

# ALBERTA DISABILITIES FORUM (ADF)

## CHOICE IN ACCOMMODATION AND CARE

### CONTINUING CARE PRIORITIES

---

January, 2007

The following tables are organized according to priority, with home living being the most desirable option, followed by supportive living and with long-term care facility living being the least desirable option. Within each table, **issues**, **solutions** and **priority ratings** are provided and where possible cross-referencing to the Standards documents.

#### Home Living

Issues	Suggested Ideas / Solutions	Priority Rating
<p>Inadequate Home Care Monthly Funding Maximum</p>	<ul style="list-style-type: none"> <li>• Review current monthly funding maximum which has not changed since 1991. Average employment earnings in Alberta have risen significantly since 1991 and the consumer price index rose by more than 35% between 1991 and 2005. (Statistics Canada) Home Care wages need to reflect the cost of living and wages for similar professions. The monthly funding maximum should be replaced with a model that addresses each individual's needs and supports their choices.</li> <li>• Increase funding based on updated care plans particularly when an individual has the opportunity to stay at home if adequate care is provided.</li> <li>• Culture shift – staying at home should always be the first option that is exhausted before considering supportive or facility living.</li> <li>• Provide homemaking as part of Home Care services.</li> </ul>	<p style="text-align: center;"><b>1</b></p> <p><i>The current monthly maximum is insufficient for many young individuals with disabilities. If individuals want to remain at home they will require more support to keep up with rising costs of health services.</i></p> <p><i>This issue is closely tied to the staffing shortage crisis that will also need to be addressed simultaneously.</i></p> <p><i>The standards do not address this issue despite it being brought up by the disability community as a significant barrier to remaining in the community.</i></p>

<p>Staffing Shortage</p>	<ul style="list-style-type: none"> <li>• Funding – standardize pay to ensure that personal care attendants are being paid fairly and equitably. Review standards of pay for similar professions. Review pay inequities between institutions and community care for personal care attendants and nursing staff.</li> <li>• Increase the budget to Home Care to allow for increased compensation (at a competitive market rate), benefits and training for personal care attendants.</li> <li>• Policy must protect funding for adequate service to persons with progressive or permanent disabilities to alleviate competition for resources by growing Home Care case loads related to early discharge from acute care beds.</li> <li>• Develop personal care attendant training models to reflect a variety of care needs, for example, chronic health and disability, progressive disability. Ensure that the training is accessible and flexible so workers can continue to work while developing skills and knowledge.</li> <li>• Provide ongoing funding for education and training to ensure personal care attendants have the necessary skills and supports.</li> <li>• Offer an equivalency exam that experienced personal care attendants can take to demonstrate that they have the skills necessary to perform the job and to gain certification without having to take the accreditation program when it comes into effect.</li> <li>• Create pre-screening mechanisms for foreign caregivers.</li> <li>• Rework policy to allow foreign workers to access affordable training to ensure a minimum standard of education.</li> </ul>	<p style="text-align: center;"><b>2</b></p> <p><i>The priority for many individuals is to have the monthly funding maximum increased to ensure that they have adequate funding to stay in the community. However, if staff shortages are not addressed, the amount that an individual has for care will be irrelevant if there are insufficient numbers of staff to provide the support/care.</i></p> <p><i>The current standards do not address HR issues such as recruitment and retention.</i></p>
--------------------------	--	---

	<ul style="list-style-type: none"> <li>• Promote higher enrollment to personal care attendant courses through increased awareness, funding and incentive programs.</li> <li>• Develop and share a staff recruitment plan for personal care attendants.</li> <li>• Professional accreditation/standards – increase awareness and (prestige) by attaching meaning to personal care attendants’ profession and the work.</li> <li>• Partner with the colleges to promote higher enrollment in personal care attendant programs. Provide grants to institutions to ensure that training programs continue to be available. Training programs should have a community living focus (as opposed to institutional care/medical model).</li> <li>• Provide grants to people who have limited personal resources and are enrolling in the personal care attendant programs. Grants need to include cost of living and tuition. Grant recipients should be required to work a minimum of two years in the field.</li> <li>• Evaluate current agreements with contract care providers and assess gaps and unmet needs.</li> <li>• Provide incentives (e.g. increased wages, benefits, mileage, living allowances) for personal care attendants/healthcare providers to work in rural areas with severe staffing shortages.</li> <li>• Staffing shortages extend beyond personal care attendants to disability support workers for people with disabilities who do not require home care, but other types of disability supports (e.g. supports for people with mental illnesses and developmental disabilities). These solutions must also be applied to those who work in these areas.</li> </ul>	
--	---	--

	<ul style="list-style-type: none"> <li>• Ensure short and long-term planning is done to address worker shortages across the entire healthcare system.</li> </ul>	
Support for family caregivers	<ul style="list-style-type: none"> <li>• Ensure the family caregiver participates in the development of the care plan.</li> <li>• Recognize the critical role of family caregivers by providing adequate respite services to reduce burden and burnout. Respite should be viewed as an outcome rather than a service. Family caregivers should have options and choice when determining respite.</li> <li>• Develop resources to ensure that caregivers understand their rights and the available services for both the client and the caregiver.</li> <li>• Provide funding for essential services such as social work to assist families to deal with issues such as grief and loss.</li> <li>• Provide homemaking as part of Home Care services.</li> </ul>	<p style="text-align: center;"><b>3</b></p> <p><i>Many individuals are able to live in the community because they have strong family/friend caregiver support. It is critical that support is provided to the caregiver to ensure that they can continue to fulfill their role. The current standards do not address caregiver supports.</i></p>
Therapeutic Services	<ul style="list-style-type: none"> <li>• Ensure reasonable access to beneficial services in the home and/or community.</li> </ul>	<p style="text-align: center;"><b>4</b></p> <p><b>Continuing Care Health Services Standards</b> <b>Standard 1.8</b></p> <p><i>Based on the outcome of the comprehensive assessment that identifies individual health needs, the services to meet those needs should be available to individuals who live at home.</i></p>
Communication	<ul style="list-style-type: none"> <li>• The client and their family need to be a part of the development of the care plan, and the care plan must be regularly updated to ensure that it still meets the client and their family's needs.</li> <li>• The client and their family need to know who they can talk to about issues. For example; many individuals do not understand the role of their Home Care Coordinator and therefore do not utilize that important support.</li> <li>• Communication needs to be incorporated into the care plan to ensure that all parties have an opportunity to participate.</li> </ul>	<p style="text-align: center;"><b>5</b></p> <p><b>Continuing Care Health Services Standards</b> <b>Standard 1.5</b></p> <p><i>The standard advises that each level of continuing care has a concerns resolution process where the concerns and complaints of clients are reviewed and reasonable steps are taken to address these concerns.</i></p> <p><i>In addition to a conflict resolution process it would be very beneficial to add a communication strategy for clients. The strategy could include an organizational chart of all the professionals and organizations involved in the person's care. This would enable clients to be more active</i></p>

	<ul style="list-style-type: none"><li>• The client and their family can be fearful of reprisal if they complain about the health care service. Policies and supports need to be in place to ensure that clients are safe from negative consequences when voicing concerns.</li><li>• The client and their family must have access to information and services in a format that is accessible to them (e.g. interpreters for people who are hard of hearing/deaf, large print/Braille/computer format for individuals who are visually impaired/blind).</li></ul>	<p><i>and responsible consumers of the service because they would have an increased understanding of how the system works.</i></p>
--	--	--

## Supportive Living: Group Homes and Personal Care Homes (PCH)

Issues	Suggested Ideas / Solutions	Priority Rating
<p>Inadequate Home Care Monthly Maximum</p>	<ul style="list-style-type: none"> <li>Many individuals have to leave their family home because their care needs have increased. A popular option for young adults is to move to a personal care home instead of a long-term care facility. Currently in many personal care homes the funding for personal care services is equivalent to what an individual qualified for when living in the community. The Home Care funding maximum affects whether an individual can remain in a personal care home and the only option left is for an individual to move to a long-term care facility. The Home Care monthly funding maximum needs to be replaced with a model that evaluates the individual and their ability to live in the community or supportive living.</li> </ul>	<p style="text-align: center;"><b>1</b></p> <p><i>Adequate funding based on individual needs would allow individuals the option to remain at home with their family or move to supportive living. The funding must be reviewed immediately to ensure that young adults are being placed appropriately.</i></p>
<p>Fully Utilize Community Resources</p>	<ul style="list-style-type: none"> <li>Support utilization of not-for-profit services like peer support, friendly visitation, advocacy, education, wellness programs, support groups, etc. Such services should be offered before a person gives up home living.</li> </ul>	<p style="text-align: center;"><b>1 (a)</b></p> <p><i>This could be implemented immediately. A partnership with community organizations would assist government, the supportive living and facility based operators and the clients/residents. Many of the suggested programs are currently being offered by organizations and would benefit from a more formalized relationship.</i></p>
<p>Staffing Shortage</p>	<ul style="list-style-type: none"> <li>Funding – standardize pay to ensure that personal care attendants are being paid fairly and equitably. Review standards of pay for similar professions. Review pay inequities between institutions and community care (for personal care attendants and nursing staff).</li> <li>Ensure recruitment and retention of personal care attendants through increased wages and benefits.</li> </ul>	<p style="text-align: center;"><b>2</b></p> <p><i>This is a top priority that must be addressed within all three systems of continuing care. Without adequate staffing levels the other recommendations cannot be implemented as they are dependent on availability of staff.</i></p> <p><b>Continuing Care Health Standards 1.13</b>  <i>The document addresses qualifications but does not speak to staff recruitment and retention strategies or education and training opportunities.</i></p>

	<ul style="list-style-type: none"> <li>• Develop personal care attendant training models to reflect a variety of care needs, for example, chronic health and disability and progressive disability. Ensure that the training is accessible and flexible so workers can continue to work while developing skills and knowledge.</li> <li>• Provide ongoing funding for education and training to ensure all care providers have the necessary skills and supports.</li> <li>• Offer an equivalency exam that experienced personal care attendants can take to demonstrate that they have the skills necessary to perform the job and to gain certification without having to take the accreditation program when it comes into effect.</li> <li>• Create pre-screening mechanisms for foreign caregivers.</li> <li>• Rework policy to allow foreign workers to access affordable training to ensure a minimum standard of education.</li> <li>• Promote higher enrollment to personal care attendant field through increased awareness, funding and incentive programs.</li> <li>• Develop and share a staff recruitment plan for personal care attendants.</li> <li>• Professional accreditation/standards – increase awareness and (prestige) by attaching meaning to personal care attendants’ profession and the work.</li> <li>• Provide grants to people who have limited personal resources and are enrolling in the personal care attendant programs. Grants need to include cost of living and tuition. Grant recipients should be required to work a minimum of two years in the field.</li> </ul>	<p><b>Supportive Living Accommodation Standards</b>  <i>The standards address the conduct of employees but do not speak to staff recruitment and retention strategies or education and training.</i></p>
--	---	--

	<ul style="list-style-type: none"> <li>• Provide incentives (e.g. increased wages, benefits, mileage, living allowances) for personal care attendants to work in rural areas with severe staffing shortages.</li> <li>• Staffing shortages extend beyond personal care attendants to disability support workers for people with disabilities who do not require home care, but other types of disability support (e.g. people with mental illnesses and developmental disabilities). These solutions must also be applied to those who work in these areas.</li> <li>• Ensure short and long-term planning is done to address worker shortages across the entire healthcare system.</li> </ul>	
<p>Limited Personal Care Home Spaces</p>	<ul style="list-style-type: none"> <li>• Increase the number of Regional Health Authority approved homes. Increased spaces must support the needs of those with a wide range of disabilities including physical and developmental disabilities and people with mental illnesses.</li> <li>• Develop and offer incentives to attract the business community to own and operate personal care homes or assistive living arrangements and involve community partners who can inform their clients of these new options.</li> <li>• Develop a community development initiative with stakeholders to promote Universal Design and an Access Awareness Campaign to stimulate more community living options.</li> <li>• Ensure a percentage of new homes reflect the needs of people with a wide range of disabilities (e.g. mental illnesses and developmental disabilities.)</li> <li>• Develop a policy to ensure that all publicly subsidized housing in the province requires a minimum number of accessible units. The number should be based on a percentage that reflects the needs of the disability community.</li> </ul>	<p style="text-align: center;"><b>3</b></p> <p><i>Currently there are more individuals needing supportive living than there are spaces.</i></p> <p><b>Continuing Care Health Care Standards Introduction</b></p> <p><i>The introduction states that there has been a shift away from institutional or facility based living care to community-based residential options such as supportive living.</i></p> <p><i>To ensure that supportive living remains an option for young adults with disabilities it will be imperative to increase the number of spaces to accommodate the demand. It is important to point out that young individuals with disabilities are not able to move into seniors' lodges and many designated living facilities, so while there are 21,000 supportive living spaces in Alberta not all are appropriate or designated for young adults.</i></p>

<p>Limited or No Transparency regarding Policies and Practices &amp; Accountability</p>	<ul style="list-style-type: none"> <li>• The health regions and owner/operators do not always provide adequate information about the policies and practices related to the operations and functions of the personal care or group home.</li> <li>• Develop training manuals to ensure that owner/operators and regional health authority staff understand policies and practices.</li> <li>• Provide residents with information package that outlines all policies that affect them. Ensure process is in place to discuss concerns. Current models include: Abby Road and Art Space in Edmonton.</li> <li>• Ensure the reporting process is formalized.</li> <li>• Regional standards need to be implemented to ensure that all Personal Care Homes are operating in a similar fashion.</li> <li>• Standardize training for staff. Training should have a community living focus (as opposed to institutional care/medical model).</li> </ul>	<p style="text-align: center;"><b>4</b></p> <p><i>Without transparency regarding policies and procedures, residents feel vulnerable.</i></p> <p><b>Supportive Living Framework</b> <i>Advises that it does not aim to prescribe what housing operators should or can provide, or the criteria that should be used to determine entrance and exit criteria.</i></p> <p><b>Supportive Living Accommodation Standards</b> <b>Standard 29</b> <i>This standard addresses policies; procedures on access, services, charges and tenure are developed and maintained.</i> <i>It is critical that this process be transparent from beginning to end and that residents and family members understand the contracts, policies and procedures.</i></p>
<p>Facility Maintenance and Repair</p>	<ul style="list-style-type: none"> <li>• Provide funding allowance and support to ensure the upkeep of the homes. Due to the shortage of nursing staff, owners/operators are not dealing with maintenance issues that affect the wellbeing of residents. For example: the Residential Access Modification Program (RAMP), formerly known as the Housing Adaptation Program (HAP) should be reviewed to ensure grants reflect current adaptation costs and should be expanded to provide assistance to maintain supportive living accommodations.</li> </ul>	<p style="text-align: center;"><b>5</b></p> <p><b>Supportive Living Accommodation Standards</b> <i>The standards advise that the real property is maintained. With the shortage of spaces and little incentive for an individual to operate a PCH the option of the Government providing support for maintenance should be explored to encourage the development of more supportive living spaces.</i></p>
<p>Lack of Therapeutic Services</p>	<ul style="list-style-type: none"> <li>• Ensure reasonable access in the community and/or in the home.</li> </ul>	<p style="text-align: center;"><b>6</b></p> <p><b>Continuing Care Health Services Standards</b> <b>Standard 1.8</b> <i>Based on the outcome of the comprehensive assessment that identifies individual health needs, the services to meet those needs should be available to residents.</i></p>

<p>Communication</p>	<ul style="list-style-type: none"> <li>• Since the landlord is also responsible for ensuring that care is provided, there needs to be an appropriate complaints and resolution process both from a tenant and care recipient perspective.</li> <li>• Residents are fearful of reprisal if they voice their concerns. Policies and supports need to be in place to ensure that residents are safe when lodging a complaint.</li> <li>• The client and their family need to know who they can talk to about issues. For example; many individuals do not understand the role of their Home Care Coordinator vs. the role of the Care Manager at the Personal Care Home and therefore might not utilize the most appropriate support.</li> </ul>	<p style="text-align: center;"><b>7</b></p> <p><b>Continuing Care Health Services Standards</b></p> <p><b>Standard 1.5</b></p> <p><i>The standard advises that each level of continuing care has a concerns resolution process where the concerns and complaints of clients are reviewed and reasonable steps are taken to address these concerns.</i></p> <p><i>In addition to a conflict resolution process it would be very beneficial to add a communication strategy for clients. The strategy could include an organizational chart of all the professionals and organizations involved in the person's care. This would enable clients to be more active and responsible consumers of the service because they would have an increased understanding of how the system works.</i></p>
----------------------	---	--

**Long-term Care (LTC) Facilities**

Issues	Suggested Ideas / Solutions	Priority Rating
Staffing Shortage	<ul style="list-style-type: none"> <li>• Ensure recruitment and retention of personal care attendants through increased wages and benefits.</li> <li>• Develop training models for personal care attendants/nursing staff to reflect a variety of care needs, for example, chronic health and disability and progressive disability. Ensure that the training is accessible and flexible so workers can continue to work while developing skills and knowledge.</li> <li>• Provide ongoing education and training to ensure all care attendants/nurse care staff has the necessary skills and supports to meet standards.</li> <li>• Offer an equivalency exam that experienced personal care attendants can take to demonstrate that they have the skills necessary to perform the job and to gain certification without having to take the accreditation program when it comes into effect.</li> <li>• Rework policy to allow foreign workers to access affordable training to ensure a minimum standard of education.</li> <li>• Standardize funding for personal care attendants/nurse care staff to ensure that staff are paid fairly and equitably.</li> <li>• Promote higher enrollment to personal care attendant and nurse care field through increased awareness, funding and incentive programs.</li> <li>• Provide grants to people who have limited personal resources and are enrolling in the personal care attendant programs. Grants need to include cost of living and tuition. Grant recipients should be required to work a minimum of two years in the field.</li> <li>• Develop and share a staff recruitment plan for personal care attendants/nurse care staff.</li> <li>• Professional accreditation – increase awareness and (prestige) by attaching meaning to personal care attendants' profession and the work.</li> <li>• Provide incentives (e.g. increased wages, benefits, mileage, living allowances) for personal care attendants to work in rural areas</li> </ul>	<p style="text-align: center;"><b>1</b></p> <p><i>This is a top priority that must be addressed within all three systems of continuing care. Without adequate staffing levels the other recommendations cannot be implemented as they are dependent on availability of staff.</i></p> <p><b>Continuing Care Health Standards 1.13</b>  <i>The document addresses qualifications but does not speak to staff recruitment and retention strategies or education and training opportunities.</i></p> <p><b>Long-term Care Accommodation Standards 31</b>  <i>The standards deal with HR policy and procedure.</i></p> <p><i>The development of LPN as a scope of practice greatly alleviated the burden on RNs for nursing care. This expanded scope of practice needs to be continued for both LPNs and more importantly, for nursing assistants, who deliver the majority of basic services to the resident/client (meals, washing, transfer, monitoring etc).  This is an urgent need, because the issues of staff shortages and staff to resident ratios are also attributable to available staff unable to assist the resident due to a limited scope of practice, which is not supported by medical or safety reasons</i></p>





<p>Care Provider to Resident Ratio (Allocation of staff hours per resident)</p>	<ul style="list-style-type: none"> <li>• Funding has to be based on individual needs – not the model for a medically stable, but fragile, senior.</li> <li>• Provide adequate funding based on care plans. If the ratio of staff was increased, care provider stress and burn out could be reduced.</li> <li>• The allocation of a standard number of hours, such as the current 3.6 hr, per resident is flawed. The assumption is that all residents can be treated according to a uniform standard which is not realistic. Residents in long-term care facilities have a wide variety of disabilities that require substantially different medical needs and attention. A resident on dialysis or who has autism will require several hours more attention than a resident with Alzheimer's.</li> <li>• Young persons with MS and other similar disabilities require more attention to medical and care needs in addition to activities.</li> <li>• Increase the number of paid hours per resident to reflect the varying needs of residents.</li> </ul>	<p style="text-align: center;"><b>2</b></p> <p><i>This issue is of equal importance as the need to deal with staffing shortages. This issue is closely linked with staffing shortages - if not addressed the use of standardized comprehensive assessment tools will be ineffective because there will not be enough staff to complete, implement, monitor, measure and assess an individual's health service needs on an ongoing basis</i></p> <p><b>Continuing Care Health Service Standards 1.8, 1.9, 1.10, 1.11</b></p> <p><i>If implemented, continuing care clients will have a "person centered" plan that is based on a client's needs.</i></p> <p><i>Increased number of staff and funding will not achieve desired outcomes if the staff is devoting large number of hours during peak times of the day or night to residents requiring complex medical support.</i></p>
<p>Age Appropriate Accommodations &amp; Disability Appropriate Services</p>	<ul style="list-style-type: none"> <li>• Self directed/client centered approach takes a holistic view of an individual's life factoring in their wellbeing i.e. age, projected length of stay at the facility, prognosis, facility longevity, status of other residents, etc.</li> <li>• Care schedule flexibility – a young person in care needs to have more control over their routine if they are to participate in the community outside of the facility. For example, use a different staffing model to allow for creative scheduling where shifts are changed to provide opportunity for individuals to sleep later and go to bed later.</li> <li>• Offer individual suites that would enable a person with a disability to be more independent. Amenities should be available that would be similar to independent living. This arrangement would provide the necessary privacy for individuals to pursue intimate relationships if they choose.</li> <li>• It is important to consider the length of stay at the facility for a</li> </ul>	<p style="text-align: center;"><b>3</b></p> <p><i>If appropriate funding and staff are in place, the client/resident should be able to expect that all reasonable efforts will be made to ensure that age and disability appropriate supports and accommodations will be offered and provided.</i></p> <p><b>Continuing Care Health Standards do not specifically refer to age and/or disability appropriate services and accommodations.</b></p> <p><b>Does the interRAI address this issue?</b></p> <p><i>The central purpose of supportive living facilities and long-term care facilities is the provision of quality health care services in a safe, comfortable, appropriate setting. (draft standards of care, 1.3)</i></p> <p><i>The needs of residents and their families must be considered in all aspects of the design and operation of supportive living and long-term care facilities. Facilities must make a concerted effort to provide opportunities for residents and their families to provide meaningful input and change.</i></p> <p><i>Expanded storage space needs to be allocated so that the move toward</i> 15 <i>greater quality of life, particularly for young persons, can be achieved.</i></p>

## Glossary

### **Personal Care Attendants (PCA)**

Otherwise known as Home Care Workers, Community Support Workers, Health Care Aids, Home Support Workers

Individuals, who provide personal care services and select health services in home living, supported living, and long-term care facility environments. PCA's also assist nurses in the provision of health services. PCA's are an unregulated/unlicensed group of workers, receive training on the job, and may or may not have graduated from a certification program.

(Supportive Living Framework, AB Government, June 2006)

Personal care services include assistance with the activities of daily living (e.g. bathing, personal hygiene, grooming, dressing, toileting, incontinence management), assistance with therapeutic regimes (e.g. range of motion, medication assistance and reminders, simple wound care, respiratory equipment, ostomy care), simple bedside care (e.g. mouth care, turning, application of lotions, therapeutic interventions for behaviour management and maintenance of health records. (Supportive Living Framework, AB Government, June 2006)

When working in home living environments, PCA's may also help with housekeeping, cooking, and laundry.