



Older Parents Caring for Adult Sons and Daughters with Disabilities

Atlantic Region Issue Paper

Older parents caring for adult sons and daughters with disabilities throughout the Atlantic Region have dedicated their lives to supporting their loved ones. Regardless of their age, parents of children with disabilities need to be valued by government and the community, and their dedication must be supported as they struggle to do what is right for their child. For older parents the need to address public policy issues related to persons with disabilities has added urgency. Older parents will not rest until positive solutions are implemented to ensure ongoing quality of life for their sons and daughters.

This Issue Paper provides a summary of the results of a Policy Forum held at Mount Saint Vincent University on May 13 and 14, 2003, combined with other project research activities. The Policy Forum was sponsored by the Nova Scotia Centre on Aging as part of a project funded by Health Canada, and implemented in partnership with organizations throughout the Atlantic Region (see page 4). The Issue Paper has been distributed to contribute to the ongoing efforts of persons with disabilities, families, community advocates, and civil servants to improve government funded services and supports.

A VISION OF INCLUSION

The report developed by the Federal, Provincial and Territorial Ministers Responsible for Social Services called “In Unison 2000: Persons With Disabilities in Canada” presents a vision for Canadians with disabilities based on the concepts of equality rights and citizenship.

The report states that: “Citizenship is the inclusion of persons with disabilities in all aspects of Canadian society – the ability of a person to be actively involved with their community. Full citizenship depends on: equality, inclusion, rights and responsibilities, empowerment, and participation... A person is able to exercise full citizenship when they do not face barriers that significantly reduce their ability to participate fully in their community. Persons with disabilities and their advocates have argued that ensuring full citizenship is not just the right thing to do, but is also a matter of fundamental rights under Canada’s Charter of Rights and Freedoms.”

SEVEN SERVICE PRINCIPLES

Support services enable full inclusion when they are:

- 1. Person Centered:** Planning supports and services are based on the wants and needs of the person who receives them.
- 2. Individualized:** Support programs ensure freedom of choice and provide individuals with the option to receive direct funding to create and manage their services.
- 3. Holistic:** Program choices and options improve quality of life on all levels (home, income, employment, health, education, recreation, etc.)
- 4. Flexible:** Services provided are responsive to individual circumstances and changes that occur over time.
- 5. Capacity Building:** Support options are developed from the perspective of the person's strengths, assets and abilities. Strong networks of family members and friends are recognized as the foundation of support and the best safeguard.
- 6. Portable:** People can move out of a home, community or province and take their funding with them. Provision must also be made for travel outside of Canada.
- 7. Universal:** All people who have determined that they need particular supports will receive those supports.

POLICY GOALS

1. Planning Supports:

Parents and adults with disabilities need to be able to easily get information on programs, as well as any help they need to create a plan and get services. People who provide planning supports as “navigators” must be qualified and independent of the service system.

2. Trust Funds: The government of Newfoundland and Labrador has passed legislation to allow parents to set up a trust fund of up to \$100,000 for their son or daughter with a disability. New Brunswick also has made provision for trust funds up to \$75,000. It is recommended that trust funds up to \$100,000 be established as a standard throughout the Atlantic Region and that such funds not affect entitlement to receive income support benefits or disability services.

3. Flexible Supports Provided

Within the Parents' Home: Adults with disabilities living in their parents' home are generally provided with supports through provincial home care programs. The home care programs provide both housekeeping and personal care support to the adults, and respite support for their parents. The following is a list of standards recommended for Atlantic Region home care programs.

- a. No waitlists for services.
- b. Adequate hours of respite support available per month,

and provided in a flexible and responsive manner.

- c. Allocated support hours may be used as needed, e.g.: to provide a weekend of respite.
- d. Temporary emergency care is available in small community based homes, or provided in the parents' home.
- e. The option of receiving direct funding is available to enable adults with disabilities and their parents to hire people they select to provide support, including family members when appropriate.
- f. The list of core home care services includes supports for community involvement and participation.
- g. Supports are coordinated when home care is provided to both an older parent (due to age or illness) and their son/daughter with a disability who is living with them.
- h. Home care, particularly following an illness or operation, may be provided to people receiving community based supports (e.g.: while living in a group home).

4. Individualized Community Based Supports for Adults:

The following is a list of standards recommended for community based support programs throughout the Atlantic Region.

- a. The government of Newfoundland and Labrador made a commitment and a plan to move people with developmental disabilities out of institutions, and worked in partnership with the community

to develop a range of community based supports. A similar commitment and process needs to be pursued within Nova Scotia, New Brunswick and Prince Edward Island.

- b. No wait lists for community based services.
- c. The option of direct funding entrenched within policies and programs.
- d. Support services are provided based on need and not on restrictive labels (eligibility criteria). This will require that governments have accurate information on the need for supports, and are prepared to make funding for community based services a priority.

5. Accessible Transportation:

Accessible public buses, accessible taxis, and specialized transportation systems need to be available in both urban and rural communities throughout the Atlantic Region.

6. Coordinated Government

Programs: Government programs need to be guided by a vision of community living; delivered by a single department; and coordinated to ensure that they support all aspects of a person's life (holistic), throughout their whole life (seamless).

7. Protection for People During

Labour Disputes: The security of people who are provided with government funded support needs to be protected during labour disputes. People have the right to live in

their homes during strike action and receive essential levels of service from people they know and trust.

CONTACT LIST

More information on current efforts to promote the policy issues and solutions identified in this paper may be obtained from the following organizations.

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