

ALBERTA DISABILITIES FORUM (ADF) ADDRESSING THE NEEDS OF SPECIAL POPULATIONS IN CONTINUING CARE ISSUES PRIORITIZATION SUMMARY

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Introduction

The Alberta Disabilities Forum (ADF), a coalition of 36 disability organizations who speak with a united voice on issues important to Albertans with disabilities, has formed a working and advisory group with the purpose of identifying and working collaboratively to address issues in continuing care. The ADF has asked the MS Society, Alberta Division to provide leadership on this issue on behalf of ADF members. The group was invited by the Executive Director with Alberta Health and Wellness Policy to submit a list of continuing care priorities pertaining to young adults with disabilities. The ADF working group undertook the task of elaborating on and prioritizing these issues. The following document summarizes and prioritizes these issues and possible solutions. A companion document “Choices in Accommodations and Care Priorities; Continuing Care in Alberta” is also provided which outlines issues and solutions in detail and is cross referenced to the Government of Alberta’s Health and Accommodation Service Standards implementation documents.

In creating this document, ADF recognized that “one size does not fit all’ and that different groups and people may perceive priorities differently depending on their circumstances. It is critical to recognize that individuals with different disabilities have different needs within the continuing care continuum. Central to this is the need for people to direct their own care; to have choices in their care and how they live. This being recognized, we believe we have achieved a reasonable level of consensus in creating this document.

This invited summary will assist Alberta Health and Wellness, Alberta Seniors and Community Supports and the Health Services and Accommodation Standards Implementation Committee to prioritize issues in continuing care for people, particularly young adults, with disabilities.

Continuing Care System

| Home Living | Supportive Living | Facility Living |
|---|--|---|
| Independent living in: <ul style="list-style-type: none"> • Houses • Apartments • Condominiums | Supported living in: <ul style="list-style-type: none"> • Group Homes • Personal Care Homes • Enhanced lodges • Assisted living (including Designated Assisted Living) • Apartments, condominiums with hospitality and/or health services | Long-Term Care Facilities: <ul style="list-style-type: none"> • Nursing Homes • Auxiliary Hospitals |
| Community and Home Care assessed health services | Community and Home Care assessed health services | Nursing home and auxiliary hospital health care services |

Background: New Health and Accommodation Service Standards

Four documents were developed after months of feedback to the MLA Task Force on Continuing Care from continuing care residents/clients and their families, industry stakeholders, facility operators and regional health authorities. These documents are:

- Supportive Living Framework
- Continuing Care Health Services Standards
- Long-Term Care Accommodation Standards
- Supportive Living Accommodation Standards

According to the Government of Alberta, the new standards lay the groundwork for a higher quality of life and health care for all Albertans receiving continuing care services in home, community and facility based settings. ***Unfortunately and importantly, many of the issues that affect young adults with disabilities have not been addressed in these documents.*** As well, the standards are focused on supportive living and facility living and provide little substance with regard to home living and the necessary health services to support that choice.

It is important to note that the issues and solutions outlined in these documents specifically address the recommendations outlined in Alberta's Health and Accommodation Service Standards implementation documents. As such, these documents cannot and do not attempt to highlight other areas in dire need of attention such as unique cultural considerations - including the significant concerns of aboriginal people, end of life care, and medical equipment and supplies.

We also have been unable to adequately address a number of disability specific issues that were brought forward in the development of these documents. Examples of these include addressing the needs of those with respiratory concerns such as ALS (e.g. the need for long-term care facilities to accept BiPap ventilation devices, and to ensure that staff are trained on these devices), and addressing the concerns of specific populations including people with mental illnesses and developmental disabilities. There is also a critical need to develop wings at long-term care facilities for populations with specific needs (e.g. younger individuals with MS and seniors who are deaf). These wings would be similar to those that exist for Alzheimer's patients. Placing persons with similar needs together in such an environment not only increases staff efficiency but speaks to the needs of people sharing their lived experiences.

While these issues have not been addressed in this document, we believe they are of critical importance and in need of immediate improvement across several Ministries and disability related programs.

Where to start?

Establishing the key focus areas when examining issues in continuing care is a significant challenge. Should the focus be on home support to ensure that individuals can remain at home or on improving supportive living and facility living? Under the current system, many individuals can reasonably expect to live in either type of situation.

After consulting with a significant number of individuals who rely on continuing care, it is clear that all three systems need to be addressed to ensure that, regardless of where an individual lives, they are provided with choices that enable them to live a life of dignity that is self-directed and meaningful. However, within this continuum, the priority for the Alberta Disabilities Forum is

for mechanisms, strategies and resources to be provided so that a person is afforded the opportunity and choice to remain in their own home. In the event that this first option is impossible, then a supportive living environment would be a natural second choice. Finally, we consider long-term care or facility living to be the least desirable and last option. Nonetheless, for those who are living in this setting, there are clearly a number of key issues that need to be addressed.

After considerable consultation, the following continuing care priorities were established. The priorities are rated according to their importance in the continuing care continuum as well as their level of priority under each of the continuing care options.

(A) Prioritized Issues – Home Living

1. Funding – Inadequate Monthly Maximum

The monthly funding maximum for Home Care has not changed since 1991 and remains at \$3,000 in spite of significant average employment earnings increases and a consumer price index increase of over 35% in Alberta in the last 15 years (Statistics Canada). Although there may be informal flexibility in allocations of Home Care funding, the official monthly maximum requires revision and should be combined with a new model of funding addressing individual choice and need.

Solution

Revise monthly Home Care funding maximum and adopt choice and needs-based model.

2. Staffing Shortage

The critical shortage of personal care attendant and nursing care staff is a key issue in the home living situation. A number of factors including the increased demand for home support workers and Alberta's current economic climate have resulted in a crisis situation for many seniors and people with disabilities who depend on staff for care and services. Many other issues are dependent on adequate staffing levels and are unlikely to be resolved if this situation remains. Key issues include staff being attracted to work in long-term care facilities where pay and benefits are better and the adoption of new home support worker minimum competency standards which could create a disincentive to engage in a field in which financial remuneration is an issue.

Solution

Enhance job scope, recruitment, training, education, accreditation, remuneration and other incentives for personal care attendants and nursing care staff.

3. Support for Family Caregivers (non-paid caregivers)

Improved support mechanisms for family caregivers are a major priority. Community-based living for people with disabilities is often associated with increased responsibility for family caregivers. There is a real need and demand for meaningful respite services to ensure that caregivers do not 'burn out.' It is equally important that the individual who requires care is provided with adequate care funding to ensure that their care needs are met. We must ensure that the bulk of care is not delegated to family members who may be expected to work and support the family or care for children, etc.

Solution

Recognize the critical role and stress on family caregivers, review and revise services and provide adequate funding and support services.

4. Therapeutic Services

It is critical that people with disabilities are able to access the therapeutic services they require. Budget cuts have greatly impacted people's ability to access these services. If the comprehensive assessment tool determines that an individual would benefit from therapeutic services, it is important that the funding and staffing are in place to ensure that this outcome is achievable.

Solution

Provide a holistic range of services (physical, occupational, recreational therapy, etc.) and incorporate these services into Home Care services planning.

5. Communication/Conflict Resolution

Client, caregivers (family) and care providers should be jointly involved in developing the care plan. Frequent and clear lines of communication are essential. As well, there must be an effective and efficient mechanism to deal with complaints that at the same time protects the interests of the individual receiving care.

Solution

Establish a team-based care planning approach, 'whistle blower' policy, and third party independent review. Develop a communication strategy to assist clients to understand the structure of the support system such as the role of the personal care attendant, nursing care staff, Home Care Coordinator, Emergency Response Team, etc.

6. Staff Support

This does not directly relate to residents but the offshoot would have a positive impact on them. If staff are well supported and are able to achieve their professional goals, they are better able to provide the best care possible. This issue directly relates to the issues around staff shortages.

Solution

Address staff to resident ratio and incorporate consultation time into care plan.

(B) Prioritized Issues – Supportive Living**1. Funding**

Increased funding (including increasing or eliminating the monthly maximum home care funding allowance) would allow individuals whose care needs are increasing to stay in the community through supported living rather than move to a long-term care facility.

Solution

Increase or eliminate Home Care funding maximum and utilize a needs-based method of assessment.

2. Community Resources

Many organizations currently offer programs and services that would benefit residents/clients who rely on continuing care. The programs and services could be offered to all continuing care clients and through partnerships could be tailored to meet the needs of different populations.

There are some programs that are small scale but very successful that could be enhanced with the support of resources.

Solution

Support and access health charity/not-for-profit services.

3. Staffing Shortage

See under Long-Term Care Facilities

Solution

See under Long-Term Care Facilities

4. Limited Supportive Living Spaces (Personal Care Homes)

It is imperative that the number of supportive living spaces be increased to accommodate the demand for service. If spaces are not increased and the monthly funding maximum for Home Care remains the same, there will be an increased demand for long-term care facility beds because individuals will not be able to access appropriate health and accommodation services to meet their needs.

Solution

Increase the number of RHA approved homes, provide builder incentives, promote universal design and access, and establish policy regarding accessible unit minimums in new developments.

5. Transparent Policies and Practices

The standards begin to address this issue. It is critical for residents and family/support systems to have a clear understanding of the policies. This piece is currently missing for many people in supportive living.

Solution

Provide access to policy documentation, develop training manuals, provide residents with information packages, formalize reporting and ensure standards are implemented.

6. Facility Maintenance and Repair

To encourage the development of supportive living residences it may be necessary to review how the Alberta Government and industry can work with operators to ensure that there is adequate funding for the maintenance and repair of facilities.

Solution

Develop funding/grant policy for upkeep of facilities.

7. Lack of Therapeutic Services

See under Long-Term Care Facilities

Solution

See under Long-Term Care Facilities

8. Conflict Resolution

See under Long-Term Care Facilities

Solution

See under Long-Term Care Facilities

(C) Prioritized Issues – Long-Term Care Facilities

1. Staffing Shortage

Staff shortages are not unique to young adults with disabilities or the continuing care system. The current staffing shortage has resulted in a crisis situation for many seniors and people with disabilities who depend on staff for care and services. If the staffing shortage is not addressed, seniors and people with disabilities will be less able to get their care needs met. Many other issues are dependent on adequate staffing levels and are unlikely to be resolved if this situation remains.

Solution

Enhance job scope, recruitment, training, education, accreditation, remuneration and other incentives for personal care attendants.

2. Care Provider to Resident Ratio

Closely linked to the need for more staff and not unique to young adults with disabilities, the low care provider to resident ratio significantly impacts people with a disabilities' opportunity to participate in activities of daily living. Many individuals have moved from their family home or supportive living to a long-term care facility because of increased care needs, yet these care needs are not being met at the facility.

Solution

Individual and care-plan based funding.

3. Age-appropriate Accommodations and Disability Appropriate Services

If staffing issues were addressed, this would be the number one priority because it deals with the issues that are unique to young people with disabilities. A self-directed and client-centered approach is necessary for young people to achieve quality of life while spending a lifetime in the continuing care system.

Solution

A flexible, self-directed, and client-centered approach to providing (a) accommodations facilitating independence and (b) age-appropriate programs/activities.

4. Bathing

This is a difficult issue to prioritize. For some this is a critical issue that requires immediate action; for others it may be a lesser priority compared to the need for therapeutic services or increased funding for health services. Individuals who receive only one bath per week consistently state that they would like to have additional baths. Clients have cited that they cancel appointments and social engagements because it does not coincide with their bath schedule and they feel very self-conscious and unclean.

Solution

Increase bathing frequency and accommodate a needs-based bathing schedule.

5. Therapeutic Services

Again this is a difficult issue to prioritize because for some it might be a concern and for others there are more pressing issues. For individuals who require therapeutic services it is critical to have access, and budget cuts have greatly impacted people's ability to access these services. If the comprehensive assessment tool determines that an individual would benefit from therapeutic services, it is important that the funding and staffing are in place to ensure that this outcome is achievable.

Solution

Provide a holistic range of services (physical, occupational, recreational therapy, etc.) and incorporate these services into care planning.

6. First Bed Policy

This policy has a negative impact on individuals who are facing a move to long-term care and will be separated from their family and support system. This is a traumatic time for many individuals so the transition should be as smooth as possible.

Solution

Revise the first bed policy to focus on accommodating individual needs and exhausting all other continuing care options prior to long-term care assignment.

7. Support for Family Caregivers (non-paid caregivers)

To ensure that residents have family caregiver support systems in place, it is necessary that support be provided or offered to the caregiver to help avoid burn out, stress and family breakdown. Young adults with disabilities are often forced to leave their family because their care needs have increased and putting enormous stress and strain on the relationship. This is a priority for individuals who want to maintain relationships, so again, it is difficult to prioritize because it would be dependent on the person's circumstances.

Solution

Recognize the critical role and stress on caregivers by providing adequate funding and support services.

8. Conflict Resolution

This is an important issue that must be addressed to provide residents with a sense of security and stability. The current standards only vaguely address this concern. Residents require a clear process that safeguards them from reprisal whether real or perceived.

Solution

Establish a 'whistle blower' policy and a third party independent review.

9. Staff Support

This does not directly relate to residents but the offshoot would have a positive impact on them. If staff are well supported and are able to achieve their professional goals, they are better able to provide the best care possible. This issue directly relates to the issues around staff shortages.

Solution

Address staff to resident ratio and incorporate consultation time into care plan.

Clearly the task of prioritizing continuing care issues is a difficult one. We recognize that there are several issues such as staffing shortages and funding that overlap the three domains of continuing care and, indeed, are not unique to special populations. Other issues are more specific and may require new ways of thinking and approaches if we are to truly address the needs of young adults with disabilities in the community. As well, the interdependence of a number of issues requires a broad based, comprehensive and integrated approach to finding solutions. Recognizing that one size does not fit all, additional consensus may have to be sought to determine what issues and solutions are achievable to ensure continuous progress.