

# In the Stream

Summer 2003

## **Feature: Defeating Apathy Attitudes & Mindsets**

*by Sandra Carpenter*

On February 14, I was invited to make the keynote address at the Annual General meeting of the Provincial Association of Senior Managers (PASM). PASM is mostly made up of people who run various attendant service projects in Ontario.

The theme of the address was, "Protecting and enhancing the values of independent living in an increasingly regulated and under-funded sector."

My perspective on independent living comes from living with a disability all my life: a disability that results in me having to be dependent on others, whether paid professional or otherwise, to get by in my daily life.

In 1954, when I was born, the only place you could get daily help was in a government or private run institution. So when I went to live in a government-run institution at age 11, I soon figured out that I didn't want an institutionalized life just because I needed someone else to help me everyday.

### **Home for Incurable Children**

For me, the roots of independent living lie in one place. Getting out of the institution.

When I was not quite 11 years old, I left my home in Ottawa and came to Toronto to live in a "crippled" (sic) children's institution.

That is the word they used then... crippled. Worse actually. I still remember the day my father carried me in and sat me in a big chair in the lobby and I looked up at a plaque with names of donors headed up with the phrase "Home for Incurable Children." So that's what I was, I thought, an "incurable child," a child that couldn't be fixed. None of us had a future, therefore no social value.

Even then it seemed that people who worked with us were a little better, and had more social value than we had. They were simply viewed as the "caretakers of the children with no social value." This began, for me, the history of an under-funded and under-resourced sector.

One day, someone figured out that there was more money in "medicalizing"

us so that's what happened.

The Government had a more generous funding formula for "hospitals" rather than "homes," so the "place" dropped "hospital, home and school" from its name and simply became a "hospital." But the more generous funding formula didn't improve my lifestyle.

Some "aids" were replaced with more highly paid "nurses" and registered nurses assistants. The "aids" that were left were deemed "nurses aids" but I didn't see them getting better salaries, benefits or working conditions.

Increased funds were used to pay for salaries of professionals and other "pretty things" like autoclave machines, thermometers and stainless steel trays with wheels.

The food didn't get any better. (In fact, it got worse, which seemed impossible but was, nevertheless, true.) There were still four of us in one room.

But at least we had more social value than before. Hospital workers had more social value. They were more organized. We became "units of labour"; the result was that we each cost the Government a lot more to "keep." The price of our "storage" went up, even though the "storage bin" was still just as small.

We also had more social value because we became a "captive" pool to the entire medical establishment for medical, therapeutic and surgical albeit, experimental disability treatments. All this was in the name of progress and discovery. We had at least as much value then as "guinea pigs." (I don't remember animal rights being around then and if they were, would they have concerned themselves with us?) Some lives were prolonged, but others were shortened and in some cases snuffed out, like kids who died in surgery or shortly thereafter from other complications.

Sometime, against this backdrop, the concept of "independent living" began to really take shape for me. The alternative to independent living (i.e. an institutional setting) was too horrible.

I saw other kids I grew up with who did not need daily care, leave the "place" and live in apartments of their own in the community. They went on to university and then jobs. That was the life I wanted.

I set about then, trying to make that happen. It all started with a question: why couldn't people come and help me at my home, instead of me living where the help was?

I read books (I was 14, 15 by then) called "Pedagogy of the Oppressed" but most importantly I read Irving Goffman's "The Asylums."

It was the first time that the place where I lived was described. The "place" had a name. Warehouse. And the things I didn't like about the "place" were given "names" too and further the "process" involved with arriving at the names was described in detail.

The clearest thing I came away with in those years, through all my reading, thought and study, was the concept of "depersonalization."

Independent Living for me then, meant more than just getting outside the walls. It also meant "personalizing" an alternative to institutions. In short, not only is Independent Living contained in a set of principles, but it is also an attitude.

Spaces in "apartment projects" were so scarce that it was only very "independent" minded disabled people who lived in them. One criterion for getting in was that you had to be working, in school or spending considerable volunteer hours in the community.

Attendants were paid accordingly as persons who provided physical care as directed by the person with the disability.

As this was happening, the Independent Living Movement was emerging. And movement it was! De-institutionalization became a popular choice for more and more people, not only for those who wanted out in the community, but for those who wanted to stay in the community.

Governments also jumped on the de-institutional bandwagon. But somewhere along the way, de-institutionalization ceased to be about people and choices and became about cost efficiencies.

## **Independent Living**

Independent Living. Independent Living Movement. Independent Living Centres. Independent Living Projects. Independent Living Skills Development. These phrases all mean something different and to further complicate the issue, mean different things depending on the person using them.

When someone from the Independent Living Movement uses these terms, then independent living, more than anything else, is an attitude: an attitude of *person first. Abilities first. Flexibility, choice, control, right to risk and responsibility. The person with the disability is best able to identify his/her needs and therefore is best able to articulate solutions for them.*

When someone from an independent living centre talks about independent living skills development, they are talking about teaching the skills necessary to learn to effectively speak up for oneself both within the disability service sector,

and in the community at large.

When someone from the medical or rehabilitation uses "independent living" or even Independent Living Skills development, they are often talking about "activities of daily living."

For many, independent living is merely a euphemism for housing with attendant services. Nothing could be further from the truth.

## **Regulation**

We have a huge problem protecting the values of independent living because of increasing regulation. Particularly because the regulations are designed by people who do not understand how regulation relates to institutions and who, even if they did, no longer understand the core reason why de-institutionalization is important in the first place. A case in point is found in a recent article from the United Kingdom.

**On Wednesday, February 26, 2003, The Guardian reported, "Lifting ban set to end: Care providers should follow HSE guidance, judge rules."**

'A high court judgment last week is expected to end blanket "no lifting" bans affecting the staff of local authorities and other agencies caring for disabled and older people in their own homes, according to disability campaigners...

The court emphasised the need for a balanced approach to the rights of the disabled person and the rights of workers to be protected by health and safety regulations...

The county council maintains it never had a blanket ban on lifting, and says it has now revised its guidance for employees...

Many care providers have relied on Royal College of Nursing guidance, which was introduced to protect nurses from injury caused by lifting heavy patients on hospital wards. The new ruling makes it clear that care providers should look to guidance from the health and safety executive, which states that lifting polices should not place any "unreasonable restrictions on clients' rights to autonomy, privacy or dignity."

We have a similar debate going on right now in Ontario with lift policy, which is being spearheaded by the Health Care Health and Safety Association of Ontario. Medical model approaches cannot be universally applied to giving someone care to a person in their own home.

CILT has been working on this issue and making its views known to PASM for some time, and although most of the PASM members agree that policies were

never written with a "blanket" ban on lifting implied, we know of cases where it has been interpreted and used that way.

## **Under-funding**

All I can say about under-funding is this: It is the same now as it was when I was 11 years old. As long as the people you work for are perceived as having little or no social value, the services designed for them will also be undervalued and under-funded. It is about how we prioritize and spend money on disability, rather than how much money there is.

Examples of this include:

- the last minute decision that saw the Rick Hansen fund get \$15 million out of the most recent federal budget;
- funding available from the federal government for acute home care; a federal funding formula which favours institutional care over community care (i.e. Provinces get a share of federal money for hospital or institutional care, not for community based services);
- empty beds in the Ontario institutional system while community based care providers are crying for more resources.

Under-funding is just a symptom of a mindset. If the mindset were changed, the resources would be found.

In my mind those two elements -- under-funding and over-regulation -- are *the* formula for re-institutionalization and not only in the disability sector. Under-funding and over-regulation are currently institutionalizing much of everyone's lives. These elements are therefore worthy of resisting; both personally and professionally.

## **Defeating Apathy**

Many consumers have come into services from family homes where they were sheltered, or institutions where they did not learn the value of independence. They may in turn be apathetic or resentful when they realize that with "control" comes a lot of work. Well, without "control" maybe in the short-term things may seem fine. There is an assumption that service providers "defend" the consumer view, but they don't. Only when the service provider has strong consumers on the Board or Management staff of the organization can that be said to be true. More often than not this is not the case. Furthermore, a widespread apathy among people with disabilities doesn't help.

It may at first seem easier and faster to just make decisions for others or let

others make decisions for you, but its like that old expression; feed a man a fish, he is full for a day, but teach a man HOW to fish and he has food for life.

## **Summary**

That's what independent living means. It's an attitude and approach to both providing and receiving services that *can* withstand the barrage of under-funding and over-regulation we now face.

And it can also be, just possibly, the ammunition that consumers and those that provide support services to them, need to gain true value in society.

Keeping "independent living" foremost, means that the core value of personalization suggesting flexibility, choice, control and right to risk must also be kept foremost. I believe that in today's impersonal society the value of personalization has become even more important: and not just for people with disabilities, for everyone.

## **Saying No to No-Lifts**

*by Bob Galloway\**

I was happy with my attendant service provider (ASP) in the years I've spent living in Toronto. I felt both empowered and protected by working with this ASP, and never once thought of having to make compromises with my physical and mental health. That all changed last summer.

## **Consumer vs. ASP: A Real-Life Nightmare**

One day last August, the manager of my attendant services program told me that the head office advised her to contact all consumers living in my housing project to evaluate their lifts and transfers. According to the manager, a number of attendants at the program's affiliates across the province applied for worker's compensation benefits after disclosing that they had injured themselves while performing manual lifts. She also said that these attendants were denied financial compensation from the Workplace Safety and Insurance Board (WSIB), which lead my ASP to draft a universal policy stating that it cannot lift a consumer who weighs over 40 pounds. I didn't think this would apply to me because my short stature and low body weight have never put anyone at risk of injury (myself included) while being lifted or transferred. I complied with the manager's request for an assessment, and in early September, I was assigned to an occupational therapist (OT).

During my first meeting with the OT, she asked me questions related to my disability, and my history with the ASP. At a subsequent meeting, the ASP manager had an attendant demonstrate my manual lifts to the OT. The attendant

who came was not used to performing my lifts, and she had trouble doing one of them. The OT, who didn't take my disability or history into account, decided my lifts were "unsafe" for the attendants, and firmly suggested I use a sliding board. I replied that I wasn't used to having any transfer equipment, and that the majority of people I've worked with have never expressed any difficulty about lifting me manually. "I still think you should try it out," she insisted. I reluctantly agreed to it.

Sliding on the board felt strange to me. When the OT asked me how I felt about the board, I told her I would need time to get used to it. The manager, however, said that she would have me train the head attendant to "apply" the board during my bookings. She also said that the OT would write a letter to the ASP's head office explaining the changes in my lifts and transfers.

At my next meeting with the OT, I reminded her that I have bones that break easily, and sliding on the board could put me at risk of injury if I was to slip or move abruptly during the transfer. Unfazed by my concerns, the OT said that she was successful in getting another person with my disability to comply, and she expected the same results with me. I suggested to her that no two consumers are alike, but to no avail.

For the next three weeks, I had some of the attendants try the board with me, but I knew deep down that this was not going to work out. I called the OT and requested that she postpone writing the letter to the ASP's head office. I also revealed that I almost slipped on the board getting out of the shower.

A meeting was arranged with the OT, the ASP manager and the team leader, on Halloween night, which turned out to be a bad omen. After the OT and the manager told me that this was how things were going to be, I felt that my back was against the wall. The manager also threatened that she would take an action that "I won't like" if I refused to comply. I tried to convince myself that I could adjust to the board. I even told a friend afterwards that I was feeling "more comfortable," but inside I felt like crap. I had given in to something that I was always opposed to, and now I couldn't get out of it. I forced myself to accept this option, because I was afraid of losing my services.

I decided to write a formal letter to the ASP manager. In the letter, I wrote that I would go along with using the sliding board, but added that maybe it should only be used by those attendants who had expressed misgivings about lifting me manually (though nobody ever expressed them to me directly). It seemed like a reasonable compromise to me, but it was completely rejected. I was told that I would have to use this board from now on.

For the first time since receiving the ASP's services four years ago, I believed that my rights and feelings as a consumer had not been taken seriously. I felt stripped of my dignity, and my confidence in myself and in the program had been shattered. The sense of living independently in my apartment was gone.

## Fighting Back

That weekend, I attended a social event in the city, hoping that it would help me take my mind off my "no lifts" dilemma. But what was supposed to be a fun evening with friends and acquaintances at a dinner and dance quickly turned into a disaster for me. After eating dinner and chatting with some friends, I felt sick, and had to excuse myself from the table. Thoughts of my failed attempts to assert my needs -- along with sliding on the board with my brittle bones -- had played out continuously in my mind during the dinner. Only after I felt physically ill did I realize how upsetting this experience had been for me. I felt helpless, vulnerable and defeated. I also blamed myself for my apparent ineffectiveness. In despair, I talked to my family and friends. They encouraged me to not give up. Gradually, a new resolve was aroused in me.

When the new week arrived, I was determined to find a constructive way to get my manual lifts reinstated without jeopardizing my standing in the program. It meant having to keep a lower profile with the ASP, and put up with more headaches and sleepless nights, but I was ready to fight back. I knew I was setting myself up for a difficult battle.

My action plan began with a brainstorming session. After consulting with an ally, I came up with several options, including: filing an appeal with the ASP's Head Office, getting an official doctor's note and obtaining a second opinion from another OT to support my position, and considering legal recourse.

After considering my options, I decided to explain my situation privately to the manager's supervisor, the ASP's Regional Manager of Central Ontario. I knew I was taking a major risk, since she had knowledge of my transfer changes. I told her that I was satisfied with my ASP up until these changes occurred, and explained to her that using the sliding board had taken a toll on my physical and mental health. She initially recommended I get another OT. I was put on a waiting list. During this time, I started skipping meals to lose weight, but this only added to my stress.

After several weeks of waiting and no promise of another assessment, I called the Regional Manager again. To my surprise, I got a sympathetic response. She wrote by email that I shouldn't be going through such stress. She also said that the "no lifts" policy allows for exceptions, and it should not be treated as a law. I was told that my situation would be reviewed at the next full staff meeting. (I also discovered during this period that the WSIB does *not* have any specific guidelines about lifting people over 40 pounds.)

Following that meeting, I was given the news that the majority of the staff did not have any reservations about lifting me manually. As a result, a decision was made to have my manual lifts restored. I was overjoyed. A month later, the

Regional Manager sent me a letter confirming the decision, and I kept it on file to present to the management if this subject were to ever come up again.

## **Conclusion**

It has been nearly a year since my conflict with the ASP. The whole situation was very distressing for me, and I still harbour some bitterness towards the ASP and condemn the OT who thought she knew what was best for me. But I firmly believe that this experience empowered me to take action and gain confidence as a self-advocate. The trauma I went through strengthened me. Writing this article has also helped to heal the emotional and psychological scars.

The experience also reminded me that disability services, like my bones, are fragile. We may have made significant gains in de-institutionalizing services. But there is a danger that we may take these gains for granted, and overlook that they can be easily taken away.

My advice to other consumers in a similar predicament is not to give up defending the principles of independent living. I believe that more consultations need to occur between consumers and service providers, so that a variety of service provisions are available to meet the needs of individuals with a disability.

*\*Bob Galloway is the pseudonym for a consumer in the Toronto area.*

## **Nowhere Fast**

*by Eli Shupak*

*This article originally appeared in the May 1, 2003 edition of NOW Magazine. Reprinted with permission.*

More than 28,000 Wheel-Trans registrants can expect longer waits for their rides when the door-to-door disabled transit service implements a 30-minute window for all its weekend trips across the city beginning in July. The extended wait time will apply to weekday trips starting in September.

About 50 riders came out to protest the move at a public meeting with Wheel-Trans officials Monday, April 28, where we were told that the changes are all about providing the maximum number of trips with limited resources.

"It provides us with a great deal more scheduling flexibility," says Wheel-Trans superintendent Bob Thacker.

But in the 10 service zones where the system is currently being tried, the riders' reviews haven't exactly been positive. A flaw in the computerized scheduling system has been giving riders half-hour windows that begin 15

minutes before a driver even starts his or her shift.

"Even the drivers hate this," says Wheel-Trans user Doug Faulkner, who is now organizing a petition to stop implementation of the 30-minute window plan. He's collected 300 signatures.

Presently, Wheel-Trans buses aren't considered late until they're at least 20 minutes behind schedule. Under the new system, riders will have to wait an additional 10 minutes before they can call to check on a vehicle's whereabouts.

A much more pressing need for Wheel-Trans is an overhaul of the seven-year-old computer system used to schedule 5,000 daily trips.

It's quite common for more than one vehicle to be dispatched to the same pickup location at the same time, each bus taking one person to the same destination or somewhere nearby. It happened twice when my neighbour Greg and I went out to support Faulkner's cause a couple of weeks ago. We were delivered on separate buses 20 minutes apart and were scheduled to go home on different vehicles as well.

We had called a couple of hours apart to book our trips the day before, but the software scheduling the rides was incapable of slotting the two of us together.

"It's something we're continually struggling with," says Thacker.

With an average public subsidy of \$24 per trip, it doesn't take long to eat up Wheel-Trans' \$48-million annual operating budget. It's easy to calculate the number of rides that can't be provided because multiple vehicles are doing the job of one.

Thacker believes that because the service is growing, the use of 30-minute windows for all rides is "a realistic approach, with all the construction and unknowns the system runs into daily."

Unless, of course, you have things to do.

## **Responding to Intimidation**

*by Marilyn Ferrel*

I have difficulty coping with intimidation.

I felt intimidated when my surgeon spoke in a hurry and was in a rush to leave interviews. I came to him with a lot of questions regarding my hip surgery. He said that he did not have time to answer them as he had a waiting room full of patients. He told me that I should trust him. There was only a five- percent

chance the operation would not work. Reason told me I should go ahead with the operation, because I felt that the odds were in my favour. My intuition told me not to trust a doctor who did not have time to get to know my individual situation. The operation made me lose the ability to walk, and left me dependent on attendant care.

I am also intimidated by "lectures" from attendant service providers. I now depend on it to provide me with housekeeping. I spoke to the manager about what I felt was a poor quality of service in the way my housekeeping was being delivered. She lectured on how I should be more accommodating, trusting, better at communicating and have "lower expectations." The lecture was delivered in an avalanche of words in a loud and fast voice. The manager said that it was my *behaviour* that needed to change. The housekeeper was able to maintain employment with little change.

I grew up in a dysfunctional family where children were to be seen and not heard. I was disciplined by temper tantrums; yelling accompanied by threats. I learned to respect authority regardless of their behaviour.

I have been thinking long and hard about how I could respond to intimation and the misuse of authority.

For me, changing my attitude towards authority is the first step in learning to advocate for myself. People in positions of real authority should be expected to have skills in listening, encouraging communication, and empowering others. People in authority who do not have these skills do not deserve my respect. They should be expected to earn my trust and respect rather than demand it. When someone is talking to me in an avalanche of words, I try to detach myself from listening and observe what is really going on. I then continue to listen only if I observe that the person seems to have my best interest in mind and is not trying to intimidate me.

If the person is intimidating me, the first response is to show I am not listening. Body language is the easiest way to refuse to listen. Although I cannot cross my legs, I am able to cross my arms. This helps me to close myself off from the other person and maintain my integrity. If I really want to show I am not listening I could look away from the other person and up at a picture, a wall, another person in the room or out the window.

The intimidating person probably will say, "You should listen to me."

A courteous response might be: "I might be more able to listen to you if I felt I was being heard. I don't feel there is any room for me to respond to what you have been saying."

If the person continues to lecture I could interrupt and describe their

behaviour: "You have use the word 'should' a number of times which I find offensive and authoritarian. Would you lower your voice, slow down and give me more room to respond to you."

When professionals demand that I trust them I could say: "My disability is a result of errors made by doctors and physiotherapists. I will trust you when I am confident that you know me as an individual."

I resorted to writing letters to my surgeon and bringing list of questions when consulting with him. This helped a little but I still wish he had spent time with me before the surgery.

In my background it was considered rude even to talk back to authority regardless of behaviour. I do have some difficulty distinguishing what is rude and what is assertive. I try hard to be courteous as well as assertive. I will probably have to depend on these people in the future.

One thing that would assist me is to role-play these responses with someone whom I trust: someone who could explore with me the difference between being rude and assertive without lecturing me. It would also be helpful to have someone I trust accompany me in a situation where I fear intimidation. I do not want them to speak for me, but ask me questions that would help me describe the person's behaviour and how I feel about it.

I found it useful to know that other people were also having problems with their housekeeping. There is strength in numbers. Consumers could organize a group. Management is less likely to discount problems and concerns if they are expressed by a number of consumers together. Consumers could support each other when encountering intimidation.

What do you think of these responses to intimidation? I would be interested in your comments. Please email them to me at [mgcf@3web.net](mailto:mgcf@3web.net) or send a letter to CILT.

### **Disability multicultural group celebrates its 10th anniversary**

2003 marks the 10th anniversary of the formation of the Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO), the province's most visible disability multicultural group.

ERDCO was formed out of the necessity of persons with disabilities from other lands and cultures to be fully included in Canadian society.

According to Rabia Khedr, longtime member and organizer of ERDCO:

"The issues on which ERDCO was founded were primarily that the ethno-

specific agencies were ignorant to the issues of disability, and if someone entered their doors who happened to have a disability despite the racial or linguistic linkages or religious linkages. They weren't able to deal with the disability component or to see past the disability component. Just because I have a disability doesn't mean that I don't have a gender and I don't have a culture. So, the whole multiplicity of the barriers or needs wasn't addressed at all by... existing organizations.

"The founders of ERDCO felt that if they came together as a group, perhaps looked at some projects and developed some research tools that would help them gather information about the issues that they and others most certainly felt as minorities with disabilities in our community... if they combined the information they found in some sort of research document, through projects which they undertook, they could help educate the system. Would help encourage understanding of multiple barriers of discrimination, of racism, of ableism."

On the afternoon of Saturday, May 3, 2003, members of ERDCO gathered at Metro Hall on 55 John Street to celebrate a decade of working for change, access, equity and human rights.

ERDCO's current chair, Ayshia Musleh, and Sandi Bell, who emceed ERDCO's first fund-raiser in the fall of 1993, hosted the event. During the event, many people were honoured with certificates of recognition for their work over the past decade. A large and delicious chocolate birthday cake was cut by two of the founders, Mazin Aribi and Nora Shankar.

Rafia Haniff-Cleofas, the first chair of ERDCO, told the history of the organization and a video scrapbook was screened, entitled *At 10*. Achilla Orru, a thumb organist from Africa, provided the musical entertainment during the afternoon.

On another occasion, Rabia Khedr has said:

"But there's a lot more work that ERDCO needs to do, in terms of bringing people together, in terms of empowering people, to not only educate themselves about the barriers, the multiplicity of barriers they may face, but also to educate those around them in terms of their family, in terms of their community, in terms of the service providers and society at large."

During the next decade, ERDCO plans to launch a media watch programme to ensure equitable portrayal of persons with disabilities in general, and ethno-specific persons in particular, in the print media, and on radio and television. Other activities for the next 10 years are being discussed.

ERDCO can be reached at 416-657-2211 or toll-free at 1-888-988-3999. You can also email ERDCO at [erdco\\_ca@yahoo.ca](mailto:erdco_ca@yahoo.ca).

- with files from Mazin Aribi & Bill McQueen

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