



President's Report Annual General Meeting November 18, 2015

Introduction

As I looked back over this last year, and contemplated what I would include in this report, it occurred to me that things have not changed significantly, although there are a few glimmers of hope. While we may make progress from time to time, family members and individuals with disabilities know that we can never rest on recent successes. We must be ever vigilant to ensure that improvements in supports and issues are not eroded, and that we continue to move forward to a time when inclusion is a given, families are not forced to fight endlessly for needed supports, and that respect and openness is built into every interaction and relationship.

FamilyNet Goals

A few years ago, the FamilyNet board made a couple of important decisions regarding goals for the society:

- First, that we should continue watching over policies and practice in community living
- Secondly, that we would focus our efforts on supports to older adults and the challenges of older parents.

My report will focus on these two areas.

Community Living Issues in 2015

Issue: Access to Supports

Many parents, siblings and advocates 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.

Our recommendations to address these challenges within CLBC:

- The roles of the facilitator and analyst will be clear and well-understood
- Support for individuals and families will be the primary goal
- Parents and siblings will be given the information they need to navigate the system
- Funding criteria will be responsive to increasing needs, especially those experiencing dementia.

- Planning will be pro-active and values-based.
- Family engagement will be meaningful, within a system focussed on the needs of individuals and families.

Issue: Downloading to Families

Parents and siblings seem to be expected to take on increased responsibilities and provide more and more supports, even as they age themselves. There are many examples of families developing housing options, creating day programs, providing residential supports as the housing options through CLBC seem to be shrinking.

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 take an even more critical role.

Safeguarding individuals begins right at the time when a placement is being planned. If home share is to be the model for most people eventually, then the following must be considered:

- There should be a long-standing, positive relationship between the individual and the home provider.
- The individual and the care provider must both want to do this.
- Informal safeguards through the involvement of family and friends, support networks, staff in other programs serving the individual should be created.
- Formal monitoring through funders, health agencies and independent agencies should be in place.
- Many different levels and forms of monitoring and safeguards should be in place.

These three issues: **Access to Supports**, **Downloading to Families** and the need for **Safeguards** have been woven into all meetings that FamilyNet Board Members have had with Ministry and CLBC representatives.

Issue: Physician-Assisted Suicide

While FamilyNet decided not to take a stand on this issue, we decided that as individual board members, we would become informed on the issues and challenges presented by the recent Supreme Court of Canada (SCC) ruling.

I attended a session at the Inclusion BC AGM and Conference in May 2015. Dr. Tim Stainton, Chair of the Canadian Association for Community Living (CACL) Values and Ethics Task Force, made an excellent presentation on what the Supreme

Court Decision said and why we should be very concerned. Essentially, the decision by the SCC is broader than any similar legislation anywhere in the world. It will have far-reaching ramifications and is not just about old folks at the end of their lives having a terminal illness. The criteria for obtaining physician-assisted suicide is the most liberal among other jurisdictions having this type of legislation. With this new legislation, a person who is depressed can refuse treatment and apply for assisted suicide. An incurable illness need not be present. And there is an assumption that disability equates to suffering, thereby making assisted suicide available to a person with a disability.

CACL continues to work on developing safeguards for people with developmental disabilities under this new legislation.

BC FamilyNet Activities in 2015

Review of the Advocate for Service Quality Position – August 2015

Following the retirement of Jane Holland in January 2015, and before the government could appoint a new Advocate, the appointment of a new Minister resulted in a review of the position by Paula Grant who also took up the position of Acting Advocate for Service Quality during the review. In August, FamilyNet made a written submission to the Acting Advocate, and four of us were able to meet with Paula in September to discuss our submission in more detail. While we had asked that the position become independent much like the Representative for Children and Youth, it was made clear that this would not happen. Rationale for this is that it is believed that internal advocacy is a more effective way to make change, getting everyone on board rather than using confrontation.

Our other suggestions were well-received, and we look forward to a new Advocate being appointed in the near future. We are hoping there will be a “provincial launch” when the new advocate begins work, and that efforts will be made to ensure that families and individuals throughout the province know of and are able to easily contact the Advocate should it be needed. We also hope that consideration will be given to our suggestion for a reference group to meet from time to time when needed as a sounding board and to identify generic issues and trends.

Presentation to Michelle Stilwell, Minister of Society Development and Social Innovation – November 2015

FamilyNet made a presentation to Minister Stilwell on November 5, 2015 in Victoria. Regrettably time did not allow us to fully understand each other’s positions. The

Minister seemed most concerned about increasing independence, while we were advocating for our loved ones under circumstances such as dementia where independence becomes severely reduced. These of course are not mutually exclusive goals, and our discussion with the Deputy Minister confirmed the Ministry understands this.

Meeting with Mr. Tom Christensen, CLBC Board Chair – November 2015

Much time has been spent preparing a discussion outline for a meeting with Tom Christensen and Seonag Macrae of CLBC on Friday, November 27. Our goal is to have a discussion about the CLBC Board, its composition and our suggestions for improvements. We also want to hear about progress on issues raised last year with Ms. Macrae.

Conclusion:

From time to time, board members question whether our FamilyNet Society is still necessary and relevant. And while we struggle with the challenges of geography and effective communication as we age ourselves, it is clear to me that we need to continue our goal of watching over community living, identifying challenges and continuing the conversation with CLBC and government.

Linda Derkach
President, BC FamilyNet Society
November 18, 2015