# In the Stream

**Spring 2006**

## Whose Life is it Anyway? Bioethics, Quality of Life and Disability

*by Nancy Barry*

Most of society sees people with disabilities as persons who are flawed, pitiful and without dignity. But we see ourselves as a vital and proud community, with values of our own that enhance our quality of life, values that could enhance life for all.

Every person's life is in some way or another touched by the 'bioethics' debate. Some lives are more affected by it than others. If we are to understand the debate of bioethics issues for people with disabilities, then we have to start by understanding the meaning of disability. There are two main views of disability: the medical model versus the 'independent living' model. The medical model sees disabled people as dependent upon society. This can result in paternalism, segregation and discrimination. The second perceives disabled people as consumers of what society has to offer, leading to choice, empowerment, equality of human rights, and integration.

The Medical Model holds that disability results from an individual person's physical or mental limitations, and is largely unconnected to the social or geographical environments. In simplest terms, the Medical Model assumes that the first step solution is to find a "cure" or to make disabled people more "normal". This model restricts disabled people's opportunities to make choices, control their lives and develop their potential, as it concentrates on "care" and ultimately provides justification for institutionalization and segregation, while fostering existing prejudices about people with disabilities in the minds of the general "non disabled" population.

Independent Living is a vision, a philosophy and a movement of persons with disabilities. Born on California university campuses in the 1970s, the movement spread to Canada in the 1980s, and has since reached around the globe and changed the way people view and respond to disability. Independent Living is founded on the right of people with disabilities to live with dignity in their chosen community, participate in all aspects of life and control and make decisions about their own lives. Within this model, the professional is viewed as a service provider who simply provides information to the consumer so that he or she can make informed choices. The consumer selects what services they believe are appropriate for their own needs, while the service provider acts as a consultant or resource provider.

Many bioethical issues, ranging from birth to death raise profound questions for disabled people's human rights. We all know that the different ways society sees disabled people affects the way they behave towards us and our human rights.

Because bioethics is related to medical research and treatment, it mostly sees disability as a medical problem. Genetic testing and screening, pre-implantation genetic diagnosis, genetic engineering, gene therapy, stem cell research, quality of life decisions, resource allocation in healthcare, decisions to treat or not to treat, infanticide, end of life decisions and so on, are about, and of direct concern to disabled people. But for most people working on bioethics, disability is a medical issue … thus disability continues to be seen within a medical model framework.

Bioethicists have power because they teach medical professionals and community elites to decide who lives and who dies. They teach these professionals and elites to put community health (and wealth) first, by weighing the cost of "taking care of" us and our apparent value to society. Up until now most of us have been excluded from debates on bioethical issues. These debates have had prejudiced and negative views of our quality of life. These views deny our right to equality and therefore deny our human rights. We must be the people who decide on our quality of life, based on our experiences. Biotechnology presents particular risks for disabled people. The fundamental rights of disabled people, particularly the right to life, must be protected.

The reason for the impact of the stereotypes and the resulting discriminatory laws can be found in the values and prejudices of people in society. (Weiss, 1987; Proctor, 1988; Brown, 1988; Weindling, 1989; Caplan, 1989) One of the primary sources of these prejudicial attitudes which led to the laws is the Eugenics Movement which has its roots in nineteenth century biology, especially the work of Charles Darwin. (Mazumdar, 1992; Stepan, 1992) Disability-rights activists have become increasingly alarmed about the economic and political issues arising from the rapidly advancing field of genetic research. The use of genetic knowledge to repair damaged genes, for the purpose of treating certain illnesses, may offer welcome benefits to some people with disabilities. But genetic research is likely to be put to other uses such as denying health insurance, even jobs, to people whose genes predispose them to medical problems. Another threat is the implementation of eugenic policies to "weed out" certain types of people from the population. Thus, along with the much-heralded scientific advances offered by genetic research, disability activists nervously witness a resurgence of eugenic thinking.

Using ultrasound and abortion to select a child's sex is regarded as unacceptable to many people. Using genetic testing to eradicate characteristics such as homosexuality is still a new concept, but is likely to cause a great deal of controversy. Yet the media and the public seem to accept, almost without question, the idea of screening for genetic anomalies that cause disabilities and then using that information to eliminate certain conditions, by eliminating their carriers before birth. Many people assume that people with disabilities would want to spare future generations from the difficulties we had to endure. But this assumption relies on another assumption, that our disabilities are inherently problematic. The disability-rights movement disputes that idea. Rather than blaming our physical or mental disabilities themselves, we see our problems as rooted in social, physical, economic and political barriers. Instead, society should commit itself to removing these barriers, and to full equality for people with disabilities.

Bioethics is concerned with the ethics of medical research and treatment, including genetic testing; genetic engineering; gene therapy; quality of life decisions; decisions to treat or not to treat; and end of life decisions. The "right to life" movement has embraced Terri Schindler-Schiavo as a cause to prove "sanctity of life." The "right to die" movement argues that people in guardianship should have no protection against private family decisions to kill them. Yet the life-and-death issues surrounding Terri Schindler-Schiavo are first and foremost disability rights issues -- issues which affect tens of thousands of people with disabilities who, like Ms. Schindler-Schiavo, cannot currently articulate their views and so must rely on others as substitute decision-makers.

That's why several national disability rights organizations adopted a position in support of Terri Schiavo's right to continue receiving food and water. This brings us to the “life versus choice” debate which is constantly under scrutiny. Two camps have long been in conflict with each other regarding end-of-life care. There is the mode of thought that feels that sanctity of life is paramount: life, no matter how diminished, should be protected whenever possible. The other side feels that autonomy is paramount: a person, directly or through a loved one, should be able to decide what treatments he or she wants or doesn't want at the end, based on his or her own value system. The public has long had a difficult time accepting that a feeding tube should be looked at no differently from a ventilator, a blood transfusion or kidney dialysis.

Disability advocates argue that parents who kill their children to alleviate suffering have committed a crime, a serious crime that deserves to be punished. Therefore there should be no lesser sentence for Robert Latimer than for anyone else convicted of a murder. To do so, devalues the lives of the disabled and may put the lives other disabled people at risk. But many others will feel that mercy killers should be convicted of a crime, but not go to jail for a decade or more. How can we possibly justify that the two situations are different?

As our legal system now stands, there are several ways that the punishment could be made to fit the crime. Unfortunately, they are either unlikely to succeed or unsatisfactory. The Crown could reduce the charge to manslaughter, which doesn't carry a mandatory minimum sentence (unless committed with a firearm). Murder may be reduced to manslaughter "if the person who committed it did so in the heat of passion caused by sudden provocation." But the Crown is unlikely to reduce a charge if the facts better fit the definition of murder because of planning or deliberation (elements that are typically present in a mercy killing).

The defence could also find a technicality that will acquit their client outright. For example, Nancy Morrison, a Halifax physician accused of killing a patient dying in an intensive care unit, was acquitted when there was doubt that the drug she allegedly injected to end his life entered the patient's bloodstream and was actually the cause of death. (By contrast, Robert Latimer immediately confessed to the police that he hooked up a hose from the exhaust of his pickup truck into the cab where Tracy was because he could not bear to see her suffer.)

If the jury feels extreme empathy for the defendant and knows the guilty verdict will send him to jail for 10 to 25 years, they could "nullify" themselves by rendering a not-guilty verdict even if the facts support the charge, effectively ignoring the law. This is unsatisfactory for two reasons: First, it undermines our justice system. Second, conviction and punishment may be warranted even if a lengthy sentence is not.

The judge could try to impose a lesser sentence, arguing that the mandatory minimum sentence is cruel and unusual. In Latimer's case a judge tried to sentence him to one year in jail, but this sentence was increased to 10 years on appeal since it violated the mandatory minimum.

After all appeals are exhausted, usually up to the level of the Supreme Court, the federal Cabinet could exercise its prerogative of mercy and reduce the sentence. This is what the 2001 Supreme Court decision in Latimer effectively invited the Cabinet to do. They have not done so. The political gain for the cabinet is slight and the risks are significant. Everyone believes the punishment should fit the crime. Cases like Latimer's and possibly Carmichael's, if the speculation is true, remind us that the principle doesn't apply in cases of mercy killings.

Past experience suggests that some bioethicists will be among his supporters. Ethicist Eike Henner Kluge has stated, "Tracy would not have been in this situation if people had not used heroic means all along. Someone should have stopped along the way and asked, 'Should we be doing this? By keeping her alive to face a declining quality of life, they were committing what ethicists call 'the injury of continuing existence.' In the end, the parents faced a situation in which they had no choice." The disability community has also witnessed ethicists deny that the Latimer case is about disability. In other cases, ethicists have advocated that children with disabilities have a right to assisted suicide. Since the Latimer case started to make headlines in Canada's media, bioethicists have been viewed as legitimate commentators. Bioethicists address health care issues and because Tracy had a disability some view this case as falling within the purview of those who address health care issues.

It is obvious to many within the disability community in Canada that mainstream bioethics bases many of its arguments on “ableist” assumptions. Today's bioethics is heavily influenced by utilitarianism, which emphasizes quality of life arguments. Anyone who has followed the Latimer case will be well aware of how ableist quality of life arguments are used to justify the termination of a life with a disability.

The concept of equality rights is an important argument for oppressed marginalised groups. The members of the population with a marginalised characteristic fight all over the world for being included in society, for equal opportunities, for Anti-discrimination and self- determination/autonomy using equality rights arguments. For the characteristic disability this means a war at least two fronts. One is the equal participation in societies which means the same access to education, buildings, services, employment, health care, equal access to life and death and equal rights in front of the law. But the fight on the second front is equally as important. That fight is about self esteem, self worth, pride, acceptance for which they are dignity and self-determination/autonomy.

End of life decision-making, the allocation of healthcare resources, the use of genetic technology (gene therapy, genetic testing), research on non-competent people, questions of futile care, selective non-treatment of newborns, debates about personhood, mercy killing and disability adjusted life years, just to name a few, are all issues that have significant implications for disabled people and are increasingly being debated by disabled people in non-academic, non-governmental settings. The increased interest of disabled people in bioethics is an indication that they feel affected by these issues. A closer look, however, reveals that those with disabilities debate these issues mostly amongst themselves and that little dialogue exists between disabled and non-disabled people on these issues. Many conferences - academic and otherwise - where these issues are debated, fail to have disabled people present. The attendance of disabled people at most academic bioethics gatherings ranges from non-existence to very low; and a disabled academic bioethicist is an uncommon species. Furthermore, it is rare that there is the representation of disabled people on government bodies and/or committees which develop policies regarding bioethics issues. Rather, it is mostly non-disabled people who are involved in the development of government policies involving these issues. The negative attitude of many disabled people towards bioethics stems from precisely these facts. Moreover, the scholarly and non-scholarly work done by disabled people on bioethical issues is often ignored by the academic bioethics community, deemed as “insignificant”.

There is a move towards understanding disability according to the social model and thus towards seeing disability issues as issues of human rights. For example, the World Health Organization (WHO) uses the term "disability" to denote a multidimensional phenomenon resulting from the interaction between people and their physical and social environment. It takes the position that an individual must not be reduced to, or characterized solely in terms of their impairments, activity limitations, or participation restrictions (WHO, 2001). Nevertheless, disabled people continue to be discriminated against in ways that other groups who have faced oppression (such as women and blacks) no longer are. People with disabilities continue to have to fight in order to have themselves seen according to the social model: as a human rights movement.

It was one of the most difficult cases the Supreme Court of Canada has ever had to judge. A British Columbia woman, dying from ALS, turned to the courts to help end her suffering. She needed the assistance of a doctor. Yet any physician who assisted her risked losing his or her medical license and would face a maximum 14-year jail term. Only 15 months before she stepped into the spotlight, Sue Rodriguez was a healthy, athletic woman. She loved aerobics, weightlifting, cross-country skiing, and was in excellent physical condition.

In early 1992, Sue Rodriguez was diagnosed with the rare disease of ALS, or amyotrophic lateral sclerosis. It's sometimes called "Lou Gehrig's disease," after the baseball star who died of it in 1941. It causes a slow deterioration of the nervous system while leaving the mind intact. It's incurable and its cause remains a mystery.

Some people with ALS can live for a long time. World-renowned physicist Steven Hawking has lived with the condition for 30 years. But for the majority, the average life expectancy after diagnosis is about three years. As it progresses, it slowly takes away an individual’s ability to walk, and then their ability to talk, and eventually their ability to breathe. Most patients eventually die by suffocating or choking.

Rodriguez had always been strong-willed. After her initial diagnosis, she spent more than $10,000 on naturopaths, acupuncturists and nutritionists, hoping to prevent the disease from advancing. Canada's most important (to date) dramatic and high-profile court case with respect to the issue of physician-assisted suicide took place in 1992-93.

Sue Rodriguez had done her research and knew fully well the death that was in store for her. Ms. Rodriguez, mother of a small child, knew that the disease would gradually rob her of the ability to walk, move her body at will, eat and finally breathe without mechanical assistance. Her mind would remain alert, however, trapped in the shell of her body. Sue Rodriguez did not find dignity in such a life and wished instead to circumvent such an end by requesting physician-assisted suicide at a time and in a manner of her own choosing. She was determined that she would like to activate a machine that would facilitate her death, but would also like to have a physician present, in case, through some unpredictable eventuality, something went wrong and she needed further aid in dying.

Christopher M. Considine, the lawyer for Ms. Rodriguez, took her case to a lower court, to the Supreme Court of British Columbia, which denied her request, and then to the B.C. Court of Appeal. In the judgment on appeal from the Court of Appeal, the decision was lost by a vote of two to one. The judge, in his dissenting opinion, based mostly on arguments relating to the Canadian Charter of Rights and Freedoms presented by Ms. Rodriguez's counsel, outlined a set of guidelines by which he felt Ms. Rodriguez could be granted her wish.

The matter then proceeded with unusual speed to the Supreme Court of Canada, which eventually dismissed the appeal of Sue Rodriguez in its decision announced September 30, 1993. The majority decision concluded that, given the concerns about potential abuse and the great difficulty of creating appropriate safeguards, the blanket prohibition on assisted suicide is "not arbitrary or unfair" and should therefore be upheld.

Chief Justice Lamer recommended that the declaration of invalidity be suspended for one year to allow Parliament to address this issue and that, during this one-year period, Sue Rodriguez and other persons who are physically unable to commit unassisted suicide, be granted a constitutional exemption that would allow them assistance under court-approved conditions and safeguards.

Sue Rodriguez lost her legal battle to die with dignity. But in the hearts and minds of millions of Canadians the legal fight of this courageous lady has not been in vain. Nor will the fight for freedom of choice in the time and manner of one's own death stop here. And while the Supreme Court did not grant her petition, Sue Rodriguez knew that she had benefited all Canadians by raising awareness of this critical issue concerning free choice in dying. Her fight may inspire Parliament to make necessary changes in the Criminal Code.

Because she was murdered by Robert Latimer, Tracy Latimer will never have the opportunity to tell the world what her life was really like. Tracy's communication books, in which her mother and others recorded the events of her life, tell the story of a happy young girl, who participated in the same kinds of activities that other Canadians, both those with and without disabilities, experience. Evidence was introduced at Robert Latimer's trial that demonstrates that Tracy's life was more than just pain and suffering.

Like other people Tracy enjoyed tasty food. In her mother's own words we hear that, "Tracy ate a good supper and had meat and potatoes at bed time." (22 October 1992) Like lots of children dessert was a favorite part of meal time. "She...ate a very good supper, especially enjoyed lemon pie for dessert." (23 May 1993) Tracy also had food preferences, "When I got home Tracy had spaghetti for supper, she ate it, but so slowly. I think she was wishing for meat and potatoes." (5 May 1993)

Tracy engaged in the seasonal pastimes that are typical childhood activities that provide a break from the childhood routine of home and school activities. Laura Latimer reports, "Tracy is going to be a princess for Halloween." (29 October 1992) "Lindsay wrote a letter to Santa for Tracy," stated Mrs. Latimer. (15 December 1992) Tracy participated in family gatherings with the Latimer's extended family. "We spent most of Easter at Tracy's cousin Lynn's place." (11 April 1993)

Like any sister, Tracy sometimes did things that got her brother in trouble with his mom. Mrs. Latimer wrote, "She loves the bells. I gave Brian heck, because I thought he was hitting his glass with a pen. We laughed when we realized that it was Tracy and her bells."

What little kid doesn't love visits with their grandparents? Tracy enjoyed being a granddaughter, in addition to being a daughter, a sister, a cousin, a school chum, a student. Tracy had many roles in life, just like other Canadians. "Tracy had a good weekend, sat on the deck lots. Grandma and grandpa came yesterday, she was happy to see grandma," wrote her mother. (23 May 1993)

When they become adults, people with disabilities, like Tracy's, often move away from home to live with their peers in group homes. Planning for this type of future had been going on for Tracy. The court records show that, "In early October 1993, Laura Latimer applied to have Tracy permanently placed in a group home. In the section of the application referring to habits and patterns she wrote that Tracy '...usually sleeps in the night, though also naps a couple of times in the day...' and '...likes to sit by the bonfire and likes to be rocked.'" (Paragraph 16, Crown's Factum, 2000) Group home residents have relationships with their peers, develop friendships, go to church if they wish, participate in vocational activities, do sports and lead lifestyles which are very similar to those of many other Canadians.

These accounts written by Laura Latimer and given by others in court demonstrate that Tracy was much more than the ‘suffering’ girl portrayed in the media. Like other Canadian girls her age, Tracy liked red nail polish, sleepovers, her grandmother and bonfires. Robert Latimer took all this away from Tracy.

One year ago, a severely disabled woman took her final breaths and slipped quietly into eternity. While discussions about the legacy of Terri Schiavo have focused primarily on the circumstances of her tragic death, it is also useful to reflect on what Terri's life can teach us. At a time where superficial, selfish and exploitative relationships have become the norm for many people -- as evidenced by all-time-high rates of divorce, domestic abuse, depression and suicide -- people with disabilities force us to move beyond ourselves and to grow to a more profound understanding and living out of authentic love. An authentic love is by its nature self-giving and patient. It is a love that is certainly demanding. However, this is precisely the source of its beauty. By the very fact that it is demanding it builds the true good of man and allows it to radiate to others. Yes, even Terri Schiavo, as a severely brain damaged woman of fifteen years, radiated that love. Ask her parents.

We live in a society where nine of every 10 Down syndrome babies are aborted once their disability is detected; a society whose courts have created a jurisprudence to justify murders of convenience. We destroy them because they are deficient, we feel, in some crucial way. Yet, it is the weak and the disabled among us who have the innate strength and ability to compel us to strive for and fulfill the most profound and difficult of human obligations -- to love unreservedly, unconditionally, even radically (Daniel Allott, Human Events, 205) we need to rediscover this authentic, self-giving love in all areas, and we can learn it from the disabled, just as Terri's family learned it from her.

The recent film, “Million Dollar Baby”, starring Clint Eastwood, Hilary Swank and Morgan Freeman, has already won a variety of honors. It has received seven Academy Award nominations including best picture. And well it should. It is a fine movie that offers a touching view of an evolving relationship between an aging fight manager and trainer, Frankie Dunn, played to the hilt as a craggy, old-school grouch by Eastwood, and Maggie Fitzgerald, a late-to-the-game, white-trash girl who has seized upon boxing as her ticket to self-satisfaction. She is played with great poignancy by Swank.

What has made the movie controversial is the twist it takes at the end. Maggie goes after the championship title against a tough, veteran boxer who is willing to do anything to win. The older pro cheap-shots Maggie after the bell rings and she falls, breaking her neck.

Paralyzed, bed-bound and permanently on a ventilator, Maggie decides that her life is no longer worth living. She asks Frankie, who has become her closest friend and father figure, if he will kill her. Frankie resists. His conscience and his Catholic beliefs make mercy killing ethically off-limits.

Eventually, however, he decides that he owes it to Maggie to help her die. And so he brings a siringe of adrenaline to the hospital where Maggie lives, disconnects her ventilator, shuts off the machine’s warning alarm and injects her with the drug. She dies moments later. Frankie heads out of town, never to be seen again, in order to escape any legal action that he might face.

The very idea that a severely disabled person might decide that their life is not worth living has driven individuals in the disability advocacy movement, as well as a few highly visible figures on the right-wing talk-show circuit and some in pro-life circles, into a frenzy.

Marcie Roth, director of the National Spinal Cord Injury Association, said she hates the film’s ending because so many people still think that “having a spinal-cord injury is a fate worse than death.”

"Unfortunately," she told The Associated Press, “the movie is saying death is better than disability."

Conservative commentator Rush Limbaugh, who has struggled with addiction to painkillers without feeling the need to defend his moral lapse, could not contain himself from ranting about how bad "Million Dollar Baby" is. He bashed the movie as the product of left-wing, secular thinking.

The Web sites and blogs of pro-life groups across the country are teeming with gripes that Hollywood dare promote a pro-euthanasia movie for so many Oscars.

Dealing with quality of life decisions about these devastating forms of disability in a thoughtful way — in a movie, book or theatrical presentation — is not selling any kind of value message about disability or, for that matter, promoting a particular ideological agenda. It is using the medium to explore some very tough ethical questions.

Maggie asks her trainer, Eastwood, to help her die. And he does. But in the real world she would not make such a request of her friend. Instead, she would ask her doctor and nurses to shut off her ventilator. She would ask to be allowed to die, not be killed. The doctors would then have to decide what to do, as was the case with Sue Rodriguez.

"Million Dollar Baby" makes us think we are more powerless than we really are. Those with a severe disability can demand that they be allowed to die — they sometimes do and they sometimes have their life-support stopped. (© *2006 MSNBC Interactive*, *Arthur Caplan, director of the Centre for Bioethics at the University of Pennsylvania)*

For the past twenty years, the field of bioethics has been challenged to become more sensitive to issues of race, class, gender, and disability. The disability critique of bioethics rests on much-disputed claims: first, that the presence of even what are perceived as severe impairments need not preclude a rewarding life for a person with a disability and for that person's family and community; second, that when a disability is alleged to diminish life quality or satisfaction, many of the explanations stem from the society's failure to fully incorporate people with disabilities into all aspects of social, political, and economic life.

## Open Letter: Regulation of self-directed attendant services

The Health Professions Regulatory Advisory Council (HPRAC) has been asked to give advice on the fact that PSWs (personal support workers) are unregulated. HPRAC is to report on whether some sort of certification is in order for PSWs. The problem is that the term 'PSW' encompasses all sorts of occupations, including attendant services. Regulation/certification of self-directed attendants is regarded by most consumers as a potential disaster and an intrusion into our ability to direct our own lives. What follows is one of the best letters CILT has seen on this subject:

Letter reprinted with permission of Hazel Self.

March 15, 2006

Barbara Sullivan, Chair
Health Professions Regulatory Advisoery Council
55 St. Clair Avenue West
Suite 806 , Box 18
Toronto, ON
M4V 2Y7

Dear Ms. Sullivan:

I am responding to the request for input into the discussion on whether some or part of the work performed by Personal Support Workers warrants the development of a regulatory body.

I am a former Registered Nurse who worked in the Princess Margaret Hospital and Toronto Doctors' Hospital. I aquired quadriplegia in 1978 as a result of a spinal cord injury and have attendants meeting my personal needs. I received attendant services, for 15 years, through Supportive Housing and for the last 11 eleven years through the Direct Funding program. For 25 years I have been involved in the work to establish attendant services in Ontario, both in the development and management of Supportive Housing and the development of Direct Funding. I am a former president of the Center for Independent living in Toronto and former board member of the Hugh Macillan Children's Rehabilitation Centre. I have also co-developed the Disability Studies component of the Physiotherapy program at the University of Toronto where I hold a status appointment.

There is a large and distinct segment of the population, myself included, who are getting on with our lives whilst coping with severe physical impairment. We work, raise families, go on holiday, laugh and cry as do our able-bodied counterparts. The attendant services, which we developed 30 years ago, enable us to manage our disability-related needs in a manner that makes ‘normal’ life possible. We call it maintaining our independence, having choice and control and being in charge of our lives. We are not sick, we know what we need. My attendants are highly qualified: they have a listening ear, they acknowledge my expertise, they have a pleasant attitude and respectful manner, they are trustworthy and reliable. These attributes are not gained by a having a PSW certificate or nursing training, as the sad litany of disciplinary actions taken by the CNO attests to. I find these attributes in my neighbour, the sales girl who helped me try on clothes, the daughter of the superintendent of my building and others whom I have met over the years and hired as attendants.

In the early years of developing attendant services many of us put career and pleasurable activity aside in order to participate with government in the countless meetings that it took to see this service conceived, developed, tested and expanded, Hence also our strong sense of ownership of the term ‘attendant’. My request to HPRAC is that it recommends to The Honorable George Smitherman, Minister of Health and Long-Term Care, that Attendant Services as originally conceived, as presently described in legislation and for the population originally be intended, be safeguarded from professionalism and restriction, and of being swept into the other 18 job titles as described in the Discussion Document.

Thank you for you time and attention.

Sincerely,

Hazel Self

## Highlights of the Ontario Government Budget

*Compiled by John Mossa*

### Social Services Backgrounder

### Improved Support for Social Assistance Recipients

The government is improving income security programs for low-income adults and families by:

- increasing social assistance basic needs and maximum shelter allowances for recipients of Ontario Works (OW) and the Ontario Disability Support Program (ODSP) by two per cent. This will provide an additional $33 million in benefits in 2006-07 and $80 million in 2007-08 and beyond to social assistance recipients; and

- making permanent the flow-through of the July 2004, 2005 and 2006 increases to the National Child Benefit Supplement (NCBS). This will provide an additional $56 million in 2006-07 and $75 million in 2007-08 to families receiving social assistance.

- the increases in social assistance benefits, combined with the flow-through of NCBS increases, mean that a single parent with two children on OW will have $1,620 more in annual income in 2006-07 than he or she would have had in 2003-04. This is equivalent to a 15.7 per cent increase in his or her social assistance income over the same period.

### Transition from Social Assistance to Employment

The government is investing $4 million in a new Employment Innovations fund, which will engage employers in expanding job opportunities for ODSP and OW recipients. This complements a number of measures the government has implemented to help people on social assistance make the transition to employment.

### Developmental Services and Other Supports for the Vulnerable

The government is making key investments to improve the lives of persons with developmental disabilities, low-income seniors and other vulnerable people in our society by:

- increasing funding by almost $80 million in 2006-07 for services to persons with developmental disabilities, which will expand residential services and community supports, help support agency operating costs, increase supports to families caring for family members, and expand day programs;

- providing increased services for children with special needs through additional funding of $10 million;

- increasing funding to domiciliary hostels — places of board or lodging for people who need supervision of their daily living activities — by $7 million in 2006-07 and developing common service standards;

- providing a two per cent increase in 2006-07 to both the Comfort Allowance for low-income seniors in long-term care homes and the

Personal Needs Allowance for social assistance recipients in care facilities;

- providing an additional $11 million in 2006-07 to enhance interpreter and intervenor services for people who are deaf, hard of hearing, or deaf-blind; and

- proposing another enrichment to the Ontario Property and Sales Tax Credits so that seniors who receive the guaranteed minimum level of income from governments would get the full benefit of the credits.

## Affordable Housing

A new Canada-Ontario Affordable Housing Program Agreement will result in an overall investment of $734 million, of which the Ontario and federal governments will each provide $301 million, with additional contributions from municipal governments. This investment will provide:

- approximately 15,000 new affordable housing units, including housing for victims of domestic violence and for persons with mental disabilities;

- approximately 5,000 housing allowances for eligible lower-income families;

- a home ownership fund to provide capital subsidies to eligible homebuyers with low to moderate incomes; and

- funding for the creation of the Ontario Mortgage and Housing Initiative to assist developers of affordable housing with low-cost, long-term financing for new rental and supportive housing units.

## AODA Update

ONTARIO’S ATTORNEY GENERAL PUBLICLY REFUSES TO COMMIT TO CONSULTING WITH PUBLIC BEFORE INTRODUCING LEGISLATION TO WEAKEN THE ONTARIO HUMAN RIGHTS CODE - CLAIMS HE’S CONSULTED BUT DOESN’T ACKNOWLEDGE THE MAJOR DISABILITY ORGANIZATIONS HE’S IGNORED.

On Wednesday, March 29, 2006, during Question Period in the Ontario Legislature, NDP Leader Howard Hampton called on the Ontario Government to undertake a public consultation on how to reform the Human Rights Commission, rather than going ahead with its plans to weaken the Human Rights Commission.

Responding for the Government, the Attorney General rejected the call for further consultations. He said: On the contrary, we've been working with those very groups for well over a year, and consulting with them.” The Attorney General’s statement in the Legislature is a slap in the face of all those individuals and community organizations who haven’t been consulted, and who have asked to be consulted. It is clear the McGuinty Government hasn’t yet gotten the message. We need you to re-double your efforts. Call as many Government MPPs as you can. Tell them how you feel about the McGuinty Government’s response to the call for consultations, set out in this exchange in the Legislature. To get their contact information, visit: http://olaap.ontla.on.ca/mpp/daCurMbr.do?locale=en for tips on what to say, review their action kit at www.aodaalliance.org

## New multiple format service for visually impaired persons offered by Canada Revenue Agency

On February 16, 2006 the Canada Revenue Agency (CRA) and the Canadian Human Rights Commission (CHRC) announced that effective immediately, the CRA will offer a new multiple format service for visually impaired individuals.

The new multiple format service will allow visually impaired Canadians to self-identify to receive CRA printed material in the alternate format of their choice by making a one-time alternate format request to the CRA.

Once an individual has self-identified, the CRA will send all subsequent material that is specific to the individual, such as a Notice of Assessment, in the alternate format of choice. To obtain publications that are not client-specific, such as generic tax information publications, visually impaired individuals will be required to make a separate request.

The new alternate format service will enable the CRA to mail certain paper and alternate format material together. Some material will still require separate mailing of the paper and alternate format. If printed and alternate format material cannot be sent together, the alternate format will be mailed within 5 days of the mailing of the paper material.

The CRA listens to Canadians in its commitment to continuously improve how it delivers its programs and services. The new alternate format procedure provides consistent and timely service to visually impaired Canadians.

For more information, visit www.cra.gc.ca.

## 2006 Census: The Most Accessible Canadian Census Ever

People with disabilities have the same range of preferences, perceptions, attitudes, habits and needs that drive consumer behaviour of people without disabilities yet marketers rarely target this niche market. This article provides advice and tips to an inclusive strategy.

On May 16, 2006, Statistics Canada will be conducting a complete Census of Population, along with a Census of Agriculture. The Census will provide a detailed statistical picture of Canada and its population at a single point of time. The 2006 Census is the most changed census in 35 years. And one of the most significant changes is that, for the first time ever, the entire Canadian population will be able to go online to fill out their forms.

The online questionnaire can be accessed by the visual impaired by using such technologies as Freedom Scientifics' JAWS Screen Reader Technology. This technology provides audible cues to the user as it scans and reads aloud each webpage of the questionnaire. Using a keyboard, the demonstration showed participants how accessible the online questionnaire is for individuals who are visually impaired.

For example, to provide a more accessible online questionnaire, a fast-path link to the page is also provided on the landing page. Online navigation can be completely conducted via the keyboard, since persons who are blind do not use a mouse with their computer. The census questionnaire is also compatible with Braille outboard displays. In addition, users with limited vision can take advantage of other software to expand the text on the screen.

The online census questionnaire has also taken into consideration other accessibility limitations such as mobility, hearing and cognitive disabilities. Canadians with mobility challenges can navigate throughout the census using just the keyboard. Individuals with hearing difficulties may complete their questionnaire over the Internet without any special accommodation as no audio sounds, music or speech are used on the online questionnaire. Persons with cognitive challenges may refer to the printed form to help them understand the questions. The wording of the online census questionnaire matches the printed format, and modified buttons, links and selected entry fields were re-aligned on the accessible form to make it easier to use and understand.

Not only is the online questionnaire option more accessible, but completing the questionnaire online can also save time. Online edits alert respondents to missing or invalid responses and automated skips ensure that respondents are not presented with questions that are not relevant to them.

Statistics Canada takes the protection of confidential information provided online very seriously. A secure login process and strong encryption are key elements in helping to prevent anyone from eavesdropping or tampering with the census information when it is completed and sent online.

The 2006 Census will be the most accessible Canadian census ever! Accessibility challenged Canadians will have several options as to how to fill out their questionnaire forms. If they do not wish to use the online application, the may choose between large-print paper questionnaires, Braille versions of the questionnaire, as well as telephone options. Respondents can complete the questionnaire via a telephone interview by calling the Census Help Line at 1 877 594 2006, TTY (1-888-243-0730).

## People with Disabilities Falling Between the Cracks

*From the Canadian Council on Social Development*

Too many Canadians with disabilities are failing to get the medication or medical attention they need according to Gail Fawcett, Senior Research Associate at the Canadian Council on Social Development (CCSD). This situation is particularly worrisome at a time when the demographic bulge of the baby boomers is heading into age groups which are at higher risk for disabilities.

Fawcett has found that nearly 15% of Canadians with disabilities report being unable to access the health care they need at some point during the year - more than three times the rate among persons without disabilities. To make matters worse, 19% of working age women and nearly 12% of working age men with disabilities are, at times, unable to afford the medication they need. Among those with severe disabilities, these figures climb to 25% for women and about 18% for men.

"It's a Catch-22 for some individuals who may not be able to work due to a lack of medication or medical attention, but for whom paid employment might be the very thing that provides better access to this required medical support" says Fawcett. "We also find that employment is strongly linked to the overall well-being of people with disabilities."

CCSD research shows that the existing Medical Expense Tax Credit (METC) is not providing relief to those who need it most. The majority of persons with disabilities don't claim the medical expense tax credit-perhaps because expense thresholds are high, the credit is worth only a small fraction of the costs incurred and it is only relevant to people with taxable incomes.

Among those persons with disabilities who do attempt to claim the medical expense tax credit and who are sometimes unable to purchase required medication, about three in ten report that they do not end up actually receiving any benefit from the credit. Moreover, those who are most severely disabled are less likely to receive the credit than those who are mildly disabled.

"In contrast, we see a lower percentage of Canadians with disabilities aged 65 and over reporting an inability to purchase required medication. This is likely due to the effectiveness of provincial drug assistance plans for seniors," says Fawcett. "We need to be looking at a fully refundable tax credit that is better structured or a drug assistance plan for working-age Canadians who are not covered by a private health plan."

The CCSD's greatest concern is that, as a society, we are not taking the measures needed to prevent people with disabilities from being marginalized. "Exclusion can start at an early age," says Fawcett. "Negative attitudes toward people with disabilities are already evident in grade school, where children with special needs are more likely to report feeling excluded at school and twice as likely to report being bullied." In addition, many people acquire their disability in adulthood. In fact, it is well known that the risk of acquiring a disability increases with age. This puts the ageing baby-boomer workforce increasingly at risk and makes it more important than ever to set in place supports which will allow people with disabilities to continue leading active, healthy lives.

For more information contact visit: www.ccsd.ca/drip/research/ or contact: 613-236-8977.

## Training Opportunity for People with Disabilities: Pre-Employment Training Program

**Location: Toronto, Ontario**

The CIBC Career Access Program is a positive measures initiative to enhance employment opportunities for People with Disabilities, which is one of the four employment equity groups defined by the Employment Equity Act.

The **Pre-Employment Training Program** (PET) is being provided to People with Disabilities through a special partnership between CIBC and JVS Toronto. It is designed to train up to 10 individuals over a six-week period. Upon successful completion of the training component, individuals who enter the program will be placed into one of the following roles: **Transaction Processor; Analyst;** and C**ustomer Services Representative.**

> Classes will be held Monday to Friday from 9:00 A.M. to 4:00 P.M. (hours may be subject to change). Enrolment in the program is free and all participants will receive a weekly stipend while undergoing the training component.

To apply, please visit **www.cibc.com/careers** and submit your résumé to file: J0206-0480.

**NOTE:** Participation in the CIBC Career Access Program is voluntary. People with disabilities interested in CIBC employment are free to enter themselves directly into job competitions, through our website at www.cibc.com <http://www.cibc.com/>, without disclosing equity group affiliation. Applicants who do not have a disability are welcome to apply to CIBC jobs through our conventional recruitment process.

CIBC thanks all applicants for their interest, however; only those under consideration will be contacted. No agency solicitation will be considered. CIBC is committed to diversity in our workforce and equal access to opportunities based on merit and performance.

## Theatre Opportunity for People with Acquired Brain Injury

**Has your life been affected by a brain injury?**

- **Are you interested in theatre?**

This project is affiliated with University of Toronto and Toronto Rehab, and is approved by the Toronto Rehab Ethics Board. It is funded through a CIHR Strategic Research and Training Program and The Change Foundation. They are looking for participants to be involved in a workshop to develop a play.

**What is the workshop?**
A group of brain injury survivors, caregivers or friends of brain injury survivors, and health care providers are coming together to brainstorm ideas on creating a play on the topic of Traumatic Brain Injury (TBI). They would like to create and produce a play based on the discussions from the workshop.

**What would be required of you?**
You will be asked to share stories on brain injury. This could include experiences with doctors or nurses, types of equipment used, rehabilitation, re-joining your community after the injury, family members etc.

No experience with theatre or acting is necessary; just an interest in sharing experiences, in the arts, and in learning. There may be the chance to be involved in the development of the production itself in the future, although this is not required.

You will be invited to participate in one workshop scheduled in the month of March or April. You will be paid a small amount for your time.

For more information, please contact Project Co-ordinator Julia Gray for more information at 416-946-8575.

## Video Research: Employment Perspectives from the Disability Community

A video producer wants to talk to — and possibly interview — employers who hire people with disabilities, and people with disabilities who have been successfully accommodated at work. It sounds like an excellent opportunity for organizations to showcase their successful job accommodation procedures, and for people with disabilities to share their perspectives on the accommodation process.

This research and video production is being done on behalf of the Counselling Foundation of Canada (cfc.net). In a nutshell, the end goal is to produce videos that:

- inform people with disabilities on how to best find an approach employment opportunities;

- inform employers of the wealth of talent and abilities within the disabled community; and

- inform caregivers and support networks how to aid in facilitating this environment.

The researchers want to reach this goal by showing the success stories. Where it's worked and why it's worked and what are the essential elements by all involved. The project is based in Toronto but will entail participation from people across the country. They are looking for people who have gone through the hiring process but they are considering including people in existing jobs who have had to be accommodated due to recent or increased disabilities (or keeping up with new software technology) because it is generally felt that employers need to be reminded that this scenario evolving in their workplaces falls under the "not if but when" category.

The researchers are speaking with as many organizations as possible across Canada so they can best narrow their choices for involvement in the video. They are hoping to have a list of prospective candidates as soon as possible so they can move on to the next step in their production schedule. If you are interested in participating in this exciting project, contact Patricia Maitland at (416) 451-2135 or by email at pmaitland@sympatico.ca.

## COMMUNITY EVENTS

### Youth Programs – City of Toronto

Two programs are being offered this summer by Integration Services, Parks and Recreation, North District for youth between the ages of 15-21 with a disability. The Integrated Youth Leadership program will teach youth to develop independent skills, socialize, lead groups, challenge staff and impact children’s lives through recreation. The Youth Mentorship Program will teach youth to develop independent skills, work in partnership with staff, gain experience in the recreation field, and impact children's lives through recreation. For more information, call (416) 395-6183.

## Volunteers Needed for SexAbility Program

Do you have a disability? Would you like an opportunity to give back to the community and gain valuable experience?

**SexAbility** is recruiting volunteer peer facilitators.

Are you willing to:

- co-facilitate workshops on sexuality and disability?
- help organize events?
- help develop and design new workshops?
- devote at least 3 hours a month?

In return, you will:

- get intensive training on sexual and reproductive health as it relates to people with disabilities;
- build on your public speaking and workshop facilitation skills;
- meet new people; and
- learn more about the disability community.

To find out more information, contact Madeline Trapedo-Dworsky at (416) 486-8666, extension 267 or by email at madeleinet@ajhs.ca

## The Earl Bales Club

Earl Bales has a Friday evening (7-9pm) recreation club geared to adults (18+) with disabilities. Everyone is welcome. The club is located at Earl Bales Community Centre, 4169 Bathurst Street (at Sheppard). For more information, call (416) 395-6016. Upcoming events include:

- Cooking Night – May 5, 2006
- Craft Night – May 12, 2006
- Games Night – May 19, 2006
- Muffin Night – May 26, 2006
- Kareoke Night – June 2, 2006
- Special Outing – June 9, 2006

## Film Launch and Community Fair

Promote your services and reserve a table at this exciting event. Experience documentary short films and other artwork and film created by people with physical disabilities.

**Tuesday May 23, 2006**
**1:00 pm to 4:00 pm**
North Toronto Memorial Community Centre
200 Eglinton Avenue West
Toronto, Ontario

For more information or to RSVP call Gita Lakhanpal at (416) 486-8666, extension 266 before April 20, 2006. Please note that space is limited.

## WHEEL-TRANSportation Links

Traveling to Mississauga, Brampton, Vaughan, Markham, Richmond Hill or Ajax/Pickering? Wheel-Trans will help you get to the nearest transfer point. Transfer points are specifically chosen for customers because they offer protection from the elements, are clean and bright, have accessible washrooms, and generally have telephones for your use.

### Transferring Locations:

**Mississauga** – Queensway (Trillium) Hospital, 150 Sherway Drive

**Brampton** – International Plaza Hotel, 655 Dixon Road

**Vaughan, Markham, Richmond Hill:**
- Tim Hortons Donuts, 3310 Steeles Avenue West (west of Jane)
- Centre Point Mall, Pickle Barrel entrance, 6300 Yonge Street
- Shops at Steeles and 404, Food Basics, 2900 Steeles Avenue East
- Tim Hortons Donuts, 4228 Midland Avenue (Steeles and Midland)

**Ajax/Pickering –** McDonald’s (Port Union Road), 7431 Kingston Road (Hwy 2 and 401)

### GTA Accessible Transit Providers:

**YORK REGION TRANSIT – MOBILITY PLUS**
Registration: (905) 762-2112, Toll free: 1-866-744-1119

Hours of Service: Monday-Saturday 6:00 a.m. to 12 midnight; Sunday and Holiday 8:30 a.m. to 10:00 p.m.

**Fares**: $2.25, 10 tickets for $21.00
**Trip Booking**: (905) 762-2112, Monday to Friday 6:00 a.m. to 7:00 p.m.

**AJAX PICKERING TRANSIT AUTHORITY – SPECIALIZED SERVICE**
Registration: (905) 683-4114, Monday to Friday 6:30 a.m. to 6:30 p.m.
Hours of Service: Monday to Friday 6:00 a.m. to 4:00 p.m.; Saturday 9:00 a.m. to 4:00 p.m.; Sunday and Holiday 10:00 a.m. to 3:00 p.m.

**Fares: $2.00, discounts available for children, students and seniors**
Trip Booking: (905) 683-4114, Monday to Friday 9:00 a.m. to 3:00 p.m.
Saturday and Sunday trips must be booked by 3:00 p.m. on Thursday.

**REGION OF PEEL – TRANSHELP**
Registration: (905) 791-1015, press “2”
Hours of Service: Monday to Friday 6:30 a.m. to 11:30 p.m.; Sunday and Holiday 9:00 a.m. to 10:00 p.m.

**Fares**: $2.25, **new registrants must** prepay a minimum of $22.50 for 10 trips.
Trip Booking: (905) 791-1015, Monday to Friday 8:00 a.m. to 8:00 p.m.

**GO Transit**
Registration: No registration necessary
Hours of Service and Fares: Please contact GO Transit for service information at (416) 829-3200, long distance at 1-888-GET ON GO (438-6646); Weekdays: 5:00 a.m. to 12 midnight; Weekends/Holidays: 8:00 a.m. to 9:00 p.m.

Accessible Bus Terminals: Union, Finch and York Mills
Accessible Train Terminals: 38 of GO’s train stations are fully accessible

Call Wheel-Trans Customer Service at (416) 393-4111 to request assistance with planning your future trips to Mississauga, Brampton, Vaughan, Markham, Richmond Hill or Ajax/Pickering. Pick-up times from transfer points may not always run to schedule, so please allow for an addition 15 minutes.

## CILT NEWS

### Book Review

*by Susan DeLaurier*

## After Disability: A Guide to Getting on with Life by Lisa Bendall

The title of this book best describes what it is all about. Ms. Bendall's book is more than an excellent resource of where to get help. She is well aware of the frustrations and mental adjustment that disability imposes and she is able to address this and also offer practical solutions. An awareness of the basic commonalities of various disabilities makes this a book that has something to offer to everyone. At first glance, this book may seem to be only for people with disabilities, however, the information will be extremely useful for anyone who also cares for, lives with, or just knows a person with a disability.

The chapters of this book each deal with categories such as financial considerations, relationships, housing, etc. These are the things that nearly everyone has to deal with and this book offers advice and excellent resources throughout Canada. Besides a listing of resources for each topic, there is a description of the concerns that a person with a disability may have. If a person acquires a disability suddenly, he or she may not be aware of the types of help available or even what his or her needs will be. This is where this book shines by offering advice and solutions for a person to go forward in his or her life. All of the listed resources contain websites of the various organizations so a person can read over the information and decide if they can offer what the individual is looking for.

Some of the advice and tips are for seemingly small things, but can have a big effect. This might include simple things like putting pull rings on zippers and using straws for drinks. Not only is this practical, but it also promotes independence which in turn, increases a certain amount of satisfaction with life.

The many quotes from people with disabilities are excellent for seeing how others cope. There are many things that a non-disabled person might not be aware of, as was mentioned in a quote from Sandra Carpenter in Toronto. She has said that having a disability means that your salary just doesn't go as far as that of a non-disabled person. She is not speaking of the obvious, such as supplies specifically to accommodate a disability, but of the more subtle things such as having to shop only at stores that are nearby and accessible regardless if their prices are higher than elsewhere. This may directly influence where a person chooses to live.

One of the unique features of this book is the section about self-advocacy and the importance of asking for what you need. This begins with accepting your disability and the fact that in some respects you will have to find new ways of doing things. Ms. Bendall describes some of the feelings that a person may have before coming to acceptance. She is also very clear that acceptance does not, in any way, mean giving up. Once a person achieves that acceptance, he or she can go forward to get help to do whatever he or she wants.

This very highly recommended book can be ordered through www.amazon.ca

**Websites:**

www.neilsquire.ca

The Neil Squire Society is the only not-for-profit organization in Canada that for the past 20 years has used technology, knowledge and passion to empower Canadians with physical disabilities. Our work helps our clients remove obstacles and barriers so that they can live independent lives and become active members of our society.

Bill Cameron founded the Neil Squire Society in 1984, in memory of his relative Neil Squire. Over the years, the Society has developed innovative programs and services and some of the world's leading edge assistive technology for people with physical disabilities. More than 20,000 people with disabilities in Canada have benefited from the work of the Society.We have a staff of about fifty and offices in Vancouver, Regina, Ottawa, Fredericton, and Moncton.

Their dream is to lead Canada in creating an environment where every person with a physical disability has access to make the most of his/her abilities and contribute to society.

www.normemma.com

Norman Kunc and Emma Van der Klift have spent the last 20 years working to ensure that people with disabilities are able to take their rightful place in schools, workplaces, and communities. They also love sailing, Middle Eastern dance & drumming, blues, good food, and are keenly interested in how story, art, and literature can be used to evoke social change.

In 1990, Norman and Emma established Axis Consultation and Training Ltd., and since then have been kept quite busy providing in-service and training in the areas of inclusive education, employment equity, conflict resolution, and other disability rights issues. They travel extensively throughout North America and, more recently, the world working with school districts, human service agencies, employers and advocacy groups.

www.raggededgemagazine.com

Ragged Edge Online is the successor to the award-winning periodical, The Disability Rag, which became Ragged Edge magazine in 1997. Today, Ragged Edge is an exclusively online publication.

The Ragged Edge examines current and emerging public issues from a disability perspective: civil rights, politics, culture, humor, sexuality, art, technology. We publish freelance journalism, essays, poetry and fiction.

Nonfiction essays and articles should be between 750 and 1500 words and must focus on issues of interest to the disability rights movement. Analysis, criticism and journalism are acceptable approaches; they publish very few first-person accounts. We are not interested in inspirational accounts. Freelancers are urged to familiarize themselves with the subjects they cover and their style and approach by browsing their website at http://www.raggededgemagazine.com.

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| Roll away cot frame (without mattress) | $50.00 |
| Dark green Loveseat | $100 |

If interested, please call **(416) 915 1491**

Concord wheelchair lift in good working condition with custom-made all-weather cover. Bought for approximately $6,000 5 yrs ago. Will sell now for $1,000. OR BEST OFFER. Buyer must arrange to have it removed and transported ASAP. Please contact Kari at kkrogh@sympatico.ca or call **416 693-4684**.