Enabling Valued Community Lives for People with Significant Disabilities

A Call to Action

19 April 2002

Participants in this workshop discussed their learning about creating community alternatives to institutional living and identified actions that will create an Alberta in which **institutions are part of our past, not part of our future**. John O'Brien wrote this summary of the main points people made in the discussion.

Participants shared in the stories of families who have created positive alternatives to institutional living for people with substantial disabilities. While each of these stories reflects the unique circumstances of the people involved, these messages tie the stories together and link them to the stories of thousands of other people around the world:

- Community life with adequate supports offers people more opportunities for a good life than institutions can, even at their best. Good supports grow from commitment to a person's well-being, sustained hard work, and creative leadership in overcoming barriers to a person's free exercise of the rights and responsibilities of community membership.

- Community supports have been developed for people with the full spectrum of needs met in institutions. No one needs to live in an institution unless public policy makes an institution the only place a person can get the supports they require by under-funding community supports.

- Enough people in Alberta benefit from good community supports to set a high standard for service provision. This standard challenges local service providers as well as the institutions. Not every community service is currently capable of providing the high quality individualized supports required to assist people with substantial disabilities to have a good life. Not every community currently has the capacity to adequately support every person. The availability of institutional placements undermines some community's will by providing a place to send people who challenge existing services, and the under-funding of community services -

caused in part by expenditures on maintaining institutions- creates an artificial scarcity of community services.

• Significant investments of money, hard work by committed staff, and good management can make institutions better than the dreary and oppressive places that a number of workshop participants had to live in before their move to community life. However, re- investing that money, talent, and leadership in well designed individualized services would yield far greater long-term benefits to people, families, and communities.

• Because there are effective ways to assist people with substantial disabilities that do not remove them from community life, institutionalization violates the rights and freedoms guaranteed to every Canadian.

Alberta's services for people with developmental disabilities have enviable strengths to build on:

• A strong public policy framework and many people who understand and care enough about the service system's vision, mission, and values to feel the many gaps between stated values and actual performance and to work to close them

• Working mechanisms for planning, funding, and managing individualized supports

• Gifted people with developmental disabilities, family members, and service providers with much practical knowledge to share about supporting people with substantial disabilities in community life

• Over past years a significant number of people with substantial disabilities have moved from institutions into community life

These strengths make it hard to understand why Alberta hasn't yet joined the jurisdictions that have either closed all their public institutions for people with developmental disabilities (as 9 US states have) or adopted a clear policy aimed at replacing all public institutions for people with developmental disabilities as soon as appropriate community supports can be developed (as England, Wales and several other US states have done, including clear target dates for developing alternatives). The fact that other jurisdictions,

many of which lack Alberta's history of accomplishment in community services, have succeeded in making public institutions unnecessary strengthens the call to action.

Institutions for people with developmental disabilities have no place in Alberta's future. Experience in Alberta and internationally clearly shows that the way to make the institution unnecessary is to assure that…

> …each person currently living in the institution has individualized community arrangements that offer supports that are at least as good as those the person gets in the institution
>
> …each person who would otherwise have been admitted to an institution receive effective individualized community supports

Workshop participants identified four kinds of action for citizens who want to open Alberta's communities to everyone now living in an institution:

<u>Gather strength</u>

• Learn about the ways people with substantial disabilities can be supported to live well in community and the benefits for people, their families, and their communities

• Learn what holds the institution in place now (of course it isn't necessary to have the answers to all these questions before taking action)

- Who are the active and committed leaders among advocates for institutions?
- How many family members/ guardians would **not** be willing to explore a community alternative if given the opportunity? How do we know this? What opportunities to explore community alternatives have been available?
- What services do institutions provide that **cannot** be provided in the community (given portability of institutional funding)?
- What services do institutions provide that **are not** provided by (some) regional boards? Is the institution bailing out any of the regional boards by taking away people that the board or local service providers believe would be difficult or expensive to serve?

- Why do people return from community services to the institution? What would regional boards have to do to learn from these failures of community services and develop more effective alternatives?
- What political interests do the institutions serve: jobs, government relationships with unions, positive impact on local economies, influential family members who prefer institutions, powerful politicians who represent these interests, other interests?
- What are the trends in institutional expenditures: wages, operating costs, maintenance, and potential construction costs?
- How do continuing expenditures on institutions affect funding for community supports? Are people and families in communities disadvantaged in any way by maintaining institutions?
- What if any barriers face people or guardians who choose to move from institutions to individualized supports in community?
- Do people and guardians have access to independent information about individualized community supports and independent opportunities to plan (as people in community services do)?

• Develop a clear personal position on why individualized community supports make more sense for the future than continuing to invest in institutions. Consider the fact that if we take nursing homes and other facilities for elders into account institutionalization faces many of us. The supports a community develops to make institutionalization unnecessary for people with developmental disabilities offer valuable lessons about creating community supports for everyone, including all of us as we age.

• Get informed on how institutions have changed. It is important to clearly recognize improvements and changes in making the case for replacing institutions with individualized community supports.

• Develop a clear personal position on what makes and keeps people with developmental disabilities safe and secure.

Reach out to families with institutionalized members or families in community who see institutions as the answer

• Build up family-to-family contact between parents and guardians who have made the journey from institution to community and those who have not

• Find ways that people who have moved out of institutions can be part of efforts to "reach-in" to people in the institution to act as contact people, advocates, and mentors.

• Continue to develop ways to build contact between experienced families and families beginning their journey and assure that they have access to good information and family support

Mobilize political will for change

• Inform families and people with disabilities now living in the community that institutions still exist and tell them why it is important to work for their replacement with community services.

• Engage the media in telling the story of community alternatives

• Lobby MLA's

• Take public action that will draw attention to the necessary changes

Build effective community supports

• Assure that public guardians responsible to people who live in institutions are advocating for the supports necessary to allow people to move into community.

• Recognize the strong links between community issues -such as good transportation and affordable, accessible housing- and the development of effective individualized supports.

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