

BC FamilyNet

Comments for November 30, 2010 Forum in Victoria

Update: November 27, 2010

BC Family Net Society, initially called BC Federation of Families, was established in 1995 by a group of family members and self-advocates. It arose out of the mounting concern over the need to hear from families who could provide an independent voice about the services available – or perhaps better said - not available for their loved ones.

Remember back to that time. The last BC institution for people with developmental disabilities had just been closed and celebrations were many. Most of the residents leaving the institutions like Woodlands and Glendale moved into group homes for four people. A whole new vision and understanding that persons with developmental disabilities could live successfully in the community and be contributing members was fostered. However, families with sons or daughters at home were still facing mounting wait lists to receive help and, in particular, children about to become adults. A decision to lobby the government of the day resulted in “Stop, Look and Listen and Honour the Commitment to Community Living” culminating in a huge Rally in Vancouver’s Robson Square. The result formed the basis for a commitment to a greater priority for service to this vulnerable population.

Now fast forward to the 21st Century. Five years ago a new delivery service was established – CLBC - with promises of choice, better planning for transition, and best of all, a seamless, lifelong delivery of services. The Board also was guaranteed to have more than 50% family composition, including 2 self-advocates. Now the board composition has changed and the children’s services have been returned to MCFD. And the cost for all this has been enormous.

We at FamilyNet hear from families who are struggling to cope with the reality of having a child with a developmental disability and often with a physical disability as well. They cope as best they can and need to rely on a community that is committed to help when in need. On the whole, support for children is available through early childhood intervention, in-home support, supported day care, inclusive school programs and special recreational programs.

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However, these services are now experiencing cutbacks which create mounting pressure on families. The next big hurdle for families is transition to adulthood when the child leaves school and services already gratefully received are terminated and any planning that is being considered is mostly delayed due to lack of resources being available.

Now we face another serious crisis in Community Living with the budget shortfall forcing CLBC to look for ways to find savings. Naturally the more costly Group Home model has been targeted. We have already heard of attempted closures without proper consultation with families who have come to rely on this resource, not to mention the residents themselves, many of whom have shared this home for many years and view it as their family. At its AGM earlier this month, FamilyNet heard from a sibling about the attempt to close a home that had been his sister's for over 20 years, and the incredible distress and frustration the family has experienced. In addition, we cannot forget the incredible support to our loved ones given by paid staff in these homes, offering expertise and loving care as well as lasting friendships that have developed over years of service.

Home sharing, foster care and independent living models have emerged over the past many years and while these are appropriate for some people, they are not without risk, especially for those without family involvement. As these cutbacks have been announced, FamilyNet has approached the Minister responsible through meetings and letters, submissions to the Budget Reviews Committee and meetings with CLBC staff expressing family concerns, but sadly there have not been any real changes.

Funding for this vulnerable sector of our society must receive a higher priority. Let families and those with expertise work together to see that service design is appropriate to the needs of the folks served and not just based on cost. Involve families in the decision-making, offer true choice and use the enormous talent that is in our communities in making community living truly possible.