



Alberta Committee of Citizens with Disabilities

Good Morning, my name is Bev Matthiessen. I am the Executive Director of the Alberta Committee of Citizens with Disabilities. ACCD is a provincial organization that has existed for over thirty years. It is Alberta's only cross-disability provincial advocacy group, managed by people with disabilities. ACCD is also actively involved with the Alberta Disabilities Forum (ADF) and is the host agency for the ADF.

Today I wish to speak to one area of concern to us. The *modified* AISH Program. As you know recipients of *modified* AISH live in care facilities. While the recommendations I am going to give you outline improvements that could be made to the existing *modified* AISH Program, the real concern is that many AISH recipients have no choice but to live in care facilities because they are unable to receive the supports they require to live independently in the community. This results in separation from family members, reduces choices in daily living, hampers full participation in the community, and fails to afford a satisfactory quality of life.

While the recommendations listed here will assist recipients of *modified* AISH to have more disposable income and get their medical needs met, these options must be made available in the community through increases to home care and other supports that would make this possible.

There are questions about the validity of the *modified* AISH Program. Why do some individuals with disabilities have their needs met, such as those living in group homes, and still receive the full AISH amount? Why

The Alberta Committee of Citizens with Disabilities
707-10339 124 Street
Edmonton, AB T5N 3W1
Phone: (780) 488-9088

are individuals with high medical needs being penalized by being forced to live in care facilities and given so little income support while others receive the full AISH amount and are living in subsidized housing where they pay 30% of their monthly income for rent?

Observations:

- There is a need for clarification and/or change of policy on which care facilities are eligible for *modified* AISH Program funding (e.g. long term care, assisted living, hospitals, etc.).
- Government pays the facility a fee of \$1,277 per month for the *modified* AISH Program recipient's housing/food/medical care.
- Recipients of *modified* AISH receive the same health benefits as other AISH recipients such as basic prescription drugs, eye care, emergency ambulance, AADL, Alberta Health Care Insurance, dental care, and essential diabetic supplies.
- Recipients of *modified* AISH will receive the supplemental benefits which will be given to all AISH recipients in October 2005 (e.g. school supplies for children, some medical supplies, overdue payment for utilities, diabetic and special diets for medical conditions, special transportation, and allowance for guide dogs, etc.).
- There is a facility fee charged to some recipients of *modified* AISH.
- Recipients of *modified* AISH did not receive the \$150 per month increase in the living allowance that other AISH recipients recently received (\$100 on April 1, 2005 and \$50 on April 1, 2006).
- Recipients of *modified* AISH receive \$175 per month.
- Personal items (e.g. shampoo, deodorant, over-the-counter

**The Alberta Committee of Citizens with Disabilities
707-10339 124 Street
Edmonton, AB T5N 3W1
Phone: (780) 488-9088**

- medications, toothpaste, toothbrushes, hair brushes/combs, clothing), dishes, furniture, mattress, bedding, towels, cleaning supplies, food (other than what is provided at the facility) and some medical items (e.g. trach sponges) are not covered. Many struggle with laundry, haircuts, and nail care costs. Personal items can also go missing more easily in care facilities than at home (e.g. many people report that clothes are lost in the laundry).
- In addition, other items such as personal care attendants, telephone, transportation, computer, cable, internet, and costs of university courses are not covered. Many facility recreation/social outings are not covered, and therefore can lead to exclusion of recipients of *modified* AISH. Recreation and social opportunities have decreased in many facilities leaving residents to seek and fund external opportunities on their own.
 - Cleaning services are not adequate in some assisted living facilities (e.g. fifteen minutes per week).
 - Access to rehabilitation services or holistic therapy is not available to recipients of *modified* AISH.
 - When individuals who are severely and chronically mentally ill are hospitalized for more than 90 days, they are put on *modified* AISH. When this happens, they are no longer able to pay for their housing in the community. At the same time, they must find a place to store their personal items, etc. When this person is released from hospital, they must start all over again to find suitable housing to reestablish themselves in the community.

- When an AISH recipient has to move into a care facility, it is usually done quickly because a bed has become available. This is costly to the AISH recipient because a minimum of a month's notice (usually two) must be given in the place where they are living. Therefore, they lose their damage deposit. There are no extra dollars to assist with the move (e.g. moving expenses, packing, loss of damage deposit due to insufficient notice of move, paying rent in both places in one month, etc.).
- There is no policy for how recipients of *modified* AISH would be treated if they were employed.
- Personal goals and aspirations of recipients of *modified* AISH are not taken into account. Many cannot reach their full potential because there is a lack of funding and disability supports. The needs and aspirations of young people on *modified* AISH are not taken into consideration. Therefore, many recipients of *modified* AISH do not feel they have the ability to fully participate and contribute to society.

Recommendations:

1. That people with disabilities be given adequate funding and supports to live in the community. Therefore, there would be less need for *modified* AISH.
2. That the recipients of *modified* AISH receive the \$150 per month increase in the living allowance that other AISH recipients recently received.

The Alberta Committee of Citizens with Disabilities
707-10339 124 Street
Edmonton, AB T5N 3W1
Phone: (780) 488-9088

3. That a study be done to find out if and why some medically necessary items are not covered (e.g. trach sponges). Have these items covered either under the facility fee of \$1,277 per month or under the new supplementary benefit's list.
4. That rehabilitation therapies (OT, PT, RT) be provided to recipients of *modified* AISH.
5. That financial assistance is provided to AISH recipients who must move into a care facility.
6. That assistance is provided for individuals who are mentally/physically ill to reestablish themselves after a stay in the hospital that is longer than 90 days. The 90 day limit should be removed and extended to six months. At the six month mark, decisions could be made on a one-to-one basis with consultation with the person with the disability.
7. That a fund be set up so that recipients of *modified* AISH can apply for financial assistance for specific items (e.g. personal care attendants, educational pursuits, lawyer's fees for making out a will, recreation, transportation, or other items that would enhance quality of life).
8. That a policy be created that answers the questions about how recipients of *modified* AISH are treated if they are employed (i.e. \$400 employment exemption).
9. That research be done with existing recipients of *modified* AISH to determine their personal goals related to community involvement and community contribution.

10. That the realization that recipients of *modified* AISH can and do contribute. Funding and supports afforded to them should be viewed as an investment.

Thank you very much for giving me the time to make this presentation. I will leave a copy of it with you. Are there any questions?

July 27, 2005

**The Alberta Committee of Citizens with Disabilities
707-10339 124 Street
Edmonton, AB T5N 3W1
Phone: (780) 488-9088**