



THE ALBERTA DISABILITIES FORUM

BI-ANNUAL REPORT

APRIL 1, 2010 – DECEMBER 31, 2010

JANUARY 1, 2011

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ABOUT THE ALBERTA DISABILITIES FORUM

The *Alberta Disabilities Forum* (ADF) is a partnership of 40 non-profit provincial disability organizations that have come together to share information and ideas and to speak with a unified voice on issues of importance to Albertans with disabilities.

ADF influences policies and services through a number of activities including:

- Creating strategies to improve services for Albertans with disabilities
- Working with government to develop and improve policies and programs that affect people with disabilities
- Building partnerships
- Developing information packages
- Informing voters during elections
- Helping people with disabilities be heard - Nothing About Us; Without Us
- Promoting International Day of Persons with Disabilities

ADF also provides services for its membership including:

- Providing educational and networking opportunities
- Providing workshops on specific areas of interest
- Providing disability-related information and resources

Decisions made by ADF members reflect the needs of people with disabilities in Alberta, and, through the combined efforts of its members, ADF works to ensure these needs are met. Key issues are determined by the ADF membership, which makes its decisions by consensus.

ADF CORE BUSINESS AREAS

ADF has identified the following core business areas:

- Influencing Policies and Services
- Member Services
- Operational Excellence

INFLUENCING POLICIES & SERVICES

By *Influencing Policies & Services*, ADF creates positive change by connecting persons with disabilities to policy makers and presenting positions on issues taken by persons with disabilities and their community organizations. Public education is targeted not only towards legislators, but also towards citizens, who have the rights and responsibilities to make their voices heard.

Objectives within *Influencing Policies & Services*:

- Creating Strategies to Improve Services for Albertans with Disabilities
- Working with Government to Develop and Improve Policies and Programs that Affect Persons with Disabilities
- Building Partnerships

MEMBER SERVICES

Organizations that join the Alberta Disabilities Forum benefit from Member Services that ensure, as has regularly been recognized by our provincial government, that issues of consensus are organized, coordinated, and disseminated to key government officials and disability organizations. Community agencies often lack the capacity to collect, review, and analyze the information available. ADF provides these services to assist in raising awareness of issues facing Albertans with disabilities.

Objectives within Member Services:

- Developing Information Packages
- Informing Voters during Elections
- Helping People with Disabilities Be Heard, “Nothing About Us, Without Us!”
- Promoting International Day of Persons with Disabilities

OPERATIONAL EXCELLENCE

ADF exists to enhance and support the capacities of disability organizations by establishing standards of Operational Excellence – opportunities through which agencies may learn and collect the tools that are required for survival in today’s voluntary sector. Collectively, and for the benefit of the sector as a whole, ADF organizes opportunities for enrichment that agencies, on their own, would have neither the time nor the resources to organize. Additionally, ADF provides opportunities to support community organizations to connect, communicate, and collaborate in an environment where it is necessary and often difficult to accomplish.

OBJECTIVE: CREATING STRATEGIES TO IMPROVE SERVICES FOR ALBERTANS WITH DISABILITIES

Along with ongoing ADF activities, including responding to member requests and keeping ADF members abreast of disability-related information and events, each year ADF takes on a number of initiatives deemed important to ADF member organizations and ADF working groups. Listed below are some activities that ADF participated in from April 1, 2010 – December 31, 2010.

ADF HEALTH WORKING GROUP

The ADF Health Working Group, which has 6 member group representatives, met 8 times from April 1, 2010 – December 31, 2010. The members of the working group receive agendas and minutes for the upcoming meeting, two weeks prior to the scheduled meeting date.

ACTIVITIES COMPLETED DURING THE REPORTING PERIOD

In September, the Health Working Group produced a position paper titled *The Alberta Pharmaceutical Strategy Phase II: Lowering Pharmaceutical Expenditures*. The purpose of this document was to present ADF views regarding the proposed purchasing systems that are considered by the Government of Alberta.

On October 20, 2009, the Government of Alberta announced Phase II of the Pharmaceutical Strategy which deals with generic drugs and the role of pharmacists in Alberta. It was announced that “prices for new generic drugs will be reduced from 75 per cent of a brand name drug price to 45 per cent”¹. In addition, the government announced that it will provide more expedient access to brand name drugs and involve pharmacists in the patient-care system.

According to various reports, the Government of Alberta has been considering several mechanisms for lowering drug expenditures and enhancing the pharmaceutical system by

- a) bulk purchasing,
- b) reference based pricing/therapeutic substitution, and
- c) a pharmacy professional reimbursement model.

ADF welcomes Alberta Health and Wellness’ continuation with Phase II of the pharmaceutical strategy; however, members caution that these mechanisms for lowering pharmaceutical expenditures have positive and negative elements, and the health and well

¹Alberta Health and Wellness. *Pharmaceutical Strategy – Phase 2*
<http://www.health.alberta.ca/initiatives/pharmaceutical-strategy-2.html>

being of Albertans should never be compromised when making policy and regulation decisions.

ADF members caution the government that when bulk purchasing pharmaceuticals at competitive prices, there can potentially be a reduction in the availability of effective medications because cost will influence decision-making rather than patient outcomes and the quality and type of medication.

There must be a guarantee that the medications purchased in bulk are produced and labelled according to the standards set up by Health Canada. Generic drug companies state that medications are measured according to the rigorous standards of Health Canada; however, the Government of Alberta needs to ensure that the purchased medications are not only safe, but have the same molecular effectiveness as the brand name.

ADF members encourage the Government of Alberta to implement a competitive tendering method. A competitive market will allow for purchasing of a wider range of medications deemed necessary for the health and well-being of Albertans with disabilities. There must be assurances that no pharmaceutical company will be considered more favourable than another. Currently, there are court cases over fair, competitive tendering methods, which can lead to high administrative costs passed on to the consumer.

ADF applauds the decision of Alberta to join with other provinces in creating a system that will be cost effective and decrease administrative costs – savings that could potentially be passed on to the consumer.

Many Albertans with disabilities or chronic illnesses are wholly dependent on specific medications to function. In some cases, a similar or alternative medication (generic or from a different manufacturer) will not produce the same patient outcomes. In order to accept responsibility for their own health, patients must have access to medications that work for them. This needs to be recognized and accommodated.

The Government of Alberta needs to ensure that the health and well-being of Albertans with disabilities will be protected, and that life-sustaining therapies will be chosen for effectiveness and not cost. The government should not devise a system that divides higher and lower income Albertans on the ability to purchase medications.

ADF supports greater involvement of pharmacists in educating and protecting the health of Albertans. However, we have a concern about the level of authority this model may provide. For example, will a pharmacist be able to refuse a drug prescribed by a doctor? In implementing this model, patient choice should be protected and pharmacists should have a defined operating scope.

Outcome:

The position paper has been made available to the public and members of the ADF Health Working Group are in the process of setting up meetings with government officials.

ACTIVITY COMPLETED DURING THE REPORTING PERIOD:

Position paper *Health Care System: The Need for Coordination, Cooperation, and Integration*.

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 Advisory Committee on Health'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.

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.

The following recommendations were stated in the position paper:

- 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.

Outcome:

The working group members submitted the position paper to the Advisory Committee on Health led by MLA Fred Horne.

Performance Indicator for the ADF Health Working Group during the reporting period:

ADF presented the position paper on July 28th, 2010 before the Advisory Committee on Health.

ADF EMPLOYMENT WORKING GROUP

The ADF Employment Working Group, which has 10 members, met 7 times from April 1, 2010 – December 31, 2010.

ACTIVITY COMPLETED DURING THE REPORTING PERIOD:

Members of the ADF Employment Working Group completed a position paper *Access to Employment Supports and Services*.

People with disabilities require equal access to employment and career opportunities to live independently and make contributions to their communities. Many face challenges when seeking employment, including difficulty accessing employment supports and services needed to find and maintain employment.

The position paper outlines the challenges and possible solutions on the following:

- Transitional planning from school to workforce
- Attitudinal barriers
- Accessibility, alternative forms of communication, and assistive technology
- Assessment and intake
- Career and development
- Employment supports
- Government policies and procedures
- Long term supports
- Information and referral

The ability to work goes far beyond economic advantages: integration into the community, acquiring a sense of confidence and belonging, and workplaces that demonstrate a commitment to full citizenship and enhancement of quality of life. Members of the Alberta Disabilities Forum ask the Government of Alberta to enhance and maintain supports and services that are needed by people with disabilities.

Outcome:

Members of the working group are planning to meet with various government officials and stakeholders to discuss issues that are affecting Albertans with disabilities when seeking employment.

Activity completed during the reporting period:

Members of the Employment Working Group are working on a position paper *Hiring of People with Disabilities*. People with disabilities demand equal access to employment and career opportunities to make contributions to their communities. However, many people with disabilities face challenges when seeking employment opportunities. These challenges

include misconceptions about hiring people with disabilities and accessing supports necessary to maintain long-term employment.

Outcome:

Currently, members of the Employment Working Group are gathering information on best practices for hiring people with disabilities.

Performance Indicator for the ADF Employment Working Group during the reporting period:

Members of the Employment Working Group are developing position papers that will reflect the perspectives of ADF member organizations regarding employment improvements needed in Alberta for people with disabilities.

ADF CONTINUING CARE WORKING GROUP

The ADF Continuing Care Working Group, which has 11 members, met 8 times from April 1, 2010 – December 31, 2010.

ACTIVITY COMPLETED DURING THE REPORTING PERIOD:

Members of the ADF Continuing Care Working Group are working on creating a position paper that will address the continuum of care system in Alberta. In creating this document, ADF recognizes 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. The position paper will address issues in Home Living, Supportive Living, and Facility Living.

Outcome:

Members of the working groups are conducting research and planning to meet with various government officials and stakeholders to gain a better understanding of the issues affecting Albertans with disabilities.

Performance Indicator for the ADF Continuing Care Working Group during the reporting period:

Members of the Continuing Care Working Group are developing solutions to be recommended to the Government of Alberta for many of the challenges that are experienced by people with disabilities.

OBJECTIVE FOR THE PERIOD: WORKING WITH GOVERNMENT TO DEVELOP AND IMPROVE POLICIES AND PROGRAMS THAT AFFECT PEOPLE WITH DISABILITIES

One of the main objectives of ADF is to work with different government ministries to assist with the development of policies and initiatives that affect Albertans with disabilities.

Activity completed during the reporting period:

Members of the Alberta Disabilities Forum have sent letters requesting inclusion in different stakeholder committees sponsored by various ministries.

Outcome:

Through ADF requests, these delegates hold/have held positions on the following Government of Alberta committees that are working to improve services for Albertans:

Bev Matthiessen, Stakeholder Working Group, Setting the Direction for Special Education in Alberta, Alberta Education

Melita Avdagovska, Supportive Living Framework Review Team, Alberta Seniors and Community Supports

Performance Indicator during the reporting period:

Ongoing invitations to participate on various government stakeholder review teams.

OBJECTIVE FOR THE PERIOD: BUILDING PARTNERSHIPS

ADF builds partnerships with government, community organizations, and businesses to provide information about and support the inclusion of Albertans with disabilities.

During this reporting period, ADF has been establishing partnerships with Alberta Health Services, Alberta Health and Wellness, and Alberta Seniors and Community Supports. In addition, ADF has been working on establishing partnerships with Alberta Employment and Immigration.

OBJECTIVE FOR THE PERIOD: DEVELOPING INFORMATION PACKAGES

ADF creates information packages on topics important to Albertans with disabilities (e.g. AISH, healthcare home care, employment). These packages are used by member organizations and people with disabilities to raise awareness about problems and potential solutions.

Member organizations are encouraged to promote ADF position papers and educate their Members of the Legislative Assembly about issues facing people with disabilities in their communities.

OBJECTIVE FOR THE PERIOD: INFORMING VOTERS DURING ELECTIONS

During municipal, provincial, and federal elections, ADF distributes information packages outlining key issues for persons with disabilities. By educating the public and candidates about key disability issues, people with disabilities are encouraged to get involved in the democratic process.

During this reporting period, ADF encouraged its members to be involved during the municipal elections and inform candidates about issues that people with disabilities are facing in their communities.

OBJECTIVE FOR THE PERIOD: HELPING PEOPLE WITH DISABILITIES BE HEARD, “NOTHING ABOUT US, WITHOUT US!”

ADF members believe strongly that to ensure the best possible outcomes for people with disabilities, people with disabilities must be involved in the development of policies, supports, and services that affect their lives. ADF finds opportunities for and supports Albertans with disabilities to speak out and become involved with issues of concern to them.

During this reporting period, ADF has been involved in the development of the Alberta Health Act. We presented our issues to the Advisory Committee, and we had a follow-up meeting with Minister Jablonski and MLA Fred Horne.

OBJECTIVE FOR THE PERIOD: PROMOTING INTERNATIONAL DAY OF PERSONS WITH DISABILITIES

December 3rd marks International Day of Persons with Disabilities. “The annual observance of the International Day of Persons with Disabilities, 3 December, aims to promote an understanding of disability issues and mobilize support for the dignity, rights, and well-being of persons with disabilities. It also seeks to increase awareness of gains to be derived from the integration of persons with disabilities in every aspect of political, social, economic and cultural life” (United Nations, 2007).

ADF has been involved in the distribution of information regarding planned IDPD events throughout Alberta.

ADF and ACCD hold an annual open house to celebrate International Day of Persons with Disabilities.

OBJECTIVE: PROVIDING EDUCATIONAL, NETWORKING OPPORTUNITIES

ADF PRESENTATIONS

The ACCD executive director and the ADF provincial coordinator conducted these presentations upon request:

- Alberta Health and Wellness
- Alberta Health Services

ADF GENERAL FORUM MEETINGS

ADF members hold three business meetings per year. These meetings are an opportunity for our members to share information and ideas, and to provide direction on ADF activities.

Activity completed during the reporting period:

General forum meetings are also an opportunity for ADF members to learn from guest speakers about various initiatives and projects that are currently taking place. During the reporting period, ADF hosted two general forum meetings during April 1, 2010 – December 31, 2010.

Outcome:

Members of ADF had the opportunity to be informed about different ministerial initiatives and policies. Here is a list of the guest speakers during the general forum meetings for the reporting period:

- Reegan McCullough, Assistant Deputy Minister, Chair, Social Base Assistance Review (SBAR)
- Dr. Stephen Duckett, President and Chief Executive Officer, Alberta Health Services
- Ruth Hofer, Executive Director, Persons with Developmental Disabilities Program, Alberta Seniors and Community Supports
- Alberta Spinal Cord Injury Strategy Task Team
- Minister Thomas Lukaszuk, Employment and Immigration
- Dr. James L. Silvius, Senior Medical Director, Alberta Health Services
- Keray Henke, Deputy Minister of Education

ADF WORKSHOP

Currently, ADF is planning a workshop to be offered to our membership during spring 2011. Many issues of interest have been presented; however, there has to be extensive preparation and financial resources when setting up an event of this nature.

OBJECTIVE: PROVIDING DISABILITY RELATED INFORMATION AND RESOURCES

ADF WEB SITE

Activity completed during the reporting period:

In 2007, ADF purchased the Adobe DreamWeaver Program in order for the ADF Coordinator to do web updates. In this way, ADF can save money because it no longer has to contract services for web maintenance. The web site is accessible to those with a variety of disabilities and is much more current with ADF news and publications. ADF's staff member updates the web site and maintains current information.

Outcome:

Currently, visitors to the web site are able to access findings of the Respite Care Community Consultations and additional information about the ADF Respite Care Demonstration Project. In addition, individuals are able to access the various position papers completed by ADF.

Performance Indicator during the reporting period:

ADF purchased urchin services for the www.adforum.ca web site in September, 2009. From April 1, 2010 – December 31, 2010, there have been 48,346 hits on the ADF web site.

ADF MAILING LIST

ADF members and friends are sent regular, relevant e-mails that include print media, research articles, workshops, current news, upcoming events, government reviews, policy and/or program changes, job postings, and other disability-related information.

Currently there are 142 individuals/organizations that subscribe to the ADF mailing list.

ADF IN THE UPCOMING PERIOD

ADF has already started to plan an ambitious schedule to March 31, 2011. The next General Forum meeting is scheduled for March 24, 2011, and we are working on inviting speakers. Because of the increased number of members attending the general forum meetings, ADF applied and was successful in receiving grants from Pfizer and Rx&D to support our expenses for meeting rooms, refreshments, and interpreters.

In addition, ADF is looking at increasing participation of ADF members at ADF general forum meetings, whose offices are outside of Edmonton. We have been considering videoconferencing as a possible solution; however, the cost for setting up videoconferencing locations has acted as a deterrent.

The current ADF membership stands at forty member organizations. Regrettably, this year we lost three member organizations due to lack of payment of membership fees.

ADF has achieved remarkable success for more than a decade working with a large and diverse group of disability organizations, who have many similarities and differences, to speak on issues of united importance. The one core value that holds our members together is the belief that Albertans with disabilities can, should, and will be fully participating members of their communities and all of Alberta's society.