**Canadians with Disabilities--We Are Not Dead Yet\***

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Presenters: Rhonda Wiebe, Co-chair of CCD Ending of Life Ethics Committee Jim Derksen, Member of CCD Ending of Life Ethics Committee

 (\* CCD acknowledges that the title of this brief is adapted from the name of the American group, Not Dead Yet, which is a disability rights group, working in opposition to euthanasia and legalized assisted suicide.)

**Executive Summary**

"I would rather be dead than live with a disability," is a sentiment that people with disabilities, particularly those with severe disabilities, hear from people without disabilities. Such a comment rests on an incorrect assumption that the quality of life is poor when you have a disability. Incorrect assumptions about quality of life have the power to trigger responses that harm people with disabilities. If a simplistic approach is applied when developing end of life policy, the long term result will be systemic discrimination against people with disabilities who are seriously ill or at end of life.

In 1996, CCD passed a resolution stating "…The CCD opposes any government action to decriminalize assisted suicide because of the serious potential for abuse and the negative image of people with disabilities that would be produced if people with disabilities are killed with state sanction…" CCD explains the rationale for its opposition to legalized assisted suicide and shares recommendations focused on staunching the forces that cause Canadians to believe that assisted suicide is a necessary option.

**Introduction**

The Council of Canadians with Disabilities (CCD), a national human rights organization, works for an accessible and inclusive Canada. Rhonda Wiebe and Dean Richert co-chair CCD's Committee on Ending of Life Ethics and Jim Derksen, who is a past Chair of CCD, is a Committee member.

Georges Minois in History of Suicide: Voluntary Death in Western Culture explores social responses to suicide; demonstrating suicide has been both condemned and honored in certain circumstances (i.e. patriotic soldiers who fight to their death in hopeless situations). Suicides by the elite have been treated differently than suicides of the poorer classes. As Minois explains, the meaning ascribed to suicide, and by extension to assisted suicide, is the product of social relations.

The disability rights community seeks to affect the social relations influencing assisted suicide. As public policy contributes to the development of social meaning, CCD welcomes the opportunity to address the Committee. We applaud MPs from different parties for collaborating on these important, but difficult, issues. CCD recommends a nonpartisan approach to disability issues. The same approach can be claimed for end of life issues, because, like disability, end of life is unavoidable. Canada's public policy on end of life will affect everyone.

CCD acknowledges disabled Canadians have not adopted a monolithic viewpoint on assisted suicide. Indeed, some individuals with disabilities have become identified with the legalized assisted suicide (LAS) cause. In Canada, Sue Rodriguez comes immediately to mind. Some academic researchers have examined the views of people with disabilities on LAS. American researchers Gill and Voss (2005) discovered that while research participants with disabilities were fairly evenly divided in their support for and against LAS for people with terminal illness, the majority opposed LAS for people with disabilities. Women, African-Americans and Latinos were most likely not to support LAS (Gill and Voss, 2005). Drawing upon past experiences, disadvantaged people have a more acute understanding of how they may be victimized. Unlike individuals, CCD has undertaken a prolonged analysis of LAS, evaluating its potential impacts against our principles. It found LAS would violate our principles supporting equal, dignified and self-determining lives for people with disabilities, thus CCD has taken a stand against LAS.

In this brief, CCD addresses a wide range of topics--requesting treatment, refusing treatment, withholding and withdrawing treatment, assisted suicide, "compassionate" homicide. When addressing end of life in the context of disability, these are the practices that affect the experiences of people with disabilities who are seriously or terminally ill. Thus, CCD adopted an inclusive approach to how it would address the areas under investigation by the Committee. There are many in the disability community with expertise on these issues and CCD would pleased be to assist MPs make contact with members of their local disability community who are knowledgeable about the issues addressed in the brief.

In summary, CCD shares its understanding of how the human rights model/social model of disability can contribute to a better understanding of the issues under consideration by the Committee, provides an overview of its relevant past initiatives and lessons learned, and offers recommendations to the Committee.

**Human Rights Model/Social Model of Disability and End of Life Issues**

Canadians with disabilities have a unique perspective on end of life issues derived from our lived experience with bodies that function somewhat differently from the norm. Gill enumerates the disability experiences that provide added value to LAS discussions: "institutionalization, neglect, abuse, discriminatory treatment, social devaluation, and impoverished resources (Gill, 2010, p. 32)".

At CCD, experiential knowledge of disability has been used to develop a model for analyzing public policy issues that melds two frameworks of analysis: human rights and the social model of disability. Theorists from the disability rights movement and academia have developed the social model of disability. The model, as it is employed by CCD, focuses on eliminating socially created barriers that hamper the equitable participation of people with disabilities. By applying such concepts as dignity and the duty to accommodate, human rights theory points a way forward to resolving the barriers our culture puts in the way of people with disabilities.

In March, Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which articulates how States Parties to the CRDP shall ensure that people with disabilities experience full enjoyment of human rights. The CRPD's Article 10 states that: "Right to Life—States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure the effective enjoyment by persons with disabilities on an equal basis with others." Article 14 obliges States Parties to ensure disabled people's enjoyment of the right to liberty and security of the person. Article 25 on Health states that "…States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services… In particular, States Parties shall: … (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability." CCD believes these articles, combined with equality and human rights guarantees made to Canadians with disabilities in the Charter of Rights and Freedoms and provincial and federal human rights laws, place upon Canada a strong obligation to ensure people with disabilities are not adversely impacted by death hastening policies or practices. CCD encourages Committee members to work in partnership with the disability community toward a Canadian CRPD implementation strategy that will uphold the commitments made in Articles 10, 14 and 25. Canada's first requirement under the CRPD will be to submit a baseline report to the CRPD Expert Committee. We encourage the Committee to use its influence to ensure that Canada's report adequately reflects how Canada is addressing its responsibilities vis-à-vis Canadians with disabilities on the issues being addressed by the Committee.

Social responsibility, rather than vitalism, is the motivation behind the disability rights movement's opposition to LAS and other death hastening practices and policies. Social responsibility motivates our actions. From our analysis, the impacts of LAS would negatively alter Canadian cultural attitudes and social practices toward people with terminal illnesses and disabilities. As all Canadians will face end of life and most will experience disability, these negative impacts would be injurious to everyone.

**The Situation of People with Disabilities**

In the 1970s, Canadians with disabilities began to organize CCD-type groups dedicated to improving our economic and social status. Disadvantage and social isolation continue to be factors in the lives of too many Canadians with disabilities. Based on the Participation and Activity Limitation Survey (PALS) of 2006, people with disabilities make up 16.5% of the adult population 15 years and older in Canada, or nearly 4.2 million people. We know that:

* Canadians with disabilities are too likely to live in poverty.
* Over two million Canadian adults with disabilities lack one or more of the educational, workplace, aids, home modification or other supports.
* Over 56% of working-age adults with disabilities are currently unemployed or out of the labor market. For women with disabilities the rate is almost 60%.
* Over 10,000 persons with intellectual disabilities are in institutions.
* Rates of violence and abuse against people with disabilities, in particular women with disabilities, are among the highest for any group in Canadian society.

**Shared Experiences**—Negative attitudes about disability, combined with poverty and social isolation, increase the vulnerability of people with disabilities, who are seriously ill or dying, to experiencing discrimination and death hastening responses in the medical system. The negative and ableist assumptions in question include the ideas that— people with disabilities have no “quality of life", that lives with disability are not worth preserving, that lives with disability are a burden. Individuals have shared their experiences publicly to encourage reform of the ableist biases that reduce access to health care for persons with disabilities.

One instructive anecdotal example comes from Judge Sam Filer.

In January, 1989, Justice Filer was admitted to hospital for a minor complication associated with his ALS. While there, he went into respiratory arrest. His wife, Tony Silberman, was called to the hospital by a nurse at Justice Filers’s request. When Ms. Silberman, arrived she was hustled out of her husband’s room by the doctors present and was told that Justice Filer was in respiratory arrest and that the end was near. She insisted that something be done to prevent this. The doctors present told her that the only possibility was to put him on a ventilator. They then told her this was not an option which they would advise. She was told that Justice Filer would always require the ventilator once it was begun, that he would, therefore, have no quality of life, that this would be financially ruinous, that it would be inhuman not to let him die with dignity and that she owed her devotion to their young daughter who was an infant at the time. She was told that she had ten minutes to decide. Silberman insisted on the ventilator and the procedure was carried out. Justice Filer continues, over four years later, to live a full, rich and happy life with his family at home and continues to perform his duties as a judge, although on a part-time bases. He is quadriplegic, is ventilated on a 24 hour basis and is fed through a gastrostomy tube. He described his experiences in a speech presented at a conference in April 1991, sponsored by the Association for Independence in Breathing…. Of particular note are the following excerpts:

“I believe that the disease is not that which afflicts me but the dis-ease with which the professionals regard A.L.S. and other progressive conditions. It has been our sense and, to some degree, our experience, that medical personnel evidence a degree of hesitancy in offering treatment to me, heroic or otherwise, leaving us with the feeling that we’re a drain on the system, and have no right being selfish enough to want to live. They’re right on both counts, but that’s too bad. As long as I’m capable of making a contribution of any kind, I will be entitled to, and fully intend to take advantage of life.” (at p.10) (CCD, 1993, p. 17)

One of our colleagues with a disability, Mike Rosner, now deceased, shared his negative experience with attitudes in the medical system with author Ruth Enns, who included it in her book on the Tracy Latimer case, A Voice Unheard:

In 1992 Mike Rosner was admitted to a Winnipeg hospital with severe pneumonia. Shortly after arriving at intensive care the doctors told him he had only hours, at most a few days to live. 'They inquired about whether I wanted them to treat me aggressively,' he said. Mike was surprised. He had assumed that aggressive treatment was the reason one goes to hospital. About four or five doctors each tried to convince him that 'I ought to let nature take its course.' They told him if he did survive his quality of life would be so poor as to be not worthwhile. They painted a very bleak picture (Enns, 1999, p. 100).

People in the disability community intervened on Rosner's behalf and he received the treatment he needed. He survived and went on to live a productive life in the community. His colleagues were able to see beyond the stereotypical assumptions about disability. They did not assume that it is preferable to be dead rather than live with a disability.

There are also court cases that demonstrate how negative attitudes about disability have an adverse impact on the medical treatment received by people with disabilities. In 1991-92, in Ontario, there was a Coroner’s inquest into the deaths of 15 children with disabilities at the Christopher Robin Home. The inquest found that the Home’s medical staff in certain cases had not consulted parents about their children’s care and medical staff had unilaterally made decisions about foregoing diagnostic testing for illnesses, not treating treatable and life threatening illness such as pneumonia, placing DNR orders on patients’ charts, and the excessive administration of morphine beyond the recommendations for children (CCD, 1993, p. 18). The jury recommended that “standards of medical care must be adhered to consistently for all children regardless of their abilities” and that “no child should be discriminated against based on disability regarding medical treatment (CCD, 1993, p. 18)."

**Overview of CCD's Work on End of Life Issues and Lessons Learned**

CCD began to work on end of life issues in the 1990s. (CCD's documents on end of life issues are available on its web site—http://www.ccdonline.ca.)

**The Personal Is Political**--Informally and at an experiential level, many of the people who make up CCD and its member organizations developed a deep personal understanding of the point at which society's thinking about disability and death intersect. It is not unusual for people with disabilities to hear from nondisabled people how they would rather be dead than live with a disability. People with disabilities in Canada and elsewhere relate very similar experiences. Such encounters have motivated some people with disabilities to think about how such sentiments affect the security of people with disabilities at various stages of the life cycle. Kevin Irvine writes,

Not Dead Yet, a disability-rights action group, is deeply concerned abut the dangers of legalizing assisted suicide. For over two years, the group has brought a different, previously unheard perspective to this debate. In doing so, we've found ourselves allied with some strange bedfellows, such as the American Medical Association (AMA), and "right to life" groups; unlike some of them, however, our motivation comes not from a religious belief in the sanctity of life but from some place deeper: Fear. We fear that the discrimination faced every day by people with disabilities will lead to widespread abuse of assisted suicide. Many people—including our friends, family members and doctors—still think (and say out loud) that it would be better to be dead than disabled (Irvine, 2002, p. 55).

In his article, Irvine self-disclosed that he was both a person living with HIV and hemophilia. He noted that while people with HIV/AIDS tend to be supportive of assisted suicide, he revised his pro-assisted suicide viewpoint when he became involved in the broader disability community and came to understand the threats posed by assisted suicide to people with disabilities different from his own, such as disabilities which are progressive. Volunteers involved in CCD have expressed similar sentiments.

**Nancy B. Case**—The Nancy B. Case provided a wake-up call for many in the disability community. For some people, the idea of living hooked-up to a machine is abhorrent—even when they are dependent on the technology for life. Nancy B., who lived in a Quebec hospital and was reliant on a respirator, went to court to have the respirator turned off and she won her case. This case helped to solidify a Canadian patient's right to refuse the continuance of treatment that they do no want. Thus there is no need for Canadians to support assisted suicide so that they can avoid a future where they will be forced to accept treatment that is unacceptable to them.

While this case was heartbreaking for some in the disability community, CCD did not become involved in this case. There were those in the community who sincerely believed that Nancy B.'s decision was not truly voluntary because she made it without sufficient knowledge about community living options where respirator-users live empowered and fulfilling lives in the community. Social arrangements about how disability services are provided made dying an attractive option. Cases such as the Nancy B. have influenced how people with disabilities think about autonomy.

**Tracy Latimer Case**—CCD intervened in the Tracy Latimer case, urging that the victim's disability not be treated as a mitigating factor to reduce the sentence to be served by Robert Latimer, the killer. The Supreme Court of Canada upheld the Criminal Code requirements. While the disability rights position was understood by the Supreme Court, the same cannot be said for the general public. CCD was dismayed by the negative sentiments expressed by the public about life with a disability throughout the duration of this case.

**Sue Rodriguez Case**—CCD intervened in the Sue Rodriguez case. Rodriguez sought a constitutional amendment which would have permitted her to have a legal assisted suicide. In its intervention, CCD argued that if legalized, assisted suicide would have an adverse impact on persons with disabilities. CCD urged a period of public discussion of LAS and strong safeguards to accompany LAS. Nondisabled Canadians became Ms. Rodriguez's supporters. MP Svend Robinson, as he then was, was on hand for Rodriguez's assisted suicide, putting himself at risk for criminal charges. The outpouring of support for people with disabilities seeking to end their lives has prompted people in the disability community to wonder why efforts to secure disability-related supports, accessible transportation, and adequate incomes do not similarly spark the imaginations of nondisabled Canadians and motivate them to support initiatives to improve life with a disability.

**Genereux Case**—CCD intervened in the Genereux Case in support of a deterrent sentence for Dr. Genereux, because CCD believed that a deterrent sentence was necessary in order to preserve life and protect the vulnerable. Dr. Genereux assisted two of his patients, who had AIDS/HIV and were depressed, commit suicide. At the time of the case, Hugh Scher, a lawyer in private practice and Chair of CCD's Human Rights Committee, as he then was, was interviewed by the CCD Latimer Watch, which shared his remarks, "This case involves Dr. Genereux a person in a position of trust and authority with respect to these individuals [whose suicide he assisted] who abused that trust and authority. He lied about what he did to the physician who was responsible for overseeing him at the College of Physicians and Surgeons. He lied about the treatment that he was providing to his patients' specialists and psychiatrists. Upon receiving a call from Mr. McGinn's friend, Dr. Genereux told the friend he should just let Mr. McGinn die and refused to take any action to assist Mr. McGinn….It [this case] clearly shows how difficult it would be to derive safeguards. Secondly, it also makes it clear that if there are no legal prohibitions against assisted suicide, then clearly the lives of people with disabilities, as well as the lives of others, would be cast into jeopardy (CCD. 1998)."

**Senate Committee on Euthanasia and Assisted Suicide**—A majority of the Committee favored a lesser penalty for homicide motivated by compassion. CCD appeared before the Committee struck to follow-up on the original Committee's recommendations and argued that this recommendation would have an adverse impact on people with disabilities. It is not uncommon for the killers of people with disabilities to have misguided concepts of compassion. While people with disabilities are as satisfied with their lives as people without disabilities, nondisabled people often wrongly assume that people with disabilities have a low quality of life.

**Private Member's Bills**—CCD has opposed Private Member's Bills by Svend Robinson, Sharon Carstairs and Francine Lalonde that, if passed, would have advanced death hastening practices. While the proponents of assisted suicide often speak of assisted suicide as if it were for people who are terminally ill and about to die, their public policy measures often include eligibility criteria broad enough to be inclusive of people with disabilities (Wolbring).Take, for example, the most recent Private Member's Bill, Bill C-384. Lalonde's bill would have made people with disabilities eligible for assisted suicide.

**Contribution to the Safeguards Debate**—In 2002, CCD published Legalizing Physician-Assisted Death: Can Safeguards Protect the Interests of Vulnerable Persons by Orville Endicott, an Ontario lawyer. This publication concluded that, "Until it can be convincingly demonstrated that all Canadians enjoy full equality and security of the person, regardless of disability, as guaranteed by the Charter of Rights and Freedoms, then any steps toward legalized assistance in dying should be resisted (Endicott, 2002, p. 72). LAS proponents suggest that safeguards would address concerns raised by CCD and others. In jurisdictions where LAS is permitted, robust safeguards have not been adopted. Instead, assisted suicides have to be reported after they have occurred. Endicott suggests that it would be very difficult to meet the two safeguards which would be of greatest value to people with disabilities: an independent tribunal that would ascertain that (1) a person seeking an assisted suicide understands his/her alternatives and that he or she is not being manipulated by others and (2) ensure that all reasonable avenues have been explored that would make dying a less attractive option. Endicott stresses the importance of achieving these criteria with clear and convincing evidence and concedes that this requirement would be very difficult to fulfill. He quotes Disability Studies scholar Catherine Frazee who states:

We need to do much more to challenge the fiction that 'what a person wants' is clear, knowable and absolute. Frankly, among humans, the phenomenon of 'what we want' strikes me as entirely fluid, capricious and transitory, and its articulation is invariably no better than an approximation (Endicott, 2002, p. 71).

**VP Network**—For two years, CCD was a partner in an academically controlled research project on palliative care and vulnerable persons which brought together academics and disability community members. From this project, CCD learned that palliative care practitioners need more information on the issues and concerns of people with disabilities and the barriers to accessing care at end of life. Palliative care practitioners are important allies for the disability community but there need to be increased opportunities for building understanding between the two communities. CCD sees the need for research projects that are controlled by disability community members so that the research agenda can be controlled by the community.

**Media Monitoring and Participating in the Public Debate**—CCD is very concerned about the way that death hastening has been portrayed in the media. Too often death is presented as a logical and acceptable choice for a person with a disability and the alternative—an active and empowered life in the community—is not presented. One blatant example is the story line in the Academy Award winning movie Million Dollar Baby. CCD seeks to challenge media portrayals that entrench negative stereotypes. We write letters to the editor, meet with editorial boards, and discuss our concerns with members of the media.

The first week of June 2010, as the fall television programming was being announced, ACTRA members were protesting that Canadians want to see their stories on television. To this point, CCD would add that sufficient realistic stories of Canadians with disabilities, portrayed by actors with disabilities, are missing from the media's programming and sufficient inclusive programming could help overcome the negative stereotypes and attitudes that are addressed in this brief. The public bodies that support the creation of Canadian cultural products have a responsibility to ensure that Canadian cultural producers with disabilities are receiving an equitable share of available funds.

**CCD's Recommendations on the Issues Being Considered by the Committee**

**Resource Shortages**—The Committee has shared a quote from Joe Comartin MP identifying, "A critical nationwide shortage of expertise and material resources in the fields of palliative, hospice and home care…." CCD concurs that there is a resource shortage. While some Canadians only begin to use home care services when they come to the end of their lives, some people with disabilities have a lifetime involvement with home care services. In 2005, CCD published the report A National Snapshot of Home Support from the Consumer Perspective. In this report, people with disabilities identified a broad range of concerns with regard to how home care is delivered in Canada, including assessment, eligibility, regionalization, portability, user fees, appeal mechanisms, staff training, direct funding programs, unionization, and privatization. While this report did not focus on the concerns of home care users with disabilities at the end of life, it seems only logical to assume that these problems would only be exacerbated in the end of life stage when people have less energy for negotiating their service needs with home care and also when people face increased physical limitations and challenges unique to their acute health condition that has brought them to the end of life stage. Throughout the history of the disability rights movement, there has been a call for home supports to be delivered in a manner that is flexible enough to meet the needs of the user with disabilities.

Due to stereotypical assumptions about people with disabilities, it is sometimes assumed that it is always the person with a disability who is the recipient of care. People with disabilities are also caregivers and they are supporting people with and without disabilities move through the end of life stage by providing informal home care support. Others people with disabilities who want to be caregivers to family members who are in the end of life stage encounter barriers because they cannot access either the equipment they need to play this role or other people to help them with some of the tasks. This creates distress for both the caregiver with disabilities and the person at the end of life. People with disabilities who are caregivers need to be at the table when services and polices are being developed to assist Canadian informal caregivers.

**Suicide Prevention**—The social conditions that lead to suicide is a concern in the disability community. Academic and disability community researchers have investigated suicide and people with disabilities. For example, American researchers Berkman et. al. report that, "Persons with MS have a double to 13 times higher suicide rate than the general population, a higher rate than patients with other chronic physical conditions, and the rate of attempted and completed suicide is higher among persons with MS than in persons with other common neurologic disorders." (Berkman et. al., 1999, p. 52). In 1996, the DisAbled Women's Network Canada investigated the links between abuse and suicidal thoughts and attempts. Of the 371 women who responded to the survey 225 had thought about suicide and 45.3 of those had attempted suicide. (DAWN Canada 1996) The DAWN Canada respondents identified some problems with suicide prevention services, particularly a lack of accessible options for follow-up and counselors' lack of comfort addressing disability issues.

Carol J. Gill in "Suicide intervention for people with disabilities: A lesson in inequality" suggests that people with disabilities face discriminatory treatment when they express suicidal thoughts. She points out that when nondisabled people express the wish to die, typically this is defined as an indicator of suicidal behavior and suicidal prevention measures are undertaken. When people with disabilities express an interest in dying, it does not elicit the same response. Instead, it is defined as a reasonable response to bad situation. Gill writes,

For persons with severe disabilities, however—particularly persons who use a respirator, feeding assistance or other life aids—the desire to die has acquired labels such as "refusal of treatment", a wish to avoid prolonged suffering or dying, a desire to let a terminal disease take its natural course (used in cases of long-term disability lacking any evidence of terminal illness!) and not committing suicide (Gill, 1992. p. 2 of 14).

Gill contends that ableist biases prevent a rigorous questioning of the assertions of people with disabilities that they want to die.

Gill provides a disability rights rationale for why this recommendation must be implemented. Any society that provides suicide prevention programs for its citizens, faces both a moral and legal duty to offer these services to people with disabilities. That there are systemic barriers that hamper people with disabilities from benefitting fully from suicide prevention services should not be surprising. The disability rights movement has encountered barriers to participation in many other systems. Gill's recommendation of involving people with disabilities from the disability rights movement in suicide prevention is a recommendation congruent with CCD's approach to creating an inclusive and accessible Canada. Two important mottos for the disability rights movement are: "A Voice of Our Own" and "Nothing About Us Without Us".

As DAWN Canada has identified suicide as a particular concern for women with disabilities, CCD recommends that the Committee consult with DAWN Canada. CCD also recommends that the Committee consult with the National Network on Mental Health. Both organizations are members of CCD.

**Legalized Assisted Suicide (LAS)--**The Committee indicates that it will be investigating abuse. The disability rights movement has concerns about the potential for abuse and systemic discrimination if assisted suicide is legalized in Canada.

**How LAS Proponents Counter Disability Rights Arguments**--The disability community's concerns have been trivialized through an inaccurate reframing of its arguments by pro-LAS activists. The Committee may hear pro-LAS advocates misinterpret the disability rights position. Disability studies scholar Carol J. Gill unpacks the fallacies in a number of "straw man" arguments, that is, weak arguments that are put forward to be attacked and easily torn down. CCD shares a summary of her work on the "straw man" arguments to assist the Committee differentiate between the valid disability rights message and disinformation (Gill, 2010). Gill divides these misrepresentations into two categories: "They're out to get us!" and "You don't understand".

**They're out to get us: Misrepresentation No. 1: Legalized assisted suicide will encourage doctors to kill disabled people—**Gill explains that it is not concern about misguided "mercy killers" in the medical profession that has caused disability rights practitioners to oppose LAS. Instead it is the increasing bias to restrict health services in the face of growing concerns about rising health costs. Negative attitudes about the quality of life with a disability affect the treatment decisions made for patients with disabilities—lives with disabilities are not always considered as meriting medical services that are in short supply. Gill describes how people with disabilities in hospitals are repeatedly asked if they have agreed to a Do Not Resuscitate Order (DNR) (Gill, 2010).

While the right to refuse treatment has been strengthened, patients have not secured the right to demand treatment (Gill 2010). Food and water is now defined as a treatment. Nancy B. won her case to have her respirator turned off, but the British man Leslie Burke, whose progressive disability would eventually prevent him from swallowing, was unsuccessful in his attempt to gain "legal affirmation of the right to receive assisted nutrition and hydration until his natural death (Gill, 2010, p. 33)". The Manitoba disability community is very concerned about the Manitoba College of Physicians and Surgeons Statement on Withholding and Withdrawing Life-Sustaining Treatment which gives doctors the sole authority to decide when to forego or stop treatments that keep people alive. CCD's member group, the Manitoba League of Persons with Disabilities, has developed the concept of a Will to Live, whereby people indicate what medical services that want when hospitalized (Wiebe, 2005).

**Misrepresentation No. 2: If assisted suicide is legalized, people with disabilities will be victimized by greedy family members who want their estates or by family members who want to be free of the burden of caregiving.** Gill suggests that this argument is disrespectful to the families of people with disabilities and ignores the social and economic dynamics of long-term illness and disability. The disability rights concern is that LAS will encourage society to lessen the support it provides to members with chronic health conditions and disabilities. It will be seen as reasonable to hasten the death of some people rather than to provide them with the services they need to be comfortable and dignified. The disability movement's concern is about abandonment of societal responsibility for disabled and ill citizens (Gill, 2010).

**You don't understand: Misrepresentation No. 3: People with disabilities do not differentiate between the eugenics practiced in Nazi Germany and contemporary assisted suicide proposals.** As Gill acknowledges, the Nazi killing of people with disabilities, a campaign against unproductive people, was yoked to Hitler's racial cleansing program and the magnitude of these combined atrocities illuminate for most people the wrongness of Nazi eugenics. The disability rights movement raises the history of eugenics because there are lessons to be learned about the factors that influence a society's definition of what constitutes valid citizenship, not because we fear a re-emergence of the Nazi's T-4 program. As Gill explains the interaction of economic problems, resource competition, attitudes about disability, productivity and quality of life served to undermine German support for people who needed societal support and resources to live (Gill, 2010, p. 34). Being aware of how these factors have influenced decision-making about people with disabilities in the past is useful when monitoring current public policy debates.

**Misrepresentation No. 4: When we raise concerns about the legalization of assisted suicide leading to unwanted deaths for people with disabilities, LAS proponents argue that we confuse assisted suicide with involuntary euthanasia.** We counter that proponents have not given sufficient consideration to what actually constitutes true voluntary choice at end of life. Proponents wrongly assume that people always have access to options. Personal circumstances such as race, age, disability, class, and gender impinge upon the choices available to an individual. As a community living with an inadequate, and sometimes nonexistent, supply of necessary disability-related services, we know that options are not always available (Gill, 2010, p. 35). In a discussion about assisted suicide in Oregon, Gill poses the following rhetorical question: "If requesters die believing that their only options are a nursing home, the degrading imposition of their intimate needs on family, or taking their chances on the help of strangers, how is that voluntary? (Gill, 2010, p. 35)"

**Misrepresentation No. 5: People with disabilities think they know what people at end of life experience.** Gill acknowledges that while no two people have the same experience of disability or any other life experience, nevertheless there are commonalities in the way similarly situated people are treated by society. As Gill points out, it is the economics and the social arrangements of disability that transform ill people into family burdens or institutional inmates (Gill, 2010, p. 36). When the Sue Rodriguez case was in the media, some of her spokespeople explained their support for her because, as they elaborated, they understood her wish to avoid the indignity of relying on others for help with toileting.

**Misrepresentation No. 6: Legalized assisted suicide will open the flood gates and many people with disabilities will be making requests.** As Gill explains, the disability movement is not concerned about a suicide contagion. The concern is about LAS worsening our culture's social response to disability thereby increasing the social exclusion of people with disabilities. With LAS, the state sanctions the killing of people with disabilities and in CCD's analysis this would reinforce negative images and stereotypes about people with disabilities.

**Arguments Against Legalized Assisted Suicide**

Assisted suicide has come to be viewed by some as a necessary treatment option at the end of life. This is not a position held by CCD. In this section, CCD shares the reasons for its opposition.

**The Illusion of Increased Control for Patients—**LAS advocates promote it as a way for an individual to control the end of his/her life. This may be more promise than reality. In addition to individuals being able to request LAS, proxies are also given this power for people no longer able to make requests themselves.

An important consideration that affects patient control is the power imbalance which exists between patients and doctors. Anthropologist Robert Pool's study Negotiating a Good Death: Euthanasia in the Netherlands describes the key role that doctors play in LAS decision-making. As the gatekeeper to a LAS, doctors are the ones who have the greatest control. What a doctor defines as LAS can be situational. Pool writes:

However, because various types of life-shortening action by physicians are continuous in practice, it is often possible for those involved to adjust their definitions and their interpretations so that their actions do not fall within the scope of the official definitions. They do not necessarily do this consciously, to hide cases of euthanasia or to avoid control, but unconsciously, and as a result of ambiguities inherent in practical situations. If a situation is equivocal, then those involved are likely to choose the interpretation that is most favorable to them on pragmatic grounds (Poole, 2000, p. 230).

Poole notes that monitoring systems for LAS are dependent upon the way that doctors, in particular, define their actions. He points out that, "… as long as there is wide variation in this, monitoring is going to be inadequate (Poole, 2000, p. 237). CCD is concerned about the point where constructed definitions of LAS and quality of life with a disability intersect. It is at this point of intersection that the danger of abuse arises. Systems reliant upon after the fact monitoring would do little to protect people with disabilities from abuse.

**Undue Burden on People with Disabilities—**If LAS laws and policies were written, so as to provide LAS to people with functional limitations, this would devalue the lives of people with disabilities. It would be hard to imagine a state contemplating LAS for other marginalized and disadvantaged groups (Krahn, 2010). Take for example if society said to homeless people with addictions, if life gets so bad that you are homeless and living on the street begging for money to support your addiction, then the state will help you kill yourself so you will not suffer anymore.

**Ineffectual Safeguards—**Safeguards are often put forward as the answer to the concerns about the impacts of LAS. In practice, LAS has tended to have only very weak procedural safeguards, such as after the fact reporting. The only effective safeguard would involve a thorough exploration that decisions were truly autonomous. This would be exceedingly difficult to implement, particularly in the case of people with disabilities. Our culture’s negative messaging on disability is so strong that some people with disabilities have internalized these message and can never move beyond the stereotype that life with disability is not worth living. At the time of disabled Canadian Austin Bastable's assisted suicide, Catherine Frazee made the following comments in the CCD Latimer Watch:

What I think is particularly important about the Bastable case is that within our community we have to be aware of the fact that there are disabled people who do support Latimer and who certainly did support Austin Bastable, that he ought to have the right to choose when and how to end his life. When you are very very vulnerable and very very depressed and you have been programmed, as it were, to believe that disability renders life not worth living, then you will make the kind of "choice" that Austin Bastable has made. What we have to realize is that as an oppressed group in society we have been bombarded with messages, not just by the broadcast media, but by virtually every person we encounter in our day to day lives, that having a disability is a tragedy, a highly negatively charged phenomenon. To be quite candid most of us spend a great deal of our lives believing that. We have to remember that there really isn't a choice when there is such a pervasive set of negative messages, values and conditions in society really shaping that choice. It is my firm belief that someone like Austin Bastable simply didn't have the support, the positive experiences, the time to work through the issues and to come out on the other side of it and declare, as many of us have, that our lives are extremely rich and gratifying and we have no desire to end them simply because we have a disability. That takes time, support and a good measure of pure luck—the luck of circumstances of having the resources to live comfortably with a disability. We don't know all the details of Austin Bastable's life, but I think from what I have been able to glean from the information available about his life that he had very little choice but to believe in the end that his life was not worth living.

With our community history of advocating for choice for people with disabilities, it may seem inconsistent to oppose assisted suicide. I don't believe it is inconsistent. It is a very shallow understanding of choice that underlies the arguments in favor of legalized assisted suicide. In our current social context one cannot make such choice freely (Frazee, 1997, p. 2).

Negative Impact on Supply of Services Available to People in Need of Support—There is a concern that LAS will undermine society’s willingness to provide supports and services to those who need care. Individualism is the ethic behind LAS. The disability rights movement takes the point of view that people are interdependent. Needing support is not viewed negatively. The value of society providing support to people with disabilities has been recognized by the CRPD.

**Shortcomings of the Existing Models**—The “on the ground” experience with LAS does not provide any comfort to CCD. Our American colleagues with disabilities have identified a number of concerns with the Oregon model. Golden and Zoanni identified the following shortcomings: “The reporting requirements lack teeth; Noncompliance is not monitored; Important questions are not asked; Abuse is not investigated; Secrecy pervades the operation of LAS; LAS data is destroyed annually (Golden and Zoanni, 2010, p.24-25)." The space limitations of this brief do not allow for an in-depth exploration of the shortcomings of existing LAS regimes. Suffice it to say that disability rights leaders have not been comforted by the way that states have operationalized LAS.

**Conclusion**

CCD concludes this brief by sharing the following resolution of the CCD National Council that presents our essential message on LAS—this is not the time to legalize assisted suicide.

Whereas it is CCD's mandate to improve the status of people with disabilities in Canada and around the world;

**THEREFORE BE IT RESOLVED THAT:**

The CCD opposes any government actions which may serve to further devalue the lives of people with disabilities in Canada, or promote the negative stereotypes about people with disabilities as suffering individuals in need of state required assistance to end our lives; and

The CCD opposes any further government cutbacks which are detrimental to or could put at risk the lives of people with disabilities by denying us essential services, including life-saving health services; and

The CCD opposes any government action which denies people with disabilities their constitutional rights to equality, personal security, and human dignity; and

The CCD is committed to actions which promote a positive image of persons with disabilities as contributing members of Canadian society; and

The CCD opposes recommendations of the Senate Committee on Euthanasia and Assisted Suicide to lessen sentences for those who kill people with disabilities for reasons of compassion or mercy in recognition that these serve to perpetuate the stereotype of people with disabilities as suffering individuals in need of state regulated assistance to end their lives; and

The CCD opposes any government action to decriminalize assisted suicide because of the serious potential for abuse and the negative image of people with disabilities that would be produced if people with disabilities are killed with state sanction; and

The CCD opposes any media action which may serve to further devalue the lives and experiences of people with disabilities in the public eye and promote negative stereotypes of people with disabilities.

(The CCD Council passed the above resolution on assisted suicide and euthanasia on 8 June 1996.)

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