

Alberta Disabilities Forum

Health Care System: The Need for Coordination, Cooperation and Integration

Presented by
Alberta Disabilities Forum

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Who We Are

The *Alberta Disabilities Forum* (ADF) 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 in a united voice on issues of importance to 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 supports, employment, education, recreation and active living, and community inclusion. ADF working groups develop strategies to help overcome barriers that people with disabilities face.

Core Recommendations

ADF welcomes Alberta Health and Wellness' pursuit of a new legislative strategy as it has the potential of improving health care access for thousands of Albertans. The rationale for change which provides scope to the Committee's mandate speaks directly to the need to see health in the broader social context as articulated by the World Health Organization. If this is the vision that guides the committee's work, then the principles and themes as stated are too narrow in focus. A broader vision and principle would be to build an integrated health and social delivery system that provides seamless access to health care, supports and services.

Our core recommendations to the Government of Alberta are to ensure that the new legislation is patient-centred, accessible to all, and supports Albertans in their communities.

Universal Access to Care

ADF requests that Alberta Health and Wellness uphold the principle of universal health care as described in the Canada Health Act. Every Albertan should be entitled to appropriate health and medical services that ensure quality, accessibility, timeliness, and safety.

The purpose of a universal health care system is to treat citizens equally so that each can access health care services without being marginalized through multiple tiers of health care services based on ability to pay rather than on need. An important aspect of Canadian society is that we be treated equally when it comes to basic health services, and we do not wish to see a class system of have- and have-nots when it comes to the health and wellness of our citizens. Albertans should not be placed in a situation that jeopardizes their health because of an inability to cover costs for health care services.

Patient-Centred Focus

The Alberta Disabilities Forum members support the patient-centered focus across a full and integrated continuum of health services from birth to end of life. We would like to be assured that people's medical concerns will not be overlooked or dismissed because of the current health care changes taking place now or in the future.

ADF requests that medical model and case management strategies give way to consideration of all factors when treating illness such as a person's physical, mental, and/or social conditions.

Community-Based Living

People should be able to age in their communities, and the Government must ensure that Albertans receive appropriate community-based services that allow aging in place. In order for this to take place, the Government must establish standardized evaluation tools and ensure that people have access to all services regardless of whether they are residing in urban or rural settings.

If the Government determines that the most appropriate type of service delivery is to contract various service providers, then it must guarantee that the contracted agencies are held accountable and be obliged to conform to standards that warrant appropriate service delivery and stringent safety measures under the public health care system. The Government must guarantee that there will be a seamless linkage between the needs of each Albertan and health care services in their communities.

The Government of Alberta must place safe guards in the health care system to ensure that Albertans are provided with care and advice by well-trained, certified medical teams. Medical teams must be evaluated on measured outcomes along with the help and assistance provided to those under its care.

Currently in the health care system, there is a lack of access to and fragmentation of services. At the time of diagnosis, there is no formal system of health care referral to individual- or community-based support services to help the family address the loss associated with career, income security, housing, transportation, and/or home care to name a few. Families get lost trying to navigate and access the maze of government programs and services that span several Ministries and may not be aware of other services available to them in the community.

Without the coordinated care, services, and supports required, people will not receive the level of care envisioned by the Minister's Advisory Committee. Where care is available, relatively small item omissions can create significant barriers.

Accessible Health Services

In addition to the long waiting times to see a specialist, one of the greatest challenges that Albertans with disabilities face, are inaccessible medical services, such as clinics, doctor's offices, medical labs, and the inappropriate equipment and apparatus' used to perform medical exams (x-rays, bone scans, mammograms, prostate exams). Furthermore, communication for deaf and hard of hearing, and visual impairment and blindness is almost non-existent.

Disability Education and Awareness

People with disabilities face attitudinal and systemic barriers almost every day from neighbours, friends, family, and the general public. This is also true in the health care system. The medical team and others working in the health care system are often unaware of the needs of people with disabilities, and studies have shown that, when in hospital, people with disabilities are more vulnerable and less understood by those in the very system designed to help them.

Home Care and Community-Based Supports

The unique circumstances of persons with disabilities and their families need to be recognized and addressed by the Home Care system. The members of the Alberta Disabilities Forum recommend the following initiatives:

- Allocate adequate funding, designated specifically for Home Care services, to ensure that the needs of clients with disabilities are met.
- Ensure Home Care support worker training addresses the unique needs of clients with disabilities in both home-based and facility settings.
- Support the rights of individuals with long-term disabilities by assisting them in their decisions to live where they choose, whether it is in their own home or a care centre.
- Develop strategies to improve the recruitment, training, and retention of Home Care support workers.
- Promote and support outreach teams that visit rural centers to share expertise in areas such as new technologies, rehabilitation procedures, assessment, and care plans.
- Design and implement recruitment and retention strategies that will enhance staffing for Home Care needs in rural Alberta. (e.g. support worker training programs, culturally focused support worker training programs on reserves, and travel bursaries for rural students to attend courses in larger centers)
- Provide newly eligible Home Care recipients and, where appropriate, their families with complete, clear, and fully accessible written explanations of all the services they are eligible for.
- Provide adequate resources to ensure that the provision of basic homemaking is an integral part of current Home Care services.

Respite Care Supports for Family Caregivers

In April, 2008, Alberta Health and Wellness contracted the Alberta Disabilities Forum to develop and undertake a Respite Care Demonstration Project to provide respite support to family caregivers across Alberta. The Project's goal was to produce evidence-based lessons to guide the future development of provincial respite supports.

"A funded program like this in the future would encourage many to think about their situation and take the necessary steps to care for oneself (sic)." – Comment from a project participant

Primary among ADF's learning is the knowledge that family caregivers of all kinds need relief, and that caregivers experience physical and emotional challenges regardless of the disability or illness for which they are providing care, their age and condition, or the nature of the family relationship (e.g. spouse, child, parent). These caregivers play a common role in Alberta's health system: sustaining community-based care; preventing hospital and long-term care placement; and enhancing the dignity and quality of life of persons with disabilities and chronic high dependence.

A large majority of family caregivers (86.6%) agreed that ongoing respite would help to sustain at-home care. This strongly states respite's importance to sustainable community-based care.

The Project represented collaboration between government, disability organizations, and individual caregivers across the province. It generated expertise and momentum throughout the community, and Alberta's government has an opportunity to involve community partners to further develop and implement respite supports.

The members of ADF recommend a Provincial Respite Care Program taking into consideration the lessons learned from the ADF Respite Care Demonstration Project:

- Respite funding should be self-directed and highly flexible.
- Assessment of caregiver needs should be simple and straightforward.
- Respite services should be defined broadly and promote innovation.
- Funding levels should be sufficient to meet caregivers' needs.
- Methods of distributing funding for respite should promote flexibility.
- Funding support for respite should emphasize accountability and transparency.

If there is a single lesson to be learned from the Demonstration Project, it is that there is a critical need for respite supports in Alberta. ADF's Demonstration Project modelled a flexible, community-driven respite program that benefitted caregivers and fostered collaboration across the province, and this momentum can and should continue.

*“We would be able to function as a family while still keeping my daughter out of hospital.”–
Comment from a project participant*

The way ahead involves evidence-based strategies and partnership between government and community, and more importantly, it recognizes family caregivers as essential participants in the health system. Family caregivers need support; they are not passive recipients. They play an essential role in community-based care, and an investment in respite is an investment in a supportive, inclusive and sustainable health system.

Continuing Care Supports

ADF strongly supports the concept of “aging-in-place” and agrees that if the necessary supports were available to them, most people would prefer to remain at home or in a home-like environment in the community rather than live in a long-term care facility. For those who cannot find the necessary supports, it is usually due to lack of Home Care services (nursing care, meal preparation, homemaking and child care), adequate funding for home modifications, accessible transportation, equipment, and meaningful responsive family caregiver respite services. Others may not have the natural supports such as family, friends or neighbours who are capable of caring for them beyond what is provided through health services.

For many young people living in care centres, there is a failure to provide a home-like living experience. Seniors facilities, such as nursing homes, were never designed to provide functionally appropriate housing. The success of Bethany CollegeSide care centre in Red Deer must not be overlooked. Residents who live there have expressed their gratitude at having the opportunity to live in an environment that encourages them to be active citizens in their community, acknowledges their need for age-appropriate programs, and food and other services are geared for individuals who have similar cognitive function.

Access to Medication

For persons with disabilities or chronic illnesses trying to access medications, the dominant barrier appears to be cost. Private insurance plans, as well as provincial and federal drug benefit programs, offer a way to get reimbursement for prescription medications. But Alberta Health and Wellness, AISH, Alberta Works, Alberta Blue Cross and private health insurers are unwilling to pay for certain types of medications ordered by physicians. These medications are often too expensive for an individual to pay on his or her own. As a result, the drug is either not taken or not taken as instructed.

A woman in her mid-30s began taking an anti-depressant drug recommended by her doctor three years ago. At the time, they were not on Alberta’s formulary. The woman went bankrupt paying for the medication. Being ill and embarrassed, she did not ask for advice on payment assistance. Unfortunately, no health professional took the time to offer information or advise her about funding options or social service programs that could assist her.

A 2003 Statistics Canada report identified Alberta's public/private drug plans as spending the third lowest amount of money per person among all provinces. As a percentage of total health expenditures, Alberta was also third lowest, spending just 13.9% of the total amount on drug expenses. The same study showed 21% of reimbursed drugs were non-prescription.

Beyond legalities, there is considerable evidence to validate more government spending in support of those who need drug therapy. Appropriate access to medication increases life expectancy, improves quality of life, and provides opportunities for people to be more productive at work or in the community. It is more cost-effective than hospitalization and has the potential to be sustainable within Alberta's healthcare system.

Alternative Therapies

More alternative, holistic therapies need to be recognized as effective and beneficial within the coverage parameters of the Alberta Health Care Insurance Plan. A 2007 survey of Canadians regarding the use of complementary and alternative medicine showed that most people choosing to use alternative therapies did so to prevent further illness from occurring or to maintain health and vitality. This is consistent with the experience of many persons with disabilities or chronic illnesses.

"My back pain only gets better with Robaxcet, lots of it and it is not covered under any health plan because it is an over-the-counter product. My doctors have tried everything but the relief I feel with Robaxcet is unique. If I need it and it is a medicine I do not understand why it is not covered simply because it can be bought without a doctor's prescription.

Virginia Oliveira, Albertan

Furthermore, a survey commissioned by the Fraser Institute showed that Canadians spent \$5.6 billion out of their own pockets in 2005/2006 on visits to alternative health providers. This is double the amount reported in 1997. An additional \$2.2 billion was spent out of pocket for books, medical equipment, herbs, vitamins, and special diet programs.

Clearly, Canadians are seeking alternative/holistic therapies at a rapidly growing pace. This trend is particularly strong in Alberta, where the survey found that Albertans are more likely to perceive value in alternative therapies than residents of other provinces.

Alternative therapies provided by regulated health professionals have proven health benefits, particularly for certain types of disabilities and chronic illnesses. But lack of public or private coverage prevents many persons with disabilities or chronic illnesses from accessing such therapies.

Alberta Health and Wellness has challenged Albertans to accept responsibility for their health and take an active role in managing their care. Expanding coverage of alternative therapies under the Alberta Health Care Insurance Plan and Blue Cross will lift a financial barrier and enable many persons with disabilities or chronic illnesses to manage their care more effectively.

Non-Group Drug Benefit

Raising the non-group program premiums as provided by Alberta Blue Cross may be fair and level the playing field for the marketplace but not for most Albertans with a disability or chronic illness. Current premiums are not affordable for those who have modest incomes and have on-going ancillary costs related to their condition (e.g. medical equipment, supplies, home and vehicle modification). Increasing the premiums will have a harsh impact on middle to lower income groups. It will result in less access to medication for more people.

Removing the Government of Alberta as first payer will have a negative impact on those individuals with a disability or chronic illness that pay for private and/or employer sponsored insurance coverage. It will make it difficult for them to overcome the limitations (annual or lifetime ceilings, high deductibles) of a single plan. What is needed is a guaranteed and transparent drug benefit program that transitions seamlessly from one payer to another, a system that is easy to understand and easy to follow.

Added living costs and insurance plan limitations faced by many Albertans need to be factored into any subsidy program equation. Considering a person's income and nothing else when determining premiums is too narrow a focus. The subsidy program should be reviewed and adapted to factor in disability-related costs.

Overall, increased premiums have the potential to impose greater costs on the health system. Studies and other sources have shown that restricted medication therapy minimizes health improvement, clinical outcomes are less favourable, and consumers use more outpatient services. Conversely, access to adequate and appropriate drug therapy reduces hospitalizations, improves quality of life, and results in people being more productive at work and in the community.

Drug Coverage for Individuals with Rare Diseases

ADF is concerned this expanded drug coverage plan is too restrictive. From our perspective, the decisions regarding coverage of catastrophic or orphan drugs should be based on individual need and circumstance rather than whether the person has a 'qualifying' disease.

While therapies to treat people with chronic conditions or disabilities may not amount to hundreds of thousands of dollars per year, some people do go without the medications they need because they are extremely expensive. Use of a rare disease category to define who qualifies for drug treatment violates the principles of universality and opens the door to discrimination by diagnosis. Drug policy should be based on inclusion, not exclusion.

If government insists on proceeding on this basis, it is strongly recommended that ADF or some other community representation be part of the panel that determines what will be included in the rare disease listing.

Timely and Transparent Drug Approval Process

A 120 day approval period in Alberta to sanction a medication after federal Common Drug Review approval is too long. The length of Alberta's proposed approval period is unnecessary given the thoroughness of the federal review. The federal process confirms the clinical benefits and cost effectiveness of any new medication and makes recommendations.

Given this rigorous review, Alberta should simply add all medication approved by the Common Drug review to the formulary. This would eliminate administrative layers, increase the speed of health services, reduce funding, and improve universal access.

Community Involvement in Medication Management Education

We are disappointed that the Alberta Pharmaceutical Strategy did not call for more involvement of health and wellness orientated community groups like those represented by ADF to help health professionals share information and provide education. Community groups are an underutilized resource that – once deployed – would incur minimal cost to the health system in the education of clients, members, and families.

The cost of underuse, misuse, and overuse of prescription medication in Canada is estimated to be two to nine billion dollars. Health professionals cannot attack this problem alone. Community groups must be involved if this waste and risk to health is to be substantially decreased.

Advisory Review Committee

In the new pharmaceutical strategy it was stated that Alberta Health and Wellness will create an advisory review committee which will be made up of government representatives, professionals and community organizations. ADF has requested information regarding this initiative and has been informed that the process to establish this committee has been delayed. ADF suggests that this committee be instituted as soon as possible because our member organizations could bring much needed expertise.

Access to Medication Recommendations

There is considerable evidence to validate additional government investment in support of those who need medication therapy. Studies have found it increases life expectancy, improves quality of life, and provides opportunities for people to be more productive at work or in the community. It is more cost-effective than hospitalization and has the potential to be sustainable within Alberta's healthcare system.

The following are recommendations by the Alberta Disabilities Forum members:

- Patient choice be increased and delays and coverage refusals be decreased by broadening the Alberta Health and Wellness Drug Benefit List to include physician prescribed medications deemed necessary for persons with disabilities or chronic illnesses. This would include medications that currently need special authorization and over-the-counter medications ordered by physicians.
- Expanding the Alberta Health Care Insurance Plan to include coverage for:
 - i. Proven alternative/holistic health care treatments chosen by patients and provided by regulated health professionals.
 - ii. Catastrophic or orphan drugs required by persons with disabilities or chronic illnesses.
- Education and counsel to persons with disabilities or chronic illnesses about medication coverage options be improved, particularly regarding the non-group coverage premium subsidy offered by Alberta Blue Cross. Community groups and member organizations like ADF should be used to share and disseminate information.

Recommendations for the Future

As you develop your new recommendations regarding the legislation please keep the following recommendations in mind.

- ADF members believe that we need to rebuild our delivery system based on improved coordination, cooperation and integration.
- ADF members encourage the Government of Alberta to focus on addressing the concept of patient and system navigation and include both health and community-based care and support services. There needs to be better utilization of community resources to enhance system sustainability and to secure the benefits of a cooperative approach maximizing efficient use of government resources while engaging volunteer and donor resources from the community.
- ADF members encourage the Government of Alberta to eliminate the under-utilization of community resources that place an unnecessary burden upon the health system. Government and health care do not have to do it all. There may be many areas where community-based and funded resources can significantly augment government and health services or perhaps replace them altogether.
- ADF members believe strongly that to ensure the best possible outcomes for people with disabilities, they must be involved in the development of policies, supports, and services that affect their lives.

The ideas brought forth in this document are on behalf of 42 provincial disability organizations that represent thousands of persons with disabilities in Alberta. We work toward “A United Voice” to make Alberta a leader in health care services for people with disabilities. We appreciate your willingness to consider our expertise as we work toward a sustainable health care system in this province.