

discussion paper

and Draft Position Statements
on the issues of

assisted suicide and **genetic and testing technologies**

Prepared by the Values and Ethics Task Force
Canadian Association for Community Living,
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Canadian Association
for Community Living

Association canadienne pour
l'intégration communautaire

Diversity includes. On se ressemble.

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Introduction

The following discussion paper has been developed by the Canadian Association for Community Living Values and Ethics Task Force in order to assist in discussions on the issues of assisted suicide and genetic and testing technologies.

These issues have been long standing concerns of our association and the Values and Ethics Task Force has been charged with developing positions and approaches to the issues.

In preparing this document, the Values and Ethics Task Force reviewed CACL positions, drew on the reports of the Values and Ethics Task Force since its inception in 2002, reviewed research documents, analysed the recent *Carter* decision on assisted suicide by the Supreme Court of British Columbia and undertook extensive discussions. The following is intended to provide a summary of that work and proposed positions for discussion at the 2012 National Conference and Annual General Meeting in order to guide the actions of the Association.

Plain Language Summary of Position Statement on Assisted Suicide

What is assisted suicide? Why is CACL taking a position on assisted suicide?

- Assisted suicide is when someone helps another person to end their own life. There are people who are pushing for the right to have the help of a doctor to commit suicide.
- CACL is taking a position on assisted suicide because we want to speak clearly about why we think it is dangerous to allow doctors to help people to commit suicide.
- The law today says that if you help or encourage a person to commit suicide, you are committing a crime.
- There are people who are trying to change the laws so that they can have a doctor help them to end their lives.

Why is CACL concerned about legalizing assisted suicide?

- CACL is concerned about changing the laws to make assisted suicide legal.
- Some people are claiming that the laws against assisted suicide discriminate against people with disabilities. They say if people with disabilities want to kill themselves and can't do it alone, they should be allowed to have help to do it.
- CACL believes that it would be dangerous to change these laws because it would promote a view that people with disabilities have lives that are less valuable than others.
- CACL does not believe that suicide is a right or freedom that is protected by law.

- We are also concerned because advocates for assisted suicide say that they want the right to “die with dignity.” Many of these people are afraid that they will become ill and need help with their personal needs.
- CACL has values and beliefs that say that dignity is something that all persons have and that people do not have any less dignity just because they have a disability or label.
- We believe that just because a person needs extra help for routine matters of their life does not mean they have less dignity.

What is CACL’s position on legalizing assisted suicide?

- CACL is taking the position that assisted suicide is not a right that is protected by law.
- We believe using the *Charter of Rights and Freedoms* to claim a right for people with disabilities to have assisted suicide damages the equality rights of people with disabilities.

What actions does CACL want to take?

- CACL will work together with the disability community and the public to challenge these views;
- CACL will assist people with disabilities and their families, and community leaders to take action on this issue.

Plain Language Summary of Position Statement on Genetic and Testing Technologies

What are genetic and testing technologies? Why is CACL taking a position?

- Genetic and testing technologies are tools that can be used during pregnancy to find out whether a fetus has any conditions that are related to disability.
- There are many different researchers, organizations and companies involved in making these tests. CACL is taking a position that clarifies our values and beliefs about these technologies and tests so that we can encourage people who are involved in making and using them to protect against negative effects that they can have on people with disabilities and society as a whole.

Why is CACL concerned about genetic and testing technologies?

- Genetic and testing technologies provide information about the potential that a child may be born with a disability-related condition.
- Sometimes when this information is provided it is full of negative views about people with disabilities.
- One of the most widely available tests is used to identify Down syndrome. In most pregnancies where Down syndrome is identified, people make the choice to have an abortion.
- CACL is not against abortion and supports women's reproductive rights. CACL also supports the parental and reproductive rights of women with disabilities.

- CACL is concerned that women are not being provided with good information that includes facts about disability so that they can make a truly informed decision. Much of the information that women receive from society as a whole and from the medical system is negative towards people with disabilities.

What is CACL's position on genetic and testing technologies?

- CACL believes in the value of genetic diversity. We believe that disability is a natural part of the human condition.
- CACL believes that the right for women to make choices about pregnancy needs to be supported with good quality information. Because people receive so much negative information about disability from the medical system and from society, it is important that this is balanced by factual information that shows the experiences of people with disabilities and their families.
- Genetic and testing technologies have impacts on people with disabilities and their families. Therefore, people with disabilities and their families need to be involved as stakeholders in discussions and decision making.

What actions does CACL want to take?

- CACL will bring these beliefs, values and principles to discussions and decision making processes that are involved in researching, creating, regulating and using genetic and testing technologies.

Assisted suicide and the case of *Carter v Canada (Attorney General)*

Background

The interrelated issues of euthanasia, assisted suicide and withholding and withdrawing of medical treatment have been long standing issues for this association. The Values and Ethics Task Force has had considerable discussions of these issues, has produced background papers and reports, brought resolutions to CACL Annual General Meeting, responded to media stories and engaged with other groups.

These efforts go back at least as early as November 1994 when CACL made a submission strongly urging the Senate Committee on Euthanasia not to legalize euthanasia or physician-assisted suicide. More recently in 2010, representatives of CACL appeared before the House of Commons Committee on Palliative and Compassionate Care and expressed deep concerns about discrimination that Canadians with disabilities experience in access to health care, and in particular the extent to which "quality-of-life" assessments can distort the advice of medical professionals and place the lives of people with intellectual disabilities in "immediate peril". To this date, however, CACL has not had a clear statement of position on the issue to guide its efforts.

These issues have recently been brought back to the forefront of public attention through the *Carter* case. The case of *Carter v Canada (Attorney General)* was initiated by plaintiffs Lee Carter and Hollis Johnson who accompanied their elderly mother to Switzerland where she obtained a physician assisted suicide. The case was later joined by Gloria Taylor—a woman from British Columbia with Amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease) seeking an end to the Criminal Code prohibition of physician assisted suicide. The case was also joined by the British Columbia Civil Liberties Association and Dr. William Shoichet, a physician from British Columbia who would be willing to participate in physician-assisted death if it were not illegal.

In June 2012, the Supreme Court of British Columbia ruled that the provisions of the *Criminal Code* that prohibit physician assisted suicide do infringe the equality rights of Gloria Taylor and the rights to life, liberty and security of the person of

Gloria Taylor, Lee Carter and Hollis Johnson. Justice Lynn Smith suspended this decision for a period of one year in order to provide Parliament time to consider and draft new legislation to accommodate the decision. The decision has been appealed to the Supreme Court of Canada.

Summary of Issues in Carter v Canada

The Court ruled that *Criminal Code* provisions that prohibit physician-assisted suicide act in violation of rights guaranteed under the *Charter* in section 15, equality rights; and section 7, protection of life, liberty and security of the person. It argued that the limits imposed by the *Criminal Code* prohibition of assisted suicide are not 'reasonable limits' as provided under section 1 of the *Charter*.

Equality Rights

Section 15 of the *Charter* says that:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

The argument regarding equality rights under section 15 is that the *Criminal Code* provision that prohibits physician-assisted suicide has the effect of denying people with disabilities equal benefit from the law. Or in other words, it creates a burden for people with disabilities who want to commit suicide that people who do not have disabilities do not experience.

Suicide and attempted suicide are not against the law in Canada. Provisions of the *Criminal Code* which made suicide and attempted suicide against the law were removed in 1972. But the *Criminal Code* provisions in section 241 prohibit providing assistance in suicide:

Every one who:

- (a) counsels a person to commit suicide, or
- (b) aids or abets a person to commit suicide,

whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years.

The B.C. Court ruled that the complete prohibition of assisted suicide by the law represents a burden on persons with disabilities who want to commit suicide, that people who do not have disabilities do not experience. It found that the law was discriminatory on the basis of physical disability.

Rights to Life, Liberty and Security of the Person

Section 7 of the *Charter* says that:

Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

This argument that Section 7 rights to life, liberty and security of the person are violated by the prohibition on assisted suicide was also argued in the case of *Rodriguez*. Ultimately, it was decided in the case of *Rodriguez* that rights to security of the person were violated by the prohibition of assistance in suicide but that this restriction was justified because of the law's purpose in protecting vulnerable people from being encouraged or coerced into suicide.

In the case of *Carter* it was argued that all three rights under section 7—life, liberty, and security of the person—were affected. Security of the person was seen to be affected in the same way as was argued in *Rodriguez*—that Taylor was being impacted in her right to make choices about her own body. In addition, the Court decided that Taylor was impacted in her right to liberty because of the infringement on her personal autonomy. It was further argued that Carter was impacted in her right to life, because by being denied assistance in committing suicide at a time when she is no longer able physically able to do so, she was in effect forced to commit suicide at an earlier time.

Regarding the interference with Section 7 *Charter* rights, it was argued that new developments in the areas of safeguards and evidence of impacts of changes in legislation on people with disabilities since the decision in the *Rodriguez* case meant that these restrictions needed to be argued anew by the courts.

Discussion

The Taskforce organized discussions of this issue according to these two primary themes that emerge in the case of *Carter*. Our discussions were not limited to the issues as they are presented in the case, and neither was our objective to attempt a legal analysis of the case. However, the case represents the most recent statement of the arguments for assisted suicide and informs the current public debate on the issue. Summarized below are key points of our discussions.

The position that we have tried to advance in the past presents us with a tangle of challenges. These challenges centre on a few main points:

- We stand firmly for the principle that people with disabilities have autonomy and that people have the right to make choices—important choices as well as everyday choices—about their lives. However, in the case of assisted suicide our position is being interpreted to mean that we stand opposed to the extension of that choice to assisted suicide.
- When we say that people with disabilities would be vulnerable to undue pressure and coercion this makes an assumption about the wishes, will and authority of disabled people. We are being challenged on this position as being paternalistic.
- We have argued that legalizing assisted suicide will imperil the lives of people with disabilities. People are socially devalued and therefore vulnerable to social forces that contend that they are lives not worth living. However, the evidence has been produced that seems to show that people with disabilities are not ‘accessing’ assisted suicide at rates any higher than the non-disabled population.
- In the past we have argued that the safeguards proposed are not adequate to protect people with disabilities. The *Carter* decision proposes a long list of safeguards proposed for this purpose.

In addressing these challenges, there are some areas that we can contest evidence and inaccuracies. However, we also need to question the very narrow way in which these issues are being framed.

- The risk for people with disabilities is not just that people will disproportionately choose suicide. The devastating social and cultural messaging that suggests that people with disabilities have lives that are less worth living, and less valuable is much harder to measure. How do you measure how people “feel about themselves,” how people are welcomed or not welcomed, how people feel safe, secure and valued? This type of evidence may not fit within the type of empirical evidence produced to support a view of assisted suicide that says that safeguards will be sufficient to enable an end to the prohibition on physician-assisted suicide.
- We know that there are many ways in which people with disabilities are currently imperilled within the medical system and often encounter denial of access to equal treatment. CACL outlined these concerns in its brief to the House of Commons Committee on Palliative and Compassionate Care (2010):

‘Quality of life’ arguments are often found at the heart of complex ethical issues related to compassionate care, palliative care, euthanasia and end of life care. For people – including infants – with significant disabilities and/or complex medical needs these arguments infiltrate their very existence. The take away message too often has been that if you aren’t going to live a “typical” life; if your life follows a developmental path different from others that your life isn’t worth living. That disability is a fate worse than death. Such judgements can place families in a heartbreaking predicament. They are told by medical professionals and experts that their family member’s life is in immediate peril. That efforts to support him or her are futile, that the family should leave their loved one be and let him or her die with dignity. Families, under pressure, often sleep-deprived and in the throes of emotional trauma rely on their trusted doctors to provide them with unbiased information. They rely on their doctors to treat their children, not simply with dignity and respect, but without question, to treat their medical conditions as those conditions would be treated in any other child. Yet, life-and-death medical decisions are being made on a particular perspective of quality of life. If one’s family member is not expected to, or has not, followed a particular path perceived by others as typical, his or her quality of their life is brought into question.

- Numerous instances of discrimination in health care have been brought to the attention of CACL that demonstrate the perilous position that people with disabilities find themselves in when they engage in the health care system. These have taken many forms—from inappropriate use of “Do not resuscitate” orders, to pressure from physicians to terminate treatment. These very real instances of the threats that are experienced by people with disabilities in the medical system show the pervasiveness of devaluation within the profession. Consideration of legalization of assisted suicide in this context has the very real danger of creating a culture of tolerance which could translate into covert or informal inappropriate termination of lives of people with disabilities in a medical context.

Much of the assisted suicide debate hinges on the concept of personal autonomy. It is argued that suicide, and in particular having the ability to end one’s own life in the manner at the time of one’s own choosing, is the ultimate expression of autonomy. It is argued that people who are prevented from choosing a method, means and time of their own death for reasons of physical disability are, in effect, robbed by the law of this important aspect of their autonomy, and as such, are discriminated against.

- We question and challenge this view of autonomy and the notion that suicide is an expression of autonomy. Suicide is not so much an expression of autonomy, or a freedom that is protected by the law, as it is a place that the law cannot touch. Suicide can be seen as an act that is an expression of ‘sovereignty’ or a fact of living, but not something that is in the domain of rights and freedoms protected and guaranteed by law. It is not a ‘benefit’ that is provided by law but something that is outside of law.
- Autonomy is also different for every person—it is connected to one’s life experience, understanding of the information surrounding the decision, and of different forces that may be at play in a decision.
- The removal of suicide from the Criminal Code is an important acknowledgement of the futility of pursuing criminal punishment in the case of tragic circumstances where a person has taken their life, or has attempted to take their life. The appropriate societal response to such an act is provision of support, treatment, assistance for someone who has attempted suicide, and one of empathy and support for grieving of the bereaved family and friends of a person who has ended their own life. We would affirm that this is not the

rightful place for criminal punishment but rather the place for interventions of support and assistance for healing or grieving.

- The idea that suicide is a right enjoyed by people who are physically capable of ending their own lives is false. Just because it is a capacity that people have, and a decision that some people act on, does not mean that it has, or should have, the protection and guarantee of the law.
- It is also false to say that the law denies to some a choice of suicide. The laws currently deny a choice of *method* of suicide. It should be clarified that what is argued for in *Carter* is a protected freedom of choice of method of death.

Suicide, and having assistance in suicide is often positioned as a response to suffering and pain. This includes both pain and suffering of a physical nature and of existential pain.

- Existential pain often comes from an experience of loss of control over one's body and functionings, or concerns about how one will be remembered.
- Existential pain has a place in the world and we believe that it ought to call from others a response of support and measures that can assist a person to cope with such suffering.
- We believe that the extension of a legal right to suicide as a response to existential pain and suffering is a disproportionate response that places an undue burden on others who experience similar types of pain and suffering.

The argument is made that a refusal of medical treatment is a method of suicide that is available to some but not to others. It is argued that refusal of treatment is a method for ending one's life that is provided to some under law, but is denied to others and that this denial amounts to discrimination based on disability.

- We recognize the right to make choices about refusal of medical treatments and call for the supports necessary that allow people with disabilities to make these forms of decisions.
- There is a leap in the arguments made in *Carter* that equivocate refusal of treatments to pursuing assistance with active measures to end one's life. To

refuse treatments is to assume a responsibility over one's own death and acknowledge that the consequence of not accepting a certain form of medical intervention will cause one's eventual death.

- Where someone has made a decision to refuse treatments or medical interventions, there is not a choice taking place about the method and means of death, as there is in an act of suicide.

The *Carter* decision argues for a right to access to assistance in suicide from an equality rights standpoint as guaranteed in section 15 of the *Charter of Rights and Freedoms*.

- We believe that the framing of suicide as a right that is guaranteed through an equality rights framework is a distortion of the notion of equality rights of persons with disabilities and trivializes the hard fought for and hard won rights under this guarantee of equality.
- We believe that what is at risk in the *Carter* case is a depreciation of the values intended under section 15 of the *Charter*. We want to protect and preserve section 15 values. If we accept the validity of a right to access to assistance in death, what does this say about the position and status of people with disabilities who do not currently enjoy a guarantee of so many of the other supports and forms of assistance that can improve and affirm a positive quality of life?
- The historic treatment of people with disabilities has been one of eugenic social policy and all manner of social harms resulting in the devaluing and imperilling of people with disabilities.

The concept of dignity, and in particular the presumed *loss* of dignity at times of grave or terminal illness, is raised consistently in arguments in support of assisted suicide. In these arguments the loss of physical or intellectual functioning, or dependence on others to assist with needs of living is equated with loss of dignity.

- Presumed loss of dignity is one of the reasons Gloria Taylor sought the right to assisted suicide. She appears to anticipate such loss of dignity in being unable to manage her own personal care. She says, "*I do want to express the fact that I, myself, will be greatly distressed by living in a state where I have no function or functionality that requires others to attend to all of my needs*"

and thereby effectively oblige my family to bear witness to the final steps of the process of my dying with the indignity a slow death from ALS will entail.”

- CACL has very clear values and beliefs about dignity. CACL believes that although dignity is admittedly “fragile” and in need of protection from harm it is also “inherent” and “inalienable” and something that “cannot rightly be ignored, diminished or taken away.” It is CACL’s firm belief that “dignity does not depend upon physical, intellectual or other characteristics.” (CACL, Statement of Beliefs and Values, 2003)
- Many people who are born with disability-related physical or intellectual conditions rely on others for intimate personal care and assistance in meeting their basic needs, and in many instances for their very survival. While people who acquire disabilities later in life or who develop progressive physical and/or neurological conditions associated with loss of function will also often require such assistance and may experience personal loss and pain as a result of growing dependence on others, this does not in and of itself constitute an indignity. If the need for intimate personal care from others is associated with indignity, then a whole class of people with disabilities by definition are not able to live in dignity. In light of equality rights protections, such a position cannot be justified. Moreover, is the fear associated with loss of function and need for assistance justification for authorizing assistance to end a person’s life? We do not believe this can be justified on any coherent theory or principle of human dignity.
- If one person’s ‘indignity’ is another person’s daily routine of life then surely we must take pause before we attach such a variable notion of dignity to such a profound judicial interpretation of what constitutes a right to autonomy over decisions that have such far reaching implications, such as assistance in death.

The concept and positioning of dignity is central to arguments about assisted suicide. Discussion of this fact has been central to our consideration of the issue. An analysis of the issues that are raised by invoking dignity in defense of a right to assistance in death is contained in a forthcoming affidavit by Values and Ethics Task Force member Catherine Frazee:

- Disability prejudice and stereotype are embedded in the discourse around physician assisted suicide. Loss of control of bodily fluids is repeatedly and emphatically represented as an assault of suffering and indignity, such as to

render life no longer worth living. Loss of mobility and diminished capacity for independent self-care are consistently described as a stripping away of dignity. Despair and surrender are uncritically accepted as the only possible response to a hopeless predicament – a predicament invariably associated with social shame. Yet the link between dignity and independent physical self-care is not absolute.

- The reasons most frequently given for people wanting to avail themselves of assisted suicide are related not to pain or physical suffering, but to anxieties about loss of independence – in particular, loss of independent capacity to bathe, dress, and go to the bathroom. Such anxieties are serious and worthy of responses that are sensitive and attuned to the circumstances of each individual, but they do not constitute a social imperative sufficiently compelling to warrant a legal measure that could imperil the life of another.
- When we accept uncritically that reliance upon assistance with bodily functions diminishes dignity to such an extent that life is no longer worth living, we trivialize the true meaning of human dignity and denigrate the lives of people who rely upon others for intimate physical support in their daily lives. Only the most simplistic and superficial formulation of autonomy can seriously posit death as a proportionate response to anxieties surrounding bodily functions.

Draft position on assisted suicide

Context

The issue of assisted suicide has recently been brought before the courts in British Columbia and Quebec and continues to be brought before Parliament in the form of private members' bills. It has emerged as an issue at the forefront of media and public attention and there is the appearance of growing support for measures to remove the *Criminal Code* prohibition against provision of assistance in suicide.

CACL has in the past held considerable discussions of these issues, has produced background papers and reports, has debated and passed resolutions at the Annual General Meeting, has issued media response and has engaged with other groups active on the issue. However, to this date, CACL has not had a clear position on the issue to guide its efforts.

The case of *Carter* which was brought before the Supreme Court of British Columbia was recently decided in favor of lifting the *Criminal Code* prohibition on provision of assistance in suicide. It is expected that this case will be appealed to the Supreme Court of Canada.

Purpose

The purpose of this position is to make clear CACL's position on the legalization of assisted suicide and the removal of *Criminal Code* prohibitions on providing assistance in suicide; to articulate our concerns about the legalization of assisted suicide; and to register our concerns about the use of sections 7 and 15 of *The Charter of Rights and Freedoms* to guarantee assisted suicide as a right protected by law and arrived at through an equality rights analysis and finding of discrimination on the grounds of disability.

Position

In forming this position on assisted suicide we are guided by our Statement of Values and Beliefs and in particular our belief in and value of the inherent, inalienable and equal dignity of all persons.

We are further guided by the United Nations Convention on the Rights of Persons with Disabilities, and in particular Article 10 in which "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others," and Article 25 in which "States Parties recognize that persons with disabilities have the right

to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”

We stand firmly on the principle that people with disabilities must enjoy autonomy and have the right to make choices about their lives—important choices as well as everyday choices. We recognize and affirm the rights of persons with disabilities to make decisions about their lives that include refusal of medical treatments and other health care decisions as provided for under Canadian law.

Our position is motivated and formed in response to the following concerns:

- We are concerned by the characterization of human dignity as tied to functional capacities or characteristics or that position dignity as inconsistent with reliance on human and other supports. Such a characterization trivializes the meaning of dignity and denigrates the lives of people who rely on such supports. The need for help with routine matters of life involving intimate personal care does not disqualify a person from dignity.
- We are concerned by any ruling or law that equates a reliance on human and other supports for routines of daily life as an ‘indignity’ that validates a claim to have assistance in death. For the courts to interpret the concept of dignity as such inflicts harm on an entire class of people and undermines a cornerstone principle of the claim that people with disabilities make to equal status and regard in the human family. We believe that there are dangerous implications if one person’s ‘indignity’ is another person’s daily routine of life.
- We are concerned by and reject the characterization of life with a disability as a life of suffering worse than death, and the related notion that existential pain experienced as a result of disability is a justification for assistance in ending one’s life.
- We are concerned by and reject the suggestion that suicide is an expression of autonomy, freedom or liberty. Suicide is an act that is, by its nature, a matter of an individual’s sovereignty over their body—but it is not a freedom, liberty or expression of autonomy that is afforded the protection of law. In stating this concern, we affirm that the appropriate responses to an act or attempt at suicide are interventions aimed at supporting healing or grieving rather than criminal punishment and we recognize and affirm this objective in the removal of suicide from the *Criminal Code*.
- We are concerned by and reject the notion of suicide as a right, and the suggestion that the law is discriminatory because it denies this right to some but not others. The laws do not prohibit suicide but do deny assistance to guarantee choice of method, means and timing of death by suicide. This choice is denied to all people, and these

laws have as their purpose the preservation of a societal respect for life.

- We are concerned by and reject physician assisted suicide as an adequate societal response to pain—physical, emotional or existential—and distinguish the issues of access to end-of-life care and pain control from the issue of removing assistance in suicide from the *Criminal Code*. We find the call for legalization of assisted suicide a disproportionate response to issues of health care that would be more appropriately addressed through quality palliative and end-of-life care and pain control and call for improvements in access and adequacy of such services.
- We are concerned for any provision that would guarantee access to assistance in death at a time when people with disabilities lack any such guarantee with respect to assistance and supports that can improve quality of life.

It is our position that provisions of the *Criminal Code* that prohibit providing assistance in suicide should remain intact. Further, it is our position that assistance in suicide is not a right and should not be guaranteed by way of a disability and equality rights analysis through section 7 and section 15 of the *Charter of Rights and Freedoms*. It is our position that such an analysis depreciates *Charter* values and trivializes the rights that have been hard fought for and hard won under this guarantee of equality, and damages, rather than advances, the equality of persons with disabilities.

Actions Needed

Since the fundamental rights and wellbeing of people with disabilities are threatened by these directions, CACL will engage in discussion of these concerns within the disability community and with the public at large; take proactive steps to share our position in forums concerned with law reform in the area; and engage leadership development among people with disabilities, their families and community leaders to develop and support champions within our movement and beyond on this issue.

Genetic and Testing Technologies

Background

Ever since the first emergence of testing technologies, and since the beginnings of the Human Genome Project, CACL and the Values and Ethics Task Force have been exploring the issue of genetic and testing technologies and the implications of these rapidly advancing technologies for people with disabilities and their families. Chief among our concerns has been the eugenic potential in the use of information garnered from these technologies and the potential that they have for shaping and forming what is valued in our society.

In 2001 the membership of CACL passed a resolution mandating the Values and Ethics Taskforce to assist in developing “comprehensive principles and ethical guidelines” to ensure that these technologies will not be detrimental to the “equal rights of people with disabilities to enjoy life, equal justice, freedom from discrimination and acceptance as contributors to our diverse society.” (CACL, Resolution 4/01)

A concern for the potential of genetic technologies and the problem of genetic discrimination also factored large in the design of CACL’s Statement of Beliefs and Values which was adopted in 2003. It opens with the statement:

All members of the human family are full persons. Our human essence cannot be reduced to words, labels, categories, definitions or genetic patterns.

It further states:

All persons have inherent and equal worth. Our value as persons is neither earned nor accumulated. It is unrelated to health status or any genetic or other personal characteristic. (CACL, Statement of Beliefs and Values, 2003)

In 2005, the membership of CACL adopted *From Values to Action*, a vision to guide the movement for the next decade. One of the goals identified in that document is to achieve equality rights and recognition. One of the benchmarks for this goal is that “by 2015 policies and practices that govern the use of genetic technologies respect human diversity and the fundamental principles of community living,” (CACL, *From Values to Action*, 2005).

Out of these statements, principles and commitments concrete actions have been taken. In 2006, a discussion guide on genetic technologies was developed by the Values and Ethics Taskforce and was piloted at that year’s annual conference. The discussion guide includes a summary of technical information about genetic and screening technologies as well as discussion questions and advice for holding community discussions on the issue

(CACL, *Health Care or the New Eugenics*, 2006). There was also an online component in the form of a discussion board.

Discussions of the issue have taken place at CACL and PTACL conferences and this has resulted in a growing number of people connected to the ACL movement who are aware of the issue and the risks. CACL also identified and initiated discussions with key stakeholders in the area of genetic counseling and agencies charged with regulation of the use of genetic technologies.

However, it is acknowledged that there has not been much progress made in reversing the trend toward the progressive identification of an increasing number of genetic conditions, or in influencing policies and practices that govern the use of these technologies. In 2007, the Taskforce took a step back to consider strategy and questioned its objectives. The Taskforce felt that a CACL strategy needed to shift its focus from the technologies themselves to encouraging public dialogue and shaping public values on how these technologies are used. Such a strategy would include developing a values statement to guide the use of genetic technologies; development of a “disability-positive” perspective to be used in genetic counseling; as well as leadership development among CACL membership and development of online information tools. (CACL, *Manufacturing Consent?* 2007)

Since the identification of these objectives in 2007, there has been further development of technologies and practice that has resulted in the testing for disability-related characteristics as a routine matter of prenatal care. New tests available internationally provide for rapid, non-invasive and inexpensive testing for the presence of Down syndrome.

The Values and Ethics Task Force has developed the following discussion document and policy position in order to continue this critical conversation and propose some new methods for achieving our objectives.

Discussion of key issues

When we look at the many victories that have been achieved by the community living movement—including challenges to non-therapeutic sterilization without consent, the progressive (and continuing) closure of institutions, progress on employment and inclusive education and so on—there is the appearance of progress on the inclusion of people with disabilities. But from another perspective, eugenic aims of elimination of disability—explicit or implied—have never been more effective. The efficiency of testing technologies has imperiled people with disabilities in a quiet but powerful way.

- Disability is a natural part of the human condition. Even despite the most forceful pursuit of eugenic aims, disability will never be ‘disappeared.’ However, there is a strong risk and likelihood that even the current availability and use of technologies for testing and screening will exacerbate systems of poverty and privilege and will shift demographics of disability to already marginalized segments of the world’s population.
- There is a disability specific eugenic potential that is represented by the rapid spread, availability and use of these technologies.
- There has been an explosion of information and development of technologies that has resulted in a rapid increase in the number of conditions that are being investigated for genetic markers. In the space of one year the number of ‘conditions’ that have been identified as having a genetic component that could potentially be tested for has increased from 74 to 60,000. These include links to Alzheimers, breast cancer, cleft lip, albinism, stuttering, genetic markers for autism, and so on.
- We are concerned by the shift toward values of perfection, and a manufactured demand for tests that are able to identify an increasing number of traits related to genetic information. This explosion of information, and increased avenues for identification and intervention, does not merely represent an expansion of choice and autonomy, but introduces several new social, cultural and economic considerations to the reproductive process that are unprecedented in their potential impact.
- These are species level interventions which have some immediate consequences that we are concerned with and have some certain unforeseeable consequences. There exists a biological imperative toward diversity and elimination of diversity poses major risks. A narrowing of the human gene pool is a limiting of the benefits of genetic diversity.

Our overarching concern is that the continued pursuit of these technologies entrenches and legitimizes a set of values about the human condition that are in opposition to the values of CACL and values which we believe are fundamental to human society.

- CACL has a valuable perspective in its vision and values that includes “genetic diversity.” This perspective may indeed touch on fundamental values that are shared by much of the public, even if they are seldom expressed. This perspective can be helpful to spur public debate and dialogue about the issue.
- The process and set of decisions that is involved with the research, development, production and use of genetic and testing technologies takes place in a public context and has public consequences.
- Research, development and use of testing technologies represent an enormous allocation of health care resources. This significant spending occurs at a time when supports to ensure quality of life for persons with disabilities are dwindling.
- In considering how to address our concerns we must consider the various decision points that occur in the development, dissemination and use of such technologies. This includes funding, research, development, approval, dissemination and end-use. In order to address these concerns we have identified a number of processes and decision points that we wish to engage, influence and intervene in. These include:

Research funding→Genetic technology development and production→Technological assessment and approval→protocols of prenatal care→Health care decision making processes (including general practitioners, genetic counsellors, obstetricians and gynecologists)

- Demand for such tests and information is formed in complex ways and is in a certain sense a “manufactured demand.” Implicit in the research, development and production are values of conformity to an ideal of perfection and genetic enhancement. The notion of perfect babies and perfect parents hold a powerful sway over the health care decisions that people currently make. These influence the set of actions that are considered to be part of routine and “medically responsible” prenatal and maternal health care.

There is a concern that people are not being provided with adequate and quality information about tests that are being done, and for what purpose. In some cases this may be a gap between policy and practice but there is also a lack of policy to guide the provision of such information.

- The current provision of information about prenatal testing in clinical settings is seen to be inadequate and is framed in such a way that it results in a profound devaluation of people with disabilities. The social, cultural and economic context in which this research and production of technologies takes place makes the possibility

of providing balanced information extremely unlikely. In order to provide balanced information that can enable truly informed decisions to take place it is necessary that “disability-positive” information be provided.

- The manner in which information about genetic and screening technologies is currently being framed—both in the context of prenatal care and in public dialogue—does a disservice to women and families. There is not presently a provision of quality information about such tests and preparation for the option to undertake such tests in the first place.
- We know that the way that information is presented greatly influences decisions that are made about engaging testing and use of the information gathered from such tests.
- There has not been sufficient attention given to the broader social, cultural and economic context in which this information and these decisions are being presented.

We are committed to affirmation of reproductive rights and choices of women and enabling women and families to make informed choices. In recognizing this commitment, we are concerned that there has not been sufficient information provided by way of disability-positive information in order to enable a context in which truly informed choices can take place.

- Women’s enjoyment and exercise of reproductive rights and choices are diminished to the extent that the health care, social and economic context in which those choices are exercised systematically devalues people on the basis of disability.
- Women with disabilities frequently encounter barriers to their equal reproductive and parental rights.
- While information that is provided must be balanced and evidence-based, a call for ‘neutral’ or ‘objective’ information is inadequate to counteract the profoundly negative messaging about people with disabilities currently. For this reason, it is necessary that a ‘disability-positive’ perspective be provided.

Draft position on genetic and testing technologies

Context

In taking this position we are concerned with the process and flow of research, development, assessment, approval and clinical and health care application of genetic and testing technologies (hereafter referred to as *genetic and testing technologies*) as well as the associated clinical, health care and public policy regulations and protocols for such technologies.

Purpose

The purpose of this position is to make clear CACL's position and bring detail to CACL's beliefs and values with respect to principles that we believe must guide the processes involved in the production and use of genetic and testing technologies.

Position

In taking a position related to genetic and testing technologies, we are motivated by the following concerns:

- We are concerned that with the rapidly advancing field of research and development of genetic and testing technologies, and with associated health care and public policy regulation and practice, there is a lack of guiding values and principles to recognize and protect against negative impacts on people with disabilities and their families including:
 - Continued and systematic devaluation of persons with disabilities;
 - The danger of an erosion of the commitment to provision of needed supports to people with disabilities and their families as a public good; and
 - Similarly, the danger of an erosion of the public commitment to inclusion and diversity.
- We are concerned that clinical ethics that do guide the current flow of research, development, approval and application of such technologies are based on a limited notion of personal autonomy and consumer choice without recognition of prevailing power structures that influence and manufacture demand for such technologies and reinforce a perceived duty to access such technologies as a matter of routine prenatal care.
- We are concerned that although this is an issue with far reaching public policy implications, there are not public spaces for discussion and negotiation of the potential impacts.

- We are concerned that the presentation of information about these technologies has strong influence over the decisions that individuals make about accessing these technologies and about using the information that is gathered from them. It is our concern that the current presentation of such information is inappropriately tilted towards a duty to engage such testing and towards a negative view of people with disability-related genetic conditions.

Given these concerns, and guided by our values and beliefs, we take the following position in relation to genetic and screening technologies:

- We recognize genetic diversity as a valuable aspect of the human condition.
- We recognize and affirm the reproductive rights of women, including women with disabilities, and while recognizing the potential for genetic technologies in the enhancement of the enjoyment of these rights, we hold that reproductive rights of women must not be reduced to a thin notion of consumer choice.
- People who are living with disability-related genetic conditions and their families are impacted by these processes in their status as equal and valued citizens and therefore hold a unique stake and must be involved in decision making;
- Genetic technologies have socioeconomic impacts and study of these impacts must be included as a fundamental aspect of research and development in this area.
- In the interests of providing fair and balanced information so that people are able to make truly informed decisions, it is necessary to incorporate a “disability-positive” perspective into all stages of the research and development process as well as in information that is provided in the context of clinical application of these technologies in order to counteract the profoundly negative messaging currently contained or implicit in the framing of genetic technologies and their use.

Actions Needed

CACL will use this statement of position to guide intervention in and dialogue with the actors and processes outlined above in order to communicate our beliefs and values and to pursue their incorporation within these processes in order to protect against, mitigate and reverse the negative impacts of genetic and testing technologies on people with disabilities and their families.

Glossary of Key Terms

The following is a guide to some of the key terms that are used throughout the document.

Assisted suicide is when someone helps another person to end their life. Providing assistance to a person to commit suicide is against the law in Canada.

Euthanasia, means literally *good death*, and refers to the practice of ending a life for the purposes of relieving pain or suffering. Euthanasia is distinguished from assisted suicide in that with euthanasia there is often a question of whether consent has been provided, whereas assisted suicide is usually proposed in the sole context of persons who provide clear informed consent.

Palliative care is a health care service that is provided help people who are suffering as a result of disease, illness or other condition. The goal of palliative care is to help relieve, ease or prevent suffering and treat symptoms as opposed to curing or reversing the underlying illness or cause.

End-of-life / Hospice care is care that is provided to a person when they are near the end of their life and in final stages of an illness. These approaches focus on treating physical, emotional or psychosocial symptoms and bringing comfort to people who are dying and their families. There is a focus on treatment and control of pain.

Autonomy is a principle in ethics and in law that refers to a person's right to make their own decisions, and not to have those decisions interfered with arbitrarily by law. There are many different philosophical, ethical and legal definitions of autonomy. In rights theory, autonomy is associated with having the freedom and ability to pursue one's own life plan.

Sovereignty and sovereign power means having the independent power and authority to rule over something. Personal or individual sovereignty is a concept of having a moral or natural right to control one's own body.

Existential pain and suffering, or the pain and suffering of existence, is fear, anxiety or other emotional distress related to living, dying, and especially illness or loss of capacities. The term is usually used to emphasize that there are other kinds of pain besides physical pain and that these types of pain need treatment in health care and attention in decision making.

Genetic and testing technologies in this discussion paper, means tests, devices and processes that can be used to obtain information about a fetus that can predict characteristics of a potential child.

Eugenics is a term that is used to refer to an attempt to “improve” the genetic composition of a population. Throughout the twentieth century states throughout the world enacted eugenic programs and laws that were aimed at stopping groups of people—including the poor, people with disabilities, and ethno-racial and cultural minorities—from reproducing. Although these laws, policies and practices have been progressively discontinued since World War II, they had horrific consequences and their legacy remains today. In this discussion paper, concerns for a ‘new eugenics’ refer to the systematic elimination of persons with disabilities using today’s tools of funding and delivery of selective abortion, and other genetic technologies, through the health care system.

Reproductive rights are legal rights related to reproduction and reproductive health. They typically include the right to a legal and safe abortion, the right to birth control, right to access reproductive healthcare and to education and access to make informed reproductive choices. The World Health Organization states that:

Reproductive rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. They also include the right of all to make decisions concerning reproduction free of discrimination, coercion and violence.

CANADIAN ASSOCIATION FOR COMMUNITY LIVING

STATEMENT OF CORE PRINCIPLES AND VALUES

April 12, 2003

(Adopted by the CACL membership at a Special General Meeting, April 12, 2003)

CACL is a Canada-wide association of family members and others working for the benefit of persons of all ages who have an intellectual disability.

CACL works strategically with other disability rights organizations and, in particular, with People First of Canada.

STATEMENT OF PURPOSE

CACL promotes the valued recognition of people with intellectual disabilities as citizens who have contributions to make to families, communities and society.

CACL promotes the valued recognition of families as gateways to inclusive community life for people with intellectual disabilities.

CACL promotes the establishment and maintenance of social and economic supports so that people with intellectual disabilities are welcomed and valued as full and self-determining members of the community.

CACL promotes a vision of society that is inclusive, respectful and supportive of the rights of all persons regardless of differences in intellectual or other abilities.

CACL promotes the elimination of discrimination on the basis of disability, gender, age, culture, race, ancestry, sexual orientation and other differences.

VALUES AND BELIEFS

All members of the human family are full persons. Our human essence cannot be reduced to words, labels, categories, definitions or genetic patterns. Every person is unique. No one can be replaced or copied. All persons are ineffable.

- All persons are entitled to respect. Respect requires recognition of and concern for the dignity of every person. Dignity is fragile. It must be protected from all harm.
- All persons have inherent dignity. Dignity belongs to us just because we exist. It is not something we earn or received
- All persons have inalienable dignity. Dignity cannot rightfully be ignored, diminished or taken away.
- All persons have equal dignity. Dignity does not depend upon physical, intellectual or other characteristics. Neither does it depend upon the opinions that other people have about these characteristics
- All persons have inherent and equal worth. Our value as persons is neither earned nor accumulated. It is unrelated to health status or any genetic or other personal characteristic.
- All persons have inherent capacity for growth and expression. Every person has the right to be nourished physically, intellectually, socially, emotionally and spiritually.
- .All persons are entitled to equal access and opportunity. Equality demands protection from all forms of discrimination or harm, and access to the supports necessary to enable equal participation.

GUIDING PRINCIPLES

CACL is guided in all of its actions by principles that are consistent with its values and beliefs. Every action will be tested against these principles. Every action, statement, policy, or publication will honour and promote the principles of:

- √ **Respect**
- √ **Dignity**
- √ **Equality**
- √ **Diversity**
- √ **Human rights**
- √ **Justice**
- √ **Self-determination**
- √ **Mutual responsibility**
- √ **Inclusion**
- √ **Moral courage**

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Canadian Association
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Association canadienne pour
l'intégration communautaire

Diversity includes. On se ressemble.