

In the Stream

Fall 2003

Disabled in the U.S.A.

by Vic Willi

"... the richest culture in the history of the world still incarcerates millions with disabilities in barbaric institutions, backrooms and worse..."

- Justin Dart's last writing[1]

As Canadians with a disability, we think enviously about our 'cousins' south of the border. "They have the ADA," we muse, "everything must be accessible!"

Physical accessibility in the USA is fantastic. However, like a four-legged stool, housing, transportation *and* personal supports are also essential to independence.

Let's examine all aspects of community supports for physically disabled persons: are the American disabled better off than us?

"...A Long and Sorry History of Discrimination..."

Historically, American State and Federal governments have demonstrated a perverse dislike of weakness or vulnerability. Consider what historians have called *"...a long & sorry history of discrimination against people with disabilities in the United States."*[2]

The Congressional Record of 1989-90 states that American society

"...is still infected by the ancient, now almost subconscious assumption that people with disabilities are less than fully human and therefore are not fully eligible for the opportunities, services, and support systems which are available to other people as a matter of right. The result is massive, society-wide discrimination."[3]

When the Americans with Disabilities Act (ADA) was first proposed in 1990, Congressional researchers discovered that individual States historically denied persons with disabilities (PWDs):

- The right to live in the community; to vote; to travel;
- The right to form families; access to the courts;

The right to an education in childhood.

The PWD community and allies got the ADA passed after hard bargaining and advocacy. It was soon under attack however, from a swarm of greedy ableists.

In one attack, the University of Alabama fought a young disabled woman all the way to the United States Supreme Court over a routine accommodation dispute. The University argued that the entire ADA should be overturned on the grounds that it was unconstitutional. On Wed. Oct 11, 2000, the U.S. Supreme Court began to hear arguments.[4]

The university's argument was that parts of the ADA violated States' Rights. In their briefs to the Supreme Court, lawyers for individuals with disabilities, as well as 'friends of the court' (Amici Curiae), contended that the history of discrimination based on disability by the 50 states, was so egregious that Congress should actually have the power to override State sovereignty.

Thankfully, the University of Alabama lost by a decision of only five to four.

"Physically defective ...cripples without means..."

There is a sordid history of bullying and discrimination against disabled citizens by many individual States of the Union.

Notable among the Garrett briefs was a "Historians' Brief" by 100 scholars, documenting individual States' discrimination. It is a sickening exercise to read the statutes and laws forcing segregation and isolation.

Alabama, for example, even had statutes codifying how American consumers were to be sterilized, institutionalized and segregated.

Dirty Language

The language used to smear Americans with disabilities in States' statutes is vicious and hate-filled: "...*mental deficient or inferiors, idiots, imbeciles, feeble-minded or morons (1959); ...any court may appoint a curator to manage property of any persons who shall become physically incapacitated... or physically defective (1975); ...children having malformation (1987); ...lunatics ...cripples without means ...and all such as will not make good and law-abiding citizens" (1907)*

Ironically, the American Constitution, the Declaration of Independence, states: "*We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness.*"

Life for us in Canada seems a cakewalk. Just examine the American system of community supports for disabled citizens: Does it even uphold the Declaration of

Independence?

Getting Rid of Rehabilitation "... *life, liberty and the pursuit of happiness*"

Tim Gilmer, writing in *New Mobility* magazine[5] points out that the foremost rehabilitation hospital in the United States, Rancho Los Amigos, is being shut down to ease California's budget deficit; and all over the United States rehabilitation is being eliminated.

Of course, deficits like California's flow from the fact that the Federal Government has let President George W. Bush squander \$600 million on the "War on Terrorism" and "Iraqi Freedom." Worse, the Bush Administration has secured huge tax cuts that give the rich \$1.6 trillion U.S. (\$1,600,000,000,000.00) through 2010![6] Feds cut the States; States cut the Disabled.

Today, the theme has become: Do Not Go To Rehab -- Go Directly To A Nursing Home.[7] Quadriplegics, for example, will now be stabilized in acute care hospitals and then shipped off to privately run[8] nursing homes (these are for-profit businesses and you can buy shares in them on the New York Stock Exchange!) The powerful nursing home industry contributes heavily to the election campaigns of State and Federal politicians.

Gilmer also questions whether or not life is an 'unalienable right' for Americans with a disability as promised in the hallowed American Constitution:

People Held Prisoner in their Home "... *life, liberty and the pursuit of happiness*"

It is called Medicare and 40 million Americans rely on this subsidized form of medical assistance created in 1965. Eligibility for attendant services requires that a disabled person must be "homebound." *One must prove -- and only a doctor can do it -- that they are so debilitated that leaving the house is nearly impossible!*

This is called the Medicare Homebound Restriction. It has been legislated by the Congress of the United States of America.

You are forbidden to leave your house for any kind of community activity. You could lose your attendant services if you are caught. It has happened to many consumers -- some using a ventilator.

The so-called "Home Health Benefit" under which one would receive the actual attendant services, is accessed by 2.5 million Americans and costs the Federal Government \$13 billion. Certain States simply cut off the Home Health Benefit to anyone who manages to live until the age of 21.

Sheila K. Kelpin of Harper Woods, Michigan, says that it takes her two hours to

get out of bed with help but she is not allowed to go outside because of the Homebound Restriction. "It quietly kills the spirit."^[9]

With regularity, Americans receiving Medicare have been cut off from attendant services. One person went to a baseball game; one woman was threatened termination when caught attending the funeral of her daughter.

The river of money flowing from Government to insurance companies, service providers, Medicare and the Nursing Home industry is murky and deep; a consumer must have Machiavellian skills to keep services. Consumers are forced to sneak around and shop at night like criminals.

One alternative to termination of attendant services is to appeal or spend every cent you own. But then what? Another alternative is to beg neighbors and friends for free help.

Lastly, one can go to a 'Death House' as some consumers call nursing homes.

American consumers report that Medicare pays nursing homes handsomely, far beyond what Medicare will give to allow a person to live in the community.

*"[Being] an Alien in Your Own Nation?"^[10]"...life, liberty and the **pursuit of happiness**" "*

Gilmer feels that American PWDs are aliens in their own country, ironic given the wording of the Declaration of Independence: "*all men are created equal, that they are endowed by their Creator with certain inalienable rights...*"

Unfortunately, if you are an American with a disability, Gilmer says, Congressmen, City Mayors, Public Works Directors and Governors will dispute your rights and freedom.

Currently, the National League of Cities is supporting the City of Sacramento's appeal to the U.S. Supreme Court asking the Court to rule that the ADA does not apply to sidewalks!

President Bush Frees Disabled ...Occasionally!

The news flashed like lightning in the July morning of 2002:

"PRESIDENT GEORGE W. BUSH: Today Medicare recipients who are considered homebound may lose coverage if they go to a baseball game -- which, of course, I encourage them to do -- or meet with a friend or go to a family reunion. So today I announce we're clarifying Medicare policy. So people who are considered homebound can occasionally take part in their communities without fear of losing their benefits." from the *PBS Newshour Coverage* (July

2002)[11]

"Dear friends of NCAHB[12],

This is a good start, but we still need a legislative remedy." Update from David Jayne (ventilator user with ALS cut off from Medicare attendant services because he reached age 21!) -- July 26, 2002.

The actual text of the clarification of Medicare Policy seems shocking to Canadians used to socialized medicine.

Absences attributable to the need to receive health care treatment, *including* regular absences to participate in therapeutic, psychosocial, or medical treatment at a licensed or accredited *adult day-care program*, will not disqualify a beneficiary from being considered homebound. For many years beneficiaries who attended adult day-care programs were routinely denied home health services.

Absences for the purpose of attending a *religious service* are deemed to be absences of infrequent or short duration. (Generally a beneficiary whose absences from the home are not considered infrequent or of short duration will not be considered to be homebound.)[13]

This Regulation to protect the most vulnerable took 35 years to be created. As a final insult, the Bush Administration will only allow these regulations to be in force as a pilot project.

Tourists -- "Are you diseased, disabled or drug addicted?"

Petra Heinzelmann, a CILT volunteer and consumer recently from Germany, visited the United States last summer. She had to fill out a visitor's visa from the US Department of Justice, Immigration and Naturalization Service.

The first question asks: "Have you an infectious disease? Are you physically or mentally disabled? Are you a drug addict?" Two answers are allowed -- yes or no.

Transportation -- "A Hell on Wheels"[14]

Eileen Brown, 52, is blind and uses the New York transit system for the disabled, Access-a-Ride. She calls her trips "the world tours" because they sometimes circumnavigate the entire City of New York for before she gets home. The system costs \$133 million a year and is administered by the Transit Authority that uses eight private firms to transport people at the highest cost in the United States -- \$56 per person.

It has been called "a disaster" by the Daily News: "On any given day, at least

7,000, or about 10%, of the system's riders are left stranded."^[15] Here is an example:

On a hot Monday in August 2001, the Rev. Podres Spencer and his uncle James Watson, who uses a wheelchair, saw Barry Bonds hit a home run at Shea Stadium. The day went downhill from there...[they] left the game early at 4 p.m...

They waited. And waited...finally, he gave up and hired an ambulette service. The two men got home at 2 am.^[16]

From Vietnam to Iraq

Fate found me working in the United States in 1964 on a "Green Card." As a Resident Alien, I had to register for the draft. The Vietnam War was heating up. President Johnson was pouring troops in. In May 1965, I was drafted but got an "occupational deferment" and returned to Toronto. That December, I broke my neck. Luckily, I was in Canada.

Later, shocking stories in *Life Magazine* highlighted the conditions of wounded Vietnam veterans. Black and white pictures of crowded, filthy wards in Veteran's Administration Hospitals. Patients complained of rats and neglect. From hero to zero.

I wonder now about the new, wounded "Heroes" who return from Iraq. If they go to their home, will they be allowed outside... occasionally?

MiCASSA -- the Final Hope

You will find some of the finest people in the United States in a group called ADAPT. ADAPT stands for American Disabled For Attendant Programs Today. They are an extremely effective, one-issue advocacy group. During the 1980's and early 90's, ADAPT fought for accessible national transportation and their subsequent victory resulted in the passing of the now-famous ADA (ironically, the disability vote elected George Bush Sr. as President).

Today, the fight is for a nation-wide attendant service program called MiCASSA ("My House" in Spanish!). It stands for The Medicaid Community Attendant Services and Supports Act, "A Community-Based Alternative to Nursing Homes and Institutions for People with Disabilities."^[17]

ADAPT almost succeeded getting a MiCASSA bill passed with President Clinton except for the opposition of neo-conservatives, many Republicans and nursing home operators.

These ableists and profiteers are from both sides of the political spectrum: unionists, nursing home owners, insurance firms and those quiet middle-class folks who assume "*that people with disabilities are less than fully human.*"^[18]

CILT talked with the ADAPT people in the early 1990's when we were trying to get the Ontario Direct Funding Program off the ground. They are tough, they are brave and they will never give up. They chain themselves to buildings; they sit-in for days; they ignore the police.

Maybe their only other choice is to die slowly in a nursing home. Whatever, I'd put my money on ADAPT.

Reflecting on Canada

As Canadians, we don't hate Americans. We just don't want to be like them. That is why we have a social welfare style of Government. Universal health care is seen as a right in Canada, not a commodity for sale. The ADA and Medicare are products of the American system of Government.

For the most part, Canadians with a disability are treated as citizens with rights. We may have to fight hard and long to establish certain services and accessibility, but generally we feel protected by the Charter of Rights and Freedoms and by Human Rights Legislation. Americans don't have that security.

Sure, we need a much stronger Ontarians with Disabilities Act (ODA) in Ontario and the same across the Nation. We need legislation with teeth.

But let's not fool ourselves: Everything is not peachy-cream in the 'Land of Freedom.'

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POST SCRIPT: Tim Gilmer, in the June issue of New Mobility^[19], reported Texas planned to cut 60,000 consumers off community attendant services. Plus, 9,000 new Americans have lost eligibility for Medicaid prescription drug benefits (covers glasses, teeth, canes, asthma medicine, etc).

In Oregon, one man has suffered massive brain damage and is in a coma after Medicaid cut him off his \$13 U.S. per day anti-seizure meds. Cost to June 1/03 for hospitalization: \$560,364.00. Insurance goes up -- nobody wins.

Bob Kafka, Stephanie Thomas and members of Texas ADAPT demonstrated daily at the Texas State capitol and forced legislators to scale back those who will be cut off attendant services from 60,000 to 20,000. (That'll leave only 80,000 on the Texas waiting list for attendants, y'all.)

[1] <http://www.mouthmag.com/justin.htm>

[2] www.raggededgemagazine.com/garrett/ (Sept/Oct 2000)

[3] Ibid.

[4] Board Of Trustees Of The University Of Alabama, Et Al., v. Patricia Garrett, Et Al. on whether

Titles I and II of the Americans with Disabilities Act are "a proper exercise of Congress's power under Section 5 of the 14th Amendment." The case involved issues around the right to employment and accommodation to access services. This was not the important issue, however, as the constitutionality of the ADA was being questioned.

[5] *New Mobility*, Volume 14, Issue 112, January 2003, p.4.

[6] "A Most Dangerous President – *How Bush's neocons and crony capitalists are ruining the economy for all of us*" by Marta Russell in *Ragged Edge Online*, July/August 2003.

(www.raggededgemagazine.com) Russell quotes the London Financial Times to make her central point: "Most extreme Republicans want a 'fiscal train wreck'" which will allow them to slash social programs in the midst of a fiscal crisis by pushing cuts through the back door.

[7] *New Mobility*, op cit.

[8] The less you cost the nursing home (nurses, food, time, drugs, etc.) the bigger the profit. ADAPT (American Disabled For Attendant Programs Today) has most of its members literally 'imprisoned' in nursing homes. The greedy owners prevent ADAPT members from entering so the 'Homes' can keep making profit – ADAPT actually does kidnapping-by-request so people can live in the community!

[9] Vol 1, Homebound Stories from the Petition from website:

www.amendhomeboundpolicy.homestead.com

[10] "Bully Pulpit" in *New Mobility*, op. cit.

[11] ADAPT, op cit, has done incredible and astonishing amounts of political advocacy over the years. It is not unusual for them to have "crawl-ins" at Federal or State Government offices. A favourite tactic is to do sit-ins which surround and block entire buildings. Read about their work at their website: www.adapt.org

[12] The National Coalition to Amend the Medicare Homebound Restriction for Americans with significant illness.

[13] www.medicareadvocacy.org/medicare.htm

[14] Daily News (www.nydailynew.com)

[15] Ibid.

[16] Ibid.

[17] www.adapt.org, op cit

[18] www.raggededgemagazine.com/garrett/ (Sept/Oct 2000)

[19] *New Mobility*, "Bully Pulpit", June 2003

The Great Escape

by Lina Di Carlo

Lina's Introduction

I graduated from York University with an Honours BA in French and Italian. I won't tell you in what year because I would have to reveal Vic Willi's age since we were at York at the same time. I have been writing ever since I can remember.

Growing up with a disability in a small community in Italy was challenging. I kept a diary where I recorded my secret dreams and aspirations and I especially liked to write about the boy next door.

My degree in French landed me several bilingual positions and eventually my current job with the Ministry of Education where I manage a language and cultural exchange program for university students.

I have been a member of CILT for over 10 years and I am an avid reader of fantasy novels.

Lina Di Carlo -- a new contributor to In The Stream!

I was the only one in my family to have had the opportunity and the ambition to go to university. I was the last of six girls and I wanted more than marriage and kids. My decision was even more significant since I had to use a wheelchair from having contracted polio at the age of 10 months. I made a lot of phone calls to ensure that the lecture halls, classrooms, library and any other building I needed access to were wheelchair accessible.

I lived in residence at York University for four years. Residence was reserved for students from out of town. I had convinced the university that the special bus I had to use for transportation was unreliable and I had convinced my parents that my studies would suffer if I spend all my time traveling back and forth to school. This was one time where being disabled was an advantage.

I went home often, but in my last year I was home only at Christmas and at Easter. I was busy meeting people, going to parties, discussing existentialism and the meaning of life. I liked my independence and I didn't want it to stop. I decided to do my Masters at Laval University in Quebec City in French-Canadian Literature. Convincing my parents was a struggle, but I succeeded.

On April 15, 1979, at the end of my first year, I handed in my last paper. Two weeks after getting back to Toronto, I had a job. Not much of a summer vacation, but it was great to have money so I didn't really mind. The only thing missing now was my own apartment.

I wanted to have my own place, but my parents' Italian mentality would not allow it. Going away to school was one thing, but a single disabled woman just didn't move out. A daughter was to live with her parents until she was married. Of course, marriage was out of the question for me, as far as my parents were concerned. I had no options, unless I could come up with a plan.

My boyfriend John and I would have long discussions about me getting my own place.

"Just tell them you're moving out." He'd say, "What's so hard about that?"

"You don't understand. It's not that simple. They would be furious and hurt."

"You have to live your life! You can't live with your parents forever?"

"I know that. I just have to find a way to do it."

One night at supper I told my parents that I had seen a sign in front of a building in the west end that advertised a wheelchair accessible apartment and that I was thinking of moving there.

"It's not that far, you could visit me." I said to my father.

He said, "You are not going anywhere. You're fine right here."

"Why do you want to leave?" my mother asked. "Don't I take good care of you?" She had tears in her eyes.

"Mom, I don't need to be taken care of. I'm not a little girl anymore. I've lived on my own for over five years. How can this be any different?"

"Eat your supper before it gets cold," my dad said.

We ate in silence.

Someone at work told me about a Social Services Agency in North York that had Italian-speaking staff. I called and made arrangements for a social worker, Mr. D'Angelo, to speak to my parents, when I wasn't home, and explain my reasoning for wanting to move out.

I called Mr. D'Angelo the day after his visit.

"I talked to your parents for more than two hours. They won't budge. I tried every angle possible. Your dad kept pouring me wine every time I tried to make a point. I'm sorry."

I thanked him, but I was disappointed.

Determined to find a solution, I signed the lease to my bachelor apartment on February 15, 1980. The apartment was on the second floor. It was small but it was wheelchair accessible and it was mine. I smiled thinking of the coincidences. The number of the unit was 222, my rent was \$220 per month and I cleared about \$220 every two weeks.

Planning for my eventual defection, I started taking some clothes with me every day and storing them at work.

"This is going to take forever," I thought.

I needed a better plan, but for it to work I needed to enlist the help of my boyfriend.

"All you have to do is to take my bed and my dresser. We'll go back for the rest of my things later."

"You want me to go into your house and steal your furniture?"

"You won't be stealing anything. That's my stuff."

"Yeah, stuff your parents bought."

"Look! I'll get my parents out of the way. You'll be in and out in no time."

"I'll have to think about it. Maybe there is another way."

A few days later John called, "I was discussing your problem with a friend who has lived in an Italian neighbourhood for a long time. He says your way is the only way."

"Great! Thank your friend for me."

I had pots and pans, plates, glasses and utensils from my years in residence, but I couldn't pack them without my parents getting suspicious, so I gave John a description of what to take and in which cupboard to find them. I had to be precise. I was not going to get a second chance.

We planned every detail of my escape. All that remained was to wait for the perfect moment. It came a few days later. My sister lolanda invited my parents and me for supper. I needed time for my plan to work so after supper my niece and her boyfriend, as prearranged, suggested that we go see a movie. I knew that my parents would wait until we came back.

By the time we drove to my new apartment on Chalkfarm, John was already waiting with the van we had rented. He hadn't wasted any time. He had thrown my bed in the van still made.

"I feel like a criminal." He said, "Your father will never forgive me."

"Don't worry. It will be O.K."

After we finished setting up the apartment, I opened the bottle of wine I had brought with me and we celebrated.

I raised my glass and said, "Mission accomplished!"

"You'd better call your parents" John said after my niece and her boyfriend had left.

I was reluctant to deal with my father, but I knew John was right.

I spoke quickly and to the point, "Dad, I won't be coming home tonight. I've moved out in my own apartment."

"Don't play game. Hurry back so we can go home."

"But dad..."

"I'll see you soon." He hung up.

"He didn't believe me," I said to John.

I called back. When my father understood that I had really left home he began swearing at me. He figured I had had help so he swore at my niece and at John as well. He hung up on me again. I made several more attempts, but he refused to talk to me. He wouldn't let my mother talk to me either.

I knew that in time my parents would accept my decision, but for now I wanted to enjoy my apartment and my new found freedom. No one was going to diminish the importance of this moment.

I had made my Great Escape.

The RWC Experience

by Susan DeLaurier

RWC stands for Rear Window Captioning (also called closed captioning) and is available in some movie theatres such as Silver City, Coliseum, and Paramount. People who are hard of hearing or deaf use RWC so they can read the dialogue of a movie. It works on the same principle as looking at your rear view mirror when driving. At the back of the theatre, the dialogue is projected and is read by looking into a type of reflector.

I tried this for the first time a couple of months ago at the Paramount Theatre in Toronto. There is a customer service desk where you ask for the reflector device. I had to sign for it, but there was no charge. This thing fits into the cup holder so if you also have a drink, you'll have to hold it between your knees. It's a rectangular shape approximately 8 X 3 inches on a gooseneck arm that you adjust until you can see the captions. There is a 'welcome' caption before the show to enable you to do the adjusting. There are no captions during the previews -- only the movie.

Unfortunately, not all movies are captioned so you may have to decide what you

want to give up: "hearing" everything or seeing what you really want to see. I went with a friend who wanted to see Terminator 3 for some reason. The value of dialogue for this particular movie was dubious, but it was good practice since there wasn't much of it.

My only complaint, besides not having every movie captioned, was that the words were quite small which meant I had to really concentrate on reading them and that was tiring after awhile. I'm not sure how this would be with a movie with a lot of talking. With captioned TV and videos, the lettering is fairly large in relation to the screen so a person can more or less read and watch at the same time.

However, I am grateful for any help and acknowledgement that people with disabilities enjoy the same kinds of entertainment that everyone else does. To find out ahead of time which films are captioned, check www.famousplayers.com, or www.chs.ca/info/mopix.html. The RWC / DVS logo will also be used in print advertising.

Along with RWC, these movies also have Descriptive Video Services (DVS). DVS makes movies accessible to people who are blind or have low vision. This service is used with a headset with volume control.

Descriptions of characters, action and settings are heard during natural pauses in the dialogue. More information can be had at: www.cnib.ca/library/whats_new/descriptive_service.html.

Is Your Doctor and/or Dentist Accessible?

by Susan DeLaurier

We would like to put together a small directory of family doctors and dentists who have accessible offices and welcome people with disabilities.

If your doctor or dentist is accessible, please let us know. If you also wish to include specific information and/or your particular disability, that would be great. Have you encountered any attitudinal barriers?

It is not necessary to include your name, but we would need to know the doctor's name or the name of the clinic, address and phone number. All information is confidential and will only be used for the purpose of compiling a directory. No personal information will be included.

We would be looking for specific information in regards to devices like automatic door openers, ramps, elevators, accessible washrooms, parking and/or Wheel-Trans drop off locations. Also useful would be any other information about both good and bad features you feel would help others to know. We would also be

interested in hearing from people with sensory disabilities -- have you encountered specific problems because of low vision, blindness or deafness?

Please let the following people at CILT know:

Susan DeLaurier, 416-599-5077 (TTY). If you do not have a TTY, please call the Bell Relay Service at 1-800-855-0511 and they will assist you. The email is library@cilt.ca.

If you prefer, you may mail any information to the above people at:

Centre for Independent Living in Toronto (CILT)
205 Richmond St. W., Ste. 605
Toronto Ontario M5V 1V3

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