

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 43 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.

The Principles

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, addresses the need to see health in the broader social context, as articulated by the World Health Organization. It is essential that the proposed principles establish a solid foundation with the purpose of building an integrated health and social delivery system that provides seamless access to health care, supports, and services. It is critical that the Committee recognize that health care must be patient centred, accessible to all, and support Albertans in their communities.

The members of ADF encourage the government to focus on a person- and family-centred health care system when considering principles for the revision of the Act. This culture shift must incorporate family members as they are essential to the health care continuum and care giving team. The move away from the needs of providers and institutions to the needs of the person and the family is crucial to engaging the person and the family as equal partners in the health care system. A vital component of this culture shift is defining health holistically incorporating physical, mental, and social well being and not merely the absence of disease or infirmity, as is recommended in the Minister's Advisory Committee on Health Report.

The government should incorporate the uniqueness of individuals and their health care needs in the principles. For example, a person with an episodic disease where the health care needs fluctuate requires flexibility in areas such as timely access to medication, aids to daily living, and care supports in their place of residence. Another example of flexibility is the application of health care technologies. A younger person with a disability with high health care needs may benefit from assistive technologies, whereas a senior might not have the same affinity for the technology.

It is vital for the new Act principles to integrate a culture of trust and respect and to include community organizations as partners in the health care service delivery system. The establishment of this partnership will enhance the sustainability of the system and increase quality care for people with disabilities and their families. Working better together, which includes community as partners within the spectrum of health care, is a philosophy that needs to be actualized.

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-centred 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.

The power of the patient charter lies in its ability to transform the current culture and hierarchy within healthcare from a traditional medical model with institutions and health care professionals at the centre to a fully integrated person- and family- centred model where a variety of disciplines of health care professionals and community organizations are actively involved and engaged.

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 live in their communities throughout their lives and the Government must ensure that Albertans receive appropriate community-based services that support aging in place. In order for this to happen, 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 are 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.

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 access to 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 they may not be aware of other services available in the community.

Without coordinated care, services, and supports required, people will not receive the level of care envisioned by the Minister's Advisory Committee on Health.

Accessible Health Services

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

Ensuring equitable access to timely and appropriate care is vital for all people despite their disease (both visible and invisible), ability, age, and where they live. Many health care services and strategies are geared to the senior's population. If we look at a holistic approach to health, then we should ensure the services and strategies embrace all ages, abilities, and diseases and that they are available in rural Alberta. The key to this principle is that there is a coordinated care, services, and support system in place so that the timely and appropriate care envisioned by this Act is available.

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 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, 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 care services.

For many young people living in care centres, there is 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, acknowledging their need for age-appropriate programs, food, and other services geared for individuals who have similar cognitive function.

Access to Medications

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.

There is considerable evidence to validate more government spending in support of those who need drug therapy. Appropriate access to medications 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.

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 of 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.

Recommendations for the Future

As you develop new principles for 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. There are a myriad of government departments and agencies delivering disability related programs and services resulting in fragmentation of delivery, inconsistency in policy and program development, wide variations in services and supports, unnecessary bureaucracy and expense, and lack of coordination across programs, regions, and organizations.
- ADF members encourage 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. 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 forward in this document are supported by 43 provincial disability organizations that represent thousands of people 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.