



May 14, 2014

The Honourable Don McRae  
Minister of Social Development and Social Innovation  
Box 9058, Station Provincial Government  
Victoria, BC  
V8W 9E2

Dear Minister McRae:

**Re: Meeting with Representatives of FamilyNet – April 15, 2014**

On behalf of FamilyNet, we wish to thank you for meeting with us on April 15, 2014 to discuss some of the concerns of our members. As a follow-up to this meeting, we are confirming the issues that were discussed.

**Our major concern for this meeting is the situation of senior parents and siblings supporting individuals with developmental disabilities, the fight to get needed services and supports as we all age, and the resulting frustration and mistrust.**

In particular, we touched on the following challenges:

**1. The long and very arduous process that many parents and siblings have had to go through to obtain appropriate supports.**

In some situations, the planning process has gone on for many months, and has been resolved only when families have threatened to go public, or found some other way to get around the numerous stalling tactics often utilized by CLBC staff. For people without families - or families not familiar with the system - it must be virtually impossible to navigate their way through. There appears to be a culture of avoiding spending money unless there is a danger of negative publicity.

We have heard from other parents that after spending a great deal of time and energy working to put a plan in place, they find there is no money to fund the necessary services.

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

As parents enter retirement themselves, many find they are expected to take on duties and responsibilities that once were part of support programs. It appears that agencies no longer advocate for individuals, nor do they provide coordination of services. Unless an individual resides in a group home or other contracted service, senior parents and siblings must coordinate programs, advocate, ensure the living situation is adequate, apply for ferry and bus passes, connect with various support workers in different programs, manage all dental and health needs, buy clothes, arrange and pay for other activities that make life fun like art lessons, physical activity, holidays – and of course all travel to and from these daily activities.

We have heard of many families mortgaging their homes in order to purchase a condo or town home – and while they want very much for their sons and daughters to live in decent housing, this can become a serious burden for many parents who are now in their 60s and 70s.

**Parents have always gone above and beyond to ensure their sons and daughters with disabilities have a comfortable life. But now it seems that we are expected to do more and more as we become less able financially and physically to do this.**

And again, what happens for individuals with no family or families who can barely manage themselves.

**3. Lack of Monitoring and Oversight**

Monitoring of service providers was eliminated with the move to CLBC. Licensing only responds to complaints. We know that monitoring is key to the health and safety of individuals, and now it seems that this role is left to parents, siblings or friends who may be very reluctant to complain to the very people providing the supports. In fact, this is the reason that many parents are extremely reluctant to complain to or about CLBC as they fear it will affect the supports to their loved ones.

**4. The move to the “home share” model – to save money and not because it is right for the individual.**

For the past 35 years or more, it has been recognized that a variety of residential supports is necessary to meet the various and changing needs of people with developmental disabilities. We know that many people thrive in group homes while others are very happy living in an individual private care setting such as the “home share” model, while many others live in their own home or apartment with minimal supports. And we know that there are not unlimited funds. But to concentrate on

closing group homes to save money only to move people into settings that may be dangerous for the individual and the “home share” family may prove to be foolhardy. In addition, it should be recognized that though an individual private arrangement and apartment living works for a younger adult, needs may change over time requiring a move to more staff and support, and even group home living. For example, people with Downs Syndrome may be very capable and independent through their teens and young adult years, but many will develop Alzheimer’s before the age of 50, requiring a move from independent apartment living to group home support.

**Some Suggestions to Consider:**

- CLBC return to the original values and principles upon which community living was based and CLBC was created:
  - Honour the needs of the individual and provide supports that are appropriate to the individual and not what is needed to balance the budget
  - Include and respect the involvement, wishes, knowledge and wisdom of the individual’s parents, siblings and advocates.
- Monitor services and supports in order to ensure that the safety and rights of individuals are protected
- Require coordination among services.

We thank you very much for listening to our concerns, and for your understanding that these issues are real and important, and critical to the welfare of the people for whom we are mutually responsible.

Sincerely,

Anita Dadson, President  
Linda Derkach, Vice-President  
Cathie Waddington, Board Member  
Karen Phillipchuk, Parent member