

Meeting with Minister Michelle Stilwell Thursday, November 5, 2015 Parliament Buildings, Victoria Room 247 at 2:00 pm

Introductions

- Maria Squance, Karen Philipchuk and Linda Derkach
- We are family members with many years of experience advocating, volunteering and working in the community living movement.

BC FamilyNet Society - Who are we?

- FN is a volunteer organization of individuals, their friends and family members advocating for appropriate supports, delivered effectively and with respect for individuals, families and their circumstances
- Our focus at present is on older folks with developmental disabilities and their aging family members

Our Goals for the Meeting

- To identify what we as family members and advocates need from CLBC based on our experiences, problems and concerns, specifically two main areas:
 - Access to Supports
 - Safeguards
- To hear from the Minister about your perspective on directions for CLBC

Key Issue: Access to Supports

The Challenge to Get Support:

Many parents and siblings have had to go through a long and very arduous process to obtain necessary supports and too often are turned down at the end, or are only able to obtain temporary "band aid" supports.

Recommendations:

- Fix the dysfunction between facilitator and analysts
- Generate a culture where support for individuals and families is the primary goal
- Give parents and siblings the information they need to navigate the system

- Create funding criteria that are responsive to increasing needs, especially for those experiencing dementia
- Embrace pro-active and values-based planning before problems arise
- Strive for meaningful Family Engagement within a system focussed on the needs of individuals and families

Downloading to Families:

Parents and siblings of older adults with developmental disabilities are expected to take on increased responsibilities and provide more and more supports, even as they age themselves.

Families have always been involved in the lives of their sons, daughters and siblings; but every family has differing needs and abilities, and things change over time.

Recommendations:

- Implement the CLBC Strategy on Aging
- Ensure that senior parents are not being expected to take on more than they are able to handle.
- Ensure that alternative options such as group homes are in place for individuals when they or their families can no longer manage.

Key Issue: Safeguards

We know that what keeps any of us safe is having family and friends in our lives every day. This is even more important for people with developmental disabilities. With the move to place more and more individuals in home share situations, safeguards and monitoring become even more important. We know from many past studies that people living in isolated situations are most vulnerable to abuse.

Home share is not for everyone. But for those who want it we know what can help to make these situations more successful and safe:

- A long-standing, positive relationship between the individual and home provider
- The individual and care provider both want to do this
- Informal safeguards through the involvement of family and friends, support networks, staff in other programs serving the individual
- Formal monitoring through funders, health agencies, and independent agencies
- The monitoring guidelines on the CLBC website prescribe a home visit at least once a year, with two weeks' notice of a visit being given to the care provider. This is totally inadequate and probably useless.
- Many different levels and forms of monitoring and safeguards should be in place.

Recommendations for safeguards:

- A comprehensive safeguarding plan should be put in place that includes:
 - o appropriate planning for home placement based on relationship and choice
 - engagement and respect for family involvement
 - o formal and informal monitoring
 - o mandatory pro-active building of friendships and circles of support

Summary and Recommendations:

- FamilyNet has been advocating for improved access to supports and a robust safeguarding plan for many years
- The recent survey of families conducted by Inclusion BC confirms our concerns
- Where necessary, funding should be re-aligned or increased to have positive results
- Work to reduce the bureaucratic jargon that makes the system difficult to understand
- We look forward to the appointment of the new Advocate for Service Quality and hope that some of our suggestions to Paula Grant will be implemented, including an announcement and launch introducing the new Advocate and a plan to ensure that families know about the position and how to contact.

Thank you for giving us this opportunity to share the concerns of BC FamilyNet.