



THE ALBERTA DISABILITIES FORUM

ADDRESSING THE NEEDS OF ALBERTANS WITH
DISABILITIES IN HOME, SUPPORTIVE AND LONG-
TERM CARE LIVING SETTINGS

March 1, 2011

Executive Summary

Who We Are

The *Alberta Disabilities Forum* is a group of 42 not-for-profit provincial organizations of and for people with disabilities who have come together to share information and ideas with the objective of speaking with a united voice on issues of importance to Albertans with disabilities. Through ADF's member organizations, we represent the perspectives of thousands of Albertans with disabilities.

ADF pulls together the collective expertise of its member organizations to develop service improvement strategies in a broad range of areas including health, housing, transportation, income support, employment, education, recreation and active living, and community inclusion. ADF working groups develop strategies to help overcome barriers that people with disabilities face.

Purpose

The purpose of *Addressing the Needs of Albertans with Disabilities in Home, Supportive, and Long-term Care Living Settings* position papers is to identify and address some of the issues that Albertans with disabilities experience in the continuing care system.

Each position paper

- Outlines the extent and nature of each issue
- Recommends solutions to address each issue

Home Living Settings

Quality of life is enhanced when people have the necessary supports and services to remain in their homes as long as possible. Home care services are crucial for supporting individuals to live independently in the community. There is a need for supports and services to be based on quality of care, continuity of services, delivery of care according to individual need, and stability of the home care support workforce. These elements are essential when providing home care supports required by persons with disabilities to maximize their independence and self-determination.

The following are some of the challenges that are experienced by people with disabilities when accessing home care services:

- Inability to receive home care services according to individual needs.
- Inability in rural areas to access home care services required.
- Home care assessments are based solely on medical needs and do not include employment, education, volunteering, transportation or quality of life.
- Inability to access necessary services such as homemaking, childcare, flexible scheduling, timely assessments, and self-managed care.
- Policies prevent portability within regions, and the inability to transfer home care services when moving to a temporary living arrangement such as a women's shelter.
- The critical shortage of home care staff creates barriers when accessing appropriate in-home care.
- There is a lack of training and retention programs for staff in home care.

- Community-based living for people with disabilities is often associated with increased responsibility for family caregivers. There is a need and demand for meaningful respite services to ensure that caregivers do not ‘burn out.’

Supportive Living Settings

The Government of Alberta defines supportive living as “both a *philosophy* and an *approach* for providing services within a housing environment. It provides a residential setting where people can maintain control over their lives while also receiving the support they need. Buildings and common areas are specifically designed to meet residents’ needs and to support their safety and security.”¹

The challenge is that many Albertans with disabilities residing in supportive living settings do not receive supports and services that meet their health, safety, and well being needs.

The following are some of the challenges that are experienced by people with disabilities in supportive living settings:

- Lack of knowledge about organizations that offer programs and services that would benefit residents in supportive living settings.
- Lack of services provided in supportive living settings, such as home care, forcing individuals to move to long-term care facilities.
- Current policies prevent portability of services within regions.
- Lack of home care workers to conduct assessments and provide services in rural areas.
- Many individuals in supportive living settings have limited income and experience out-of-pocket expenses for medications, foot care, laundry, cleaning, supplies, bedding, telephone, clothing, and food.
- Lack of appropriate staff/patient ratio at supportive living facilities.
- Shortage of supportive living spaces forcing individuals to move to long-term care facilities to have their health and accommodation needs met.
- Inability to find necessary information about policies, procedures, and services available to people who are accessing services in supportive living centres.
- Many supportive living facilities are old and in desperate need of upgrade and renovation.

Long-Term Care Living Settings

Provision of long-term care is a pressing problem. This issue has been impacted by immense demographic changes in the population, the increasing demand for long-term care facilities from an aging population, and the growing number of individuals with disabilities and progressive illnesses.

Alberta is facing concerns that many Albertans with disabilities and progressive illnesses in long-term care settings do not receive sufficient or age-appropriate supports and services to meet their health, safety, and well-being needs. In addition, people experience isolation as they lack the ability to be part of their communities.

The following are some of the challenges that are experienced by people with disabilities residing in long-term care living settings:

- A large number of young adults with disabilities currently reside in long-term care facilities without age-appropriate settings and programs.

¹ Alberta Seniors and Community Supports. (2007). *Supportive Living Framework*. Retrieved on September 30, 2010, from <http://www.seniors.alberta.ca/continuingcare/system/standardsframework.pdf>

- Many new initiatives are geared toward seniors and not towards younger people with disabilities.
- Perceptions that long-term care facilities house only seniors, so volunteer programs are geared toward this population.
- People in care facilities do not know what programs and community resources are available to them, and they become isolated from the community.
- The Government of Alberta provides a relatively comprehensive disability support system for people with disabilities up to the age of 18; however, when people with disabilities turn 18, programs and services become fragmented and uncoordinated.
- There is a lack of transitioning services to and from long-term care facilities.
- Lack of information about policies and procedures. Individuals and their families have to navigate through various departments to find out what they are eligible for to get their needs met.
- Lack of adequate supervision because of inappropriate staff-resident ratios in long-term care facilities.
- Residents are left in bed for longer periods because of staff shortages or inappropriately trained staff.
- Lack of privacy for residents fosters a diminished sense of dignity and a compliant/accepting attitude towards their situation of no privacy.
- Individuals receive one bath per week. This does not maintain health and hygiene levels appropriate for living in congregated settings. Residents have cancelled appointments and social engagements because it does not coincide with their bath schedule, and they feel self-conscious and unclean.
- People are being evicted from long-term care facilities because of an inability to pay for additional necessary services.
- Families sustain financial stress when a loved one is moved to a long-term care facility and two residences have to be maintained.
- Lack of transparent and consistent intake processes. The decision is often based on the discretion of intake personnel.

Solutions

Members of the Alberta Disabilities Forum understand that there are many complexities to the issues outlined above. The way ahead involves partnerships between government and community, and we are willing and interested in working with the Alberta Government to address these issues through the development of creative solutions to support an improved quality of life for Albertans with disabilities in home, supportive living or long-term living settings.

ADDRESSING THE NEEDS OF ALBERTANS WITH DISABILITIES IN HOME LIVING SETTINGS

Quality of life is enhanced when people have the necessary supports and services to remain in their own homes as long as possible. Home care services are crucial for supporting individuals to live in their own homes. There is a need for supports and services to be based on

- Quality of care,
- Continuity of services,
- Delivery of care according to individual need, and
- Stability of the home care support workforce.

These elements are essential when providing home care supports required by persons with disabilities to maximize their independence and self-determination.

The following chart describes issues experienced by Albertans with disabilities that choose to live in their communities, and it presents solutions proposed by members of the Alberta Disabilities Forum:

Issues	Current Situation	Solutions
<i>Home Care Services</i>	<ul style="list-style-type: none"> • People with disabilities are unable to receive home care services according to individual needs. • People with disabilities residing in rural areas are not able to access the home care services they require. • Home care assessments are based solely on the medical needs of people with disabilities. • People with disabilities are not able to access necessary services such as homemaking, childcare, flexible scheduling, timely assessments, and self-managed care. • Policies prevent portability within regions, and the inability to transfer home care services when moving to a temporary living arrangements such as women's shelters. 	<ul style="list-style-type: none"> • Home care services should be consumer directed, flexible, timely, and meet the needs of the individuals who are being assessed for the services, regardless of location. • Home care assessments should have a holistic approach and should promote full participation, independence, and quality of life issues. • Home care information and referral programs should be easily accessible and incorporated into information hubs such as the Alberta Supports service.
<i>Staff Support, Training and Retention</i>	<ul style="list-style-type: none"> • The critical shortage of home care staff creates barriers for people with disabilities when accessing appropriate in-home care. • There is a lack of training and retention programs for staff in home care. • The adoption of home support worker minimum competency standards has led many individuals to choose other professional opportunities. • Government wages are substantially higher than those paid by community agencies making it difficult for community agencies to attract and retain workers. 	<ul style="list-style-type: none"> • Enhance job scope, recruitment, training, education, accreditation, remuneration and other incentives for home care staff and personal care attendants. • Increase personal care attendant wages to be competitive. There must be wage parity among workers wages and benefits. • Develop a disability support worker advisory committee to address recruitment and retention of workers. • Attract more people from outside Canada to help alleviate the shortage of workers. Implement programs that provide cultural support for immigrant workers. In addition, create opportunities for programs such as the Personal Attendant Community Education program to be available to Albertans with Disabilities.
<i>Residential Access Modification Program (RAMP)</i>	<ul style="list-style-type: none"> • To access RAMP, the total gross household income must be \$36,900 or less (some child and spousal deductions are available). This earning exemption does not account for the additional cost of disability related expenses that people must pay (e.g. vehicle modifications, specialized equipment, and families' loss of income). Some individuals are forced to move inappropriately and prematurely to supportive living or long term care facilities or face the physical and social isolation of living in an inaccessible environment. • Individual funding ceiling for each RAMP grant (\$5,000) and lifetime funding restrictions. 	<ul style="list-style-type: none"> • Increase the RAMP total gross household income amount. When setting eligibility levels, consider the additional cost of disability related expenses that people must pay (e.g. specialized equipment, supplies, vehicle modifications, and families' loss of income). • Take into consideration the cost of home modifications and adjust the amount annually to reflect increasing costs. • Remove the 'lifetime' restriction on the RAMP program to allow people to apply to the program as changing needs and circumstances arise.

Issues	Current Situation	Solutions
<i>Alberta Aids to Daily Living (AADL)</i>	<ul style="list-style-type: none"> • Lack of coverage for certain necessary items (e.g. medical gloves, lubricant and tubing for catheter, cloth leg straps, ceiling tracks for lifts, and diabetic supplies). • The length of time a person must wait before being able to re-apply for certain items (e.g. one hearing aid per individual per 5 years). • Maximum allowed amounts for certain items (e.g. catheters) are not sufficient, and there is limited flexibility in items that are offered by AADL. • Lack of knowledge about services and products offered under the AADL program, AISH or DRES. 	<ul style="list-style-type: none"> • A gaps assessment of the AADL program should be completed. AADL clients should be involved in this gaps assessment. • The results from the Client Satisfaction Survey should be published and available to all interested parties. • Add repair and maintenance of equipment, especially power mobility aids provided by community agencies, to the list of benefits offered through the Special Needs Assistance program.
<i>Support for Family Caregivers</i>	<ul style="list-style-type: none"> • Community-based living for people with disabilities is often associated with increased responsibility for family caregivers. • There is a need and demand for meaningful respite services to ensure that caregivers do not ‘burn out.’ 	<ul style="list-style-type: none"> • Establish a provincial respite care program. • Recognize the critical role and stress on family caregivers. Ensure that the bulk of care is not delegated to family members who may be expected to work, support the family, and care for children. • Respite funding should be self-directed, highly flexible, and promote innovation. Funding levels should be sufficient to meet caregivers’ needs and methods of distributing funding for respite should promote flexibility. • There have been studies and pilot projects conducted in Alberta regarding caregivers and the recommendations from these studies should be implemented.
<i>Appeals and Transparency</i>	<ul style="list-style-type: none"> • Individuals attempting to access services such as home care, AADL, respite care, and accommodations experience barriers finding necessary information, policies, and procedures. • Lack of awareness about conflict resolution and communication strategies that would assist individuals with the appeal processes. 	<ul style="list-style-type: none"> • Information about policies and procedures should be incorporated into the Alberta Supports information hub. • Establish consistent conflict resolution and communication strategies to enable clients to understand and be more active and responsible consumers of services.
<i>Appropriate Housing</i>	<ul style="list-style-type: none"> • Housing is a critical issue facing low-income Albertans. Many spend more than 30% of their income on rent, and in some cases, become homeless because they cannot afford rising rental costs. • The Affordable Housing Task Force made excellent suggestions to address the housing shortage. • The Alberta Building Code requires that if Government of Alberta funding is provided for a residential project, a percentage of units are made ‘adaptable’ to meet barrier free design principles, but there is currently no definition of adaptable in the code. • Rent subsidy is not applicable to all forms of rental accommodation and therefore limits housing options for people with disabilities at a time of severe shortage of accessible and affordable housing. 	<ul style="list-style-type: none"> • Increase funding to the Direct to Rent Supplement Program that provides a housing subsidy to low income Albertans. • Implement the recommendations from the Affordable Housing Task Force to ensure that Albertans with disabilities have access to accessible, affordable, and safe housing. • Alberta Seniors and Community Supports should work with Alberta Housing and Urban Affairs and Alberta Municipal Affairs and members of the disability community to define what is meant by adaptable. • Rental subsidy policy should be determined by client need and circumstances and not by the type of rental accommodation. The policy can be seen as discriminatory and should be changed.

ADDRESSING THE NEEDS OF ALBERTANS WITH DISABILITIES IN SUPPORTIVE LIVING SETTINGS

The Government of Alberta defines supportive living as “both a *philosophy* and an *approach* for providing services within a housing environment. It provides a residential setting where people can maintain control over their lives while also receiving the support they need. Buildings and common areas are specifically designed to meet residents’ needs and to support their safety and security.”² The challenge is that many Albertans with disabilities residing in supportive living settings do not receive supports and services that meet their health, safety, and well being needs.

The following chart describes issues experienced by Albertans with disabilities when choosing to reside within supportive living settings, and presents solutions proposed by the members of the Alberta Disabilities Forum:

ISSUE	CURRENT SITUATION	SOLUTION
Community Supports and Resources	<ul style="list-style-type: none"> Lack of knowledge about organizations that offer programs and services that would benefit residents in supportive living settings. 	<ul style="list-style-type: none"> Designate a lead agency to coordinate services for people in supportive living settings. Establish information and referral or a central registry of available services that people can access, such as Service Alberta.
Home Care Services	<ul style="list-style-type: none"> Lack of services provided in supportive living settings, such as home care. Individuals are forced to move to long-term care facilities. Current polices prevent portability of services within regions. Lack of flexibility in service provision to allow for services to be provided in shelters, emergency situations, and vacations. Lack of home care workers to conduct assessments and provide services in rural areas. Lack of appropriate and timely home care services to allow for independence control, and quality of life. 	<ul style="list-style-type: none"> Provide services and programs to meet the needs of people in supportive living settings so they do not have to move to long-term care facilities. Coordinate services and programs within regions to ensure services can move with the person. Develop services that are flexible so that they can be accessed in various situations such as moving to a shelter, emergencies or going on a vacation. Develop programs to attract home care workers for rural areas. Home care services and assessments should be consumer-directed, flexible, and meet individual needs.
Additional Costs	<ul style="list-style-type: none"> Many individuals in supportive living settings have limited income and experience out-of-pocket expenses for medications, foot care, laundry, cleaning, supplies, bedding, telephone, clothing, and food. Families incur costs for travel when visiting family members in supportive living facilities. 	<ul style="list-style-type: none"> Provide funding for individuals in supportive living facilities to access items that cost extra (e.g. Modified AISH). Assist family members with travel expenses when visiting a relative in supportive living facilities.
Staff Training, and Retention	<ul style="list-style-type: none"> Lack of appropriate staff/patient ratio at supportive living facilities. Lack of appropriate disability training and knowledge. 	<ul style="list-style-type: none"> Enhance job scope, recruitment, training, education, accreditation, remuneration and other incentives for staff who work in supportive living centres.
Limited Supportive Living Spaces	<ul style="list-style-type: none"> There is a shortage of supportive living spaces forcing individuals to move to long-term care facilities to have their health and accommodation needs met. 	<ul style="list-style-type: none"> Increase the number of supportive living approved homes, provide builder incentives, promote universal design (enforce the Alberta Building Code), and establish policies regarding accessible unit minimums in new developments.
Policies and Practices	<ul style="list-style-type: none"> Inability to find necessary information about polices, procedures, and services available to people who are accessing services in supportive living centres. 	<ul style="list-style-type: none"> Create a central registry for programs and services that are available for individuals in supportive living settings, such as Service Alberta. Assure that policies and procedures are easily accessible for people with disabilities and their families. Include people with disabilities in supportive living settings as stakeholders for any policy development.
Facility Maintenance and Repair	<ul style="list-style-type: none"> Many supportive living facilities are old and in desperate need of upgrade and renovation. Many supportive living facilities lack cleanliness to meet the health and safety needs of residents. 	<ul style="list-style-type: none"> Develop funding/grants for upkeep of facilities. Enforce cleanliness standards in supportive living settings.

² Alberta Seniors and Community Supports. (2007). *Supportive Living Framework*. Retrieved on September 30, 2010, from <http://www.seniors.alberta.ca/continuingcare/system/standardsframework.pdf>

ADDRESSING THE NEEDS OF ALBERTANS WITH DISABILITIES IN LONG-TERM CARE LIVING SETTINGS

Provision of long-term care is a pressing problem. This issue has been impacted by immense demographic changes in the population, the increasing demand for long-term care facilities from an aging population, and the growing number of individuals with disabilities and progressive illnesses.

Alberta is facing concerns that many Albertans with disabilities and progressive illnesses in long-term care settings do not receive sufficient or age-appropriate supports and services to meet their health, safety, and well-being needs. In addition, people experience isolation as they lack the ability to be part of their communities.

The following chart describes issues experienced by Albertans with disabilities in long-term care facilities and presents solutions proposed by members of the Alberta Disabilities Forum:

ISSUE	CURRENT SITUATION	SOLUTION
<i>Age-Appropriate Accommodations and Services</i>	<ul style="list-style-type: none"> • A large number of young adults with disabilities currently reside in long-term care facilities without age-appropriate settings and programs. • Unsuitable definitions regarding what is considered as a young adult (18-65), and what is meant by age-appropriate living settings. • Lack of living settings that distinguish between individuals who are independent and those who are less independent, causing incompatibility issues among residents. • Many new initiatives are geared toward seniors and not towards younger people with disabilities. • Many safety issues and incidences of abuse are due to lack of supervision. 	<ul style="list-style-type: none"> • Define an appropriate age range for young adults and gear programs and services toward those individuals. • Create flexible, self-directed, and client-centered approaches to providing accommodations facilitating independence, compatibility, and age-appropriate programs/activities. • Ensure that new program initiatives include young people with disabilities. • Schedule meals, bathing, dressing, and going to bed to be flexible and meet the needs of the residents. • Create protection mechanisms for individuals who do not have the capacity to report abuse.
<i>Community Volunteer Programs and Resources</i>	<ul style="list-style-type: none"> • Inconsistencies in procedures to monitor volunteers' activities in long-term care facilities. • Perceptions that long-term care facilities house only seniors, so volunteer programs are geared toward this population. • People in care facilities do not know what programs and community resources are available to them, and they become isolated from the community. 	<ul style="list-style-type: none"> • Enhance and promote volunteer recruitment and training programs such as the Friendly Visitor Program and other similar programs delivered by community organizations. • Create a central registry of various programs and community resources that are available for people with disabilities in long-term care facilities. • Enhance and promote the CAP-C program sponsored by Alberta Seniors and Community Supports.
<i>Transitioning Services and Policies</i>	<ul style="list-style-type: none"> • The Government of Alberta provides a relatively comprehensive disability support system for people with disabilities up to the age of 18; however, when people with disabilities turn 18, programs and services become fragmented and uncoordinated. • There is a lack of transitioning services to and from long-term care facilities. • Current policies do not allow families to bring in staff to help their loved one living in a long-term care facility. • Lack of information about policies and procedures. Individuals and their families have to navigate through various departments to find out what they are eligible for. 	<ul style="list-style-type: none"> • Evaluate how well Government of Alberta programs support Albertans with disabilities through life transitions. • Create transition planning based on best practices for individuals entering and leaving long-term care facilities. • Establish cross-ministerial cooperation and collaboration between the various programs and services that support individuals in long-term care facilities. • Allow families to hire independent staff to assist their loved ones in a long-term care facility with additional care. • Provide and maintain access to all policies and procedures.
<i>Staff Training and Retention</i>	<ul style="list-style-type: none"> • Lack of adequate supervision because of inappropriate staff-resident ratios in long-term care facilities. • Residents are left in bed for longer periods because of staff shortages or inappropriate training. 	<ul style="list-style-type: none"> • Enhance job scope, recruitment, training, education, accreditation, remuneration, and other incentives for staff.

ISSUE	CURRENT SITUATION	SOLUTION
<i>Safe and Clean Accommodations</i>	<ul style="list-style-type: none"> • Lack of accessible long-term-care facilities. • Inability to maintain proper hygiene for residents and cleanliness of the facilities. • Lack of privacy for residents who have a diminished sense of dignity and a compliant/accepting attitude towards their situation of no privacy. • Individuals receive one bath per week. This does not maintain health and hygiene levels appropriate for living in congregated settings. Residents have cancelled appointments and social engagements because it does not coincide with their bath schedule, and they feel self-conscious and unclean. 	<ul style="list-style-type: none"> • Enforce the Alberta Building Code and Universal Design standards so that long-term facilities are accessible. • Set up standards for hygiene and assure that they are enforced. • Establish and enforce procedures that support the privacy of residents. • Increase bathing frequency and accommodate a needs-based bathing schedule above a minimum standard to ensure adequate hygiene, health, and safety measures. • Encourage the development of private washrooms and bathing facilities.
<i>Additional Expenses for Services</i>	<ul style="list-style-type: none"> • People are being evicted from long-term care facilities because of an inability to pay for additional necessary services. 	<ul style="list-style-type: none"> • Assist individuals to access funding programs.
<i>First Bed Policy</i>	<ul style="list-style-type: none"> • Individuals who move to long-term care facilities are often separated from their families and support systems. • Families sustain financial stress when a loved one is moved to a long-term care facility and two residences have to be maintained. 	<ul style="list-style-type: none"> • Revise the first bed policy to focus on accommodating individual needs and exhausting all other continuing care options prior to long-term care placement. • Assist families with travel expenses when visiting their loved ones.
<i>Intake Policies and Procedures Discharge and Appeal process</i>	<ul style="list-style-type: none"> • Lack of transparent and consistent intake processes. The decision is often based on the discretion of intake personnel. • Families are told to do research and go through interviews, but are denied services because it is deemed the individual with the disability has highly complex needs. • Individuals with disabilities and their families do not know how to appeal discharge. 	<ul style="list-style-type: none"> • Establish transparent and appropriate intake policies and procedures that are consistent and implemented at all long-term care facilities. • Assist families in researching, going through interviews, and finding appropriate services for their loved ones with highly complex needs. • Establish an appeal process that is easy to understand and follow.

Members of the Alberta Disabilities Forum understand that there are many complexities to the issues and solutions outlined above. We are willing and interested in working with the Alberta Government to address these issues through the development of creative solutions to support an improved quality of life for Albertans with disabilities in home, supportive and long-term care living settings.