ARCH·TYPE

the magazine that defends the rights of people with disabilities

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Children, Youth and Disability

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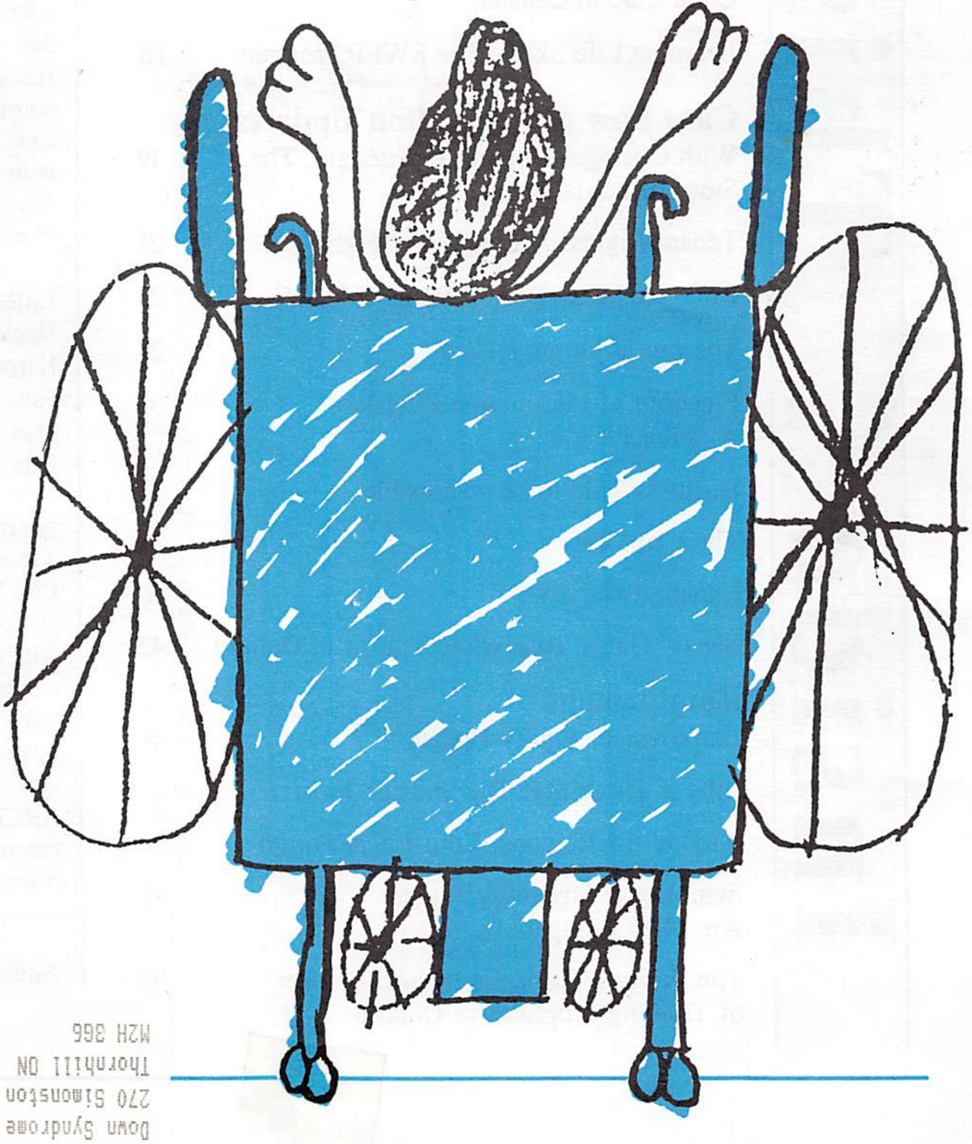

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Guest Editorial

Generation X Confronts Seniority in the Disability Movement

Randy Warren

Every great movement in the world, whether based on morality or out of the ashes of oppression has survived or flourished when its tactics, approach and leadership change.

This statement is particularly true for the movement of people with disabilities. Our struggle has been a long one around the world with a rich history and many victories. For far too long, the struggle was one of basics where year after year, we simply hoped for recognition and worked to be noticed as a disadvantaged group. We struggled to be permitted equal access to a real education, and to have a voice at the table to determine our own futures. We have won many victories, but have many more to achieve that are as yet unimaginable.

History proves that a movement dies with an aging leadership, or stagnates when dominated for too long by one individual or a small group of individuals.

The success of people with disabilities in affecting changes in attitude, living standards and laws cannot be denied and can be traced to the last 30 years. Many of the people who worked for these changes are the leaders of the Disability Movement today. In fact, most of the leadership of the disability community are their early fifties and older.

It can be argued that if this trend continues, the movement for change for people with disabilities will stagnate and eventually die, having to recharge without any foundation.

Young men and women with disabilities living today have grown up with the changes made as facts in their lives. The dreams of our leaders are reality for these individuals, and those realities are now the starting point of their dreams, hopes and aspirations. Since they are starting from different realities, their expectations and attitudes are also different.

However, the Canadian disability rights movement does not allow for new participants, ideas and strategies. It seems that our movement has become one of cliques worried about losing some imagined power. Today, we have one of the most educated populations of individuals 25-40 years of age who are effectively shut out of the decision-making process and whose views are translated by another generation. Worse than that, we have youth and young adults with disabilities controlled by service providers or parents.

Youth and young adults must be allowed to assume important roles in the movement, drawing on the resources and great knowledge of their predecessors. They can then look into the mirror of wisdom, and see not only their role models, but themselves.

Randy Warren is 32 years old. He is a member of PUSH-Ontario Board, the CEO of Thalidomide Victims Association of Canada, Co-Chair of the Advisory Committee for PUSH Youth Network and the Coordinator of PUSH/CAW Project., 519-681-6916 685-1518(fax).

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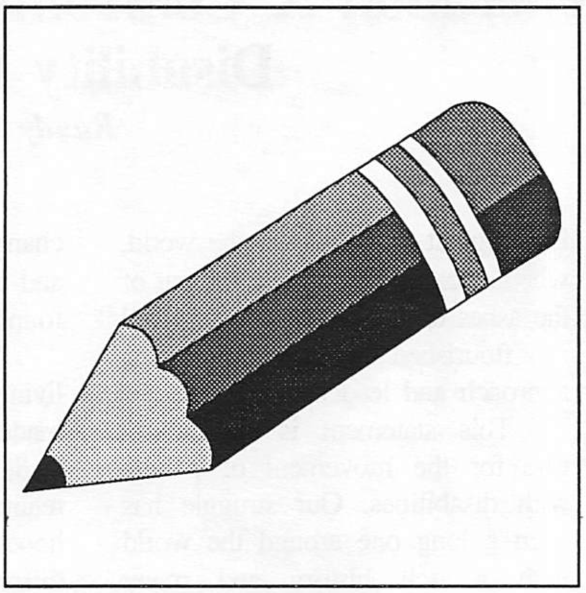
As always, ARCH•TYPE welcomes your comments, reviews or rebuttals on this and other articles.

Are We Finally Getting There? Integrating Students with Developmental Disabilities



By Louise Bailey

It's all well and good to write yet another objective article on integration. But how does that convey the continuing enormous pain and frustration of those of us who have been fighting for equity for students with developmental disabilities for the past decade?

When my daughter was born in 1982 with Down Syndrome, I promised her that she would have as good and full a life as any of the other children in the newborn nursery. These are dreams which I had for her then, and which I refuse to relinquish today. They are the same dreams that any parent has for their child: a good education, friends, a good job, personal fulfilment, -marriage, relationships and family.

However, while the stepping stones in the building of my dreams seem to fall neatly into place for my son, who is a "typical" child, I soon discovered that the "helping systems" in place for my daughter were based on the assumption that she was different, that she would never belong, that there were no dreams.

I, along with other parents, had no idea that when our children were ready for school, they were expected to exist in a kind of parallel universe, otherwise known as special education. At that point it became clear to me and many other parents, and luckily some professionals, that there were major changes which needed to be made in education on our children's behalf in Ontario.

Without going into a lot of history, suffice it to say that in 1982/83, a number of organizations developed whose primary focus was equality for our children. The Down Syndrome Association of Metro Toronto, other Down Syndrome Associations and the Integration Action Group, focused on the right of our children's right to learn in the regular classroom in their own neighbourhood schools, harnessed the imaginations and energies of parents across the country.

I made a presentation to the Standing Committee on Administration of Justice on segregated education in February, 1986. At that time, integration was still very much a contentious and even bizarre idea for many MPPs, not to mention public school boards.

Out of that Committee presentation grew the All Party Working Group on Integration in Education, co-chaired by Lynda Langdon and myself. This Committee raised the consciousness of sitting MPPs and educated them about integration. It also provided a focus for lobbying.

Integration has been a very long andtough battle in which 7 and 8 year old children have been the footsoldiers. Families have made major stands and sacrifices: Court battles, Human Rights Commission battles, education tribunals, keeping their children out of school, moving across the province or country to find inclusive schools, changing their religion, opening their own schools. The pressure they put on school boards and government could not be ignored.

The All Party Working Group lived through three governments. The Ministers of Education refused to see us. With the election of the NDP government (including several MPPs who had been long standing members of the Working Group), our hopes were raised not only for direct access to the Minister, but for long awaited legislative change.

In January, 1990, in a meeting with Lynda and myself, Marion Boyd pledged her Ministry to the implementation of integration with legislated guarantees. This was reaffirmed by her successor, Tony Silipo and once again by our third Minister of Education, Dave Cooke, who speaks very passionately on behalf of our cause.

At this point, the Ministry is working to bring together a wide variety of people interested in the issue (including those vehemently opposed) whom they call stakeholders in an attempt to massage out an integration direction acceptable to all of us.

The parameters of this new direction seem to be somewhat in flux, but basically include: the concept of neighbourhood school, equity of resources (between integrated/segregated class-room), parental choice, a time- line for retrofitting, and disputes over implementation dates ranging from "not soon enough" to "if ever is too soon". The Ministry foresees planning and implementation phases which include legislative guarantees.

> ***Integration has been a very long and tough battle in which 7 and 8 year old children have been the footsoldiers***
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The Ministry has focused on students with developmental disabilities as a priority, and of course we are the community which is demanding it. They appear to be saying that students with other labels may opt in by parental choice. However, they have muddled the waters enough so that groups representing students with other disabilities fear they will lose their segregated settings. Of course, that has resulted in much in-fighting and as usual, the needs and rights of children with developmental disabilities get compromised and pushed to the bottom of the agenda yet again.

Ministry personnel feel they have gone too far down the integration road to turn back now, and are more committed to the issue than ever before. They feel responsible to meet the needs of our children who have not been served well by Bill 82. Dave Cooke is hoping to have something definitive to bring to Cabinet this winter. A climate of expectation has been created.

However, with the exception of Alix Hyset (whose integration victory was a result of a pre-trial settlement), there have been no concrete gains since this government took office. Not one more student with a developmental disability has been integrated in Ontario as a result of the Ministry's evolution towards an inclusive philosophy.

We have a sympathetic Ministry yet to use its power on our behalf. Those of us who represent children's rights in these stakeholders meetings experience great frustration and pain. It is very difficult for us to believe that as we prepare to move into the 21st century, we are still discussing whether or not people with developmental disabilities are entitled to equal rights.

Nevertheless, families and advocacy groups will not give integration for our children from this or any other government.

Integration is not an education issue - it is a civil rights issue. Its time has come. This Ministry and the public school boards have reluctantly come to accept it.

We need all people of good will to support our children in their struggle to move out of the educational backwater into which they have been streamed and slated for a life of dependence and isolation, and into the regular classrooms in our neighbourhood schools where they too can be "one of the kids" and look forward to preparing themselves for real futures.

> *Integration is not an education issue - it is a civil rights issue. Its time has come*
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Louise Bailey is the Executive Director of the Down Syndrome Assn-Tor; 97 Main St., (416) 690-2503.

Freedom to Learn: Children with Learning Disabilities

Pat Hatt

I am not and have never claimed to be a writer. But sometimes the only way to reach a specific audience is through the written word. I will attempt to express my views on the relationship between the public education system of Ontario and persons with learning disabilities.

My interest is quite personal. I have a learning disability that interferes with my ability to read and write. At present, I view myself as quite normal, but that has not always been the case.

The fact that I interacted with the world differently did not adversely affect me during my preschool years. I felt that while I was different, I was not abnormal.

It was when I began my relationship with the formal education system that I began to feel that there was something "wrong" with me.

The teachers and other students didn't call me stupid, but I felt incompetent. I felt that I could not do things the right way, the careful way, the thoughtful way. There was no help available, or known, for the vast majority of children with learning disabilities. It was not to be 'discovered' until the 1960's.

Like other people, whom society views as different, I tried desperately to conform to the norm; I would hide my 'problem' to melt into the 'woodwork'. Like many others who were not mainstream, I believe that the worst years of my life were those I spent in elementary and secondary school.

Later, as I finally passed Grade 13 (after a second try) I went to teacher's college. In the first couple of years teaching, I was drawn to children who seemed to read, spell and write like me. Like all good teachers, I studied these children, and learned how to help them. But I knew that they didn't need to be fixed. They needed to be free to learn and express themselves in their own way, and my job was to assist them. As time passed, I joined the Learning Disabilities Association and helped to bring adults with learning disabilities "out of the closet".

Great excitement and hoopla met the monumental proclaiming of Bill 82 in 1982, and the change in the *Education Act* to give children the right to an appropriate education. Twelve years later, I wonder what has been achieved.

In reviewing the impact of Bill 82 on the education of children with learning disabilities, one of the most glaring areas of discrimination is the lack of an appropriate appeal procedure regarding the type of program in which a child with a learning disability is placed. At present, there is no right of appeal if the program is unacceptable. Only how the student is identified and location/hours of placement can be appealed.

While children with learning disabilities are being identified (more than 44,000 children in Ontario), identification of a learning disability is not enough. Many children are still not being accommodated, and I wonder if they are any better off that I was?

The education system still sees these children as in need of being "fixed". Millions of dollars are spent annually remediating and fixing kids. Good innovative teachers try to squeeze time in their programs to assist these children to understand their learning disabilities and find ways to work with it.

But on the whole, children with learning disabilities are still being judged as "unfixable".

As some accommodation services are now being provided at the community college and university level, and as employers start to fall in line with the *Employment Equity Act*, why is the public education system at the elementary and secondary level still in its infancy in understanding that people with learning disabilities are neither broken nor abnormal, but in need of accommodation. The "fixing" of children seems to be the basis upon which programs for these children were developed.

Children with learning disabilities must be given back the respect that they have been denied. They need to be viewed as normal children with needs for accommodation.

The Government of Ontario recently did an internal review of systems, programs and policies which found systemic discrimination against persons with learning disabilities. If the government wishes to do something about this form of systemic discrimination, it would seem to me that there needs to be a shift in the focus of education for children with learning disabilities.

In my literacy class, I see the result of the lack of respect and access to an appropriate education. The education system of Ontario needs to accommodate these unique individuals and allow them the same opportunities to succeed as it does other children.

Children with learning disabilities must be given back the respect that they have been denied. They need to be viewed as normal children with needs for accommodation. They need to be taught how to deal with their disability in a positive and productive way.

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Patricia Hatt is the Past President of the Learning Disabilities Assn of Ontario and Toronto, and has recently obtained her Master's Degree in learning disabilities from York University. She currently works in adult education with the North York Board of Education.

Deaf and Hearing Youth & Multiculturalism

Tanis Doe

There are quite a few Deaf people who do not consider themselves disabled. Instead, they feel that they belong to a cultural and linguistic minority. Belonging to this minority group, Deaf people use American Sign Language and have a sense of pride in Deaf heritage and identity.

For many young Deaf people, this pride and identity does not come automatically. Most Deaf youth have parents who are hearing and have little exposure to the Deaf community. Some Deaf children with Deaf parents have been raised in the Deaf community since their birth, but most Deaf children have to FIND the Deaf community.

In schools, there is always pressure to conform with the "norm", the hearing students and the society which is, to a large extent, hearing. But Deaf students also feel the need to be "who they are" and not imitations of hearing people. Deaf students in high schools may find a sense of belonging when they meet Deaf adults or have Deaf teachers. In Deaf schools there are more opportunities to explore Deaf culture and activities with the community but many students are not in Deaf schools and often miss the chance to develop a sense of identity in adolescence.

Participants in the ISYD Program

In this way, Deaf students are very much like immigrants as well Canadian born racial minorities. They may attend the same school and become friends with anglo, white Canadians but never feel the sense of connection they do with friends of the same cultural or racial heritage. The major analogy here is language. Linguistic minorities-French, Spanish, Sign Language users, etc., value their uniqueness and feel comfortable in the company of peers.

Deaf youth have not often had the opportunity to explore their similarities and differences with other minority groups because of the "language barrier".

Other reasons include fear, ignorance and lack of interest and the pressure of having to "choose" one identity over another. People who are racial minorities and who are also deaf are often faced with a "choice" between becoming a full member of the Deaf community, or a partial member of their culture of birth. While further disadvantaged groups (e.g., lesbians/gays, ethno-racial minorities, people labelled with developmental and psychiatric disabilities) experience discrimination within the Deaf community, they nonetheless share a common culture and language which creates a strong bond.

On the other hand, while some find a way to talk to their families and are partially assimilated into their communities, as "deaf" people, they are never fully integrated.

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> ***People who are ethno racial minorities and who are also deaf are often faced with a "choice" between becoming a full member of the Deaf community, or a partial member of their culture of birth***
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This past summer, Deaf youth who were ethno-racial minorities and white had the chance to meet students from across the globe. This exciting project was a natural growth from a year-long program to create awareness among international students about the issues of Deaf people and their culture.

Pearson College, otherwise known as Lester B. Pearson College of the Pacific (located on the southern tip of Vancouver Island), is one of several United World Colleges which educate students from all over the world with the goal of international peace and understanding. By living together and sharing experiences about social issues, environmental pro-tection, etc., all students learn to respect each other's differences.

During summers, however, a special activity called the International Seminar on Youth and Development (ISYD) brings together international students and Canadians for a three-week intensive learning experience. Because of the success of one of the community outreach projects to learn about Deaf culture and Sign Language,, it was decided that deaf youth should participate in the Seminar.

In August, 1993, five Deaf youth were part of a pilot project to bring Deaf Culture to the ISYD experience. One Pearson student with sign language skills helped facilitate the week, but most of the 17-19 year olds from developing countries and Canada were novices at Sign Language.

The focus was on Deaf culture as a minority issue which could be compared to other disadvantage groups (e.g., based on race, religion, disability, etc.). Information was provided to discuss the issues of Deaf people in developing countries and there was an attempt to draw parallels between development and disability.

A group of 15 students volunteered to work with the Deaf youth for 5 days during the Seminar. These youth were selected and sponsored by Deaf Youth Canada, a national non-profit organization which provides leadership training and support for Deaf youth.

The first week of the seminar involved learning about development and the environment and in particular, about First Nations and Aboriginal issues. The 15 students in the "Signing and Sharing" Program also had the opportunity to learn basic Sign Language skills and Deaf culture issues. Using videotapes, work-shops, Sign Language instruction and humour, the students communicated with the Deaf youth.

All five Deaf students were enthusiastic participants who made the effort to communicate through writing, gestures, and any other way necessary when

Sign Language did not work. Interpreters were available for formal sessions, but most of the time the Deaf and hearing youth were expected to communicate independently.

Interpretation problems that arose were part of the learning process for all the students. Deaf youth experienced the same kinds of frustration as students from other countries who are sometimes left out or misunderstood. Hearing students learned the difficulties of talking through a third party and of learning with an interpreter all day.

Although most of the hearing students were able to accept the Deaf youth as peers regardless of their "disability" some of the Deaf students resisted being identified as disabled and felt their cultural identity was different. They argued their culture was tied to Sign Language more than tied to physical disadvantage.

A special guest from Alberta, Vincent Chauvet, taught the Deaf students that they must have pride in their language and understand oppression in order to understand Deaf culture. He also presented to the entire group and answered questions. Chauvet's presentation was a highlight for many of the Deaf students who felt proud of having a Deaf leader teach the rest of the program. "Vincent Chauvet was helpful in teaching hearing people a lot about the Deaf. He taught them more about my culture."

There were some instructional meetings but it seems that the most educational part of the entire session was the time that Deaf and hearing youth could interact.

As one Deaf student suggested for future activities:

"Hearing people should be involved more, have more activities together and they will understand more about our culture, and in the future give more support to the Deaf."

It seems that this Deaf youth had ideas very similar to Nobel prize winner Lester B. Pearson, who said:

"How can there be peace without people understanding each other, and how can this be if they don't know each other?"

Pearson College was built as a permanent legacy to Lester B. Pearson, and clearly the campus is being used to benefit all those who visit. Deaf youth who attended this year's pilot project strongly urged organizers to have a fully integrated program with more Deaf students who participate for the entire three weeks.

Funding and adminis-tration of the International Seminar on Youth and Development comes primarily from students in Canada. This pilot project was funded in part through donations and Deaf Youth Canada. In order to have a better, more fully integrated multicultural experience in the coming years, more funding is needed. Deaf youth have a lot to offer to hearing people, and have a lot to learn from people of other cultures. The ISYD Deaf participation project is a real chance to learn a "different" approach to "disability."

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The group is looking for Deaf participants in gr. 11 or 12 for next summer. For more information write to Tanis Doe, #3-1150 Yates Street, Victoria, British Columbia V8V 3M8 or Fax 604-380-7910. Tanis Doe co-ordinated the Deaf Participation project of the International Seminar on Youth and Development, and is active in both development and disability rights organizations. TTY ONLY 604-380-7675.

Youth, Disability & Abuse Prevention

The Centre for Independent Living in Toronto has begun a project looking at the issues of abuse and violence among young people with disabilities. This project started in early October of 1993 (with the recruitment of six participants) and will continue until next summer. The "Youth, Disability and Abuse Prevention Project" is unlike any other project because it emphasizes youth involvement and decision-making. That is, young people with various disabilities are encouraged to take total responsibilty in initiating and planning the project. Six young adults (between the ages of 18-25) are now meeting weekly to share their ideas, concerns and thoughts about abuse prevention. This project has created an atmosphere where young people can engage in frank and friendly discussions. Most of these discussions have been centered on their perceptions of abuse and violence and how this relates to young people with disabilities. In other words, the participants are working together to give their definitions of physical, sexual and verbal abuse, and how it has affected their lives. The youth are constantly being encouraged to explore, share, and identify group needs.

Above all, this project is emphasizing the importance of listening to young people as they share their common

To All Youth Readers!!

This project is being done to try and help ourselves - youth with disabilities everywhere. Unfortunately this will not be possible if you do not take part in the survey that we as a group have put together. There are six youth with disabilities in this research group (our disabilities include cerebral palsy, vision impairment, multiple disabilities, hard of hearing, low vision and a person who had a stroke at the age of 15) and we spend a lot of time on this project. We want to help all youth with disabilities to better understand abuse and violence. It will take just a few minutes of your time but the difference you will make will be well worth it. Please telephone Naz at 599-2458 for information on this survey form. On behalf of myself, John Burlie, and the other Co-researchers (Sricamalan, Christine, Glen, Ray and Gail) we would like to thank you for making this effort to participate in this project.

From The Co-researchers, "Youth, Disability and Abuse Prevention Project" concerns. They are now designing an educational activity that will assist them in further understanding what abuse is. For this purpose, the participants, known as the Youth Co-researchers, are putting together a survey that asks for general information on abuse perception and prevention. At this time we need your help!! If you are between the ages of 18-25 and would like to be interviewed (either by telephone or personally) for this project, please call us here at the Centre for Independent Living (CILT) office at 599-2458. Your name will **not** be mentioned in the study. The project's sucess depends on your involvement, so please contact us!

And They Call It Help: The Psychiatric Policing of America's Children

By Louise Armstrong,
Reviewed by Don Weitz

This book is dynamite - a maddening expose and indictment of psychiatry turned loose against some of the most vulnerable people in society - troubled, confused and abandoned children. Louise Armstrong (author of the critically-acclaimed work on incest, Kiss Daddy Goodnight) reveals how all too many psychiatrists and other "mental health" professionals in children's private "residential treatment centres" and psychiatric hospitals are exploiting and abusing troubled, "out-of-control" kids. Coercive confority, otherwise known as "treatment" is used as a form of social control. Fortunately, Armstrong's delightfully snarky-sarcastic comments save the book from reading like one long horror story.

This treatment given thousands of deeply troubled kids, Armstrong tells us, often turns out to be a hellish nightmare. The treatment prescribed for "Delia", "Mike and "John" consisted of "licensed kidnapping" (Armstrong's apt term for the tactics used by parent-hired private security police officer), psychiatric assault such as forced drugging and staff punishment of solitary confinement, concealed by the euphemism "time out". The active involvement of many child psychiatrists, psychologists, social workers, nurses is not only cowardly and shameful but unethical.

If the treatment doesn't get you, the diagnostic label and stigma will. Armstrong is right to slam the psychiatric sham known more conventionally as psychiatric diagnosis, and its bible officially titled, Diagnostic and Statistical Manual of Mental Disorders (or DSM for short). Armstrong compares this propaganda manual to the Malleus Maleficarum, the official medieval handbook used to invalidate, stigmatize and murder women by labelling them witches.

For daring to show defiant conduct, children in residential treatment centres and psychiatric hospitals are quickly and permanently stigmatized by "diagnoses" such as personality disorder, attention deficit disorder, adjustment disorder, bipolar affective disorder, ad nauseam et absurdum.

Armstrong reminds us that these labels are inherently pernicious and harmful, mainly because they serve as negative stereotypes and social obstacles.

For example, by openly admitting to prior psychiatric hospitalization on college/

university admission and job application forms, children and adults alike inadvertently shut the doors on virtually any educational or professional career. In Ontario, employment application and college admissions forms requesting information re illness, disability or hospitalization violates the *Ontario Human Rights Code.*

"Delia" was one of several child-survivors of parental and psychiatric abuse whom Armstrong interviewed in depth for this book. Delia is (or was) a very talented child. Because of family problems, she lost interest in school, her grades started falling and she got into some drugs. Her father soon arranged to have her picked up (without warning or warrant) by a private police force ("S & L Teen Shuttle"), who forcibly drove Delia to a psychiatric hospital.

> Her hospital records state: ...overall depressed...she has no psychological insight ...she consistently minimizes the extent of her problems...(she) is suffering both a severe personality disorder and a major affective disorder...if appropriate, anti-depressant medication will be instituted...Further residential treatment after hospitalization may be indicated. (pp.37-38).

When Delia resists the treatment, staff suggest "the cure for her disorder is to **break her will** by sentencing her to 8-hour isolation for accepting a cigarette from a friend..." (my emphasis). Because of the various labels and "treatment" imposed on her, Delia is now stigmatized for life and will have emotional scars.

Armstrong also examines the forced drugging with Ritalin of "hyperative" or restless kids, and the racist "violence initiative" proposed by American psychiatrist Frederic Goodwin and the National Institute of Mental Health which targets poor, young Black boys as carriers of an aggression/violence gene.

The solution for inner city violence? Don't eliminate racism - just drug the hell out of Black kids! (see Vol.11 No.2 of ARCH•TYPE).

Although Armstrong focuses on private institutions, there is no doubt that numerous abuses and human rights violations occur in those public/government-run institutions known as children's mental health centres.

No criminal charges have been laid, despite the fact that at least six children's public institutions in Ontario have recently been investigated by the police regarding several allegations of physical and verbal assaults by staff against young children, including racism. There is also the shame of Ontario government stalling re criminal prosecution of several staff who sexually abused over 100 girls in Grandview Training School. Government cover-ups of institutional child abuse continue.

Louise Armstrong has performed a public service in exposing institutionalized child abuse - it is now up to the police, governments, advocates and all of us to start protecting kids in crisis and start laying criminal charges against these professional child abusers. Perhaps one of Armstrong's next books will feature some legal victories for children's human rights and some humane, community alternatives to treatment institutions.

This book deserves to be widely read and put on the reading list of courses in child psychology, child advocacy, sociology and "deviance", and particularly psychiatry. Children in crisis deserve better - a lot better.

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Don Weitz is a psychiatric survivor, antipsychiatry activist, and co-editor of the book, Shrink Resistant: The Struggle Against Psychiatry in Canada (1988).

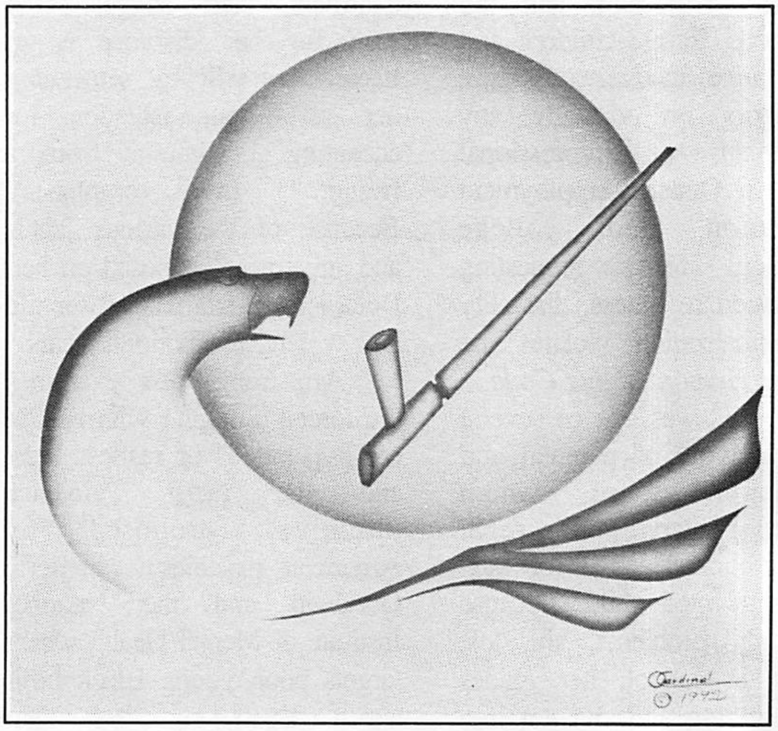
Welcoming Home Aboriginal People with Disabilities

Doreen Demas

In recent years, the Aboriginal community has taken steps to redress the far reaching effects of the residential school system. One group within the Aboriginal community, people with disabilities, continues to be removed from their families and sent to urban centres in order to receive various treatment, services and specialized education.

While the residential school system has been terminated, in 1993 Aboriginal people with disabilities are still being removed from their communities. Many of these individuals are lost to their communities for years, with numerous Aboriginal people with disabilities living out their lives in institutions.

This is particularly true for people with severe mental and multiple disabilities. For the healing of the community to be complete, the issues of persons with disabilities who have been removed from their communities must be factored into current healing strategies.



Drawing from: "Access to the Sweet Grass Trail", Ed. Doreen Demas

Many parallels exist between those who were forced to leave their communities to attend residential schools and those who because of disability left their communities to receive services that are unavailable in their own area. Leaving your community means that you lose contact with your family, culture and language.

While those who attended residential schools at least were among other students who were similar to them in many respects, those Aboriginal persons with disabilities who found themselves in urban rehabilitation settings and segregated schools for disabled children were often very much in the minority. Thus they faced double disadvantage. Not only were they disabled people living in an non-disabled world; they were also Aboriginal people living in a non-Aboriginal world.

During the 1960s, when I was 6, a lack of services made it necessary for me to leave my family and my community to attend the School for the Blind in Brantford Ontario. The school system in my community was not equipped to educate a student with a visual impairment.

Although the School for the Blind was geared to educating visually impaired children, it did not take into account the non-disability needs of students. It was not sensitive to the cultural heritages of students and did not promote contact with their families.

While no one forbade me to speak my language, there was no other person residing at the school who was fluent in Dakota. Thus over time, English became my first language. Home visits were brief and infrequent. I lost meaningful contact with my family, community, language and my culture. In a very real sense, I became a visitor in my own home, in my own community.

My experience was by no means unique. Segregated education was thought to be the best method for educating children with disabilities. All over this country, there are Aboriginal people with disabilities who were removed from their families and educated in segregated facilities. Thus like me, they were deprived of their culture, their language and contact with their families during their formative years.

I was one of the lucky ones, leaving the Ontario School for the Blind as a teenager and returning to my family in Manitoba. While it was not a transition without its problems, I was reunited with my family, and benefitted from receiving some of my education in the non-segregated public school system.

Today, while people with visual disabilities tend to be educated in the public school system, children and adults with developmental, emotional and multiple disabilities continue to be institutionalized. In Manitoba, for example, Aboriginal people with disabilities can be found in St. Amant Centre in Winnipeg and the Manitoba Developmental Centre in Portage La Prarie.

Adults with severe disabilities, such as high level quadriplegia, also find themselves living in nursing homes and other types of institutions.

Aboriginal people with disabilities are incarcerated in institutions, because many Aboriginal communities have not yet established attendant care services and other personal service programs which would enable them to live independently in their communities.

Those Aboriginal people with disabilities who live in institutions have few resources available to help them leave these custodial settings. In many respects, these people have been disempowered by their experiences and continue to remain voiceless in the decision making processes of Aboriginal communities.

Aboriginal communities need to become more sensitive to the concerns of these people. One way for nondisabled Aboriginal people to come to a deeper understanding of the conditions faced by those who are institutionalized is to reflect back on the experiences of those who lived through the residential school system. There are many similarities between these two experiences.

Aboriginal people with disabilities who have been institutionalized, their families and their advocacy organizations must be included in the decision making processes which redress the impact of removing generations of people from their communities.

If this inclusion does not occur, Aboriginal communities will not be able to fully heal themselves, because many families will remain separated from their brothers, sisters, cousins and other family members who have been institutionalized.

Do you have a relative who is living away from your family, because they have a disability and there are no services to assist them in their community? Unfortunately, too many Aboriginal people will be forced to answer yes to this question, because there is a high rate of disability amongst our people, and our communities have not yet established service systems to facilitate community living for them.

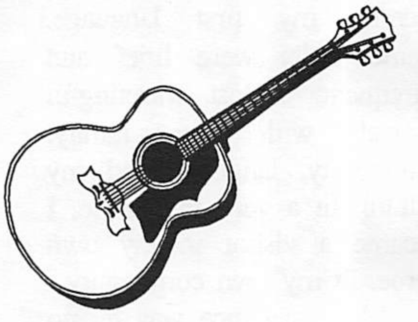
It is time that Aboriginal communities welcome home their relatives with disabilities.

Doreen Demas is the Executive Director of the Manitoba Aboriginal Network on Disability, and currently sits on the Board of Directors of the National Network on Disability.

Right Off The Bat:

A Study of Inclusive Child Care in Canada

By The Roeher Institute
Reviewed by Lisa Weitz



For anyone concerned about disability and children's rights, *Right Off The Bat* is an excellent and timely resource for advocates, families, researchers, child care and health professionals and, most certainly, our newly elected federal politicians.

The book provides a thorough and up-to-date analysis of the child care system (or, rather, non-system) in Canada, and the particular barriers faced by children with disabilities in receiving quality child care in an integrated environment.

While a national policy with legislative guarantees for quality, accessibility, affordability and comprehensiveness is critical for the development of children (**and** for the advancement of women's rights), there has been very little meaningful action beyond formal declarations of principles. In fact, social analysts compare today's child care system to the public education system in the 1850s and 1860s in terms of its fragmentation, complete absence of political mandate, and severe under-funding.

The following figures illustrate this political and legal void as it relates to child care in the 1990s, and certainly should give rise to further political action.

- over 79% of women between the ages of 25 and 44 work in the paid labour force
- one in 20 children under 15 in Canada has a disability
- **less than 4% of Canadian children with a disability have access to child care.**

The first chapter, "The Ball Park: Models of Child Care and Family Support", is in essence, a snapshot of the "child care field" (including such community programs as respite care, peer support and play groups developed by families in response to the distinct needs of children with disabilities). The second chapter focuses on how we come to see what's in this picture, what the authors call "The Rules of the Game".

This includes a definitive description of the legislative and political framework at the federal, provincial, territorial and local levels. What becomes clear, since there is no national "coach", is that no one plays by the same rules.

Each province/region varies

in licensing and regulatory standards, the level of funding child care receives, and training. The one "rule of the game" each of the regions seems to follow is political inaction. Nowhere in Canada is integrated childcare legislated.

The chapter, "Not A Level Playing Field.." delves further into the implications of this legislative void, particularly the onus it places on parents, child care providers, women's and disability rights advocates to lobby for political action to develop programs in their local communities.

Locating funding sources, wading through bureaucratic red tape and and actually seeing some results, is a testament to their hard work, despite the odds against winning the game.

Some of these "odds" include: stringent eligibility criteria, high cost of services, system discretion, lack of linkage to other services (e.g., transportation, therapies, etc.), mile-long waiting lists, lack of funding for accommodations, and staff training. These are only a few of the numerous problems plaguing child care integration efforts. The additional barriers faced by Native and other racial "minority" children with disabilities are also discussed. It is little wonder that some parents are wary of taking their children out of special needs (segregated) programs, given the void that currently exists in integrated child care.

Their final chapter, "Home Plate" is especially forward looking and empowering. It provides excellent models for goal setting, outlining all the essential elements of quality,accessible child care. The social, moral (and economic) cost of ignoring strategies to "reach home plate" and make the transition from segregated to inclusive child care is one we can't ignore. These models will help all players get there, especially the children. This book is a "must read" for the Prime Minister and his new government.

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Right Off The Bat is available from the Roeher Institute, Kinsmen Bldg, York University, 4700 Keele St. North York ON M3J 1P3, (416)661-9611, 661-2023 (TTY).

Learning Life Skills: The SWEP Program

Brian Masse

What types of summer jobs have you held as a student? Perhaps you have worked at a summer camp providing activities, supervision and guidance for children, worked preparing foods in the busy kitchen of a restaurant that was enjoying brisk summer business; or applied your typing or data entry skills at a professional office?

These are just some of the positions students with a developmental disability occupied during the summer of 1993. Like all ambitious students, participants in the Summer Work Experience Program (SWEP) had the opportunity to participate in the work force and gain valuable life skills necessary to attain employment upon their graduation from school. Jessica, who worked as a day care assistant, feels it is important to work as a student "...to get experience to have a background for when I get a job". Another student, Christina, feels it is important, "to get experience in the work force. So that on my resume, when I go for a job, they can see the work experience that I have had in the past." This summer, Christina's job description included word processing, data entry and organization of documented files.

> ***The most important feature of SWEP is the experience of community integration***
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The SWEP program consists of three staff providing "supportive employment" for students with a developmental disability living in the Mississauga community. Guided by the Support Services department of Community Living Mississauga, SWEP staff provide resources and leadership necessary to ensure effective coordination of the program.

The objective of SWEP is to assist students to successfully find and maintain eight weeks of work experience in a fully integrated work setting. This summer, SWEP provided fourteen students vocational support at a variety of positions including counsellor, store clerk, car washer, person friday, bicycle assembler and day care assistant.

Vocational support depended upon the needs of each individual student. Some students required additional training to learn new tasks, while others requested the occasional visit or assistance to learn independence skills. Learning a transit system, for example, provides a student with autonomy and freedom of movement. Jessica comments, "I think that when I have help, like on the bus, it keeps me going...so that I can go to places on my own". Similarly, Matthew worked at an automobile lot, moving, cleaning and washing cars. The majority of his support consisted of two visits every week to talk and discuss work related issues. He commented on supportive employment, "It's good. Because if there are any problems you are there. I just like talking to someone".

The initial stage of SWEP is to meet with participating students and their families to find areas of interest and career oriented goals. Once jobs related to these specifications are defined, SWEP staff canvass the Mississauga business community looking for summer employment positions or work experience corresponding to what a student has specified. When interested employers are discovered, the student is interviewed giving the opportunity for employers to interview a prospective employee. If the student has a successful interview, s/he begins summer employment. Whether the student volunteers for a work experience opportunity or finds paid competitive employment, the student, employer and SWEP staff must agree that the student is to be treated as any other employee.

Although the SWEP program offers rare supportive employment services for students with a development disability, there are number of obstacles which limit the scope of the student's experience.

One primary concern is the degree and hours support staff may spend with each individual student. An ideal situation would provide the student access to more support time, and employment for longer than eight weeks. However, because there are only three SWEP staff members, each student participating in the program can only receive a certain amount of support hours each week.

Decisions regarding hours of employment, SWEP staff support and goal setting are made jointly between all three parties. SWEP encourages students and employers to come to a mutual agreement regarding whether a person requires additional support and to what degree.

Another limitation is that once the SWEP program concludes, the employment situation usually does as well. Some employers and students would participate part time in the fall and winter but SWEP staff are no longer available.

> ***People with disabilities are part of the society...People like me shouldn't be turned down for a job but be accepted for who we are so that people can know who I am and what I am like***
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To address this problem, SWEP has begun to make students aware of strategies to find and maintain employment on their own. This year, for example, students and their families were given an information package detailing employment strategy tips for resume writing, interview skills, and techniques used to market oneself to employers.

Despite these limitations, SWEP provides youth the opportunity to learn, make decisions, build self esteem and help with the transition to adulthood. Christina commented on her work experiences, "...I always wanted a job, it has changed me dramatically because I have a lot of experience. Before I would have a negative attitude about work, but now I have a positive attitude about work".

These basic life opportunities have a profound impact simply because experience is an education which cannot be substituted. In fact, experience as a means of education, is an important criteria for transition from adolescence to adulthood.

Decision making and responsibility are exercised in new patterns. Matthew feels "It helped me, I had a summer job which was pretty good. I just like working and getting paid.".

In addition, many of the skills on the job translate to practical tools often used in daily life. Penny worked at a restaurant this summer. "I wanted to learn how to cook, to prepare food...because it would be nice not to stay at home but work...I was in a restaurant, prepared foods, frozen foods and put them in bags, a prep." Comparable to all teenagers, participants in SWEP are building skills necessary for personal growth and professional development.

However, the most important feature of SWEP is the experience of community integration. Community integration provides real opportunities and dispels myths often associated to persons with a disability. Jessica states, "Yes it is important to me. When I'm volunteering I get to meet new people". Similarly, Christina advocates:

> "Support for people with a disability in the work force is important for them to know what its like to work with someone who has a disability. They show that people with disabilities shouldn't be left out and not getting a job. Because people with disabilities are part of the society...people like me shouldn't be turned down for a job but be accepted for who we are so that people can know who I am and what I'm like.".

For more information about SWEP, and to participate or set up a service in your area, contact Nancy Stafford at: Community Living Mississauga, 2444 Hurontario Street, 3rd Floor, Mississauga, Ontario, L5B 2V1 or phone (905) 615-1630.

Brian Masse was a Vocational Support Worker and Co-ordinator of SWEP, and is currently researching a Masters thesis on the vocational employment of persons labelled with a developmental disability.

With Courage, Humour and Strength: The Story of Laura Booth

Prologue (by Anne Molloy)

In June 1989, Laura Booth filed a human rights complaint of discrimination on the basis of disability against the Board of Education for the City of Etobicoke. At the time, she had just completed Grade 2 at Dixon Grove Junior Middle School. Laura has spina bifida and uses a wheelchair. Her complaint was about the inaccessibility of her school. ARCH was her legal counsel.

The complaint wound its way through the Ontario Human Rights Commission process until March 1993 when the Commission appointed a Board of Inquiry to conduct a hearing into the complaint. At that point, some but not all of the school's accessibility problems had been addressed. As part of the preparation for the upcoming hearing, ARCH asked Laura to reflect upon how the lack of accessibility at her school affected her and perhaps to write about it. What follows is her article written in the spring of 1993, accompanied by an illustration drawn by her sister, Leslie.

Make Our World Without Stairs

Laura Booth

When buildings were built in the past, with stairs, only people without disabilities were thought of. People with disabilities have just as many rights to get around in a building as people who don't have disabilities. Stairs are barriers to a person who uses a wheelchair.

When I first went to school, all of my classes were on the ground floor, but as the years have gone by, I have run into many problems with the stairs. Some of my grade 3, 4 & 5 classes were upstairs. I was left alone in the classroom. That made me feel very left out. Some of the classes sounded really interesting and I felt like I was missing out on learning and it hurt. How would you feel if you were in this position? I want to be independent and be able to go to all of the classrooms just like everyone else.

I have a Stair Track at my school and I only got it this year. I have to depend on somebody to run the machine because it is not made to be operated by the person riding on it, ME. It also takes a long time to get me ready because someone has to take my anti-tipper bars and backpack off of my wheelchair. Otherwise, my wheelchair won't fit on the stair track. By the time we take the stuff off my chair, get me loaded onto the stair track and up the two flights of stairs, I'm really late for my class.

Another thing is that sometimes the person who regularly takes me upstairs is away, so either one of my two vice-principals or my principal takes me up. Sometimes when the person who usually takes me upstairs is away and both vice-principals and principal are busy, I have to stay downstairs and go to the library and work on

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homework from the previous class.

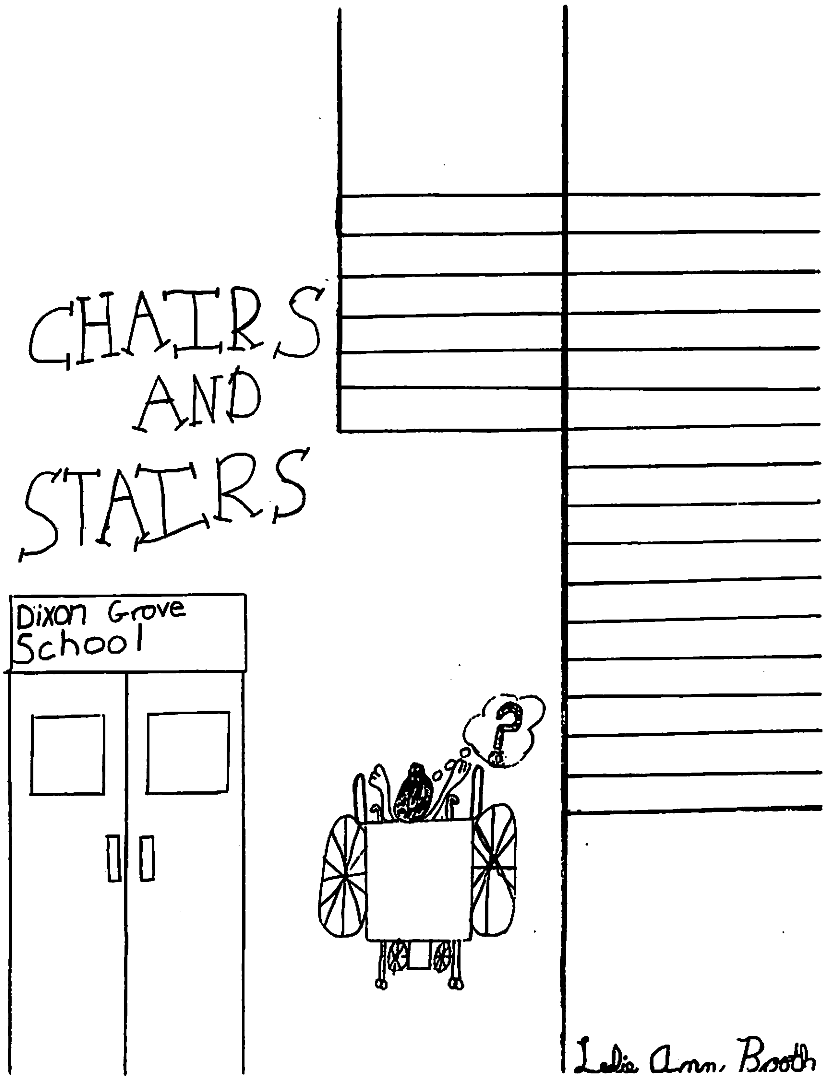
I want an elevator in my school. I want to be independent. If I had an elevator, I wouldn't be late for class. I wouldn't have to wait for other people to assist me.

When the school board thinks about this sort of thing, all they think about is the cost and not how it affects the person with the disability. Even many of the teachers in my school don't understand why I need the elevator and why it is important to me.

One of my teachers at my school said, "It seems like a waste to spend so much money on one person". I thought to myself, "we are all individuals, we all have the same rights. You don't know what I am going through. You are not in this position". It made me mad. It made me furious. It made me hurt inside. If that teacher is ever in my position, then she'll know how it feels to hear such comments.

I do not look at myself as being different. I am just a person sitting down, not standing up.

The world was not built for me and other disabled people. I hope what I am doing today will pay off for other children, so that they won't have to go through what I have...**And I sure hope I get that elevator!!**



Epilogue (Anne Molloy)

Laura's story had a happy, although not perfect ending. The human rights hearing was adjourned to permit the parties to discuss settlement and ultimately an agreement was reached in the fall of 1993.

Laura did not get her elevator. By then, she was in Grade 7 and the passage of time had made it a virtual impossibility to have an elevator installed before her graduation from Dixon Grove school.

However, the high school Laura will be attending is fully accessible to students with disabilities.

The settlement argument was based on firm commitments by the school board to ultimately make all its facilities, including its own head office, fully accessible to persons with disabilities. The school board approved and developed a plan to implement that commitment over time with priority given to:

- full accessibility for all new construction and major renovations
- retrofitting facilities which offer unique programming
- ensuring that accessible schools are strategically located so that students can remain in their own communities.

The settlement terms required the school board to provide some additional ramping at Dixon Grove School, to relocate one of Laura's classes from the second floor to the ground floor, and to use its best efforts to schedule Laura's programs to minimize the necessity of having to take the Stair Track to the second floor. The Board also agreed to distribute the principals and vice-principals a policy statement on the steps which should be taken to accommodate students with disabilities and to make that issue a discussion item for their next principals' meeting.

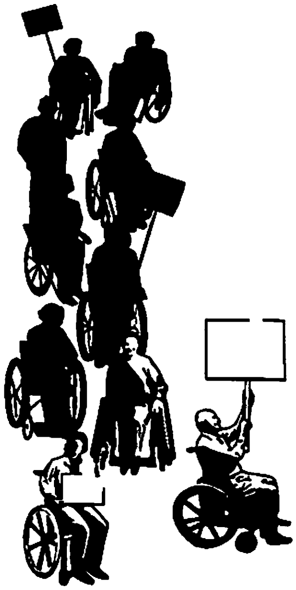
When it came to the issue of damages, Laura decided not to seek any financial compensation for herself. She exaplained that for her, the important thing was to change things for other students. The Board agreed instead to dedicate a minimum of $3500 to retain speakers for a full-day training session on disability awareness and accessibility for its staff, to be developed in consultation with the Human Rights Commission and ARCH.

ARCH salutes the Etobicoke Board for its positive attitude towards accessibility for all people, regardless of disability, and for their willingness to deal with this issue in a broad and systemic way. Most of all, we applaud and congratulate Laura Booth, a young woman with courage, humour and the strength of her convictions. It is heartening to find such insight and leadership abilities in young people, the future of the disability rights movement.

Anne Molloy is Legal Counsel at ARCH,

Tenant Rights - A Long Hard Fight

Patti Bregman and David Baker



It was a long, hard fight for persons with disabilities to escape institutions. Since services are required in some form or another, it was assumed that institutional living was the only option. However, the persistence of disability rights activists finally paid off, and living in the community was not only a dream, but a reality. For those who succeeded in moving to the various types of housing in the community, such as boarding homes, senior's apartments and Support Service Living Units (SSLUs), the change was dramatic - at least at first.

The institution followed people with disabilities into the community. Instead of being subject to the control of institution staff, they were subject to rules set up by service providers

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After the honeymoon was over, people began to see that the institution followed them into the community. Instead of being subject to the control of institution staff, they were subject to rules set up by service providers. The powerlessness, the repression of dissent and the dehumanizing inflexibility of institutional living were still all there.

Although there are many reasons why community living retained an institutional feel, one major problem stemmed from the fact that protections provided under the *Landlord and Tenant Act* did not cover people living in housing where care is provided because they did not fall under the provisions for residential tenants. Since many service providers were also landlords, they claimed to be exempt from the residential tenancy provisions. Therefore, the protection that most tenants have from arbitrary eviction and their rights to have the property kept in good repair were not available to many people with disabilities. As a result, service providers could use the threat of eviction to keep tenants in line and compliant.

The pervasiveness of this problem became clear to the ARCH intake staff and lawyers received an increasing number of calls from tenants living in various types of supported housing, who felt that they were treated arbitrarily by their landlord-service providers. They feared that if they pursued their rights, they would be evicted and, because of the lack of alternatives, forced to return to an institution.

Initially, ARCH involved the Ministry of Community and Social Services (COMSOC) through the Office of Child and Family Advocacy Services. Since many of the services were funded through COMSOC, the Ministry could intervene in the most extreme cases through operational reviews of the services provided. In some cases, just the threat of a review was enough to result in at least a temporary change in the attitude and behaviour of service providers.

> ***Protections provided under the Landlord and Tenant Act did not cover people living in housing where care is provided because they did not fall under the provision for tenants***
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It was clear, however, through the increase of intakes about problems in supported housing environments, that the Child and Family Advocacy Office had only limited success. ARCH began to consider other ways of approaching the problem, including restructuring the way in which services are provided, and changing the *Landlord and Tenant Act.*

One suggested approach was to increase the number of SSLUs in which tenants had control over the services and/or housing by participation on the Boards of Directors. Organizations such as Handicapped Action Group Inc. (HAGI) in Thunder Bay voluntarily agreed to be subject to the *Landlord and Tenant Act*. In practice, this meant that HAGI's tenants have the option of seeking services from an organization other than HAGI without losing the right to occupy their apartment. The threat of eviction could no longer be used to control a tenant's behaviour.

During this period, ARCH was not the only legal clinic getting more calls about the problems faced by tenants with disabilities living in housing where services are provided. The Advocacy Centre for the Elderly was getting calls from seniors complaining about outrageous rent increases because this type of housing is not subject to rent review. Neighbourhood Legal Services also received calls from tenants living in non-profit housing which provided "facilitative management", supposedly a form of care for people who are "hard to house". They were also denied protection of the residential tenancy provisions of the *Landlord and Tenant Act.*

The tenants affected by this lack of protection were particularly vulnerable because there is little in the way of alternaltive housing. There are long waiting lists for accessible, affordable housing, so tenants either end up "on the street" or in an institution if they are evicted. While tenants are not always right, in many cases, they had justifiable complaints. In this type of situation, injustice and abuse can exist unchecked.

Although organizations such as ARCH were aware of these problems, there was little awareness on the part of the general public. That changed in 1990 when Professor Ernie Lightman was appointed to review the situation with respect to unregulated housing. The review came about as a result of joint efforts by the legal clinics, including ARCH, and front-page stories about the death of a tenant in an unregulated boarding house. Professor Lightman's report, A Community of Interests, was released in the spring of 1992. One of the major recommendations was to amend the *Landlord and Tenant Act* to eliminate the exemption from residential tenancy protection for people living in housing where care is provided.

At first, there was little action. However, within months of the report's release, funding was given to Persons United for Self Help (PUSH) Ontario to establish a Tenants' Rights Advocacy Project (TRAP) to help tenants with disabilities from tenant organizations and fight for their rights. Sam Savona is the staff person responsible for the project. Within months, an advisory committee working with Sam began to develop a strategy to organize tenants and to lobby for the amendment recommended in the Lightman Report.

The fight was not an easy one and success came only after a concerted effort by TRAP, the Roomers and Boarders Coalition and other tenants' rights groups. Their efforts were bolstered by a series of court challenges seeking to strike out the exemption section in the *Landlord and Tenant Act* on the grounds that it discriminated against people with disabilities, and was therefore contrary to s.15 of the *Canadian Charter of Rights and Freedoms.*

> ***The tenants affected by this lack of protection were particularly vulnerable because there is little in the way of alternaltive housing....Tenants either end up "on the street" or in an institution if they are evicted***
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The Peterborough Legal Clinic, acting for a group of nine tenants with disabilities, brought an application to prevent their eviction from a retirement home, Rubidge Hall. The landlord wanted to evict the tenants, most of whom have developmental disabilities, so that it could bring in tenants who could pay higher rents. PUSH Ontario, the Federation of Metro Tenants and other tenants' groups intervened in this case in support of the Peterborough tenants. It has not yet been argued in court.

In Windsor, two tenants who were threatened with eviction at the Apartments for Living for Physically Handicapped (ALPHA) also took legal action. For both of these tenants, eviction would have meant returning to an institution. ARCH was retained as counsel, and filed an application to challenge the exemption section last spring. That case was adjourned until April, 1994 to await the outcome of the proposed legislation (Bill 120). In the meantime, the court granted an interlocutory injunction that prevented ALPHA from withdrawing the services or housing while the case proceeds. Also, Citizen Advocacy Windsor and Concerned Citizens, both of which have board members residing at ALPHA, have been very active in seeking to ensure that tenants' rights are protected, and have played a major role in supporting the tenants who are involved in litigation.

The political lobbying by TRAP and other tenants groups focused on the Minister of Housing, Evelyn Gigantes. Although the Ministry of Citizenship was the lead Ministry initially dealing with the Lightman Report, the Ministry of Housing took over that role on an interministerial committee. There were several meetings with Ministry staff and several demonstrations which made it clear that this was an issue about which people were willing to fight long and hard.

On November 23, 1993, the results of this work paid off. The Minister of Housing introduced the Residents' Rights Bill (Bill 120) which, among other things, will give tenants in housing where care is provided the same rights as all other residential tenants in this province. This came one week after the ALPHA case in Windsor was adjourned in anticipation of the introduction of this piece of legislation. The adjournment is until April 1994 to give the government an opportunity to pass the legislation.

If passed, Bill 120 will benefit all tenants with disabilities living where care is provided, particularly those in SSLUs, most group homes and seniors apartments. The Bill received 2nd reading on December 8, 1993 and the Minister expressed the hope that it will receive 3rd reading in the spring. It will be considered by the Legislative Committee January and February. All members of the public are invited to make submissions.

For the tenants at ALPHA, the story is not over. ALPHA sent letters to tenants within days of the introduction of Bill 120 saying that they cannot continue to provide attendant services unless the government changes the proposed legislation and, therefore, will terminate services March 31, 1994.

The Windsor Star reported that ALPHA claims 25 jobs will be lost and 22 residents forced into nursing homes or other institutions. However, the Long-Term Care office in Windsor sent letters to the tenants on the same day assuring them that the services will not be interrupted.

While the tenants were initially shocked, they immediately turned to their advocacy groups, Concerned Citizens and Citizen Advocacy Windsor, and faced the situation head on. They have initiated meetings with the Long Term Care office, and on Sunday, December 12, 1993, tenants attended an initial meeting to consider forming a tenants' association. There are still legal matters involved and ARCH continues to represent the two tenants, but for the first time, the tenants feel that they may soon have control over their lives.

Whatever the outcome, it is clear that the empowerment of tenants with disabilities has come a long way. Even after the care exemption disappears from the *Landlord and Tenant Act*, issues remain about how services will be provided, and what rights consumers have with respect to those services. It is important that people continue to be active and engaged. It is only through active participation and making your voice heard that changes to benefit people with disabilities will come about.

The Clerk of the Standing Committee on General Government is holding public hearings on Bill 120. Make your views known. Write to the Clerk of the Standing Committee on General Government, Room 1405, Whitney Block, Queen's Park, Toronto ON M7A 1A2. Deadline is January 31.

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If you'd like to get involved in tenant issues, contact Sam Savona, Coordinator, TRAP PUSH, 1700-180 Dundas St. W., Tor, (416) 596-1766 (voice), 974-9390 (TTY).

David Baker is the Executive Director of ARCH. Patti Bregman is a staff lawyer working primarily on community health and housing issues.

Bill 120: Residents' Rights Bill: What Does It Really Mean?

Patti Bregman

On November 23, 1993, the government introduced Bill 120, the Residents' Rights Bill. This Bill provides tenants with disabilities the same rights as other tenants in Ontario by amending several Acts including the *Landlord and Tenant Act* and the *Rent Review Act.*

How does it change the rights of tenants in Support Service Living Units (SSLUs)?

The changes to the *Landlord and Tenant Act* (LTA) are simple. Right now, there is a section in the *Act* that says tenants living in apartments where care is provided are not residential tenants and therefore don't have the protection ordinarily given to other tenants. This includes some SSLUs. The Residents' Rights Bill eliminates that exemption and defines tenants living in all SSLUs as residential tenants.

What are the rights?

There are a number of rights under the residential tenancy sections (Part IV) of the LTA. Some of the most important are:

- **Lease**: You have a right to get a copy of your lease and service contract.
- **Repairs**: Landlords must keep their buildings safe and clean and make sure things are working well.
- **Eviction**: Tenants can only be evicted for the reasons listed in the *Act* such as non-payment of rent or if the landlord needs the apartment for their own use or the use of their immediate family. The landlord must tell you the reason for your eviction in the notice. If you disagree with the reason, the landlord must go to court and you have an opportunity to respond. Only a judge can make you move!
- **Services**: A landlord cannot withhold vital services such as heat, fuel, electricity or other services that are required under the lease.
- **Harassment**: A landlord cannot try to get you to move or prevent you from enforcing your rights by making rules that interfere with your use of the property.If the landlord breaks these rules, tenants can go to court. The judge can tell the landlord to stop or to give back some rent money to the tenant.

How Will This Affect Attendant Services?

The Residents' Rights Bill does not deal directly with attendant care services. In most SSLUs where the LTA now applies, the lease and service contracts are completely separate documents. In an increasing number of cases, the landlord and service provider are two separate companies or organizations.

However, because of the rights tenants have under the LTA, it means that you cannot be evicted just because you are not getting some or all of your services from the landlord. Therefore, even if you get your services from a different provider, you will still be allowed to remain as a tenant in your apartment.

The government is now looking at ways to protect your rights in the area of service contracts.

The Sue Rodriguez Case

Anne Molloy

Sue Rodriguez has amyotrophic lateral sclerosis (ALS). She was concerned that she might want to end her life at a point when, because of the effects of her disease, she would no longer have the physical ability to do it on her own. Her quest through the courts for the right to an assisted suicide captured the attention of the nation.

She argued that section 241 (b) of the *Criminal Code* (which prohibits assisted suicide) violated her constitutional right to life, liberty and security of the person under s.7 of the *Canadian Charter of Rights and Freedoms* and had a discriminatory impact on persons with disabilities, contrary to s.15 of the *Charter*. Her case was unsuccessful before the British Columbia Supreme Court and the British Columbia Court of Appeals. She then appealed to the Supreme Court of Canada. The media attention centering on her case sparked a national debate on the ethical pros and cons of this issue.

The issues raised were not easy ones for anyone, but the debate was a particularly difficult one within the disability community. On the one hand, disability advocates recognized immediately that at the heart of the case was the right to self-determination and the dignity of choice - principles which are the very foundation of equality rights for persons with disabilities.

On the other hand, it was impossible to ignore the real vulnerability of persons with disabilities and the danger for these people if assisted suicide were legalized without safeguards to protect against abuses.

As the date for argument of the Rodriguez appeal in the Supreme Court of Canada approached, various groups sought leave to intervene. COPOH (now the Council of Canadians with Disabilities) retained ARCH and was among those groups granted standing before the Supreme Court. Other interveners included religious and pro-life organizations, the Physicians for Life Society, Dying with Dignity, the B.C. Coalition of People with Disabilities and People in Equal Participation Inc. (a disability group from Winnipeg, Manitoba). The case was argued in the Supreme Court of Canada on May 20, 1993. The argument was televised live for only the second time in the Court's history. Judgment was released on September 30, 1993. In a split five-four decision, the Court denied Ms. Rodriguez's request.

COPOH's position before the Supreme Court of Canada

COPOH's position before the Supreme Court of Canada reflected the diversity of views in the broarder disability community. COPOH supported Sue Rodriguez's right to exercise her free will to be acommodated if, because of her disability, she needs physical assistance to exercise that choice.

Taking one's own life is not a crime in Canada. But it is not an option which is open to somebody who, because of disability, is unable to commit suicide without some assistance. COPOH argued that the *Criminal Code* provision prohibiting assisted suicide has a disparate impact on persons with disabilities and, therefore, violated the equality rights guaranteed by s.15 of the *Charter*.

However, COPOH was careful to distinguish the situation of assisted suicide from that of euthanasia or "mercy killing," in which the decision to end a person's life is made by somebody else.

COPOH also argued the Court to consider carefully the vulnerability of persons with disabilities and to recognize the need for safeguards to ensure that decisions to have an assisted suicide are made as an exercise of free will, with knowledge of what the options are, and without any coercion or undue influence.

COPOH recognized that there are valid reasons for enacting protections to prevent abuse in the area of assisted suicide, although we said as well that a complete *Criminal Code* prohibition simply went too far and broad in its application.

The Supreme Court of Canada Decision

Note: Judges are referred to as Justice (J.) Justices (JJ.) and Chief Justice (CJ.) The Supreme Court of Canada ruled against Sue Rodriguez. Five judges concurred in the majority decision. Separate dissenting judgments were written by Chief Justice Lamer (concurred in by Cory, J.) and by McLachlin, J. (concurred in by L'Heureux-Dube and Cory, JJ.).

(i) The Majority Decision

The majority of the Court (Sopinka, J. writing on behalf of himself and La Forest, Conthier, Iacobucci and Major, JJ.) dealt with the case under s.7 of the *Charter*. Sopinka, J. affirmed that:

> *"the right to personal autonomy, at least with respect to the right to make choices concerning one's own body, control over one's physical and psychological integrity and basic human dignity are encompassed within security of the person, at least to the extent of freedom from criminal prohibitions which interfere with these."*

On this basis, s.241 (b) of the *Criminal Code* was found to deprive Sue Rodriguez of her right to security of the person. The Court's analysis under s.7 does not end there, however, but goes on to consider whether that deprivation was in accordance with the principles of fundamental justice.

In this regard, the Court balanced the individual rights against the state interest underlying s.241 (b) (which is to protect vulnerable people and uphold the sanctity of life). The Court concluded that the *Criminal Code* provision was in accordance with fundamental justice and that there was, therefore, no violation of s.7.

The majority decision does not deal with s.15 of the *Charter*. Instead Sopinka, J. found that even if s.15 was violated by s.241(b) of the *Criminal Code*, the provision was saved under s.1 of the *Charter* as being a reasonable limit.

The analysis under s.1 was similar to the fundamental justice analysis under s.7. The Court found that the government had "a reasonable basis for concluding" that s.241 (b) did not go too far in protecting vulnerable people. It seems clear, from the language, that the Court considered this to be a delicate balancing process and preferred to leave to Parliament the" fine-tuning" in matters of this nature. As stated by Sopinka, J.:

> *"it is not the proper function of this Court to speculate as to whether other alternatives available to Parliament might have been preferable."*

(ii) Chief Justice Lamer's Decision

The Chief Justice wrote a dissenting judgment (concurred in by Cory, J.) based on an analysis of the case under s.15 of the *Charter*. In doing so, he confirmed that the concepts of adverse impact discrimination developed under human rights legislation will be applicable to s.15 of the *Charter*.

He also rejected as absurd any suggestion that legislation that is broad in its application cannot be discriminatory, and emphasized that it is the **effect** of the legislation which is important. He cited with approval the Saskatchewan Court of Appeal decision in the Huck case, which held that identical treatment of persons with disabilities is meaningless without accommodation and accessibility.

Having concluded that s.241(b) of the *Criminal Code* had an unequal effect on persons by depriving them of any ability to commit suicide without breaking the law, the Chief Justice went on to consider whether that unequal effect amounted to discrimination.

It could only be considered to be discriminatory if it constituted a disadvantage or burden. In deciding that there was a disadvantage, Lamer, C.J. declined to consider the theological, moral or philosophical questions of suicide. Rather, he focused on the importance of individual and self determination and found that it was the removal of choice for persons with disabilities which created the infringement of s.15 of the *Charter*.

Having found a s.15 violation, the Chief Justice went on to consider whether this violation could be saved under s.1 of the *Charter* and concluded that it could not. He recognized that s.241(b) was legitimately directed towards protecting vulnerability but found that it was too broad in its application under s.1.

His words in this regard are well worth repeating. He stated:

> *"It was argued that if assisted suicide were permitted even in limited circumstances, then there would be reason to fear that homicide of the terminally ill and persons with physical disabilities could be readily disguised as assisted suicide and that, as a result, the most vulnerable people would be left most exposed to this grave threat. There may indeed be cause for such concern. Sadly for our society, increasingly less value appears to be placed on the lives of those who, due to illness, age or disability, can no longer control the use of their bodies. Such sentiments are often shared by persons with physical disabilities themselves, who often feel they are merely a burden and an expense to their families and society as a whole."*

Moreover, as the intervener COPOH observed in its written submissions:

> *" the negative stereotypes and attitudes which exist about the lack of value and quality inherent in the life of a person with a disability are particularly dangerous in this context because they tend to support the conclusion that a suicide was carried out in response to those factors rather than because of pressure, coercion or duress."*

While I share a deep concern over the subtle and overt pressures that may be brought to bear on such persons if assisted suicide is decriminalized even in limited circumstances, I do not think legislation that deprives a disadvantaged group of the right to equality can be justified solely on such speculative grounds, no matter how well-intentioned.

Similar dangers to the ones outlined above have surrounded the decriminalization of attempted suicide as well. It is impossible to know the degree of pressure or intimidation a physically able person may have been under when deciding to commit suicide.

The truth is that we simply do not and cannot know the range of implications that allowing some form of assisted suicide will have for persons with physical disabilities.

What we do know and cannot ignore is the anguish of those in the position of Ms. Rodriguez. Respecting the consent of those in her position may necessarily imply running the risk that the consent will have been obtained improperly. The proper role of the legal system in these circumstances is to provide safeguards to ensure that the consent in question is as independent and informed as is reasonably possible.

In my view, the fear of a "slippery slope" cannot justify the over-inclusion reach of the *Criminal Code* to encompass not only people who may be vulnerable to the pressure of others, but also persons with no evidence of vulnerability and, in the case of the appellant, persons where there is positive evidence of freely determined consent.

Sue Rodriguez is, and will remain, mentally competent. She has testified at trial to the fact that she alone, in consultation with her physician, wishes to control the decition-making regarding the timing and circumstances of her death. I see no reason to disbelieve her, nor has the Crown suggested that she is being wrongfully influenced by anyone.

The issue here is whether Parliament is justified in denying her the ability to make this choice lawfully, a choice that could be made by any physically able person

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Ms. Rodriguez has also emphasized that she remains, and wishes to remain, free **not** to avail herself of the opportunity to end her own life, should that be her eventual choice. The issue here is whether Parliament is justified in denying her the ability to make this choice lawfully, a choice that could be made by any physically able person.

Therefore, Chief Justice Lamer would have found in favour of Sue Rodriguez and would have granted her an individual remedy. In terms of the broader constitutional remedies, he would not have immediately struck down s.241 (b) but would have suspended operation of the declaration of invalidity for one year in order to give Parliament time to enact a more precisely tailored protection if it wanted to do so.

In the mean time, he proposed that other individuals in situations like Sue Rodriguez's could apply to a superior court for a constitutional exemption.

(iii) Madame Justice McLachlin's Decision

Madame Justice McLachlin (with L'Heureux-Dube and Cory, JJ. concurring) elected not to decide the case under s.15. She wrote:

"I have read the reason of the Chief Justice. Persuasive as they are, I am of the view that this is not at base a case about discrimination under S.15 of the charter...and that to treat it as such may deflect the equality jurisprudence from the true focus of a.15 - "to remedy or prevent discrimination against groups subject to stereotyping, historical disadvantage and social prejudice in Canadian society (R. v. Swain)."

She then goes on to consider the case under s.7 of the *Charter*. On the issue of deprivation of security, her rationale is similar to that expressed by Sopinka, J. They differ substantially, however, on the issue of fundamental justice. McLachlin, J. found that depriving persons with disabilities of a right to choose to commit suicide when non-disabled persons were free to do so could not be consistent with fundamental justice.

Therefore, she found that a.241 (b) of the *Criminal Code* violated s.7 of the *Charter*. She further held that the provision could not be saved under s.1 because it was overly broad.

Conclusions

The Supreme Court of Canada ruled against Sue Rodriguez. As such, the decision is a considerable setback to the advancement of the right to autonomy and self-determination of persons with disabilities.

There is, however, much in the reasons for the decision which will be helpful in disability rights cases to come. The most obvious illustration of this is, of course, the decision of the Chief Justice on s.15 of the *Charter*. While it is concurred with by only one other judge, it must be noted that none of the other judges expressly rejected it either (with the possible caveat that McLachlin and L'Heureux-Dube found s.15 to be inapplicable without expressing reasons).

Chief Justice Lamer's decision on s.15 - as it relates to disability discrimination and, in particular, adverse impact disability discrimination - is outstanding in its logic and in its grasp of the reality of disability-based discrimination. It will be of considerable assistance in equality rights cases to come.

> ***Chief Justice Lamer's decision on s.15 - as it relates to disability discrimination and, in particular, adverse impact disability discrimination... will be of considerable assistance in equality rights cases to come***
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There is also much which is helpful in the decision of McLachlin, J., particularly with respect to the finding that depriving persons with disabilities of a choice that is given to other persons cannot be in accordance with fundamental justice.

Even the majority decision is helpful in the general rulings that the right to human dignity and self-determination are part of the right to security to the person under s.7 of the *Charter*.

The majority decision dealing with the fundamental justice component of s.7 is disappointing in that it permits an overriding moral view held by the state to take priority over the self-determination of persons with disabilities.

It must be remembered, however, that Rodriguez is an extreme case in its facts; future courts may be less willing to balance fundamental justice in favour of the state in a case which is not literally determinative of life or death. Accordingly, there are some considerable gains for disability rights in the broader perspective to be found in the Rodriguez decision. As for the more specific concerns about assisted suicide, the responsibility for reform now rests squarely on Parliament's shoulders.

Four of the nine judges on the Supreme Court bench found that s.241 (b) was overly broad in its application. The other five upheld it under s.1, but did so on the basis that fine distinctions of this nature should be made by governments rather than courts.

It now remains for disability rights advocates to capitalize on the gains made in the decision. They must work towards requiring Parliament to institute real and effective safeguards that will both protect vulnerable people and support the right of autonomy for persons with disabilities.

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Freedom of Information Decision: A Setback

Patti Bregman

On September 24, 1993, the Information and Privacy Commission released a decision which dealt with the obligations of the government to accommodate people with disabilities when responding to requests for personal information. The case was about a request for copies of the individual's Vocational Rehabilitation Services record. The requester, who has a visual disabilityd, asked that one copy be sent to him in regular type and the other in 24-point-bold print.

The Ministry provided him with a copy of his file in regular print but refused to provide the enlarged format. They argued that they had allowed a Ministry staff person to spend several hours with the individual and his wife reading parts of the record and that the cost of providing the entire record in large print would be too expensive (estimated at $2,688.

Although during the course of mediation the individual was provided with 39 pages of the record in large print, he proceeded with his appeal of the Ministry's decision relying on the *Freedom of Information and Protection of Privacy Act (FOIPPA)* and the *Human Rights Code.*

Section 48(4) of the *FOIPPA* deals with the disclosure of information. It requires that information be disclosed in a "comprehensible format". The Ministry argued that this means that the format would provide an opportunity to understand the information. They also argued that the copy provided to the individual in this case could be shown to a doctor or professional to be interpreted, and that the requester was given assistance by the Ministry staff.

The lawyer for the requester argued that the standard should be that the form is comprehensible to the individual.

The Assistant Commissioner in this case followed an earlier decision of the former Chief Commissioner Linden who ruled that the test of what is comprehensive should be based on an objective standard; i.e., whether the average person could understand the record. As a result, the Assistant Commissioner ruled that in this case the Ministry complied with its obligation under s. 48(4) of *FOIPPA.*

The Assistant Commissioner also considered whether the *Human Rights Code* must be considered in interpreting s. 48(4) of *FOIPPA*, in particular ss.1, 11(1)(a) and 11(2). Section 1 prohibits discrimination on the bass of "handicap" while s. 11 deals with, among other things, undue hardship.

The decision states that the *Human Rights Code* must be used as a guide when interpreting the provisions of *FOIPPA.* He concluded that:

> ...had the Ministry interpreted s. 48(4) of the *Act [FOIPPA]* based on an objective standard and applied the provision in this fashion without any effort to assist the requester, there would have arisen a restriction of the appellant's rights as a handicapped person pursuant to s. 11(1)(a) of the *Code [Human Rights Code]*, and a prima facie breach of the provisions of the *Code.*

However, he also stated that he believed the Ministry took steps to accommodate the individual and that they do not need to transcribe the entire file into large print.

The Assistant Commissioner, however, added a postscript to his decision urging the government to develop clear guidelines for access to records by persons with visual impairments for both personal and general information.

Information & Privacy Commission Order P-540/ Sept. 24, 1993; Appeal P-9200830 (Ministry of Community and Social Services).

Business Told To Be Accessible

Stephen McCammon
& Helen Wagle

If you are a person with a disability and you have been denied access to a service or facility customarily available to the public, don't give up hope! In 1993, people with disabilities fought and won important victories in two precedent setting human rights decisions, on in Ontario and the other in Saskatchewan.

In October 1991, Judith Ryan, who is "physically reliant on a wheelchair", and who had been a resident of the same Regina neighbourhood for two and a half years, filed a complaint with the Saskatchewan Human Rights Commission. She argued that Henry Ripplinger, the respondent and sole proprietor of Collections Fine Arts Gallery and Henry's Cafe, (hereafter Henry's Gallery and Cafe), was in violation of section 12(1) of the *Saskatchewan Human Rights Code (Sask. Code).* That section of the *Sask. Code* requires that "no person... shall... deny to any person the...services or facilities to which the public is customarily admitted...because of the...disability of that person or class of persons..."

The Board of Inquiry continued, declaring that Henry Ripplinger "...had failed to establish...that the cost or business inconvenience that would be occasioned in the provision of amenities and ramps would constitute an undue hardship"

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As Judith Ryan discovered on her first visit to Henry's Gallery and Cafe, all of the facilities at Henry Ripplinger's place of business were inaccessible to a person using a wheelchair. When she noticed that extensive renovations were being made to Henry's Gallery and Cafe, Ms. Ryan called and asked to speak to the owner. In asking if the building would be made wheelchair accessible, she was told by the person on the phone that he was not sure.

After noticing that the renovations had not made the building wheelchair accessible, she filed a complaint with the Saskatchewan Human Rights Commission. After the Commission's attempts to negotiate a settlement with Mr. Ripplinger failed, a Saskatchewan Board of Inquiry was appointed by the Minister of Justice.

In Ryan v. Ripplinger, the Board of Inquiry held that Henry Ripplinger was "in violation of section 12 of the *Code* in that...[Henry's Gallery and Cafe]...denies access to persons with a physical disability." The Board of Inquiry continued, declaring that Henry Ripplinger "...had failed to establish...that the cost or business inconvenience that would be occasioned in the provision of amenities and ramps would constitute an undue hardship."

Under the *Sask. Code*, the

term "undue hardship" is defined in a set of regulations. Section 1(d) of the regulations says that: "undue hardship; means intolerable financial cost or disruption to business." This section goes on to list four areas for a Board of Inquiry to consider when deciding whether or not a particular set of accommodations constitutes undue hardship.

The Board of Inquiry looked at the financial stability and profitability of the business. It examined the value of the building and the property and compared that to the cost of providing physical access to a wheelchair user. In assessing the essence or purpose of the business, it noted that "the purpose of the business is to offer services to the widest possible public. Everyone enjoys eating and most people enjoy art."

Finally, it laid out the effects on employees and customers of providing ramps and wheelchair accessible washrooms.

As a result of its contextual analysis, the Board found that Henry Ripplinger could make his business wheelchair accessible without undue hardship. According to Ripplinger's own figures, the cost of making Henry's Gallery and Cafe fully accessible would be $30,000. The Board of Inquiry outlined that since he performed most of his own renovations in the past he could probably do so in the future and that in any case he need not make all of the changes indicated in the $30,000 estimate to comply with the *Sask. Code.*

Henry Ripplinger was ordered to renovate his business so as to make it wheelchair accessible. The type of renovations was to be determined by Mr. Ripplinger in consultation with the Human Rights Commission, but if the parties could not reach an agreement, the Board of Inquiry would be reconvened to make specific orders. Mr. Ripplinger was also ordered to pay Ms. Ryan $500.00 compensation.

In the municipal region of Niagara-on-the-Lake, Ontario, Marjorie Elliot, another woman who uses a wheelchair, initiated a complaint against Epp Centres Inc. which operates Village Green Plaza. The trouble started for Marjorie Elliot when she decided to have lunch one afternoon in 1988. She and a friend headed for a restaurant at the Village Green Plaza, but could not find accessible parking in the plaza parking lot.

Ms. Elliot uses a motorized wheelchair and drives a van equipped with a lift device. As a Board of Inquiry noted, "...these two pieces of technology give her a fairly high degree of independence and mobility despite her severe handicap. On the other hand, these two pieces of technology require that she have a wider than usual parking space." It was in her search for suitable parking that Marjorie Elliot encountered discrimination in contravention of section 1 of the *Ontario Human Rights Code (Ont. Code).* That section says that "every person has a right to equal treatment with respect to services, goods and facilities, without discrimination because of...handicap."

While at the Plaza, Ms. Elliot could find neither a designated "handicapped parking" space nor a double space that would allow her enough room to operate her lift. What she did find however, was a large entrance way that already had a car parked in it. She parked there, but was ordered to leave. A man who identified himself as the owner of the plaza told her "I don't want you here."

When Ms. Elliot pointed out that she was disabled, that she had stickers designated her vehicle as a special vehicle, and that she could not park anywhere else as the spaces would not accommodate here, he replied, "I don't care, I don't want you here." When it became clear that he was not going to provide any kind of accessible parking and that the encounter took on a decidedly unpleasant tone, Ms. Elliot left the Village Green Plaza, diminished appetite in tow.

In testimony before the Board of Inquiry, it was established that the Plaza had established that the Plaza had no handicapped designated parking and the Board held that this was a violation of section 1 of the *Ont. Code.*

As in the Ryan decision, the Board found that the respondent, Epp Centres had not succeeded in showing that it would face undue hardship by providing designated handicapped parking.

In fact, Epp Centres never made any arguments relating to undue hardship "in terms of the limitations spelled out by the *Ont. Code* itself, those being cost or health and safety requirements."

Instead, Epp Centres tried to convince the Board that it would cause them undue hardship if the Board ordered them to provide designated parking for the handicapped as that would bring them into **potential** conflict with existing zoning by-laws under the *Planning* Act and regulations under the *Municipal Act.*

Here, as in the Ryan decision, a Board of Inquiry held that human rights law has "paramountcy over other existing legislation unless specifically excluded by that law."

As a result, the Board ordered Epp Centres to provide designated "handicapped parking" space, to reserve and mark it for people with disabilities, to construct a ramp to connect that space to adjacent sidewalks, and to pay Marjorie Elliot the sum of $1,000 to "compensate her for the infringement of her right to be free from discrimination."

What is most significant about both the Elliot and Ryan victories is that:

1. They re-affirm that human rights codes take precedence over any other legislation unless that other piece of legislation specifically states that it is exempt from human rights requirements;

> ***[As] in the Ryan decision, a Board of Inquiry held that human rights law has "paramountcy over other existing legislation unless specifically excluded by that law."***
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2. They clearly identify business practices that discriminate against people with disabilities;

3. They begin to lay the foundation for a human rights case-law on what constitutes "undue hardship". They make it clear that businesses have a positive duty to accommodate and must endure some hardship in complying with the goals and spirit of human rights legislation, such as providing accessible public facilities and services; and finally,

4. They order remedies that get at reducing the barriers to the full participation of people with disabilities, and compensation that is tangible and symbolic redress for people with disabilities who still suffer discrimination every day here in Canada.

These are indeed encouraging decisions. They send businesses and service providers a strong message and they should inspire people with disabilities all across Canada to continue to fight for their rights.

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