The Roadmap to Independent Living in Ontario – May 2014

Supporting Adults with Disabilities

Ontario Association of Independent Living Service Providers (OAILSP)

Provincial Acquired Brain Injury Network (PABIN)

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EXECUTIVE SUMMARY

The United Nations' Convention on the Rights of Persons with Disabilities, Article 19 b), states that "[persons] with disabilities must have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." The Convention was ratified on April 3, 2008 and became legally binding on May 3, 2008. The Canadian House of Commons unanimously endorsed Canada's ratification of the Convention. Internationally disability is viewed as a social construct. Attitudinal shifts occurred globally as a result of the UN Convention. This means that people who have a disability are not to be pitied and treated with a paternalistic approach but they are considered people with rights capable of living freely, with equality and independence.

In the province of Ontario there is a rich 40 year history with strong philosophical roots regarding the provision of services to adults with physical disabilities. Over the past twenty years supports for persons with acquired brain injuries have developed in order to repatriate people from the U.S. and to ensure that services are delivered close to home.

The time for action is now; there have been numerous reports, studies, research and detailed recommendations stating that an investment in the community services sector supporting our most vulnerable citizens in the province is urgent and necessary. Contained in this report are the following recommendations; This will be accomplished by creating a local strategy that includes investment in community providers offering complex supports to adults with disabilities focused on relieving waiting lists and creating a more seamless and coordinated healthcare experience with specific resources. A **policy framework must be developed** including a vision and directional plan for a **province wide strategy** to provide an integrated model of care for persons with disabilities; the focus to be on individuals with physical disabilities and brain injuries. Strong **engagement and leadership** from key stakeholders will be required along with investment of new funding.

The goal is to make Ontario the healthiest place to grow old for all citizens regardless of ability, function and circumstances. For all citizens having services closest to home means service that makes sense that are wrapped around them, and designed based upon their needs. (The right care, in the right place at the right time delivered by the right provider). A great example of that is; John Doe from the Waterloo Wellington area who was in an ALC bed waiting to go to an ABI Specialized Rehabilitation bed. The wait was predicted at approximately 3 months. The ABI specialized Nurse Practitioner completed an intake and assessment in the hospital on a weekend and quickly arranged ABI Outreach services and an ABI Day Program spot twice a week, so the client could **wait for his rehabilitation bed at home!**

We are experiencing a shift in focus from acute care to community care. Through this transition there have been many initiatives to support older adults to live in the community with dignity and independence. Unfortunately the unintended consequences of those initiatives are the growing waiting lists for other vulnerable citizens. For persons with physical disabilities who need support **the wait is measured in years**. For Acquired Brain Injury services it is the same.

- ✓ This report was commissioned by the **Ontario Association of Independent Living Service Providers (OAILSP)** and **the Provincial Acquired Brain Injury Network (PABIN).** The goal of this work is to capture the current state of services for persons with physical disabilities and brain injuries in Ontario and provide recommendations for future policy and funding enhancements.
- ✓ To develop our report an extensive review of previous research, reports and studies was conducted, **a detailed on line survey was completed by health service providers** for qualitative and quantitative input and reporting on disability population statistics.
- ✓ Through this report we have provided an overview of services for persons with physical disabilities and acquired brain injuries and in limited way older adults.
- ✓ The **identification of gaps and opportunities** has been well reported through the summary of previous reports and input from providers across the province.

Through this investigation we have uncovered waiting lists that are astronomical. These waiting lists tell us the story of a fragmented, underfunded system of care. We learned that it is not only a funding issue to support adults with physical disabilities and those with ABI, it is a matter of uncovering the upward substitution of care that occurs across the province. According to CIHI, 7% of residents in long term care homes across Ontario are under 65 years of age. In addition, Canadian Institute for Health Information has reported that 18% of residents in Ontario hospital-based continuing care facilities were younger than 65.

As with seniors, adults with disabilities are living longer and with advance age comes additional co-occurring chronic health issues such as diabetes and the related complication of stroke, renal failure, COPD, etc. Caregivers are also aging and often only one remains and struggles to care for their son or daughter with a brain injury or physical disability. This in turn puts stress on the health care system as both clients and caregivers present to emergency departments and vie for placement in LTC when in reality community supports could maintain them, either through supportive housing/assisted living our outreach services.

THE PROVINCIAL CONTEXT

The Province of Ontario has taken a proactive approach to the demographic and fiscal challenges that all Ontarians are faced with in upcoming years. On average 10% of the population of Ontario has a disability but compounding the demographics is the increasing cohort of seniors who are requiring assistance as the baby boomers age. In response to this looming crisis the province has taken heed of the expertise in our health care system, paying particular attention to Dr. Walker's ALC Report, Don Drummond and his economic recommendations and finally the Senior's Strategy authored by Dr. Sinha. These three reports reinforce the content of Action Plan for Health Care which is the guiding document used by the Ministry of Health as the basis for their health transformation agenda.

Dr. David Walker travelled across the Province of Ontario consulting with stakeholders as part of his research in compiling his report on Alternative Level of Care (ALC). Many of his recommendations speak to the need to address the entire continuum of care and to focus on the premature placement into Long Term Care. Resourcing supports at the community level provides the necessary diversion from the emergency room and if coupled with restorative and rehabilitation supports, allows individuals with high level needs to live independently in a community setting. The informative report also identified that **increased resources** would be required to support both the addition of assisted living spaces and to increase the coordination and access to those venues. Having **established connections to primary care** is also a key component and a key recommendation of Dr. Walker to supporting older adults and enabling them to remain in a community setting. In addition, Dr. Walker recommended investigating other models of assisted living.

> **"A system ready for change:** From administrators through to frontline nurses, from doctors to patients, there is an eagerness to re-tool the system for the challenges of tomorrow. With all hands on deck, our shared commitment will achieve the goal of a sustainable health care system that is there for generations to come." *Ontario's Action Plan for Health*

The Drummond report contained examples detailing the importance of shifting our focus from institutional to community health care. We know that many individuals occupying acute care beds would be better served in more appropriate settings in the community. The lack of services at the community level means "upward substitution" of a more expensive model of care. We also know that population growth of seniors 75 years and older will impact our health care system. Long-term care (LTC) will not be able to keep pace nor is it always the most appropriate place for many seniors. There is a need to look at other options. The Drummond Report references models of care in places such as in Denmark, where government stopped adding new LTC beds and instead put health care

funding into a broad spectrum of community residential options. Disparities in funding in the LTC, community care and home care sectors were highlighted in the report, as well as the need for increased integration. Drummond also recommended the testing of the service models. Following were the report's top recommendations;

- ✓ Support a gradual shift to mechanisms that ensure a continuum of care and care that is community-based.
- ✓ Funding for community-based care may need to grow at a higher rate in the short to medium term in order to build capacity to take pressure off acute care facilities; on the other hand, with a shift away from a hospital focus, hospital budgets could grow less rapidly than the average.
- ✓ Do not apply the same degree of fiscal restraint to all parts of health care. Some areas — including community care and mental health — will need to grow more rapidly than the average.
- ✓ Increase the focus on home care, supported by required resources, particularly at the community level
- ✓ Match seniors to the services that they need from the earliest available care provider, reduce alternate level of care days, and improve co-ordination of care through the use of referral management tools for long-term care, home care and community services.
- ✓ Implement the recommendations contained in "Caring for Our Aging Population and Addressing Alternate Level of Care," a report prepared by Dr. David Walker and released in August 2011.

> Dr. Samir Sinha's report stated that "building the strong communities that we desire will require partnerships between municipal governments and the province, especially around the provision of accessible and affordable housing…that will support Ontarians to age in the place

More specifically, the government should move quickly to implement his proposals that "[the] continuum of community care must be supported through additional and sustained resources to integrate, co-ordinate and enhance traditional sectors and assisted living arrangements while bridging gaps through new models of care that serve populations whose care needs exceed what is currently available." He also strongly recommended that to improve the co-ordination of patient care, all health services in a region must be integrated. This includes primary care physicians, acute care hospitals, long-term care, CCACs, home care, public health, walk-in clinics, Family Health Teams (which for the purposes of this chapter includes Family Health Organizations [FHOs], groups and networks), community health centres and Nurse Practitioner-Led Clinics (NPLCs).

It is important to note that one of Dr. Samir Sinha's key recommendations was the development of Assisted Living and Supportive Housing to reduce the reliance on much more costly institutional options. He also stated in his report that "providing a wider range of home care, community support services, and affordable housing options will enable us to offer the care and support that will allow more people to remain independent and age in the place of their choice, rather than

requiring more costly and sometimes less desirable care or living options.*(Sinha, December 2012)*[1].

Ontario's Action Plan for Health Care & Ontario's Action Plan for Seniors

In January 2012, the Ministry of Health and Long-Term Care (MOHLTC) released Ontario's Action Plan for Health Care. The plan calls for better patient care through better value for health care dollars.

A cornerstone of the plan is the idea of providing "The right care, at the right time, in the right place delivered by the right provider." Putting more care and support into the community will provide both appropriate care and decrease the upward substitution of more expensive options like long-term care and hospital. As we continue to be plagued by the ALC statistics across the province the focus of the health care system has to be on caring for people at home or in the community in more appropriate venues. The entire health care system benefits from the focus on community care as our hospital beds will be used more appropriately and be available for urgent care.

Ontario's Action Plan for Health Care (January 2012), and the provincial budgets of both 2012 and 2013 are strong indicators of health care transformation and actions that will help to achieve the government's goal to "*make Ontario the healthiest place in North America to grow up and grow old."* The 2012 provincial Budget committed to **increasing investments in home care and community services by an average of four per cent per year.** The 2013 Budget proposed an additional one per cent per year – for a total increase of over $700 million by 2015-16 compared to 2012-13.

Ontario's Action Plan for Seniors, which includes Dr. Samir Sinha's report -- ***Living Longer, Living Well*** draws on new and existing government programs to ensure seniors and their caregivers have access to the services they need, when and where they need it. This includes better access to health care, quality resources, and improved safety and security for seniors.

> *"Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."* (World Health Organization Definition of Health, 2012)

The most significant part of the Ministry of Health's action plan for health focuses on the goal of making sure people get care and support in the most appropriate place along the continuum. In order to achieve that goal the health care system needs to be restructured and refocused to meet the needs not only of those older adults requiring care but persons with disabilities, brain injuries and mental health issues. As often stated by Dr. Samir Sinha we are faced with both the demographic and fiscal imperatives that require

[1] Sinha, Shamir Living Longer, Living Well, December 2012, page 16

different approaches to health care. We need increased inter-ministerial cooperation, partnerships, sustainable alternatives to premature institutionalization across Ontario.

A further recommendation by Dr. Sinha is for the Ministry of Health and Long Term Care to lead a capacity planning process to meet the needs of older adults in the most appropriate care venue. A similar capacity planning must include adults with disabilities. The development of provincial, regional and local alliances with the housing sectors is essential to fully realize the shift in community supports and care from institutions to community. There is an acknowledgement across all sectors that housing and health are intertwined, however making the right connections when a person is in need can sometimes be nearly impossible. In order to have successful community-based models of care, both the housing and health issues related to aging in place must be addressed simultaneously. This shift has begun with the enactment of the *Housing Services Act* (2011). This legislation requires that all service managers develop long range strategic Housing and Homelessness plans that include supportive housing.

The 10-year strategic Housing and Homelessness Plan must reflect the evolving demographics of communities and address the needs for specific target populations, including older adults. It will be essential to contribute to and inform the Housing and Homelessness Plans to reflect health issues related to housing.

Policy Development

- *1989 - Living in the Community: New Directions in Residential Services for Frail Elderly People*
- *1994 - Continuum of Opportunity for People in Ontario with Acquired Brain Injury*
- *1994 - Long-Term Care Supportive Housing*
- *1996 – Attendant Services Guidelines*
- 2011 - *Assisted Living Services*

Historical Context

After significant lobbying from the public, the Government of Ontario began to **fund supportive housing projects for people with physical disabilities in 1976**, beginning with four pilot projects. These projects were referred to as Support Service Living Units (SSLUs). This same program now referred to as supportive housing, was formalized in 1980 through the Ministry of Community and Social Services (MCSS).

By 1989, the Elderly Services Branch of MCSS released *Living in the Community: New Directions in Residential Services for Frail Elderly People.* To expand upon the original policy statement, the provincial government commissioned a paper that identified the need to change the focus of supportive housing by delinking the providers of housing from the providers of service. This separation was recommended to reinforce tenant rights without impacting access to services.

In 1994, the Ministry of Health and Long-Term Care commissioned a planning report, *Continuum of Opportunity for People in Ontario with Acquired Brain Injury* (Sherk,

December 1994)[2]. Although some of the recommendations from the provincial report have been implemented, many have not and remain relevant today. Of particular concern are the recommendations concerning population-based planning and providing the resources to ensure ABI services meet the current and future needs of the population.

Additionally, in the early 1990s, the Ministry developed the infrastructure for a significant increase in community-supported independent living and long-term residential programs. Much of this was developed in order to repatriate Ontarians with ABI who were being treated in the United States and was administered in the absence of a policy framework for ABI services. The Repatriation Community Programs pilot project was funded by the Ontario Ministry of Health in 1990. Its mandate was to **facilitate the return of brain-injured individuals from U.S.** rehabilitation facilities to their home communities in Ontario. Most Ontario residents receiving rehabilitation in the U.S. fell into one of two 'hard to serve' groups: (1) those with severe behavioural difficulties; and (2) those at various levels of post-comatose unawareness whose families are unwilling to accept chronic care 'maintenance'. The pilot programme was charged with demonstrating the feasibility of community-based care for severely brain-injured individuals and their families, as well as developing a model of service delivery and interagency collaboration which would expedite province-wide implementation of similar programmes. This began not only the exodus of adults with brain injuries back to Ontario but as the province of Ontario realized significant cost savings, ensured that a steady flow of ABI specific funding was provided to community support service organizations.

At the same time, in 1994, the Ontario Ministry of Health developed **a Supportive Housing (SH) Policy (1994)** to provide the framework for "the coordination of personal support services, homemaking and accomodation in community settings. (Ontario Ministry of Health, December 1994)[3].

Assisted Living Services for High Risk Seniors (ALSHRS) and Supportive Housing (SH) Policies

More specifically, the government of Ontario released two policy documents that have implications on the residents of Ontario who are vulnerable; the 1994 *Long-Term Care Supportive Housing* Policy and, more recently, the 2011 *Assisted Living Services for High Risk Seniors Policy.*

The **Supportive Housing (SH) Policy (1994)** provided the framework for "the coordination of personal support services, homemaking and accomodation in community settings. (Ontario Ministry of Health, December 1994)[4]. The policy offered the necessary direction for "the coordination of personal support services, homemaking and accommodation in

[2] Sherk, Carolyn, A Continuum of Opportunity for People in Ontario with a Brain Injury, December 2006
[3] Ontario Ministry of Health, Policy Branch, Long Term Care Division, Population Health and Community Services System Group. Long Term Care Supportive Housing Policy. December 1994. Page 21
[4] Ontario Ministry of Health, Policy Branch, Long Term Care Division, Population Health and Community Services System Group. Long Term Care Supportive Housing Policy. December 1994. Page 21

community settings." [5] The intent was to "clarify the role supportive housing [would] play in the Long-Term Care (LTC) system by focusing on services to people who would be candidates for LTC facilities if their needs cannot be met in their present community."[6] The key principles of the framework include individualization, flexibility, integration, independence, stability, safety and self-help. The characteristics of the supportive housing framework act as a guide in the development of supportive housing for all client groups whether they were people with disabilities, seniors, and people with HIV/AIDS or acquired brain injuries (ABI). The characteristics included tenancy, clustered accommodation, tenant mix, community integration, not-for-profit service providers, off-site administration and delinked services.

Unfortunately the funding levels provided to implement the 1994 policy did not allow organizations to keep pace with emerging gaps in the system, most particularily the service required by the ever growing seniors cohort. As a result, **in 2011 the Ontario government responded to** the pressure and issued a new policy. **The Assisted Living Services for High Risk Seniors (ALSHRS) Policy (2011) .** This was "developed to address the needs of high risk seniors who can reside at home and require the availability of personal support and homemaking **services on a 24-hour basis"[7].**

In no way was this policy intended to replace the SH policy of 1994 and while each of the policies outline the intended recipients and the service guidelines, the two policies are actually linked because the ALSHRS policy provides updates to the provisions in the SH policy that relate to services for seniors. When the ALSHRS policy was enacted providers adpoted the framework with enthusiasm. Models of service were rapidly designed and rolled out. One example is the Supports for Daily Living programs (SDL) situated around the province which have cascaded from the mandate within the ALSHRS policy. For example the Mississauga LHIN developed an SDL program just prior to the enactment of the ALSHRS policy. This has caused some confusion as some are interpreting the SDL model as the standard for cost and program design regarding the implementation of the ASLHRS program.

It should be kept in mind that the SDL model is only one example of how the ALSHRS policy can be implemented. The Supportive Housing (SH) policy was the original policy and has been in place for twenty years. It is the framework used to "provide alternatives

to LTC facilities while maintaining people's independence and their integration into communities."[8]. There are four different specialized populations indentified in the SH policy; Adults with physical disabilities, people with brain injuries, HIV/AIDS and frail or cognitively impaired elderly people. The ALSHRS policy therefore, is only intended to provide futher clarity to the services for the frail eldery seniors. The most important message to take away from this section is that the ALSHRS policy is not intended to govern the services provided to the three other population groups.

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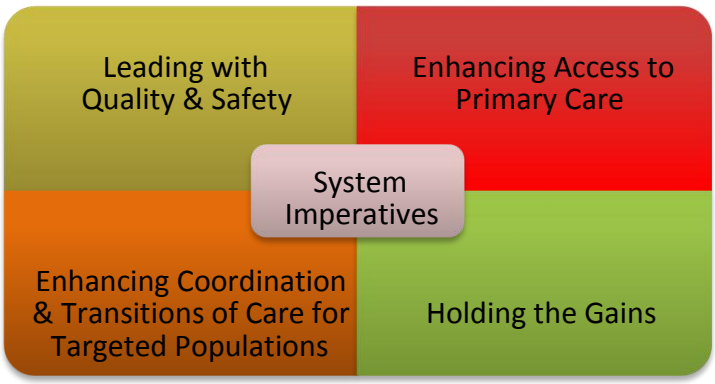
[5] Ontario Ministry of Health, Policy Branch, Long Term Care Division, Population Health and Community Services System Group. Long Term Care Supportive Housing Policy. December 1994. page 21.
[6] Ibid
[7] Ontario Ministry of Health Assisted Living for High Risk Seniors Policy. 2011. Page 4.
[8] Ontario Ministry of Health, Policy Branch, Long Term Care Division, Population Health and Community Services System Group, Long Term Care Supportive Housing Policy, December 1994. Page 16

For purposes of this discussion, the chart below will provide a comparison of the key components of the SH Policy 1994 and the ASLHRS Policy 2011.

Table 1	Supportive Housing Policy (1994)	ALSHRS (2011)
Housing	Specific sites, Affordable Housing, Non profit	Geographic Hubs Variety of settings
Age Eligibility	16+ of age	None
Service Group	ABI, physical disabilities, HIV/AIDS, seniors	Seniors
Services Provided	As outlined in 1994 SH Policy	As outlined in 1994 policy plus security checks and case management
Hours of Service	24/7	24/7
Assessment	Internal tools and/or InterRAI Cha	InterRAI assessment tool
Access	Multiple points	Multiple points

A comparison of the two policies reveals that there are many similarities. Both policies clearly describe the targeted population(s). The service limits are the same in each policy being 180 hours per month although the SH policy does allow for an increase to service levels in special circumstances. In the ALSHRS policy it is quite clear that should the service levels go beyond the maximum, placement in LTC or CCC should be considered. Both policies list similar services which are categorized as personal care and homemaking. The ALSHRS policy explicitly describes security checks and care coordination as additional services. While these are components of the SH policy, they are referenced as being provided by other providers.

There are other differences in the two policies. Although both policies describe the housing component, the ALSHRS is "prescriptive" and describes in detail the eligibility criteria which is based upon the services required including intensity and range verses the form of housing that is acceptable. It allows services to be provided in a variety of settings (ownership, rental, private landlord, not-for-profit) and allows for services to be provide in a geographical area called a "hub" based out of a designated building. The SH policy specifically cites the setting as being not-for profit or affordable housing. Both policies support the "delinking" of services so that the housing provider is not also the service provider.



System Imperatives

When you consider over 10% of the population have a disability and the fact that the number of chronic conditions older adults have increase with age, **the time for action is now**. Across each LHIN there are thousands of adults with disabilities requiring the same consideration as older adults but with the

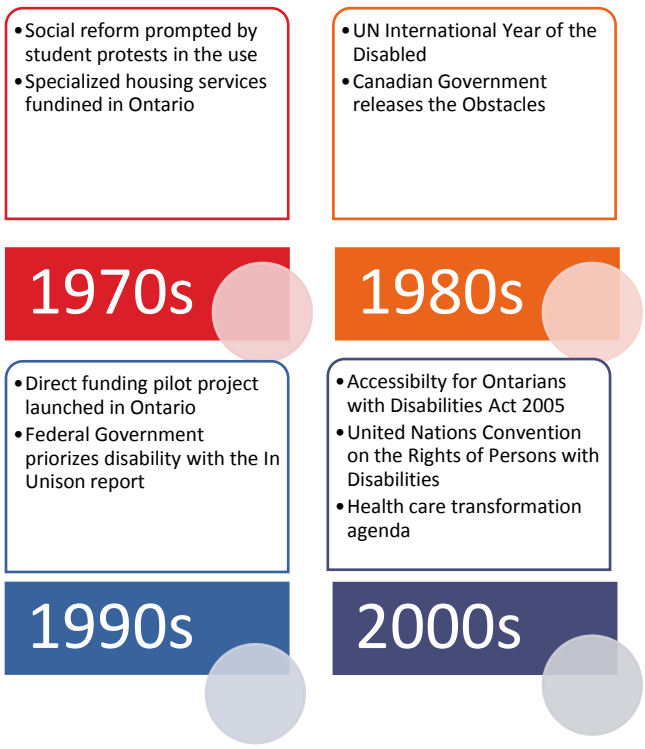
requirement for specialized services. The chart below captures the population of each LHIN, the corresponding population statistics for persons with disabilities and examples of LHIN priorities relative to disability.

Table 2 LHIN	Population	10 % of disability	Examples of LHIN specific priorities that relate to disability
Erie St. Clair	640,000 people	64,000	Priority on high users and ALC , primary care, enhancing coordination and transition of care for targeted populations
South West	1M	100,000	Priority to see a focus on quality and system integration
Waterloo Wellington	775,000	77,500	Integration and coordination
Hamilton Haldiman Brant	1.4 M	104,000	Community care networks , integration and quality
Central West	800,144	80,000	Improve access to services, transition and coordination of services
Mississauga Halton	1.1M	100,000	Access, transitions and sustainability
Toronto Central	1.15M	100,000	address the needs of the 1% of highly complex patients with the greatest needs, requiring the most resources
Central	1.8M	180,000	Specialized Supports for young people with complex medical needs in so that they can live in a home setting, rather than the hospital. Health care, housing, care coordination and support services to respond to a health care service gap
Central East	1.6M	160,000	Community first and seniors focused
South East	500,000	50,000	Rural, Patient centred, transitions and coordination
Champlain	1.2M	120,00	Seniors with disabilities,
North Simcoe Muskoka	453,710	45,000	Care connections, governed by councils of health service providers, design and implement a LHIN wide in home community capacity strategy
13North East	565,000	56,000	Care coordination and transitions
14North West	231,000	23,000	Integration, coordination and transitions

Model of Care that Works

"A new model of care, and a new way of life, for young adults with complex medical needs" (Central LHIN) "At Central LHIN, we truly believe that leading through collaboration results in outcomes that surpass what any one or two organizations could ever accomplish on their own. An example of this is a new model of care that was developed for seven young people with complex medical needs in Central LHIN so that they can live in a home setting, rather than the hospital, and enjoy a new way of life. This was achieved by bringing together health care, housing, care coordination and support services to respond to a health care service gap identified by the Central LHIN."

Why Plan Differently for People With Disabilities?



Consider the rehabilitation journey of a young man with a spinal cord injury; it starts in intensive care, immobilized and hanging on to the hope of survival. It moves along to in-patient long term rehabilitation where the individual learns how to do all of those everyday activities in a highly adaptive way. The individual also learns that whatever they are unable to do they learn how to direct that task to a personal attendant. (For example; complicated bowel and bladder routines). Our mainstream health care system is not designed to support individuals with complex activities of daily living. For example, CCAC Funded Services have policies prohibiting certain types of bowel and bladder care, transfers and ventilator care.

The current system of supports for adults with disabilities evolved from the "Independent Living Movement". This grass roots culture stemmed from other equality movements that were becoming popular across the country. The students at the University of California Berkley began to protest for the rights of the disabled and independent living movement in the 1960s. The mistreatment and institutionalization of persons with disabilities was fought alongside of issues such as racism. This movement prompted significant changes for persons with disabilities across North America.

Services for persons with disabilities are delivered through many different models that offer a continuum of care enhancing ease of transition for the person as they access the health care system. The "independent living" philosophy is the cornerstone of service delivery for this population. This model considers a person with a disability in a holistic manner and takes into account his or her lived experience. The account of the person's lived experience includes the barriers faced living with a disability and the supports necessary to living fully integrated into society with a secure income, housing and non-medical daily supports. This holistic approach does not discriminate around the type of disability and is the cornerstone for the philosophy for those with a brain injury and physical disabilities.

Prevalence of Disability for Adults by Sex and Age Group, Ontario, 2012 (Statistics Canada)

Table 3
Prevalence of disability for adults by sex and age group, Ontario, 2012
This table displays the results of prevalence of disability for adults by sex and age group. The information is grouped by age groups (appearing as row headers), total population, persons with disabilities and prevalence of disability, calculated using numbers and % units of measure (appearing as column headers).

Age Groups[Note 1]	Total population	Persons with disabilities	Prevalence of disability
	Number		%
Both sexes			
Total - aged 15 and over	10,727,900	1,651,620	15.4
15 to 64	9,065,910	1,035,090	11.4
15 to 24	1,782,160	87,700	4.9
25 to 44	3,600,580	277,390	7.7
45 to 64	3,683,180	670,000	18.2
65 and over	1,661,990	616,530	37.1
65 to 74	942,530	282,800	30.0
75 and over	719,460	333,730	46.4
Males			
Total - aged 15 and over	5,244,970	732,070	14.0
15 to 64	4,501,260	487,850	10.8
15 to 24	908,800	47,750	5.3
25 to 44	1,775,070	130,820	7.4
45 to 64	1,817,390	309,280	17.0
65 and over	743,710	244,220	32.8
65 to 74	447,600	115,650	25.8
75 and over	296,120	128,570	43.4
Females			
Total - aged 15 and over	5,482,930	919,550	16.8
15 to 64	4,564,650	547,240	12.0
15 to 24	873,350	39,950	4.6
25 to 44	1,825,510	146,560	8.0
45 to 64	1,865,790	360,720	19.3
65 and over	918,280	372,310	40.5
65 to 74	494,940	167,150	33.8
75 and over	423,340	205,160	48.5

Note 1.
Age is calculated as of May 10, 2011.
Notes: **Collection took place in 2012 for a sample selected from the 2011 population.**
The sum of the values for each category may differ from the total due to rounding.
Source: **Statistics Canada, Canadian Survey on Disability, 2012.**

Service Principles for Persons with Disabilities

- *Individualization* - Services support people with varying degrees of needs and create appropriate service plans that reflect their individuality. Service plans are developed in a manner that put emphasis on the needs of the client.
- *Flexibility* - Services offer maximum choice to the client to maximize preferences.

- *Community Integration* - Services are provided in housing locations that promote opportunities for social interaction with others.
- *Independence* - Self-determination is promoted and clients are able to influence provider decisions about housing and support services.
- *Stability* - Continuity in housing and support services are paramount to successful living.
- *Safety* - Service delivery incorporates client choices without compromising client safety. The service is delivered in order to promote and maintain safety while preserving the clients right to the dignity of risk.
- *Self Help* - Services are designed to augment social interaction with friends /family, not replace it.

The Canadian Institute for Health Information recently reported that 18% of residents in Ontario hospital-based continuing care facilities were younger than 65. In the report, "When a Nursing Home Is Home: How does Canadian Nursing Homes Measure Up on Quality?" CIHI reported 7% of Ontario's Long Term Care Home Residents are under the age of 65.

There has been a strong emphasis on the needs of older adults as a focus for health and community planning. As this focus and planning is embedded into each of the 14 LHINs it is essential that we don't lose sight of other citizens of Ontario that require supports to live at home independently. Since the announcement of Aging At Home funding in 2007, planning and policy initiatives have focused significantly on older adults. The focus on older adults in the province of Ontario may have unintended negative consequences for our most vulnerable citizens.

Since the inception of the LHIN structure to be responsible for local funding, planning and accountability there have been various reports and studies conscripted to highlight both the systemic and specific issues across the province. The target groups of persons with disabilities have not been excluded in this search for solutions. Policy to address the rising needs in the supports necessary to keep for persons with disabilities in their home living independent dignified lives makes sense from a both a financial and a human rights perspective.

Research completed by the University of Toronto Joint Centre for Bio Ethics conducted a study that examined the type and adequacy of supports for persons with disabilities. The research identified that the current system of home care does not encompass all of the conditions necessary for a full and meaningful life. The deinstitutionalization of persons with disabilities is not enough to foster and promote independence. Providing shelter and support to a young person with a disability in a Long Term Care home further marginalizes that person.

From the data gathered through this research project it was identified that seven conditions are required in order for persons with disabilities to live in an environment that respect the rights that are enshrined in the Charter of Human Rights and UN Convention on the rights of persons with disabilities.

Those seven conditions are:

> **Meaningful relationships, community and civic life, control and flexibility, self-expression, participation in work, school and leisure, security and safety.**

(Dignity Enabling Home Environment, Key Messages from an Ontario Study. Barbara Gibson. Et al)

When individuals with disabilities are faced with a premature placement in Long Term Care it can be devastating. A survey of the Independent Living Service Providers (OAILSP and PABIN) across Ontario identified that **people with disabilities are waiting in ALC beds, Long Term Care homes, with family, Mental Health Beds, Correctional programs, Homeless Shelters and Acute Care beds**. This is the most "ineffective and expensive" use of health care and most significantly a reduction in the independence and productivity for the person with a disability. When the person with a disability waits at home the time spent on the waiting list contributes to caregiver burnout and eventually crisis planning for the individual.

Health Links

"Health Links will break down barriers for Ontarians, making access to health care easier and less complicated. By encouraging local health providers to work together to co-ordinate care for individual patients, we're ensuring our most vulnerable patients – seniors and those with complex conditions – get the care they need and don't fall between the cracks.**"***Deb Matthews, Minister of Health and Long Term Care*

Across Ontario there is considerable emphasis on Health Links. As stated by Deb Matthews Health Links is for seniors and those with complex conditions. As the health care system moves in different, creative and innovative directions there is much to be learned from Attendant Services. For decade's adults with complex conditions, (i.e. Cerebral Palsy, Spinal Cord Injury and Stroke) have been supported through comprehensive, integrated service plans created through shared service planning with their attendant services provider.

Role of the CCAC's Supporting People with Disabilities

From the early 2000's the CCACs as a provincial organization have had been seeking involvement in supportive housing and other community support services funded by the Ontario Ministry of Health and now the LHIN. As the beginning of increased integration within the community has evolved, a working group with the CCACs and the LHINs was formed. The working group would focus on the new CCAC regulations that contained a clause that would enable the expansion of their role should the LHIN make the decision to take that direction.

Conceptually an integrated system of care is a bold and significant move to improve the health care system. **In a future state of integrated care for persons with disabilities the**

Community Support Services providers need to play an equal role in the engineering and planning of the system with significant input from the client and the caregivers.

There is a strong role for the OACCAC and local CCACs to play in the provision of care to adults with disabilities, but the services must be specialized so that best practice and logical care paths are developed that actually provide community based rehabilitative care. Similar to the community based Stroke services offered by the WWCCAC, other disability groups could benefit from specialized Care Coordination and therapy services. Adults with a brain injury for example will not respond effectively to a traditional therapy program due to their cognitive impairment which includes memory deficits, lack of insight and behavioural components.

"The medical model focuses on treating only the illness whereas assisted living needs to be responsive to the persons WHOLE life, focusing on ADL's and IADL's. The medical model doesn't need to be transferred or extended to the community. A social model of care is more valuable to the clients when they are at home. They need to have their physical, social, emotional and mental health needs met to remain safe and well at home",

Colleen Taylor, E. D., Access Better Living, Timmins, Ontario

Health Human Resources

The majority of front line employees supporting individuals to remain in the community are personal support workers or in some cases other unregulated professions, i.e. Gerontology, Social Service Worker, and Developmental Service Worker. In the community home care system the majority of front line staff is Personal Support Workers that have completed a college certificate program.

As the health care system prepares to make the paradigm shift from institutional to the community, it is essential to address the long standing issues with the front line that support our most vulnerable populations. Recently there has been a renewed interest in the personal support worker/attendant care worker and the need to address the long standing issues of working conditions, compensation, and training.

Working conditions can greatly impact the safety, quality of life and overall work satisfaction for workers in the community. **Fair and equitable compensation** and parity with counter parts will be an important strategy in order to sustain the current work force and to attract individuals to the profession. The wage disparity between home and community care, long-term care and, to some extent, between long-term care and hospital settings are significant barriers to recruitment and retention.

Medical VS Social Model of Care

Internationally disability is viewed as a social construct. Attitudinal shifts occurred globally as a result of the UN Convention on the Rights of Persons with Disabilities. This means that people who have a disability are not to be pitied and treated with a

paternalistic approach but they are considered people with rights capable of living freely, with equality and independence.

http://www.pwd.org.au/student-section/the-social-model-of-disability.html

Adapted from Carol J. Gill, Chicago Institute of Disability Research and Aggelton and Chalmers, 2000

The World Health Organization (WHO) defines health as, "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." An integrated approach to the social and medical model of care is essential to support persons with disabilities who have high attendant care needs. The approach to the care must be person centred and holistic. The social model of care for persons with disabilities respects their dignity and freedom of choice. Despite this, the medical model of care is not to be discounted or considered secondary. For a person with acute care needs, the medical model of care is essential to a swift reaction and remedy. The important consideration is that medical model used in an acute situation transition back to the social model when the client is ready to work on independence and moving back into the community.

Table 4 MEDICAL MODEL	SOCIAL MODEL
1. Disability is a deficiency or abnormality.	1. Disability is a difference.
2. Being disabled is negative.	2. Being disabled is neutral.
3. Disability resides in the individual.	3. Disability derives from interaction between the individual and society.
4. The remedy for disability-related problems is cure or normalization of the individual.	4. The remedy for disability related problems is a change in the interaction between the individual and society.
5. Patient is a set of complex parts and systems	5. Sees the medical system as just one component of overall health

ADULTS WITH PHYSICAL DISABILITIES

Adults with physical disabilities have long fought to live independently in the community of their choice. The people who pushed for the independent living movement on the campus of Berkley State are now moving out of supportive housing after thirty-five years of living in the community and like many others, seeking the comfort and supports of long term care facilities. For some this is because of the natural aging process and for others it is due to the progression of their disability. The younger generation of people with disabilities take their

independence for granted. They know they have the right to services in the community and they are choosing to exercise those rights. There are two key services for adults with physical disabilities; Assisted Living/Supportive Housing and Outreach Attendant Services.

Supportive Housing

Although the functional centre is funded under assisted living, to be very clear this is not assisted living for frail seniors but should be referred to as supportive housing.

The Supportive Housing (SH) Policy was approved by the Ontario Ministry of Health in December 1994 and services are delivered by non-profit organizations in an apartment complex or homes that are in close proximity to the provider. A landlord/tenant relationship exists so the client maintains their own lease. Units that are specifically designated for supportive housing are clustered in a specific building. Tenants/clients are responsible for all living expenses (i.e. rent, food, social activities).

Services provided include but are not limited to; personal hygiene activities (bathing, toileting, dressing), homemaking, housecleaning, laundry, ironing, mending, shopping, banking, paying bills, meal planning and preparation, caring for children, security checks and reassurance. The clients must direct their own services, which in essence means that the attendant is just an extension of them, providing personal support at directed. Both scheduled and unscheduled visits are available on a 24/7 basis with the frequency of visits is dependent on individual client care plans.

Delinked versus Linked Housing

This refers to a very specific situation and is dependent upon who owns the building that hosts the supportive housing units. In the situation where the organization that provides the 24/7 attendant services also owns the building, these services are consider to be "linked". If the building is owned and/or managed by a provider that does not provide the direct service, these services are considered to be "delinked". Linked services are not necessarily recommended as a best practice model as there can be issues when the client has landlord/tenant contraventions that do not relate to service delivery or vice versa. It is important to have very specific processes in place to separate landlord verses services issues.

Outreach Attendant Services

The Attendant Outreach (AO) Policy was developed in 1996, by the Ministry of Health and replaced the 1984 provision guidelines that were developed by the Ministry of Community and Social Services. The AO Program was seen as a progressive step by the sector to respond to people's desire to remain in their homes and not have to move in

order to receive services. It created further deinstitutionalization options for people with disabilities. Organizations began to provide personal assistance and homemaking in the community in the client's home.

The intention of the policy was similar to the Supportive Housing Policy (1994) but went a step further in supporting people to be independent. The policy states that the program is to:

• assist people with physical disabilities to pursue a participatory life style and live independently

• assist people with physical disabilities in maintaining paid employment and/or pursuing adult education programs to obtain a degree/certificate/diploma

• prevent the need for inappropriate admission to a chronic care or other facility

• enable people with physical disabilities, where possible, to leave institutional facilities

• assist/support family members in providing support

This service is provided in the client's home on a scheduled basis. In order to qualify the client must require personal support but during the same visit can also receive homemaking supports. The service provided must be personal care and is most often on a daily basis. Attendants provide the same services as supportive housing such as bathing, grooming, bowel and bladder routines, ventilator care, diabetic care, etc. Outreach is intended to provide a minimum of 3 hours per day of service with many clients needed 6+ hours a day as they age in place.

In many cases Outreach Attendant Services are supplemented by other programs such as CCAC homemaking services as Attendant Service providers are not provided with increases in funding to accommodate the changing needs of the clients as they age. Often at this point families and private services may be brought in to also bolster the service requirements which can create crisis and caregiver burn out. Beyond personal supports there is often a requirement for mental health and addictions supports to be put in place to maintain the stability of the client and their family.

Direct Funding

The Direct Funding program "began as a pilot project, developed by clients and the provincial government in 1994. It was so successful that it became a permanent program in July 1998." It is administered by the Ontario Network of Independent Living Centres which consists of 11 Independent Living Centres throughout Ontario.

As an alternative to Attendant Outreach or Supportive Housing, Direct Funding enables adults with a physical disability to take full responsibility for managing a budget and hiring and supervising their own attendants. There are over 700 individuals and their families in Ontario who manage their own attendant services through this program and employ their own attendants. Individuals receive the same assistance as the Attendant Outreach and Supportive Housing and have the same eligibility criteria. Individuals are attracted to this model because of the flexibility for service times and reliability of receiving consistent services from the same person(s). The additional eligibility criterion includes having the skills to manage the funds made available to them. As a participant in the program, participants must be able to:

- manage money, time and personnel
- apply for a business number
- make payroll deductions
- keep records for employer/employee taxes [9]

The premise for this model of care is that the person with a disability is the employer and they hire, train and supervise their own workers. The Personal Attendants provide support with activities of daily living. This innovative program is geared to those individuals who have the skills and ability to take on the duties of being an employer and generally have the need for a flexible schedule of services i.e. individuals attending school and work. The Direct Funding program is funded by the Ontario Ministry of Health through the Toronto Central LHIN and administered provincially through the Centre for Independent Living. The Centre for Independent Living in Toronto has partnerships with Independent Living Centres across the province.

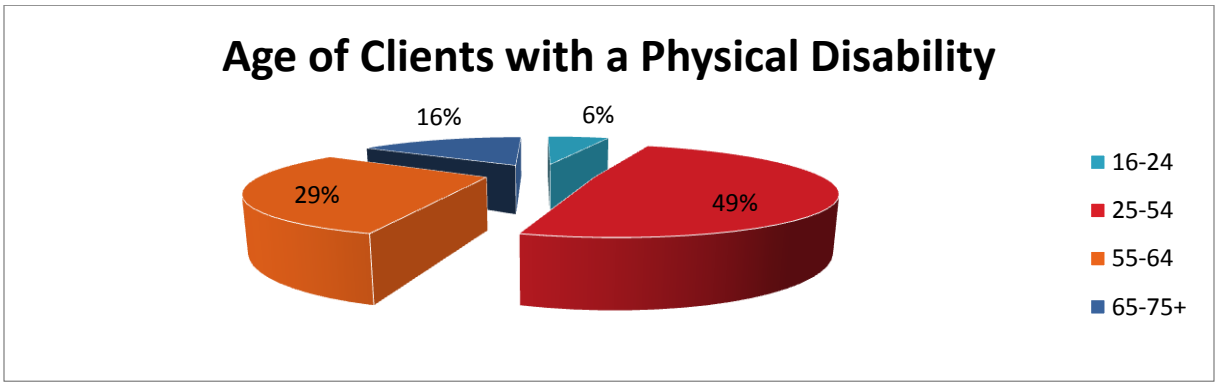
> "Many people with disabilities want to manage their own care because it provides them with greater choice, control and flexibility. Direct funding also results in better value for our precious health dollars, because it relieves pressure on our health care system and frees up resources to provide care for others. That's why we're committed to expanding this program to help more people live more independently at home and in their communities. "
>
> *Deb Matthews, Minister of Health and Long-Term Care*

Demographic Profile

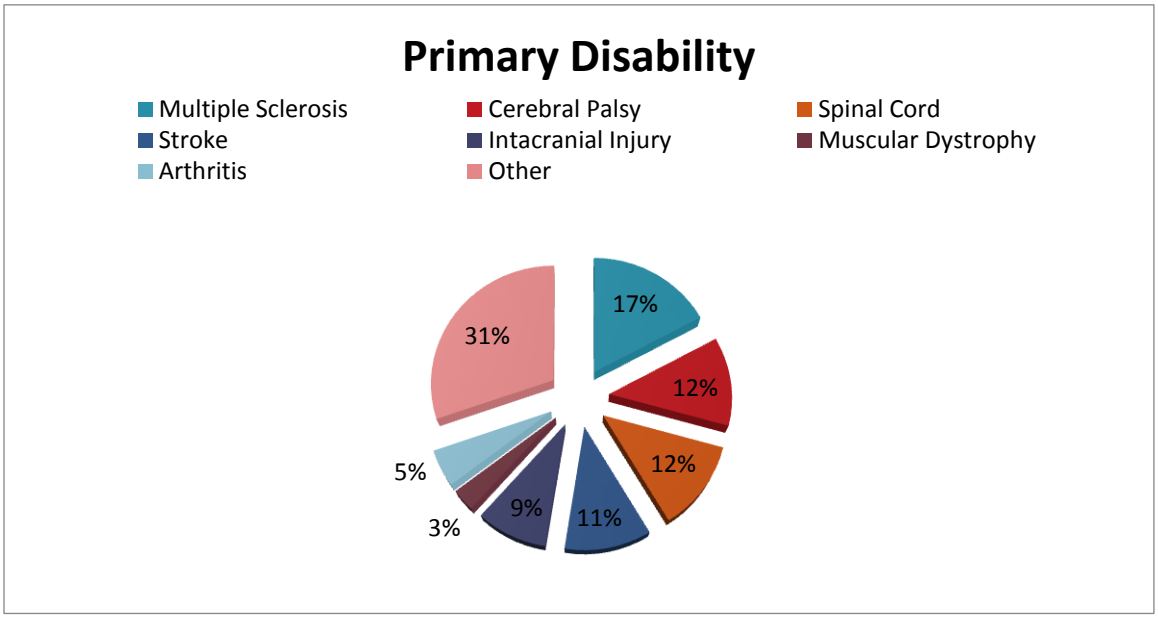
The Ontario Association of Independent Living Providers (OAILSP) provided **demographic data for this report which is representative of 3100+ adults with physical disabilities** who utilize attendant services across the province. This data is representative of clients, some of whom have been receiving services for more than thirty years. This is borne out when looking at the age banding of the clients that are being served in the province. While close to half of the clients are

[9] Centre for Independent Living Toronto. Direct Funding General Information. http://cilt.ca/Documents%20of%20the%20CILT%20Website/df_info_guide.pdf accessed May 1, 2013.

within the age of 25-54, the next largest percentage is clients who are 55-64. With that being said there is 11 percent of the clients who are within the 65-74 age range. As we know, adults with disabilites age more quickly than the non disabled population. The fact that the adults over the age of 65 are in supportive housing is significant and an indicator of how attendant services can support an older person to sustain health and well being. It is also encourging to see that adults with disabilites in the prime of their life are living in a supported situation where they can maintain independence and and contribute to their community.



As you can see, the "other" section is close to 31% of the primary disability. This is an indicator of the many, many different reasons why a person may have a physical disablity. When looking past that, the largest single disability group is around those who suffer from multiple sclerosis followed equally by cerebral palsy and and spinal cord injuries. Multiple sclerosis is an extremely progressive disease which provides challenges for service providers as the acuity of their disease changes. These clients often present with the highest InterRaiCha MAPle scores and they require upwards of 6 hours a day of support .



Waiting Lists for Attendant Services

The attendant service providers that responded to TRI-UHN provincial survey reported that there were 3,654 people on wait lists for the Direct Funding Program, Attendant Outreach, Assisted Living in Supportive Housing and Shared Living Programs. Extrapolating from this survey, ***there are over 5,000 individuals waiting for service across the province.***

Wait times to receive Direct Funding ranged from 2.25 to over 7 years and for Supportive Housing Services people can wait up to 10 years. What is troubling about this fact is that over one-quarter of people leaving the wait lists are ending up in long-term care (LTC) homes. This is occurring at a time when seniors with high end needs requiring alternate levels of care (ALC) are in hospital beds because they are on a wait list for LTC homes.[10] *(Unleashing Attendant Services for People with Physical Disabilities, March 2013)*

The Attendant Services wait list issue is costing the taxpayers and the health system millions of dollars every year because these people are:

- Waiting in ALC hospital beds
- Inappropriately placed in LTC Homes, forcing seniors on wait lists to stay in ALC beds (contributing to hospital capacity issues)
- Living with elderly parents who can no longer manage their needs, resulting in physical and mental health issues for both parties
- Ending up in Emergency Rooms with secondary complications
- Prevented from pursuing work opportunities and contributing to the economy (Unleashing Attendant Services for People with Physical Disabilities, March 2013)[11]

*The following chart represent the numbers captured formally in March 2013. In a very informal survey of OAILSP members , numbers in South West, North Simcoe Muskoka and South East LHINs** have been adjusted to reflect current state. The trend of note is that waiting list numbers have increased significantly since the 2013 study was completed.*

Table 5	Direct Funding Program		Outreach Attendant Services		Supportive Housing	
	rec'g	wait	rec'g	wait	rec'g	wait
Erie St. Clair	15	4	147	89	135	90
**South West	26	18	147	180	78	109
Waterloo	36	11	194	30	79	100

[10] Unleashing Attendant Services for People with Physical Disabilities, March 2013)

[11] tibd

Wellington						
Hamilton Niagara Haldiman Brant	57	53	150	171	201	234
Central West	22	20	90	42	17	33
Mississauga Halton	38	15	100	46	66	154
Toronto Central	75	37	123	**302	*174	662
Central	80	44	160	91	135	137
Central East	57	27	431	160	105	124
**South East	26	9	159	67	34	37
Champlain	90	26	293	113	168	183
**North Simcoe Muskoka	40	10	129	111	61	27
North East	83	49	188	60	92	87
North West	31	12	24	40	63	55
TOTAL	676	335	^2353	1304	1380	1932

Wait List and Wait Time Analysis of Community Support Services for Persons with a Physical Disability in Ontario, July 2012

Toronto Rehabilitation Institute (Toronto Rehab) was approached by the Provincial Liaison Committee for Persons with a Physical Disability (PLCPPD) to collect data on wait lists and wait times for home and community support services for persons with a physical disability in Ontario. Both the PLCPPD and Ministry of Health and Long-term Care (MOHLTC) identified that there is a research gap in this area and that data is necessary to support evidence-based policy-making related to community support services for adults with disabilities. The project was funded through Toronto Rehab's grant from the MOHLTC Ontario Provincial Rehabilitation Program.

Service providers identified 5 distinct barriers to addressing current wait lists for community support services:

Current **funding levels do not match the demand for services** in the community support services/disability sector.

There are **not enough supportive housing units available** nor have there been new investments in supportive housing, including access to capital funds for providers to build more units; the lack of physical capacity coupled with extremely low turnover rates mean long wait lists for supportive housing

A **lack of accessible and affordable housing** in the community results in longer wait times for supportive housing as well as inappropriate placement of people

with disabilities in institutions; many people waiting for supportive housing could continue to live safely in the community with supports if they had suitable housing options

Inflexible service models and policies inhibit wider provision of services; for example, age related diseases affect people with disabilities sooner than non-disabled people, yet funding programs prioritize services for the aged who are 65+

Silos between provincial health and housing Ministries result in the **lack of a shared vision, understanding and development of mechanisms** to address the full range of health and well-being issues for adults with disabilities [12]

Gaps, Opportunities and Priorities

As part of the research for this report a province wide survey was created for members of OAILSP to complete. Members were asked to identify gaps, barriers to service and priorities. The feedback was rich in content and provided consistent themes. Following are their quotes directly from the surveys;

Human Resources: "There is a lack of Personal Support Workers in the health care system especially in this sector as there is significant wage disparity with hospitals and long term care homes. There is a competition for staff, versus a strategic approach. There is considerable difficulty recruiting in the rural areas due to the lack of population to draw from". "Capacity building within the Personal Support Worker profession as provider skill sets are challenged to support individuals with increasing and complex needs".

Funding: "A flexible funding model is required to support the ongoing needs of clients. There is an increase in reporting requirements, services being downloaded to this sector while dollars are not flowing with the redistribution of services/tasks. Funding models are not flexible such a supportive housing dollars which are fixed and make it difficult to run a hub model or a cluster model. The lack of annual funding increased means that service providers must continually search for clients who require light care when vacancies occur".

Lack of housing: "There are tenants within Supportive Housing with needs that increase as they age; this means that when there is a vacancy **the provider of service can only accept a client with low needs** as funding does not correlate with client needs. The result to the health care system is that the client with a high acuity of need will stay on a waiting list or remain in an inappropriate setting".

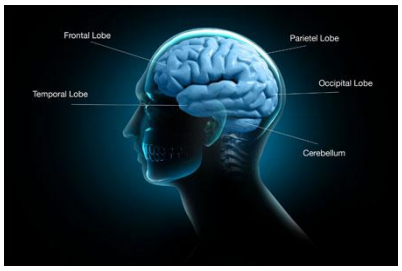
Lack of planning: "Generally there is short term planning for individuals with long term needs. Clients are referred in crisis. The biggest barrier to providing services to those on the wait list is the good health of the clients receiving service and clients receive services on a lifelong basis".

[12] Wait List and Wait Time Analysis of Community Support Services for Persons with a Physical Disability in Ontario, July 2012

New Models of Care: "More innovation and development of new models of care is required". "Creative solutions to new apartment units coming on line are one such idea. It would be great if there was flexibility to assign hours of service determined by client's specific needs, not programs targets, or historical service hours in the budget".

Awareness: "Attendant Services is the best kept secret; there is a lack of awareness and understanding of what services are provided. Attendant Services provides all of the necessary aspects of supports so individuals can remain in their homes. That being said, people need the homemaking assistance integrated into their personal support and homemaking assistance is being eroded from client service plans. This is due to the fact that providers are moving to essential services due to the lack of increases of funding". We need recognition that the CCAC does not represent the community support services sector, increased community recognition for our sector (CSS) with LHIN and MOHLTC, in order to highlight that the services provided are essential".

ADULTS WITH ACQUIRED BRAIN INJURY



The Ontario Brain Injury Association's definition for ABI is; "*Damage to the brain, which occurs after birth, as a result of a traumatic or non-traumatic event and is not related to a congenital or a degenerative disease and can result in temporary, prolonged or permanent impairments in cognitive, emotional, behavioural or physical functioning is considered to be an ABI"*[13].

Each year approximately 50,000 Canadians suffer an Acquired Brain Injury. In Ontario approximately 795 children out of 100,000 will suffer a brain injury this year. An injury to the brain is often likely to result in death or permanent disability. Brain injury is the leading cause of death and disability worldwide.

Brain injury can range from mild concussion to permanent disability and can have many causes. An acquired brain injury (ABI) is damage to the brain which occurs after birth due to a traumatic event, such as a blow to the head, or a non-traumatic event, such as a medical event (stroke, etc). It is not due to a congenital disorder or a progressively degenerative disorder. As the brain is a complex and delicate organ, damage to the brain can produce long term difficulties.

Facts

- ✓ Brain injuries occur 10 times more often than spinal cord injuries.

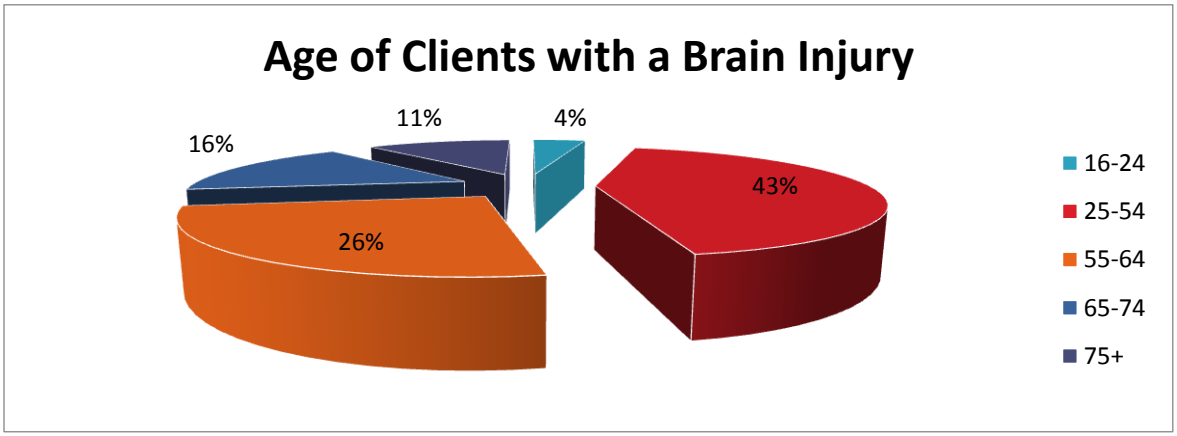
[13] http://www.obia.on.ca – What is Brain Injury, May 10, 2010

- ✓ Brain injuries are the leading cause of death and disability for Canadians under the age of 35; with the highest rate of injury occurs between the ages of 15 – 24 years.
- ✓ More than 800 Ontarians die each year due to brain injuries.
- ✓ More than 12,000 people in Ontario sustain brain injuries each year.
- ✓ Males are more likely than females to incur a traumatic brain injury.

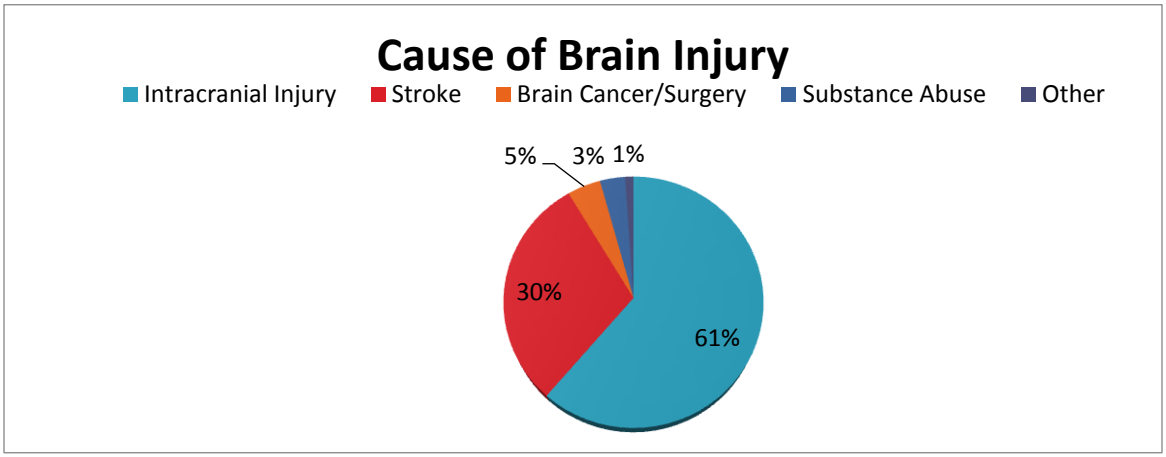
Demographic Profile

The Provincial ABI Network provided **data on 4,230 clients** receiving services in the province of Ontario. Of interest is the fact that 42% of the clients, so almost half are within the ages of 25-54. These are young people who have suffered a brain injury with a long life ahead of them. While there are studies that indicate that they may age more quickly than the average population, they do expect to live an independent and productive life. This then requires an integrated system of services that offers a seamless and coordinated health care experience from the point of the acute injury through rehabilitation, to the community supports required to maintain their independence.

There are different needs and service requirements for different ages. Specifically the transitional years between childhood and adulthood (15-21 years) can present challenges both with respect to the nature of the issues during this time period as well as the change between paediatric and adult service systems as they graduate from one to the other. Given that there are existing service paths for the paediatric population (paediatric specialized acute service, for example, The Hospital for Sick Children and Bloorview Kids Rehab) which provide services for individuals up to age 18, this report is focused on adults age 16+.

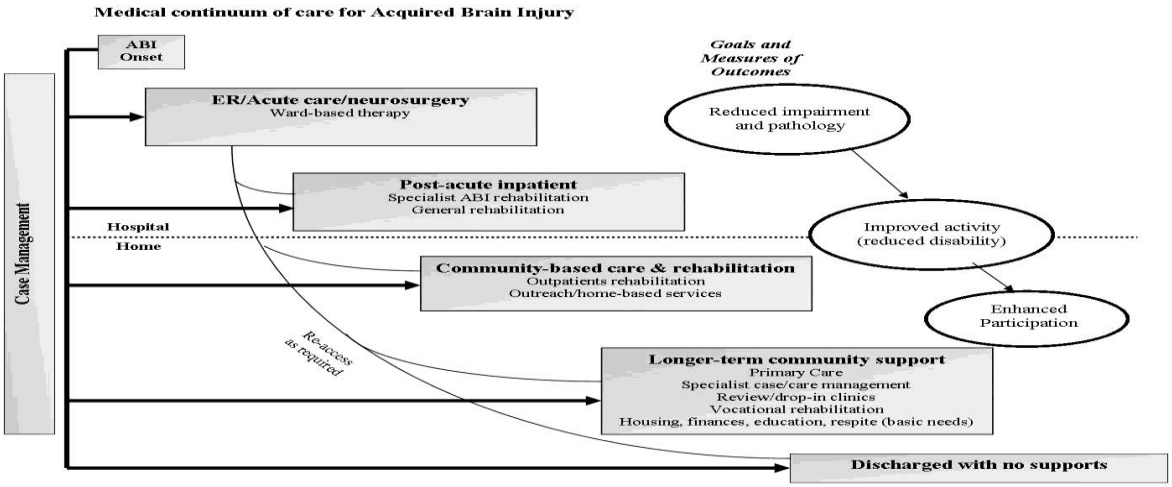


Often in order to develop a service plan both in hospital and in the community sector, the client's ABI will be classified as mild, moderate, or severe (catastrophic). This diagnosis is dependent upon a number of tests and assessments that are often only performed if the brain injury is moderate or severe, such as the Glasgow Coma Scale.



Through discussions and consultation with key stakeholders it was identified that there is a more clearly defined pathway for service access when the client has been determined to have a severe brain injury. **The lack of services and clear pathway for mild and moderate ABI is an issue** and evident on all levels. There is just now becoming an understanding of what a mild brain injury actually is and what symptoms and services a person who had experienced such an injury may require.

ABI clients[14] have wide variations in their experiences accessing service. They stated that there is **no evident and clearly accessed system of service for ABI clients**. In this section, we have mapped the more typical stops on a client's journey through the available services. This experience has been articulated in the graphic below[15]



Adapted from Royal College of Physicians and British Society of Rehabilitation Medicine. Rehabilitation following acquired brain injury: national clinical guidelines (Turner-Stokes L, ed). London: RCP, BSRM, 2003

[14] Some individuals with an ABI self-identify as 'survivors'. For consistency in this report we have used 'client'.

[15] Adapted from Royal College of Physicians and British Society of Rehabilitation Medicine. Rehabilitation following acquired brain injury: national clinical guidelines (Turner-Stokes L, ed). London: RCP, BSRM, 2003

The diagram above identifies the client's **ideal** experience in hospital at home /community. It has been designed to specifically speak to rehabilitation services but also represents the client's journey through the system. There is much variation in clients' experience and they may skip some of the stages or re-access some services. The ovals to the right identify rehabilitation goals and outcomes in each step.

The client's experience typically includes both an acute care hospital setting related to the onset of the injury and moving to community support services as their acute care requirements diminish. **Generally it is thought that there is significant under-reporting of ABI**. This is because some clients may have an onset which is reported only to a family physician or not reported at all, not diagnosed appropriately as an ABI, or not coded in a hospital in a way which would identify them as having an ABI. As a result, the supporting data across the province is limited and does not reflect the actuality of brain injury in Ontario.

ABI is typically described according to two broad categories, **Traumatic Brain Injuries (TBI) and Non-Traumatic Brain Injuries (non-TBI).** As we review the WWLHIN resident experience below, we have identified some of the data according to these categories. Collecting data is complicated by a number of things including but not limited to, the diverse number of conditions which can cause a brain injury. When a TBI is one of a number of injuries sustained, of which one or more could be considered primary or life threatening, the presence of a brain injury may not be recorded (coded as the main diagnosis). Also, individuals who sustain a mild brain injury may not initially seek medical attention and when attention is sought the original insult may go unconnected to the symptoms that are coded.

According to data collected from April 2004-March 2007, the annual TBI patient rate in the province was 1.3 per 1000 persons. For the same period, the annual non-TBI rate was 0.9 per 1000 persons[16].

Alternate Level of Care and Wait Lists

Alternate Level of Care (ALC) is defined as follows; An ALC patient is one who "has completed the acute care phase of his or her treatment but remains in an acute care bed (CIHI 2009). In 2010 the Ontario Neurotrauma Foundation (ONF) published the ABI Data Set Project, with Angela Colantonio, Senior Research Scientist, Toronto Rehabilitation Institute, University of Toronto as the Principal Investigator. This study was funded by ONF with acknowledgement of support offered to the Ministry of Health and Long Term Care.

This report provided conclusive evidence that between the years of 2003 – 2010 the average rate of brain injury, within the population of Ontario was around 1.5 % per 1000 people. With that being said, **on average the median number of ALC days per ABI episode was around 19 days per person**. The inpatient rehabilitation median length of

[16] Ontario Neurotrauma Foundation, ABI Dataset Pilot Project-Phase 1, Colantonio, A., Parsons, D., Vander Laan, R., Zagorski, B. June, 2009

stay was 39.4 days with some LHIN areas as low as 15 days (Erie St. Clair) and some as high as 73 days (North West). The average age of the patient was 67.3 years old.

Ontario Neurotrauma Foundation & Toronto Rehab Report

The Systems Analysis of Health and Community Services for ABI in Ontario was initiated to describe the scope and nature of health and community services, the linkages that exist at the various points of the continuum, as well as linkages across transitions from children to adult services.

. What the ABI Systems Analysis found;

- Across all stakeholder groups, a higher proportion of organizations reported a **wait time for accessing services as opposed to wait time for intake**.
- Across all the LHINs, the most dominant reasons for the wait list were **not enough staff and not enough funding** for services to meet demand.
- **ABI patients have difficulty transitioning out of ALC acute care beds** because of psychiatric issues, behavioural needs, medical /nursing needs, and substance use (rank ordered).

Long wait lists reflect gaps or unmet needs for psychological/mental health, drug and alcohol abuse, emotional supports/counseling, social and cognitive needs, job skills/vocational support, rehabilitation, no suitable discharge destination due to geography, lack of suitable services across all areas to deal with the complexities and long-term needs such as behaviour, substance use, mental health, cognition and continuing rehabilitation.

Recommendations from respondents in regards to ALC:

There is a high prevalence of ABI and mental health and/or substance abuse and behavioural issues, **making this population particularly vulnerable to being designated ALC.** Fourteen percent of individuals with ABI have ALC days. The reported mean number of ALC days in acute care is 22. *(Ontario ABI Dataset, Colantonio et al, in press).* Furthermore, ABI has the longest inpatient rehabilitation ALC days. *(Utilization of Adult Inpatient Rehabilitation Services in Ontario Hospitals 2003/04 – 2007/08, April 2010, Ontario Ministry of Long Term Care)*

ALC Solutions

Skills and training in primary care and community sector for managing ABI are needed

- Provision of enhanced ABI services on acute care units to assist with behavioural issues, impulsivity control, safety risks, and family support.

Programs

- Invest in more ABI specialized outpatient rehab services and community support services such as ABI Outreach and Day Programs
- Increased behaviour support programs/services

- Increased integration between ABI and mental health/addictions
  Linkages and collaboration between hospitals and community based organizations to enable transitions
- A particularly compelling solution/area of investment for the high number of ALC days in the ABI population is the need for more community-based programs. This enables individuals to live at home in a familiar, comfortable environment, leading a greater likelihood of engagement in daily activities. Active collaboration between hospitals and community-based services is needed to allow for this transition of care, with follow-up support and outreach teams.
- LHIN-designated ABI funds could be used to support strengthening of the linkages between hospitals and community-based services, with a focus on coordinating care and improving service flow.

System Flexibility

- Increased flexibility is needed in service criteria, rules about eligibility, and number of hours of service.
- In some cases, a few additional hours/week from ABI Outreach or ABI specialized supports through the CCAC enable individuals of all ages to return home to the community and remain there, thus alleviating ALC, providing appropriate care for the individual, and avoiding inappropriate admission to long-term care facilities.

Increased provision of a range of housing and support for individuals with an ABI on a continuum to serve variable needs and to enable people with ABI to be in the community rather than in a more costly institutional setting this would allow for clients to transition and movement to a final place in the community.

Track innovative models currently being tested and share results across LHINs:

Toronto Central CCAC's population-based service model
Waterloo Wellington LHIN – Traverse Independence Transitional Living Program
Travelling outreach teams
Short stay beds specifically for ABI

PABIN Waiting List Data – A Total of 2,079 Clients Waiting for Service

Table 6 Type of Program	Average Wait Times
Assisted Living	7-15 years
Transitional Living Programs	3 months – 2.5 years
ABI Day Programs	4 months – 2.5 years
ABI Outreach Program	3 months – 3.0 years
ABI Supportive Housing	8 months – 15 years

The provincial ABI providers showed a variety of waiting times for all programs with the **longest being 15 years for supportive housing**. It makes sense that the programs that

have client flow will have shorting waiting times such as the day programs and the outreach programs. This may also be an indicator of some funds being received to enhance these programs. The most significantly blocked program is the supportive housing which is often the final destination for the person as they recover and work on skills acquisition.

These same providers show **2,079 clients waiting for ABI services** with the largest number waiting for ABI Outreach and ABI Supportive Housing.

The final question on the survey was in regard to referral rates verses clients who come off the service for whatever reason. In looking at the numbers, it becomes very apparent that more clients are being referred to service than there are openings as the **referral rate exceeds the graduation rate by approximately 45%.**

> *"Easily accessed, effective system navigation assistance, multiple access points with equitable access to services is required given the changing needs of clients and/or their caregivers over the course of their life, effective transitions and flow of clients across services providers, ABI knowledgeable case management to assess, plan and facilitate access to a continuum of services and supports from ABI onset to lifelong living, linkage to primary service."*

Through this system wide survey the members of PABIN identified that the reason the majority of clients are in an ALC bed is because of either lengthy waiting lists for services or because the client requires a solution that is crafted specifically for them. Often this requires cross sectoral cooperation and collaboration as a client specific care plan is designed. The most challenging clients in our system are those with concurrent disorders that include a brain injury combined with mental health and addictions. Further complicating this ALC crisis is the lack of ABI specialized therapeutic resources and lengthy waiting lists at the provincial ABI Regional Centres.

Client-centred Flexible Service Coordination and Navigation

When a brain injury occurs, there is massive upheaval not only for the brain injured client but also for family members including grief, guilt, loss and turmoil. **A simple, easy to access system of services** is needed in order to enable clients and/or their caregivers to get the service they need when they need it.

Access issues in terms of health service services (e.g. rehabilitation, transitional care, primary care) are common problems facing individuals with neurotrauma. Some groups in particular may be at risk. For example, "a survey of over 900 homeless men and women in Ontario found that the lifetime prevalence of TBI was 53% and 70% reported that their first TBI occurred before the onset of homelessness." *(Health Horizons Issue #8-January 2010).*

It is also an important area for education regarding the needs of the client and what to expect during the post acute stage. Individuals with brain injury and/or their caregivers experience falling between the cracks as they move between different services, lacking someone who is responsible to provide long-term coordination. The British Society of Medicine stated, "Life-long contact is needed to meet the changing clinical, social and psychological needs of patients and their families/servicers."[17] (Adapted from Rehabilitation following acquired brain injury, National clinical guidelines, British Society of Rehabilitation Medicine).

Current State – ABI Services in Ontario

Across the province of Ontario ABI services have evolved in a dynamic and individualized manner. When comparing services through the Provincial ABI Network (PABIN) which is a long standing network including the majority of service providers offering brain injury supports in Ontario, there are some key services that are critical to supporting the transition of a client from the acute incident to a final state of independence in a setting appropriate to their recovery. This report is focussing on the community support services (CSS) that are most commonly put in place once the client has stabilized and completed inpatient rehabilitation.

Persons with a brain injury can have a complex series of physical challenges such as paralysis or sensory loss; cognitive problems such as short term memory loss and language difficulties and/or behavioral problems such as personality changes, severe mood swings or acting out. In addition, because of the complexity of the brain and the variety of insult to the brain that may occur, each individual who has a brain injury is unique. Our mission is to provide services to these individuals to assist them in attaining their optimum level of functioning and to continue on living, loving and doing.

" In the past three plus decades of services we have identified that up to 65% of individuals we serve have a co-occurring Axis 1 Diagnosis (psychiatric), which may have been pre-existing the injury or due to damage of the mechanical, electrical and/or chemical mechanisms in the brain following an injury and/or sentinel medical event in the brain. Of these 65% of individuals 80% have a further co-occurring addictions issue which may have been pre-existing or subsequent to the event. To add to this complexity 60% of the individuals we serve have had involvement with the criminal justice system (50% as perpetrators and 50% as victims of crime) and have a history of violence they can be excluded from services. Since mainstream mental health and addictions services are overburdened at best, individuals presenting with these complex, multi-jurisdictional issues cannot be served". [18]. (*Standing Committee Report, Alice Bellavance, CEO, BISNO)*

[17] Royal College of Physicians and British Society of Rehabilitation Medicine. Rehabilitation following acquired brain injury: national clinical guidelines (Turner-Stokes L, ed) p. 17. London: RCP, BSRM, 2003

[18] Standing Committee Report, Alice Bellavance, BISNO

Services that are Consistently Offered

The building blocks of an easily accessed brain injury system include the following services;

ABI Transitional Living: This is therapeutic program that offers a variety of skill based supports in a variety of settings. The goal is to teach/train the client to learn the skills required to transition to a final independent living situation appropriate to their rate of recovery. Length of stay in the transitional living program can be anywhere from 3 months – 2 years.

ABI Outreach: This highly specialized service offered by skilled workers can maintain a client in the community **for as little as 2 hours a week**. The focus is therapeutic in nature and is intended to support the client to remain stable and in the community. Workers assist clients to access primary care and support the client to maintain all social determinants of health. It assists in ED avoidance in a significant manner as workers assist clients to maintain stability. This is a highly efficient and cost effective program. As an example; at a unit cost of $45.00 per hour so $90 per week versus $6,860 per week ($980 per day) for an ALC bed this service has a significant impact on efficiencies in the health care system. On average residents are staying in ALC beds for 12-26 days at $980.00/day or $11,760.00-$25,480.00 per year versus $4,320.00 per year for Outreach services.

ABI Assisted Living/Supportive Housing: This service is a 24/7 support provided in a common and/or congregate setting. Workers offer ongoing support to the client in many significant areas. Often clients have concurrent disorders including a brain injury, mental health and addictions. The role of the worker is to ensure the that client is supported through crisis, maintains connection with primary care and external supports and is keeping up with responsibilities to housing, food, budgets, medications, etc. These supports ensure the client remains stable and do not access emergency departments, corrections systems or become homeless.

ABI Day Programs: These specialized environments support clients to maintain their community based placements. At a fraction of the cost of an ALC bed, the day programs provide peer to peer support, staff support to ensure all determinants of health are being met in the client's life. ABI day programs have evolved differently in all of the geographic areas, but the key principals are maintained in regard to supporting individuals to attain their optimum level of functioning and to continue on living, loving and doing.

Gaps in ABI Services in the Province of Ontario

- ✓ Seamless and coordinated health care from acute injury, through rehabilitation to community support services
- ✓ Integration with mental health and addiction programs that specialize in ABI and concurrent disorders
- ✓ Affordable and available supportive housing/assisted living

- ✓ Equitable services across the province including access to day ABI day programs and ABI Outreach services no matter where you live
- ✓ Caregiver support including ABI respite beds

In examining brain injury service across the province, it is not surprising that there are a significant number of gaps for clients and their families. One of the key points in the Ontario Action Plan for Health Care states that "There are still too many instances where patients don't know how to access the care they need, don't know what services are available or are waiting in hospital until home care or long-term care are available. Better integration through our local health networks will put the right care, in the right place delivered by the right provider for the benefit of patients and the system. We can do better. We need a patient-centred system that has better integrated health providers — such as family health care, **community care**, hospitals and long-term care — that moves patients more seamlessly from one care setting to another." *(Ontario Action Plan for Health Care.*

People who have survived a brain injury do not know where to access service. Services are inequitable across the province, with each LHIN area offering bits and pieces of an ABI system. Some areas are more significantly developed than others, but services are not integrated into the existing system. Full integration with mental health and addictions is required as 40-60% of all clients with a brain injury have concurrent disorders that involve multiple diagnosis and challenges.

Often clients who are in the brain injury system are transient, travelling from one LHIN area to the next. They receive regional services in one of the ABI Regional Centers and the most challenging are maintained on a provincial ABI "Pressures" list. The Hamilton Health Sciences (HHS) Acquired Brain Injury Program currently maintains the ***Provincial Pressures List*** and is made up of those individuals with ABI who have been assessed by Hamilton Health Sciences and who are considered in need of highly specialized, provincial ABI resources. This list is comprised of ABI individuals from across the 14 LHINs in Ontario. **As of January 2014 the list identifies 27 high-risk individuals**, however the list is fluid with individuals being added to the list at a much quicker rate that those who are removed.

When space becomes available at one of the Ministry funded ABI programs, priority placement is given to the ABI client with behavioral support needs on the list that match the level and type of resources available and the receiving program determines and confirms suitability. When new funding becomes available, the behavioral support needs of the entire list is considered. Final decisions by the Ministry about how the funding will be allocated are generally matched with the clinical profile of those ABI clients most at risk and how available resources can be matched to accommodate their service needs. Access to the specialized provincial resources is severely limited as clients who are ready to move to a more independent setting have no opportunity to do so because of the scarcity of adequate options in their home community.

This list is categorized according to the complexity of the individual and their subsequent complex and immediate resource needs. The majority of the most complex ABI individuals present with significant behaviour control deficits as well as co-occurring mental health and addictions issues while a smaller percentage presents with additional complex medical conditions. As a result of their needs the majority of these individuals require 24/7 residential support from staff with a skill set specific to ABI and behaviour management.

As a result of the complex nature of this population some are currently blocking highly needed acute care, specialized rehabilitation or mental health hospital beds. Some are inappropriately housed in Long Term Care facilities or Lodging Homes and some are living at home but are a continual stress and strain on their caregivers. Finally some have consequently ended up incarcerated with an impending release, and some utilize shelters or are homeless.

There is also a group who are identified as ***Future Need*** and these include ABI individuals who are currently supported by ill or aging caregivers and individuals whose insurance funds are near depletion leaving them with an inappropriate level of care and support and no personal funds to purchase them.

The Provincial ABI Network, when surveyed in February 2014 collectively responded that the most significant gaps in the ABI system are reflected in the lack of appropriate housing, resources and ABI specialized staff. **A key ABI program component is the ABI Outreach Program**. This program can quickly and efficiently stabilize a client, reduce their crisis and result in ER deferment. This program is not consistently available across the province.

Beyond the Outreach Program, **affordable, safe "assisted" housing options** are required to maintain a client. Social determinants of health are significantly compromised in the ABI population when they are continually threatened with homelessness, lack of food, shelter and basic primary care.

The most challenging of ABI clients are the high users of the ER department and as the Health Links evolve in their case studies and file review, will start to emerge as part of the 5% of the population that is targeted. An ABI specialty has not yet been added to the majority of Health Links province wide and should be mandated as part of a **provincial ABI strategy**.

Brain Injury and Substance Abuse

A significant number of people with a brain injury have substance abuse issues. "Substantial numbers of people with a history of brain injury go on to have post-injury substance use difficulties in the long run. Several studies conducted over the past eight years have found that between 40% and 60% of people presenting for treatment of alcohol dependence screen positive for a history of acquired brain injury. One recent study using a stringent method of defining brain injury found that more than 70% of

patients accessing services for concurrent disorders (mental health and addictions) have histories of at least one brain injury with loss of consciousness."[19]

Despite the high prevalence of co-morbid brain injury and substance use, few programs in Ontario accommodate the special needs of this complex population. A 2005 survey of Toronto ABI Network member agencies found that a small minority of rehabilitation programs consistently screened for substance use problems and none of the surveyed addictions programs systematically screened for brain injury. *(Carolyn Lemsky, PhD, C.Psych).*

It has been common to dismiss individuals known to be actively using substances from rehabilitation on the theory that they are unable to benefit from the care offered. People with brain injury presenting to addictions programs may also be lost to care because they appear unmotivated for treatment as a result of difficulty getting organized to keep appointments, remembering relevant information, being impulsive or disinhibited, and following through with treatment recommendations. Dr. Lemsky has designed and implemented a program specific to Substance Abuse and Brain Injury (SUBI). This model of specialized addictions treatment for those with a brain injury is not consistently applied across the province.

Due to the concurrent nature of ABI and mental health issues, **building strong linkages across mental health and ABI systems with collaborative service**, resulting in joint responsibility moving to a collaborative treatment/service model is imperative. Breaking down barriers through cross training, information sharing, consultations, and utilization of OTN for consultations and training will accomplish this.

Caregiver and Respite Services that are specialized for those who have a brain injury are seriously lacking. As a result families and caregivers experience burn out, illness and exhaustion. It is important to create flexible models of respite and support to address needs of families and Caregivers. This can be made possible by enhancing capacity by collaborating and integrating with other population groups/initiatives wherever possible.

> "Primary care, rehabilitation and the community support sector have limited knowledge of ABI as a specialized population. Education and expertise in regard to behaviour and cognition which are core to brain injury services needs to be promoted and offered as part of the provincial strategy".
>
> ***Veronica Pepper,***
> ***ABI System Navigator***

CONCLUSION

Health care reform and the implementation of the Local Health Integration Networks have been instrumental in changing the landscape of the health system in Ontario. At the present time as recommended in many reports prior to this one, there is a great opportunity to impact on the lives of the residents of Ontario - not only seniors but those with disabilities. The

[19] Things I Didn't Know about Substance Use and Brain Injury, Posted on June 9, 2012in Summer 2012 , Carolyn Lemsky, PhD, C.Psych

LHINs have an opportunity to target funds locally where they can make a difference. Sectors are paying attention to "integration" and this means that as each new initiative moves forward the health care journey of the residents of our communities becomes more seamless and coordinated. There have been many reports written about the importance of all models of Attendant Services for persons with disabilities and the current and expanded need for services for those with Acquired Brain Injuries. The timing is perfect to shine a light on this work and implement the long standing recommendations.

As we experience the paradigm shift for funding to be channelled to communities most initiatives are focused on older adults. As we know from the demographic imperatives we face as a province this targeted approach is essential. We strongly believe that there needs to be a broader approach to funding in order to capture all vulnerable citizens in the province.

The Ontario Ministry of Health is to be congratulated on the release of the Assisted Living Policy for High Risk Seniors as the framework for funding and program development is well laid out. Some of the identified gaps that have occurred as a result of this policy release are:

1. Policy updates have not yet been developed for the other target populations covered in the 1994 Supportive Housing Policy- Persons with disabilities, Persons with Acquired Brain Injury and Persons with HIV/AIDS.
2. People with disabilities and acquired brain injury services are waiting for services in hospitals, long term care homes or with minimal CCAC services. This creates an upward substitution of care which is costly to the system.

Across the province of Ontario the Local Health Integration Networks have examples of creative and innovative ways of supporting people with disabilities close to home. A provincial strategy would greatly assist to share this knowledge and spread the innovation. For example, Central LHIN has taken the bold step to fund Ontario March of Dimes to develop a specialized program for those with high care needs. This program has resulted in individuals who called hospital home for many years to move into their own apartment. Each LHIN has examples of innovation and creative programs that need to be shared across all 14 LHINS. A LHIN CEO Champion would provide the vision and leadership necessary to make improvements.

A solid commitment of funding to alleviate the decade long waiting lists and to provide an immediate increase to the Personal Support Worker wages is required in order to stabilize the sector and prevent further pressures on the rest of the health care system. The 4% in funding allocated to the Community Support Services sector on annual basis is one source of funding. In addition to this funding a reallocation of funding from the CCACs could be a more cost effective and appropriate use of funding.

An essential next step is to develop a province wide strategy that include provincial stakeholders, the Ministry of Health Policy Division, Ministry of Housing and Municipal

Affairs and the LHINs to take the recommendations contained within this report and begin to develop action plans for implementation.

The time is now for a provincial strategy targeting services for adults with disabilities including policy updates and targeted funding. With these bold moves the people with disabilities in Ontario will live high quality and dignified lives in the community and not in hospital or long term care where they block beds and are prevented from having a meaningful life.

RECOMMENDATIONS

1) **Create a local strategy that includes investment in community providers offering complex supports** to adults with disabilities focused on relieving waiting lists and creating a more seamless and coordinated healthcare experience with specific resources to address;
    a. Supportive Housing
    b. ABI Outreach and Attendant Services Outreach for adults with physical disabilities
    c. Innovative and creative new programs
    d. ABI Day Programs

2) Develop a **policy framework**, vision and directional plan for a **province wide strategy** to provide an integrated model of care for persons with disabilities; the focus to be on individuals with physical disabilities and brain injuries.
    a. Include dialogue with the **Ministry of Municipal Affairs and Housing** to address the lack of affordable and supportive housing
    b. Conduct **extensive stakeholder engagement** across the province inclusive of providers and clients and caregivers and ensure results are reflected in policy framework
    c. All health system partners should play a role in the engineering and planning of the system
    d. Include a provincial review to assess the volume and needs of **all adults in ALC beds with a physical disability or brain injury**
    e. Directive to the **Health Links** to ensure adults with disabilities are identified separately and provided with a care plan that addresses their specialized needs
    f. Similar to Behavioural Supports Ontario each LHIN to develop an implementation plan based on their current and future state.

3) Promote **strong engagement and leadership** from the following stakeholders in the provincial framework; Ontario Association of Independent Living Service Providers, Provincial Acquired Brain Injury Network, Ontario Community Support Association, Ontario Association of Community Care Access Centres and the Ontario Hospital Association with support from the Ontario Ministry of Health and Long Term Care policy branch and the LHINs.

4) A Pan-LHIN immediate investment of new funding to **address salary** enhancements for staff working in the community (i.e. PSW, Attendants, Rehab Workers) to improve wage parity with long term care environments and rehab programs.

References

Reports and Publications

A Vision for the Community Support Services Sector: A key player in supporting people who are *difficult to serve* North Simcoe Muskoka, June 2013 Kinnon and Associates

Banerjee, A. An Overview of Long-Term Care in Canada and Selected Provinces and Territories, 2007.

Commission on the Reform of Ontario's Public Services, 2012

Gibson, B , Disability and Dignity-Enabling Home Environments: Key Messages from an Ontario Study, University of Toronto Joint Centre for Bioethics, 2010

Gray, Carolyn Steele PhD. Candidate, University of Toronto Janet Lum, PhD., Ryerson University Policy, Performance Measurement and Supportive Housing , 2009.

Hutchison, P Research in Action, Role of Consumer Driven Disability Organizations in the Non Profit Sector, 2005

Jagal, S., PhD Murphy, B., MSW, Wait List and Wait Time Analysis of Community Support Services for Persons with a Physical Disability in Ontario, Toronto Rehab, University Health Network, 2012

Ontario Ministry of Health and Long Term Care, Assisted Living for High Risk Seniors Policy, 2011

Ontario Ministry of Health and Long Term Care, Ontario's Action Plan for Health, 2012

Ontario Ministry of Health Long Term Care Supportive Housing Policy Branch Long Term Care Division, 1994

Ontario Neurotrauma Foundation, ABI Dataset Pilot Project-Phase 1, Colantonio, A., Parsons, D., Vander Laan, R., Zagorski, B. June, 2009

North East LHIN Enhancing the Personal Supports Occupations (PSO) Workforce, November 2011

North East LHIN Assisted Living Strategy, 2013

Royal College of Physicians and British Society of Rehabilitation Medicine. Rehabilitation following acquired brain injury: national clinical guidelines (Turner-Stokes L, ed). London: RCP, BSRM, 2003

Sinha, Samir, Dr., Living Longer, Living Well, 2013

Supportive Housing and Assisted Living Services for High Risk Seniors in the NSM LHIN: A review of the policy components and its application, Cindy Kinnon, Kinnon and Associates

Walker, David Dr., Caring for Our Aging Population and Addressing Alternate Level of Care, 2011

Unleashing Attendant Services: Enhancing People's Potential, Reducing Wait Times for Acute Care and Long Term Care, Attendant Services Advisory Committee, OCSA- Ontario Community Support Association, 2008

Internet resources

Ontario Association of Independent Living Providers, www.oailsp.ca

Ontario Brain Injury Association, www.obia.ca

CIHI, www.cihi.ca "When A Nursing Home Is Home: How do Canadian Nursing Homes Measure Up on Quality?"

Direct Funding, Self-Managed Attendant Services in Ontario www.dfontario.ca

Direct Funding, Self-Managed Attendant Services in Ontario www.dfontario.ca

Centre for Independent Living Toronto, www.cilt.ca

Government of Canada Statistics Canada http://www.statcan.gc.ca/start-debut-eng.html

Social Model of Disability, http://www.pwd.org.au/student-section/the-social-model-of-disability.html

Social versus Medical Model of Disability, Adapted from Carol J. Gill, Chicago Institute of Disability Research