

**FamilyNet Meeting with Seonag Macrae, CEO Community Living BC
Wednesday, November 5, 2014 at 1:00 pm, Airport Square
Agenda**

Welcome

Welcome Ms. Macrae to her new position and thanks for meeting with us

Introductions

- FamilyNet History
- Initial hopes for CLBC

Our Purpose for Meeting

- As one of few volunteer advocacy organizations in BC, we feel it is important that we bring forward the issues and concerns that we have experiences, or that other parents, sisters and brothers identify and bring to our attention.
- We want to present the challenges that families and individuals are experiencing with CLBC, give some examples of those challenges, and discuss what might be done in the future.
- While our examples are from our experience and thus deal with issues of older parents, we know that many parents are experiencing similar challenges and fears.
- Although insufficient funding is an ongoing challenge, many concerns relate to issues of values and process that don't necessarily require additional money.

Issue One:

The long and very arduous process that many parents/siblings have to go through to get the appropriate supports for their family member

- Dysfunction between Facilitators and Analysts
- Apparent focus on protecting funds and the system rather than supporting individuals and families, for example:
- Withholding information that would help with navigating the system
- Ignoring the service plan
- Funding criteria not responsive to changing needs, especially for those experiencing dementia
- Lack of pro-active planning

Issue Two:

More Being Downloaded Onto Parents

- As I think back to my time as a member of the Transition Steering Committee that prepared for the creation of CLBC, I remember government stating that parents and the community will be expected to do more. That notion is alive and well – and quite frankly insulting and ill-conceived. To say that parents/siblings have always done a lot for their sons and daughter with disabilities would be an understatement.

- And now parents are being expected to do more and more even as we get older too.
- Personally, I see that that functions previously done by support workers are being downloaded to parents. Some things are fairly small – applying for bus and ferry passes – but others are significant: coordination with staff in different programs, taking care of all health and dental needs, monitoring what’s happening since no one else seems to be doing it. And most importantly, making sure our sons and daughters have a decent place to live because no one else is going to do it. For us and many parents this means purchasing a condo and taking care of everything that that entails.
- In addition, there are the things that parents and siblings will do and have always done – purchasing clothes, medical and dental appointments, holidays, activities sports, entertainment, etc.

Issue Three:

Lack of Monitoring and Oversight

- Monitoring of service providers was eliminated with the move to CLBC and the elimination of social workers who filled this very important role
- Licensing only responds to complaints
- Service providers can pretty much do whatever they want and then ask for forgiveness later.
- People with disabilities are very vulnerable.
- Monitoring is absolutely key to their safety and happiness.
- It seems that this role has been left to parents, siblings, family and friends who would be very reluctant to complain to the very people providing supports, or who really do not know what is happening on a daily basis.
- Ann many parents will not be seen to be unhappy or complaining about CLBC as they fear it will affect the supports to their loved one.

Issue Four:

Need for a Range of Appropriate Residential Options and Flexibility for Change as People’s Needs Change

Some points to offer:

- For the past 40 years in BC, it has been recognized that a range of supports is required to meet the needs of individuals - independent living, supported apartments, individual private care, group homes, living at home with parents, micro-boards – these are the living situations that in the past have been available to individuals based on their needs.
- Up to now, it appears that CLBC has concentrated on moving people from group homes to home share as an inexpensive option which may or may not be appropriate for the individual.

- Group homes are not for everyone – and neither is home share or individualized funding or living on your own. And most importantly, people’s needs change over their lifetime – and so must the services we provide.
- Home share can work well when properly monitored and supported and if both parties are happy, and include involvement of families. In the past, day program staff and social workers were involved in monitoring and keeping people safe.
- On the other hand, it is not appropriate to move people to group homes just because there is a vacancy or because of concerns about safety issues and fear of law suits.
- Information that has come to light recently that further illustrates our point is that many parents of younger adults are increasingly creating their own day programs and scrambling to create different living situations for their sons and daughters because they are not happy with the options that appear to be available now. So – yes – parents are doing more! Consequently, those who can manage to mortgage their homes and buy a condo for their kids are doing so, while others are doing such creative things as taking out life insurance policies on themselves so that when they die the mortgage gets paid off. Alternatively, many older parents without the energy or money are just very worried and do not know where to turn.

How Can We Start to Fix This

CLBC needs to go back to the original values and principles upon which community living was based:

- Honour the needs of the individual and provide supports that are appropriate to the individual
- Include and respect the involvement, wishes knowledge and wisdom of the individual’s parents/sibling/friend/advocates
- Welcome the good news and the bad news so that parents feel comfortable bringing forward negative comments and criticisms and suggestions for change.

In other words: Create a culture where individuals and families are the first priority.

Create a system that is responsive to the individual

- Plan proactively in conjunction with other services (eg, health) for changing needs as people age.
- Adjust funding criteria to meet increasing needs of people with dementia.
- Change the facilitator’s role to actively problem solve with families by providing information about available services and supports, and the process/criteria/timelines for funding a desired service or support. Individuals and families need someone working on their behalf as did the social workers prior to CLBC.