

The Eight Needs of Senior Families Caring for Adult Children with a Disability

New Brunswick Association for Community Living/Seniors United Network

September 2008

Many families who have a son or daughter with a disability continue to provide a home and support to their loved one well into their sixties, seventies, and even eighties. As parents age they wonder what will happen to their sons and daughters when they are no longer able to care for and support them. In addition, a number of challenges often arise that have an impact on the lives of adults with disabilities and their aging parents:

- Sometimes, parents assume other care giving responsibilities for their spouse or other aging relatives. This can create additional stress and hardship at a time when individuals may be facing their own health issues or a loss of some of their previous abilities.
- In some households, one of the parents has pre-deceased the other leaving the support responsibilities in the hands of the surviving parent. This “single parent” status often means that the female parent is the person who has assumed the role of continuing to support an adult child with a disability, often with limited resources.
- As parents age, they often require assistance because their own declining health and abilities. As a result, their own capacity to provide support to an adult child with a disability decreases over time.
- Many aging parents have indicated that their supporting role has gone unbroken for many years resulting in the complete lack of any personal time away from their responsibilities. Some aging parents have not had a vacation in over 20, 30 or more years because of their on-going responsibilities.

Senior families have identified eight key needs that require attention and coordinated action at the community and government levels. These needs are described below.

- 1. Access to timely and helpful information about available support and options.** It is clear that aging families need help at a number of levels. They have noted that they only learn about possible support when they ask the right questions or when another family has received some help that they may be also eligible to receive. Families say they need support programs to take a proactive approach to providing information about available support.

- 2. Access to adequate support while they are providing a home and support for their adult son or daughter.** This need has a number of elements including access to respite/relief support and support for the physical care and community involvement of their adult sons and daughters, assistance with finding adequately trained and reliable support workers who are available when needed, an adequate back-up system when support workers are sick, assistance with book-keeping and record keeping (including a less frequent financial reporting period for government funded services), and help with developing and implementing emergency support plans when the parent is sick or hospitalized.
- 3. Access to assistance for the facilitation of informal networks of support for the adult family member with a disability.** Many adults with intellectual and other disabilities face increasing social isolation as their parents age. The facilitation of informal networks of support has proven to be a viable way to avoid this isolation and to ensure access to natural supports. Families need access to trained people who can effectively facilitate these informal networks as well as funding to pay for facilitation. Families also say that they need help with learning to “back away” from the full time responsibility they have as parent and care-givers.
- 4. Access to support to develop and implement transition/future plans for their adult sons and daughters.** This need involves having ready access to a resource with expertise in planning that can support families and individuals with disabilities to plan for the time when parents will no longer provide a home and support. This support has to involve the ability to plan for 2 to 3 years ahead and involve such help as linking people together who may want to live together and share support. It must also link with other planning mechanisms that support people to access government programs and funding sources.
- 5. Access to supported living options for adult sons and daughters of senior parents.** Many families want to develop and secure alternative living arrangements for their sons and daughters that will provide them with a good home of their own in the community with individualized supports. Families need access to a sustainable community mechanism/agency that will assist with the implementation of supported living arrangements. This will involve providing assistance to identify and recruit support providers, monitor living arrangements, address issues that arise from time to time (including crisis) and if necessary, take on the responsibility for handling funding and doing paper work.
- 6. Access to affordable housing options.** The development of alternative living arrangements for the adult sons and daughters of senior families will also require access to affordable housing in the community. Many of these

individuals with disabilities live on fixed incomes (often social assistance) and cannot afford market rents. Families say that they need housing programs that will provide choice about affordable housing options and that are not restricted to available housing units. This means access to housing programs that will attach funding for affordable housing to individuals rather than buildings.

- 7. Access to supportive public policy and resources.** To ensure that the above needs are addressed, families also need supportive policies and adequate resources. This does not mean that addressing all of these needs is a government responsibility – rather, the responsibility is clearly a shared one that involves strong leadership and support from government. Supportive policy will ensure that there is a framework for developing the capacity to provide supported living for adults with an intellectual disability, flexible funding for disability supports and affordable housing, funding through the Disability Support Program for the facilitation of networks of support, the provision of opportunities for transition/future planning and opportunities for families to contribute financially to their sons and daughters without penalty.
- 8. Access to advocacy support when issues arise.** Families say they need good access to advocacy support to address the issues that they encounter. As senior families age, their ability to advocate for themselves and for their adult children diminishes. In part, this advocacy support will continue to be provided by organizations such as NBACL. In addition, as informal networks of support are developed this advocacy role can be assumed by others. But families need access to government decision makers to address the issues that they are facing (e.g. designated people within government who can be approached on a regular basis). Families need a clear path to be able to have their issues and concerns addressed in a reasonable and timely manner.