. RISKS TO INDIVIDUALS AND SOCIETY ASSOCIATED WITH PHYSICIAN-ASSISTED DYING

1. Stigma Against People with Disabilities

Our community partners are concerned that physician-assisted dying will increase the stigma against people with disabilities. They are concerned that people with disabilities will become more marginalized, as greater fear and prejudice against people with disabilities may develop from the proposed

changes in legislation. Because of this, our community partners believe that the legislation, and procedures, must both acknowledge the particular concerns of people with disabilities, and take steps to prevent marginalization.

At the most basic level people are concerned that PAD will send the message to society that encouraging persons with disabilities to accept PAD is preferable to forcing society to bear the cost of providing effective services and supports to this population. The government must take action to ensure that a PAD regime does not help promote the idea that the lives of persons with disabilities are of less value to society than the lives of persons without disabilities.

Thus, ARCH supports our community partners' position on this issue; they universally agreed that legislation should:

- Express a commitment to improving programs which support persons with disabilities;
- Require rigorous reporting and data collection to monitor quality and improve offered services; and
- Acknowledge the value and quality of life of persons with disabilities, and increase public awareness through programs and public education about disabilities and persons living with disabilities.

2. Vulnerability Resulting from Social Isolation and Lack of Supportive Services

Social marginalization can increase vulnerability and can have mental and physical health consequences. Thus, the social circumstances of persons with disabilities can make them vulnerable. In some cases this vulnerability may lead to people choosing the PAD option to deal with vulnerability and marginalization

rather than to eliminate actual physical pain. In order to ensure that people do not seek PAD for the wrong reasons, the government must ensure that the support and service needs of persons with disabilities are fully met. There are already concerns that PAD will be offered as a means of reducing the government's obligations to provide services, support and palliative care to persons with disabilities. The government must therefore do everything possible to ensure that no-one chooses PAD because a lack of services and supports has made their life intolerable.

Our community partners felt that PAD should be limited to those persons who feel life has become intolerable, *despite* the range of supports and services available to alleviate their condition. PAD should not be an option people choose due to the lack of necessary services and supports. As persons with disabilities are more likely to require public services and supports, any failure to provide necessary services could be interpreted as a form of discrimination against persons with disabilities; discrimination that could lead to people with disabilities accepting death over life for the wrong reasons.

Those consulted agreed that, to eliminate the risks of PAD becoming the solution to living without necessary services, the government should take steps to ensure:

- Increased access to accessible housing, supported housing and affordable housing;
- Increased access to expanded support services;
- Improved and expand palliative care regimes;
- Increased access to alternative programs including: animal therapies, hybrid homes (where, for example, nursing homes are combined with

daycare programs), music therapy, and experiential opportunities that will improve quality of life;

- Increased access to rigorous, supportive counselling services;
- Improved and expand long-term care services and environments;
- Improved and expand homecare services; and
- Increased systemic support for people with mental health disabilities to help reduce vulnerability.

3. Over- and Under-Inclusivity

Our community partners were concerned about the permissive language in *Carter v Canada*. Since it allows people who are not terminally ill to access physician-assisted dying as an option, there was some concern that too broad a range of people could choose to have a physician-assisted death.

Our community partners were particularly concerned about individuals with ongoing or episodic mental health disabilities. For individuals who are capable, but experiencing serious suffering as a result of their illness, there was some concern about what processes and safeguards might be necessary to ensure such patients receive alternate treatment before accessing this choice, if it is available.

There were concerns expressed about how PAD might function in relation to persons with intellectual disabilities. Some were concerned that stigma and negative assumptions about persons with intellectual disabilities would result in persons with intellectual disabilities being assumed to be incapable to understand and appreciate the information necessary to seek PAD, when they very well might be capable.

Participants also noted that some persons with disabilities, particularly those with intellectual disabilities and neurological conditions may have difficulties communicating their wishes to others. An inability to communicate should not be accepted as evidence of incapacity to pursue PAD.

4. Communication

All participants emphasized the importance of effective communication between physicians and individuals seeking physician-assisted death. They suggested the following:

- There must be certainty that consent is coming from the person, so that there is no relationship of coercion
- An individual must be able to make the request for PAD themselves (although with accommodation if required) and participate in any processes related to PAD.
- There must be extensive support to ensure that all barriers to communication are addressed without prejudice
- Physicians should not necessarily be the only professionals to play a role in managing or processing requests for PAD.
- Plain language documents and communication should be available to avoid exclusionary practices
- There must be a robust system of interpreters and facilitators to ensure that communication needs will be met
- There must be access to services and supports outside medical facilities

We heard from representatives from the communities of persons with speech and language disabilities. Although it is necessary that persons who wish to pursue PAD to communicate their wishes clearly, this may be more challenging for persons with speech and language disabilities. Given the likelihood that some persons with terminal or intolerable medical or mental health conditions may be unable to communicate clearly and effectively, it is essential that proper supports and accommodation are provided to all persons who need them throughout any PAD process.

People with severe speech and language disabilities are often not provided with the supports they require to communicate accurately in legal decision making situations within the health care and justice systems in Canada. Often a person's capacity to make certain decisions can be under- or over-estimated because legal and health care professionals may not have the experience and skill necessary to differentiate between speech, language and cognition or to ensure that communication is authentic and accurate.

People with speech and language disabilities report that they are often ignored and left out of decisions that affect them simply because no-one takes the time to allow them to communicate their wishes effectively. They are often assumed to be incapable of making decisions simply because others cannot understand their communication. They also fear their decisions being misunderstood or misinterpreted; a situation which can have serious consequences.

To ensure that persons with speech and language disabilities are provided with equal access to PAD on the same basis with other persons, it is essential that throughout any PAD process persons with speech, language or communication disabilities have access to qualified communication intermediaries to allow them to communicate effectively.

Communication intermediaries are speech-language pathologists who are trained by Communication Disabilities Access Canada (CDAC) to provide communication assistance to people who have speech language disabilities. Their role is similar to, but different from a sign language interpreter or translator. Just as people who are culturally Deaf, oral deaf, deafened and hard of hearing should not be denied access to ASL deaf interpreting services, or other accommodations, a person with other speech and language disabilities must receive accommodation from persons who are properly trained to provide the specific types of accommodation they require.

For more on the CDAC National roster of communication intermediaries go to: <http://www.access-to-justice.org/communication-intermediaries/roster/communication-intermediaries>

5. Investment in Alternative Options

Most of our community partners are concerned that Physician-Assisted Dying will be used as a replacement, not an alternative, for palliative care treatments, or that some alternatives to Physician-Assisted Dying will not be presented to patients. Our community partners propose the following:

- Any patient wishing for a physician-assisted death should only be able to do so after a detailed and individualized plan for high quality palliative care (which included relief to suffering) has **been presented, reviewed, and refused by patients;** and
- Patients who are not terminal should only have access to this option after they have sought out and received ongoing relevant counselling that is available to non-disabled (or in this case, non-irremedial) persons.

Individuals from our Mental Health Disabilities focus group added that:

- Recovery should be a priority before PAD becomes an option; and
- Prompt, improved, and accessible services should be made available.

Furthermore, these individuals added that investment in alternative options should include **affordable treatments for individuals with a mental health disability**. For example, cognitive behavioural therapy is often unaffordable for individuals seeking this treatment, yet it is a necessary element to their care and well-being. It is therefore a necessary element of care that any treatment plan or counselling be affordable (or free) for individuals who require these options.

D. SAFEGUARDS TO ADDRESS RISKS AND PROCEDURES FOR ASSESSING REQUESTS FOR ASSISTANCE IN DYING AND THE PROTECTION OF PHYSICIANS' FREEDOM OF CONSCIENCE

From the perspectives of our community partners, their concerns centered upon the procedures for assessing requests, rather than the protection of physician freedom. As such, our submissions reflect this same focus.

1. Proper Access to Assistive Programs as a Safeguard

Our community partners universally agreed that palliative care, home care, and other assistive programs must be available to ensure that individuals considering Physician Assisted Dying have access to true alternative options.

Participants in our focus group on Mental Health Disabilities added that without supportive services, it is difficult to determine why individuals would choose PAD. For individuals with a Mental Health Disability, this raises a specific concern:

The circumstances are different [for people with a terminal diagnosis]; people may have a really good life up until the time of that diagnosis, and may still have a good life, but may rapidly deteriorate, and that must be frightening – I can sympathize with that. People within our population [individuals with Mental Health Disabilities], more so, believe that because of a lack of supports, it's hard to know why people are making the decision [for physician-assisted death]: is it because of the illness, impairment, whatever you want to call it, is it because of the lack of supports that are making their life miserable, or a combination of this and other factors? I think it's a dangerous precedent if it's allowed without adequate supports.

2. Accessibility and Consistency

Our community partners were concerned with ensuring that any system for PAD is not overburdened by processes which create delays. Some community members suggested processing requests based on urgency (a pseudo-triage system).

The main recommendation from our community partners was to create a central body set up by subject matter experts across fields, which provides a one-stop location for various related services (similar to a Service Ontario model, for instance).

Community partners also recommended that an appeals board exist for individuals who are refused access to PAD. Some proposed an appeals board for families, or possible forms for families to submit in cases where they were concerned about their loved one's capacity to choose the PAD option. A peer panel was also proposed. However, none of these measures were universally liked.

3. Inter-Provincial Safeguards and Time-Related Concerns

The general consensus was that in cases of terminal illnesses, the PAD process should not be so lengthy as to impose unnecessary suffering and frustration on a person who has already decided that their condition is intolerable. At the same time many people, particularly persons with mental health disabilities, felt that in cases where a terminal condition was not involved, there may be some advantage to a process that allows for counselling, discussion and offers opportunities to re-consider or re-assess the situation.

Overall participants wanted to see a PAD process or processes that included safeguards and allowed for reflection and re-consideration while at the same time balanced the need for caution with an appreciation of the serious negative impact unnecessary delays may have on not only the individuals seeking PAD, but also their families and care-providers.

4. The Physician's Role

Most of our community partners felt that the following should be required of physicians:

- An obligation to refer if they are unwilling to participate in physician-assisted dying;
- An obligation to discuss all possible courses of treatment, including palliative care, counselling, and physician-assisted dying;
- Regular reporting from physicians, hospitals, and other institutions certified to perform physician-assisted dying;
 - Which would be made to a centralized, specialist body;

- Participation in a rigorous training schedule, which should be put into place quickly and effectively, and administered with highly consistent programming;
- Participation in data collection, and periodic review (every 2-5 years); and
- When deciding with a patient to pursue this option, physicians must supply some evidence that they have discussed other options and offered other alternatives.

CONCLUSION AND RECOMMENDATIONS

ARCH's consultations confirmed that there is a diversity of opinion within the community of persons with disabilities concerning all aspects of PAD. We urge the Panel to take this range of opinion into consideration. We can highlight a few key areas where there was a degree of consensus or at least a majority of persons consulted agreed. While we feel it is useful to acknowledge consensus where it exists, we also caution against over-estimating the level of consensus within the community of persons with disabilities. The community itself is diverse. Persons with certain disabilities or conditions, such as Parkinson disease or ALS, are far more likely to see themselves as potentially considering PAD than persons with disabilities or conditions that are less likely to become terminal or life-threatening.

The following are the key points upon which a majority of participants agreed:

- 1) The decision to pursue the PAD option must be made by a person themselves;
- 2) The decision to pursue PAD must be a fully informed decision;

- 3) A person must receive all necessary accommodation and assistance to allow them to understand and process information necessary to making a decision to pursue PAD and to express their wishes and participate fully and actively in all aspects of the PAD process;
- 4) A PAD process must include an obligation to obtain and provide at least one “2nd” opinion as to an individual’s prognosis;
- 5) Whatever process is used to determine person’s ability to decide whether to pursue PAD should consider international trends in capacity law such as the UN Convention of the Rights of Persons with Disabilities;
- 6) There must be an obligation that doctors, medical staff or other professionals provide individuals who wish to pursue PAD with information about all available treatments, long-term care, palliative care or community care options or other alternatives to PAD and full support to allow persons to investigate and/or pursue these options if they so choose;
- 7) Any PAD process should include counselling as well as at least one opportunity to reconsider whether to continue with the PAD process;
- 8) A PAD process should offer individuals an opportunity to challenge any decision that they are not eligible to or able to pursue PAD; and
- 9) Legislation should ensure that PAD is an option pursued only when all other options have been presented and refused, have proven insufficient to relieve suffering or have been insufficient to make a person’s condition tolerable. The government must ensure that other options are not only available, but also viable. This means that alternative options to PAD such as supportive housing, community support, long-term care or palliative care must be funded to the extent necessary to ensure that services are available to all who need them. These services must be of sufficiently high

quality to ensure that no-one chooses PAD because a lack of services, poor service quality or inadequate service renders their situation intolerable. This is particularly important for persons with disabilities. There is genuine fear among these populations that PAD is being offered as a means of reducing public obligations to provide adequate support and accommodation to persons with disabilities.

The last point is particularly true when it comes to persons with non-terminal illnesses or those who have no physical illness but who suffer from mental or psychological conditions that may cause them to feel that their conditions of life are intolerable. Far more research is required to understand exactly how the availability of PAD will have an impact upon the populations of persons with mental health disabilities or intellectual disabilities or other persons who may suffer severe pain and emotional turmoil due to a non-terminal condition.

Clearly the extension of the PAD option to persons who may otherwise live for many years requires careful consideration. It is necessary to determine whether the same rules and processes that may be applied to persons with terminal conditions will also apply to those with non-terminal conditions; or whether a separate process should exist for persons with non-terminal conditions who seek the PAD option.

These submissions are the result of careful, but limited consultation. ARCH has done its best to present the views of the populations of persons with disabilities in Ontario. ARCH respects the views of our community members; however, the views expressed here are the views of individual community members and not necessarily the views of ARCH. ARCH felt it was important to present the views of the communities without imposing a particular legal analysis or critique on the material (except where we felt it necessary to offer information on the recent United Nations approach to capacity to place the views of the community into a larger context).

The comments presented here are preliminary. We offer them as a starting point to help understand the key concerns, fears and assumptions of persons with disabilities regarding the implementation of PAD. We feel that these submissions are but the tip of the ice-berg. More information is required to truly understand how various segments of the population of persons with disabilities will respond to PAD. It is also necessary to apply a more formal legal analysis to a number of the questions raised by the comments of the community.

In the past, ARCH has been commissioned by the Law Commission of Ontario to prepare research papers on issues of relevance to the legal status of persons with disabilities. ARCH would be pleased to assist the Panel with similar research. We could gather more detailed information from particular populations of persons with disabilities and respond to any specific legal questions the Panel may wish explored.

Thank-you,

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