

transition

BC COALITION OF PEOPLE WITH DISABILITIES

NOV./DEC. 1997



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Planning with Representation Agreements
AIDS and Aging
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transition

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Cover photo, by David Low,
of his grandmother

in this issue

Letters to the Editor	2
Editorial	
by Tina Matysiak	3

F e a t u r e s

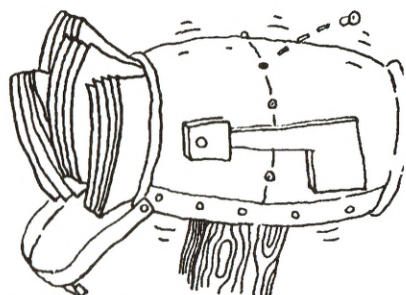
AIDS and Aging	
by Tom Mountford	5
Latimer Decision Shocks Community	
BCACL and BCCPD	7
Deaf Community Wins at Supreme Court	8
Action Needed to Protect Seniors	
by Scott Adams	9
Parents Launch Human Rights Action	
by Carol Walshe	11
Climbing the Mountain of Aging	
by Barbara Alldritt	17
Planning a Safe and Secure Future	20
Aging with a Spinal Cord Injury	
by Coleen Heenan	24
Planning with a Representation Agreement	26

N e w s & N o t i c e s

Travel Info	8
Changes to CPP	11
Government Backtracks on Education Cuts	13
Sunnyhill Health Centre for Children	14
International News	15
Inclusion Resource Network Closes	19
Board Members Retire	22
Job Placement Program	23
Classified Ad	28

Editorial Note: The views and opinions expressed within the pages of Transition are not necessarily those held by the total membership or Board of Directors of the B.C. Coalition of People with Disabilities. The material presented herein is meant to be thought-provoking and to promote dialogue. Transition is your opportunity to share information and to introduce issues which you feel should be brought to the attention of the disabled community and the general public. It is also an opportunity for disabled individuals to display creative talent.

November/December 1997



letters

Thanks to Massie

DEAR EDITOR:

In September 1997, Margo Massie stepped down from the BCCPD Board of Directors after eleven years of service. I would like to wish Margo well in her new life as she takes up residence in Victoria.

As a fellow advocate and past board member of the Coalition, I would also like to acknowledge some of the contributions that Margo made to the disability community. When she first joined the Board in February 1986, a BCCPD task force was touring the province to find out people's concerns regarding transportation. Two years later, during her first year as BCCPD president, a major goal became a reality when lift-equipped buses were introduced in Vancouver.

Margo was president of the BCCPD for seven years. Some of the achievements of the organization during this time include: implementa-

tion of Section 3.7 of the building code, initiation of the AIDS as a Disability project, the beginning of Advocacy Access, a program which grew from two employees to the current ten, the introduction of the Mental Health Empowerment project, and support for Sue Rodriguez during the very difficult controversy surrounding assisted suicide.

Most recently, Margo was a member of the advocate team that successfully lobbied for changes in legislation with respect to GAIN for Handicapped.

People know Margo as a warm, genuine person with a love of advocacy and a deep commitment to people with disabilities. She is highly respected within the disability community and, together with her many friends and colleagues, I would like to say "thank you." Thank you Margo, for your leadership and the countless volunteer hours that you dedicated to planning strategies, preparing briefs, lobbying, managing the business of the Board, working on committees and attending numerous meetings with individuals, community groups, non-profit society representatives, government officials and others.

Welcome to Vancouver Island and best of luck—wherever your future path may lead.

SINCERELY,
RONNIE PHIPPS
DUNCAN, BC

Latimer

DEAR EDITOR:

In considering the death of Robert Latimer's daughter, Tracy, people with disabilities seem to have lost sight of something that is outside of being disabled. Our fight for our rights in so many areas has been long and it is easy to be locked into a way of responding to Tracy's death, as though we were defending the rights of a disabled person. This blinds us to what we are really defending: the right of a severely suffering young person to be treated with the same compassion as anyone else, regardless of the fact that she is disabled.

I am familiar with the condition of being in constant, unendurable suffering. As a widow with two young children, I was largely bedridden for most of three years. Constant pain when one is a parent can be endured if one can still carry on. But unendurable pain and inability to function is something else. I realized I could not be a parent to my

(continued on page 28)

by Tina Matysiak

Disability

We've all heard the statistics about our aging population. According to Health Canada, by the year 2016, 16% of Canadians will be over 65. And, because we are living longer, more and more people will be joining the ranks of the "middle-old" (75-84) and the "old-old" (over 85) in the coming decades.

A statistic we don't hear as much about, though, is the increasing number of the "aging and disabled." That is, people with disabilities who are growing older and older people who are becoming disabled.

The National Coalition on Disability and Aging in the United States has estimated that approximately 85 million people in the U.S. will be aging with disabilities by the year 2000. This is more than the rise of a new "special interest" group; this is an issue which has relevance for all of us as we continue on our way to joining the ranks of the "old-old."

It is also a development that demands cooperative efforts between disability and aging organizations to ensure that the concerns of people aging with disabilities are addressed.

There are a number of issues that arise when

looking at aging with a disability. One of these is understanding how the aging process interacts with an existing disability. Some connections have been made. For example, research is showing that people who have Down's Syndrome are at higher risk for developing Alzheimer's disease and are more likely to develop symptoms at a younger age. Also, according to the American Association on Mental Retardation, people who have been taking some psychotropic or anti-seizure drugs for extended periods of time may be more likely to develop conditions, such as tardive dyskinesia or osteoporosis.

Overall, though, very little research exists which explores the relationship between aging and disabilities. Does the aging process aggravate particular conditions? Are people with certain conditions more liable to develop secondary disabilities as they age? This gap was highlighted for me while I was searching the World Wide Web to research this article. I came across a web page titled "Cerebral Palsy and Aging" (<http://www.geocities.com/Tokyo/7970/cpage.htm>) and, instead of the medical and social information I was

(continued on next page)

(Editorial, cont'd from previous page)

expecting, there was a plea from the page owner for more information so that he could post it and share with others. Obviously, there is a need for more information and it needs to come quickly for those approaching middle and old age.

On the other hand, there is much more information available about how people can become disabled as they age. Considerable

Overall, very little research exists which explores the relationship between aging and disabilities.

research exists explaining how vision and hearing changes, arthritis, osteoporosis, heart disease, stroke, etc. can cause impairments among older people. However, since these impairments are associated with aging, they often are dismissed as simply "part of getting old" and not considered distinct disabilities. As a result, older people may not receive the same acceptance and support for their conditions as younger people with similar impair-

ments do. They also may be discouraged from using services and assistive technologies that could help them maintain their independence and autonomy because many are geared more to the needs of younger people. We also have to be aware that, as life expectancy increases, so does the length of time older people will spend living with these disabilities. This makes the promotion of more appropriate and supportive attitudes and services even more critical.

There are many other issues which need to be considered. If more people are aging with disabilities and are living longer, the need for more accessible (and affordable) housing and transportation becomes even a higher priority.

Income support is also important for people with disabilities as they age. Some people with disabilities have spent little or no time in the paid work force and, as a result, have no employment pensions to draw on when they become seniors. Another problem is personal care/support for people as they age. There is a long-standing myth that families have abandoned

their oldest members. In fact, according to research done for Health Canada, 80-90% of "dependent" seniors are cared for by their families, generally spouses and daughters. If supporting people to live in the community and in their own homes remains a priority, more effective ways to assist and support their caregivers need to be found. This is especially true when the caregivers themselves are elderly and disabled.

This is just a brief overview of some of the issues, but I hope that it begins to bring the common ground between people with disabilities and older people into clearer focus. Issues particular to each group should continue to be addressed separately, but it can only strengthen our collective voice to work together whenever possible. In doing so, we can help ensure that everyone can enjoy an old age characterized by dignity, autonomy and respect.

Tina Matysiak is a residential supervisor with a local Community Living Society and is also a graduate student in social work at the University of British Columbia. ≈



AIDS & Aging

by Tom Mountford

There are many different issues to look at when we consider AIDS and aging. Very little information exists relating directly to the more than 10% of people with HIV infection who are over 50 years of age. Also, the progression from initial infection with HIV to full-blown AIDS is a unique aging experience. Along with the successes of the new combination drug therapies, comes the problems associated with a growing elderly population disabled by AIDS.

For example, the behavioral risks of the elderly have not been dealt with adequately. A study was done by scientists at the University of California, San Francisco and supported by the National Institute on Aging and the National Institute of Mental Health. It found that older, at-risk heterosexual individuals are one-sixth as likely to use condoms during sex and one-fifth as likely to have been tested for HIV when compared with a group of people in their 20's who take the same risks. The most prevalent types of behavioral risks reported in

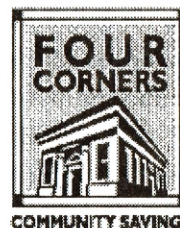
this age group were having multiple sexual partners, having a partner with a known behavioral risk or having a blood transfusion before the mid 1980's. Growing evidence exists that many individuals are sexually active well into their 80's and that they seldom use condoms (DeHertough, 1994). However, our ageist society refuses to believe that older people are sexually active.

It was reported in the New York Times (July 31/97) that the cases of HIV infection in women over 60 have nearly tripled in the last ten years. The immune systems of these women have slowed down and they often do not see themselves at risk. A decade ago, the majority of infections in women were the result of tainted blood transfusions, while 69% can now be attributed to heterosexual contact. Since women are often not diagnosed, or are misdiagnosed, the statistics available do not reflect the extent of the increasing problem. A surprising 13 of 257 persons (5%) 60-years or older who died in a major New York hospital were

found to be undiagnosed HIV positive at the time of their death (El-Sadr & Gettler, 1995).

Older HIV-infected individuals deteriorate more rapidly than younger patients due to an accelerated loss of CD4 helper T-cells. Scientists from Geron Corporation and the UCLA

(continued on next page)



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We'd like to thank the following people for helping out at our casino fundraising this year. This is a big commitment of volunteer time and their support is much appreciated.

Mark Rogen

Steve Wong

Brian Thomas

Mary Ayles

May Ng

Freda MacLellan

Carol Dixon

Linda Neumann

Tom McGregor

(AIDS and Aging, cont'd from previous page)

School of Medicine examined the immune cells of patients with late-stage HIV. They found that these cells had apparently aged to a level similar to those of a normal 100-year-old person. It appears that the immune system is working overtime during many years of fighting the virus, resulting in the premature aging of certain immune cells. Immune cell senescence or aging is a newly described feature of HIV disease. It has previously been implicated in atherosclerosis, an age-related cardiovascular disease, and may have implications for therapeutic intervention in AIDS.

As baby-boomers increase the numbers of those over 50, the care and support of those surviving with HIV disease will be challenging health-providers and support organizations. The support systems of older people with AIDS may not include those who are able to provide the complex and intense care they need. Our elders are often a silent population and need advocates. They must not be forgotten or excluded from testing, education and services. Research is needed to learn better ways to reduce their risk of infection and provide health care that meets their needs. ~

Have a Disability? Need More Money? Disability Benefits from BC Benefits, Ministry of Human Resources: How to apply



Alternate formats



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The audiotape version is also available on loan from:

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Vancouver, BC
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Fax: (604) 822-6113**

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Latimer Decision Shocks Community

Joint statement from
BCACL & BCCPD



The BC Association for Community Living (BCACL) and the BC Coalition of People with Disabilities (BCCPD) are greatly concerned that the use of a constitutional exemption to reduce Robert Latimer's sentence to two years less a day has put the citizenship rights of Canadians with disabilities into serious question.

The unprecedented leniency given Mr. Latimer has signaled that we have taken a giant step toward creating two standards in law—one for Canadians who are deemed to be able-bodied and competent, and another for people with disabilities. Mr. Latimer's original charge of first degree murder had already been reduced to second degree murder, despite the fact that he intentionally murdered his 12-year-old daughter Tracy.

We believe that the extraordinary accommodation now given Mr. Latimer has virtually eclipsed the rights of his daughter and has put the very lives of

many children and adults living with disabilities at risk.

What does this sentence tell people with disabilities about the value of their lives? What does it say about the vulnerability many people with disabilities now face should an individual, charged with responsibility for their care, decide to end their lives?

Tracy Latimer was not dying of her condition, and there is no evidence that she wanted to die. Whatever motivated Mr. Latimer to take it upon himself to kill his daughter, it is critical that society does not allow someone's perceived pain or suffering to become legitimate grounds for murder.

Many of the assumptions about Tracy's quality of life reflect society's limited understanding about people with disabilities generally and the mythology that surrounds them.

Not only did Tracy lose her citizenship rights, but we fear her murder will be used as a lever to erode the rights of others. ≈

Comments from the Council of Canadians with Disabilities

"The victim's disability did not confer upon her father the right to end her life, nor should it now confer upon the court the right to reduce the mandatory sentence called for by the conviction." Eric Norman, Chairperson, CCD

"In reducing the sentence, the court is clearly saying that it has sympathy for the convicted murderer, and to a chilling degree is validating similar actions against people with disabilities. It is also lending support to the notion that the killing of a person with a disability is different from the killing of any other person." Hugh Scher, Chairperson, CCD Human Rights Committee

Travel Info

The Fall 1997 edition of *We're Accessible: News for Wheelchair Travellers* is full of travel tips and tales. Stories are included from wheelchair users who travelled to South America, Austria and the no-less-challenging Ottawa. There are also miscellaneous tips and a guide to travel information for people with disabilities on the Internet.

For more information, contact Lynn Atkinson, 32 - 1675 Cypress Street, Vancouver, BC V6J 3L4, tel/fax (604) 731-2197, E-mail lynn@istar.ca



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Deaf Community Wins at Supreme Court

In a historic and unanimous decision, the Supreme Court of Canada has ruled that BC's medical services must include sign language interpretation for Deaf persons. The Court decided that the refusal to fund this service discriminated against Deaf persons on the basis of disability. The Women's Legal Education and Action Fund (LEAF) and its coalition partner, DAWN Canada: DisAbled Women's Network Canada, intervened in this case in April of this year to address the effect of the exclusion of sign language interpretation on Deaf persons.

BC's courts decided that there was no discrimination because sign language interpretation is not itself a health care service. In a stunning reversal, the Supreme Court ruled that a cornerstone for effective medical services is the ability to communicate with one's doctor. Communication cannot be separated from health care. Therefore, to the extent that they cannot communicate with their doctors, Deaf persons receive substandard health care solely because of their disability. Such differential treatment of Deaf persons is

prohibited by the *Canadian Charter of Rights and Freedoms*.

The law in question did not specifically target Deaf persons for discrimination; it simply did not mention them. The Supreme Court reiterated its earlier rulings that discrimination need not be intentional, but can also arise as a result of "adverse effects." The Supreme Court also acknowledged that people with disabilities will often be negatively affected by legislation that appears neutral.

The Supreme Court also clarified when non-governmental organizations must conform to the *Charter*. Ordinarily, the *Charter* only applies to provincial and federal governments. BC had argued that because hospitals—not the government—provide health services, the *Charter* could not apply. The Supreme Court dismissed this argument and ruled that whenever anybody carries out a government objective, for which it is funded by the government, that body must conform to the *Charter* just as the government must.

(From *Women's Legal Education and Action Fund (LEAF)* ≈

Action Needed to Protect Seniors

by Scott Adams

The Representation Agreement Act, the Health Care and Care Facility Admission Act, the Adult Guardianship Act and the Public Guardian and Trustee Act are all 100% unconstitutional. All four Acts begin by giving "the adult" more or less complete authority concerning his or her affairs, rights and health care.

However, they end by saying, in effect, that the Office of the Public Guardian and Trustee (OPGT) can under certain circumstances override an adult's request or decisions. The way it is explained, this sounds reasonable. But in practice, these four acts and the existing Patients Property Act allow and condone the arbitrary confinement and extortion of our elderly citizens—and some who are not so elderly. Many of those who are confined have absolutely nothing wrong with them except a hearing problem or some other minor disability which

makes them appear incapable to the casual observer.

My experience is that with age comes wisdom. Some of the things younger people say, think and do seems to prove the point.

The Charter and Constitution make it clear that the Patients Property Act is unconstitutional. Our courts should not have the right to take away anyone's rights on the opinion of any

two doctors or psychiatrists. Every Canadian must have the right to refuse medication or treatment and to leave a hospital or other institution at any time.

I believe that the Action Plan for Representation Agreements from the Community Coalition for the Implementation of Adult Guardianship is the best way to go. However, if the
(continued on next page)



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<http://www.cta-otc.gc.ca>)

Canada

(Seniors, cont'd from previous page)

existing Patients Property Act is not overruled, and specifically, if our courts retain the authority to take our rights away as they are now doing, even a Representation Agreement will be of little or no help to most of us.

We should not think that the conventional legal process will be of any help; our government and courts are not going to convict or discipline themselves. Our courts do award certain individuals justice from time to time, but only to those with media attention or those who have strong

friends or relatives, good lawyers, and money. But for the vast majority, the whole appeal process is a sham.

So, I am tentatively suggesting that we hold peaceful rallies on a regular basis, perhaps on the first Saturday of each month. Also, we need a campaign of letter-writing, phone calls, faxes and e-mails. Hopefully, the daily newspapers and talk shows will also join in and oblige our politicians and courts to act on behalf of our elderly citizens.

I'd also like to clarify a paragraph in my article that was published in the June/

July /97 edition of *Transition*. A sentence in paragraph one, page 12 states that, "...our Charter, Constitution, and the Patient's Property Act allow the arbitrary confinement of our elderly citizens." With the exception of Section 33, the "notwithstanding" section, our Charter and Constitution are excellent.

If you would like to help, meet with me or get more information, please write to me at:

Habitat Canada
Box #538 - 1027 Davie St.,
Vancouver, BC
V6E 4L2. ≈

A list of actual English subtitles used in films made in Hong Kong:



- I am damned unsatisfied to be killed in this way.
- Fatty, you with your thick face have hurt my instep.
- Same old rules: no eyes, no groin.
- A normal person wouldn't steal pituitaries.
- Damn, I'll burn you into a BBQ chicken!
- Who gave you the nerve to get killed here?
- You always use violence. I should've ordered glutinous rice chicken.
- I'll fire aimlessly if you don't come out!
- You daring lousy guy.
- Beat him out of recognizable shape!
- I have been scared s_____tless too much lately.
- I got knife scars more than the number of your leg's hair!
- Beware! Your bones are going to be disconnected.
- The bullets inside are very hot. Why do I feel so cold?
- How can you use my intestines as a gift?

(From The Sun, Saturday, Oct. 18/97).

As you may be aware, the federal government is making various changes to the Canada Pension Plan as a whole. One of the most important changes is around the eligibility criteria for Canada Pension Plan Disability Benefits (CPP Disability).

The amount of CPP Disability Benefits a person receives is entirely dependent on how many years she or he has worked and contributed to the plan. Currently, the period of time that an applicant must have worked and contributed to the Plan is two out of the



Changes to CPP What You Need to Know

last three years or five out of the last ten years.

As of January 1, 1998 the period of time that a person must have worked and contributed to CPP will be four out of the last six years. This could mean a number of people who are

currently eligible for CPP Disability Benefits will not be entitled to benefits.

This new legislation will only effect the amount of contributions and the period of time in which the contributions were made. It does not change the disability criteria. At this point, we understand that there will be no changes to the legislation around incapacity and late applications.

If you are in this category, and have any questions, please contact Cindy Marshall or Ted Hobbs at the BCCPD's Advocacy Access Program. ≈

Parents Launch Human Rights Action

by Carol Walshe, Citizen Staff Reporter

The parents of a Lake Cowichan girl with a medical condition that requires catheterization have launched a human rights complaint against School District 79.

Kevin and Fiona Lawrence maintain their daughter's rights have been violated by the school district and allege bureaucratic procedures have taken precedence over her health.

Six year old Kristi Lawrence was born with spina

bifida, and requires catheterization three times daily. The process involves inserting a sterile tube into the urethra to allow her to relieve herself.

The aid Kristi became comfortable with in Kindergarten is certified to catheterize her. Her parents wrote to Dr. Ed Armstrong of SD 79 in June, outlining Kristi's medical condition and asking that the aid she was comfortable with continue to care for her. They

received no reply to the letter.

Kevin Lawrence says he and his wife had no idea how the school district's hiring processes worked, and assumed that the nature of Kristi's case would guarantee special consideration.

A district wide "cattle call" at which teacher's aides and assistants are given an opportunity to choose assignments with
(continued on next page)

(Parents, cont'd from previous page)

particular students resulted in an aide with more seniority from the former District 65 being assigned to Kristi.

The new aide, a former nurse, is fully qualified to catheterize Kristi. Described by her parents as a sensitive child unwilling to allow a relative stranger to catheterize her, Kristi has steadfastly refused to allow the new aid to perform the catheterization....

"Kristi has been severely traumatized by years of poking and prodding," said Fiona Lawrence. "It's unrealistic to expect her to allow just anyone to perform

something as personal as a catheterization on her."

Armstrong and Alastair Ferguson, special services district principal, acknowledge the role played by amalgamation in the bumping of Kristi's aide. Both agree that if the job selection process had been done according to the old school district boundaries, the aide Kristi had in Kindergarten

infection and be in hospital getting IV antibiotics for ten days."...

Armstrong says the school district has some discretionary powers, but is ultimately bound by hiring practices dictated by the collective agreement with CUPE.

"The situation is akin to that found in a hospital," he said. "In a hospital, you have no choice about which nurse cares for you."

Ferguson says he understands the concerns of the family, but sees no way around the terms of the collective agreement. "I don't have the answer to this," he said....

Kevin and Fiona Lawrence expect the human rights suit could take up to 18 months to be settled.

"We don't have that kind of time. Kristi's progress has already been set back a year. She was getting to the point where she was beginning to feel comfortable about herself, and learning to catheterize herself, but now that's all been set back."

The family is investigating further action against the school district.

(From the Duncan Citizen, Sunday, Nov. 9/97). ≈

Kevin and Fiona Lawrence maintain their daughter's rights have been violated by the school district and allege bureaucratic procedures have taken precedence over her health.

would likely have stayed assigned to her....

Kevin and Fiona Lawrence say the bureaucratic aspects of the case don't interest them. They say their primary concern is for the health of their child.

"Seniority and the collective bargaining process are endangering our child," said Kevin Lawrence. "If she is not catheterized regularly, she could develop a bladder

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Government Backtracks on Education Cuts

The provincial government had planned funding cut-backs for people with disabilities seeking post-secondary education. Lobbying by BCCPD and others resulted in a reversal of the decision. The following is from a letter sent to Tom McGregor at BCCPD from the office of David Mitchell, Manager of Vocational Rehabilitation Services.

I am writing to thank you and your organization for your valued input into proposed changes to Vocational Rehabilitation Services (VRS) operational policy over the recent past months, and to advise you that, although we will not be introducing any changes to VRS policy at this time, we are continuing to explore opportunities to expand community-based services and through these, address the growing demand for services.

Over the past few weeks, the Honourable Paul Ramsey, Minister of Educa-

tion, Skills and Training, has been actively lobbying the federal government on the issue of post-secondary student debt. As a result of these discussions, the Ministry has decided to put on hold any changes to VRS policy that would require students with a disability to seek Student Financial Aid funding for post-secondary education. This decision may be reviewed after the federal government has had an opportunity to respond to the many calls for greater post-secondary student funding assistance.

VRS is committed to assisting people with disabilities to access the goods and services necessary for education, skills training and employment. Our goal is to provide services to more people next year than we have this year. In order to accomplish this, we will need your help. It is our intention to expand our current partnerships with agencies and contractors,

and to develop new services for people with disabilities as much as our current budget and program allow.

We recognize there will be some challenges as VRS seeks ways to improve its service delivery system.

(continued on next page)

Mothers In Transition Support Group

Mothers who have lost custody of their offspring due to mental illness can meet other Moms of like mind and situation for coffee meetings.

We share experiences and interests and create friendships. We hope together to lessen the burden of living without our offspring.

We meet one-to-one with Dawn and as a group.

For more information, call Dawn at 871-0151.

(Government, cont'd from previous page)

Some of the steps that VRS will be taking over the coming months include:

- Development of new VRS and Student Services Branch program brochures that will provide people with a disability and service providers with up-to-date information on what is available through these two funding sources.
- VRS and its Community Partners will work with Special Needs Coordinators in Colleges to ensure that students have support to secure funding and other assistance needed to participate in post-secondary education.
- The Ministry of Education, Skills and Training will be conducting a formative evaluation of VRS to determine the effectiveness of our delivery model and to recommend changes to improve the level and quality of service being provided.

Thank you for your continued support. ≈



**HEALTH CENTRE
FOR CHILDREN**

The Sexual Health Resource Network (SHRN)

is a provincial service which includes:

- Directory of Service Providers
- Training and Education
- Resource and Information Library

The main goals of the SHRN are:

- to increase the understanding of healthy sexual development among children and young people with disabilities, and
- to ensure those who have experienced sexual abuse will have access to information about available services.

You can reach the SHRN by:

Mail:

Sunny Hill Health Centre for Children
Sexual Health Resource Network
3644 Slocan Street, Vancouver, BC
V5M 3E8

Phone:

1-800-331-1533 (toll-free across Canada)
1 (604) 434-1331 ext. 335 (General Information)

Fax:

1 (604) 431-7395

E-mail:

mharber@sunnyhill.bc.ca

There are about 140 million disabled children in the world.

97% of disabled children in poor countries have no rehabilitation.

98% are without education.

90% of disabled children will not survive beyond the age of five.

This horrible list of statistics about disabled children opened the Thematic Day of the United Nations Committee on the Rights of the Child on October 6.

The members of the Committee on the Rights of the Child looked at the right of disabled children to life, development, inclusion and self-representation.

There were two of us who had been disabled children; there were parents of disabled children, and, for the first time ever at such a meeting, there were two young girls from South Africa who spoke about their own experiences.

Pearl, deafened by rioting in Soweto, spoke of her loneliness and isolation from her hearing friends. Chantal told how she and her family had had to move from their home to the city



Report on the Committee on the Rights of the Child: Disabled Children

so that she could get medical support, crutches and an education.

They had both experienced the stigma that is attached to disabled children and their families. They had experienced the poverty and difficulties in just trying to lead an ordinary life.

Family members spoke with passion about the stigma and fear which give society the excuse to support eugenic laws of abortion and sterilisation.

We all spoke about the huge numbers of disabled children who are abused and abandoned, whose rights to life and inclusion

are violated on a massive scale.

The Committee set up a working group which will include representatives of international disability organizations. The Committee will monitor what countries are doing for disabled children when they do their regular work of looking at member states' reports on their implementation of the Convention on the Rights of the Child.

They stressed that all articles of the Convention impact on disabled children and must be monitored accordingly. They have issued a statement which says that the violation of the right to life was the worst discrimination and abuse faced by anyone. Their statement calls for governmental and legal action. But above all they called for an end to the stigma and a celebration of diversity.

It is up to all of us to ensure that our governments take action and that disabled children take their rightful place within their families and their communities.

(From Disability Awareness in Action, November 1997, by Rachel Hurst). ≈

YOUR MEMBERSHIP IS VALUABLE

The B.C. Coalition of People with Disabilities is a province-wide, non-profit organization run by and for people with disabilities. We are an umbrella group representing all people with disabilities and our strength comes from membership support.

Will you join the Coalition today and help build the voice for people with disabilities?

As soon as you begin your membership, you'll enjoy a number of benefits:

- an organization that can lobby the government on behalf of people with disabilities—too many

helping agencies depend on government funding and fear funding cuts. They need an independent advocate like the Coalition to lobby for their interests.

- policy research and development on areas of concern to you.
- membership voting rights, if you are a person with a disability.

If you would like more information on BCCPD, please feel free to contact the office at the address below, or call (604) 875-0188.



Membership Acceptance Form

I accept your invitation to join the BC Coalition of People with Disabilities.

**Membership Fee (groups and individuals)
\$10**

- ☐ New Membership *or*
☐ Renewal?

All memberships are renewable annually from the date of application.

☐ Voting Member *or*
(self-help groups where at least 51% of members have disabilities or a person with a disability)

☐ Non-Voting Member
(all other groups and able-bodied members)

Voting and Non-Voting Members: All individuals and groups are welcome to become members of BCCPD. However, voting rights are limited to people who have a disability and groups composed of a majority of people with disabilities (i.e. Self-help groups).

Name _____

Address _____

City _____ **Postal Code** _____ **Phone** _____



Please return your cheque or money order, with this form, to
BCCPD, 204-456 W. Broadway, Vancouver, BC V5Y 1R3.
We thank you for your support.



Illustration by Maria George

I always thought that life after 50 would be meaningful and productive. I'd travel, write stories inspired by my life's experience and devote more time to good causes. In the meantime, however, I had a list of goals to achieve in my career, education, fitness and wilderness adventures. One of these goals was climbing Mount Kilimanjaro.

Then three years ago, at 41, I was diagnosed with multiple sclerosis. It was said to be chronic progressive MS which has no "cure", only drug therapy for acute symptoms. In other words, I was told the odds were that my health and functional ability would continue to decline, although I should still have a near-normal life expectancy.

Assimilating this information, and my creeping functional losses, forced me to come to terms with my own mortality and the knowledge that my body was aging much faster than normally expected (one naturopathic doctor told me my biological age was 65).

I realized that if I maintained my achievement-oriented mindset, and accepted my prognosis as presented, I would have to use my declining energy to "fast track" those goals still within my abilities. Alternatively, I could put my list aside and simply try to live well each day, looking outside of the conventional medical system for therapeutic approaches that would restore my shattered sense of hope and control in my life. I chose the latter course.

My choice was influenced initially by my sociological education which had taught me that the determinants of health have more to do with lifestyle choices and social factors than with the offerings of the dominant "drugs-and-surgery" oriented medical care system.

Statistically, access to our "high tech" medical care system explains only 12 to 25% of the collective health status of Canadians. Another 12% can be explained

by genetics (for people with MS this figure is 25%). The remainder, however, is related to environmental factors, such as air and water quality, to lifestyle choices such as diet and exercise, and to social factors, such as whether one has an adequate income, a sense of purpose and a supportive network of family and friends.

These factors resonated with memories of my mother who was a lifelong devotee of what is now known as "alternative" or "complementary" medicine. She was a
(continued on next page)

(Mountain, cont'd from previous page)

traditional healer who understood the healing powers of foods, herbs, hot baths and vinegar packs, as well as the power of love and prayer. Her wisdom and skills were often the first option for many with aches and pains in the small Mennonite farming community where I grew up.

My mother insisted I take a tablespoon of cod liver oil and a handful of vitamin and mineral rich kelp and malt tablets every day no matter how foul they tasted to me. Science is now proving that daily supplementation with a vitamin and mineral tablet boosts the immune system, and that a deficiency of the omega 3 essential fatty acids, abundantly present in ocean fish (including the infamous cod liver oil) and flax seeds are a factor in many debilitating chronic illnesses including MS.

My mother insisted that helping her plant, nurture and harvest our five acre garden (which also provided an abundance of organic vegetables) was good for both of us. Science is continuously validating the fact that regular exercise is not

only essential to recovery from injury and chronic illness, it is one of the best anti-aging strategies as well—and that it is never too late to start. Getting regular exercise for strength, flexibility and aerobic capacity is more challenging with a

Many scientific studies are now demonstrating the health restoring effects of stress reduction, meditation, support groups, creative visualization, spiritual beliefs and simply having faith in one's health care team and therapies.

disability, but not impossible, as I am learning.

My mother believed in the redemptive powers of the practice of hope, love and prayer. Many scientific studies are now demonstrating the health restoring effects of stress reduction, meditation, support groups, creative visualization, spiritual beliefs and simply having faith in one's health care team and therapies.

We need to redefine health care to include all these elements: therapeutic choices that put the individual, not the expert, in control; a clean environment; a secure and adequate income; and, a society structured to value its members and provide a sense of connection and purpose.

I hope to see the day when my neighbourhood health clinic will provide nutritional balancing, therapeutic touch, massage, energy balancing, yoga classes, and psychological and spiritual counselling, along with antibiotics and wound stitching. Right now, this is just a pipe dream, but at one time, so was universal access to hospitalization and medical care. Collective action changed that.

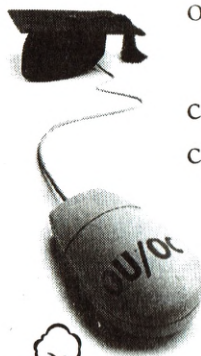
I don't know what the future holds, but I still plan to climb Mt. Kilimanjaro one day. My mother always said that luck favours prepared ground, so it's up to me to use the power of my own thoughts and actions to redirect my health. She also said that every problem has a solution. And if my own

legs won't carry me up Mount Kilimanjaro, there is always the option of hiring porters to do the job for me. In any event, that's where I plan to be for my fiftieth birthday on March 1, 2003.

Whatever my future holds as I approach my second half-century, I believe the lessons of my disability have given me the grace to accept the inevitable aging of my body earlier than many. It has also taught me that I am in control of making that process as painless and fulfilling as possible. ≈

Learning that fits your lifestyle

The Open University and Open College's Disability Services Office can help students with disabilities earn a fully accredited education. Study on your time, at your own home, and at your own pace.




SERVICES OF THE
OPEN LEARNING AGENCY

Course options range from high school completion and adult basic education courses to college and university courses.

For more information,
call 431-3238 in the Lower
Mainland, TTY 431-3360,
or 1-800-663-1663 in BC.
E-mail: dsoserv@ola.bc.ca



Network Closes

The Inclusion Resource Network (IRN) is no longer available for consultative services for educators and parents of children with special needs. After three years of operation, the BC Ministry of Education has decided not to continue funding this service.

However, the BC Teachers' Federation will continue to update the IRN Homepage which includes the opportunity to browse the IRN database. Watch for the Elementary Modified and Adapted Materials database to also be online. After October 1997, the IRN database will not be updated.

Some of the materials that were distributed through the IRN will be available for purchase through the BCTF Lesson Aids Service. See their online catalogue through the BCTF's Web site (www.bctf.bc.ca).

Planning a Safe and Secure Future



Many people haven't heard of the Planned Lifetime Advocacy Network (PLAN). We're often asked, "Who is PLAN?" and "What do you do?" Maybe the best way to answer these questions is to tell a story. Consider the story of John.

John was a healthy and active boy living in the lower mainland of B.C. In addition to the many interests young boys have, John was a mountain bike enthusiast. John rode his bike everywhere. No hole was deep enough, no curb high enough.

One day during John's 12th year, he collided with a transport truck. John sustained severe head and spinal cord injuries. John's injuries were so severe he spent the rest of his adolescence in Sunny Hill Hospital. He was unable to speak or move any part of his body, except his mouth, and was completely dependent on others for all of his care. His family, overwhelmed by the loss of their healthy son, and their inability to communicate with him, eventually stopped visiting. John

became increasingly lonely and isolated.

Fortunately, a visitor to the hospital noticed John and told PLAN about him. Members of PLAN met with John and, shortly thereafter, PLAN "adopted" John. We developed a circle of caring and committed individuals, enrolled John in school again, and eventually moved him back into the community. PLAN has made a lifetime commitment to John—to advocate for him, to monitor his quality of life, and to maintain his circle of support.

John is now 26 years old. He enjoys laughing, joking, loud music and watching sports, especially hockey. His great gift is a winning smile and his ability to draw people into a relationship with him. With PLAN's help, John has affected many people and in return many people have affected him. This is one example of what PLAN does.

PLAN works with families who have a relative with a disability. The group was formed in 1989 by a group of senior parents of adult

children with disabilities. These parents recognized that the closure of institutions and the re-introduction of individuals with disabilities back into community meant many parents were the primary supports for their adult children with a disability. These parents also acknowledged their own aging and realized they would need a plan to ensure

Most importantly, we develop and maintain circles of support which surround the individual with a disability with caring and supportive people.

a safe and secure future for their son or daughter with a disability when they were no longer around to care for and advocate for them.

These parents also shared a common desire—to establish a system of support independent of government whereby the care provided to their sons and daughters would not depend upon the goodwill of politi-

cians. They also believed service providers need to be regularly monitored and held accountable, and that those attempting to hold government accountable could not themselves become reliant upon government for their own financial survival. As a result, the founding members of PLAN resolved to provide services for adults with disabilities without the financial support of the government.

PLAN is unique in other ways too. We are the only organization which plans for the future. PLAN designs and offers services to provide a safe and secure future for individuals with a disability. We advise families on will and estate planning, assist in identifying and securing housing options, including home ownership for an individual with a disability. Most importantly, we develop and maintain circles of support which surround the individual with a disability with caring and supportive people. PLAN monitors the quality of services provided to an individual with a disability

and advocates on his or her behalf when necessary. And we will provide these services for the life of the individual with a disability. This is just what those senior parents wanted when they first met in 1989.

PLAN has grown over the years. We now provide advice and assistance to over 3,200 families across Canada. We have 450 PLAN associates and maintain circles of support for 42 individuals. And these numbers are growing daily. If you are aware of a family who might benefit from PLAN's expertise and services, give them our phone number.

You may also consider purchasing a copy of our book, *Safe and Secure*. The book outlines six steps relatives should consider, as well as seven worksheets and an appendix of resources for securing the future of an individual with a disability.

For more information, contact PLAN at 101B - 3790 Canada Way, Burnaby, BC V5G 1G4 or phone (604) 439-9566. ≈

Board Members Retire at AGM

At our AGM this year, two long-time BCCPD Board Members resigned. Margo Massie and John Maddison have both been with the BCCPD for so long, during so many important times, they will be greatly missed.

In the fall of 1979, John Maddison was introduced to the BCCPD through his work with Jill Weiss on transportation issues. This work led to the creation of the handyDART custom transit service. During his many years as a Board Member, John has held various positions on the Executive Committee. He was also a member of the Human Rights Committee of the Coalition of Provincial Organizations of

the Handicapped, now known as CCD.

John will continue his work on transportation issues as Chair of COMPACT, the Committee to Promote Accessible Conventional Transit, and as a Board Member of Pacific Transit Cooperative.

John's wisdom and clarity of thought—and that distinctive voice—will be missed by all of us.

Ronnie Phipps' Letter to the Editor in this edition is a very fitting tribute to our other retiring Board Member, Margo Massie. Margo has filled numerous roles at BCCPD over the years, and has been a tireless and dedicated voice for people with

disabilities on many issues. BCCPD was honoured to have her as Chair for many years and, through her work and sincerity, Margo became a respected figure both within the disability community and government.

Perhaps most of all, we all remember Margo's warmth and humour, and wish her all the best in her well-deserved retirement. We know that Margo will continue to be involved in the community in her new home on the island.

The BCCPD Board of Directors would like to thank John and Margo for the years of support they've given us and the disability communities.



Mission Statement

The BC Coalition of People with Disabilities was founded upon the belief that:

- people with disabilities want and are entitled to equal opportunities in all the activities and privileges that other Canadians take for granted,
- full inclusion of people with disabilities within our communities is a fundamental necessity for a diverse, productive and economically vibrant social environment, and
- people with disabilities have the right to expect equality, fair treatment and respect.

Because of these beliefs, the purposes of the BC Coalition of People with Disabilities are:

- to use education, advocacy and special projects to work toward the dissolution of the physical, attitudinal and systemic barriers in our society that deny us equal opportunities,
- to provide a strong coherent voice for the cross-disability communities in B.C.,
- to share information with and support other self-help disability organizations with common goals, and
- to carry out our mission and projects within a self-help model.



JOB PLACEMENT PROGRAM

Are you looking for work? Do you have any type of disability?

Our program has been developed to assist you in securing quality employment or reaching other vocational goals, such as further education.

We provide funding for education and transportation.

WHO QUALIFIES?

- Anyone who has a barrier to employment such as a disability.
- You must live in the New Westminster or Burnaby Area.

WHAT ARE THE BENEFITS?

- Professional Resume and Career Counselling
- We find your next employer.
- Funding for education.
- Funding for transportation.
- Funding for a special modification to the worksite you may need to do your new job.
- All services are free!

WHERE?

BC Rehabilitation and Recovery Centre
#208 - 88 10th Street
New Westminster, BC V3M 6H8
Tel: 520-3468 Fax: 520-6240

Aging with a SPINAL CORD INJURY

by Coleen Heenan, MS, RN

Aging with a spinal cord injury (SCI) is a relatively new occurrence. Due to highly technical and developed health care, a person with a SCI is not only expected to survive the early years, but is in the unique position of having to cope with growing older. For the first time, this population is experiencing aging-related concerns. Now that people are not dying from medical problems related to their disability (renal problems and pressure areas), they are experiencing problems related to normal aging, as well as problems related to aging with a disability.

Aging is not necessarily a medical problem or a sickness that needs to be treated. It is a new stage in life and with this new stage comes changes in physical function and changes in people's lives. Planning for changes in lifestyle and care needs can help maintain a sense of control and ease about the future.

People are noticing physical changes the longer they live with a SCI. Fatigue and chronic exhaustion, for example, associated with

reduced energy are common complaints. People are finding they need to pace their daily activities and often need to reduce the number of activities in a given day. This might mean rescheduling daily activities so important things are done earlier in the day, cutting back hours of work or getting assistance with personal care so there is energy left over for spending time with family and friends. There may be a need to re-think their day-to-day lives and focus on putting energy into the things that are most meaningful.

Muscle pain and joint pain are also common complaints. Wrist and shoulder wear-and-tear from years of doing adapted repetitive tasks, such as pushing a wheelchair, can affect function. Many people find rest and change in routine helpful in relieving pain. Doing things differently, however, may mean altering equipment and mobility techniques to decrease discomfort and prevent further problems. For example, switching to a power chair,

a van with a hydraulic lift, a sliding board for transfers, or a manual chair for those who previously walked.

Adapting to age-related changes and decreased function is not easy for people to accept. Change that results in an altered lifestyle may increase emotional distress. An individual's sense of self-reliance can be threatened by a fear of loss of independence. In addition, people may have feelings of failure or "giving in" to the disability. For others, their quality of life becomes the issue.

Declining function and energy can threaten a lifetime of self-confidence. As all of us age, we become set in our ways, less tolerant of change in routine, environment and companions. Therefore, as physical functions decrease, we resist new equipment, new procedures, new ways of doing old things at a time when we need to be open to making changes in our way of doing things. Understanding the importance of making changes early can increase people's quality of life. Finding new ways of doing old

things requires great courage, but allows people to do more with less pain, less fatigue and more mobility, resulting in more independence.

A person's level of perceived control over their life also correlates with measures of well-being. Research has found that those living with a disability for twenty

or more years perceived their lives to be as good as the able-bodied population.

Environmental factors can also play a significant role in how well people age. These factors include income, transportation, family and interpersonal supports, and availability of assistance for personal care needs

(continued on next page)

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the bottom line isn't just the profit line

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(Spinal Cord Injury, cont'd from previous page)

if required. The majority of people with physical disabilities are on fixed incomes, so growing financial demands are a serious concern for individuals trying to maintain independence. For example, shoulder pain and weakness from years of overuse may lead to a decreased ability to maneuver a manual wheelchair; however, a power chair is an expensive alternative. Increasing economic constraints can be another worry for people trying to adapt to changes accompanying the aging process.

Dealing with disability takes time and energy. With aging comes a decrease in both. Priorities must change. People who have survived many years with disability are not just lucky, they are capable, resourceful, knowledgeable individuals who know their bodies and take responsibility for themselves.

(Coleen Heenan is the Canadian Coordinator of BC Rehab's Spinal Cord Program). ≈

Planning with a Representation Agreement

Many people think about making a will—taking care of their affairs after they die—but they don't plan for what might happen if they are alive, but unable to manage their affairs.

Powers of attorney, which many people make, only apply to legal and financial matters. They do not cover personal and health care decisions such as consent for medical treatment or admission to an extended care facility.

Representation agreements do. They are a new type of legal document in B.C. that allow adults to name someone they trust to represent them if they should need help managing their affairs. The agreements are flexible, allowing representatives to help out temporarily, permanently, or on an as-needed basis. The agreements can also include statements of your beliefs and priorities, or important instructions.

Don Beddows, a senior from White Rock, is one of the volunteers with the new Representation Agreement Resource Centre, currently

housed at BCCPD. Don meets with individuals and groups to give them information about representation agreements.

"I used to be immortal and invulnerable," explains Beddows. "But once you get past 70, life gets to be quite dangerous. It is vital to be able to pre-plan not just wills and funerals, but the sorts of care we need and decisions that might have to be made on our behalf."

For people who have extensive contact with the health care system, it is particularly important to appoint a representative for health care. Although many people do make written plans such as living wills, pieces of paper are not as effective as a person you trust, who can be on the spot talking to the medical staff when you are unable to speak for yourself.

Your health care representative has legal access to medical records and legal "clout" in decision making. Your representative can ask questions, demand explanations, explain your wishes and defend your rights.

B.C.'s *Representation Agreement Act* has not yet been proclaimed, but people are already making and using representation agreements now, and getting them ready for when the law is proclaimed.

The Representation Agreement Resource Centre was founded by the Community Coalition for the Implementation of Adult Guardianship Legislation which includes BCCPD, the BC Association for Community Living, the Alzheimer Society and the Council of Senior Citizens Organizations.

The Resource Centre is a volunteer-driven non-profit society which assists people to make representation agreements. The Centre offers workshops for community groups, and training for community advocates and peer counsellors on how to help others to make representation agreements.

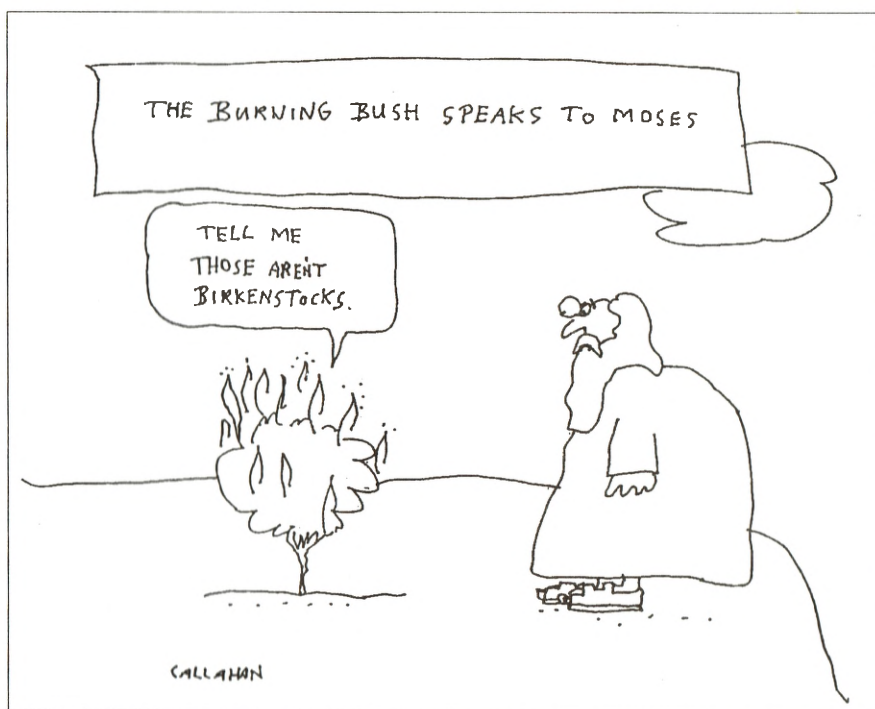
For more information on the Representation Agreement Resource Centre, contact Donna McMahon or Christine Gordon c/o BCCPD at 875-0188. ≈



Want to start your own multi-million dollar business, plus put people to work? My wife and I have invented and patented a padded "Street Hockey Suit." With this Suit, plus wearing elbow and knee pads, helmet and cup—and your favorite NHL team jersey—you will be fully protected. You can use a regular hockey ball without fear of bruises and welts.

Because I have a disability, we are not able to start our own business. So, we are selling the patent for the "Street Hockey Suit." Part of the proceeds of the sale will go to the BC Coalition of People with Disabilities. A prototype has been made and tested—the kids love it.

Please contact Joanne and David Gray, phone or fax (604) 572-8539.





Norma's will continue to accept new ads as usual by phone, letter or email. These will be posted to the Internet as soon as received. Ten dollar ads will appear in the next printed issue, so, in effect, one-month ads will be valid for up to three months.

To encourage email ads, I am offering free one-month ads (Internet only—print version not included) throughout this period.

NIDEC's ads will continue to be free for viewing on the internet. Our address is <http://www.lights.com/classifieds/> This list will be updated every Thursday and so will remain an up-to-date service.

NIDEC is a service dedicated to helping people with disabilities buy the equipment they need at a reasonable price, or sell/exchange used disability equipment. You can contact NIDEC at Norma's Independence & Disability Equipment Classifieds (NIDEC), 269 Carleton Dr., Saskatoon, Sask. S7H 3P1, Tel/fax: (306) 955-0071, Email: idec@sk.sympatico.ca

Classified Ad

© For sale: electric, adjustable bed. Remote controlled. Double size. Excellent condition; very clean. \$800. Call 985-3730 (evenings).

(Letters, cont'd from p. 2)

children, nor could I endure the untreatable pain (my doctors had made a decision not to do further surgery). I planned my own death to liberate me and my children who could then be adopted and have a chance for normal lives. A sudden emergency changed my plan and I was rushed to hospital. My doctors then decided they would do a further drastic operation. Due to unanticipated complications, I am now permanently disabled, but I am free of all pain. I now have a worthwhile life.

Tracy's situation was far worse than mine and for so many more years of her short life. When one has experienced the pain that I did, then one is able to speak with the knowledge of what she was going through. It is true that more community support could have helped Tracy's courageous parents, but Tracy's worsening condition could not be alleviated by further medical intervention.

I don't doubt that her loving parents knew, without her being able to talk, that it was her wish to cease her anguished living. It is true that our compassion is aroused when we think of her and hear the details of her life. It is aroused, not because she is disabled, but

because of her unbearable life. It is simply ignorance that equates suffering with disability. This is not necessarily true, as I know so well.

YOURS TRULY,
DAPHNE NAEGELE
VANCOUVER, BC

DEAR EDITOR:

We should all be grateful to the Saskatchewan jury who convicted Robert Latimer for the murder of his 12 year-old daughter Tracy. That conviction not only affirmed that all members of our society have intrinsic value—in the end, it meant that Tracy died a "citizen."

We at the BC Association for Community Living do not underestimate the obstacles many parents of children with disabilities face in attempting to secure opportunities, support services, and an acceptable quality of life for their sons and daughters.

However, regardless of Robert Latimer's personal feelings or motivations at the time, it is clear that he murdered his daughter without her consent. Acting entirely outside the law, he took away Tracy's fundamental right to live. The fact that Tracy lived with a disability does not, and should not, lessen the crime.

We will never know what Tracy Latimer would have wanted for herself. But we assume we know.

We assume her needs outweighed her gifts. We assume her pain outweighed her joy. We assume that because she could not speak for herself she was neither intelligent, nor thoughtful, nor talented. And perhaps, most disturbing of all, we assume her death was a liberation.

Viewed this way, is it not we who are confined by our severe ignorance and profound misunderstanding of who Tracy Latimer was? Is it not we who suffer in our limited understanding of who she was and who she may have become? And in the wake of her death, is it not our ability to grow and reach for the stars that is now truly at stake?

Should Latimer and his supporters now be successful in their bid to weaken Canada's existing murder laws, not only will Tracy's citizenship be put into question—so will the citizenship of all those Canadians who live with disabling conditions.

We should all think twice before allowing Tracy's murder to be used as a lever to erode the rights of others. If we don't, the unfortunate

legacy of Tracy's death will be to have put any one of us who experience pain or who require multiple surgeries at the individual mercy of those who are charged with our care and well being.

Our collective challenge now is not to find a way to make murder easier. The challenge is to change those attitudes and assumptions that are based on lack of knowledge and fear of difference. We must be willing to discover and learn about the abilities, dreams and wishes of those who have been labelled profoundly handicapped. We must be willing to put an end to the isolation and lack of support experienced by people with disabilities and their families, and we must be willing to ensure that those who are vulnerable enjoy the same fundamental human rights afforded all citizens in this country.

Without commitments such as these, we will continue to put those who are deemed less valuable at risk and we will have lost a tremendous opportunity to transform perceptions based on "pity" into actions based on "respect."

ANITA DADSON, PRESIDENT
B.C. ASSOCIATION FOR
COMMUNITY LIVING
VANCOUVER, BC ≈

r e s o u r c e s

Women with Disabilities

We came across some information about a doctor who is doing research around menopause, osteoporosis and women with disabilities. Unfortunately, we heard about her just as Transition was going to print.

If you would like more information in this area, please contact: Dr. Sandra Welner, MD, 8484 16th Street, Suite 707, Silver Spring, MD 20910, Tel: (301) 587-6396, Fax: (301) 585-5467, Email: welnersmd@aol.com

People with Developmental Disabilities

In July 1996, the BC Association for Community Living held a Forum on Aging and People with Developmental Disabilities. A 30-page report, including recommendations, is available.

For information, contact BCACL at #300 - 30 East 6th Avenue, Vancouver, BC V5T 4P4, Tel. (604) 875-1119, fax (604) 875-6744.



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