Message from the Editor

We are back and very excited about this first issue of ARCH TYPE in more than 18 months. ARCH Publisher is undergoing some major changes in its publication schedule. We will keep you informed of new changes in the coming year. To all our readers, past and present, we would like to extend our appreciation for your patience and support.

ARCH: A Legal Resource Centre for Persons with Disabilities has also undergone major changes this year. As part of the restructuring process, a new Board of Directors was elected in December of 1999. Join John Feld as he interviews ARCH’s new Executive Director, Phyllis Gordon, and new Board President, Kathleen Haswell (p. 3). Learn about ARCH’s new Board of Directors (p. 5). ARCH also saw several staff changes this year. Find out more about our new team (p. 6).

ARCH continues to uphold its mission to defend and advance the rights of people with disabilities in Ontario. Read a first-hand account of the Supreme Court of Canada case on Robert Latimer from ARCH lawyer, Lisa Cirillo (p. 13). Learn the implications of Allan Granofsky’s rejected claim of discrimination under the Canada Pension Plan (p. 14) from Alexander Sabharwal.

ARCH pays tribute to two leaders of the disability rights movement, Dick Santos and Marsha Forest, both of whom died this year. Join us in their memory (p. 23).

Harry Beatty, Editor-in-chief

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ARCH is a non-profit community legal clinic, which defends and promotes the equality rights of people with disabilities through litigation, law and policy reform and legal education. ARCH is governed by a Board of Directors comprised of elected representatives of member groups reflecting the community of persons with disabilities.

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Interview with New Executive Director and Board President

By John Feld

In June of this year, ARCH hired Phyllis Gordon as its new Executive Director. This is a milestone for ARCH, as Phyllis becomes the second Executive Director in ARCH’s history. Another milestone for ARCH took place last December when a new Board of Directors was elected to govern ARCH. Kathleen Haswell was elected as the new Board President. I had the pleasure of meeting both Phyllis and Kathleen this summer and they were excited about discussing their new roles with me.

JF: Welcome Phyllis and Kathleen. Please introduce yourselves to our readers. Who are you? What are your backgrounds? Let’s start with Phyllis.

PG: I have had a quite varied legal career, which I hope will be valuable in the position of Executive Director of ARCH. My first law practice was in Hamilton some time ago. From the start, I combined lawyering with participation in community organizations and working on social justice issues. My practice emphasized family law, with sub-specialties in human rights and immigration. When I moved to Kingston, I established a similar practice, although the focus shifted to labour and employment law. I often represented individuals either institutionalized in psychiatric or long-term care facilities and in prisons.

For the last ten years, I have pursued a career which combined legal and senior management work. I was the Clinic Director of Parkdale Community Legal Services for five years. Parkdale, the largest of the community legal clinics in the province, is a sister clinic to ARCH. It provides service to the ethnically and linguistically diverse community of Parkdale, one of the poorest areas in the City of Toronto. A major focus of its activities is the advancement of the rights and living situations of homeless people and psychiatric survivors.

I then became the Chair of the Pay Equity Hearings Tribunal. This position involved adjudication, regular contact with government officials, and management. I have more recently been doing similar adjudication work as a labour relations arbitrator and spent two years as a Commissioner on the Canadian Human Rights Commission. On a more personal note, it may also be of interest that in my pre-law teaching career, I taught children with significant mobility problems, developmental challenges and autism. I have a child, who, on a daily basis, faces educational challenges and, as in most families, I have family members with significant disabilities.

JF: Kathleen, it's your turn now.

KH: I come from Brampton, where I lived for many years. My background is in business. I used to work as a credit manager and then I owned a business for several years. I became the Executive Director for the Learning Disabilities Association of North Peel. I started that
agency because I had two children who were dyslexic and there weren't any services in the community at the time. I did that for several years and then I moved on to the Association for the Neurologically Disabled of Canada. We taught families how to do a daily therapy program to stimulate the senses. After that, I retired until my current position at ARCH!

JF: ARCH is an important pillar of the disability rights movement in Ontario. People with disabilities and agencies that work with them look to ARCH for legal advice and guidance. There is concern in the community about what's been happening at ARCH. Can you tell me about the restructuring that is taking place?

KH: With the support of Legal Aid Ontario, which retained and provided funding to hire a consultant, the new Board of Directors that was elected in December of 1999 is taking the whole organization through a restructuring process. In the first stage, the consultants got initial feedback from other legal clinics, ARCH staff, and some of our member organizations. Then they made significant recommendations for internal and external improvements, which are currently being looked at by staff and board.

PG: Over the summer, we implemented some of the organizational recommendations on an interim basis, working in teams, so that we could come back to the restructuring meetings with an understanding of what works and what doesn't. There is a keen interest and willingness on the part of all staff to build an effective team. The first stage of the restructuring focused on strengthening ARCH internally. The initial consultation was not designed to be broad-based; rather, it was conducted so that the consultants could better understand ARCH and the community it serves. ARCH board and staff are now beginning to design the second stage of the consultation process. We will be focusing on ways to inform the community about our options and to receive the most effective input.

JF: So, this issue of ARCH TYPE will be coming out at an appropriate time. It's really a new beginning for ARCH, isn't it?

PG: In some respects, yes. Agencies and organizations over time need to review their activities and renew themselves. Often renewal initiatives come out of periods of stress, as occurred at ARCH. But let us not forget that ARCH has thrived in the past and performed a valued function. Until we complete our restructuring process and received the community's input, we can't predict how ARCH will look in the coming years. It may be that ARCH will take a different path, or, it may be that we will be delivering essentially the same service. Whatever the outcome, our goal is to make this review process a meaningful and responsive exercise.

JF: What can people with disabilities expect from ARCH in the future? Will ARCH continue to provide the same level of services?

KH: Hopefully ARCH will be able to provide a more responsive service to more individuals in the future. What the current board is looking for is that the community of people with disabilities will reshape ARCH and will be able to bring together a new and more responsive service for them to receive.

JF: What message would you like to send to ARCH TYPE readers about the renewal that has taken place at ARCH?

KH: ARCH is a very beneficial and worthwhile community agency that helps individuals with disabilities through legal summary advice, and the larger community
of persons with disabilities when ARCH takes on precedent-setting cases. It is the only legal centre dedicated to helping persons with disabilities in Ontario.

The expertise that has developed over the years is as a legal resource to general legal practitioners throughout Ontario and, in this way, ARCH acts as a catalyst for legal information and casework specializing in disability issues. Although ARCH has experienced internal difficulties over the past months, we have been blessed with a group of dedicated board members who have assisted ARCH staff through this period of upheaval and flux. Additionally, Legal Aid Ontario has given financial and internal support, which has enabled us to weather the storm.

In conclusion, our member agencies will be part of the rebuilding of ARCH and, through their participation and direction, we hope to be able to rebuild ARCH into a more viable and responsive agency for all persons with disabilities.

JF: Thank you both and good luck.

A New Board of Directors for ARCH

In December of 1999, ARCH held its Annual General Meeting at which a new Board of Directors was elected. The names were put forward according to criteria established by the Nominations Committee. These criteria included experience in responsible board governance; knowledge of disability issues, knowledge of financial management and principles of accounting; expertise in organizational health, workplace equity and human resource management; and skills in fundraising and communications.

A strong and experienced team of board members with a diverse range of skills and perspectives has been elected to govern ARCH, and provide leadership in defending and advancing the equality rights of persons with disabilities. The following people comprise the current Board of Directors of ARCH:

Kathleen Haswell, President [Brampton] was Executive Director of the Association for the Neurologically Disabled of Canada and the Learning Disabilities Association of North Peel. She has two adult children with disabilities and has worked as an advocate for the rights of people with disabilities.

Sandi Bell, Vice-President [Toronto] works in private practice as a mediator, facilitator and trainer. She served as a School Trustee for the Hamilton Board of Education. Her community experience includes the Ontario March of Dimes and the Ethno-Racial People with Disabilities Coalition of Ontario.

Marilyn Warf, Vice-President [Thunder Bay] is the Regional Director of Persons United for Self-Help (PUSH Northwest), a disability and seniors' rights organization. Among her many community activities, she has served as a board member for the Lakehead Social Planning Council.

Gerald N. Ford, Treasurer [Toronto] is a Chartered Accountant and Senior Professional Financial Manager. He will soon be Controller for Sunrise Assisted
Living of Canada. His community-related experience includes service as Treasurer and Director for the Stanley Knowles Housing Cooperative, Transportation Action Now and Participation Apartments in Toronto.

**Fraser Valentine**, Secretary [Ottawa] is a Doctoral Student at the University of Toronto. His dissertation is entitled, "*Progress in Hard Times: Disability Politics in Canada and the United States.*" He has worked with the Association of Independent Living Centre (CAILC), the Roeher Institute, and the Caledon Institute of Social Policy. Fraser recently received the John Lord Award presented annually by the Canadian Association of Independent Living Centres for research activities in the field of disability studies.

**Lana Frado** [Toronto] is Executive Director of Sound Times Support Services, a member-driven initiative that provides support based on peer relationships for mental health consumers and psychiatric survivors. She serves on numerous boards and committees involved in advocacy initiatives.

**Marian MacGregor** [Toronto] is a staff lawyer with the Housing Division of Parkdale Community Legal Services. She specializes in all areas of poverty law. Her community experience includes service for the Federation of Metro Tenants’ Associations and Legal Assistance of Windsor.

**Naomi Overend** [Toronto] has worked for ten years as Legal Counsel to the Ontario Human Rights Commission. Her community involvement includes the DisAbled Women’s Network (DAWN) and Wen Do Self Defence for Women.

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**Past Meets Present–A Big Hello to New and Old ARCH Staff**

In addition to Phyllis Gordon joining ARCH as Executive Director this year, many fine and talented people have recently come on board, while others have continued with ARCH for many years.

**Hester Aschah**, a staff member of ARCH since 1995, continues as a Community Legal Worker. Hester brings a strong background in both social work and nursing to her work.

**Harry Beatty**, the longest serving ARCH staff member, has resumed his regular duties as Director of Policy and Research, after serving as Acting Executive Director. Harry will continue with his research, law reform and public legal education activities, especially in the area of disability income programs.

**Ena Chadha** came to ARCH as Senior Litigation Counsel in May with a strong background in human rights and refugee law. Ena has litigated extensively on behalf of the Ontario Human Rights Commission.

**Lisa Cirillo** has been with ARCH as Junior Litigation Lawyer since the beginning of the year. Lisa also has a strong human rights background arising from her work with the Ontario Human Rights Commission.

**John Feld** joined ARCH on contract to conduct interviews and assist with the editing of this issue. He was the editor of ARCH TYPE from 1988 to 1991.
Lana Kerzner assumed her responsibilities of Health Law Mentor in September. She has a great deal of experience in disability law through her previous work with both ARCH and the Advocacy Centre for the Elderly (ACE), as well as in private practice.

Catherine Larkin joined ARCH in 1997 and, after leaving to pursue full-time studies, has rejoined ARCH as a Community Legal Worker. Catherine has experience with crisis intervention, literacy training and issues related to learning disabilities. She is working towards a B.S.W. at York University.

Alfonso Salvador is ARCH's Office Administrator. Alfonso brings an extensive accounting background to his position with experience in the United States and in the Philippines, as well as in Canada.

Catherine (Kit) Stone joined ARCH in 1998 and continues as Litigation and Administrative Assistant. Kit brings strong technological skills to her position.

Amanda Ward is ARCH's Receptionist. She keeps ARCH staff well informed of all intake calls and assists staff with clerical duties. She studied fine arts at York University for two years and is furthering her education in the area of multi-media.

Bettina Worth joined ARCH in August of 1999 as part of the Litigation and Administrative Support Team. Bettina has a strong background in communications and she is a certified member of the Registered Graphic Designers Association of Ontario. Bettina assists the Editorial Team in producing ARCH publications.

Thanks to recent colleagues Dora Nipp and Pria Krishnan. Dora Nipp, a lawyer with extensive human rights experience, has joined the Ontario Privacy Commission as an adjudicator. Pria Krishnan, a lawyer in private practice in India, has returned home after a three-month placement at ARCH through the Canada Crossroads International program.

HEALTH INFORMATION IN PLAIN LANGUAGE AND ALTERNATIVE FORMATS

Many people require help understanding recommendations for self-care, reading an appointment slip, interpreting prescription information, and so forth. Moreover, many people with disabilities are at a high risk for health problems.

Given that a large percentage of the disabled population experiences difficulty reading and understanding basic health information, the British Columbia Coalition of People with Disabilities (BCCPD) launched the Wellness and Disability Initiative (WDI) Resource Centre offering consumer health information in plain language and alternative formats.

The WDI Resource Centre seeks to breakdown barriers and minimize the obstacles that prevent people with disabilities from learning and living with full understanding of vital information.

The Wellness and Disability Initiative (WDI) Resource Centre provides current preventative and related educational material in a variety of formats to people with disabilities, their families, and caregivers, as well as healthcare professionals and educators.

For more information or to access the WDI Resource Centre, call Shelly Houston, Director toll free at 1-877-232-7400 or write to her at:

Wellness and Disability Initiative
British Columbia Coalition of People with Disabilities
204-456 West Broadway
Vancouver, BC V5Y 1R3
ARCH MEMBER GROUPS

- AIDS Action Now!
- Amyotrophic Lateral Sclerosis Society of Toronto (A.L.S. Society of Toronto)
- Arthritis Society
- Association for the Neurologically Disabled of Canada
- Autism Society
- Bob Rumball Association for the Deaf
- Brain Injury Association of Toronto
- Canadian Cystic Fibrosis Foundation
- Canadian Diabetes Association
- Canadian Hard of Hearing Association
- Canadian Hearing Society
- Canadian Mental Health Association
- Canadian National Institute for the Blind (CNIB)
- Canadian Paraplegic Association Ontario
- Centre for Integrated Education & Community
- Cheshire Homes Foundation
- Down Syndrome Association Toronto
- Easter Seal Society
- Epilepsy Association Toronto
- Epilepsy Ontario
- Ethnic Organization for the Handicapped
- Extend-A-Family
- Family Alliance Ontario
- Fibromyalgia Society of Ontario
- Friends & Advocates
- Frontier College
- Greater Toronto Area Augmentative & Alternative Communication Advocacy Group
- Hemophilia Ontario
- Houselink Community Homes
- Huntington's Disease Resource Centre
- Integrated Action Group Ontario
- Kidney Foundation – Eastern
- Kidney Foundation – Central
- Kidney Foundation – Greater Ontario
- Learning Disabilities Association of Halton
- Low Vision Association of Ontario
- Margaret Fraser House
- Mood Disorders Association of Metropolitan Toronto
- Multiple Sclerosis Society of Canada – Toronto Chapter
- Muscular Dystrophy Association of Ontario
- National Educational Association of Disabled Students (NEADS)
- National Federation of the Blind
- National Network for Mental Health
- North American Chronic Pain Association
- Ontario Association for Community Living
- Ontario Association of the Deaf
- Ontario Federation for Cerebral Palsy
- Ontario Fibromyalgia Association
- Ontario March of Dimes
- PATH Employment Services
- Peel Association for Handicapped Adults
- People First of Ontario
- Persons United for Self-Help Northwest (PUSH Northwest)
- Queen Street Patients Council
- Reena Foundation
- Spina Bifida/Hydrocephalus Association
- Thalidomide Victims Association
- Tourette Syndrome Foundation
- Transportation Action Now
- VIEWS – For the Visually Impaired
ARCH Bulletins

- Extended Dental Care Plan for ODSP Recipients

As of July 1, 2000, the dental benefits available under the Ontario Disability Support Program (ODSP) have been extended by the Ontario Ministry of Community and Social Services (MCSS). The new benefits are called the "Dental Special Care Plan" (DSCP). Everyone listed on the ODSP dental card is eligible. This includes ODSP recipients; spouses and same-sex partners; children included in their parent’s ODSP benefit unit; and children whose parents are recipients of Assistance for Children with Severe Disabilities (ACSD).

The dental services required are only covered by the Dental Special Care Plan if the dental treatment is required as a result of the person’s disability, and if the dental treatment is required as a result of the person’s prescribed medication or prescribed medical treatment. NOTE: These conditions are only being imposed for the new DSCP. The existing ODSP dental plan (and benefits) is not being changed.

To receive approval under the DSCP to provide services, the treating dentist must submit a treatment plan on one of two forms: MCSS Form 2928 Dental Special Care Plan or Ontario Dental Association Approved Standard Dental Pre-Treatment Form. As the MCSS Form 2928 is specifically designed for this purpose, it may be easier for the dentist to use it. This form is being sent to all dentists in Ontario.

Approval under DSCP must ordinarily be obtained in advance, but post-treatment approvals may be allowed by MCSS where emergency dental services are provided, or the dental services are provided under general anaesthetic and the examination could not be performed in advance.

Dental treatment plans are valid for a maximum of five years. If dental services are required which are not on the ODSP-approved plan, the dentist must submit a new treatment form.

The DSCP only covers the following procedures: recall packages, scaling and/or root planing, fluoride treatment, custom fluoride trays, crowns where the patient uses a mouth-operated device, bruxism appliance, and mucogingival grafts. This leaves many costly dental services uncovered by either the basic ODSP plan or DSCP, i.e. crowns, where no mouth-operated device is used. ARCH is interested in learning of situations in which ways have been found to have these services provided, as well as situations in which they were not.
Where the DSCP covers dental services not provided at all by the basic ODSP plan, the dentist receives a partial subsidy and can also require the ODSP client to contribute the rest of the fee. This will prove very difficult for many ODSP clients to do. But where the DSCP covers services also covered by the basic ODSP dental plan except that the DSCP covers an increased quantity or frequency, the dentist should accept the DSCP payment without requiring an extra payment from the patient. Further details regarding the DSCP may be obtained from the ODSP Branch of MCSS.

■ Promoting Equality: A New Vision


■ The Democratic Right to Vote—Still Not Fully Guaranteed

The process of an election is of great importance to all citizens, including persons with disabilities. Municipal elected officials make decisions about the accessibility of buildings and transportation systems, about the employment of persons with disabilities by municipalities, and about the supports and services which communities will provide. School trustees are responsible for educational programs and supports for students with special needs. Yet in too many Ontario communities, citizens with disabilities are not provided with an equal opportunity to vote. Polls continue to be established in locations inaccessible to persons using wheelchairs or scooters. Persons who are blind or have low vision, or who are unable to read, are still often required to tell someone else who they wish to vote form, although relatively simple and inexpensive methods of allowing them to cast their ballots in privacy have been available for some time. Most municipalities with web site information about the upcoming election didn't address these issues at all.

The Municipal Election Act gives municipalities and election officials the authority to make voting places and procedures accessible, but little specific direction. Section 45(2) of the Act says that:

"In choosing a location for a voting place, the clerk shall consider the needs of electors whose mobility is impaired...."

It would make more sense to require all polls to be in accessible locations. Similarly, Section 41(3) of the Act leaves changes to make ballots accessible to blind or low-vision voters entirely up to the clerk's discretion.
The Charter and the Human Rights Code require equal access to voting procedures in principle, but litigation should not be necessary to ensure the provision of the fundamental democratic right to vote to all citizens with disabilities. Municipalities throughout Ontario should ensure that everyone is able to vote in the future.

ARCH Held a Municipal Elections Workshop

In preparation for the municipal election, ARCH sponsored a workshop primarily for individuals with disabilities and others concerned about advocacy issues. The facilitators for this event were: Sandi Bell, ARCH Vice-President, who chaired the workshop; Matthew Perry, of HIV & AIDS Legal Clinic of Ontario, who provided information on social service issues; Lana Frado, of Sound Times and one of ARCH’s Board of Directors, who provided information on homelessness and consumer/survivor issues; Jerry Ford, of Transaction Coalition and an ARCH Board of Directors, who provided information on TTC and Wheel-Trans issues; and Harry Beatty, of ARCH, who provided information on the municipal elections process.

Ontario Human Rights Commission: Consultation Paper on Aging

The Ontario Human Rights Commission prepared a draft discussion paper, “The Changing Face of Ontario: Discrimination and our Aging Population”. Individuals and organizations are invited to comment on the issues raised in the paper and the priorities identified by the Commission. ARCH has prepared a submission that discusses the inter-relationship of age and disability. A copy of the Commissioner’s Draft Discussion Paper is available on http://www.ohrc.on.ca.

ARCH has presented three submissions in the past few months concerning enhanced access to legal services for persons with disabilities.

- A written submission to the Law Society Task Force on courthouse facilities.

- Oral and written submission to the Task Force of the Legal Aid Tariff. The tariff is the schedule which sets out the rules for private practice lawyers who represent clients on legal aid certificates.

- Oral and written submission to the Law Society on its document "Implementing the Law Society’s Competence Mandate".
Supreme Court of Canada Hears Latimer...Again

By Lisa Cirillo

On June 14, 2000, Canada's highest court considered the case of Robert Latimer for the second time. ARCH counsel Lana Kerzner, Ena Chadha and Lisa Cirillo traveled to Ottawa to hear this important appeal.

The facts of the case are chilling and notorious. Robert Latimer was convicted of killing his 13-year old daughter, Tracy, who had cerebral palsy. The portrait of Tracy's life painted by her family and by the press is of a medically fragile child who weighed a mere forty pounds, who could not walk, talk or feed herself, and who suffered from constant and agonizing pain. But, according to the evidence presented at the trials and canvassed in Ruth Enns' recent book, "A Voice Unheard: The Latimer Case and People with Disabilities", Tracy's life was more than this—her pain did not blot out her life or her humanity. The journals of the child care workers of the group home where she lived the summer before she died, and even her mother's diaries, describe a child full of smiles, who was generally happy, who enjoyed the outdoors and who loved to cuddle. Despite her medical limitations, Tracy rode the bus to school every day, just like all the other farm kids.

Tracy had three surgeries to deal with the medical complications arising from her condition and was scheduled to undergo a fourth on November 4, 1993. This surgery was to reconstruct her dislocated hip, and it was hoped that the procedure would go a long way towards easing Tracy's pain and discomfort. On October 12th, the Latimers learned that instead of the planned hip reconstruction, the doctors were now planning to remove the upper part of her femur or thigh bone, leaving her leg limp. The Latimers testified that they were horrified at the prospect of this proposed "mutilation" of their daughter. It was at this point, Robert Latimer testified that he decided to end Tracy's life. He claimed that he made the "heart-breaking" decision to kill his daughter because he felt that she was better off dead than living a life of constant, excruciating pain.

On the morning of October 24, 1993, Robert Latimer waited until his wife Laura and their three non-disabled children left for church and then carried out the deliberate and premeditated murder of his eldest daughter. He carried Tracy to his truck and propped her up in the cab. Then he piped exhaust fumes into the cab for thirty minutes. During this time, he sat in the back of the truck and watched his daughter die. After her death, he carried her body back to her bed in the room she shared with her younger brother. Shortly after the family's return, Laura went to rouse Tracy and discovered that she was...
dead. The family called the authorities to report that Tracy had died in her sleep. Robert Latimer maintained this story to the police and to his wife for eleven days. On November 4, 1993, after being questioned, he confessed and was charged with first-degree murder.

In November of 1994, a jury found Robert Latimer guilty of second-degree murder in Tracy's death. The verdict was surprising to many in the disability community given the clear evidence of foresight and premeditation, requisite elements for a conviction of first-degree murder. Many believe that the jury opted for second-degree murder which lowers the period of parole ineligibility from twenty-five to ten years out of a sense of compassion for Robert Latimer and his family. Latimer appealed his conviction all the way to the Supreme Court of Canada. In February of 1997, the Supreme Court overturned his conviction and sent the case back for a new trial due to irregularities in the jury selection process.

In November of 1997, a second jury found Robert Latimer guilty of second-degree murder. As previously noted, the prescribed sentence for a second-degree murder conviction is life imprisonment with no eligibility for parole for at least ten years. However, at sentencing, the trial judge granted Latimer a constitutional exception to the mandatory minimum sentence on the basis that the imposition of such a sentence in his case was cruel and unusual punishment and therefore violated his constitutional rights. Instead, Latimer was sentenced to two years less a day, one year to be served in prison and the second on his farm.

Defence counsel argued that this was "not a case for labels"...this was a case of a man who "loved his child too much".

Crown cross-appealed the sentence. In November of 1998, the Saskatchewan Court of Appeal dismissed Latimer's conviction appeal but allowed the Crown's appeal on sentence and imposed the mandatory sentence of life imprisonment with no chance of parole for ten years. In May of 1999, Latimer was granted leave to appeal both his conviction and sentence to the Supreme Court of Canada.

Seating at the Supreme Court was at a premium on the morning of June 14, 2000 as observers began lining up early for one of the few seats available to the public. By the time the court convened, the gallery was filled with representatives from various disability groups interested in the case, including Canadian Association for Community Living (CACL), Council of Canadians with Disabilities (CCD), and Persons for Equal Participation (PEP). In addition to the appellant (Robert Latimer) and the Crown, the court heard submissions from seven intervenors, two in support of Latimer's arguments and five supporting the Crown.

Prominent criminal law lawyer Eddie Greenspan represented Robert Latimer before the Supreme Court, assisted by Saskatchewan counsel Mark Brayford, who has represented Latimer since November 1993. Mr. Greenspan dealt with the conviction appeal. Greenspan began his submissions by commenting that this was "not a case for labels" and that the defence was not saying that, "the lives of disabled persons are not worth living". This was a case, he argued, that turned on the specific facts at hand, and was really a case about a "man who loved his child too much". Tracy's pain, her "unenduring pain", was the constant refrain to Greenspan's submissions as he advanced a number of
arguments in support of the conviction appeal. Although the court had granted leave with respect to the defence's "suicide by proxy argument", this argument was abandoned before the Supreme Court. Also referred to as "surrogate suicide", this argument supports the rights of parents and guardians of those who are unable to speak for themselves to "commit suicide" for them.

Mr. Brayford dealt with the sentence appeal. He argued that the mandatory minimum sentence of 10 years’ parole ineligibility was “grossly inappropriate in the circumstances of this case” and urged the court to restore the trial judge’s sentence of two years less a day. In his argument, he made repeated reference to the “huge outpouring of public support for Latimer”.

The Canadian Civil Liberties Association (CCLA) and the AIDS Society intervened in support of some of the arguments made by Latimer’s counsel, although neither organization took a position on the facts of this case. CCLA argued that the mandatory minimum sentence of second-degree murder was unconstitutional. The AIDS Society, proponents of the right to assisted suicide, urged the court to take care in their ruling not to make broad pronouncements in the Latimer case that might affect the movement to have the right to assisted suicide legalized.

As respondent to the appeal, the Saskatchewan Attorney General’s office spoke first of the groups opposing the appeal. The Attorneys General of Canada and Ontario both intervened in support of the constitutionality of the mandatory minimum sentence for second-degree murder. Lawyer Robert Richards was up next, representing a coalition of six disability groups including CCD, CACL, People First Canada, Saskatchewan Voice of People with Disabilities, DisAbled Women’s Network (DAWN) and PEP.

Mr. Richards spoke powerfully and eloquently as he urged the Court to reject the discriminatory notions underlying the defence’s arguments and the public’s support of these—the view of disabled persons as leading "empty or tragic lives", "lives of diminished value". Such a view, in his words, is not only profoundly patronizing but as this case clearly demonstrates dangerous.

In urging the Court to uphold the mandatory minimum sentence of ten years for Robert Latimer, Mr. Richards argued that such a ruling was necessary to reaffirm the message that the law offers equal protection to persons with disabilities. Following Mr. Richards, the last two intervenors, the Catholic Group for Health, Justice and Life and the Evangelical Fellowship of Canada, addressed the court.

The panel of seven Justices reserved its decision, and the court’s decision is not expected until next year.

Persons with Disabilities Face Inequality Under CPP

By Alexander Sabharwal

In an important case for persons with disabilities recently argued before the Supreme Court of Canada, Allan Granovsky asked the Court to find that the
Canada Pension Plan (CPP) discriminated against him on the basis of disability, and to order that he be granted a disability pension. The Council of Canadians with Disabilities (CCD) intervened in the case and was represented by John Rook of Osler, Hoskin, Harcourt, a member of ARCH's Dickson Circle. The challenge was argued under section 15 of the Charter of Rights. Section 15 guarantees everyone the right to equality and prohibits the government from discriminating against persons on a number of grounds including "mental or physical disability".

Unfortunately, the Supreme Court did not seize the opportunity to remedy the inequality Mr. Granovsky faced under the CPP. In a decision written by Justice Ian Binnie that was released on May 18, 2000, the Court rejected Mr. Granovsky's claim of discrimination. Justice Binnie's decision signals a disturbing change in how s.15 should be interpreted, which may pose barriers to persons with disabilities in their attempts to advance equality claims in the courts.

Mr. Granovsky was denied a pension on the ground that he did not satisfy the 'recency of contributions' requirement of the plan. In order to qualify for a disability pension under the CPP, claimants must prove not only that they have a disability that is both severe and prolonged, but also that they meet the contribution requirement of the plan. At the time Mr. Granovsky applied for a pension, applicants had to meet the minimum contribution level for five of the ten years immediately prior to their application, or two of the last three years.

In 1980, when he was 32 years old, Mr. Granovsky suffered a back injury while at work. Initially, he was only partially disabled and it took some years for the injury to degenerate into a permanent disability. He worked sporadically when he was able. By 1993, when he was 45, his condition had degenerated to the point of a permanent disability and he applied for a pension. Had Mr. Granovsky's disability been permanent in 1980 when he first became injured, he would have met the 'recency of contributions' requirement of the plan. However, because he did not become permanently disabled until 1993 and had a sporadic work pattern during the intervening years, his contributions were no longer recent enough to meet this requirement.

Mr. Granovsky challenged his denial, arguing the contribution rule discriminated against him on the basis of disability. He argued that since he would have been able to contribute to and meet the requirements of the plan had he not been disabled, he had been subjected to adverse-effects discrimination.

In demonstrating that he suffered discrimination, Mr. Granovsky compared himself to non-disabled persons who are capable of working and meeting the 'recency of contributions' requirement of the plan.

To lend support to his argument that he was disadvantaged compared to non-disabled persons, and to show that it would not be too onerous for the government to make an exception for people in his position, Mr. Granovsky pointed to the fact that two exceptions had already been made to the contribution requirements of the plan. He pointed to the "caregiver drop out" in the CPP that applies to parents (primarily women) who work at home caring for children. He also pointed to the "disability drop out" that applies to persons who are permanently disabled. In calculating whether each of these categories of persons meet the contribution requirements, the CPP "drops out" the
years they were unable to work due to care-giving obligations or permanent disability.

In rejecting Mr. Granovsky’s appeal, the Supreme Court applied the 1999 Nancy Law (Law) decision which set out certain guidelines for determining whether the government has discriminated against a person contrary to s.15 of the Charter.

The principal point that has come out of the Law case is that in order to establish discrimination, it is no longer enough to simply show that the affected group has been disadvantaged by the government on one of the enumerated or analogous grounds listed in s.15, which was established in previous equality rights cases since 1989. According to the Law case, to qualify as "discrimination", the person must now also show that the differential treatment has deprived the person of their human dignity. As the Court said in the Law case, the question is:

"Does the differential treatment discriminate, by imposing a burden upon or withholding a benefit from the claimant in a manner which reflects the stereotypical application of presumed group or personal characteristics, or which otherwise has the effect of perpetuating or promoting the view that the individual is less capable or worthy of recognition or value as a human being or as a member of Canadian society, equally deserving of concern, respect, and consideration?"

As well in analyzing Mr. Granovsky’s claim, the Supreme Court did not focus on the CPP’s contribution requirement, which is what Mr. Granovsky wished to challenge. Instead, it characterized the case as a challenge to the "disability drop out" provision. As well, Justice Binnie rejected Mr. Granovsky’s claim that the proper comparator group was persons who are “non-disabled”. Instead, the Court said the proper comparator was the "permanently disabled" who qualified for the "disability drop out", and said Mr. Granovsky belonged to a group described as the "temporarily disabled".

Justice Binnie wrote that Mr. Granovsky had met the first two branches of the s.15 test in that:

(1) As a member of the "temporarily disabled", he had suffered differential treatment since he did not qualify for the "drop out" available to the "permanently disabled".

(2) The group that he belonged to (the "temporarily disabled") qualified as the type of group covered by s.15.

However, Justice Binnie found that the claim failed on the third branch of the test, which was introduced in the Law case, since Mr. Granovsky could not show that the disadvantage deprived him of human dignity. As Justice Binnie said in his decision:

"In other words, the appellant has not demonstrated a convincing human rights dimension to his complaint. Assuming he can show an impairment and significant functional limitations, he fails to show that the government’s response through the design of the CPP or its application demeans persons with temporary disabilities, or casts any doubt on their worthiness as human beings."

Rather, Justice Binnie saw Mr. Granovsky as "more fortunate" than the "permanently disabled", and said that the government is
free to use the CPP to target less fortunate groups for a subsidy. As Justice Binnie said in his decision:

"The differential treatment afforded by the s.44 drop-out provision ameliorates the position of those with a history of severe and permanent disabilities. It does not assist more fortunate people such as the appellant, but in the context of a contributory benefits plan, Parliament is inevitably called upon to target the particular group or groups it wishes the CPP to subsidize. Drawing lines is an unavoidable feature of the CPP and comparable schemes. Parliament did not violate the purpose of s.15(1) by seeking to benefit individuals with a history of severe and prolonged disability."

The Court's decision has made it difficult for persons with temporary, episodic or progressive disabilities, or disabilities whose prognosis is uncertain, to qualify for a CPP pension. In addition, there are a number of trends in the decision that could potentially make it more difficult for persons with disabilities to advance Charter equality claims in the future.

One dangerous trend in Justice Binnie's decision, and in the Law case as well, is the movement of the Court towards a requirement that people seeking protection from discriminatory government treatment now be required to prove not just that they have been treated less favourably by the government on the basis of (for example) disability, but also that this less favourable treatment has humiliated or degraded them in some way. This is disturbing because it suggests that being treated less favourably because you have a disability is not in itself humiliating and degrading.

Perhaps Mr. Granovsky's case itself is the best example of the potential consequences of the new s.15 test. Mr. Granovsky applied for a disability pension to replace his income, which had disappeared as a result of his disability. In order to qualify, he was required to make a minimum level of contributions to the plan through work. This requirement is one that non-disabled persons are capable of meeting and, in fact, Mr. Granovsky did meet the test himself when he was non-disabled. However, because and only because he now had a disability, he was no longer able to meet the 'recency of contributions' requirement even though he had a severe and prolonged disability at the time he applied for the pension. Viewed in this light, the case presents quite a stark example of discrimination, but it was one that the Court refused to acknowledge because, in its eyes, Mr. Granovsky was not sufficiently humiliated.

Another concern with the new dignity requirement is that such an approach may signal a fundamental limit to the scope of the protection afforded by s.15. A denial of dignity will naturally be easiest to establish with respect to the most straight-forward deprivations of equality, such as openly disparaging treatment or inaccessible buildings. However, the deprivation will be more difficult to establish in respect of seemingly neutral laws or laws that expend government resources, such as was involved in Mr. Granovsky's case. If this is the case, s.15 could potentially be limited to protecting against direct forms of discrimination (i.e. negative government action), instead of encouraging and requiring more active government measures (i.e. positive action) to eradicate inequality in society. Thus limited, s.15 would become not so much a guarantee of equality as a protection against discrimination.
Such an approach in practice would result in an unfortunate reversion to outmoded notions of formal, as opposed to substantive, equality—despite the fact that the court has said in a number of decisions, including *Andrews*, *Eldridge* and even *Law* and *Granovsky*, that the Charter is intended to achieve substantive equality. A reversion to formal equality would be particularly unfortunate for the disability community because, in respect of government, the discrimination disabled persons most often face and which tends to disadvantage them economically and socially primarily arises in more subtle forms than direct discrimination. As the late Justice John Sopinka wrote in 1997 in the *Eaton* case:

"...The discrimination does not lie in the attribution of untrue characteristics to the disabled individual. Rather, it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not result in the relegation and banishment of disabled persons from participation, which results in discrimination against them. The discrimination inquiry which uses the 'attribution of stereotypical characteristics' reasoning as commonly understood is simply inappropriate here."

Another concern with the decision in Mr. Granovsky's case is that the Court refused to subject to Charter scrutiny the legislative provision Mr. Granovsky wished to challenge. His challenge was to the rule relating to 'recency of contributions'; despite this, Justice Binnie treated the challenge as being to the "disability drop out" provision that applies to persons who are permanently disabled. In doing so, the Court characterized Mr. Granovsky's challenge as though it was being made by someone from an advantaged group who was challenging an exception that had been made for a more disadvantaged group. This was an unfair characterization of the issue since Mr. Granovsky was not from a more advantaged group but belonged to the same group, the community of persons with disabilities.

In the same way, the Court replaced Mr. Granovsky's proposed comparator group (i.e. persons what are non-disabled) with one of its own choosing (i.e. persons who are "permanently disabled"). In doing so, the Court went against the established trend of the caselaw which says it should look at discrimination from the perspective of the person claiming Charter protection and, in general, accept the comparator group chosen by that person. The court's approach would also seem to have the effect of "pitting" one category of persons with disabilities against another.

Such an approach to the issue of comparator groups also presents a practical difficulty to persons with disabilities in advancing equality claims. That is, due to the diverse nature of the disabled community, the government will, in all likelihood, often be able to point to another grouping of persons with disabilities who are more disadvantaged than the particular claimant before the Court. However, the fact is that, despite variations in the nature of their particular disabilities, the various members of the community do share a common exclusion from "mainstream" non-disabled society. This artificial division misses the fundamental point that all persons with disabilities share the common problem of barriers to full participation in society, as compared to the able-bodied—and that is where the true nature of the inequality lies.

Finally, it should be noted that, in addition to the general legal approach adopted by the court in its s.15 analysis, Justice Binnie used some unfortunate language in the
decision that tended to minimize the hardship faced by Mr. Granovsky and by persons with disabilities generally. Language is not trivial. It is significant to the extent to which it demonstrates respect, or a lack of respect, for disadvantaged persons because language will tend to condition "mainstream" society's views of the disadvantaged group. For instance, in the following passage, Justice Binnie suggests that what Mr. Granovsky is asking the court to do is to eliminate his disability:

"The Charter is not a magic wand that can eliminate physical or mental impairments, nor is it expected to create the illusion of doing so."

It is worth pointing out that the situation is not entirely bleak. Section 15 of the Charter is only fifteen years old and the provision is still in its infancy. It would be premature to predict it will only be interpreted in a way that will fail to guarantee full substantive equality for persons with disabilities.

A more benign interpretation of the decision is that it simply demonstrates a lack of understanding on the part of the Court as to the true meaning and implications of the notion of equality and various forms of disability. It could well be that this lack of insight has been shaped by the types of cases that the court has tended to deal with in its first 15 years of applying s.15, that is, cases involving relatively blatant forms of inequality.

If this is the problem, then there is much positive work that can be done by the community of persons with disabilities to educate the Court, by ensuring that a greater diversity of equality claims are put before it. In this way, the Court's understanding of the true meaning of the guarantee of equality can be advanced on a case by case basis, which it is hoped will ultimately lead to a richer understanding of the guarantee; thereby helping in the struggle of persons with disabilities to achieve full legal equality in Canadian society.

Footnotes:


Proposal For A National Personal Supports Fund

By Sherri Torjman

National Priorities

Health care emerged as the number one issue on the agenda at the recent meeting of First Ministers in Winnipeg. The provinces and territories want Ottawa to restore the funds it had withdrawn over the years as part of major federal cutbacks.

An issue apparently not high on – and not even on – the First Ministers’ list was supports for persons with disabilities. These supports ensure that people are able to live independently in communities and stay out of hospitals, group homes and institutions.

Ironically, these are the very supports that would help respond to rising demands on the health care system. In looking for ways to reform costly health care, governments need to develop more community services that prevent institutionalization and enable people to live at home.

An adequate system of personal supports would fill a major gap – lack of community options for independent living – that is creating huge pressures for costly, hospital-based care. This concern applies to more than the 16 percent of Canadians – or 4.2 million people – identified as disabled by the 1991 Health and Activity Limitation Survey (latest national data).

The costs will only increase with an aging population. The incidence of disability rises with age. Statistics Canada reports that nearly half of older Canadians experience some form of functional limitation. The disability rate for Canadians age 65 and older is 46 percent; it jumps to 70 percent for those age 85 or more [Alcock 2000: 3].

If governments took action to ensure the availability of personal supports, they would be making great strides on both the disability and health care fronts. Yet while they are pressing for restored health care dollars – almost at the expense of everything else – the disability agenda moves nowhere. This lack of action is distressing, especially in light of a written commitment governments already have made.

A Commitment to Act

On October 27, 1998, all governments except Quebec signed a national agreement on disability entitled In Unison: A Canadian Approach to Disability Issues. In Unison is seen as a vision paper because it sets out a clear picture of the ideals that a nation should strive to achieve.

It is a vision in which persons with disabilities participate as full citizens in school, work, culture, recreation and community life. It is a vision in which they have access to required supports and in which barriers that prevent participation in the mainstream are removed. It is a vision in which persons with disabilities have control over their lives, the policies and programs set up to meet their needs and the decisions that affect them.
In Unison identifies three ‘building blocks’ - personal supports, employment and income - in which changes are required to promote full participation. These building blocks are intrinsically linked. Access to personal supports helps ensure that persons with disabilities can go to school, partake in training or get a job. The ability to work reduces the need for income assistance. An adequate income enables the purchase of required supports.

In Unison commits all governments to work toward ensuring access to personal supports, decent employment and adequate income. Equally important, it represents a commitment for all governments to work together to reach these objectives.

There is no question that In Unison embodies a bold agenda, made more complex by the fact that its essential parts are closely intertwined. But while the agenda is big, it is not impossible. The best way to tackle the broad agenda set out in this vision document is to carve out small steps along the right path. One way to start is for governments to ensure that personal supports are more widely available.

**Personal Supports**

‘Personal supports’ refer to a range of goods and services that help offset the effects of a disabling condition. These can be classified into three streams: technical aids and equipment, personal services and brokerage.

**Technical aids and equipment** include such items as wheelchairs, visual aids, volume control devices and prosthetic appliances, and work-related equipment such as scanners, TTYs (teletypewriter devices) and large computer screens. This category also incorporates health-related goods such as special dressings, oxygen equipment, dialysis equipment and surgical dressings.

**Personal services** include several major components. Attendant services provide assistance with personal needs such as feeding, bathing and dressing. Homemaker services help with household tasks such as meal preparation and home maintenance. Home health care provides health care services, such as dialysis, at home. Respite refers to assistance primarily for families caring at home for children with severe disabilities - and even aging parents. Interpreter, reading and other communication services are another important component of personal services.

**Brokerage** includes the information and counselling services required to identify, organize and manage disability supports. Brokerage services ideally are delivered independently from the provision of aids and personal services. Brokerage helps ensure that personal supports can be chosen and supervised in ways that respect the preferences, choices and dignity of the individual.

**Access to Personal Supports**

i. **Technical aids and equipment**

The provision of technical aids and equipment defies simple description. Patients in hospitals or special residences generally receive the aids and equipment they need as part of their treatment.

Access is far more complex for those living independently in the community. Ministries of education or health usually assume the cost of technical aids and equipment for children in public schools. Adults have access through different routes, depending on the jurisdiction and types of programs in which they are involved.
Some provinces operate programs designed solely for the provision of technical aids and equipment. In some cases, these programs include a range of assistive devices. Alberta Aids to Daily Living, for example, helps individuals who have a chronic disability or illness gain access to medical supplies and equipment required for independent living at home. The Saskatchewan Aids for Independent Living Program and the Assistive Devices Program in Ontario also make available a range of technical aids for those who qualify on the basis of the program criteria. In other jurisdictions, only certain types of equipment (e.g., hearing aids, respiratory equipment or wheelchairs) are provided or only persons with designated conditions (e.g., paralysis, cancer or cystic fibrosis) can qualify for assistance under the program.

### ii. Personal Services

It is difficult to generalize as to how these services are provided. Ministries of health and/or social services throughout the country control the financing and delivery of personal services. Some provinces, such as Newfoundland and New Brunswick, have combined these two domains within a single department responsible for health and community services.

Services that are primarily health-related tend to be furnished through various health settings. Certified professionals or paraprofessionals may deliver home health care in the person’s own residence. User fees may be charged if the services are delivered outside a hospital, clinic or physician’s office.

Supports that are clearly social in nature, such as homemaker services and respite, generally are provided - or at least paid for - by ministries of social services. These supports often are delivered by non-governmental organizations (e.g., visiting homemakers’ associations) in local communities. User fees may be charged to help offset costs.

It is not easy, however, to distinguish between ‘pure’ health and social services. Attendant services are an example of a support that may combine elements of both health and social services. These supports may fall under the responsibility of provincial ministries of health or social services. Services may be provided directly by governments and through voluntary organizations. Often both are involved - governments pay for the services, which are delivered by voluntary organizations.

Finally, ministries of education are involved in most jurisdictions in the provision of supports required for educational purposes. But these same supports may not be available once the child has left the school. An attendant who assists in the classroom may not be provided to enable the child to attend a recreational program in the community. Parents may have to pay privately for this service or approach a local organization, such as a service club, to sponsor this support.

### iii. Brokerage

There are only a few nonprofit organizations throughout the country that offer independent brokerage services. The earliest model of community-based brokerage was developed in British Columbia in 1976 by the Woodland Parents Group to ensure appropriate community options for the de-institutionalization of their children. Brokerage services - where they exist - typically are funded by provincial departments of social services. Some provinces, such as Alberta, include an additional amount within a person’s package of services in respect of the assistance and management required to
coordinate a diverse range of personal supports.


Persons with disabilities who have no access to supports through an existing program must purchase these goods and services on their own. They may claim certain costs under the medical expense tax credit. Those who cannot afford to make the up-front payments generally must rely on provincial/territorial welfare programs to help pay for personal supports.

The primary role of welfare is to provide financial assistance for basic needs such as food, clothing, shelter and utilities. But welfare also plays the important role of making provision for special needs arising from health-related or disabling conditions - e.g., wheel-chairs, hearing aids, prosthetic equipment, medications or medically prescribed diets, special eyeglasses or other assistive devices for independent living or work. There are serious limits, however, in that certain items may not qualify or the special needs budget may be exhausted.

Some provinces, such as Alberta and Ontario, have set up a designated income program intended only for persons with disabilities. The Ontario Disability Support Program, for example, provides income benefits to persons over age 18 who meet the definition of disability and are in financial need. Recipients also may be eligible to receive prescription drugs, dental services, eyeglasses, hearing aids, benefits for special diets and special necessities, such as surgical dressings and wheelchair batteries. But problems in access arising from tight eligibility criteria have been reported, including a high incidence of legal appeals [Torjman 2000].

v. Tax Credits

In addition to various programs supported by provincial and territorial ministries of health and/or social services and/or education, there are several relevant federal income tax measures: the medical expense tax credit, disability tax credit, infirm dependant tax credit and caregiver tax credit. These measures do not pro-vide any supports directly but rather help offset their cost once purchased by a household.

a. Medical Expense Tax Credit

The medical expense tax credit reduces the cost of a designated list of disability supports. Because the credit may be claimed in respect of the health-related expenses of an individual, spouse or dependants, it is available to all Canadians and not just persons with disabilities.

Total medical expenses must be more than $1,614 or three percent of net income, whichever is less. The expenses deemed eligible for the credit include:

- payments to medical practitioners, nurses and hospital services
- attendant care
- registered nursing services, including home care
- care at a school or institution where special care and training are provided
- ambulance services
- personal transportation for medical care (trips over 40 km.)
- travel costs of an attendant
- medical devices (e.g., artificial limbs, wheelchairs, braces, eyeglasses and a list of prescribed devices)
- expenses for guide and hearing-ear dogs
- expenses related to bone marrow and organ transplants
- home modifications for accessibility
- rehabilitation therapy
• prescribed drugs
• diagnostic services
• dental services
• contributions to private health services plans

There is a separate employment and training related deduction for attendant care (up to $5,000) if the individual is entitled to claim the disability tax credit. The expenses must have been paid to a person who is not a spouse and who is 18 years or older. The expenses must have been paid for care in Canada that enabled the individual to earn income from employment or self-employment, take a designated training course, or conduct research or similar work for which a grant was received. (These costs cannot be claimed as medical expenses.)

b. Disability Tax Credit

The disability tax credit provides modest tax relief for the additional — but often hidden and indirect — costs of disability. In contrast to the medical expense tax credit, there is no designated list of allowable expenses. The hidden costs of disability include, for example, higher utility costs for heat or air conditioning, additional transportation costs, higher prices for goods because of fewer shopping choices and reduced capacity to earn income.

There are also hidden costs related to the care of children. A child with a disability may require, for example, a trained caregiver rather than a babysitter. The child with a disability may need a caregiver or babysitter even at an age when a child typically would not require such supervision. Other hidden costs include dietary supplements, special toys, adapted equipment, tailor-made clothing or other goods, such as diapers.

In order to qualify for the disability tax credit, claimants must have a physical or mental disability that is severe and prolonged, which markedly restricts their ability to perform one or more activities of daily living all or almost all of the time. ‘Prolonged’ means that the impairment has lasted or may be expected to last for a continuous period of at least 12 months. ‘Severe’ and ‘markedly restricted’ mean that all or almost all of the time the person is unable, or requires an inordinate amount of time, to perform a basic activity of daily living, even with therapy and the use of appropriate devices and medication.

The specific diagnosis or condition is irrelevant. What is important is the impact of that condition upon the person’s ability to carry out one or more basic activities. These include feeding and dressing oneself; eliminating (bladder or bowel functions); walking; perceiving, thinking and remembering; and speaking and hearing so as to be understood in a quiet setting, by another person familiar with the individual.

The 2000 federal Budget introduced several changes to the disability tax credit. It brought in a supplement of up to $500 to provide more assistance for the caregivers of children with severe disabilities. Eligibility for the disability tax credit was broadened to include individuals with severe and prolonged disabilities who require extensive therapy on an ongoing basis. The unused portion of the disability credit may be transferred to a wider group of supporting relatives, such as siblings or aunts and uncles.

c. Infirm Dependant Tax Credit

The infirm dependant credit is available to the caregiver of an infirm dependant who must be age 18 or older and must have a net income of less than $13,853. While the income tax provisions provide no clear
guidance as to the meaning of ‘infirm,’ the credit may be claimed in respect of dependants with physical or mental disabilities. The lack of standard eligibility criteria and information about the credit means that there is no consistency in who claims the credit and in the determination of eligibility.

d. Caregiver Tax Credit

As of the 1998 taxation year, a caregiver tax credit may be claimed by taxpayers who maintain a dwelling, either alone or with another person, in which an adult dependant lives. The credit is intended to provide some support for family caregivers. The dependant must have been born in 1980 or earlier. The dependant must be reliant upon the taxpayer by reason of mental or physical infirmity, except for taxpayers’ parents and grandparents over 65 for whom evidence of infirmity is not required. The dependant must have a net income of less than $13,853.

i. Availability

The availability of personal supports varies widely throughout the country. The current ‘system’ – such as it is – defies simple description. It is a hodgepodge of public and private arrangements. Provinces and territories (municipalities in some jurisdictions) are responsible for the provision of these supports. In many cases, nonprofit organizations actually deliver the services - when these happen to be available.

The supports that may be provided in one jurisdiction may not exist elsewhere. The services to which individuals have access are a function of where they live. Problems of availability are particularly acute in rural and northern regions of the country.

The provision of technical aids and equipment illustrates the complexities of the system. As noted, patients in hospitals or special residences generally receive the aids and equipment they need as part of their treatment. Access is far more complex for persons living independently in the community.

Ministries of education or health usually assume the cost of technical aids and equipment for children in public schools. Adults gain access to technical aids and equipment through different routes, depending on the jurisdiction and types of programs in which they are involved. Those participating in some form of rehabilitation or training funded under an employment or income program, such as workers’ compensation, may receive these supports as part of the program. Individuals not involved in rehabilitation or training – e.g., they may be at university, seeking work or at home – generally must make provision for special needs on their own.

Problems with Personal Supports

While there appear to be many avenues for obtaining personal supports or offsetting their costs, the current ‘system’ is plagued by myriad problems. Many Canadians who require assistance to live independently or who want to participate in education, training or the labour market are unable to do so because they have limited access to these supports [Crawford 1997].

Forty-four percent of persons with disabilities are not in the paid labour force; they cite barriers and other disincentives, such as lack of supports, as the reason. One-quarter of Canadians with disabilities on income support programs cite loss of supports as a reason for not looking for work. Problems have been identified with respect to availability, cost and responsiveness.
Goods and services that are more health-related in nature usually are provided through various health settings and are delivered without charging additional user fees because these supports are considered ‘insured services’ under medicare. But user fees may be charged if the services are delivered outside a hospital, clinic or physician’s office or at home.

Persons with disabilities also may be denied access to supports because of age; level of income; the nature, cause and severity of their condition; or participation in training or the labour market. In some cases, for example, medical diagnosis rather than functional ability is the primary eligibility criterion for certain equipment, such as wheelchairs. Persons with disabilities may be denied access to a given support because they do no have the ‘correct’ diagnosis even though their functional capacity may be almost identical to those with the designated condition.

Traditional service providers who carry out needs assessments often define consumer requirements within the parameters of their own services. If an agency delivers homemaker assistance, for example, a person’s needs typically are translated into a given number of hours of that service. Similarly, when a health care worker determines needs, these take the form of hours of nursing or therapy.

Aboriginal Canadians with disabilities face even more barriers. (The percentage of aboriginal Canadians with disabilities is more than double the 16 percent national average.) They too experience a lack of personal supports and serious problems related to availability and access. But their problems are compounded by jurisdictional complexities. Their eligibility for personal supports is determined not only by the factors earlier identified but also by their status – whether they are Inuit or have been deemed by government to be Status Indians, non-Status Indians or Métis.

ii. Cost

Affordability creates problems of access. The cost of personal supports can be prohibitive and only limited assistance is available to help offset these costs. The national Health and Activity Limitation Survey estimated that some 36 percent of adults face costs related to their disability that are not reimbursed by any public or private plan [Crawford 1997: 6].

The cost of certain supports can be reduced by various income tax measures. As noted, the medical expense tax credit helps offset the cost of a designated list of personal supports. The disability tax credit also provides some tax relief for the additional expenses associated with disability.

But these tax credits are not without their problems. While the medical expense tax credit, for example, currently comprises a long list of allowable claims, many areas are not covered. Nutritional supplements are excluded, for instance, even though these are essential for persons with certain conditions, such as AIDS.

The credit also gives scant recognition to the care provided by families. The current tax credit helps offset the medical expenses incurred for care delivered by professionals primarily outside the home. Yet many families with a child who is disabled provide hours of care – often around-the-clock – to their child at home. Ironically, the cost of this child’s care would be paid for fully or at least partially by governments if the parents were to place the child in a home or institution - an unacceptable and inappropriate solution [Torjman 1999].

There have been some minor
enhancements to the medical expense tax credit in the past few years. The 1998 federal Budget announced that a medical expense claim may be made for the amount paid for a tax filer, or the relative of the tax filer, to learn to care for an individual who is mentally or physically infirm. The infirm individual must live in the taxpayer’s household or depend on the taxpayer for support.

The 1999 Budget allows a medical claim for the amounts paid to individuals providing care and supervision in a group home for persons with severe physical and mental disabilities who are eligible for the disability tax credit. This is an admittedly small but welcome measure. The change does nothing, however, to afford additional assistance to families looking after their members at home, again reinforcing the institutional bias of the credit.

Perhaps the most serious problem with the medical expense tax credit is that many persons with disabilities could not benefit from its provisions. Prior to 1997, the medical expense tax credit was nonrefundable. This means that the credit reduced income taxes owing but did not benefit Canadians with incomes below the taxpaying threshold. The medical expense credit was therefore of little or no assistance to very poor households.

The 1997 Budget rectified this problem somewhat by making the credit partially refundable. It announced that the existing medical expense tax credit would be supplemented by a refundable tax credit for low-income working Canadians with high medical expenses. The maximum credit is the lesser of $500 and 25 percent of eligible medical expenses. Taxfilers must earn at least $2,000 to qualify for this refundable portion.

While this change is an important step in the right direction, the fundamental problem remains. Low-income earners typically cannot pay up front for medical expenses, even if they will be reimbursed later.

Households that have no access to technical aids and equipment through an existing program or that derive no benefit from current tax provisions must purchase these goods and services on their own. Those who cannot afford to make the up-front payments generally must rely on provincial and territorial welfare programs to help offset these costs.

While welfare may provide last-resort assistance, it is a classic case of ‘Catch 22.’ The provision of this ‘income-in-kind’ makes it difficult to move off welfare for fear of losing special supports. An improvement in financial circumstances through employment, inheritance or other source means that persons with disabilities risk their security, and possibly their lives, if they cannot gain access to these supports.

Moreover, there is no guarantee that welfare actually will pay for all – or even some – disability supports. If a province or territory has exceeded its special needs budget prior to the end of the fiscal year, it may decide to stop paying for special assistance until the next fi-cal year. The required item may not be included in the list of permissible costs altogether – e.g. a wheelchair designed for sports or recreation may not be covered.

iii. Responsiveness

Even when personal supports are available or affordable, problems may arise around responsiveness. Supports for persons with disabilities need to be highly individualized. Each person requires a different configuration of personal supports - a unique package to meet his or her needs.

Supports often are not available at the
place they are required. While some services may be provided to individuals in their own homes, these may not be delivered in settings such as public schools, workplaces or recreation centres.

Certain services operate as though they are needed only between 9:00 a.m. and 5:00 p.m., Monday to Friday. Individuals typically have little say in how services are delivered or managed. Consumers often are afraid to voice their concerns for fear of personal reprisal or losing the service altogether.

**Approaches to Reform**

There are several approaches to improving the availability, affordability and responsiveness of personal supports. One route involves incremental improvements to the existing system: enhancing the quality of existing services, ensuring that persons with disabilities have more income to purchase supports and providing more avenues for offsetting costs.

The quality of existing services could be improved in several ways. An important start would be to ensure that consumers have more say in the governance of these services to ensure their appropriateness and responsiveness.

There are also many possible options for bolstering the income of persons with disabilities [Torjman 1996b; Beatty 1992; Muszynski 1992]. Increased income would enable persons with disabilities to purchase the supports they require.

Another possibility is to improve various tax-related measures [Torjman 1999; Beatty and Baker 1996]. As noted, specific reforms include enhancing the value of the medical expense tax credit, increasing its refundable portion and expanding the list of items that may be claimed.

The disability tax credit also can be made refundable to provide some assistance to persons too poor to pay income tax. Its eligibility criteria can be relaxed somewhat to ensure that persons who could qualify are not left out. The rules now require that the impairment be continuous for at least 12 months, effectively eliminating many individuals with severe and prolonged disabilities that happen to manifest themselves episodically or intermittently rather than chronically. The infirm dependant tax credit can be enhanced and gradually extended downward in terms of ages covered.

But none of these options – improving the quality and responsiveness of existing services, bolstering basic income or offsetting costs through tax breaks – does anything to expand the supply of available supports. There still would be fundamental problems of access.

A more far-reaching proposal for reform focuses upon building the supply of personal supports. The existing network of personal supports not only must be improved. The network also must be expanded because it is inadequate to meet the range of needs of persons with disabilities. Nor will it be sufficient in future to respond to the increased demands of an aging population.

One way to augment the network of services is through a Personal Supports Fund that invests in the network of provincial and territorial services. The Fund also would allow for the payment of supports through individualized funding, described below.

This proposal is consistent with the spirit of the Social Union Framework Agreement. In February 1999, the federal and provincial/territorial governments except Quebec signed a Social Union Framework Agreement.
Agreement that sets out the general rules for how governments should work together in future. It is intended to promote a respectful and collaborative approach to resolving social issues that are not clearly defined as exclusively federal or provincial. The Agreement speaks to the need to protect the mobility rights of Canadians and the importance of accountability - both priority issues for persons with disabilities.

**Personal Supports Fund**

**i. Purpose**

The purpose of a Personal Supports Fund is to consolidate existing programs and promote the development of a comprehensive network of goods and services throughout the country. The Fund would achieve this objective by expanding the quantity of existing supports, reducing their cost, improving their quality and ensuring their portability across sectors and regions.

The proposal recognizes that the federal, provincial and territorial governments already invest in a wide range of personal supports. The proposed Fund would help generate new and continued investment over a sustained period of time in the provision of personal supports. The federal portion allocated to provinces and territories would be directed toward all three streams of personal supports - technical aids and equipment, personal services and brokerage – and not solely to one area.

**ii. Financing**

To make a real dent in the availability problem, Ottawa would invest a substantial sum of money in respect of personal supports – in the order of $1 billion a year over a five-year period. Federal funds would be divided among the provinces and territories according to a formula based on projected population growth and economic need.

The federal investment is intended to lever similar provincial and territorial contributions derived from a combination of sources: provincial and territorial revenues, municipalities, community funds and geared-to-income fees. Subsidized goods and services would be available to low-income individuals and households.

In order to ensure adequate investment as well as stability in the financing arrangement, the Personal Supports Fund would set out a five-year schedule of funding. Adequate and stable funding is an essential prerequisite to a successful initiative. The arrangement would be evaluated after three years and modified accordingly. It would be assessed again and renegotiated at the five-year point.

While provinces and territories would be the primary beneficiaries of federal funds, the disability community would be actively involved in decisions regarding the design, delivery and governance of personal supports in all jurisdictions.

The proposed financing would take the form of a block fund that would allow flexibility in design and delivery and would enable the integration of disparate supports. The integration of these services would help eliminate the barriers created by current funding arrangements, which effectively require artificial distinctions among health, social and educational services.

Another major strength of this proposal is that a Personal Supports Fund would establish a national mechanism separate from income programs to provide for personal supports. It no longer would be necessary for persons with disabilities to apply through welfare systems or to rely on
a given income program in order to obtain essential supports.

Despite the flexibility that the proposed Personal Supports Fund would allow with respect to program design and delivery, it nonetheless would operate according to clear guiding principles to which provinces and territories would adhere in order to receive federal funds.

This practice is consistent with the current funding arrangement for medicare. The Canada Health Act sets out the key principles which provinces and territories must respect in order to maintain federal transfers. All jurisdictions would be required to provide financial and program information on their use of dollars allocated under the Personal Supports Fund.

iii. Guiding Principles

The system of personal supports would operate according to a clear set of guiding principles identified as essential in reports over the years, including A Consensus for Action: The Economic Integration of Disabled Persons [Canada 1990]; the Mainstream Review [Federal/Provincial/Territorial Ministers 1992]; The Grand Design: Achieving the Open House Vision [Canada 1995]; Equal Citizenship for Canadians with Disabilities: The Will to Act [Federal Task Force 1996]; and In Unison: A Canadian Approach to Disability Issues [Federal - Provincial - Territorial Ministers 1998]. The principles identified in these reports include self-determination, comprehensiveness, accessibility, portability and accountability.

Self-determination is a central guiding principle. Ideally, all services would be self-directed and self-managed in order to meet individual requirements. Consumers would play an active role in the design and planning of personal supports at the policy level as well as in their local governance to ensure responsiveness. Direct cash payments in the form of individualized funding (described below) could be made to allow greater choice and flexibility.

Comprehensiveness: Personal supports should be available within a coherent system, assuring a wide range of goods and services. The system would be 'seamless' in that these goods and services would be available wherever required rather than in disaggregated pieces that fall under the auspices of education, health care, social services, employment or recreation.

Accessibility means that personal supports would be available to all Canadians who need them. Functional ability would be the primary eligibility criterion. Access would not be based on such factors as age, employability or cause of disability. The Quebec method of determining eligibility by functional ability is an exemplary model.

The principle of portability seeks to ensure that persons with disabilities have access to the forms and levels of support they require in any part of the country without having to establish residency, undergo a waiting period or 'present with' a certain medical condition. Personal supports would follow the person – into the classroom, training program, workplace, home or recreation facility. The provision of personal supports would not be tied to a designated location or income program.

To honour the principle of accountability, governments would agree to organize in their respective jurisdictions an advisory group consisting primarily of the consumers of personal supports. These groups also would include representatives from the service-providing community, and the research and policy sectors. Governments would be expected to
monitor the provision of personal supports and report publicly on their progress on an annual basis.

**A Note on Individualized Funding**

The purpose of the proposed Fund is to bolster the supply of personal supports throughout the country. In some cases, however, provinces and territories may wish to ensure the availability of certain supports by means of individualized funding.

Individualized funding refers to the transfer of dollars directly to individuals to enable them to purchase personal supports [Torjman 1996a]. Individualized funding allows services to be tailored to individual needs. By definition, it requires differential treatment. In fact, this is precisely what individualized funding seeks to achieve: a unique response to each person’s unique circumstances. The amount of payment is different for every person and is determined on an individualized basis depending on specific needs.

In order to arrive at an appropriate amount of individualized payment, an assessment is carried out – with the involvement of the person with a disability – which identifies the required supports and, in the case of a service, how much time is needed. An amount is allocated for each component of need and a total is determined. The individual then purchases the required supports according to his or her preference.

The dollars enable consumers to create the most appropriate set of arrangements. For example, they may need a certain service early in the morning, in the evenings or on weekends - requirements that are often difficult to meet through traditional provision. Moreover, needs are not necessarily met only through formal services. Often there are other solutions that do not involve traditional service providers.

Individualized funding also has the potential to respond to the lack of disability supports. It is not simply a transfer of dollars to allow consumers greater choice among existing options. It represents, in effect, a form of purchasing power that can play an important role in generating a greater supply of supports. If consumers require various forms of assistance that are not available - and this is particularly relevant to rural and northern regions of the country - then the money to purchase these supports may help create the supply.

Despite the many advantages of individualized funding, there are several potential problems in this arrangement. There are limits to what it can achieve - especially in the short term. It may not produce new services right away or even in great numbers.

Certain services do not appear simply because they are required in a given community. It may take months or even years to develop something like specialized apprenticeship or job coaching arrangements. Appropriate housing will not spring up just because individuals happen to have the money. Many persons with disabilities decide to 'buy a bed' in a group home even though they have individualized dollars because it is the only realistic option; the group home may be physically accessible, may provide interpreter services, may be well located or may be less expensive than other arrangements.

These limitations mean that funds must continue to be directed toward the supply of personal supports - to ensure the presence of a basic core of goods and services. There must be something to purchase.

A major concern with respect to
individualized funding is the issue of accountability - i.e., how to monitor the use of funds paid directly to individuals. But this concern should not prevent progress in this area; safeguards can be built into any program to ensure accountability. Claimants would enter into agreements with the providers most appropriate to their requirements. Individuals would agree in writing that funds would be spent only for disability-related purposes and that all expenditures would be documented and receipted.

In fact, there is precedent in the country for a widespread system of individualized funding. It is called the income tax system.

**Next Steps**

The next step is the first step. The Federal / Provincial / Territorial Working Group on Disability Supports and Services must begin to put in place a concrete plan for how to improve the availability, affordability and responsiveness of personal supports. Whether it is through this proposal or some other means, there is a pressing need to make real the *In Unison* commitment to action.

**References**


Torjman, Sherri. (1994). *Small Technicality; Big Problem.* Ottawa: Caledon Institute of Social Policy, April.


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MARK YOUR CALENDAR

FOR ARCH’S AGM

The next Annual General Meeting of ARCH will be held on February 27, 2001, weather permitting, or March 1, 2000. Advance notice will be given to ARCH member groups via ARCH ALERT. Consider your nominees for Board membership now! To receive your nomination form, contact the Nominations Committee of the Board, c/o Phyllis Gordon at ARCH, 255-40 Orchard View Blvd., Tor., ON M4R 1B9 (416) 482-8255, email at gordonp@olap.org.
In Memoriam

Marsha Forest was an important figure in the disability rights movement and a good friend of ARCH. She was co-founder with her husband, Jack Pearpoint, of Inclusion Press and the Centre for Integration and Community. With permission from her husband, we are reprinting the obituary that appeared in the Globe and Mail and the Toronto Star on June 10, 2000.

FOREST, Marsha-Educator, Author, Publisher, Organizer, born August 10, 1942 in Brooklyn, New York. Moved on June 2, 2000, Toronto, Ontario. With her husband Jack Pearpoint by her side holding her hand, and a small circle of friends nearby, Marsha let her spirit move on. Twelve years of battling cancer ended calmly Friday June 2 at 11:30 p.m.

Circumstances make leaders of some of us. Marsha created the circumstance. Chance sometimes brings us to awareness. Marsha didn't leave awareness to chance. She knew we must be aware of the need to accept others. We must build community.

Many try to measure worth by the usual standards of money, things and property. Marsh's value to us all is immeasurable, boundless, because the currency of the heart is love.

For thirty years her message of Inclusion For All worked because it is built by that love. The strength of her spirit challenges us to individually accept her call, her call to do something for others. Friends and colleagues the world over take comfort in the certainty that her work will continue because of its intrinsic value, because it's right! We will remember: Together we're better!

For more information on of Marsha Forest visit http://www/inclusion.com/marsha.memoriam.html.

In Memoriam

Dick Santos was a veteran leader of the disability rights movement. He died in Toronto in October 1999.

Born in the United States and blind from his youth, Dick was a militant in Berkley, California in the early days of the independent living movement in the 1960s. He moved to Canada in 1981 where he lived until his death.

He was a skillful and passionate organizer who was a founding member of Blind Organization of Ontario with Self-Help Tactics (BOOST), a pioneering group advocating for the rights of blind people. He was Provincial Coordinator of Persons United for Self-Help Northwest (PUSH Northwest) and served as President of ARCH in the late 80s where he was loved for his warmth of character and passion for baseball. He played a prominent role in a large number of other disability rights groups.

Dick was recruited by Bob Rae's NDP Ontario government in the early '90s and, subsequently, worked in the Ontario civil service. He was a fighter all his life. At the time of his death from a stroke, he was challenging in court his dismissal from his civil service job by the Harris government on the grounds of discrimination on the basis of disability.

Dick Santos was respected as a highly principled and thoughtful person with a rich sense of humour. He leaves behind his wife, Jennifer Griffiths, a long-time ARCH employee and comrade-in-arms.
ARCH and ARCH TYPE: What's In A Name?

By John Feld

Many people continue to ask what is behind the meaning of ARCH and ARCH TYPE.

When the clinic started in the late '70s, the name ARCH served as the acronym for Advocacy Resource Centre for the Handicapped. In the mid-90s, because many people thought that the word "handicapped" conveyed the wrong message, the name was changed to ARCH: A Legal Resource Centre for Persons with Disabilities. (However, the original name is still the legal name.)

The name for the magazine ARCH TYPE was originally intended as a pun on the word archetype (the letters "ch" in archetype are pronounced like the k in ark), which means, according to the Oxford English Dictionary, "The original pattern from which copies are made; a prototype."

So, if you are puzzled by these names, you have every right to be.

We hope that the services ARCH provides to the community of people with disabilities are much more clear cut.

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DISABILITY AWARENESS IMPORTANT TO ECONOMY

One in ten people world-wide have a disability. In Canada, the disability rate is 17.7% and is rapidly increasing. Therefore, disability awareness training is becoming more important to the economy as well as to the general population.

The New Brunswick Easter Seal March of Dimes is one agency that has placed disability awareness as a top priority. They are a non-profit organization that works in partnership with people with physical disabilities so that they may attain independence and equality of opportunity generally available in the community. They are also dedicated to educating the public on disability issues by providing a variety of services including a library where the public can access information on disability issues and by providing lectures on disability training for employees.

In order to educate more people on disability issues, the New Brunswick Easter Seal March of Dimes developed the Disability Awareness Training (DAT) CD-ROM. The program covers Vision, Hearing, Mobility and Speech disability awareness. "We're targeting employers to increase their comfort level so they may look beyond the disability and see a person with ability", says Glen Hughes, Rehabilitation Technology Coordinator.

Proper training will enable employees to effectively and respectfully serve persons with disabilities. As well, the population is aging and the incidence of persons with disabilities is rising, therefore, it is economically essential for companies to have the skills and knowledge to provide the best service to their patrons. This is a unique training program that all companies and organizations will benefit from.

For more information on the Disability Awareness Training CD-ROM contact:

New Brunswick Easter Seal March of Dimes
(506) 458-8739 or visit their web site at:
www.discribe.ca/crcd/