

Neo-Asylum Era: Institutions Without Walls

Introduction

I spent the first part of my life struggling to get out of an institution. Since my “great escape”, I’ve been spending the rest of it fighting to keep the institution from descending upon me. What exactly is meant by that statement?

Because the goals of de-institutionalization were never effectively identified, other than identifying de-institutionalization itself as a ‘goal’, the stage is set for institutionalizing community-based services - services that were originally conceived of as an alternative to institutionalizing people who could not perform ordinary activities of daily living.

From my own experience the goals of de-institutionalization were conceived of as personalization, integration, flexibility, consumer control, participation, choice, effectiveness, safety/security. Simply put, I wanted to get out of an institution, and live a normal life in the community.

De-institutionalization failed because community-based services are now creating similar barriers to personal empowerment, mobility and participation that existed in institutions. For example; services are only provided to a person with a disability at home or at a fixed location.

I will show this first, by tracing the history of attendant service development in Ontario. Secondly, I will illustrate a further entrenchment of institutional ethics by briefly examining the phenomena of health regionalization across Canada, and then by a more specific examination of the implementation of the Local Health Integration Networks (LHINs) in Ontario. Thirdly, I will identify de-institutionalization goals¹ from a variety of perspectives. Finally I will analyze these goals and discuss to what extent current services approach them.

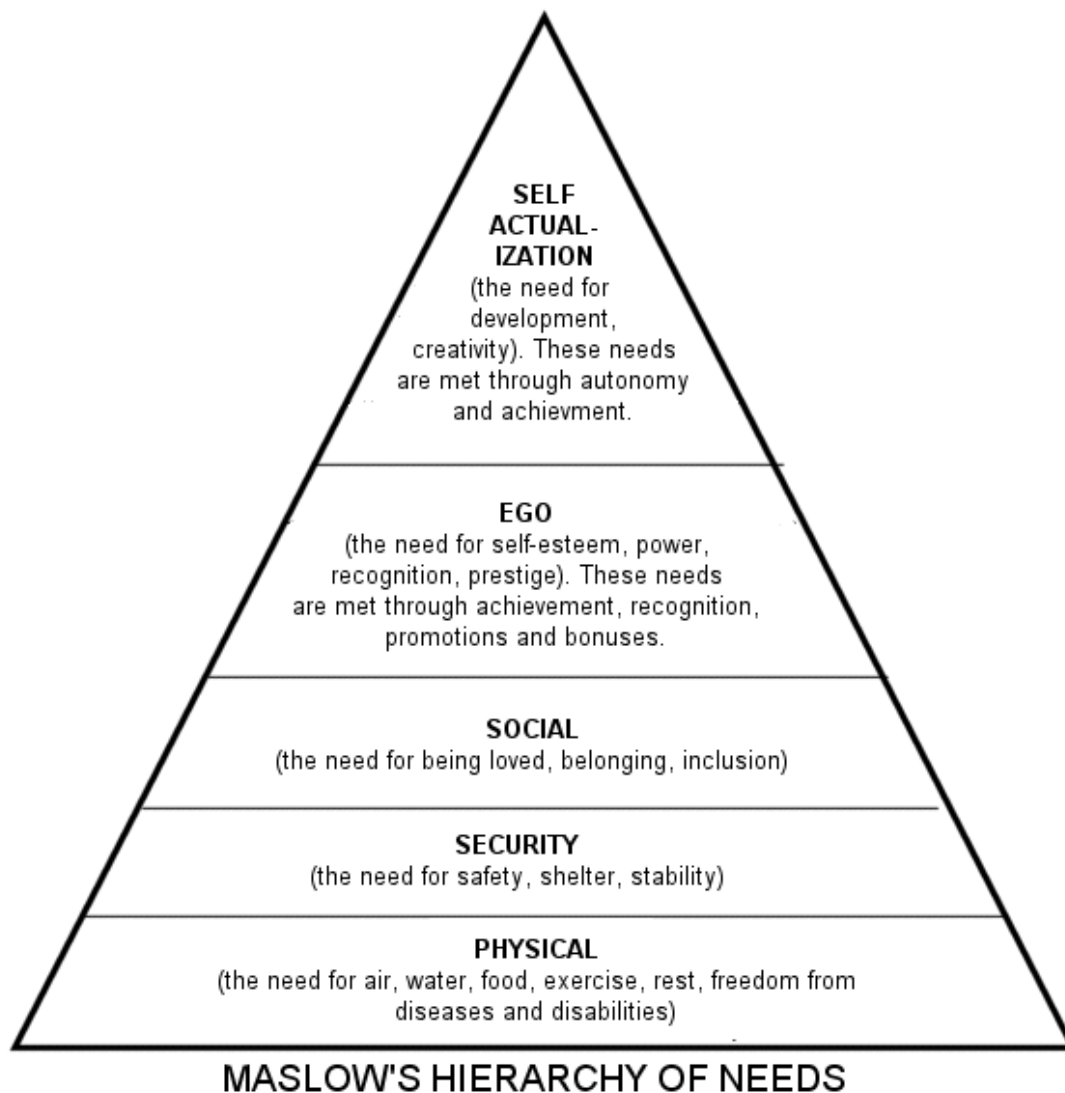
Why is it important to explore the outcomes inherent in de-institutionalization? Because all citizens have the right to be free and this right should not be sacrificed solely because a person with a disability needs assistance with daily living. This idea was eventually crystallized in the Independent Living Movement’s concept of “empowerment”. But to use more common “social service” language, the fight to escape institutionalization is grounded in Maslow’s hierarchy of needs; the pinnacle of which is the principle of self-actualization. (Wikipedia Contributors, 2006)(see Figure 1).

Maslow has been so often cited in books and texts, and his pyramid so customized by whoever is using it, that its evolution is hard to track and the original pyramid difficult to identify. However, the language used by advocates of

¹ Goals are now more often referred to as “outcomes” but in this paper I have used the terms goal or goals.

de-institutionalization is usually captured by terms like 'self-determination' or 'empowerment', synonymous with self-actualization.

It is easy to see from Maslow's Hierarchy of needs, that institutional life prevents an individual from progressing up the pyramid. If anything, a person will hover at the bottom in the physical realm and stay there because they are regarded as not "free" from disability. The development of community based alternatives was a recognition that although a person may not be "free" from disability, that they none-the-less have the desire, and right to progress up Maslow's pyramid.



[Figure 1]

Maslow's hierarchy of needs to illustrates how institutionalization, while providing for the most basic of needs (i.e. the provision of food, shelter), does little and, in

many ways, prevents the attainment of higher fundamental needs – social inclusion, empowerment and self-actualization.

Almost anything can be defined as an institution or as institutional. Education, human rights, in fact anything once socially entrenched, inevitably becomes institutionalized or bureaucratized. But specifically this paper wants to trace the evolution of a very specific type of institution. The residential institution that at one time was called an “asylum”. Therefore in order to clearly identify a definition of institutions for the subject of this paper, Goffman’s (Goffman, 1962) definition of total institutions is used, namely:

- “...All aspects of life are conducted in the same place and under the same authority...
- Each phase of the member’s daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same things together...
- All phases of the day’s activities are tightly scheduled, with one activity leading at a pre-arranged time into the next, the whole sequence of activities being imposed from above with a whole system of explicit, formal rulings and a body of officials...
- The various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution...” (Goffman, 1962:6).

Based on this definition, Goffman describes five types of institutions: Those intended to care for others (homes for the blind, nursing homes); those intended to care for others whom unintentionally may pose a threat to the community (sanitariums, mental health hospitals); those intended to safeguard the community against an intended threat (jails, prisons); purpose built facilities (army barracks, boarding schools and even servants quarters) and finally, things that might classify as retreats. (Goffman, 1962:).

Inevitably a split between the inmates (residents) and staff will emerge.

“Each grouping tends to conceive of the other in terms of narrow hostile stereotypes, staff often seeing inmates as bitter, secretive and untrustworthy, while inmates often see staff as condescending, highhanded and mean. Staff tends to feel superior and righteous; inmates tend, in some ways at least, to feel inferior, weak, blameworthy and guilty”.(Goffman, 1962:7).

These points resonate with my experience as resident of an institution for physically disabled children. From the age of almost 11 (1965) to a few months

past age 19 (1973), I lived in a state funded “hospital, home and school”, later re-constituted as a “hospital”.

As I read Goffman’s book I was struck by the similarities to my own experience even though the examples he used to support his point were from prisons, mental hospitals and other state schools of reform, protection, training or rehabilitation.

During that time (mid 60’s to 70’s) institutional alternatives for people who needed daily physical support emerged (Cheshire Homes London, 2005). It would be nice to look back at those years and say that those were exciting times, but I can’t. 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.

And so, for me, those years were desperate. I needed community-based alternatives to be developed² by the time I turned 19 years of age so I wouldn’t be sent from Bloorview to a worse institution. Perhaps because of this haste no other goal, than the goal of de-institutionalization, was identified. I here will show that a highly important step was missing in the de-institutionalization process.

Background/Methodology

Most critiques and analysis of institutions appear to focus on those with an intellectual disability, a mental health issue or senior care need. The institutionalization of people with physical disabilities who need daily physical supports is not clearly addressed in the literature. There may be good reason for this apparent lack. First, unless there were some level of intellectual disability a person was not eligible for institutionalization. Because of a lack of community support and resources many people with physical disabilities were inappropriately diagnosed with an intellectual disability simply so they would qualify for admission. Secondly, the numbers of people with physical disabilities alone, weren’t high enough to warrant the building of the large institutions³ typical during what Radford and Park refer to as “the asylum era” of the early to mid 20th century (Radford & Park, 2003). This resulted in the inappropriate designation of what was then called ‘mental retardation’ to someone with a physical disability. Thirdly, and again since numbers are so low, if a person with a physical disability needed daily help that families couldn’t provide they were often placed in senior’s facilities. Even now, especially in smaller communities in Ontario, people of a very young age are found living in senior’s institutions. This has resulted in a difficulty looking specifically at the population of physically disabled adults who need daily assistance because it is a primarily hidden group.

² Those involved with the early development of these alternatives were parents of disabled children, some social service staff, and some people with disabilities themselves.

³ Although Radford’s work focuses on Ontario, this occurred throughout North America.

As such I have used the goals I had set for myself when I left the institution as a touchstone for this discussion. My goals are a core source of comparison for other “goal holders” identified and discussed in this paper.

The primary subject population studied is the population of adults with (primarily) physical disabilities. This population has been selected in order to enable me to use my own personal experiences and relevant work history as an analytical tool. For the same reason, the primary service reviewed is attendant services i.e. daily support for core activities of daily living including bathing, dressing meal preparation etc. This need resulted in my own institutionalization. The development of community-based alternatives that addressed this need were primarily responsible for my ‘escape’.

My experience is contextualized first, by briefly reviewing health regionalization across Canada. I then focus on Attendant Services in Ontario, specifically Toronto, and how attendant services may be affected by the current implementation of Local Health Integration Networks (LHINs). The LHINs are Ontario’s response to the phenomena of health regionalization across Canada.

Goals for de-institutionalization are inferred from a range of writings, reports and experiences and summarized in a chart presented later. Goals for de-institutionalization are often inferred or inverted from the goals for community living which were presented in a more positive light, i.e. the option for a thing, as opposed to a negative, against a thing.

I Spent the First 20 Years of My Life Fighting to Get Out of an Institution, Only to Spend the Rest of It Keeping the Institution from Descending upon Me

When I was born, in the 1950’s, 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, it wasn’t actually diagnosed until I was 3 years old and was subjected to a gamut of tests at the Shriners’s Hospital in Montreal. In the 50’s medicare did not exist. The Shriner’s Hospital was a Charitable Hospital. As a charitable hospital, I was able to receive 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: Spinal Muscular Atrophy which is a type of Muscular Dystrophy.

By the ‘60’s my parents had broken up but we continued to live at home with my mother. I remember going to a “regular” school; a right for which my Mother had to fight with the local board of education. And then because of ongoing difficulties with me getting the support I needed to be really integrated, for example with accessible transportation or assistance going to the washroom, I was sent to the

“Crippled Children’s School”. At first, I was bused (or rather taxied) to this special 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 we were. The regular school wouldn’t let me in, and neither would the “segregated” school. The only recourse for us was home teaching, which was paid for by the board of education, but my mother was starting to panic. Her concern was mostly around isolation and under-stimulation and she regarded us both as “smart” and “needing to use our brains”.

When the visiting nurse came by she advised my mother to send us to a residential school for disabled kids. It seemed like the best option 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 I went to live at Bloorview. At that time Bloorview was billed as “Bloorview Hospital Home and School”.

My father lived in Toronto (home was Ottawa) and so he came down to pick me up and drive me to Toronto. The first thing I saw on arrival was a plaque in the lobby with the header “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 mistake had been made.

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 was spent in “therapy”, organized “recreation” or communal dining. My parents weren’t supposed to even come and see me for the first few months in case they undermined my “adjustment” but I do remember my dad coming every week anyway. And as soon as he could, he took me out on weekends.

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 “regular high school”. The schooling at the institution was not up to standard. Other kids from Bloorview got to go out to school. But although they had disabilities, they could do 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 go to the washroom at school, 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.

From the start I had a dream of living in the community and not going on to another institution when I was too old for Bloorview. I had a dream that was inspired by other kids with disabilities of going to University and working. 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. In those days all I figured 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 did that or who were married or living at home and had the help they needed from family. 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.

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 examples of communities developed by Captain Leonard Cheshire (authors unknown, 2006). Although there is current tension between Cheshire Home and the disabled community (Clark, 2001), then Cheshire homes served as a successful example of a community based alternative for those with physical disabilities who were dependent on daily physical help.

The first Cheshire Home in Toronto was McLeod House (Smith, 2000), and although it was for people with physical disabilities, it was for ambulatory people only and was not even originally equipped with a ramp.

A new model had to be developed for those who needed basic help, and so by 1974 Clarendon Foundation's⁴ 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.

The key concept that guided these non-institutional alternatives was that of "normalization". A theoretic 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

⁴ 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.

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 theoretic, coupled with pragmatic logic showing that community-based alternatives were cheaper than institutional options, (Parmenter, 2001), led to funding support from government for these alternatives.

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.

Apartment Projects were then 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 services. Attendants were the “arms and legs” of the disabled person, a phrase meant to denote that attendant were providing physical support services to people with disabilities, not decision making, supervisory or care-taking services over someone with a disability.

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.

Meanwhile, the Independent Living Movement, a movement led and governed by people with disabilities, was gaining momentum (Driedger, 1989).

Radford and Park (Radford & Park, 2003) refer to this same evolution but from a different or geographical perspective. In their article called “Historical Overview of Developmental Disabilities in Ontario” these shifts are captured by placing social approaches to disabilities in three categories: the Pre-Asylum Era characterized as a state non-intervention phase, the Asylum Era characterized through the emergence of large and thought to be socially progressive buildings housing thousands of people with disabilities and the Post Asylum Era characterized by de-institutionalization and the emergence of community-based alternatives.

It was thought that, because of the shift away from the Ministry of Health, which funded hospitals and institutions, toward the Ministry of Community and Social Services, there was a renewed commitment to community services.(Radford &

Park, 2003) And indeed, most of the early community based programs were funded through the Ministry of Community and Social Services. However, by the late 80's and early 90's, these programs were re-conceptualized as Long-Term-Care programs. Initially a tri-Ministry initiative including some programs from the Ministry of Health (all home care programs), the Ministry of Community and Social Services (all attendant service programs), and the Ministry of Citizenship, Office for Disability Issues (seen as the advocacy ministry), all home care and attendant service programs were first consolidated and then managed under one Ministry: the Long-Term-Care division of the Ministry of Health. This move was made in spite of community protests regarding the philosophical shift this signaled. First, because The Ministry of Health had the largest budget of all Ontario Ministries, bigger by far than the budget of the Ministry of Community and Social Services. Secondly, by re-conceptualizing these services as "health services", Ontario was able to make a better case to the federal government to include those programs in its cost sharing arrangements.

Simply put, the federal government would pay a higher share of money if a province could demonstrate that the money was spent on health care, but not for other community based programs not defined as health programs.

There was also a much more insidious shuffling of responsibilities between Ministries. The Ministries were trying to redefine themselves and the service they offered in terms of core businesses. Clearly once a program became defined as long-term-care, it was defined as a health service and so the shift, although philosophically flawed, was inevitable.

This shift was eventually felt on the ground, a fact to which I will later return.

In February of 2003 I was asked to make a presentation to the Provincial Association Senior Managers group Annual General Meeting. The theme of the talk was "How Do You Protect The Values Of Independent Living In An Increasingly Over Regulated And Under Funded Sector"?(Carpenter, 2003)

At that time the regulations under consideration were Employment Standards, Health and Safety Legislation, the Long-Term-Care Act, Pay Equity and the range of collective agreements that the various providers were trying to juggle. However because the legislation itself focused on the relationship between workers and employers, the end users of the service were secondary.

For example, there was situation where an attendant service provider, out of concern for the health and safety of the workers, pulled them all quickly out of service in the building I lived in. This allowed insufficient time for someone such as myself who lived alone to replace this service. Because many of us were dependent on an overnight on call emergency service, i.e. once I am in bed I cannot get up on my own or even change positions, this decision severely

jeopardized our health and safety. This became a secondary issue to the primary one that as an employer the responsibility to the worker was paramount.

It took several weeks of negotiating to have this essential service replaced.

Since that time (2003) the Protection of Personal Health Information Act was passed and now the implications of Bill 36 Local Health System Integration Act, 2006 must be assessed. That's a lot of legislation applied to a relatively small and selective sector, and to a sector meant to empower and support individuals.

Society is rapidly losing the capacity for individualized response in almost every facet of life. In this climate it becomes even harder to maintain services from devolving into what threatens to become so standardized that only the most common needs of a person can be addressed. It is ironic that this "standardization" occurs in the name of "equity". Once again the dilemma emerges to show that "same treatment" often does not result in an "equality of outcome".

Currently in Ontario there are three primary options for obtaining attendant services. Two are managed systems and one is self managed. The two managed systems are, Supportive Housing Units, where funding is allocated though the Ministry of Health (MOH) to provide attendant service to people living in designated units in a multi-unit apartment building, and Outreach Attendant Service, where funding is provided for an attendant to provide service in an individuals own home or apartment. In both these case funding is provided to a registered non-profit organization. The third option is Ontario is Direct Funding, where the Ministry provides funding to an organization 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.(Centre for Independent Living in Toronto (CILT) Inc., 2005)

With the advent of the Local Health Integration Network (LHIN) system attendant services and other Ministry of Health funded community-based programs will be under the same authority as all other "health" and hospital programs. Although in one sense, all of these programs are under one authority i.e. The Ministry of Health, there are some significant differences. The next section will focus on LHINs, Ontario's answer to the regionalization of health services common across the Country and in fact appearing in places all over the world.

North American Free Trade Agreement (NAFTA)

NAFTA is having an undue influence on the provision of health care in Canada because it is designed to make all services accessible to private market.

The story begins with the North American Free Trade Agreement (NAFTA). While I don't want to hijack this paper by focusing too much on NAFTA, I

would be remiss in not saying something about it. At the root of organized labour's campaign to stop the LHINs(Ontario Health Coalition, 2006) is the concern that LHINs will open the door to privatized medicare. Once this door is open it will be almost impossible to close because of the way NAFTA is structured.

In the book, "Clear Answers"(Taft & Steward, 2000), Taft and Steward offer this quote from Barry Appleton, of Appleton and Associates International Lawyers.

The NAFTA is structured to protect and encourage government measures that increase access to markets. This results in the NAFTA irreversibly protecting the trend towards private health care while eroding the government's ability to reverse this trend.(Taft & Steward, 2000:102)

The book goes on to quote a senior US trade official:

The United States is of the view that commercial opportunities exist along the entire spectrum of health and social care facilities, including hospitals, outpatient facilities, clinics, nursing homes, assisted living arrangements and services provided in the home.(Taft & Steward, 2000:104)

Emphasis mine.

Although I see this as a little bit of the, "which came first- the chicken or the egg?" question, it almost doesn't matter. It remains that, in the name of some imagined or real efficiencies, regional health authorities have contracted with private health care providers and NAFTA will make it impossible to go back.(Taft & Steward, 2000).

Local Health Integration Networks

Health regionalization across Canada, the process by which provinces devolve health authority to regional bodies within the province, is at least 10 years old and there has yet to be an effective evaluation of the real impact of this phenomena. Although based on the theory that health regionalization will result in decision making that is closer to communities, Bach points out that regionalization may make it more difficult to negotiate for things such as inclusion, due to an increase in the number of "decision centres". (M. Bach, 1999:51).

Nowhere is it shown that placing decision making closer to communities creates a better or worse health care system. In fact The Society for Rural Physicians state in their 2004 report:

"...In some provinces this has included a broad range of services, such as acute care, home care, public health, mental health.... Some provinces have made many smaller

units, and others have made fewer larger units, but all exercises in regionalization have driven a centralization of services.

Many communities have lost services, sometimes including their hospitals.

There is a lack of Canadian research into issues of the effects of regionalization, among other things, on access to care, quality of care and recruitment and retention of health care professionals. There is little research on the optimum size and design of health regions”.(Konkin, Howe, David, MB BS, & Soles, 2004:257-9)

The report then makes several recommendations the first of which would be that before implementing regionalization a province should have “Stated, measurable goals”.

“Regionalization experiments have been initiated by governments without clearly outlined goals and the tools of evaluation needed to monitor and measure these goals. Many governments turned to regionalization as a means to contain the increasing costs of health care, yet the massive reorganization of many provinces' health delivery systems has not demonstrated savings. The information about the cost to the system of regionalization is not available, in some cases 10 years after the initial experiments” ...(Konkin et al., 2004:257-9)

They also recommend a clear “Definition of a viable region” and then state:

“It is hard to believe that there are not standards and definitions for viable, effective regions in this country....When determining regional borders, the realities of geography must be taken into account, from the vagaries of local weather patterns, to impassible mountain passes, and average number of days per year when air evacuation is impossible, to name a few” (Konkin et al., 2004:257-9).

The report goes on to make further recommendations but I have only highlighted these two. It is clear that rural physicians question whether needs will be addressed through the LHIN system.

Although it can only be surmised that regionalization may result in majority interests dominating, disadvantaging small statistical groups such as rural physicians or people with disabilities, that has yet to be proven.

In spite of any clear evidence on either side, Ontario’s answer to health regionalization is the LHIN system.

In a government issued flyer entitled “How LHINs Are Good For Your Health”, it states:

“The goal of LHINs is to restore equity to Ontario’s health care system, ensuring quality care for every patient, in every community in the province.

Under LHINs, community health care priorities would be identified at the local level by the people closer to what is really going on.

LHINs would ensure that health care dollars are spent in the most efficient and effective way possible...Accountability agreements between health care providers and LHINs and between LHINs and the government, would ensure the responsible use of precious health care resources, and the sustainability ...”(Ontario Ministry of Health, 2006a)

Sound good? Maybe. Until you realize just how wide the LHIN net is cast.(Ontario Ministry of Health, 2006c) Not only are hospital and health care programs involved, but all services including those that are community-based and are funded through the Ministry of Health are included. This makes it hard for people with disabilities, who view attendant services as critical to maintaining community participation, and who have also spent the last 30 years distancing themselves from terms like “patient” to feel any sense of confidence in this development.

Another sector that seems to be most concerned with LHINs is organized labour, notably the Ontario Health Coalition (OHC) (Ontario Health Coalition, 2006) comprised of CUPE, OPSEU, SIEU and ONA. Although the root of their concern lies with the implications of NAFTA and job security, their campaign “Stop the LHINs”, centres almost exclusively on job security. The OHC states that the LHIN system will erode job security and pave the way for privatization of health care. They fail to draw a clear connection to show that the LHIN system makes it easier for the NAFTA agenda to be realized. It appears that implications of NAFTA are simply too remote and complex to really grab the imagination of the average worker in the health care field.

LHINs were born in response to the problem that too much was spent on the administration of health care and not targeted towards the service of health care.

In her book, “The Cult of Efficiency”(Stein, 2001), based on a Massey Lecture Series, Janice Gross Stein clearly tracks the shift of the very concept of ‘efficiency’ from a means to an end to an end itself. She states:

“Efficiency is only part of a much larger public discussion between citizens and their Governments. Efficiency is not an end, but a means to achieve valued ends. It is not a goal, but an instrument to achieve other goals. It is not a value, but a way to achieve other values... When it is used as an end in itself, as a value in its own right,...it becomes a cult”.(Stein, 2001:6).

Early Bulletins (Ontario Ministry of Health, 2006b) issued from the Ministry of Health illustrated the inefficiencies of a health system by pointing out the number of agencies, councils and government administrative structures that were all

involved with health service planning or allocation. On the other hand, individuals were waiting for unacceptably long periods for certain health services.

From the beginning the Ontario Liberals were interested in “transforming” health care. Unfortunately it appeared that lessons learned in other jurisdictions were either ignored or misinterpreted. Government failed to realize that systems cannot be “transformed” through top-down initiatives. Community development cannot occur unless there is true community based bottom-up development. The LHIN initiative involved intensive community consultation and development but it was highly controlled and key decisions regarding strategy and direction were already decided. These decisions came from the “top”. Examples of this are numerous and include: the process and delineation of boundaries, the elimination of decision and planning centres, the consultation process and who would be included, and the very idea of a regional health planning and allocation structure.

The initial consultations were based on “open space technology”, itself a misnomer. How it worked was like this:

Staff at the Centre for Independent Living in Toronto, myself included, were among 600 individuals invited to attend an all day meeting held at the Metropolitan Trade Centre at the CNE, Toronto in December 2004. Groups were selected based on which LHIN area the group was in and this was decided through the postal code address. I should here state that LHIN areas – boundaries – were determined through an analysis of hospital discharge patterns that were used to create a map of each LHIN area.

Based on this and a mailing list of groups funded by the Ontario Ministry of Health, the invitation to attend a consultation meeting was issued. Because this consultation was made up of representatives from groups that were already funded by the Ministry of Health, groups such as ours were vastly outnumbered by more traditional health care groups such as doctors, hospital administrators, nurses, therapists, counselors, addictions and mental health services staff, staff from Community Care Access Centres and so on.

In a group the size of 600 people, it rapidly became a numbers game. I couldn't help but make the connection with certain “reality TV” shows like “Survivor”⁵. First of all, all the participants, if they were interested in leading a workshop, had to scribble a brief explanation of the topic down on a piece of paper and tape it to the wall. Those of us who were in wheelchairs (four of us) were highly disadvantaged even in this exercise because 1. We couldn't run up to the front to grab a piece of paper from the floor. 2. We had no where to write and couldn't use the floor like everyone else did and 3. None of us had the ability to tape

⁵ “Survivor” was a popular television show in 2000 to 2004 in which the contestants, were divided into teams and placed into a harsh environment. They were expected to compete with each other for food or other survival essentials. Each week someone, was voted ‘off the island’ by the group of contestants and the last person remaining was considered the winner.

anything on a wall. Luckily we had one of our staff who was not in a wheelchair do these three steps for us.

The next step was that “volunteers” from among the 600 went around and put similar sounding topics together. Once that was done the 600 went around and using cards, voted by putting their cards in the envelope describing the workshop. The next step was to count the votes that each one received. Only the top 20 were picked.

The rest of the day was spent in workshops and when those results were shared, there was another voting process so that only the top 5 of the 20 would be priority areas for that LHIN to work on. In other words, the majority ruled and it is a well know fact among equity seekers that majority decisions often disadvantage minority groups.

This exercise was duplicated for the 14 LHIN areas across Ontario and resulted in the 14 separate Integration Priority Reports.(Ontario Ministry of Health, 2006b)

It is interesting to note that although the one criticism that everyone shared i.e. that the boundaries made no sense, to which the LHIN architects all responded by saying that “the boundaries weren’t laid in stone and were being revised” the original LHIN boundary map still stands.

In November of 2005, the Ontario Liberal Government introduced legislation that would enact LHINs and spell out the relationship between LHINs and CCACs. Even before this legislation was in place, the recruiting process for key LHIN Boards and staff began. As of March 2006 Bill 36 passed third reading and currently awaits proclamation. Organized labour began its campaign (Ontario Health Coalition, 2006)when the Bill was in hearings. But others recognized that LHIN might pose a threat much earlier. The Centre for Independent Living and the Attendant Consumer Action Coalition rapidly shared information and developed a common strategy aimed at “protecting the integrity of attendant services”, specifically Direct Funding, which it feared would be eroded by LHINs.

To get back to Maslow’s hierarchy (Wikipedia Contributors, 2006) LHINs only address the physical needs layer, and is therefore seen as counter to the disabled community’s steady progress towards self-actualization.

By February 2005, the Centre for Independent Living in Toronto and the Attendant Consumer Action Coalition, received confirmation that Direct Funding (DF) would not be rolled into the LHINs. This was important for a few reasons. First, as supporters of DF have seen with other similarly structured programs in other provinces, the key issue of portability within the Province was lost. A person who lives in one region cannot move to another unless he or she is willing to start all over again. The dollars do not follow the person. Supporters did not want to see DF carved up into 14 areas. One of their key principles was that by

having one program which blanketed the Province the significant barrier of portability (within Ontario) was eliminated. This was important to enable people to move for employment, education or personal reasons and not be a prisoner to 'remaining in place' because that's where the resources were. A second key reason is that by carving DF up people who wanted to move would be at the mercy of whatever the priorities of a particular LHIN were at the time and if, in fact, there were resources to access.

Supporters of DF shared this information with other attendant service providers, and in fact, tried to make a case for the utility in having them as a separate, outside or parallel structure to the LHINs. An un-submitted draft proposal was written with this in mind but due to a lack of consensus among attendant service providers was never properly completed. Many attendant service providers viewed LHINs as a positive development and most others were unsure of the implications. And so to date, they are or will be under the jurisdiction of the LHIN system.

A third and more insidious reason, for keeping DF outside of the LHIN system, centred around the very concept of what an attendant is. Part of the "win" for keeping DF outside the LHIN system was the detailed explanation of what attendants do. (see Chart 1) But rather than succeed in showing how important it was that the understanding of attendant's job functions must be kept separate from the understanding of a Personal Support Worker's (PSW) job function, the term PSW is increasingly used by the Ministry, service providers, and organized labour interchangeably with the term attendants. If people with disabilities wanted to keep attendants out of being included in the PSW umbrella, we were told that maybe we should come up with a new term for attendants. This signals how quasi-medical attendant service has become. Personal Support Worker (PSW) training has become increasingly medical, and this is not viewed as a problem because most of the students in that program will eventually work in nursing or long-term-care homes. But nevertheless this is a problem because the term PSW has become a generic catch-all phrase, and is not used to refer to those workers or students who have completed the training but rather, refers to all who work in the field of long-term-care. This includes all attendant service provider agencies funded through the long-term-care mechanism of the Ministry of Health.

For all of these reasons DF is outside the LHINs. Although there was a brief feeling of success regarding this "win", supporters of DF, myself included, expect to be revisiting this issue once again, when Government changes or even when Government doesn't change but a new Minister of Health is installed. When LHINs are fully implemented, we will be dealing with a whole new set of bureaucrats too and expect the education process to begin once again.

LHINs, as the following sections illustrate, are the current 'institution' albeit without walls.

Issues

There is evidence that both the bureaucracy of the Ministry of Health and the Government have a very limited understanding of what barriers to Independent Living really are. This government failed to connect the fact that full implementation of a LHIN system which included services and supports to disabled people undermines the stated goal of this same Government which was implementing the Accessibility to Ontarians with Disabilities Act.

This issue is most clearly illustrated from correspondence and background material supplied to a Member of Provincial Parliament by Audrey King, disability activist and consumer of attendant services. She states:

“As you already know, the barriers are structural and physical in nature, as well as ‘attitudinal’ - both subtle and obvious. One of the most challenging is the pervasive belief that people with disabilities are “sick, “deficient,” “dependent” and requiring “care” by professional healthcare experts who work within authority-driven, institutionalized 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. These beliefs exist within society as a whole, but of even greater concern is their deep entrenchment within the health care system, where the training of professionals is “pathology” based and “deficiency” driven.”
(King, 2005)

Another issue was that in spite of the fact, the difference between PSW and attendants was discussed at length with the designers of the LHIN system and the Ministry of Health, the same Ministry embarked on a consultation process which asked the question “Should PSW’s be regulated”? It was clear from this exercise that the distinction between a PSW and an attendant was lost.

Again, the best illustration of how an attendant might be different from a PSW is the chart developed by King and submitted as background to the above noted correspondence.(see Chart 1)

Comparison of key job functions: CAC Home Care PSWs DF Attendant Services

Personal Support provided	Only specific acts allowed, e.g. assistance with dressing, laundry, minimal clean-up, meal preparation, feeding, bathing, showering, making beds, transferring,	Any normal routine activities of daily & community living that the consumer would otherwise do for himself, but is physically unable to, is permitted
Training & Orientation	College PSW diploma –“deficiency” medical model training “takes care of”, “does for” client oriented to “supervision” of client not oriented to “assisting” client in carrying out client’s intentions e.g. assisting with supper preparation, organizing fridge, putting things away under client’s direction etc	Attendant is interviewed, selected, trained and directed by the consumer (DF self manager) according to the unique individualized needs of the consumer employer
Restricted Acts	Many functions not allowed, e.g.. no “cooking,” (only heating a frozen dinner), no cutting of finger or toenails, no escorting to appointments, no assistance with shopping, errands, changing light bulbs or other simple house maintenance	Attendants provide all normal routine activities of daily living in a “seamless,” integrated manner, as directed by the consumer employer
Prohibited acts (RHPA)	PSW’s not allowed to assist with routine daily suctioning, catheter care, bowel treatment needs or assisted coughing	Attendants are well trained and expected to assist with all routine & necessary acts of daily living.
Worker Accountability	To the employing agency	Directly to the DIF Self-Manager consumer, who is the “employer”
Administrative & legal Responsibility and Accountability	Employing agency	DIF Self Manager, who carries full legal responsibility
Flexibility	None – service delivery times are	Flexibility

	set	accommodated & arranged between worker & consumer as required
Location Service	of Client's home only	Home, workplace, community, educational setting, hotel, offices – according to need
Choice Worker	of Minimal, not involved in the selection process. Can complain but many have no other choice	Attendant is interviewed & chosen by the consumer
Assistive Devices & Equipment	Not allowed to assist with oxygen or vent equipment. Can only use a transfer lift if “signed off” by an RN (client not considered able to teach PSW)	Trained & expected to assist as part of job expectations
Integration of normal activities of daily living	High degree of fragmentation due to many restrictive policies & only specific functions allowed – thus increasing burden on client & family to find/organize/co-ordinate other many other personnel in order to accomplish necessary acts of daily living (e.g. cutting toenails, shopping, cleaning fridge, errands	Assistance provided with all normal routine physical activities of daily living – that a person would otherwise do for themselves.

[Chart 1](King, 2005)

Goals

It's easiest to start with my own goals related to de-institutionalization, particularly because most of the literature on this topic is focused on discussion related to de-institutionalization of people with intellectual disabilities. I suppose the group of people with only a physical (mobility) disability, but who also share a history of getting out of an institution, either was not large enough to warrant study or this population was masked by ascribing intellectual disability as well as a physical disability to them in order to qualify for placement in an institution.

It is also easier, in retrospect, to break these goals down and to give them names. (See Chart 2) But the driving force for me to get out of the institution was

simple. It was escape. And although it was more felt than named and thought out, this escape had to do with my fundamental need to escape a medical system – hospital – which was what Bloorview had become.

Bloorview was dominated by health and social service professionals and so part of this escape also had to do with a need to escape the dominance of professional groups (French & Swain, 2001) which held so much power over me. There was a preoccupation with my deficits which were always couched as negative and problematic and in need of Bloorview's "more objective" judgment of what they perceived to be in my "best interests". If they had their way, I wouldn't have gone to school, college or live in the community, let alone work.

I remember a day when I was about 17, that 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. They were pretty proud of the place particularly because there was a section of looms there and a few of the women worked the looms. 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.

The irony here is that once I was in the community and as such accessed my own General Practitioner (Family Doctor), the GP pretty much let me call the shots. He never treated me as a dependent, helpless or sick person. This was opposite to my experience living at Bloorview.

It would be nice to say my journey for life in the community stopped there but it didn't. I remained unable to do things totally by myself although at the time it didn't matter because I was living with others who did these things for me. However, I knew that sooner or later I would have to move into some community based alternatives that were evolving. As I watched them, I felt they missed the mark. They missed the essence of what my flight from institutionalization was. This was the beginning of what for me became the need to prevent the institution without walls from becoming a reality.

Goals, even though they may have the same name, mean different things to different people. Take "control" as an example. For me control means consumer control. Control might be shared across the spectrum but manifest completely differently depending upon from perspective it is viewed. Control, from the labour perspective might mean control over their own work, control from a service organization perspective might mean administrative control. To government, control might refer to spending control. For this reason the following chart has

focused on some key stated or experienced goals but avoided goals shared across the spectrum that would not share any interpretation.

The Chart below represents my analysis of goals inferred from many sources and documents, memories and experiences. It is offered here as a device to begin to think about how goals will differ depending on the perspective of who may be holding the goal. It offers a way to clearly see where goals may be complimentary, or mutually supportive, and where goals from various perspectives may contradict or be in isolation from other goals.

Goals	Individual	Community	Government	Service Organizations	Organized Labour	Residential Institutions
Personalization	X					
Normalization		X				
Integration	X		X			
Inclusion		X				
Flexibility	X	X				
Consumer Control	X	X				
Empowerment		X				
Patient Centred				X		
Participation	X	X				
Contribution			X			
Choice	X	X				
Effectiveness	X	X				
Efficiency				X		X
Safety/security	X	X	X	X		
Health and Safety			X	X	X	X
Devolution			X			
Fiscal Restraint			X			
Shorten Wait Times for Service	X	X	X			
Job Security					X	
Equitable Pay					X	

Goal holder perspectives related to de-institutionalization [Chart 2]

It should be stated, that the concept of “empowerment” came at a slightly later time. I was already out in the community and wanted to stay there. “Empowerment” then, for me, was less of a goal of de-institutionalization, and more of a goal against re-institutionalizing a person. It became the mantra for the roots of the disability led independent living movement.

I turn now briefly to my thesis statement: 'I spent the first 20 years of my life fighting to get out of an institution, only to spend the rest of it keeping the institution from descending upon me' and address another aspect of meaning in that statement.

Houston (Houston, 2004) makes a similar point when he writes:

"My social reality and universe is not in isolation to that of others with severe physical impairments. The threat, risk, and fear to my independent living and liberty is something I have in common with other people with severe physical impairments". (Houston, 2004)

He also makes a distinction between "empowerment" and "enablement" and illustrates this through some analysis of the impact of the 1996 Direct Payment Act. (Houston, 2004)

In Ontario, Direct Funding mirrors the UK program realized through the Direct Payment Act. Direct Funding (DF) is also closest to a rights-based model. (see Chart 3). How will the LHIN system impact this program? Although CILT was earlier told that DF would be outside the LHINs, it has not specifically been told under whose authority it will fall. Until this question is addressed uncertainty will remain as to whether DF, in the end, will be accountable to the LHIN and therefore subject to priorities identified by the LHIN Boards.

Discussion and Analysis: Impact on self-directed community based supports

This section asks: to what extent have the goals of de-institutionalization, from a variety of perspectives, been realized?

Personal Goals

As the previous chart illustrates (see Chart 2) my personal goals were variously conceived of as personalization, integration, flexibility, consumer control, participation, choice, effectiveness, safety/security. Simply put, I wanted to get out of an institution, and live a normal life in the community. Living a normal life meant I would get an apartment, a job and do things everyone else my age was doing; having a good time in my spare time.

Personalization meant that I would be treated as a human individual rather than a case to be "managed" or a unit of labour. Personalization was the opposite of "objectification" which was mainly the results of the support systems I had experienced throughout my institutional years. Everything else flowed out of that concept.

If I was treated as a person, not a thing, I would be fully integrated. If I was treated as a person my supports would be flexible enough to accommodate the

range of activities I aspired to do. If I was treated as a person I would be in control of my services, my destiny and if the services were effective it would mean that they would enable me to work or play in a variety of places of my choice. Safety and security meant that I would have access to the core supports I required when I required them.

And so enter the first generation of community-based non-institutional supports: managed attendant services. These services were effective at resulting in my integration. I was able to live in my own apartment in the community. I was able to schedule these services so that I could be on time for the bus which took me to work. I was working in an office along with other non-disabled people and not in some “sheltered workshop”. Because I had a regular job, I was able to buy a van which, although I could not drive, my friends could. I felt this arrangement was far more personalized than my institutional experience but not totally. First, I only had service at home. Not at work or anywhere else in the community. Secondly, there was a lack of flexibility and choice related to service because a managed system meant that it was shared with other people who needed the same assistance I did...so although some efficiencies were realized that way (one attendant helping five women for example) effectiveness was sacrificed. I could not sleep in on the weekend unless I wanted to sleep in until noon. I only had half an hour for supper if I wanted to eat when I returned from work, unless I waited until after 9 in the evening. Safety/security as a goal was only realized when I was at home. I felt that this arrangement did not really meet the goals I had set for getting out of an institution.

I had come to the conclusion that a managed model could not realize the goals I had set. I felt very much, and still do that, because we have a capitalist economy, and the goals I had set were grounded in an ability to function independently in a capitalist system, the solution would have to enable me to function effectively in a capitalist system.

The United Kingdom has a scheme through the Direct Payments Act.(Houston, 2004) of enabling people with disabilities to hire their own attendants and receive a grant for doing so. The equivalent in Ontario is the Direct Funding Program(Centre for Independent Living in Toronto (CILT) Inc., 2005). Ontario’s Direct Funding program is the closest to a rights-based model (see Chart 3) and all the opportunities that represents. Its limitations centre around three main items. First, it has a limitation of maximum hours under the program. Participants have to work within an average of six hours per day. Secondly, the program is now only for attendant services and not other types of disability supports. The final limitation in the program is the money management aspect. This is discussed further in the following section.

Community Goals⁶

Community goals related to deinstitutionalization were similar to my personal goals but community goals can be thought of as broader and perhaps more complex. For example; what I had conceptualized as my need to be treated in a more personalized or individual way, became the more complex idea of “normalization” (Parmenter, 2001). This idea which went beyond personalization and included a range of social activities; my desire to be integrated, morphed into inclusion (M. Bach, 1999), which recognized that integration without access to the services and supports that enabled full participation, someone could be just as isolated from society as a person in an institution.

Flexibility, choice, effectiveness and consumer control, included not only just the needs of the person with the disability but also of those who were part of the immediate network of support. Empowerment built on the notion of self-actualization or self-determination but included a range of methods towards that goal. In a sense though empowerment, self-actualization and self-determination all captured the same idea. This is illustrated in a return to the articulation of self-determination in a 1999 cross Canada evaluation report of deinstitutionalization initiatives. (Roehrer Institute, 1999).

However, it seems as though the community perspective, involving and led by many who have significant people in their lives who often could not advocate effectively without supports, have come to the same conclusion. Managed models of support fall short of the goals of deinstitutionalization. And yet the option for self-management of dollars in lieu of support poses other problems. For some time the community has been trying to promote a model that would be a bit of a hybrid of these two options – managed vs. self managed attendant services – and looks at systems where the money can be managed by a body selected by the person with a disability. Nabors (Centre for Independent Living in Toronto (CILT) Inc., 2006) is one such brokerage model (Salisbury, Dickey, & Crawford, 1987). Also the idea of microboards⁷(Adams, 2002) is currently generating some interest.

Most recently a group is forming, calling itself the “Portability Coalition” with a renewed commitment to this issue driven in part by a concern of an unforeseen impact of the LHIN system on the daily lives of people with more severe disabilities.

⁶ I am including here the network of Community Living Groups, and support networks of others with a higher level need for daily support

⁷ Microboards are legally incorporated small bodies of individuals formed for the sole purpose of supporting one person with a disability who cannot or does not want to manage support funding directly.

Government Goals

It is easy to think that government may share some personal or community goals, for example integration. But when government talks about integration, the commitment is less ideological and more practical. If in fact community services were more expensive than institutional ones, the impetus for change would not have occurred. Historically governments adopted community based models because of a concern with overcrowding in institutions coupled with the costs associated with increasing the size of existing “asylums”. Communities themselves did the convincing of the cost-effectiveness or efficiency of non-institutional approaches. Communities themselves demonstrated the value of integration as an enabler for a disabled individual’s ability to contribute to society. So although government adopted contribution as a goal, they had to be convinced that individuals with disabilities had something to offer society.

Safety and security of service recipients is thought to be addressed through a range of policies of the service provider and so Government only seems to get concerned about this when there is a problem when this issue hits the media. For example, in Ontario, health and safety legislation is geared, from an employer’s perspective, for the worker.

Although, not a publicly stated goal, all levels of Government have been in the midst of devolving services and responsibility for the last 15 years or more, the latest iteration occurring through the exercise of amalgamating Metropolitan Toronto. The new Toronto, for example consists of a previous 5 municipal governments. However, this change does seem to be ideologically driven. There appears to be no model of success elsewhere. All of these changes have been driven by a mantra of fiscal constraint and it did not seem to matter that these changes failed to realize any savings.

Across Canada the response to the health care crisis, shrinking resources and demand outstripping supply has been strategies aimed at reducing wait times for health services. Ontario is no different in this regard. When the Ontario Liberals gained power in fall 2004 there emerged several transformation agendas. This “transformation agenda” was realized through the creation of the LHIN system in Ontario, which, at its core was aimed at reducing wait times for critical health services. (Ontario, 2006)

To conclude however, it does not appear that government had goals related to deinstitutionalization, independent of community or sector specific goals. It merely appears to allow itself to be “convinced” of one direction vs. another as long as no new money was involved, as long as the actions taken were not too controversial, and as long the direction was not one that would alienate too many voters.

Service Organization Goals

With respect to service organizations, and here I am specifically addressing service organizations that deliver community or home based attendant services, the concept of patient centred, replaces consumer control. What's more, there seems to be a lack of understanding that there is any substantive or qualitative difference between those two ideas. Efficiency, although a stated goal of these organizations, seems to have been thrust upon them by government, and really has come to mean working within your budget and accounting for it. Again, safety and security, is a concern as long as an organization can avoid scandal. Health and safety is a concern primarily from the employer perspective as a responsibility to those in its employ.

Organized Labour

There were no real goals related to deinstitutionalization that I could find. However goals that might either impede or facilitate the deinstitutionalization process relate to health and safety for the worker, job security and equitable pay.

Currently organized labour in Ontario has engaged in a "Stop the LHINs" campaign(Ontario Health Coalition, 2006)Partially for similar reasons i.e. health and safety, job security and equitable pay.

Residential Institutions

Obviously the closing of an institution may mean huge job loss standing to negatively impact a community, particularly a small community where the institution may have been the primary employer. As such a residential institution cannot be said to have a goals related to deinstitutionalization.

Characteristics

Characteristics	Total Institutions	LHINS including Community Based Services	Rights-Based
Where service offered	All aspects of life are conducted in the same place and under the same authority	All aspects of health are conducted in a variety of places under the same authority	Location of services irrelevant
Congregate/individual	Each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same things together	Each phase of the health or core personal support of an individual can occur in a private, semi private or congregate setting, are treated alike but not necessarily required to do the same things together	An individual system which is both flexible and portable
Scheduling responsibility	All phases of the day's activities are tightly scheduled, with one activity leading at a pre-arranged time into the next, the whole sequence of activities being imposed from above with a whole system of explicit, formal	All phases of the health or core personal support activities of an individual are tightly scheduled and rationed from above according to legislative requirements and service standards, and available resources. The system is governed	The person with the disability self-manages all scheduling

	rulings and a body of officials	by a hierarchal structure or authority largely contained of individuals appointed by Government	
Who benefits	The various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution	The various planned and forecast needs are managed to fulfill official aims of health authorities, service providing agencies and Government.	The person with the disability benefits directly

[Chart 3]

The foregoing chart illustrates where the current community based system and the evolving LHIN system is situated as compared to “total institutions” as defined by Goffman (Goffman, 1962) on the one hand and the ideal of a rights based system on the other. Current examples of rights based systems include Direct Funding, an Ontario based program(Centre for Independent Living in Toronto (CILT) Inc., 2005) and in Britain the Direct Payments scheme(Houston, 2004).

In their final evaluation report of the Self Managed Attendant Services Pilot (Roeher Institute, 1997), which is now referred to as the Direct Funding Program (DF) several outcomes or indicators were identified that could serve as markers for an effective program. Flexibility, choice and control over attendant services, quality of life and economic/social participation. They also looked at the cost-effectiveness of the program which was government’s interest. In the end this it was recommended that DF become a permanent program because it was effective at striking the balance between individual and government goals. Although this is definitely a rights based program (see Chart 3 above), this report does not position DF squarely in that arena. Rather DF seems to have been positioned more as a “health and well-being” strategy which, in 1997 had a greater influence in the system than “rights”, and unfortunately, this is still true today.

Conclusion

What can be said to our young people now that...persons without consciences, without sense of pity or shame have taken all the money in the treasuries of our government and corporations and made it all their own? (Vonnegut, 2005:88).

Because goals associated with actually getting out of the institution were never effectively identified, it has remained difficult to identify these elements when they are applied to the community-based programs, upon which people with disabilities depend daily. This has made arguments against re-institutionalization more difficult because it has become hard to say exactly why home care differs from institutional care. In both situations someone else calls the shots. Institutions have become slightly more responsive and flexible and home based programs have become less responsive.

The one beacon of hope that remains for a consumer like me, is what in Ontario called Direct Funding. Direct Funding, like the UK scheme of Direct Payments, is a self managed system. And although both of these programs fall short of the goal of “empowerment” they can be said to “enable” participants. I believe that this approach works well in our society for two reasons. First because this approach creates true consumers in a capitalist society and secondly because this approach is more of an accommodation of disability in society or rights based approach, than it is a medical or health service.

Because the LHINs make no real differentiation between health or medical services for people with disabilities and rights or accommodation of disability, coupled with the fact that LHINs are dominated by medical, health and social service professionals, LHINs are seen by many as a return to medical model domination.

Direct Funding, in fact, takes the money from “treasuries” and gives it to individuals, thus giving them more power, control, portability and flexibility for the purchase of attendant support than was ever in existence before. It is an equalizer in society because program participants do not have to pay more than someone who does not require attendant support. It approaches a rights-based model and talks more about accommodation of disability in society, rather than as a service, treatment or amelioration of disability.

It has been an uphill battle since the administration of this program has been through the Ministry of Health. The tendency has been to see this program through the same analytical lens as every other health programs. This may not bode well for the range of other managed programs that deliver attendant services. This Ministry wants those programs to abide by similar rules and standards that were set for CCACs, long-term care homes and to an extent, hospitals. It insists on thinking of attendant service providers as health service providers regardless of the fact that they are providing service in an individual's

own home. Legislation and policies that were crafted for CCACs and Long-term Care Residential Homes are applied to all attendant services.

Will full implementation of LHINs exacerbate this situation? When 14 separate LHINs eventually evolve into 14 separate negotiations?

Although the Direct Funding Program was successful in negotiating that it remain outside the LHIN system, this is not an arrangement that proponents of a self-managed system regard as permanent. The minute senior bureaucrats and governments change, proponents expect to be spending energies re-convincing the Ministry to leave DF outside the LHIN system.

In the meantime, other attendant service providers will be in LHINs, and time will show if they fare better or worse in this system, both economically and philosophically.

My bias is clear. I do not think the implementation of the LHINs will better serve people with disabilities. It is a medical model although LHIN designers say it is not. If it is not, why then is their literature filled with the word “patient”? If it is not, why are LHINs dominated by health, rehabilitation and institutional professionals?

This system sees no qualitative difference between concepts like “patient-centred” and “consumer controlled”. The latter implies governance as well as control. Or in Maslow’s words – self-actualization.

The distinction between a PSW and an attendant will be totally lost. (See Chart 1). Already attendants in the managed system are referred to as PSW’s whether they have PSW certificates or not. If I was to add a third column to Chart 1 headed ‘Service Provider Agency Attendants’, there would be almost no difference between the CCAC home care providers column and the new one, although it started off to much more closely resemble the content head DF attendant service. The primary difference now centres on training.

From the beginning it was hoped that through demonstration the efficacy of Direct Funding models could meet a range of goals on all sides. It was hoped that by now it could be emulated by other communities as an option to have disability supports addressed. Now the concern may be that there are differential programs in 14 different areas. There is also a concern that some of these programs may go to the lowest bidder.

I spent the first 20 years of my life fighting to get out of an institution, only to spend the rest of it keeping the institution from descending upon me. What I mean by that is that the LHIN system will connect, coordinate and plan all health service delivery within their area. It is indeed an institution without walls and I will be in the middle of it, and unless DF stays outside the LHIN system, I will be controlled by it and accountable to it. And while that might not be bad for the

individual who wants to speed up access to treatment, and for whom the time with LHIN intersection is limited, my concern remains for people –like me - who will be intersecting with a LHIN for daily, essential support.

References

- Author Unknown. (2006). *Leonard Cheshire: Creating Opportunities with Disabled People*. Retrieved March 5th, 2006 from <http://www.leonard-cheshire.org/>
- Adams, J. (2002). *Microboards: A Legal Entity for Your Individual with Special Needs*. Canada: Family Support Network.
- Bach, M. (1999). *Towards Inclusion: National Evaluation of Deinstitutionalization Initiatives*. Ontario, Canada: Roeher Institute.
- Carpenter, S. (2003). *Keynote Address for Provincial Association of Senior Managers: Annual General Meeting, February 2003*. Unpublished manuscript.
- Centre for Independent Living in Toronto (CILT) Inc. (2006). *Ontario Attendant Services Directory*. Retrieved 26 March, 2006 from <http://www.cilt.ca/greenbook.aspx>
- Centre for Independent Living in Toronto (CILT) Inc. (2005). *Attendant Services Overview*. Retrieved 17 February, 2006 from <http://www.cilt.ca/overview.aspx>
- Cheshire Homes London. (2005). *Cheshire: Making Independence Possible*. Retrieved March 5th, 2006 from <http://www.cheshirelondon.ca/about.html>
- Clark, D. L. (2001). *Leonard Cheshire Vs. the Disabled Person's Movement: A Review*. United Kingdom: University of Leeds. Retrieved March 5, 2006, from <http://www.leeds.ac.uk/disability-studies/archiveuk/Clark,%20Laurence/leonard%20cheshire.pdf>

Driedger, D. (1989). *The Last Civil Rights Movement: Disabled People's International* (First ed.). London and the United States: C. Hurst & Co. (Publishers) Ltd.

French, S., & Swain, J. (2001). The Relationship Between Disabled People And Health And Welfare Professionals. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *In Handbook of Disability Studies* (pp. 735). United States of America: Sage Publications Inc.

Goffman, E. (1962). *Asylums : Essays on The Social Situation of Mental Patients and Other Inmates*. Chicago: Aldine Pub. Co.

Houston, S. (2004). The Centrality of Impairment In The Empowerment of People With Severe Physical Impairments. Independent Living and The Threat Of Incarceration: A Human Right. *Disability and Society*, 19(4), 307.

King, A. (2005). In Carpenter S., others (Eds.), *LHINS, Us and AODA Last Night*. Toronto: N/A.

Konkin, J., MD, Howe, David, MB BS, & Soles, T., MD. (2004). SRPC Policy Paper on Regionalization. [Electronic version]. *Canadian Journal of Rural Medicine*, 9(4), 257-9. Retrieved April 2, 2006,

Ontario. (2006). *Local Health Integration Networks*. Retrieved March 20, 2006 from <http://www.lhins.on.ca/english/main/Home.asp>

Ontario Health Coalition. (2006). *Stop Local Health Integration Networks*. Retrieved 16 February, 2006 from <http://www.stoplhins.ca/>

Ontario Ministry of Health. (2006a). *Local Health Integration Networks: Building a True System*. Retrieved 16 February, 2006 from

http://www.health.gov.on.ca/transformation/lhin/lhin_mn.html

Ontario Ministry of Health. (2006b). *Local Health Integration Networks: Bulletins*.

Retrieved 16 February, 2006 from

http://www.health.gov.on.ca/transformation/lhin/lhin_mn.html

Ontario Ministry of Health. (2006c). *Local Health Integration Networks: Geographic Boundaries And Supporting Information*. Retrieved 16 February, 2006 from

http://www.health.gov.on.ca/transformation/lhin/lhin_mn.html

Parmenter, T. R. (2001). Intellectual Disabilities: Quo vadis? In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *In Handbook of Disability Studies* (pp. 267). United States of America: Sage Publications Inc.

Radford, J. P., & Park, D. C. (2003). Historical Overview of Developmental Disabilities In Ontario. In I. Brown, & M. Percy (Eds.), *Developmental Disabilities in Ontario* (Second Edition ed.) (pp. 3-18). Ontario, Canada: Ontario Association on Developmental Disabilities.

Roehrer Institute (1997). *Self-Managed Attendant Services In Ontario: Direct Funding Pilot Project* (Final Evaluation Report. Toronto, Ontario, Canada: Roehrer Institute.

Salisbury, B., Dickey, J., & Crawford, C. (1987). In Rioux M. (Ed.), *Service Brokerage: Individual Empowerment And Social Service Accountability*. Canada: The G. Allan Roehrer Institute.

- Smith, J. (2000). *Welcome To Mcleod House: A Residential Home For People With Physical Disabilities*. Retrieved March 5th, 2006 from <http://www.mcleodhouse.com/mcleodhouse.html>
- Stein, J. G. (2001). *The Cult Of Efficiency* (Revised ed.). Canada: House of Anansi Press Limited.
- Taft, K., & Steward, G. (2000). *Clear Answers: The Economics and Politics of For-Profit Medicine* (First ed.). Edmonton Alberta Canada: Co Published by Duval House Publishing, University of Alberta Press & Parkland Institute.
- Vonnegut, K. (2005). In Bleifus J. (Ed.), *A Man Without a Country* (First ed.). United States of America: Seven Stories Press.
- Wikipedia Contributors. (2006). *Abraham Maslow*. Retrieved 16 February, 2006 from http://en.wikipedia.org/w/index.php?title=Abraham_Maslow&oldid=39573824