

Access to Medications for Albertans with Disabilities

An Information Brief

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LACK OF ACCESS TO MEDICATIONS = PAIN AND SUFFERING

Beth is a senior citizen and a cancer survivor who suffers from scoliosis, a painful deterioration of the spine. She needs medication to battle the constant pain, to help her eat and sleep and to keep her high blood pressure in check.

While on Assured Income for the Severely Handicapped (AISH) her medications were paid for. Beth was removed from AISH and lost her benefits when she became eligible for Old Age Security. She is forced to work to pay for her eight prescriptions even though her doctor says working is dangerous to her health.

Clare is a single mom with a six-year-old and a two-year-old. She is upgrading her education. She is on anti-anxiety medications. She covers the cost of the medication using her student loan. She has also borrowed money to pay for it. Without the medication, Claire would be unable to attend school or care for her children. Without medication, it is likely the children would end up in foster care and Claire would be homeless.

Rebecca is a young person with a mental illness. She relies on prescription medication to function. She was enrolled in a program that helps people access training and obtain employment. But her rent increased and she could not afford her medication. She dropped out of the program and ended up in hospital. Rebecca returned to the program sometime later after a special request to government to pay for her medications was approved. She is now employed full time.

Derek is a 21-year-old who has a form of arthritis that affects his spine and joints. On his birthday, he was dropped from his father's medical insurance plan because of his age. Alberta Health won't pay for his treatment and he can't obtain private coverage by himself. His condition will worsen without the medication he needs and he will likely have to quit his job.

Every day, thousands of persons with disabilities suffer pain and financial burden because of an inability to pay for medications. A pharmaceutical strategy in Alberta that recognizes this deficiency and corrects it would demonstrate compassion and understanding. It would also reduce pressure on other parts of Alberta's health and social service systems.

BACKGROUND

The Alberta Disabilities Forum (ADF) is a consortium of 40 organizations that represent a wide spectrum of disabilities and chronic illnesses such as multiple sclerosis, Parkinson's disease and arthritis. Member organizations have known for some time that persons with disabilities or chronic illnesses have difficulty accessing health services and supports, particularly medications. This is evidenced through anecdotal stories, demands for information and research studies.

"In matters of health, everyone should be treated equally. Yet people with disabilities have been discriminated against throughout history."

*Dr. G. Harlem Brundtland,
Director-General, World
Health Organization*

This prompted ADF to commission an on-line survey¹ in the spring of 2007. The survey confirmed that persons with disabilities or chronic illnesses in Alberta are experiencing difficulty accessing medications and alternative forms of health care.

Among individual respondents:

- 72% have been refused private and/or public coverage for one or more prescribed medications in the past.
- 24% are waiting for prescribed medications to be funded by a plan or program.
- 54% have had to wait for prescribed medications to be funded.
- 46% have had a prescribed medication refused funding or significantly delayed.
- 51% require special authorization in order to get one or more of their prescribed medications.
- 74% seek out and use alternative/holistic therapies. Among these respondents, most get no funding support for these therapies.

¹ The study was launched on May 18 and closed the end of June, 2007. Member organizations were invited to respond. They in turn communicated to their own clients and members of the opportunity to participate on an individual level. n=80 for individual respondents; n=19 for member organizations.

Among organization respondents:

- 32% report people they represent (clients or members) do not have a funding plan of any kind to cover the cost of drug therapy.
- 50% report medications or supplements required by people they represent are not covered by a plan.
- 29% report people they represent have had to wait to get prescribed medications funded.
- 39% report people they represent have been refused funding for a prescribed medication in the past.
- 33% report people they represent have required special authorization for a medication.
- 86% report they are aware people they represent are using alternative/holistic therapies to help them manage their chronic illness or disability.

It is clear from the survey and anecdotal evidence that many persons with disabilities or chronic illnesses have restricted access to drug treatment. Further, they are seeking out alternative therapies to find pain relief and manage health conditions related to their disabilities.

Restricted drug treatment may not be the reason many people seek out alternative therapies but the result to the pocketbook is the same. Most alternative therapies are not covered by Alberta Health and Wellness.

ACCESS BARRIERS

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 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.

"When I was diagnosed at the age of two, life-expectancy (for Cystic Fibrosis) was six years. When I graduated from college at 31....life expectancy was 32 years. During those intervening years the disease did not change. What did change was the discovery of new treatments for Canadians...Unfortunately universal access is no longer the case."

Chris MacLeod, speaking in Toronto to the 2002 Commission on the Future of Health Care in Canada

Every province and territory has its own approach to deciding which prescription drugs are covered under its insurance plan. Statistics suggest Alberta's public health insurance plans have more rigid approval criteria for drug therapies than most other jurisdictions in Canada.

Drug Spending Per Capita (\$) 2003											
	Can	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NF
Private	382	297	354	367	312	431	355	488	440	525	373
Public	239	176	204	232	238	244	293	189	198	163	213
Total	621	463	558	599	550	675	648	677	638	688	586

Source: Canadian Institute for Health Information, Statistics Canada. 2003 forecast

Alberta compares even less favourably to other modern, industrialized areas of the world. An Organization for Economic Cooperation and Development (OECD) study shows Canada ranks poorly among industrialized countries regarding public health coverage for drug treatments. Only the United States, which has no national universal health care program, spends less public money per capita on drugs.

Drug Spending Per Capita (%) 2004										
	Can	US	France	Italy	Spain	Germany	Japan	Norway	Sweden	OECD
Private	62	76	29	49	28	25	31	40	31	39
Public	38	24	71	51	72	75	69	60	70	61

Source: OECD Health Data 2006

Limited access to proper drug therapy minimizes health benefits to patients and has the potential to impose greater costs on the health system. A 2007 Canadian study led by researchers at the University of Quebec at Montreal concluded that, "better access to drugs may be an effective strategy to decrease overall health care costs. Freeing up healthcare dollars by reallocating spending towards drugs could provide opportunities for overall health care cost savings without negatively impacting the health of the population".

Rob Lougheed, Chair of Alberta's Premier's Council on the Status of Persons with Disabilities, suggested in a member statement to the Alberta Legislature in May 2007 that tens of thousands of Albertans with disabilities might be working if given the right opportunity and support.

Job support for persons with disabilities goes beyond training programs. It must also include timely and appropriate health care such as drug therapy. However, those with limited incomes or spouses without generous health plans often go without the medications they need. This precludes them from seeking, obtaining and retaining employment.

According to the Canadian Association of Community Living's Roeher Institute, about half of all adult Canadians with disabilities regularly take medications because of their condition. This equates to about 166,000 Albertans (2001, Statistics Canada). The Institute found nearly one-third of these have medical expenses that are not reimbursed by any public or private plan. This is consistent with the findings of ADF's survey.

Seventy-two percent of people in the ADF survey said they have been refused coverage for one or more prescribed medications in the past. Reasons given include expense, allergies, legal reasons (pending lawsuits) or it was a new medication. Those who were refused coverage said they reduce dosage, go without, pay out-of-pocket, get samples or go to another jurisdiction. A few are able to pick up other coverage.

It is understandable that the rising cost of prescription drugs is a concern for both government and individuals. An IMS Health Canada report estimated the average Canadian family of three spent \$1,209 on prescription drugs in 2002. It is generally accepted that this figure will continue to rise as the role of drugs to help manage disabilities and chronic illnesses increases to keep pace with our aging society. However, a Canadian Patented Medicines Pricing Review Board (PMPRB) study suggests drug costs are not outracing other expenses. It showed that the price of patented medicines in Canada from 1988-2000 was equal to or less than the Consumer Price Index (except for 1992). It attributed rising pharmaceutical costs during that period to a significant increase in the amount of prescriptions.

"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

Despite rising costs, health professionals point out that there is room for considerable savings. In 2002, the Canadian Pharmacists Association estimated the underuse, misuse and overuse of prescription drugs cost Canadians between two to nine billion dollars. Eliminating this waste in Alberta would mean a savings of \$200M to \$900M. More extensive education of consumers and health care professionals is one strategy that would significantly reduce waste. Savings could also be found through bulk buying from a variety of manufacturers of the most commonly prescribed medications, as is done in Quebec.

Routinely, physicians have access to and consumers are made aware of new medications long before they are approved for funding under health plans. However, usually only patients with good private plans or sufficient funds can access them. According to a 2007 IMS Health Canada report, Alberta was second last among provinces in the approving new single-source medications for public funding.

Provincial Listing of Single-Source Drugs approved by Health Canada										
September 1, 2005 to August 31, 2007										
n = 88										
Listing	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NF
Full	4	9	9	11	10	16	8	13	5	12
Restricted	15	6	14	8	7	23	13	11	5	17
Total	19	15	23	19	17	39	21	24	10	29

The slow process of adding medications to approved funding lists is detrimental to patient health and ignores the potential savings new drug therapies have in other areas of health spending (e.g. fewer sick days, quicker recovery, reduced hospitalization stays, etc.). Restricted status makes access time-consuming and difficult.

A 2006 US study that tracked nearly 200,000 Americans demonstrated a cap on drug benefits was associated with unfavourable clinical outcomes. “In patients with chronic disease, the cap was associated with poorer adherence to drug therapy and poorer control of blood pressure, lipid levels and glucose levels. The savings in drug costs from the cap were offset by increases in the costs of hospitalization and emergency department care,” found the report.

This was echoed by a 2006 study commissioned by the National Bureau of Economic Research in Cambridge, Massachusetts. It found that consumers use more outpatient services when they lose access to drugs due to higher costs. “Higher drug co-payments save money on drug spending but cost money on outpatient and possibly inpatient spending and have smaller effects on overall spending,” said the study’s authors.

In addition to reduced or refused coverage, many persons with disabilities or chronic illnesses experience long delays in getting approvals for some medications. Staff in some non-profit organizations report spending time tracking down alternatives and educating clients/members about different payment options.

Many have turned to alternative/holistic therapy to fill the void. Most of the 74% of survey respondents who use alternative/holistic therapies say they pay for these treatments themselves. They do so, despite the financial burden, because it is accessible and responsive to their health needs.

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.

NO CHOICE FOR PATIENTS

The Alberta government's promise of patient choice in a health system that is accessible to all is not being fulfilled for persons with disabilities or chronic illnesses. This reality is contrary to the values expressed in the *2006 Health Policy Framework* approved by the Government of Alberta:

Value #1: Health Care must be people-centered.

Specifically: The system must allow Albertans to make choices based on full and complete information.

Value #3: Access to services must be timely and fair

Specifically: Timely and fair access to health services must take into account differing levels of clinical activity. There must be no barriers to access based on a person's ability to pay.

Value #5: Albertans must be able to choose what is best for their own health and wellness

Specifically: The health system must provide Albertans with information and advice and support them in preventing disease and injury. Albertans should be able to choose the health services that best suit their needs and circumstances.

The importance of managing chronic conditions is highlighted in Alberta's *Healthy Aging and Seniors Wellness Strategic Framework 2002-2012*. The model for healthy aging in Alberta has four components. One of these is Managing Chronic Conditions. It notes the importance of "enabling people to effectively manage conditions caused by injuries and diseases by facilitating self-care and independence and using collaborative approaches with professionals and caregivers."

Alberta's new pharmaceutical strategy, currently under development, has an opportunity to recognize that when it comes to drug treatment one size does not fit all. Many persons with disabilities or chronic illnesses are wholly dependent on specific medications to function. This needs to be recognized and accommodated.

"Greater pharmaceutical consumption leads not just to longer lives but also to a higher quality of life, as measured by the number of years people can expect to live without disability health conditions....In general, countries that currently spend the least on pharmaceuticals would see the greatest benefits from an increase in that spending."

*Richard D. Miller & H.E. Frech,
authors, Health Care Matters,
2004*

The strategy should also recognize that patients have the right to work with their doctor and other members of the healthcare team to find a treatment plan that works for them. Treatment options like drug therapy should not be denied to a patient simply because he or she can't afford it.

"I have been on AISH Max since 1983. At present I have six prescriptions that are not covered."

Dianne A. Funk, Albertan

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.

Further, the Fraser Institute commissioned survey 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.

It is clear that Canadians are seeking out 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. The experience of professions such as Naturopathic Doctors supports this conclusion. The Alberta Association of Naturopathic Practitioners report that its members are experiencing greater than 10% annual growth in numbers of patients and patient visits. Patient visits to Naturopathic Doctors totaled 500,000 in 2006.

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 own health and take an active role in managing their own 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 own care more effectively.

"States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning."

Medical precondition; Standard Rules on the Equalization of Opportunities for Persons with Disabilities, United Nations, 1993

The 2007 Fraser Institute survey showed a slight majority of Canadians believe complementary and alternative medicine should not be included in provincial health plans. However, it also revealed that 35% of Albertans support public financing of alternative therapies even if it means less money for conventional health care.

Government's Responsibility

A Supreme Court of Canada 1997 decision (*Eldridge v. British Columbia*) confirmed three things.

- Governments have a responsibility to identify, remove and prevent barriers that keep and prevent people with disabilities from benefiting from society's opportunities and services.
- Governments cannot escape their responsibilities to citizens with disabilities by delegating responsibilities to other authorities such as hospitals and clinics.
- Government cannot escape their duty by claiming it costs too much to accommodate people with disabilities.

Beyond legalities, there is considerable evidence to validate more government spending in support of those who need drug 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.

"It took me five years to find a replacement for an antidepressant medication that government no longer permitted. At times I was bedridden. It was just a horror show. Now I'm able to function and deal with everyday needs."

Howard Allan, Albertan

RECOMMENDATIONS

The Alberta Pharmaceutical Strategy provides an opportunity to remove a major health barrier for thousands of Albertans. In addition to being patient-centred, ADF believes the following recommendations should form part of the Strategy.

1. Increase patient choice and reduce delays and coverage refusals by:
 - a. Broadening the Alberta Health and Wellness Drug Benefit List to include all 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 a physician.
 - b. 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.
2. Improve education and counsel to persons with disabilities or chronic illnesses about medication coverage options, particularly the non-group coverage premium subsidy offered by Alberta Blue Cross. Utilize community groups and member organizations like ADF to communicate information and provide advice.