

Disability and Social Equality: The Centrality of Independent Living

Sandra Carpenter¹

I have been struggling for equality for over 30 Years. When I was born in Ottawa, in the 1950s, children with disabilities were either kept at home with their parents, or sent to live in a state or charitably run “home”. Although I was born with my disability, I wasn’t actually diagnosed until I was 3 years old and subjected to a gamut of medical tests at a charitable hospital in Montreal. In the 50’s Medicare did not exist, so as a charitable hospital, I was able to receive diagnostic testing that my family could not otherwise afford.

When my sister was born, four years after me, she was eventually diagnosed with the same disability as me: Spinal Muscular Atrophy which is a type of Muscular Dystrophy. I remember going to a “regular” school; a right which my Mom had to fight for with the local board of education. And then because of ongoing difficulties with me getting the support I needed to be really integrated in regular school, for example with accessible transportation or washroom assistance, I was sent to the “Crippled Children’s School”. At first, I was taxied to this school, but after a couple of years of going there, I was deemed ineligible for this “special program” because my disability “didn’t improve with therapy”.

So there I was. The regular school wouldn’t let me in, and neither would the “segregated” school. The only recourse was home teaching, which was paid for by the board of education. Mom was starting to panic about what was becoming an increasingly isolated and under-stimulated life. She regarded us both (me and my sister) as “smart” and “needing to use our brains”. She worried about a future where neither of us would have the education to get into High-school or University which would lead to a job.

Although she wouldn’t have been aware of any higher-level analysis at the time, her instincts were right on. If a child with a disability experiences inequity right from the start in terms of education then inequality follows them

¹ Sandra Carpenter was born with a disability in Ottawa in the 1950s. She has been actively involved with the evolution of services and supports for people with primarily physical disabilities most of her life. She is currently the Executive Director of the Centre for Independent Living in Toronto. Email: execdirector@cilt.ca

throughout life, meaning they won't get a job. If the prevailing social interpretation assumes that people with disabilities are unable to do anything, these inequities persist. All you need to do is compare the employment statistics of people with disabilities and people without disabilities.

When the visiting nurse from Easter Seals came by for her regular visits she advised my Mother to send us to a 'residential school' for disabled kids. It seemed like the best option for us and that was what Mom told me: "It was a 'boarding school'. Kids went away to 'boarding school' all the time." And so, by 1965 just shy of my 11th Birthday, I went to live at Bloorview, billed at the time as "Bloorview Hospital Home and School" in Toronto.

When we got there, Dad carried me into the lobby of the old Victorian home and sat me down in a big green faux leather upholstered chair. I looked up. Opposite me was a plaque that read "Home for Incurable Children". I could not resolve the message on that plaque with the place where I thought I was going, which was to a "boarding school". Something was not right. Some terrible mistake had been made. My heart was broken. I felt like *Oliver Twist*!

This drove home what society's expectation was for me, anchoring my inequality or otherness in my own consciousness. In fact, all oppressed groups are also made to internalize their socially determined inferiority. Society says this is *your* problem or pathology as opposed to proposing solutions to the barriers created *by* society: how it's organized and how its resources are utilized or prioritized. I remember my Mother saying 'you can't do anything about your disability, but you can sure as hell make them build a ramp.'

Over the next few weeks as I absorbed, or in their words "adjusted" to, my new reality I realized that where I had come to live was not a "boarding school" at all. I did not automatically return home between terms, most notably for summer holidays. I was not allowed more than three weeks home in the summer. One week at Christmas and one week at Easter. No "boarding school" had rules like that.

Only about four hours a day were actually spent in school. The rest were spent in "therapy", organized "recreation" or communal dining. My parents weren't even supposed to come and see me for the first few months in case they undermined my "adjustment".

Eight months later my younger sister followed. The fact that she was there forced me to keep up appearances, and make things at Bloorview better for her. At some point I realized that the only way to make things better for her, was

to make things better for all the kids there. I credit this awareness for my lifelong, if at times somewhat disheartened, dedication to disability activism.

With the support of my parents and teacher, I pushed to be allowed to go out to a “regular high school”. The schooling at the institution was sub-standard (meaning I’d never qualify for University admission) and other kids from Bloorview got to go out to school. But although they had disabilities, they were the more ‘able disabled’, doing everything for themselves which mostly meant they were able to go to the washroom. Although I couldn’t do that task without the help of someone, I pushed and pushed and finally they allowed me to go out to regular high school on a trial basis. When the anticipated problems didn’t emerge, like the problems associated with not being able to perform that task, the arrangement continued. This made it easier for other kids who were not totally independent, to go out to high school in the future. For example, it wasn’t half as hard for my sister because I had already set the precedent.

When I was about 17, a group of us went to Corbrook Sheltered Workshop. Sheltered workshops were places where disabled people went to work sorting nuts and bolts, or other menial tasks on a piecework basis. They were careful even then to never make more than the allowed amount so the Government Disability Allowance wouldn’t be cut off. The staff were pretty proud of the place, in particular the ‘loom room’. Working the looms was an advancement of sorts because there were so few spots and there was a long wait to get one. “This”, some proud custodian said, “is where you will work one day”. I actually couldn’t believe that this was all they expected me to achieve. I resolved then that no matter what, I wouldn’t end up in a sheltered workshop (sheltered from what I wondered) sorting nuts and bolts for a couple of dollars a month.

This made me even more determined to have a life in the community rather than going to another medical model institution when I was too old for Bloorview (which had an age limit of 18). According to the traditional medical model, physicians and other professionals are the experts one must obey. They tend to see people with disabilities as child-like people who are unable to run their own lives. In dramatic contrast, IL philosophy recognizes that people with disabilities can and do take action in their own lives and have the right to do so.

I was inspired by older kids with disabilities both going on to University and then acquiring jobs. The fact that these kids were not like me, in that they did not need any help with ordinary activities of daily living, was irrelevant to me. After all, I reasoned, one didn’t need a nursing degree to put on someone’s socks. I saw that kind of help as an extension of the kind of help that

any parent gave to infants and small children until they learned how to do up their own buttons, zippers and laces; definitely not medical.

In those days all I figured for my future was that I would go to school, University and then get a job where I could afford to pay a helper myself. Even in those years I knew people who avoided institutional life by doing just that or they would get help from a spouse or family member. A situation our brothers and sisters south of the border still face.

When the conversations first started in the early 70's about non-institutional alternatives for people with physical disabilities who were not totally independent, there was a lot of interest in the communities developed by Captain Leonard Cheshire (Leonard Cheshire, 2006). Cheshire homes served as a successful example of a community based alternative for those with physical disabilities who were dependent on daily physical help.

A new model had to be developed for those who needed that help, and so by 1974 Clarendon Foundation's first Vaughan Road site was established, largely driven by parents, teachers, and some interested administrators of Bloorview. Some people with disabilities, such as myself, were also involved with developing these alternatives.²

The key concept that guided these non-institutional alternatives was that of "normalization". A theory adapted by Wolfensberger which included sub concepts and models such as "Citizen Advocacy", "Social Role Valorization" and "devaluation" of people with disabilities (Parmenter, 2001). Devaluation was an important concept because it effectively labeled a range of sub-standard programmatic approaches towards people with disabilities and forced the acknowledgment of the double standard inherent in them. In order to correct devaluation, it was necessary to adopt approaches which could "empower" individuals. This theory, coupled with pragmatic logic showing that community-based alternatives were cheaper than institutional options, led to funding support from government for these alternatives (Parmenter, 2001).

In Ontario, Apartment Projects as they were called then, were fully funded through the Ministry of Community and Social Services. They were not staffed by trained Nurses or even Nurses Aids but by Attendants who were trained on-the-job by other attendants and by the people who would use their

² Clarendon was the first project modeled after Cheshire Homes that provided attendant services for people with physical disabilities, unlike McLeod House which, although it predated Clarendon, did not provide attendant services.

services. Attendants were the “arms and legs” of the disabled person, a phrase meant to denote that attendants were providing physical support services *to* people with disabilities, not decision making, supervisory or care-taking services *over* someone with a disability. These were early examples of non-institutional, non-charitable or non-medical models of community based supports for people with disabilities and daily support needs.

And yet as I watched development of these early projects, staff and administrators seemed to be unable to escape the idea that the residents of these projects were somehow in their charge – their responsibility. This still reinforced social inequality by instilling a culture of dependency rather than independence, pity rather than assistance. While institutionalization provides for the most basic of needs (i.e. the provision of food, shelter), it does little and, in many ways, prevents the attainment of higher fundamental needs – social inclusion, empowerment and self-actualization. Simply put, I wanted to get out of an ‘institution’, and live a ‘normal’ life in the community.

Not so simply put, equality was my recognition of equal capacity, value as a human being, and the dignity inherent in independent living approach. It was not a recognition of an abstract equality of physical ability which is never equal between any two people in any case. All people need assistance of some sort. This is the nature of social life and further, depending on your environment, this assistance might take the form of a device. For example, as my good friend Audrey King points out ‘we are all disabled on the moon or even under water’.

When I left Bloorview, it took close to a year for the first Clarendon Project to become fully realized and take in its first residents. I was among one of the first to live there but left very soon after. I felt very strongly that many of the things I was trying to escape from the institution had merely followed me there namely, inflexibility, depersonalization, isolation/segregation and lack of choice and control. The ideal of ‘normalization’ was still elusive. It would be 6 years until I tried living in an “apartment project” again.

The crucial turning point in the struggle for social equality was the emergence of the Independent Living Movement, a movement led and governed by people with disabilities (Driedger, 1989). This movement was gaining momentum in the United States and was spreading to Canada. During that time (mid 1960s to 70s) institutional alternatives for people who needed daily physical support did emerge. It would be nice to look back at those years and say that those were exciting times, but I can’t. The ‘emergence’ of alternatives did

not keep up with the demand. Therefore, for the person with the disability, I would characterize those years as ‘desperate’. Unless one came from a family with the resources for a child with a disability to return home, you went from the children’s institution to an adult, or worse, senior’s ‘home’. Invariably these people faced an early death from neglect of their human needs and potentials.

And so, for me those years were desperate. I needed community-based alternatives to be developed by the time I turned 19 years of age so I wouldn’t be sent from Bloorview to a worse institution.³ Luckily community-based alternatives were just around the corner. However, before those alternatives could come to fruition, a new problem emerged: isolation and lack of information. Yes, we had made some success in achieving integration, but it became more like a file-and-forget type of integration. Still not quite hitting the vision that we had for our future.

Fast forward ten years to the 1980s. Slowly but surely Independent Living Centres were emerging across Canada largely in response to this emerging need. And largely in response to the fact that considering the millions of dollars that government was pouring into supports and services for us, we – people with disabilities – derived very little benefit. The struggle for equality was only going to be won through our own efforts. The new Independent Living Centre thus committed to employing the very people they were set up to serve. They were *social enterprises*, and objective proof of both the equal capacity for self-determination on the part of people with disabilities and that the deepest problem we faced was not physical disability, but socially imposed barriers.

By around 1984-85 I was working as the Executive Director of the Centre for Independent Living in Toronto. One day, 30 odd years ago, a guy named Al Simpson phoned me up, several times as I recall, until finally I agreed to attend a meeting in Ottawa. Al was the kind of guy who didn’t like to take no for an answer. Over the course of all these calls he talked to me about this “independent living” movement that was growing in the US and now Canada, a model with a philosophy that people with disabilities have the same rights, options, and choices as anyone else. But mostly he expressed a concern that if we – the current Centres – didn’t get out ahead of what seemed to be a growing wave of emerging Centres anyone could hang out a shingle and say they were an Independent Living Centre. That sold me.

³ Those involved with the early development of these alternatives were parents of disabled children, some social service staff, and some people with disabilities themselves.

Al, along with Henry Enns, had gathered all the IL-like organizations across Canada to meet. In those days it was relatively easy. There were probably only 6 of us. This is where, according to my memory, we first began to hammer out the principles of the umbrella organization standardize the development of ILCs in Canada. We were pretty much able to reach consensus on governance, principles and a strategy to develop more IL Centres across Canada. We agreed that the philosophy would be founded on five principles:⁴

- Consumer control: in recognition that self-governance was a key concept for IL.⁵ Nothing about us, without us!
- Cross-disability: i.e. multi-disability rather than being divided by a medical diagnosis;
- Full participation and integration of all people with disabilities: as opposed to having rationed services or priorities set by others;
- Community based: implying that different solutions may be indicated for different communities i.e. language, culture, geographic location and that people with disabilities were the experts on how to address their own needs;
- Not-for-profit: to avoid any conflict that may emerge between a profit motive and service quality and ensuring a commitment to equality of service without regard to the differences in income.

By 1986, the first governing body for the Canadian Association of Independent Living Centres was made up of current or recent past Executive Directors of ILCs. This approach was based on the IL principle of ‘consumer control’, however in this case the ‘consumers’ were the Centres. We were truly, and saw ourselves as, an **association** of Independent Living Centres. We also agreed that, as a minimum, to actually be an Independent Living Centre, the programs had to be consistent with the principles. We settled on:

⁴ Although only four principles are enshrined in the 1990 ‘Guide to Independent Living Centres’, discussion of the not for profit, went without saying.

⁵ Inspired by the Ralph Nader consumer movement in the USA, in our case people with disabilities were reconceptualised as ‘purchasers’ of disability services and supports denoting more power over the quality of outcomes of those services and supports.

- Information and referral: now containing the concepts of networking, navigation and community engagement. This evolved from the simple concept that having knowledge is in itself power; I&R works with individuals to reduce their isolation from the community. We can refer people to the appropriate range of resources to potentially broaden both opportunities and horizons in the self-chosen area.
- Peer Support or self-help: people with disabilities are often more helpful to each other than traditional professionals that can have diminished expectations of what PWDs can achieve and who can create artificial dependencies. Based on the observation that supportive peer environments provide positive role models which enable individuals to gain skills and the self-confidence needed to overcome barriers; PS encourages people with disabilities to speak with others and share thoughts, concerns, successes and hopes with each other; PS promotes exchanges and discussion between individuals who have lived experience;
- Individual Advocacy: as opposed to systemic advocacy. Based on the simple notion that ‘feed a person a fish, you have fed them for a day, but teach a person how to fish, they are fed for life’; The IA goals are to support individuals in learning to manage, coordinate and negotiate a wide range of community resources; assist consumers to exercise their rights and to provide support to people in pursuit of their individual advocacy goals; enhance their problem solving skills; encourage proactive, solutions based approaches to conflict and problem solving and to provide tools, support and resources to create lasting positive change.
- Demonstration Capacity: or service development capacity. Giving Centres the ability to develop IL consistent projects, programs or initiatives but to not necessarily keep them.

For Toronto two examples of ‘Demonstration Capacity’ are the Direct Funding – Self-Managed Attendant Service Program (DFP) and the Parenting with a Disability Network. But I’m just going to talk for a minute about DFP. Through the DFP we fund other most other Ontario Centres, and ourselves to the tune of over \$1M. We really feel that this is a good example of a Social Enterprise that aligns with IL philosophy and principles that other Centres may wish to explore. But don’t think for a minute that it will be easy. It was over 10

years of hard negotiating with the Ontario Government to make this happen and now the program is 21 years old. DFP provides funding to us, through the Ontario Ministry of Health and Long-term Care, to act as banker for the program participants who negotiate an agreed upon budget so that they can hire, schedule or terminate their own attendants. Currently this model is under consideration for other populations as well. DFP allows for great service efficiency and is administratively light. A future webinar may be planned if there is interest in knowing greater detail about this program.

The final area I want to talk about are the key differences between the IL and medical models. In order to do that, I'd like to go back to my original story – being at Bloorview vs where I am now – on Direct Funding.

Although there are growing examples of how the medical model is changing, one of the most challenging assumptions within institutions and society is the pervasive belief that the disability is a pathology to be wiped out. Examples of this are numerous – genetic counselling, immigration policy, and most recently Medical Assistance in Dying. People with disabilities aren't 'sick', 'deficient', 'dependent', or an incredible burden to their loved ones or society. We don't necessarily require expensive 'care' by health professionals who tend to work within authority-driven, risk adverse systems. For those of us who are "disabled" (not "sick") yet require routine daily assistance with normal activities of daily living (e.g. assistance with dressing, transferring, shopping, errands, meal preparation), such deficiency-based assumptions continue to present a problem. And when we are sick, we do need medical model services – but viewed through a disability positive lens – like anyone else.

The IL Movement has developed its own unique identity in response to the traditional rehabilitation services model. The problem does not reside in the individual, but often in the solution offered by the professional. According to the traditional medical model, physicians and other professionals are the experts one must obey. These experts take charge; they tend to see people with disabilities as child-like, as weak and uninformed, people who are unable to run their own lives; as passive grateful recipients of services. In dramatic contrast, IL philosophy recognizes that people with disabilities can and do take action in their own lives and have the right to do so. IL has a self-empowerment, self-help method that leads to a new kind of social and political power.

Through fierce determination, Allan Simpson, Henry Enns and the thousands of others involved in the IL movement, have changed the course of history and changed the world in which we all live. Canada became one of the

first countries to accord people with disabilities constitutional protection of their equality rights. IL has taught us to be proud of who we are and not to be ashamed of our disability. We don't need fixing and we don't need managing. We just need the right information, support and services that are flexible enough to accommodate the range of activities I/we aspire to do. I/we want to be in control of my services and my destiny. I/we want services that are effective and enabling so I can work or play or meet a host of other social roles in a variety of places of my choice. If I get all these things, it means I get to live a full independent productive life. It cannot be said enough that IL philosophy is of utmost importance to people living with disabilities and that our IL Centres are and must be the delivery agents of this philosophy. An example of this is the story a woman tells about working with a man in Kapuskasing that hadn't been out for dinner with his wife in years. He lived with Parkinsons and was too embarrassed of his shaking hands to eat out in public. The Centre suggested to him that he was allowing others to prevent him from doing things in the community that he loved to do and that he had right to do, and that maybe if people saw him out in the community more often, maybe he could learn how not to be embarrassed of his disability and in turn the community could learn from him too. He took his wife out for dinner the following week and continued doing so on a regular basis afterwards and yes people did eventually stop staring at him because he became a regular participant in the community, and he felt he was no longer strange or different but became the 'new normal'. The example of this man shows that inequality for disabled people is a four part problem:

1. There are insufficient resources invested in accessible societies and its attendant institutions – transit systems, schools, hospitals, museums, art galleries etc.
2. Lack of awareness that access is not just about design. There are services and supports which also require investment.
3. The dominance of the medical model which continues to drive social assumptions about what disabled people can or can't do.
4. The way in which disabled people ourselves have internalised this social stigma as other historically oppressed groups have.

The independent living movement challenges all four areas. We have systematically improved access, put resources under our more direct control, we live in the community with our fellow citizens, and consider our lives to be

equally valuable. The progressive process of living independently is the counterpoint, freeing us from the imposed social and medical stigmas.

The Centre for Independent Living in Toronto (CILT) Inc., where I work is run by people with disabilities for people with disabilities. Our Centre, established in the mid 1980s, was developed in response to an increasing demand for alternatives to institutional living and an increasing need for appropriate community based support. However, examples of inappropriate institutionalization still exist. As recently as July 9th 2017 a *Toronto Star* headline stated “care homes not suited to young” (Goffin, 2017). There continue to be forces out there that still view institutions as the solution. What is most disturbing in this debate is how little is actually known of these alternatives to institutionalized supports, how much more economically efficient they are and how the capacity to promote autonomy, dignity, equity and respect exists in these models.

As our movement has shown, the only way forward for social equality is to demand that governments expend resources to support and build our capacity for independent living. No matter how well-funded or organized, ‘care’ homes will always perpetuate the paternalism and injustice of the past, when disability was confused with illness and disabled people were assumed to be helpless dependents. Burdens. Like other oppressed groups, disabled people have proven by the success of our own struggles that we are capable of living on our own, working and contributing as equal citizens. The barriers we have faced are more concerned with the organization of social life and institutions than our own bodies which – like everybody – is limited in different ways. Whether limitation and disability becomes a source of inequality depends not on the disability, but the extent to which society values disabled persons *as* persons and invests in the social infrastructure the expression of our *abilities* require.

Independent Living Perspectives		
	Traditional “Medical” Perspective	Independent Living Perspective
Perception of the Situation	Person with disability is a “patient” who is “sick” & dependent on others	Person with a disability is a “citizen” with equal rights to participate & contribute to his society
Focus of Problem	The person with the disability	Societal beliefs, which create inaccessible environments, both attitudinally & physically
Role of Disabled Person	Be compliant, grateful, appreciative, complaining, dependent	Ask questions, learn, take control, negotiate, make decisions
Role of Professionals	Be an expert, authority, take charge, make decisions regarding persons with disability	Be a supporter, enabler, collaborator with disabled person
Focus of Intervention	Curing, rehabilitating, alleviating the “patient’s” functional deficiencies	Maximizing the strengths, abilities, skills & hopes of the person who lives with a disability
Authority and Responsibility/Best Interest Determination	Resides with funders, professionals, agents in the chain of command	Resides with the person living with a disability and/or his family
Location for Receipt of Supports/Services	Institutions, bureaucratic systems and dominant hierarchies	The individual’s home, community, school and workplace
Ultimate “Solution” for Resolving Disability Issues	Cure, rehabilitate and alleviate the disability	“Accommodate” disability by changing attitudes, creating accessible environments & providing required personal supports

References

- Driedger, D. (1989). *The Last Civil Rights Movement: Disabled People's International*. London: C. Hurst & Co. (Publishers) Ltd.
- Goffin, Peter. (2017, July 9). "Disabled adults stuck in long-term care void." *The Toronto Star*.
- Leonard Cheshire. (2006). Creating Opportunities with Disabled People. <http://www.leonard-cheshire.org/>.
- Parmenter, T. R. (2001). Intellectual Disabilities: Quo vadis? In *Handbook of Disability Studies*. G. L. Albrecht, K. D. Seelman & M. Bury (Eds.). Sage: Thousand Oaks, CA.