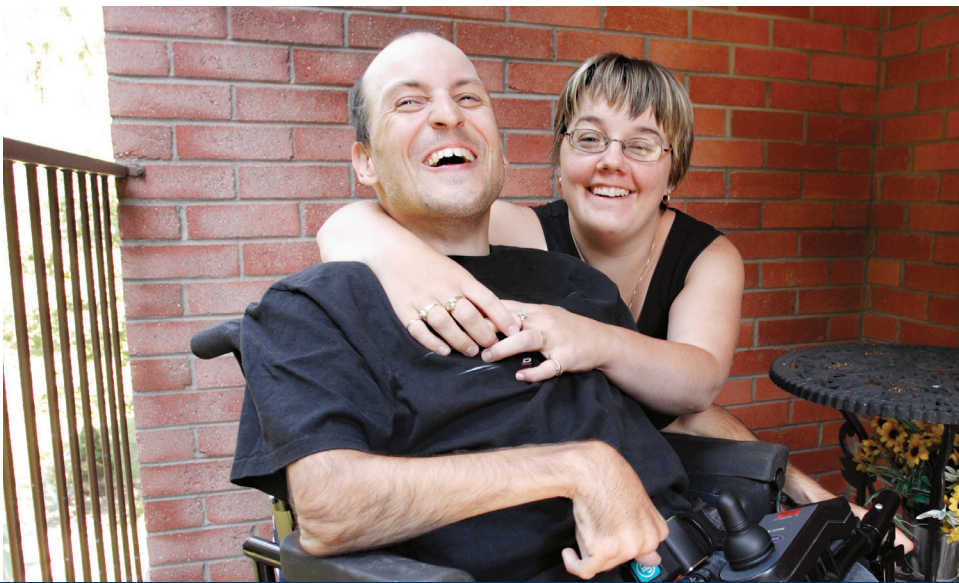


OCSA

Ontario Community
Support Association



UNLEASHING ATTENDANT SERVICES: Enhancing People's Potential, Reducing Wait Times in Acute and Long-Term Health Care

Attendant Services Advisory Committee
Ontario Community Support Association
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TABLE OF CONTENTS

Don, who has a spinal cord injury that resulted in quadriplegia, has been ready to leave hospital for 3 years, but is on a wait list for Self-Managed Attendant Service – Direct Funding. This has cost \$1,200/day to the tax payers, instead of the \$200/day it would have cost if he had attendant services at home. Twelve other consumers/year could have received Attendant Services with the over \$1.3 million in hospital spending over the 3 years, and a bed/day would have been freed up at the hospital to move a patient from ER or reduce wait lists for surgeries.

EXECUTIVE SUMMARY	3
A. Introduction	6
B. The Current Service Delivery System	7
C. The Roots of the Current Attendant Services Delivery System: The Independent Living (IL) Model of Service Provision for Persons with Disabilities	8
D. Providing Attendant Services: The Preferred Option over More Costly and Institutional Care	9
E. Chronic Diseases & Aging Among Persons with Disabilities	10
F. Wait Lists for Attendant Services in Ontario	10
G. The OCSA Attendant Services Advisory Committee’s Recommendations for Action	12
H. Next Steps	13
APPENDIX A OCSA’s Attendant Services Advisory Committee: Mandate and Membership	14
APPENDIX B The History of the Independent Living Model and Legislative Changes	14
APPENDIX C A Day in the Life of a Consumer with Attendant Outreach Services	16
APPENDIX D Listing of Attendant Service Providers across Ontario	17

Acknowledgement: Thanks to Jamie and Alison for permission to use their photograph. See their story on page 9.

The Ontario Community Support Association, a provincial association, is the voice and representative body of home and community support in Ontario, working to ensure Ontarians of all ages and conditions have access to an integrated range of healthcare solutions outside of hospitals and long-term care facilities.

EXECUTIVE SUMMARY

The United Nation's Convention on the Rights of Persons with Disabilities' Article 19 b) states: **"Persons with disabilities 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 May 3, 2008**. Canada's House of Commons has unanimously endorsed Canada ratifying the convention.

Currently in Ontario, there is unmet need, extensive wait lists and long wait times for Attendant Services for persons with physical disabilities [mobility impairment]. The number of people with disabilities is growing, and this population is aging, as are their family supports whose health status is declining. This is putting pressure on other parts of the health care system as people needing attendant services remain inappropriately in long-term care homes, acute care beds, chronic continuing care hospitals, and rehabilitation facilities at much higher costs to

the system. Attendant Services should be a right for persons with physical disabilities, but instead the majority of consumers are either not getting the services or not getting the right services in the right place.

Ontario has an opportunity to play a leadership role by rectifying the situation and showcasing a provincial strategy to help Canada meet its obligations under the UN Charter.

Who the Consumers of Attendant Services Are:

Those who use Attendant Services are adults, ranging in age from 16-93 years of age, with physical disabilities. Conditions include Cerebral Palsy, Arthritis, Stroke, Multiple Sclerosis, Muscular Dystrophy, Spinal Cord Injury (SCI), Spina Bifida or Huntington's Disease. Many people have two or more disabilities. Consumers direct their attendants to perform the services they need to perform the activities of daily living. Attendant Services are an "Independent Living" model of service – as directed by the consumer (a model that grew out of the civil rights and human rights movements in the 1960s in the U.S.).

This report is intended to bring to the attention of the general public, politicians, the Ministry of Health & Long-Term Care (MOHLTC) and the 14 Local Health Integration Networks (LHINs) the current Attendant Services situation across the province and to make recommendations about how to move forward with an effective strategy for the health care system and persons with physical disabilities who require Attendant Services.

The current Attendant Services funded by MOHLTC and the LHINs serve 6,000 consumers across Ontario:

- **Self-Managed Attendant Service - Direct Funding (DF):**

enables adults with a physical disability to take full responsibility for managing a budget and hiring and supervising their own attendants. **Current provincial funding is \$22.1M.**

- **Attendant Outreach Services:** service is provided in the consumer's home between the hours of 6 a.m. and midnight on a pre-scheduled basis. Services may also be provided at the workplace, college or university. **Current provincial funding is \$48.8M.**
- **Assisted Living Services in Supportive Housing:** Supportive Housing providers typically offer several accessible, affordable apartments integrated throughout a larger apartment building. Most Supportive Housing providers offer Attendant Services to their tenants on a pre-scheduled and on-call 24-hour basis. Also included in this category are cluster models that provide service to consumers within a set radius of the office location, and congregate living and group homes which offer a communal home setting with attendant services for people who may have limited capacity to self-direct or who have multiple service needs. **Current provincial funding is \$80.2M.**

Who the Service Providers are:

Self Managed Attendant Service-Direct Funding flows directly to the provider agency, for instance the Centre for Independent Living Toronto (CILT), from the Provincial & Priorities Programs Branch, MOHLTC. For both Attendant Outreach Services and Assisted Living Services in Supportive Housing, funding is provided to registered non-profit community support services organizations directly by Local Health Integration Networks (LHINs). Currently there are 47 local agencies or provincial organizations across the province providing Attendant Services to persons with disabilities.

The OCSA Attendant Services Advisory Committee has four key recommendations for action by MOHLTC and the LHINs:

- **Recommendation #1: that MOHLTC and the LHINs host a special forum** with a broad representation of attendant services consumers, service providers and relevant provincial associations to ensure the Ontario Government and the LHINs integrate the needs of persons with disabilities into any policy and program health system strategies being developed. This would include initiatives such as the Aging at Home Strategy, the Diabetes Strategy, the Chronic Diseases Prevention and Management Strategy, the Provincial Poverty initiative, the Accessibility for Ontarians with Disabilities Act and any provincial supportive housing enhancement plans. Recommendations from the forum could be referred to future Joint Work Groups to explore and develop implementation strategies.
- **Recommendation #2: Add the lengthy wait times for Attendant Services and Supportive Housing to the MOHLTC Provincial Wait List Strategy** and ask the

Ontario Health Quality Council to report on progress. To address the wait lists for all Attendant Service programs would take \$73 million - \$10 million in each of the next three years and \$21.5 million in years 4 and 5 to allow time for the development of affordable housing stock. Supporting persons with disabilities at home will help reduce wait lists for acute care, complex continuing care and rehabilitation facilities and enhance the health status of aging family supports.

- **Recommendation #3:** Institute individually-based funding for all persons requiring Attendant Services. Funding should be determined based on an assessment of the individualized services needed, with funding adjustments as conditions change. A secure level of ongoing services to maintain independence and base stabilization funding for service providers would ensure the ongoing infrastructure and capacity to meet growing service needs.
- **Recommendation #4: MOHLTC should immediately provide an increase in funding of \$12 million/year in each of the next three years to the Attendant Services sector** to allow providers to be able to continue to deliver the same level of service to current consumers, to deal with existing consumers' increasing needs as they age and/or as their disability progresses. The funding would also be used to build on the current successes and innovative ways of providing quality, cost effective services. Community support services have lost 23% of their spending power in the last 10 years because funding has not kept pace with inflation. Efficiencies and cost-saving partnerships continue but are not enough to keep up with increasing costs like employee compensation and fuel prices.

Why it is imperative that action be taken to enhance Attendant Services in Ontario:

- 1 People who need Attendant Services use services for the entirety of their lives, are living longer with medical technology, have changing needs as they age, and acquire age-related diseases earlier than the general population, at 50 years of age. They also have much higher incidents of chronic diseases like diabetes and arthritis.¹
- 2 The numbers of people requiring Attendant Services is growing and funding is not keeping pace with the demographics.² For instance, the wait list for Assisted Living in Supportive Housing and Attendant Outreach services in Toronto alone is 900 people, with 10% of these people inappropriately living in hospital Alternate Level of Care beds, chronic care hospitals or long-term care homes.

The costs to the system when Attendant Services are not available and people are forced into other inappropriate health care settings:

Service Location	Average Cost/Day
Hospital bed	\$1,200
Complex Continuing Care Hospital bed	\$900
Long-Term Care Home bed (up to 2 hours of care/day)	\$135
Community Care Access Centre (3 hours of care/day)	\$150
Assisted Living in Supportive Housing (average of 4 hours/day):	\$132
Self-Managed Attendant Service - Direct Funding: (a maximum of 6 hours/day - with an average of 5 hours/day):	\$87
Attendant Outreach (average of 2.5 hours/day)	\$80

¹Canadian Council for Social Development, Fact Sheet #14, "Persons with Disabilities & Health", 2004.

² The prevalence of disability is 15% of the population, increasing to 43% among seniors. And the number of seniors is expected to double in the next 16 years.

- 3** People with physical disabilities cannot continue to rely on aged family supports that are physically unable to transfer them or are in inaccessible homes without proper equipment. The aging family supports cannot cope with the caregiving burdens and their health is declining as a result, adding more costs to the health care system. In the end, they will no longer be there to provide ongoing support. Of those on the Toronto wait list for attendant services, 15% are currently living with their parents, many of whom are seniors.³
- 4** Recruitment and retention of staff is a serious concern and will force people to more costly acute care settings if workers are not available to deliver the services at home or in the community. The wage gap is widening between workers in attendant settings versus long-term care homes and hospitals. A strategy to keep workers in the community is needed immediately.
- 5** The poverty rate for adults with disabilities is 25%, which is 15% higher than the general population.⁴ This means that affordable housing stock is integral to any strategy to address this population's needs.

Evidence in other Jurisdictions:

In British Columbia, Vancouver Coastal Health targeted the highest need groups (adults with disabilities and seniors requiring complex care) and linked community care funding to system outcomes (e.g. Alternate Level of Care bed reductions⁵) and shifted the focus from residential care beds to assisted living in supportive housing (with 4,000 assisted living units created). Residential care beds have decreased by 25-30%; ALC beds were reduced from 12% to 6% and 17 in-patient hospital beds were freed up.

The OCSA Attendant Services Advisory Committee is confident that the above recommendations for consideration:

- Are in keeping with the Ontario Government's commitment to promote citizens' autonomy and self-determination
- Supports the LHINs' new integrated, community-focused direction
- Empowers consumer involvement and control of their own lives and health
- Helps the Government with its Wait List Strategy for health services
- Provides services to people in the right place, by the right provider, at the right time, and at the appropriate price for the taxpayers
- Can be an integral part of the Aging at Home Strategy, and
- Achieves health equity

³ 58% are over 50 years of age and 24% are over 65. There are two 65 year olds still living with their parents.

⁴ Advancing the Inclusion of Persons with Disabilities, 2002, Human Resources & Social Development Canada, Figure 20, p. 47

⁵ ALC (Alternate Level of Care) is defined as hospital beds being occupied by persons who are not or no longer in need of acute care but remain in hospital because there are no supports to get them home or get the services they need there.

UNLEASHING ATTENDANT SERVICES: Enhancing People's Potential, Reducing Wait Times For Acute Care And Long-Term Care

A. Introduction

In March 2008, the Ontario Community Support Association (OCSA) created an Attendant Services Advisory Committee⁶ made up of consumers and Attendant Service provider organizations to give the Association advice on what steps should be taken to ensure persons with physical disabilities [mobility impairments] get services to maintain their autonomy and be contributing members to Ontarian society.

There is unmet need, long wait lists and long wait times for Attendant Services for persons with physical disabilities. The number of people with disabilities is growing, and consumers are aging, as are their family supports.

This report is intended to bring to the attention of the general public, politicians, the Ministry of Health & Long-Term Care (MOHLTC) and the 14 Local Health Integration Networks (LHINs) the existing Attendant Services situation across the province and to make recommendations about how to move forward with an effective strategy for persons with physical mobility disabilities who require Attendant Services.⁷

Who are the Consumers of Attendant Services

Those who use Attendant Services are people with physical disabilities with conditions such as Cerebral Palsy, Arthritis, Stroke, Multiple Sclerosis, Muscular Dystrophy, Spinal Cord Injury (SCI), Spina Bifida or Huntington's Disease. Many people have two or more disabilities. Consumers direct their attendants to perform the activities of daily living (ADL) they require to get on with their day-to-day lives. Attendant services include: bathing and washing, transferring, toileting, dressing, skin care, essential communications, and meal preparation. The consumer is responsible for the decisions and training involved in his/her own services.

Canada has signed the United Nation's Convention on the Rights of Persons with Disabilities. Article 19 b. of the Convention states:

"Persons with disabilities 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".⁸

Ontario has an opportunity to play a leadership role in the world by ensuring that the convention is instituted in the province. An expansion and enhancement of Attendant Services would demonstrate the Ontario Government's commitment to the United Nation's Rights of Persons with Disabilities Convention and the Government could showcase its strategy with its Federal/Provincial/Territorial partners in Canada.

Among the issues that need to be addressed are:

- People using Attendant Services use services for the rest of their lives, are living longer with medical technology and rehabilitation, have changing needs as they age, and acquire age-related diseases at an earlier age than the general population.⁹
- Consumers are also more likely to be poor than the general population. From 1993 to 1998 an average of 25% of adults with disabilities were living in households below the Low Income Cut Off (LICO), compared to an average of 10% of those without disabilities and LICO did not factor in the additional costs associated with a disability.¹⁰ As a result, affordable housing stock is one of the issues that needs to be addressed.
- The numbers of people requiring Attendant Services is growing and funding is not keeping pace with the demographics of a growing number of people needing services and growing wait lists.¹¹ In fact, funding increases have not kept pace with inflation and there are significant increases for operating costs and collective agreements. Providers have lost 23% of their spending power in the last 10 years. There will be fewer people receiving services than are currently being served if funding issues are not addressed immediately. This, in an environment where the rate of increase in the wait lists is growing and will be expected to grow dramatically as the population ages. The number of seniors is expected to double in the next 16 years.¹²
- Not taking action on this issue will force people to rely on more costly acute care settings like hospitals, resulting in increasing wait lists for other peoples' desperately needed surgeries or patients not being able to leave ER for acute care because hospital beds are inappropriately being used.

⁶ See Appendix A for the list of Advisory Committee members.

⁷ This report addresses attendant services only. There are many important, related services for persons with physical mobility disabilities funded by MOHLTC and other funders that are not addressed in this report, i.e. transportation, youth transition programs.

⁸ The United Nation's Convention on the Rights of Persons with Disabilities, ratified on April 3, 2008 and legally binding May 3, 2008. The Canadian House of Commons has unanimously endorsed Canada ratifying the convention

⁹ There is research evidence that persons with physical disabilities age prematurely, J Kailes, "Aging with Disability", Rehabilitation Research and Training Centre on Aging with Spinal Cord Injury, California, 1998.

¹⁰ *Advancing the Inclusion of Persons with Disabilities*, 2002, Human Resources & Social Development Canada, Figure, 20 p. 47.

¹¹ Statistics Canada's 2007 'Participation and Activity Limitation Survey' relates that over a five year period from 2001 - 2006, "the severity of disabilities for adults aged 15 and older increased in a stepped fashion", with an increase of 16.4% reporting a very severe disability. [p. 3]

¹² Statement by former Minister of Health & Long-Term Care, George Smitherman, in an interview with the Toronto Star, April 24, 2008.

- Recruitment and retention of staff is a serious concern, particularly given the much higher salaries and benefits in hospitals, long-term care homes and for the Developmental Support Workers in the Ministry of Community and Social Services who recently received a large increase in hourly wages. A shortage of Attendant Service workers will force people to use more costly acute care and long-term care settings if Attendant Service workers are not available to deliver the services in people's homes. A health system human resources strategy is required.
- Traditional family roles are under stress, both health wise and financially¹³ and family supports will decline over time as the population ages. The lack of Attendant Services funding will mean that dependent adults remain with family well beyond the family's ability to humanly, physically and financially cope – unable to transfer, inaccessible environments with inappropriate assistive devices, and then the family support dies.

The time is right for the Ministry of Health & Long-Term Care (MOHLTC) and the Local Health Integration Networks (LHINs) to hold a forum and work with consumers and providers to develop provincial policies and fund local programs to enhance Attendant Services to ensure people with physical disabilities get the services they need in the community.

Many people are inappropriately forced to turn to the more costly acute care hospitals or long term care homes for seniors because the more appropriate and cost-effective services in the community are not available. As well, the Community Care Access Centres are having to try to cobble together home care services because there are insufficient or non-existent Attendant Services in certain areas. Home care services are not the right services for this consumer group and are more costly than attendant services to the health care system.

B. The Current Service Delivery System

Currently in Ontario, \$150.4 million/year in funding is provided for Attendant Services to about 6,000 people by MOHLTC. Following are the Attendant Service categories¹⁵ for persons with physical disabilities that are funded by the Ministry of Health & Long-Term Care (MOHLTC) and in need of enhancement and expansion:

- **Self-Managed Attendant Service - Direct Funding (DF):** enables adults with a physical disability to take full responsibility for managing a budget and hiring and supervising their own attendants. **Current provincial funding is \$22.1M.**
- **Attendant Outreach Services:** service is provided in the consumer's home between the hours of 6 a.m. and midnight on a pre-scheduled basis. Services may also be provided at the workplace, college or university. There is currently a ceiling of 90 hours of service per month. The policy for attendant outreach requires that persons who need more than 90 hours per month to receive Ministry approval. Consumers are advised to have back-up support available, as Outreach cannot be provided on an on-call basis. **Current provincial funding is \$48.8M.** (See Appendix C for a day-in-the-life of an Attendant Outreach Services consumer on page 16.)

"People with disabilities should have the same kind of opportunities as everyone else. They should be able to do the things that most of us take for granted – going to work or school, shopping, taking in a movie or eating out." (The Ontario Ministry of Community & Social Services Website).

What happens when Attendant Services are not available

In 2004, 'Don' entered hospital with complications arising from his earlier spinal cord injury that resulted in quadriplegia. He has been ready for discharge since March 2005, yet living in a hospital for over 3 years because he is on a lengthy wait list for Self-Managed Attendant Service-Direct Funding in his home. The cost/day for Don to be in the hospital is \$1,200/day or \$438,000/year.

Don is extremely frustrated because he knows he could be in his own home with the right services he needs at a cost of \$200/day – 6 hours of service during the day and an attendant available overnight. The hospital bed could have been freed up to reduce the wait lists for surgeries and Don would have been independent in his own home.

The additional cost to taxpayers to date as a result of Don not being able to access the right service in the right place at the right time has been over \$1.3 million over 3 years. The additional inappropriate hospital costs could have provided Attendant Services to 12 people per year.¹⁴

¹³ "Numerous studies have shown that supports to individuals with disabilities and their families are often insufficient...The extent of their caregiving responsibilities can take a major toll on caregivers' economic security and physical, emotional and psychological health", p. 6, "Beyond Conjugality: Recognizing & Supporting Close Personal Adult Relationships", Law Commission of Canada, 2001

¹⁴ The average cost for Self-Managed Attendant Services in Ontario is \$87.00/day.

¹⁵ Attendant services include: bathing and washing, transferring, toileting, dressing, skin care, essential communications, and meal preparation. The consumer is responsible for the decisions and training involved in his/her own services.

- **Assisted Living Services in Supportive Housing:** Supportive Housing providers typically offer several accessible apartments integrated throughout a larger apartment building. Most Supportive Housing providers offer Attendant Services to their tenants on a pre-scheduled and on-call 24-hour basis. Also included in this category is funding for congregate living and group homes which offers a communal home setting with attendant services for people who may have limited capacity to self-direct or who have multiple service needs. **Current provincial funding is \$80.2M.**

Eligibility Criteria

To be eligible for attendant services, people with physical disabilities must:

- Be insured under the health Insurance Act of Ontario (i.e. possess a valid Ontario Health Card)
- Be at least 16 years of age or older
- Have a permanent physical disability and require physical assistance with activities of daily living such as bathing, dressing, transferring and toileting
- Have the ability to direct their own services - communicating with the attendants about what they want done, when they want it done and how, and
- Be able to have any medical/professional needs met by the existing community health network on a visitation basis

Who the Service Providers are

For both Attendant Outreach and Assisted Services in Supportive Housing, funding is provided to registered non-profit community support service organizations by the Local Health Integration Networks. Currently there are 47 local agencies or provincial organizations across the province providing Attendant Services to persons with physical disabilities, other than Self-Managed Attendant Service-

Direct Funding. This program is coordinated through CILT (the Centre for Independent Living Toronto) in partnership with the Independent Living Resource Centres of Ontario across Ontario as Direct Funding follows the client regardless of which LHIN they live in. Funding for this program flows directly from the Provincial Programs Branch of MOHLTC.

Attendant Service workers have a broader scope of services than Personal Support Workers, including some functions that must be delivered by nurses or doctors in health care settings, i.e. ventilation, bowel & bladder, tracheal suctioning, tube feeding, assisting with medications under the direction of the consumer (exemption under the Regulated Health Professions Act) and assisting consumers with communication, including the use of Augmentative & Alternative Communications (AAC) equipment. Note: Attendant Services do NOT include: professional services such as nursing care, physiotherapy, occupational therapy, respite care, physician services, “care” or taking responsibility for the person with a disability.

Other than the funding received from MOHLTC for Attendant Services, many agencies also receive targeted funding from MOHLTC and other sources to provide a variety of other services, i.e. youth services, transportation programs, transitional & life skills programs, and escort services for social/recreational activities. Agencies work collaboratively within their communities to integrate services and provide a continuum of supports for people.¹⁶ They also work with each other to ensure efficient use of limited resources, i.e. sharing back office resources, shared wait lists.

The Attendant Outreach Service Providers and Assisted Living Services in Supportive Housing Providers across Ontario are listed by LHIN in **Appendix D**. There are gaps in service in certain parts of each LHIN and in some parts of the province there are no attendant services whatsoever – an issue that needs to be addressed.

C. The Roots of the Current Attendant Services Delivery System: The Independent Living (IL) Model of Service Provision for Persons with Disabilities¹⁷

Attendant Service provision for persons with physical disabilities developed in the 1960s and is based on the Independent Living model of service rather than the medical/rehabilitation or ‘charity’ models of service. The movement began at the Berkeley campus of the University of California by a group of students with disabilities and quickly spread throughout the United States and Canada and is now a world-wide movement.

Attendant Services evolved out of the desire and the need of persons with disabilities to lead independent lives. It is a unique model which enables people with disabilities to direct their own services in the community. Before the advent of attendant services, most people with physical mobility disabilities would have remained in chronic care hospitals, lived in institutions, or been cared for by family members long after the age when most non-disabled people would choose to live independently.

¹⁶ It should be noted that some attendant service providers partner with Acquired Brain Injury (ABI) services to provide attendant services when required.

¹⁷ For a full history of the Independent Living Model and the Milestones for persons with disabilities, see Appendix B, p. 14.

The Independent Living model embraces the notion that rights and responsibilities are shared between citizens and the state, focusing on building a society based on the principles of inclusion, equity, affordability and justice. It is founded on the right of people with disabilities to:

- Live with dignity in their chosen community
- participate in all aspects of their life, and
- control and make decisions about their own lives.

"For me, the roots of independent living lie in one place. Getting out of the Institution...When I was not quite 11 years old in 1965, I left my home in Ottawa and came to Toronto to live in a "crippled" (sic) children's institution. That is the word they used then...crippled. Worse actually. I still remember the day my father carried me in and sat me in a big chair in the lobby and I looked up at a plaque with names of donors headed up with the phrase "Home for Incurable Children." So that's what I was,

I thought, an "incurable child," a child that couldn't be fixed. None of us had a future, therefore no social value.

Even then it seemed that people who worked with us were little better, and had little more social value than we had. They were simply viewed as the "caretakers of the children with no social value".¹⁸

Sandra Carpenter, Executive Director, Centre for Independent Living Toronto (CILT)

D. Providing Attendant Services: The Preferred Option over More Costly and Institutional Care

The evidence:

- In British Columbia, Vancouver Coastal Health targeted the highest need groups (adults with disabilities and seniors requiring complex care) and linked community care funding to system outcomes (e.g. ALC bed reductions¹⁹) and shifted the focus from residential care beds to assisted living in supportive housing, (with a total population of 1 million people, the Health Authority is creating 4,000 affordable, assisted living apartments for seniors and persons with disabilities with a budget of \$380M for shelter and affordable housing in 2008.)²⁰ Residential care beds decreased by 25-30%; ALC beds were reduced from 12% to 6% and 17 in-patient hospital beds were freed up.²¹
- In 1988, Denmark passed legislation limiting the construction of new long-term care facilities. Denmark's health and social services are now provided according to need wherever people reside. As a result of this policy, the number of nursing home beds decreased by 30% from 1987 to 1997. In that same period the number of supportive housing units increased by 250%.²¹ This strategy also supports the philosophy of people with disabilities over time being able to age in place – at home.
- Utilizing respite units in supportive housing alleviates ALC bed pressures and decreases wait times in ERs.²³

Health services like acute care which reflect a medical model of health care, where people are assisted with an acute illness or people are treated to recover from diseases are not the kinds

of services that persons with disabilities need on an ongoing basis. Persons with physical disabilities need Attendant Services for their lifetime, and need supports in order to be engaged in employment, education and volunteer work so they can be productive and contributing citizens. Affordable housing, physical accessibility, health & wellness programs and income supports need to be in place.

CONSUMER PROFILE:

Jamie and Alison Assisted Living in Supportive Housing, Cheshire - London

Jamie and Alison both have Cerebral Palsy with Jamie using a wheelchair. Before they married, Alison lived with her parents. Jamie had lived with his parents until finding a new way of independence, moving out on his own into one of Cheshire's supportive housing units in London. "I was getting older and Mom and Dad were getting older too," Jamie says. "My needs were changing yet I still wanted to maintain my independence. Alison and I have many friends here and heard great things about the building. That, with the excellent, friendly, helpful staff made the decision to move here on my own very easy. It feels very complete having Alison with me now."

¹⁸ Sandra Carpenter, *In the Stream*, Summer 2003, Feature: "Defeating Apathy Attitudes & Mindsets"

¹⁹ ALC (Alternate Level of Care) is defined as hospital beds being occupied by persons who are not or no longer in need of acute care but remain in hospital because there are no supports to get them home or get the services they need there or, if required, in other settings like long-term care homes.

²⁰ Press Release, Vancouver Coastal Health website, May 23, 2007.

²¹ Nancy Rigg, Executive Director, Community Care Network, Vancouver Coastal Health, Presentation at the Supportive Housing Symposium, October 15, 2007, Richmond Hill, co-sponsored by the Canadian Research Network for Care in the Community and the Ontario Community Support Association.

²² Eigil Boli Hansen, Professor of Economics, Institute of Local Government Studies, Denmark, Presentation at the Supportive Housing Symposium, October 15, 2007, co-sponsored by the Canadian Research Network for Care in the Community and the Ontario Community Support Association.

²³ Supportive Housing providers in Ontario who have been funded for respite units have been able to divert consumers who would have otherwise ended up in the hospital or can expedite discharge from the hospital after a short-term illness.

E. Chronic Diseases & Aging Among Persons with Disabilities

The Canadian Council for Social Development in 2004 released a Fact Sheet #14 entitled *Persons with Disabilities & Health*. It highlights that the greatest difference between persons with or without disabilities is the rates of arthritis/ rheumatism. It shows that about two-thirds (66%) of women with disabilities aged 65 and older reported arthritis/ rheumatism, compared with 39% of their non-disabled counterparts. Close to one-half of senior men with disabilities (48%) reported arthritis/ rheumatism, compared with less than one-quarter (23%) of their non-disabled counterparts.

Diabetes is also an issue for persons with disabilities, especially as they age:

"Persons with disabilities are more likely than those without disabilities to have diabetes, and this is particularly pronounced among seniors. Among senior men with disabilities, nearly one in five (19%) reported having diabetes, compared with 12% of their non-disabled counterparts.

Among senior women with disabilities, 14% had diabetes, compared with 9% of their non-disabled counterparts." [CCSD 2004, p. 7]

Other conditions and diseases in addition to those above, which are more likely to have an impact on seniors are high blood pressure, with a 10% higher rate for persons with disabilities, and heart disease, with a 15% higher rate in persons with disabilities that are 65 years of age and over. It is also known that persons with physical disabilities acquire age-related diseases at a much earlier age – approximately 50 years of age.

It will be important that health and wellness programs for persons with disabilities are promoted as part of any strategy to address the needs of persons with disabilities in the interests of managing the provincial health care costs and obtaining the best population health outcomes in Ontario.

F. Wait Lists for Attendant Services in Ontario

Wait Lists are mounting, as are the length of time people have to wait. As a result, people are inappropriately living in long-term care homes (which are inappropriate locations for a non-seniors population), and are also in hospitals and complex continuing care hospitals at much higher costs to the government.

For 12 years until 2003 there were virtually no funding increases to base budgets for community support services in Ontario which not only has affected the level of service, it in fact has eroded the infrastructure of agencies – ending up with a net loss after cost of living adjustments of 23%. This year the increase is 2.25% which is equal to the Consumer Price Index. There are agency worker salary increases, mounting transportation and insurance costs, and increased staff training costs because of the high turnover due to the low wages in comparison to other health care sectors and the service industry. (For instance the Community Care Access Centres have received a 4% increase to their base budgets and the hospitals have received 4.9%, with the promise of more to come later in this fiscal year).

The Ontario March of Dimes is a provincial organization that provides Attendant Services across the province with offices in all but two LHINs. It has a centralized wait list with:

- 398 people waiting for Attendant Outreach Services, and
- 369 people waiting for Assisted Living in Supportive Housing

The 'known' wait lists for Attendant Services across the province can range from 4 to 10 years. The 'turnover' for attendant services is very low because people need these services for the rest of their lives. Many people do not bother to fill out application forms with such long wait times, so it is difficult to determine the true needs across the province.

John's Story: Yearning to be in the Community

At 29 years of age, John, who has Multiple Sclerosis (MS), has lived for 3 years in a chronic care facility because there is no age-appropriate housing options for persons with physical disabilities in his community. He is desperate to leave and live in the community with attendant services. Says John: "At the age of 29, I need to be out in the community, being productive and socializing, rather than sitting everyday on a chronic care floor..."²⁴

²⁴ "Finding My Place: Age-appropriate housing for younger adults with multiple sclerosis, MS Society, Ontario Division

- **CILT (Centre for Independent Living in Toronto), which manages the Project Information Centre (PIC) wait list for Attendant Outreach Services and Assisted Living in Supportive Housing in the Toronto area²⁵, has 900 people on the list. Of this total:**
 - 10% of the people are waiting in LTC homes, chronic care hospitals and in ALC²⁶ beds in hospitals which are needed for seniors and acute care patients.
 - Another 14% are living with their aging parents, and
 - 18-20% are over 65 years of age - 2 of whom are living with their elderly parents.
- **There are also over 453 people with physical disabilities on CILT's wait list for Self-Managed Attendant Services-Direct Funding across the province. Only 29 spots become available each year.²⁷**
- **Since 1989 when the Common Waitlist for Attendant Services was created in the greater Ottawa area, the wait list has grown 10 fold. Within this group are people who are unable to work or participate in social and recreational activities until they have the attendant services they need in place.²⁸**
- **In London, Cheshire, which provides both supportive housing and outreach services to 212 people, has a wait list of 137 people who have been waiting for years.**
- **The South East Community Care Access Centre (CCAC) in Smith Falls has tried to "patchwork" home & personal support to get services to persons with physical mobility disabilities, but the acute care model is insufficient and not the appropriate services.**
- **There is currently limited Attendant Services in places like the far north and the Renfrew County area. Ottawa providers are asked to go to communities like Almonte to try to help out. Demand exceeds current capacity.²⁹**

Hospitals and long-term care homes do not have staff with the expertise to serve persons with disabilities in the Independent Living model of service. Attendant Service providers are often asked by nurses for training in bowel routines and ask for attendants to support their clients with personal care and activities of daily living while in the hospital. In the case of long-term care homes, persons with disabilities are often placed in the Alzheimer/dementia care wings, because other parts of the institution do not have a high enough level of service for the unique needs of persons with disabilities.

A 2006 study by the Canadian Institute for Health Information (CIHI) found that 20% of resident Ontario hospital-based continuing care facilities were younger than 65, and the Canadian Healthcare Association found that 40% of complex continuing care facilities' residents were under 65 years of age and the number is increasing.³⁰

The Ontario Human Rights Code states: "Respect for the dignity of persons with disabilities is the key to preventing and removing barriers. This includes respect for self-worth, individuality, privacy, confidentiality, comfort and autonomy of persons with disabilities."³¹

CONSUMER PROFILE:

'Sam' PACE-Independent Living, Toronto

Sam is a tenant in a supportive housing unit for persons with physical disabilities in Toronto. He is 35-years-old with cerebral palsy and uses a wheelchair and an augmentative communication device. He directs the Attendant Services provided by PACE to meet his daily needs. Sam has been living in his own apartment which he shares with another person, since 1997. Staff is available 24 hours a day, but only go to his apartment at times agreed upon in advance. Sam uses about 6 hours of service/day.

Until the age of 21, Sam had lived at Bloorview Children's Hospital at which time he was discharged as his age disqualified him from eligibility for service there. Before he moved to PACE, he lived for 2 years at the Toronto Grace Hospital, a chronic care hospital - spending his days with seniors over 75 years of age or just sitting in the hallway.

Sam recently competed on a hockey team in the Canadian Electric Wheelchair national finals. "His passion is sports, he regularly attends baseball games, is active in his church, and enjoys concerts and other entertainment venues in the community.

²⁵ The Project Information Centre (PIC) at CILT in Toronto is the centralized point of access for individuals with physical disabilities applying for Attendant Services Outreach and Assisted Living in Supportive Housing in the Toronto area.

²⁶ ALC (Alternate Level of Care) is defined as hospital beds being occupied by persons who are not or no longer in need of acute care but remain in hospital because there are no supports to get them home or get the services they need there.

²⁷ CILT's Direct Funding Statistics, March 2007.

²⁸ "More than Ramps, Advancing Inclusion for People with Physical Disabilities Living in the Champlain LHIN", March 2007, VHA Health & Home Support, Ottawa, p. 7

²⁹ Ibid. VHA 2007

³⁰ "Finding My Place: Age-appropriate housing for younger adults with multiple sclerosis, MS Society, Ontario Division (CIHI), 2006, Facility-based Continuing Care in Canada, 2004-05, p.9; ²⁹ Canadian Healthcare Association Policy Brief #5, 2005. Stitching the Patchwork Quilt Together, p. 30)

³¹ <http://www.ohrc.on.ca/en/resources/factsheets/disability2>

The Costs of Service by Provider:

Service Location	Average Cost/Day
Hospital bed	\$1,200
Complex Continuing Care Hospital bed	\$900
Long-Term Care Home bed (up to 2 hours of care/day)	\$135
Community Care Access Centre (3 hours of care/day)	\$150
ATTENDANT SERVICES³²	
Assisted Living in Supportive Housing (average of 4 hours/day):	\$132
Self-Managed Attendant Service – Direct Funding: (an average of 5 hours/day):	\$87
Attendant Outreach (average of 2.5 hours/day)	\$80

Integrating services for persons with disabilities should be factored in to any strategy the Government or LHINs are planning or implementing, i.e. poverty reduction, the Aging at Home Strategy, the Diabetes Strategy, the Chronic Disease Prevention and Management Strategy, and provincial supportive housing ventures.

People with a permanent physical disability should receive individually-based funding for the Attendant Services that they will require for their lifetime. Funding should be determined based on an assessment of the individual Attendant Services need and regular re-assessment for the level of ongoing services required to maintain independence – the right preventative services to keep them out of the acute and long-term care systems. It would also ensure that people can contribute their maximum to their workplaces and communities. The funding

should then follow that individual, regardless of whether it is Self-Managed Attendant Service-Direct Funding, Attendant Outreach Services or Assisted Living Services in Supportive Housing. As well, base stabilization funding for service providers will also be needed to ensure the ongoing infrastructure and capacity to provide the Attendant Services needed.

CONSUMER PROFILE:

Darlene

Self-Managed Attendant Service-Direct Funding

Darlene is in her mid-forties and lives alone in a rental accessible unit. She receives funding for 144 hours of Attendant Services/month. This translates into about 4.5 hours/day.

Darlene is self-employed and her work takes her away from home on some occasions. When she requires Attendant Services while traveling, she hires locally by getting in touch with other self-managers within the area where she is travelling, through the Direct Funding Ontario Network of Self-Managers - a peer support network facilitated by CILT (Centre for Independent Living Toronto).

G. The OCSA Attendant Services Advisory Committee has four key recommendations for action by MOHLTC and the Local Health Integration Networks (LHINs).

- **Recommendation #1: that MOHLTC and the LHINs host a special forum** with a broad representation of attendant services consumers, service providers and relevant provincial associations to ensure the Ontario Government and the LHINs integrate the needs of persons with disabilities into any policy and program health system strategies being developed. This would include initiatives such as the Aging at Home Strategy, the Diabetes Strategy, the Chronic Diseases Prevention and Management Strategy, the Provincial Poverty initiative, the Accessibility for Ontarians with Disabilities Act and any provincial supportive housing enhancement plans. Recommendations from the forum could be referred to future Joint Work Groups to explore.

This Forum could address the unique demographic of Ontarians with physical disabilities with their need for a life-span strategy by exploring wellness models and innovative ways of delivering service. For example, the “Clustering Model” of service provides service to groups of consumers in the same geographic area in close proximity to

a supportive housing or Attendant Outreach service agency. The model is a cost effective way to expand services on a 24/7 basis without having to build bricks and mortar and provides a more stable income for Attendant Service workers who can serve a larger number of people because of their proximity to each other.³³

- **Recommendation #2: add the lengthy wait times for Attendant Services and Supportive Housing to the MOHLTC Provincial Wait List Strategy** and ask the Ontario Health Quality Council to report on progress. To address the wait lists for all Attendant Service programs would take \$73 million - \$10 million in each of the next three years and \$21.5 million in years 4 and 5 to allow time for the development of affordable housing stock. Supporting persons with disabilities at home will help reduce wait lists for acute care, complex continuing care and rehabilitation facilities and enhance the health status of aging family supports.

³² There is a wide variation in the costs/day in Attendant Services as some consumers, for instance, in supportive housing have very high needs, i.e. are technologically dependent and have 24/7 on-call and pre-arranged services.

³³ This model is already in place in a couple of locations, with requests for funding underway in other parts of the province.

- **Recommendation #3:** Institute individually-based funding for all persons requiring Attendant Services. Funding should be determined based on an assessment of the individualized services needed, with re-assessments and funding adjustments as conditions change. A secure level of ongoing services to maintain independence and base stabilization funding for service providers would ensure the ongoing infrastructure and capacity to provide the services needed.

When the Ministry of Community & Social Services (MCSS) embarked on the deinstitutionalization of persons with developmental disabilities in the 1990s, the dollars followed the individual. Persons with Acquired Brain Injury (ABI) also have individualized funding for the services they need.

- **Recommendation #4: MOHLTC should immediately provide an increase in funding of \$12 million/year in each of the next three years to the Attendant Services sector** to allow providers to be able to continue to deliver the same level of service to current consumers, to deal with existing consumers' increasing needs as they age and/or as their disability progresses. The funding would also be used to build on the current successes and innovative ways of providing quality, cost effective services. Community support services have lost 23% of their spending power in the last 10 years because funding has not kept pace with inflation. Efficiencies and cost-saving partnerships continue

but are not enough to keep up with costs like salary adjustments and climbing fuel prices.

The current provincial total funding for Attendant Services is \$150 million. MOHLTC funding increases to agencies over the years have been less than cost of living increases, (funding increased by 2% in 2002/03, 1.5% in each of the past 4 years, and will increase by 2.25% in 2008/09). Insufficient funding is eroding agencies' abilities to maintain their current infrastructure or continue to provide current service levels, let alone address lengthy and growing wait lists.

People with physical disabilities need to know that there is a foundation of support available to them. Conditions and structures need to be created that honour their choices. These building blocks would include:

- Independent planning and facilitation
- Portability of funds and supports
- Person-directed approaches and client-focused funding
- shared responsibility and accountability and
- economic conditions that enable full participation

"Equity for people with disabilities is based on the principles of choice, flexibility, control, portability, mobility and full community participation."³⁴

H. Next Steps

The OCSA Attendant Services Advisory Committee will:

- Meet with MOHLTC to recommend that it host, with the LHINs, a one-day Forum to discuss a Strategy to address the needs of persons with physical disabilities
- Working with local service providers and their board Chairs, meet with representatives from each LHIN to raise awareness about attendant service issues and work in partnership to address current consumer needs and begin to address the growing wait lists for service
- The OCSA Attendant Services Advisory Committee will commit to releasing an Ontario progress report on May 3, 2009 – the one year anniversary of the United Nations Convention on the Rights of Persons with Disabilities becoming legally binding.

The OCSA Attendant Services Advisory Committee believes that the recommendations made to establish a MOHLTC/LHIN Task Force to review the current and future provision of Attendant Services for persons with physical disabilities, enhance funding to address current consumer needs, deal with Attendant Service wait lists, and change the Attendant Services funding formula:

- Are in keeping with the Ontario Government's commitment to promote citizens' autonomy and self-determination
- Supports the LHINs new integrated community-focused direction
- Helps the Government reduce wait lists for health services
- Empowers consumer involvement and control of their own health
- Promotes services to people in the right place, by the right provider, at the right time, and at the appropriate price to taxpayers
- Could be an integral part of the Aging at Home Strategy, and
- Would achieve health equity

We look forward to provincial support from the Ontario Government and strong attention by the LHINs to the needs of persons with disabilities in their communities. Addressing Attendant Services issues for persons with disabilities is the right thing to do and will also help to reduce wait times for acute and long-term care for other Ontarians who need those services.

³⁴ Charton, J (1998), *Nothing About Us Without Us*, London, University of California Press. The Local Health System Integration Act, 2006 preamble supports this view: "The people of Ontario and their government...confirm their enduring commitment to the principles of public administration, comprehensiveness, universality, portability, accessibility and accountability..."

APPENDIX A: The Ontario Community Support Association's (OCSA) Attendant Services Advisory Committee

The goal of the Attendant Services Advisory Committee was to provide direction and advice to the Ontario Community Support Association related to the needs in the community

related to services for persons with physical disabilities, the primary focus being the need for enhanced and expanded Attendant Services across Ontario.

Committee Membership:

- 1 Sandra Carpenter, Executive Director, Centre for Independent Living Toronto (CILT) & consumer representative
- 2 Judi Fisher, Executive Director, Cheshire London
- 3 Lee Harding, Director, Ontario March of Dimes – provincial organization
- 4 Ian Parker, Manager, Direct Funding, CILT, Toronto & consumer representative
- 5 Terry Richmond, Executive Director, Cheshire Homes (Hasting & Prince Edward) Inc.
- 6 Valerie Scarfone, Executive Director, ICAN-Independent Centre and Network, Sudbury
- 7 Joanne Wilson, Executive Director, PACE-Independent Living, Toronto (and VP, Board of Directors, OCSA)

Ontario Community Support Association:

Lori Payne, Manager, Communications & Development
Cheryl Gorman, Consultant

In the production of this paper, consultations were held with a number of organizations, consumers, and key informants.

APPENDIX B The History of the Independent Living (IL) Model of Service for Persons with Physical Mobility Disabilities in Ontario

Before the advent of the Independent Living movement and the introduction of Attendant Services, most people with physical mobility disabilities would have remained in chronic

care hospitals, lived in institutions, or been cared for by family members long after the age when most non-disabled people would choose to live independently.

**Catherine Frazee, Professor
School of Disability Studies & Co-director
Ryerson RBC Institute for Disability Studies
in Toronto and a person with a
physical mobility disability:³⁵**

“Twenty-five years ago, the average Canadian thought it too expensive or impractical to make urban environments, buildings and services accessible to disabled people or to desegregate *‘public’* schools. Significant numbers of disabled workers, outside the protections of legislated employment standards, laboured in sheltered workshops for considerably

less than minimum wage. And by and large, the average Canadian was not troubled by this reality.

A quarter century later, according to a 2004 Environics poll³⁶, more than 8 in 19 Canadians believe that disabled people should be supported by public funds to live in the community rather than in institutional settings... Canadians believe that our governments have a major role to play in supporting persons with disabilities with quality health care, accessible transportation, adaptive technology and appropriate education.”

³⁵ In an address to the “End Exclusion Forum” in Ottawa in November of 2006.

³⁶ Environics, *Canadian Attitudes Towards Disability Issues*, 2004, Available: <http://www.sdc.gc.ca/asp/gateway.asp?hr=en/hip/odi/documents/attitudesPoll/index.shtml&hs=pyp>

MILESTONES³⁷

- The Independent Living Movement was born at the University of California Berkeley campus in the late 1960s by a group of students with disabilities and quickly spread throughout the United States, Canada and the world. It was a unique model which enables people with disabilities to direct their own services in the community.
- In the 1970s in Ontario, the Ministry of Community & Social Services began funding Independent Living services for persons with disabilities and established the first Support Service Living units (SSLU) in Ontario. Funding and program management for community support services, including Attendant Services, was transferred to the Ministry of Health & Long-Term Care in 1993.
- In 1981, the United Nations General Assembly declared the International Year of Disabled Persons, "heralding a global commitment to ensure people with disabilities share in the full benefits of citizenship."³⁸
- That same year a Parliamentary Committee on the Disabled and the Handicapped, released **Obstacles** "providing a roadmap for improvements in legislation, programming, public recognition, research and the physical accessibility to public buildings, including federal buildings, including federal offices, Parliament and the Government of Canada facilities abroad."
- In 1983 the Ministry of Community & Social Services initiated Attendant Outreach Services for persons with disabilities to live independently in their own homes.
- In 1994, the Ministry of Health & Long-Term Care, with the Centre for Independent Living Toronto (CILT), launched the Direct Funding Pilot Project. Self-Managed Attendant Service - Direct Funding enables persons with physical disabilities to hire, train, pay and manage attendants directly.
- Twenty- five years ago, a young man by the name of Justin Clark had to take on his parents in court to get permission to leave the institution he had lived in since age 2. Justin Clark used a wheelchair and did not communicate verbally. When he won the right to make his own decisions and moved into a house in Ottawa with three other people at age 20, he made history."³⁹
- In 1997 the Canadian Government released another report with the intent to "make disability issues a collective priority in the pursuit of social policy renewal."⁴⁰ ***In Unison: A Canadian Approach to Disability Issues*** was prepared by the Federal/ Provincial/Territorial Ministers Responsible for Social Services. John Lord, Judith Snow and Charlotte Dingwall in an article entitled ***Building a New Story: Transforming Disability Supports and Policies*** note that:
 - "In ***Unison*** has created an important value base for moving disability issues ahead in Canada. The principle of rights and responsibilities, empowerment and participation, and equality and inclusion create a sound framework for thinking about transforming existing policies and programs."
 - The Accessibility for Ontarians with Disabilities Act is passed by the Ontario legislature on June 13, 2005.
 - In March 2007, Canada signed the United Nation's Convention on the Rights of Persons with Disabilities. The Convention was ratified by the requisite number of UN countries on April 3, 2008 and **was legally binding effective May 3, 2008**. All parties in the House of Commons have unanimously committed to Canada ratifying the convention.

United Nation's Convention on the Rights of Persons with Disabilities

Article 19 - Living independently and being included in the community

Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities 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;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

- In 2007, the Honourable David Onley, Ontario's Lieutenant-Governor, became the first person with a physical mobility disability to be appointed to the position. Renovations are underway to make the Lieutenant-Governor's quarters at the Ontario Legislature accessible for persons with disabilities.
- In a March 15, 2008 article in the Toronto Star, Helen Henderson tells the story of Justin Hines, a young man with a physical mobility disability. Justin Hines has had two songs on the charts from his debut album.

"Twenty-five years ago, a young musician in a wheelchair might have been little more than a curiosity, a performer barred from many venues by a shortage of ramps and an oversupply of closed minds. Today, Hines has toured from London to Dubai with no problem."⁴¹

³⁷ Includes excerpts from "TRANSFORMATION: A New Lens for Looking at Disability Policy & Change in Canada", Compass, Judith Fisher, Executive Director, CHESHIRE, London, ON Canada.

³⁸ ***Accessibility for All: Eighth Report of the Standing committee on Human Resources, Skills Development, Social Development and the Status of Persons with Disabilities, Government of Canada***, October 2005

³⁹ Henderson, Helen, ***After 25 years of activism, the emphasis is finally on ability - not disability***, Article in The Star, March 15, 2008

⁴⁰ ***In Unison: A Canadian Approach to Disability Issues***

⁴¹ Henderson, Helen, see www.com/downloads.php.

APPENDIX C

A Day in the Life of an Attendant Outreach Services Consumer in Sudbury

The type of support provided by ICAN - Independence Centre and Network Outreach Attendant Services program is unique in both the amount and the flexibility of service.

The profile described below captures the range of support provided and the locations that services are provided in.

'Jill' is a young woman 35 years old who was born with Cerebral Palsy. As a result of her disability she requires assistance with all aspects of daily living including communication. She lives at home with her mother in a completely accessible home.

Jill attends Cambrian College working towards a General Science diploma and actively participates in the technically assisted learning centre at the local campus. While at school Jill is able to access the pre-arranged attendant services provided by ICAN - Independence Centre and Network. All personal care needs are met while enrolled in courses at the post secondary institution.

It is important for Jill to be able to have regular, reliable staff to meet all of her personal care needs as that is what allows her to pursue his goals and live her life. Jill requires support to get up in the morning, so by 6:00 a.m. the Independent Living Assistant is there to complete the routine of getting up which takes an hour and forty-five minutes to complete. Rising for

the day involves transfers using appropriate equipment to ensure comfort and safety. The early service makes it possible for Jill to take the Handi Transit to school or to pursue other recreational opportunities when school is finished or on break.

At the end of the day the Independent Living Assistant provides attendant support so Jill can retire for the evening complete with personal care needs met. As Jill uses augmentative communication device, service can take longer as there is the need to communicate and direct the care that is provided in her home.

Overall, Jill receives three to four hours of support per day from the Outreach Attendant Care program of ICAN - Independence Centre and Network. It must be noted that there are more extensive care needs that Jill has and those are provided by members of Jill's family.

There have been occasions where Jill has accessed the Supportive Housing respite unit in order to provide the family with the opportunity to travel out of town on family business. The respite unit offered a completely accessible environment while at the same time allowed Jill to have an experience living away from her parents. Unfortunately, two years ago the respite beds were closed due to lack of funding and the family had that support removed from their choice of service.

APPENDIX D

Attendant Service Providers Across Ontario Funded by MOHLTC (other than Self-Managed Attendant Service-Direct Funding)* - July 2008

* **Note:** Self Managed Attendant Service-Direct Funding whereby consumers are directly funded to manage their own attendants is administered by CILT (the Centre for Independent Living Toronto) for all of Ontario in partnership with the Independent Living Resource Centres of Ontario

**Codes: OAS: Outreach Attendant Services ALSH: Assisted Living in Supportive Housing
CSH: Cluster Supportive Housing**

Service Provider	Types of Services Provided	Cities
LHIN #1 - Erie St. Clair		
Association for Persons with Physical Disabilities (APPD)	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Windsor
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH) Attendant Outreach (OAS)	Chatham, Sarnia
LHIN #2 - South West		
Cheshire Homes of London Inc.	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Clinton, London, St. Thomas, Stratford, Woodstock
Participation House - London	Attendant Outreach (OAS)	London
Participation Lodge Grey Bruce	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Owen Sound, Hanover, Holland Centre
VON Canada - Middlesex-Elgin	Supportive Housing (ALSH)	London
LHIN #3 - Waterloo Wellington		
Guelph Independent Living	Supportive Housing (ALSH) Attendant Outreach (OAS)	Guelph
Independent Living Centre Waterloo Region	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS) University Attendant Service	Cambridge, Waterloo, Kitchener
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH)	Drayton
Participation House - Waterloo Wellington	Supportive Housing (ALSH)	Waterloo, Wellington
LHIN #4 - Hamilton Niagara Haldimand Brant		
Conway Opportunity Homes - Cheshire Homes	Shared Living (ALSH)	Hamilton
Halton Cheshire Homes	Shared Living (ALSH)	Burlington
Helen Zurbrigg Non Profit Homes Inc.	Shared Living (ALSH))	Hamilton

Niagara District Homes Committee for the Physically Disabled Inc.	Shared Living (ALSH)	Welland
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH) Attendant Outreach (OAS) University Attendant Services	Hamilton, Niagara Falls, Thorold, St. Catharines, Simcoe
Participation House Brantford	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Brantford
Participation House - Hamilton & District	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Hamilton, Stoney Creek, Binbrook, Burlington, Mississauga

LHIN #5 - CENTRAL WEST

Ontario March of Dimes (OMOD)	Supportive Housing (ALSH) Attendant Outreach (OAS)	Brampton, Fergus, Milton, Shelburne
Peel Cheshire Homes (Brampton) Inc.	Shared Living (ALSH)	Brampton

LHIN #6 - MISSISSAUGA HALTON

Joyce Scott Non-Profit Homes Inc.	Shared Living (ALSH) Attendant Outreach (OAS)	Milton
Nucleus Independent Living	Supportive Housing (ALSH) Attendant Outreach (OAS)	Mississauga, Toronto
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH) Attendant Outreach (OAS)	Mississauga, Oakville
Peel Cheshire Homes (Streetsville) Inc.	Shared Living (ALSH)	Mississauga

LHIN #7 - TORONTO CENTRAL

Bellwoods Centres for Community Living Inc.	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS) Transitional Living Program (ALSH)	Toronto
Canadian Paraplegic Association-Ontario (CPA)	Attendant Outreach (OAS)	Toronto
Clarendon Foundation (Cheshire Homes) Inc.	Supportive Housing (ALSH)	Toronto
Community Health Services - Canadian Red Cross	Attendant Outreach (OAS)	Toronto
Gage Transition to Independent Living	Transitional Living Program	Toronto
Nabors	Supportive Housing (ALSH)	Toronto
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH) University Support (ALSH)	Toronto

Three Trilliums Community Place	Supportive Housing (ALSH) Attendant Outreach (OAS) Work Place Outreach	Toronto
Tobias House Attendant Care Inc.	Supportive Housing (ALSH)	Toronto

LHIN #8 - CENTRAL

Access Apartments for Physically Disabled Adults in Toronto	Supportive Housing (ALSH) Attendant Outreach (OAS)	Toronto
Arts Carousel	Attendant Outreach (OAS)	Toronto
North Yorkers for Disabled Persons Inc.	Shared Living (ALSH)	Toronto
Ontario March of Dimes (OMOD)	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS) University Attendant Services (ALSH)	Toronto, Newmarket, Richmond Hill, Thornhill, Markham
PACE Independent Living	Supportive Housing (ALSH) Attendant Outreach (OAS)	Toronto
Participation House Markham	Shared Living (ALSH) Supportive Housing (ALSH)	Markham, Toronto, Thornhill

LHIN #9 - CENTRAL EAST

Kawartha Participation Projects (KPP)	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Lindsay, Peterborough
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH)	Oshawa, Whitby
Participation House Project (Durham Region)	Shared Living (ALSH)	Oshawa

LHIN #10 - SOUTH EAST

Cheshire Homes (Hastings-Prince Edward)	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Belleville, Hastings & Prince Edward, Picton
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH) Attendant Outreach (OAS)	Brockville, Leeds, Grenville
Providence Continuing Care Centre	Supportive Housing (ALSH) Attendant Outreach (OAS)	Kingston, Lennox, Addington, Frontenac

LHIN #11 - CHAMPLAIN

Algonquin College Attendant Services Carleton University Residence Attendants	Supportive Housing (ALSH) University Support	Ottawa
Community Health Services - Canadian Red Cross	Supportive Housing (ALSH) Attendant Outreach (OAS)	Cornwall

Disabled Persons' Community Resources (DPCR)	Supportive Housing (ALSH)	Ottawa
Ontario March of Dimes (OMOD)	Supportive Housing (ALSH) Attendant Outreach (OAS)	Nepean
Personal Choice Independent Living (PCIL)	Supportive Housing (ALSH) Transitional Living (ALSH)	Ottawa
VHA Health & Home Support	Attendant Outreach (OAS)	Ottawa

LHIN #12 - NORTH SIMCOE MUSKOKA

Simcoe County Association for the Physically Disabled (SCAPD)	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS) Cluster Living Support (CSH)	Barrie, Collingwood, Midland, Orillia
The Friends	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Bracebridge, Parry Sound

LHIN #13 - NORTH EAST

Access Better Living Inc.	Supportive Housing (ALSH) Attendant Outreach (OAS)	Timmins
ICAN - Independence Centre and Network	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Sudbury, Sudbury West, Manitoulin
Ontario March of Dimes (OMOD)	Shared Living (ALSH) Supportive Housing (ALSH) Attendant Outreach (OAS)	Elliot Lake, Sault Ste. Marie
Physically Handicapped Adults' Rehabilitation Association (PHARA)	Supportive Housing (ALSH) Attendant Outreach (OAS)	North Bay
Timiskaming Home Support/Soutien à domicile	Supportive Housing (ALSH) Attendant Outreach (OAS)	Timiskaming

LHIN #14 - NORTH WEST

HAGI Community Services for Independence	Supportive Housing (ALSH) Attendant Outreach (OAS)	Geraldton, Thunder Bay
Northwestern Independent Living Services Inc.	Supportive Housing (ALSH) Attendant Outreach (OAS)	Kenora/Rainy River Districts