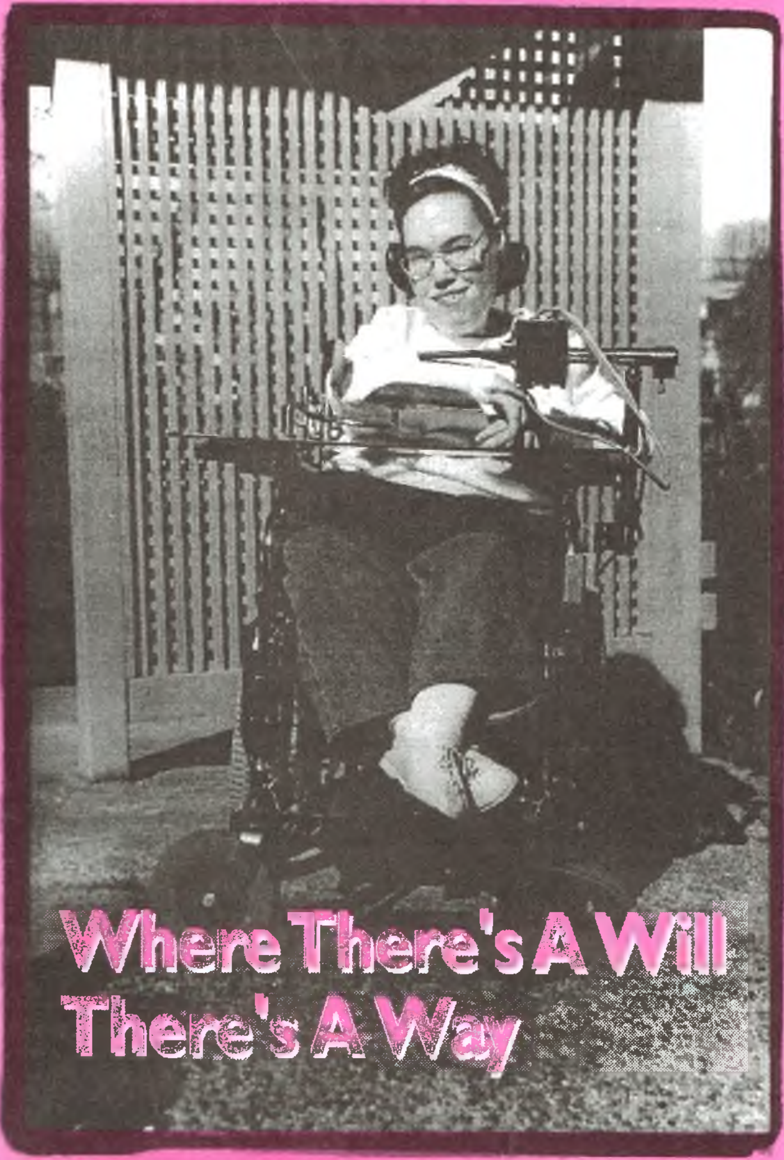
transition

BC COALITION OF PEOPLE WITH DISABILITIES MARCH/APRIL 1997



Where There's A Will There's A Way

Mary Lambert
on individualized funding:

also in this issue:
IF: An International Perspective
BCCPD Supports IF Projects
More Cutbacks from MHR
No-Fault Update

A community education festival called the Community Development Institute (CDI) will take place this summer on the Sunshine Coast in Sechelt, BC during the week of July 28 to August 1.

The CDI is an excellent opportunity for people of all ages and sectors to acquire and impart information and skills on local leadership for sustainable communities.

Community economic development, environmental stewardship and local goveranance will be some of the topics covered through over 60 workshops offered by experienced and skilled facilitators. There will also be many opportunities for learning practical skills and for having fun: permaculture, straw-bale construction, site visits to community projects, art, theatre and much more. A limited number of bursaries will be made available.

For more information, please contact Zarina Mulla at SPARC of BC at 736-5576.

Monday, July 28th to
Friday, August 1st, 1997
Sechelt, Sunshine Coast

BCTV Offers Scholarship

In recognition of Don Smith's long-term contributions to the broadcasting industry, BCTV is pleased to establish a trust fund in his name that will provide scholarships to a maximum of $2,500 per year for up to four students enrolled in a recognized Broadcast Communications Program, or a university program with an emphasis on broadcast journalism, leading to a journalism degree. Funds will be payable each semester, based on continued excellent performance and commitment to the program.

These scholarships are intended to encourage entrance to a career in broadcasting within groups which are currently under-represented in the broadcast industry. These groups are: First Nations peoples, people with disabilities, visible minorities and women.

A letter of application, accompanied by a resume, current scholastic record, and two personal letters of reference must be submitted to the following address before May 1st of each year: Scholarship Selection Committee, BCTV, A Division of Westcom TV Group Ltd., P.O. Box 4700, Vancouver, B.C. V6B 4A3. ≈

transition
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We welcome articles, graphics, creative writing, et al (maximum length for articles should be1000 words). The editors reserve the right to edit material.

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in this issue

Features

News & Notices

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.

No-Fault Coalition Meets with Premier

The following letter was sent to Premier Glen Clark March 27, 1997 following a meeting with the representatives of the Coalition Against No-Fault in BC.

DEAR MR. PREMIER:

On behalf of the Coalition Against No-Fault in BC we would like to thank you for taking time to meet with us.

We have since discussed the issues raised in our meeting with the Steering Committee of the Coalition and can confirm our mutual agreement in regard to the following:

1. The Coalition will participate in discussions with your staff to develop a third option to reform the auto insurance system.
2. Your office will assist the Coalition in obtaining access to all financial records from ICBC which would be pertinent to the development of a third option. This access needs to be available as soon as possible.
3. Assuming that good faith is demonstrated by the Coalition and Government, respecting the above-mentioned matters, the Government will involve the Coalition in a review and discussion of any new legislation and regulations prior to their introduction.

It is clear that there are key issues outstanding which will require considerable attention during future discussions. However, we are confident that reforms can be made which will improve road safety, maintain the rights of accident victims, keep premiums at their current level this year and stabilize them in future years.

Thank you for your assistance with this important matter.

SINCERELY YOURS, GORDON ADAIR, CA
COORDINATOR, COALITION AGAINST NO-FAULT IN BC ≈

editorial

by Paul Gauthier

This issue of Transition is devoted to a "new" generation of service delivery systems influenced by people with disabilities and their families. The terminology used to describe the method of service delivery varies. It may be called “individualized funding” or “direct funding,” “autonomous planning” or “brokerage." Despite the emphasis on “funding” or “planning” in the terminology, the heart of the matter is power and empowerment for the individual.

Individualized funding is such a common sense idea that the best way to describe it may be to point out the lack of sense in the block-funding system.

In block funding, various divisions of government ministries contract with profit and non-profit agencies to provide services to individuals based on their disability. The needs and plans that the individual may have for her or his life are rarely taken into account. It is up to us to negotiate for our needs with these government divisions: with Continuing Care for personal assistance hours at home, with the Vocational Resources Society for hours at work or school and transportation to and from work or school, etc. In each case, the money goes from the ministry delivering the service to the various agencies who tell us what they will consent to do.

So we get services we don't need or want, while solutions which are less expensive and more appropriate are refused because they do not fit in with what the ministry has contracted for or the agency is prepared to deliver. It is common practice for considerations of economy of scale, or the cost of training or supervision to be primary considerations above the needs of the individual.

At the age of nineteen, I became intensely aware of the difference between this approach and a more person-centred one, and how crucial this difference is in planning one’s life. I had carefully planned the process of moving from a children’s group home to my own apartment. For me, this was a breathtaking adventure—both a risk and a bolt for freedom. I had people I trusted who knew my needs and who had agreed to be my personal assistants, at least for the transition period until I “had my act together”. As I began to lay out my transition plan in detail, I was brought up short by the director of the home support agency that Continuing Care was about to contract to provide my services. She informed me that the agency would sup-

(continued on next page)

(Editorial, cont'd from previous page)

ply my assistants from their staff.

I was told the following "rules." There would be a fixed schedule that would be the same for all days of the week. For special occasions, it "might" be possible to make some changes "depending on the requirements of other clients and the availability of staff." These changes would have to be made through the agency office. Direct communication between assistants and clients outside of work hours was forbidden, and services had to be delivered in the home. This meant no assistance at school, no assistance at work, no assistance while out on the town, etc.

The agency was determined and felt justified to deliver services in a way that was next to useless to me, despite the fact that what would be useful was no more expensive, just different.

Fortunately, through persistence and determination I was able to discover that service users had begun the process of trying to find concessions on these matters. The first step was a program called the Enhanced Consumer Participation Model (ECPM) which allowed a small amount of control to the consumer—at least allowing her or him the right to recruit suitable assistants and to have direct contact with them, the right to set work schedules for the assistant, and the right to arrange for the services to be delivered in the community, although the employer of the assistant was still the agency.

These concessions made an amazing difference to those people with disabilities who were able to take advantage of them. The success of the ECPM became a stepping stone for the development and acceptance of Choices In Support for Independent Living in which the consumer employs personal assistants directly using the same amount of funds. Even though the costs are the same, there is a huge difference in the amount of flexibility allowed to an individual to become a student, an entrepreneur or to secure a job. Not surprisingly, this model received raves from the clients.

Services need to become more accountable to people using them. This Transition looks at people's experiences with individualized funding and the ways that this movement is gaining momentum. ≈

WALKANDROLL.COM/ATTENDANT

The Individualized Funding Project of the BCCPD has established an Internet personal attendant pool.

This pilot project aims to enable people with disabilities who are using individualized funding to access personal attendants who are available for work.

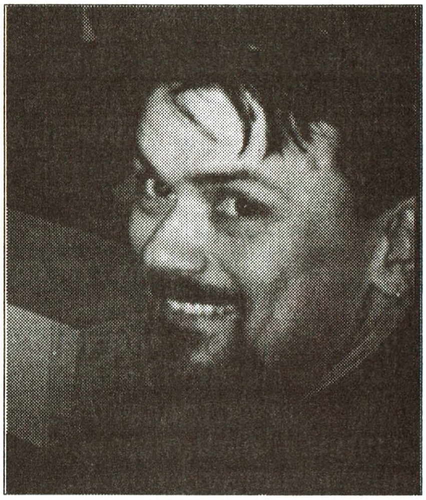
The idea for the Internet linkage came from a meeting in November, 1996 of people who are using individualized funding. Participants at the meeting expressed a need for ready access to personal attendants, especially for back-up or emergency assistance. People realized that as individuals they knew of attendants who were available for work and that, if everyone pooled information, it could be a valuable resource for people using individualized funding.

So a web page was developed through the Community Resource Network at WalkandRoll.com/attendants. Then a questionnaire was designed that outlined the abilities, experiences and availability of people who want to be attendants. The information from these questionnaires will be entered into the Web page. People who are in need of attendants can visit the Internet site and look for a candidate(s) suitable for interview.

It is important to note that WalkandRoll.com/attendants is a source of information that both personal attendants and people with disabilities who need their services have to use with care and responsibility. The Internet resource is not recommending or screening people—it is just linking people to one another. It is not a substitute for good interviewing or reference checking. That is the responsibility of its users.

BCCPD's Individualized Funding Community Development team will be evaluating the effectiveness of the Internet Attendant pool after a few months of use. The team will also be coordinating an Internet buddy system that teams up people who are not on the Internet with those who are, so that the information can be available to all who want it.

Contact Roger Jones at Walk and Roll or Christine Gordon at BCCPD for more information. ≈



McMurchy Takes Early Retirement

At the end of March, the BC-CPD said goodbye to one of its long-time supporters and employees. Well, not good-bye exactly–Geoff McMurchy will continue to keep his hand in Transition, designing covers, and advising on the Editorial Committee and Transition Board.

Geoff has worn many hats over the years, including Board member, on-call graphics and computer guru, and staff member on numerous projects, most recently with the AIDS and Disability Action Program.

BCCPD will miss Geoff's many talents and we'll all miss his presence around the office. We wish him all the best in his plans to expand his already-considerable artistic talents.

BCCPD Sponsors IF Projects

The BCCPD has recently started up two projects geared toward spreading the word about Individualized Funding—both within disability communities and within the broader communities that affect policies and services.

The Individualized Funding Community Development Project

The B.C. Coalition of People with Disabilities, with a grant from the Ministry of Children, Youth and Families, is sponsoring a community development project to promote individualized funding. The project is being facilitated by Christine Gordon, Paul Gauthier, Mary Lambert and Brian Salisbury.

In British Columbia, people with disabilities have had some opportunities to use individualized funding through the Choices for Support in Independent Living (CSIL) program, the three-year Community Brokerage Services Society (BCSS) project and microboards. Their experience with all of these programs has been overwhelmingly positive. Building on the strength of this experience, the Individualized Funding Community Development project will work to increase people's knowledge and skills to use individualized funding. It will also try to reduce some of the barriers to greater acceptance of individualized funding within government, service provider agencies and labour unions.

if
Individualized Funding
PROJECT

Some current activities of the project include:

- Monthly meetings of consumers and personal supporters.
- The development of a web page site on the Internet listing personal attendants who may be available to work for people with disabilities.
- Planning for a June conference that will promote individualized funding.
- Providing information and assistance to consumers who are using individualized funding or would like to.

If you would like to become involved in this project, please call Christine Gordon or Mary Lambert at BCCPD. ≈

CONFERENCE

BCCPD is sponsoring an individualized funding conference this June. We are sending invitations to 125 individuals in the community who:

- have used or would like to use individualized funding
- are leaders in or promoters of individualized funding
- represent consumer groups, government, labour unions and service providers

The objectives of the conference are to:

- enable people with disabilities and their personal supporters to learn about individualized funding.
- promote the development of a network for users of individualized funding to share information and provide support.
- increase knowledge and understanding of individualized funding in the government, labour unions and service provider sectors.
- promote individualized funding by developing action plans for implementation.

Day One • Forum for Consumers & Supporters

The program will include sharing stories of experiences with individualized funding; skill-building workshops; discussion of the values and principles of individualized funding; and, development of a consensus statement on individualized funding.

Day Two • Forum for Government & Service Providers

The program will include a history and international perspective on individualized funding; experiences with individualized funding in B.C.; discussion of the consensus statement from Day One; and, an examination of the roles and responsibilities of government and service providers.

If you would like information on the conference, contact the BCCPD office.

June 8 and June 9, 1997

Community Living Advocacy Project

by Jan Taylor

The last issue of Transition included an announcement about the Community Living Advocacy Project. This article will tell you more about the Project, including our background, our services, our future plans and how to reach us if you want to know even more.

The Community Brokerage Service Society pilot project (which provided individualized funding and autonomous planning to 20 adults with developmental disabilities) closed last Spring. Two projects were then developed to try to continue to build support for individualized funding. Both projects were approved for funding and began work this past Fall. The projects

(continued on next page)

(Community Living Advocacy Project, cont'd from previous page)

are funded by the Ministry for Children, Youth and Families and are administered by the BCCPD.

The Individualized Funding and Autonomous Planning Project (IFAP), facilitated by Christine Gordon, works with service providers, unions and government to stimulate discussion about individualized funding. This project is described on page 6.

The second project, the Community Living Advocacy Project (CLA) is based at the Coalition's New Westminster office. This project is designed to help individuals and their personal networks advocate for access to a range of services. Working closely with the IFAP project, the CLA Project is building support for individualized funding within a broadly-based network of families.

Working with the Community FamilyLink Society, CLA's first initiative has been the development of a framework for service and support for adults with developmental disabilities. This framework is based on a commitment to individualized funding. We have been meeting with families to discuss and refine the framework. Through a series of small, informal discussion groups, as well as a couple of larger meetings, we are raising awareness about individualized funding and its benefits for consumers. After more consultation from families around the province, we hope to present our framework to the Minister of Children, Youth and Families.

We have also been meeting with people with physical disabilities who share our interest in individualized funding. We have had a good exchange of experiences and ideas, and are encouraged to learn that support for individualized funding is growing across the disability community. Through this process, we are developing a set of fundamental principles for individualized funding.

We are also looking for other ways to share information about individualized funding, including the use of e-mail and the Internet, and speaking to allied organizations, such as the Autism Society of BC.

A conference on individualized funding is planned for early June in Vancouver. This conference will bring together individuals, family members, unions, service providers and government to talk about the implementation of individualized funding.

If you haven't been able to come to one of our meetings yet, but would like to, or if you would like a speaker to come to one of your group's meetings, please give us a call at 525-0701.

Jan Taylor is Coordinator of the Community Living Advocacy Project. ≈

BC REHAB

Aging with Spinal Cord Injuries

Issues for People with Long-term Injuries

This is a forum for consumers, families, caregivers and health care providers. Discussions will cover issues surrounding the physical, functional, emotional and social aspects of aging with a Spinal Cord Injury. Practical solutions for preventing and managing the potential changes that come with aging will be identified.

May 20, 1997 (8:00 a.m. - 4:30 p.m.)

Location: Best Western Richmond Inn
7551 Westminster Highway
Richmond, BC

Fee: $95.00
(lunch and refreshments included)

Contact: Michelle Webster
Phone: 604-737-6460 • Fax: 604-737-6359

Consumer Choice News

Consumer Choice News is a publication of the National Institute on Consumer-Directed Long-Term Services, a partnership between The National Council on Aging, Inc. (NCOA) and the World Institute on Disability (WID). The mission of the Institute is to enhance consumer-directed choice in long-term services through education, training and research.

The Institute is housed at NCOA, a private, non-profit organization founded in 1950 that serves as a resource for information, training, technical assistance, advocacy and leadership in all aspects of aging. WID, a non-profit organization founded in 1983 by leaders of the Independent Living Movement, serves as a centre for the study of public policy on disability and independent living.

Consumer Choice News is available free of charge. To subscribe, please fax The Editor at 202-479-0735, or write to NCOA, 409 Third Street SW, Washington, DC 20024. ≈

Individualized Funding

An International Overview

by Brian Salisbury and Tim Stainton Ph.D.

Since the 1970's, many users of community services that support people with disabilities have come to realize that citizenship, so much valued by non-labelled individuals, remains an elusive dream. The root of the problem is the service system itself which lacks accountability and is inflexible and unresponsive when it comes to meeting unique individuals needs.

In response, many people with disabilities and their advocates have begun to question the very manner in which required services are developed and delivered. In short, government's direct provision of services, or its use of block funding of non-profit and for-profit organizations to provide services in response to "categorical" needs, are seen as increasingly problematic.

People with disabilities are now demanding that funding used for disability-related services/supports should be provided to them on an individualized basis, using a mechanism known usually as direct or individualized funding. This funding is then used by the individual to purchase only those services and supports that are best suited to meeting their personal needs. Thus the person served determines the actual parameters of service provision.

Many people believe that if people with disabilities are empowered to have meaningful decision-making opportunities, service will necessarily become more flexible, responsive and accountable. Indeed, a truly "demand driven" paradigm means that professionals and service providers must listen and respond to what people want if they expect to continue to provide services.

Individualized funding began in BC in 1976 with the creation of the Community Living Society. It was the vision of families, anxious to deinstitutionalize their sons and daughters from Woodlands, to use individualized funding and the services of an independent planner (referred to as a broker), to help their family members return to the community. This small development, while an anomaly at the time, has led to a major social policy thrust that focuses on transforming people with disabilities from passive service recipients to empowered decision makers.

> *Many people believe that if people with disabilities are empowered to have meaningful decision-making opportunities, service will necessarily become more flexible, responsive and accountable.*

Efforts to implement individualized funding are underway throughout the world, although some pilot projects are "revisionist" because they do not meet important operational criteria (funding based on the person's unique circumstances and needs, or funding portability that enables services to be purchased from a variety of sources). However, there can be no doubt on one point. The "cat is out of the bag"—people with disabilities understand that there are now ways to truly gain control over how services respond to their needs.

Some of the major initiatives are listed below.

- In Great Britain, the recently passed Community Care (Direct Payments) Act 1996 will enable local Social Service Authorities to provide funding directly to individuals with physical and intellectual disabilities, and the elderly. The Bill's passage followed an extensive consultation process and represents the first time anywhere a government has passed legislation for individualized funding. While implementation is likely to be more restrictive than many would like, the Bill has served to galvanize various disability movements in the United Kingdom and gives hope to many of "full community inclusion".

(continued on next page)

(An International Perspective, cont'd from previous page)

- In BC, Microboards and Choices for Support in Independent Living (CISL) exemplify how decision-making control over funding has effectively been placed in the hands of people with disabilities. Microboards are non-profit societies created by individuals and their support networks in order to receive funding that has been negotiated directly with government. Each society negotiates directly with service providers or support staff. In the CISL project, approximately 240 individuals with physical disabilities negotiate individually with Long Term Care within the Ministry of Health for individualized funding to purchase attendant care services. CISL is similar to a scheme operating in Manitoba and the Direct Allocation program in Quebec, as well as many others operating throughout the United States and Europe.
- Along with these changes in how funding is allocated, a number of "support" services have also developed to both simplify and enhance people's use of individualized funding. Projects which include a brokerage-type component typically help the person with a disability to establish (or link with) advocacy, accounting, staff recruitment, and training and management support services. This helps people to make the most of their individualized funding with a minimum of bureaucracy and hassle.
- In the US, the World Institute on Disability, in partnership with the National Council on Aging, is conducting a range of research projects that focus on increasing consumer direction/control in home and community-based services. Elsewhere in the US, the Robert Wood Johnson Foundation has just completed an independent evaluation of the "Monadnock Project", a self-determination demonstration project for about 40 people in New Hampshire. The preliminary data is very positive in all areas, including personal and financial, with individual budgets averaging between 12 and 15% lower than prior costs. The RWJ Foundation has also recently awarded 18 grants to begin Self Determination/Individualized Funding projects throughout the United States, with the Massachusetts, Texas and Hawaii projects standing out for their emphasis on minority populations.

> *Also, various government departments claim to utilize individualized funding and planning, although closer analysis reveals that such approaches are quite similar to traditional case management.*

Many other initiatives underway also claim to implement individualized funding. Unfortunately, while their efforts to increase empowerment are well-meaning, the concept is nevertheless being compromised. For example, some projects incorporate individualized funding/planning within a community agency that has sole responsibility for meeting the needs of an entire group of disabled consumers. While proponents argue that "one stop shopping" represents a major step forward, the question must be asked if such a model is significantly different to current block-funded service arrangements. Also, various government departments claim to utilize individualized funding and planning, although closer analysis reveals that such approaches are quite similar to traditional case management.

So, while many claim that they are using an individualized funding model, it would seem that some initiatives have merely incorporated cosmetic, rather than substantive, changes.

This article has outlined only a few of the individualized funding initiatives underway in the world. The reader should be clear on one point, however: interest in individualized funding is growing rapidly as people with disabilities seek more meaningful ways to ensure that they have control over their lives.

Brian Salisbury works as a disability policy consultant and contract Instructor in Human Services at Kwantlen University College. He previously worked as a service broker with the Community Living Society and Community Brokerage Service Society. He has consulted extensively internationally on individualized funding and service brokerage. Anyone interested in joining an international email discussion group on individualized funding can contact Brian (bsausbur@direct.ca).

Tim Stainton is a lecturer at the University of Wales, Swansea. He received his Ph.D. from the London School of Economics. He was one of the first service brokers with the Community Living Society in Vancouver. His book Autonomy and Social Policy *deals with issues of disability rights and the theory behind individualized funding.* ≈

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ANECDOTES
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Seminars Explode Body Image Myths

Does the woman who dies the thinnest with the least wrinkles win?

Joy Cohen, a Vancouver-based Fitness and Wellness Consultant, is presenting a series of seminars addressing the often painful subject of body image and how closely held notions about "fatness" can create barriers to well-being and achievement. From March to June, 1997, Cohen, in association with Wellness Management Research consultant Denise Hodgins and Registered Dietitian Sandra Turnbull, will offer new awareness, important guidelines and practical help to a variety of groups concerned with weight loss, health and body image.

Upcoming seminars include:

- Weight Loss Mental Floss: Stopping the Diet Yo-yo
- Hey, Fat Kid!
- Food, Fat, Fitness and Children: Focus on Eating Disorder Prevention
- Self-Esteem for All Sizes

Seminars are $35 each and are held at the offices of Cohen & Associates, #222 - 2628 Granville Street, Vancouver. To register, call (604) 730-1020. ≈

United States

The latest US survey of members of support groups for people with genetic disorders has found that 43 per cent of those surveyed had experienced genetic discrimination.

The survey, by Virginia Lapham of Georgetown University in Washington DC, found that employers, health insurers and life insurers all discriminated.

The report of the survey in *Science* magazine quoted a number of examples of discrimination.

In one case, a man was refused a job because, at the pre-employment medical, it was discovered that he had Klinefelter's syndrome, although there was no suggestion that this might affect his ability to do the job. A company official admitted that this was the reason the man was rejected, but said that the company would deny it, if asked.

Home Swap Register

Travelling to other areas of your country—or to other countries—can be difficult because of the lack of accessible hotels and other holiday accommodation.

This means that even those who could afford to take a holiday often miss the chance to explore and see other parts of the world.

The non-profit Special Families Home Swap Register enables people to swap their home in a two-way or one-way swap for holidays or breaks at any time of the year.

Subscribers get a quarterly register of homes available. The service started out with provision just in the UK, but has recently begun to provide worldwide information.

The homes all have different facilities for people with physical impairments, full details of which are included in the register. This enables subscribers to facilities to suit them.

Contact:
Special Families Home Swap Register,
Erme House, Station Road
Plympton, Plymouth
Devon PL7 3AU
United Kingdom
Web site: http://members.aol.com/sfhomeswap/trust.htm

(Courtesy of Disability Awareness in Action, March 1997) ≈

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.

Mentoring Project Helps Students

The following is an article by Kirsteen Main, a high school student who was matched up with a mentor through the Neil Squire Foundation's Mentoring Project called "Preparing for Success". A panel of people with disabilities who are well-established in their careers talk with young people who have disabilities about the importance of school and share their personal experiences regarding school, choosing a career and finding employment.

I met Melinda through the Neil Squire Foundation and she is my mentor. I meet with her every two weeks at her group home, and we talk about my life and how I am doing. I really look forward to meeting with Melinda. I feel like she is a really good friend to me and I am lucky to be able to go see her. I can say exactly what I am going through and Melinda can understand me. I can learn a lot through my experience with Melinda, and I hope Melinda feels that she is learning too.

I think about doing challenging things when I talk with her, and she always encourages me to follow through. I want to be like Melinda when I am older, and I hope I can be a mentor to someone else one day. I feel like having Melinda for a mentor has increased my confidence in myself. I also feel like I am learning more about myself and my strengths.

I like going to visit Melinda a lot and I think I am lucky to have such a good friend. I know I still have a lot of work to do on myself, but I know I can trust Melinda to help me. Maybe one day I can return the favour to someone else.

For Melinda

Before I met you I was not
understood by others.
However, now I am able to
be understood.
You feel what I feel
You see what I see
You hear what I hear
You laugh when I laugh
You cry when I cry
Real people seldom come
into my life
But you are real
For each thing that you are
to me,
And for providing me with
your friendship,
I thank you.

CHRC Reports Poor Year for Disability Rights

By any measure of progress, 1996 was a disappointing year for people with disabilities, says the Canadian Human Rights Commission.

In its 1996 Annual Report, released in March by Chief Commissioner Michelle Falardeau-Ramsay, the Commission urged the federal government to introduce a long-awaited amendment to the Canadian Human Rights Act requiring employers and service providers to accommodate the special needs of people with disabilities.

The Commission also expressed concern that fiscal restraint at all levels of government has had a disproportionate effect on people with disabilities.

"A few relatively isolated breakthroughs aside, this was a year of almost complete stagnation and, in some ways, even of losing hard-won ground," the report says. "When public transport, social housing, or hospital budgets are cut, the effects are felt most severely by those most in need of such services."

On employment issues affecting people with disabilities, the Commission reports little progress. "Unless there is a more concerted drive to improve the hiring and retention of people with disabilities across the board, the situation seems fated to go from bad to desperate."

For more information, contact Donna Balkan at (613) 943-9120. ≈

Assisted Suicide Debate Continues

When Sue Rodriguez was in the courts fighting for the legal right to end her life when she chose, the BCCPD was there as a supporter. The BCCPD took the position that legislation, including strong safeguards against abuse, was needed to give people with severe physical disabilities this right. The following article offers another view.

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by Nat Hentoff

Ten years ago, before Dr. Jack Kevorkian became a Halloween mask, I went to a conference in Minnesota of disability rights activists. Much of their anger was directed at the American Civil Liberties Union which some of them had previously regarded as an ally.

The Southern California affiliate of the ACLU had gone to court to establish the right of a woman with cerebral palsy and other disabilities to get help in committing suicide. The ACLU did not succeed, and its client, having recovered from clinical depression, decided she did not want to die after all.

Since then, the Michigan and Florida affiliates of the ACLU have vigorously supported assisted suicide, and the national office, being politically correct in these matters, goes along. Now, at last, the ACLU does seem to have won this battle for death-on-demand. Both the 9th and 2nd Circuit Courts of Appeals have ruled not only that assisted suicide is legal, but that a doctor may prescribe pills for the despairing patient and, under some circumstances, directly administer a lethal injection. That is, the doctor can commit an act of euthanasia.

Of all those opposing these lethal court decisions, the most apprehensive and enraged are various disability rights groups. An alliance of the dissenters has created a new force. It is called Not Dead Yet. One of the organizers is Woody Osburn, a full-time civil rights specialist with the Pennsylvania Coalition of Citizens with Disabilities. He is a quadriplegic. "Americans with disabilities," he and the others say, "don't want your pity or your lethal mercy. We want freedom. We want *life*. We, the people living with severe disabilities and chronic illnesses, are the most affected by assisted 'suicide.'

"Our deaths are being viewed as more desirable than providing services such as in-home care that would allow us to live as free and independent citizens. Instead, many of us are caged in nursing homes and other institutions or dependent on a family member—the two main circumstances that lead to assisted 'suicide'."

Not Dead Yet is circulating a prescient, ominous statement by Dr. Kevorkian on the social value of assisted suicide. He presented it to a Michigan circuit court in 1990. Said the good doctor: "The voluntary self-elimination of individual and mortally diseased or crippled lives, taken collectively, can only *enhance* the preservation of public health and welfare."

Those who are not dead yet are afraid that much of the general public uncritically assumes that the "voluntary" part of Kevorkian's prophecy will be exactly that. After all, not a few of us do not like to look at—or think about—"defective" people and believe that the severely disabled probably do wish, in their heart of hearts, to be "liberated" by suicide.

Through the years, in hospitals, some of the disabled have been told, one way or another, that their "quality of life" is hardly worth their effort to preserve it, let alone the efforts of their doctors or the cost to society. And with some of the disabled, that assessment of their lives can become persuasive.

One of the witnesses during a recent hearing on assisted suicide by the House subcommittee on the Constitution was Diane Coleman, executive director of the Progress Centre for Independent Living. Because of spinal muscular atrophy, she has been a wheelchair user since the age of 11.

She told the subcommittee about court decisions that over the past decade have allowed life-sustaining treatment to be withdrawn from persons "with substantial, though not terminal, disabilities. This trend is rooted in pervasive and largely unconscious societal prejudices against people with disabilities."

In a publication called *Mouth*—a lively and continually challenging advocate for disability rights (61 Brighton St., Rochester, N.Y. 14607-2656)—Joe Ehman, a reporter with disabilities, tells of his encounter with a prejudicial view of his own "quality of life": "A few hours after surgery, still delirious from the anesthesia and from post-surgical morphine and Demerol, I had to hear from a social worker who wanted to force-feed me a Do Not Resuscitate [order to the doctors]. I mustered my strength and screamed, 'I'm 30 years old. I don't want to die.' Another nurse came into the room. She asked why I was verbally abusing a staff member. I responded that there was nothing in arm's reach to throw. . . ."

Not dead yet.

(From The Responsive Community, Volume 6, Issue 4, Fall 1996) ≈

Footnote

The Sun recently reported that the world's first law allowing "voluntary euthanasia" was overturned in Australia. The law was passed in July of 1996.

The bill to overturn the controversial law was passed in a conscience vote by 38 votes to 33.

According to the Sun, "the moral, legal and medical issues surrounding euthanasia became obscured by arguments about states' rights."

Four people with terminal cancer had died under the law since its July last year.

Where There's A Will, There's A Way

by Mary Lambert

"Three years after moving to Pearson Hospital, I knew that if I didn't move out soon that I never would."

Whenever I face something new or challenging, I hear an echo from my past of my mother saying, "where there's a will, there's a way". Looking back on my life, I realize this to be true.

In 1977, I moved from my home and family in the Okanagan to Pearson Hospital. Like most teenagers, I had dreams and aspirations. I wanted to graduate from high school and continue on to university. The school system in my small home town was unable to meet my educational needs, so I moved to the big city. A rehab counsellor, who was advising me and my parents, told us that I could move into Pearson Hospital for a few weeks until a group home became available and I could attend a regular high school.

What I was promised and what I got were two different things. When we went to see Pearson Hospital, my family and I were told that everyone on the ward I would be living on went to school and worked. But when I moved in, I found there were only four of us out of the 36 "patients" who actually went to work or attended school. Instead of attending a regular high school, I ended up in a "special school room" in the old Children's Hospital, and I waited three years for a group home to be offered to me.

Back then, I would dream of the ideal living arrangement for me, taking into account my physical disability. My dream was to be living in my own home, having a one-to-one attendant that I would hire, working in a meaningful and rewarding job, making a reasonable income to support myself and to pay for my attendants, and sharing a fulfilling life with family and friends.

This was virtually unheard-of and considered totally unrealistic by most people then. At that time, there were basically three options for someone like me: living with one's family, living in an institution or living in a group home (if you were lucky).

Three years after moving to Pearson Hospital, I knew that if I didn't move out soon that I never would. I could feel the effects of institutionalization changing me—my spirit was suffocating. My roommate and I moved out of Pearson Hospital and rented a house together where we shared live-in attendant services provided by an agency. With Long Term Care paying for our attendant care and with the two shelter components from our GAIN cheques, we were able to afford a three-bedroom house in East Vancouver without further subsidy. We both found employment and were active in the advocacy movement for people with disabilities.

Approximately a year later, my roommate and I went our separate ways, so we were each able to have our own attendants. I was getting close to my dream, but I still hadn't quite reached it.

Over this time, I have witnessed many changes in Continuing Care, but too many things have stayed the same. When my roommate and I moved out of Pearson Hospital in 1980, we were given four hours a day each of attendant care by Long Term Care. People moving out into the community today are still given just four hours per day. It astounds me how rigid the Continuing Care system has been.

All along this journey to independence, I have asked why I couldn't manage my own care, why I couldn't get the money and hire my own attendants—but to no avail.

For years, I had been doing what officially became known as the Enhanced Consumer Participation

(continued on next page)

New Service for Drivers with Disabilities

Whether you're going to visit a friend, to work, or out for the evening, driving is often the main source of transportation. For many of us it represents freedom, independence and convenience, but we must always remember safety.

We all know that good driving decisions require good sensory, perceptual, cognitive (reaction time, attention, decision-making) and motor abilities. Difficulties in any of these areas can lead to problems on the road.

If this is of concern to you, you'll be interested to know about The Driver's Companion Group. We are a team of highly-trained professionals who have designed a program called Drive-Able® for drivers with disabilities to help you become the best driver possible.

For more information and a brochure call or fax: Dr. Norm Forman or Carl Wiese, The Driver's Companion Group Ltd., 416-429-8511, (fax) 416-429-7857. ≈

(Where There's a Will, cont'd from previous page)

Model (ECPM). Under the ECPM program, an agency would hire and be the employer for attendants that individuals would recruit, interview, train and supervise at the individuals' own expense. I had chosen not to participate in this program because it didn't offer any true improvement for me, but it was and still is a valuable option for many other people.

Then, in 1994, Continuing Care started a one-year pilot project for direct funding called Choices in Support for Independent Living (CSIL). After twenty years of being involved with Continuing Care, I was given the great opportunity to participate in this pilot project where I receive funds from the government to hire my own attendants. My dream has come true, except for the part about making a reasonable income to support myself and to pay for my own attendants. In today's economy, it is very difficult for everyone to get a decent paying job. But I am also prevented from seeking full-time employment by the per diem (user fees) that Continuing Care charges. In spite of this, I have found meaningful and rewarding work through volunteering in many ways. I always found enough work, just not enough pay. Continuing Care has been reviewing their policies regarding income calculation and assessment of per diems. I have the will (and always have had) and now I'll have to wait and see if Continuing Care has the way to let me try to achieve the rest of my dream.

As an advocate, I see people struggling every day for their basic needs to be met. While I haven't lost sight of my original dream, I know how easily it can all be taken away. If I can help just one other person along their road to independence, I will have accomplished something money can't buy and no one can take away from me. ≈

ADVOCACY without BURNOUT

BCCPD's Advocacy Access Program has a project dedicated to providing services to people who wish to apply for or appeal applications for Canada Pension Disability Benefits. We can assist people at the application, first level appeal and tribunal stages.

As part of this program, we have developed a manual entitled **Advocacy Without Burnout/ Canada Pension Plan Disability Benefits Appeal Kit**.

This manual is a self-help guide to help people appeal a denial of CPP Disability Benefits.

The Appeal Kit discusses why you need an appeal kit, how to start an appeal and provides a step-by-step process to help reach a successful outcome.

If you like a copy of the manual, or more information about our program, please contact us at the numbers below. Copies are available for $5.00 per copy, plus $2.00 for shipping and handling.

Our CPP advocates would also be pleased to offer a workshop to explain how the Appeal Kit may help your organization.

For information, call (604) 872-1278, Long Distance Toll-Free: 1-800-663-1278, TTY (604) 875-8835, fax (604) 875-9227. ≈

BCCPD 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.

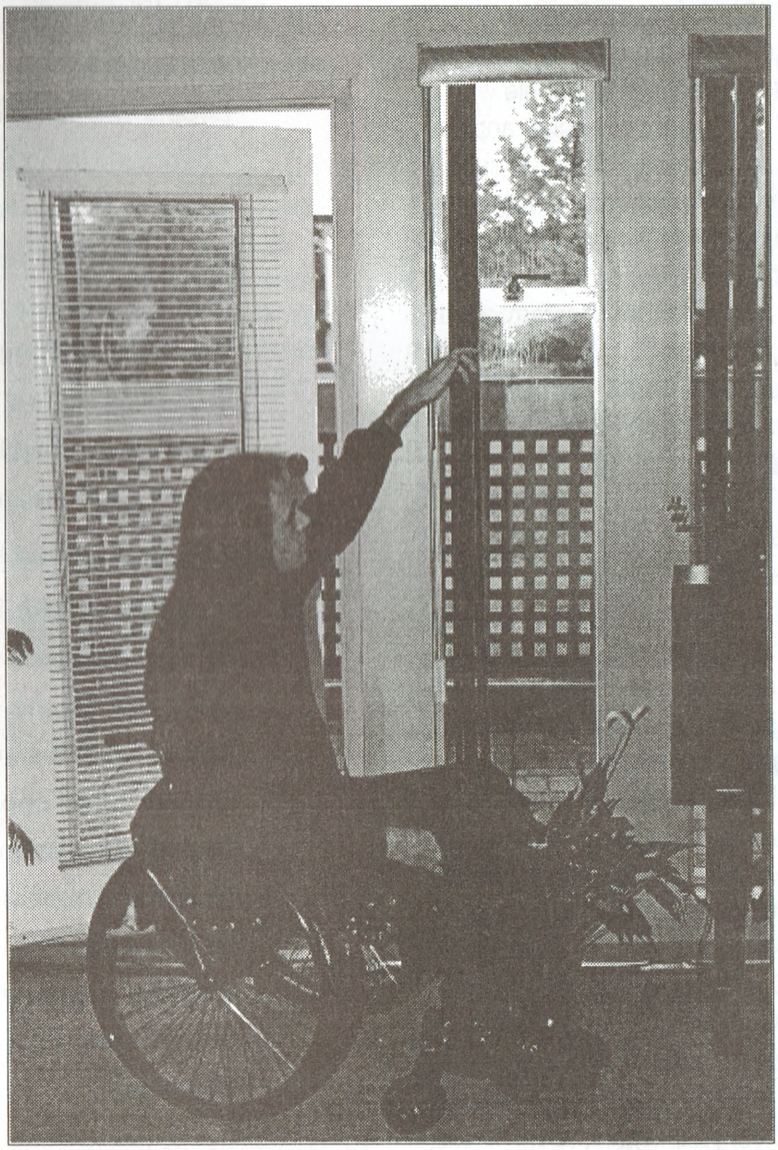
Because of these beliefs, the purposes of the BC Coalition of People with Disabilities are:

- 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.

Consumer Evaluation of Accessible Housing

A big thanks is due to all Transition readers who participated in the CMHC study of wheelchair accessible non-profit housing. The study has now been completed and provides a comprehensive evaluation of accessible design elements. The 99-page report includes photos, diagrams, discussions, quotes from participants and recommendations.

The intent of this study is for the findings and recommendations to serve as a foundation to build better housing for people with disabilities in the future. One important factor for designers to consider is that the profile of occupants of wheelchair accessible non-profit housing units is changing. This research indicates a population which is more physically disabled than the "young paraplegic" who is the model for many of the standards. Current trends, including the aging population and decreased use of institutional care, are probably contributing to a consumer profile with different, and



The patio door behind the tenant is very appropriate. It has a low bevelled threshold, and the door has a lever handle with a large offset deadbolt that is easy to manipulate. This door is much easier to open and lock, and the threshold is easier to cross than a sliding patio door.

possible greater, physical requirements.

The research also showed that, while many of the existing guidelines are appropriate and adequate, in many projects they are not incorporated into the design or construction of units designated as wheelchair accessible. In evaluating the units, problems with compliance appeared to be common. The report therefore recommends that the mechanisms for ensuring the provision of these features be reviewed.

Anyone interested in the report can obtain a free copy from the Canada Housing Information Centre in Ottawa at (613) 748-2367. The report is titled: Consumer Evaluation of Wheelchair Accessible Housing, and was prepared by Options Consulting in Vancouver. You can also call Katherine Taylor of Options Consulting at 736-9225 for more information. ≈

More Cutbacks from MHR

Effective March 31, 1997, the new Disability Benefits Program Act and Regulations have been in place, along with the rest of the BC Benefits legislation. However this piece of good news has been overshadowed by further welfare cuts.

The most important cut for the disability community has been the elimination of the "unemployable" category. The new "persons with special needs" classification that has taken its place is extremely restrictive. Predictions are that only one quarter of those who are classified as unemployable now will fit into the new "special needs" category. This means that about 15,000 people will likely have their welfare cheques reduced by $96 from June 30/97 on. Also, the application process has been changed, so that it is now necessary to fill out a "special needs" application which is sent to Victoria.

This appears to be another example of the Ministry of Human Resources reducing the living allowances of the poorest of the poor. We'll give you more details in the next Transition, but if you want more information in the meantime contact as at Advocacy Access 872-1278 or toll-free at 1-800-663-1278. ≈

Netherlands Study Looks at Restrictive Measures

by Gerda Wever

Over the last several years, more emphasis has been put on the privacy and freedom of people who use health care facilities in The Netherlands. Several new laws and regulations reflect this growing interest. One of these new laws (the Law for Special Admission to Psychiatric Hospitals) protects the autonomy of patients by prohibiting the use of coercion and restrictive measures, unless strict requirements are being met. This law protects the autonomy of patients in 24-hour health care, such as psychiatric hospitals, hospital psychiatric departments and the institutions for people with mental disabilities that offer 24-hour care.

However, other facilities such as day care or semi-residential facilities, are not explicitly covered by the legislation. This article summarizes a research project that looked at how restrictive measures are used in the excluded facilities. The organization studied is a semi-residential organization in The Netherlands for people with mental disabilities that manages small projects such as daycare centres, sheltered workshops and sheltered homes. The research was limited to the sheltered homes only.The core questions in the research were:

- What is the nature and frequency of restrictive measures used in sheltered homes?
- What is the motive of sheltered home caregivers in using restrictive measures?
- Are restrictive measures used in compliance with individuals' personal plan?

There are two categories of restrictive measures: measures taken for reasons of protection (that can be coercive) and general rules that regulate how people live together, i.e. house rules. In this article, "restrictive measures" are being defined as "all protective, coercive and educational measures used to restrict the individual person (including the use of behaviour influencing medication). House rules are rules that limit the individual freedom of people in order to make living together possible; they are rules for general understanding of each other, respect and good manners.

What is the nature and frequency of restrictive measures used in sheltered homes?

It was striking to note that the most frequently used "house rules" did not appear to fit the definition of houserules, but had the character of individual restrictive rules Some examples of individual restrictive rules referred to as a "houserule" are rules concerning frequency of showering, changing clothes, shaving, etc; restrictions in using rooms (including one's own room) and materials in the house.

Most commonly used individual restrictions are the consumption of food/ drinks, controls on personal dispensation of medication, individuals being sent to their room, restrictions in leaving the house and restrictions in use of public transportation. Financial restrictions, taken under the guide of "house rules" are also common.

What is the motive of sheltered home caregivers in using restrictive measures?

The most frequently mentioned motives are: protection of the person and of others; an attempt to influence the person's behaviour; and, practical reasons. This last motive usually reflected the personal values of the caregiver, rather than any clear "practical reason."

Are restrictive measures used in compliance with individuals' personal plan?

The percentage of measures taken in general comply closely what has been recorded in the personal file (between 67% and 100%). It is striking, though, that only 25% of the most radical restrictive measures (separation and being sent to their own room) were taken in accordance with the person's policy plan.

The results of this research led me to recommend the implementation of a standard procedure for houserules and regulations for sheltered homes in The Netherlands. Individual rules imposed on residents who need more regulation and structure should be entered into the personal file as a general policy for this person, and evaluated on a regular basis.

Consistency in the actions and decisions of the caregiver was shown to be lacking, i.e., 75% of the radical restrictive measures were not registered in the person's policy plan. The fact that caregivers use restrictive measures because certain behaviours conflict with their personal standards and values is also an important issue.

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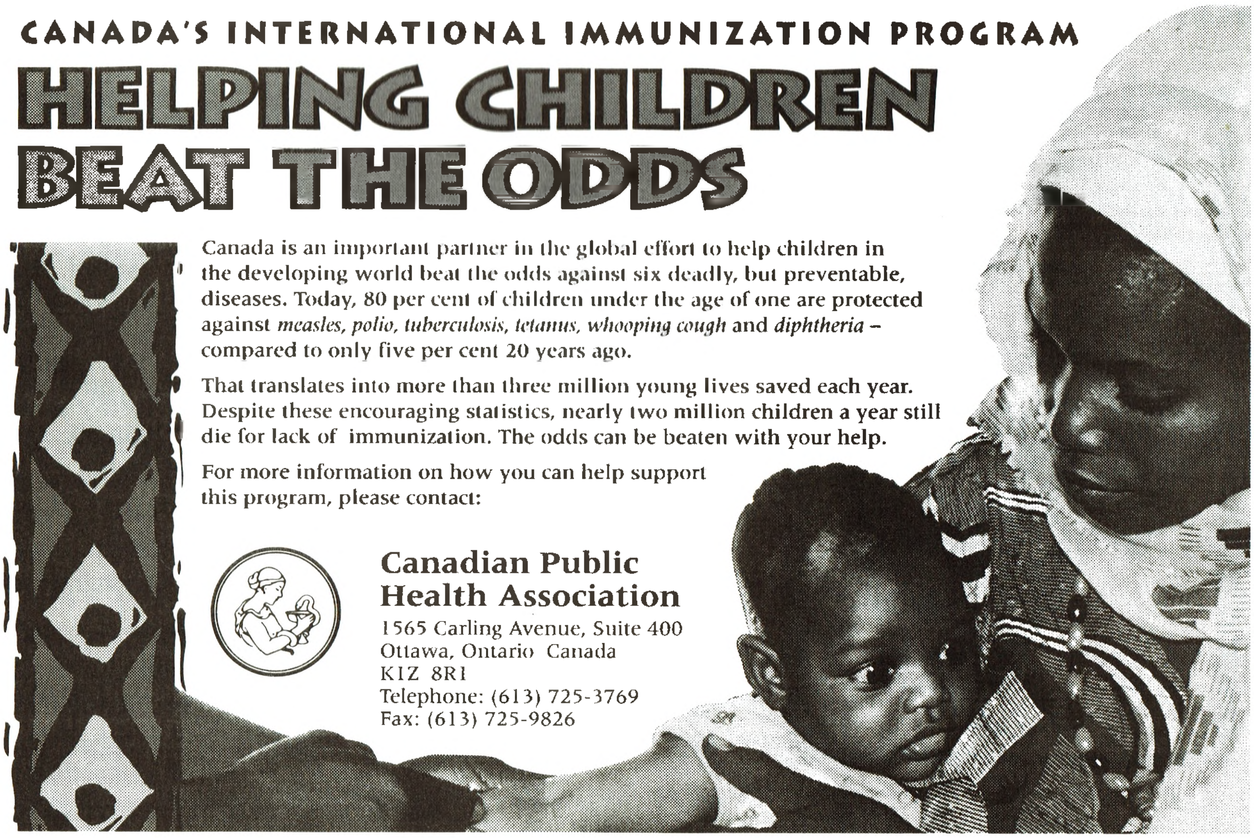

(Netherlands, cont'd from previous page)

Specific education and training of caregivers in sheltered homes can contribute to the consistency and efficiency of care. The goal of this training should be to achieve consistency between the actions of the caregiver and the agreed-upon personal policy plan. A second aim should be to encourage caregivers to become more conscious of the privacy, autonomy and right to self-determination of people with mental disabilities and an awareness of caregivers' influence on these rights. Finally, training should increase caregivers' awareness of their personal values and standards and, how these influence their actions.

Besides training and promotion of expertise of professionals in the special needs area, it is recommended that a committee be struck to evaluate the restrictions which are implemented according to the treatment plan or personal policy. Staff-determined restrictions entered into residents' files are not necessarily ethical. A committee consisting of lawyers, health professionals and parents could evaluate these restrictive measures and contribute to the improvement of the quality of these health care projects in The Netherlands.

For more information on this report or on any related topic, call or write Gerda Wever, 3030 - 9131 Capella Drive, Burnaby, B.C. V3J 7K4 , (604) 421-7345. ≈

Resource for Deaf Women

The members of the Comité d'aide aux femmes Sourdes de Québec are happy to announce the publication of the document entitled *Intervening with Deaf Women who are Victims of Spousal Violence.* This 169-page document is intended for resource persons with expertise in spousal violence who may wish to extend their services to Deaf women.

The authors, three intervenors and one Deaf woman, have written this document following consultations with Deaf women, intervenors working with the Deaf community and shelters for women victims of spousal violence.

Following a descriptive profile of Deaf women and their distinctive culture, the document presents specific aspects of spousal violence as experienced by these women and an outline of the difficulties they encounter. The core of the document proposes elements important to an intervention adapted to the needs of Deaf women and presents various tools designed to support and maximize the intervention process. The last chapter contains recommendations aimed mainly at facilitating Deaf women's access to resources intervening in spousal violence and at sensitizing the Deaf community to this specific issue.

For more information or to order copies of the document ($25), please contact: Comité d'aide aux femmes Sourdes de Québec, 1480, 80e rue Est, C.P. 59030, Charlesbourg, Quebec G2L 2W6. ≈

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COALITION AGAINST NO-FAULT
NO FAULT
IN BC

There's Still Time to Speak Up on No-Fault!

The government of BC has not finalized its decision on what changes will be made to our auto insurance system. Now is the time to speak up and let the government know you don't want a no-fault system. If you want information on how no-fault will affect innocent accident victims, contact the BCCPD office.

To voice your opposition to no-fault, call Premier Clark at 387-1715.

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