Alberta Disabilities Forum
Getting on with Better Health Care
Survey Response
November 2005

Action 1: Put an overall health policy in place

What do you think?

October 2005
Announce a new Health Policy Framework

Public Consultation on Health Policy Framework
While members of the Alberta Disabilities Forum (ADF) support the principle of an overall health policy in Alberta to set a clear vision for the future of our province's healthcare, the limited information on what this policy might include makes it difficult for us to respond at this time. As part of the October 2005 Health Policy Framework announcement, ADF members ask that a public consultation be held outlining what the Framework will include so that we are given the opportunity to respond to how it might best meet the needs of Albertans with disabilities.

Health Mandate beyond the Department of Health
ADF members believe that a Health Policy should look beyond the Department of Health and Wellness' specific health mandate to achieve optimal health outcomes. Adequate income support, housing and transportation are vitally important to the overall health of people with disabilities and, without proper access, can result in health being compromised (e.g. cannot get transportation to medical appointments, rent takes so much of a person's income they must cut back on food). To proactively address the overall health needs of people with disabilities, the Department of Health and Wellness should work closely with departments dealing with income support, transportation and housing to ensure that these areas are adequately addressed as part of an individual's health needs.

Provincial Standards of Care
ADF members believe a provincial health strategy should set province-wide standards to ensure consistent service levels from one region to another. While we appreciate that regional health authorities were created to provide the flexibility needed to allocate resources according to the unique circumstances that characterize each region, people with disabilities experience barriers to receiving consistent levels of service when moving from one region of the province to another.[1] This is due to differences in regionally set service levels in a number of areas (e.g. rehabilitation, home care, self-managed care). For those moving to another region, levels of service are not confirmed until a person has had an assessment in the new region. Without a guarantee of the same or a greater level of service in the new region, people with disabilities are deterred from taking the risk that their level of service will be maintained or improved. This inability to move results in people being 'trapped' in the region in which they live which can have severe consequences such as loss of employment, education, health circumstances, or support networks.

> *"I definitely feel that the services offered should be consistent throughout the province; my medical situation did not change when I moved, yet my services did."*
> -Home Care recipient

[1] Alberta Disabilities Forum. *Portability of Home Care Services.* July 2001.

Definition of Personal Responsibility within a Health Policy Framework

Our members voiced concern with the meaning of the term "personal responsibility" in the introductory paragraph to Action 1. Members of the ADF believe that "personal responsibility" should not be the major focus of an overall health policy. People play an important role in their health and should make the best choices possible no matter what their age, situation, or ability; however, we believe that an individual's health extends beyond the responsibility of the individual and his/her family to the community and our society as a whole. To appreciate this broader context, an overall health policy should not focus on personal responsibility without considering how our society supports each individual to achieve their optimal health.

Barriers to Better Health for People with Disabilities

For many people with disabilities, there are barriers that affect their ability to achieve better health (e.g. accessibility, level of support, nature of a disability). Further, the reality for many Albertans with disabilities is that their ability to earn an income is limited. While an individual may want to take steps to have a healthier lifestyle, the cost can be prohibitive (e.g. healthy foods, vitamins, recreational activities). As part of a strategy to provide greater opportunity for low-income Albertans to maintain a healthy lifestyle, the Alberta government should ensure adequate income support to offset the cost to buy healthier foods. To encourage a healthier lifestyle, free access to recreational facilities that are accessible and accompanied by adequate supports will also result in opportunities for better health.

In 2006

Develop a new Public Health Strategic Plan focusing on what needs to be done to protect the overall health of Albertans

Consumer Input into the January 2006 Health Services Plan

Health service provision is also an important area affecting many Albertans with disabilities. As part of the January 2006 Health Services Plan, we ask that ADF member organizations be given the opportunity to provide input regarding the health services Albertans with disabilities will receive, how quickly, and where. While we appreciate the expertise that health boards bring to service delivery, the consumer perspective also brings expertise.

Action 2: Improve Access and Efficiency

What do you think?

Members of the Alberta Disabilities Forum support increases to access and efficiency that result in better outcomes for Albertans. We congratulate the government for creating the Alberta Waitlist Registry, and we are encouraged by the pilot projects that are being launched.

Improving Access to Long-Term Care Funding in the Community

For individuals with permanent disabilities, access to long-term care services is as important as access to acute care services such as the hip and knee replacements and coronary artery bypass surgeries included in the pilot projects outlined in Action 2. Many people with disabilities do not receive adequate long-term care services such as home care, self-managed care, rehabilitation and mental health services in the community. The lack of these services makes meeting daily needs difficult and can lead to a number of negative outcomes such as declining health, family/friend burnout, increased hospitalizations, financial stress, loss of independence and depression.

In some cases, a lack of adequate services in the community can lead to individuals being forced into institutional settings when they should remain in the community. No-one wins when this happens. The government pays more to support the costs of an individual in an institution, and the person loses the freedom associated with remaining with his/her family and having the opportunity to participate in the community even if they do require higher levels of care.

In other cases, people with higher needs (e.g. those requiring 24-hour care) must move into long-term care facilities because legislation (such as the Home Care Act) restricts the amount of care an individual can receive in the community. People with disabilities should be provided the option to remain in the community no matter what level of care they require.

To ensure that people are able to remain in their communities, we recommend that adequate funding be specifically allocated through the regional health authorities to meet the needs of people with permanent disabilities.

> *I am a 37 year old woman with a severe neurological disorder called Infantile Spinal Muscular Atrophy Type II. In January 2000, I was dealt a devastating blow when my illness progressed to the point that I needed a ventilator and could no longer get enough self-managed care to remain in my home safely and was forced into an assisted living centre that houses people who have respiratory needs. When I first entered the facility, I was devastated. My life stopped. My personal care sank to an all time low and my self-esteem was shot. I sank into a clinical depression which lasted a year and a half (and still can be an issue). After three years in the facility I developed incontinence as a result of long waits to toilet. My body is very disabled but my mind and drive for life are there. I still have dreams and want to better what life I have left. I want to attend classes and audit classes. In the community I had a life. I had an aid. I had pets. I'd get my groceries, volunteer and go out.*
> -Woman with disability in assisted living facility

Access to Supports for People with Permanent Progressive Disabilities

The unique needs of people with permanent progressive disabilities (e.g. multiple sclerosis, muscular dystrophy) must also be taken into consideration when improving the access to and efficiency of health services. The *In Synchrony* report, developed by Muscular Dystrophy Canada in connection with a number of other organizations who represent people with progressive disabilities, recommends ways that these needs can be addressed. These recommendations include creating a definition to distinguish progressive disabilities as well as a policy lens to ensure people with progressive disabilities are considered when developing disability policies and programs. Please find attached the *In Synchrony* Executive Summary (Appendix A) which provides more information about how the health needs of this group can be best met.

Quality of care and Employee Job Satisfaction over Efficiency

We would also like to caution that efficiency is not always associated with job satisfaction for employees and positive outcomes for patients. Quality of care should not be sacrificed as part of an unrealistic expectation of efficiency.

> *We've been increasing "efficiency" so much in the system that quality has disappeared leading to even less efficiency and dramatically less effectiveness than when we started out. Indeed the lack of quality, proper attention and oversight may well be causing some of the increased demand on the system.*
> -Caregiver of mother with dementia in long-term care facility

Action 3: Getting serious about wellness and injury prevention

What do you think?

Do you believe you have adequate access to the information you need to make the choices necessary for a healthy and active lifestyle for you and your family?

Cost is a Barrier for Healthy and Active Lifestyles for People with Disabilities
Respondents felt that there was adequate access to the information, but that the cost of such a lifestyle was difficult for individuals who live on fixed incomes.

There is usually a cost associated with recreational activities such as joining a sports team, going to the gym, buying a bicycle, swimming, yoga or paying for transportation to get to a recreational activity. Further, people with disabilities often need to have access to physically accessible recreational sites and activities as well as personal supports to accompany them to these activities.

Cost is also a factor when purchasing healthy foods. While people may know that whole-grain foods, lean meat, fruits and vegetables are the healthiest alternatives, these types of foods cost more than ones that are heavily processed and refined.

As stated in Action 1, as part of a strategy to provide greater opportunity for low-income Albertans to maintain a healthy lifestyle, the Alberta government should ensure adequate income support to offset the cost to buy healthier foods. To encourage a healthier lifestyle, free access to recreational facilities that are accessible and accompanied by adequate supports will also result in opportunities for better health.

Healthy Messages Support Healthy and Active Lifestyles
In addition to ensuring affordability of recreation and healthy foods, marketing healthy eating t0hrough various avenues would help counter the constant barrage of advertisements advocating the consumption of unhealthy foods and would help advance healthy eating as more desirable.

Smoking
The municipal, provincial and federal levels of government should continue with their successful efforts at a number of levels to send a clear message that smoking is not healthy or socially acceptable. The government should ensure that resources such as pamphlets and smoking cessation treatments are marketed to demographics that have a higher incidence of tobacco use.

If Albertans take steps to be active, lose weight, or address risk factors, should they get a benefit on their taxes or health care premiums? What do you see as the pros and cons of such an approach?

While ADF members fully support the government promoting a healthy lifestyle for Albertans, we believe that providing incentives to Albertans through tax breaks and lower health care premiums could create an unfair advantage. A number of people with disabilities do not pay taxes or health care premiums because of their level of income. As a result, tax or health care premium incentives would be of no benefit to these individuals. If such a program were implemented, the Government would also need to ensure that resources to be active, lose weight and address risk factors were available to those who are not able to afford them. Further, keeping track of information to determine who would receive such incentives could create a bureaucratic nightmare. If an incentive program is implemented, it is imperative that such a program be equitable to all Albertans.

What other ideas would you suggest to encourage Albertans to take greater responsibility and adopt healthier lifestyles?

We believe that people with disabilities would gain more benefit if health programs were provided free or at a low cost (e.g. implementing free fitness and health and lifestyle classes, encouraging local communities to form recreation groups, offering free non-smoking information classes).

Action 5: <u>Improve access to mental health services</u>

What do you think?

ADF members are encouraged by the Government of Alberta's steps to ensure that those affected by mental illnesses get appropriate treatment. Please find attached the Alberta Alliance on Mental Illness and Mental Health's (AAMIMH) Election 2004 package (Appendix B) that outlines key issues and recommendations for improving Alberta's Health system for individuals with a mental illness.

As part of improvements to access for people with a mental illness, we ask that consumer and stakeholder organizations be part of the development and ongoing review of the activities through the Mental Health Innovation Fund as well as setting clear expectations and measuring results through the regional health authorities. The personal experiences and perspectives of individuals who have experienced mental illness and dealt with the mental health care system provide an important viewpoint that will create innovate strategies for improving community mental health services.

<u>Parents and Children with Mental Illness</u>
As part of the Mental Health Innovation Fund, we ask that attention be given to parents with mental illness as well as children with mental illness.

Action 7: <u>Expand primary health care</u>

What do you think?

<u>Accessibility of Healthcare Services for People with Disabilities</u>
For many people with disabilities, expansion of primary care must go beyond availability of health care providers to include physical accessibility and other necessary supports. For a person who uses a wheelchair, getting onto an examination table without a lift, or having a mammogram that requires a transfer, can be very difficult. For individuals who are deaf or deafblind, interpreters and interveners must be provided to ensure that they are able to communicate with their medical provider. For those who are blind or have a visual impairment, it can be difficult to access medical records and other medical information in formats that are accessible (e.g. Braille, large print, electronic formats). As part of expanding primary care, facilities must include physical access and other necessary supports. These requirements must be provided not only in offices of general practitioners, but also in other primary care facilities such as dentists' offices, physiotherapy clinics, x-ray labs, etc.

To learn more about accessibility of physicians' offices, we have enclosed the document *Making our offices universally accessible: guidelines for physicians* by Karen E. Jones, BSc, MD, and Itamar E Tamari, MD (Appendix C). With an aging population and an increasing demand for

accessibility of facilities, accessibility guidelines must be developed and implemented as part of the Government of Alberta's initiatives to expand primary health care services and increase access and efficiency.

Holistic/Alternative Approaches to Healthcare

ADF members support expanding the definition of primary care to include holistic/alternative approaches. As part of this expansion, the services and treatments of holistic/alternative practitioners should be included under Alberta Blue Cross as well as government subsidized health programs.

Doctors must also be made aware of the contribution that these approaches can play in wellness for people with disabilities. Doctors often respond to medical issues with pharmaceutical solutions when they could also let patients know about holistic/alternative approaches that may be available. For certain disability-types, pharmaceutical and/or holistic/alternative solutions should be explored.

As part of ongoing research into disability-management, a greater level of research should be conducted into holistic/alternative approaches to measure the validity of these approaches and to ensure doctors can be confident in making recommendations in this area.

Fall 2005
Launch new training initiatives for interdisciplinary and chronic disease management teams

Consumers and stakeholders should work with the federal and provincial governments to create and deliver training initiatives to people involved in local primary care networks. An example of an effective consumer training initiative is Patient Partners. This intensive program trains people with Arthritis to teach medical students about Arthritis. These instructors with Arthritis then form part of an education team and become part of the medical school curriculum to ensure medical students are given personal instruction on how to conduct a vital Musculoskeletal (MSK) Exam. The program enables students to learn the curriculum with the additional value that is gained from learning about the disability from the perspective of someone who experiences it first hand. These instructors have also made an impact in the community by volunteering their time to teach the MSK exam to practicing family physicians as part of a Continuing Medical Education program. This type of program could be expanded to address people with disabilities in general as well as other specific disability types.

Action 8: Make changes to legislation and regulations

What do you think?
Step 1: Change regulations

ADF members believe in equal access to healthcare for all Albertans regardless of ability to pay. We support expanding choices and removing barriers that stand in the way of innovation by regional health authorities. We also strongly support provincial standards of care that outline the levels of service provided in each regional health authority to ensure consistency throughout the province.

Providing Choice for Albertans with Disabilities: Supplementary Insurance, Hospital Rooms, & Medical Goods and Services

Members of the ADF do not believe that supplementary insurance is the best way to provide a greater level of choice to Albertans. Additional choices can be added to the current system by

expanding in some areas and saving in others. For example, the cost of providing appropriate mental health services in the community can save money by decreasing the likelihood that a person with a mental illness will need to be hospitalized. Also, providing adequate community supports, such as home care, will reduce the number of people with disabilities who must live in institutions. The cost-savings and other benefits of keeping individuals in the community have been well documented.

In Alberta and in Canada, there are many goods and services that are more easily available to those who have greater economic resources. Healthcare is one area where we support the fundamental premise that access should be equal for all. This equality in healthcare creates a leveling affect among our citizens ensuring that access to health services is based on citizenship and not on an individual's resources. If supplemental insurance is implemented, Alberta will do away with this leveling affect and will be creating a class system where those who can afford increased choices will receive better care than those who cannot afford these choices. ADF members support equal access to healthcare and do not support a move to a class based healthcare system which includes supplemental health insurance.

While the option of supplementary health insurance may increase choice for some, it does not increase choice for those who cannot afford to pay for it or do not qualify for it. How will increased choice be provided to those people with disabilities who cannot afford or qualify for supplementary insurance, yet need insured services? What is considered a basic or enhanced good or service? Will individuals be able to receive enhanced goods and services if they do not have supplementary insurance? We do not support new regulations if these regulations will result in a 2-tier health system based on ability to pay rather than individual need.

Step 2: Consider a new Health Care Assurance Act for Alberta

What do you think?

Do you agree with the idea of a single Health Care Assurance Act in order to provide an assurance framework on access and quality health services in Alberta, and to streamline a broad array of current legislation governing health care in Alberta?

Members of the ADF support a Health Care Assurance Act that encompasses the principles of the Canada Health Act and would result in equitable access to better and more effective health delivery for all Albertans. In developing this Act, a meaningful public consultation must take place to ensure that all Albertans have the opportunity to give input into the Act's development.

As part of this consultation, Albertans should be given clear information about all aspects of the Act's development and implementation. Further, the consultation should not be entered with preconceived notions of what the outcome will be. One of the points outlined in the government's *Getting on with Better Healthcare* initiative 2 is to "describe what health services would be covered by public health insurance and which ones could be provided by private or not-for-profit health plans." Questions regarding greater privatization or a not-for-profit health plan should not be asked before Albertans are given the opportunity to respond to whether they want greater privatization or a not-for-profit health plan. To answer these questions, Albertans need to be given information about what these options could include so that they can make an educated decision on what would be the best approach.

Action 9: <u>Control spiraling drug costs and increase coverage</u>

What do you think?

September 2005

Consider consolidating and managing all provincial drug subsidy programs through a single ministry

Members of the ADF do not support the consolidating and managing of all drug subsidy programs into a single ministry. The drug subsidy program provided to people with disabilities through Alberta Seniors and Community Supports is intended to address the unique needs of Albertans with disabilities by covering medications that are specific to them. ADF members believe that if these programs are consolidated into one larger subsidy program, the specific needs of Albertans with disabilities will not be adequately met. The coverage and budget allocation of medications specific to people with disabilities will have to compete with medications from other user groups for priority.

The consolidation would also affect the intent of the Ministry of Seniors and Community Supports. In November 2004, a number of the 32 disability programs that existed within 11 ministries were brought under the umbrella of Seniors and Community Supports. The intent of this amalgamation was to improve coordination of services for people with disabilities and decrease the widespread confusion and frustration people with disabilities and their families were experiencing accessing disability-related supports. If the drug subsidy program is moved outside of Alberta Seniors and Community Supports, it will be disconnected from those programs that it directly relates to such as AISH. This will recreate an increased need for coordination and management of disability programs across a number of ministries instead of ensuring consolidation and improved coordination within the Ministry of Seniors and Community Supports.

What do you think?

Would you support the idea of an Alberta non-profit pharmacare insurance program to keep our health system affordable?

In order to properly respond to this question, ADF members would need more information about what a non-profit pharmacare insurance program could include and how this program would impact people with disabilities. In order to ensure the needs of Albertans with disabilities are met by such a program, people with disabilities, their families and interested stakeholders must be given the opportunity to discuss possible proposals for this program and give input into how such a program would best work.

As costs for drugs continue to increase, we must ensure that all Albertans get timely access to the medications they need while also ensuring the sustainability of the program. ADF members support collaborative approaches such as “working with other provinces and the federal government to launch a national framework for expensive drugs for rare diseases” and “working with neighbouring provinces to establish a western Canadian consortium” to decrease pharmaceutical costs as long as this does not mean the wait time to get new medications will increase.

As with health services, ADF members believe that everyone should be able to receive the medications they need regardless of ability to pay. For those who cannot pay, medications should

be covered. For people who are able to pay into a program (e.g. Blue Cross non-group coverage), cost should not be tied to the amount of medication that the person needs (e.g. a person should not have to pay more because they need expensive medications).

An Alberta pharmacare program would enable people to share the costs of drugs based on their ability to pay and it would also take into account a number of health related factors, such as people who live with chronic illnesses. What other factors are important to consider when looking at possible pharmacare models?

ADF members believe that an Alberta pharmacare program should result in everyone having equal access to medications and that payment levels should not be attached to the level of use. ADF members do not support mechanisms that restrict access to medications and patient and physician choice when accessing medications (e.g. alternative pricing, maximum allowable cost pricing or capping medication funding). For many, providing the right medication in a timely manner can help control and prevent disease and avoid more expensive and invasive treatments. [2] Along with saving money, prescription medicines "increase our life expectancy, reduce disability and absenteeism, and dramatically improve the quality of life for millions of Canadians." [3]

Further, with certain disabilities, subtle differences in medication types can result in a person reacting well to one medication, but not another. People should not be restricted to the cheapest drug option or have to wait for long periods to get the medication that best meets their medical needs, especially if a case can be made for why a more expensive medication is more suitable.

It is important that people with disabilities receive access to the medications they need even when these medications have a higher cost. To ensure affordability, mechanisms should be kept in place to ensure that all medications are affordable. We support the continuation of the $25.00 maximum co-payment for prescriptions through the Blue Cross non-group insurance as well as other mechanisms that ensure the affordability of medications for all Albertans.

Action 10: <u>Improve quality in long term care</u>

What do you think?

What do you think about the idea of Albertans being able to invest in some form of insurance or a savings plan to cover the costs of their long term care needs when they are older?

ADF members support a universal healthcare plan which ensures adequate long term care for those who need it. Health care costs should be paid for through the tax system. An insurance or savings system could result in those who have paid into a plan receiving better care than those who have not, and we do not support providing long term care services based on an individuals ability to pay.

It is also important to remember that it is not only those who are older who access long term care services. Albertans with disabilities also access these services, and we must ensure that the needs of this group are addressed. For Albertans with disabilities in long term care, it is important that

[2] Canada's Research Based Pharmaceutical Companies (Rx&D). "Discovery." *Restrictive Drug Policies Impact Patient Care in Canada. Spring 2005, Alberta Edition.*
[3] Same as above

their families are not over-burdened with costs associated with ensuring their loved ones needs are properly met.

Will the new hours of care be enough?

ADF members do not support allotting an exact time to the care needs of individuals in continuing care, but rather allotting time based on an individual's needs and circumstance. We support patient centered care that focuses on ensuring that an individuals' full spectrum of needs are met, and that an individual is able to maintain dignity and be treated with care and respect. Increasing the amount of time available to residents and addressing the severe understaffing of continuing care facilities is an important step, but an individual's needs and circumstance should be the most important factor in providing care. No-one should have to suffer because they have a higher level of need.

The unique situation of people with disabilities under the age of 65 must also be considered when allotting time for care. Many people within this group have the same aspirations as anyone else their age – to go to school, have a job and take part in social activities. As part of an individualized plan for people with disabilities in continuing care, an individual's age and stage of life should also be factored into decisions about the level of supports required.

> *The MS Society receives calls from staff at facilities that are looking for information about how they can reduce the time spent on care. The most recent example of this is a facility phoned to enquire if a resident should be switched to a liquid diet because feeding her was taking the nursing staff too long. A liquid diet should be considered when the person has a medical need for the change, not because someone does not feel that they have time to sit and feed the person! In this particular case, a liquid diet would be extremely inappropriate. Following the call we decided to visit the individual and found that she was still in bed at 11:30 a.m. and had not been fed breakfast and was very hungry.*
> -MS Society submission to Continuing Care Health Services and Accommodation Standards Review – Summer 2005

If implemented, do you believe that continuing care insurance will be a tax on seniors?

Yes, for many seniors and people with disabilities who are in long term care, continuing care insurance will be a tax. For people with disabilities under 65 who are in continuing care, such insurance could also significantly affect their family income if they must maintain the cost of supporting their loved one in a long term care facility on top of the costs associated with maintaining their family.

How will we know the standards meet professional practice guidelines and provide assurance that Albertans in continuing care are treated with respect and dignity?

To ensure continuing care standards meet professional practice guidelines, ADF members fully support the implementation of the *MLA Task Force on Continuing Care and Accommodation Standards Review* recommendations regarding *Resident and Family Satisfaction and Concerns Resolution*.[4] These recommendations should be implemented immediately with the input of individuals who reside in long term care facilities and their families.

Monitoring, Compliance, and particularly *Enforcement of Basic Standards* are also crucial to ensuring that people in continuing care are treated with dignity and respect. ADF members support the immediate implementation of the Task Force's recommendations in these areas.

[4] Government of Alberta. *Consultation on Continuing Care and Accommodations Standards*, 2005. http://www.continuingcare.gov.ab.ca/index.htm

Additional comments:

As part of the recent Continuing Care Health Services & Accommodation Standards Review, a few ADF members, the Alberta Committee of Citizens with Disabilities (ACCD) & the Multiple Sclerosis Society of Canada, Alberta Division (MS Society-Alberta Division) made presentations and recommendations regarding people with disabilities and continuing care. The topic of ACCD's presentation was *modified* AISH (Appendix D), and the topic of MS Society - Alberta Division's presentation and recommendations were individuals with chronic, progressive disabilities in the continuing care health services spectrum (Appendix E). We will not go into the details of these presentations and recommendations in this submission, but have attached them to illustrate some of the areas of need for people with disabilities in continuing care.

Action 11: Increase the supply of health care providers

Summer 2005 and ongoing
Take proactive steps to recruit and retain health care providers

ADF members fully support the Government of Alberta's steps to work with members of government and the community to "recruit rural Albertans and offer training in rural communities, expand the recruitment, retention and training of health care providers, and increase the participation of aboriginal people in health disciplines."

Health support workers/personal care attendants (individuals who provide medical supports and other required supports to ensure that people with disabilities can remain as independent as possible) are particularly important to people with disabilities living in the community and continuing care facilities. To ensure recruitment of health support workers/personal care attendants, training and access to funding for training, must be made available to those interested in working in these areas. This must include those who live in rural areas and those who are from a foreign country.

To ensure retention of health support workers/personal care attendants for people with disabilities, these individuals must be provided with fair market wages for their work. Increasing wages from their current levels would result in better retention of workers which would result in better consistency of care for those receiving these services.

Action 12: Address the health needs of rural communities

What do you think?

ADF members congratulate Alberta Health and Wellness for moving forward on initiatives to improve health care in rural areas. Developing and meeting access standards in the areas of primary care, home care, self-managed care, rehabilitation and mental health services in rural areas will make a significant difference in the lives of Albertans with disabilities. Currently, people with disabilities in rural areas face considerable challenges in accessing the services they need. Often services are so difficult to get that people with disabilities must make the difficult decision to leave their rural community and support networks to move to a major urban centre where services are more readily available. As part of this expansion, we encourage Alberta Health and Wellness to consult with consumers in rural areas to discuss concerns and develop solutions.

Aboriginal people in Alberta have a significantly higher incidence of disability than other Albertans. The health needs of Aboriginal people on reservations pose a challenge for addressing barriers to healthcare for rural constituents. Geographic isolation, cultural and language differences are only a few of the barriers that Aboriginal people on reservations face when looking for health services. To ensure that improvements to rural healthcare identify and address the unique health-related issues of this group, Alberta Health and Wellness should work with members of the Aboriginal community who live on reservations to find out how this group's health needs can best be met.

Update August 10, 2005: Supplementary health insurance

What do you think?

Is there a role for supplementary insurance to cover the costs of non-emergency health services in the future?

Members of the Alberta Disabilities Forum do not support a role for supplementary insurance to cover the cost of non-emergency health services in the future. We believe an individual's ability to receive a medically necessary procedure, whether it is considered an emergency or not, should have no bearing on whether an individual can afford to pay for supplementary insurance.

As stated in our response to Action 8, we support all Albertans having equal access to healthcare services and believe that by providing this equal access we create a leveling affect in our healthcare system where we ensure that those with more financial resources are not able to access better healthcare than those who do not have these resources.

If a system of supplementary insurance is implemented, people with disabilities will be at a great disadvantage. Many people with disabilities already bear increased costs associated with living with a disability e.g. specialized housing and transportation, nutritional supplements, medical supplies that are not currently covered, etc. These costs are often compounded by the fact that having a disability can limit a person's employment opportunities and the level of income that he/she can generate. Adding the additional cost of supplemental benefits to this list would be prohibitive for those who are low-income and would bring people with disabilities and their families who are barely able to afford their current costs further into poverty.

Further, if supplemental insurance coverage is implemented, it is unlikely that people with disabilities will be able to access such insurance. Insurance is based on risk-assessment with those who are at a higher risk for needing the service being charged higher premiums or being denied coverage because of the level of risk associated with their preexisting condition. While charging an individual higher premiums based on their disability is a form of discrimination, if such a situation were to occur, people with disabilities would not be able to afford coverage for services that they may already need or may likely need in the future.

> *My husband is self-employed and receives no medical benefits through work. We have had to secure our own health care benefits. We haven't been able to find any extensive coverage for our son due to his "pre-existing" medical condition. He qualifies for only the most basic of health care plans. As health care needs occur, we will pay large portions out-of-pocket.*
> -Mother of child with spina bifida

Greater private insurance can also lead to an increase in discrimination in the workplace. Some people with disabilities have higher medical needs and use a greater number of medical services

through company insurance plans. Increasing privatization of medical services and relying on individuals and companies to pay for a larger number of services would result in people with higher medical needs increasing company insurance premiums. The additional insurance needs of companies would result in those with higher medical needs creating increased costs to company.

The implications of instating supplemental insurance also extend far beyond healthcare. Forms of insurance can be tied to other areas such as obtaining life insurance, mortgage insurance and private extended medical plans. Loaning institutions can deny access to funds such as a mortgage based on an individual inability to get other forms of insurance e.g. life insurance, health insurance, etc.

What types of service do you consider non-emergency?

In order to understand this question better, ADF members ask that clarification be given regarding what is meant by medically necessary health services and non-emergency services as these terms are confusing. Most services that people with disabilities receive are medically necessary, but may not need to take place immediately (e.g. surgeries, blood work, visiting a health provider such as a physiotherapist or a specialist). Even if a wait for these procedures may not put a person in imminent danger, not receiving these services can result in the procedures becoming an emergency, or, if not addressed, a deterioration of the person's health. ADF members believe that if a service is necessary to ensure the best possible health outcome(s) for an individual, that the service should be covered to the same extent for all Albertans regardless of an individual's ability to pay for supplemental health insurance.