

Stories and Letters outlining concerns and impact of funding and service cuts:

Sent: Fri. October 20, 2006
To: OfficeofthePremier, Office PREM:EX

Subject: Something good

Dear Premier Campbell,

I have been thinking about you a lot as of late and wonder how you must be feeling after all the negative publicity The Liberal Government has been receiving about People with Disabilities.

This is the perfect time to redeem yourself, do something good for these people who are suffering on a daily basis without even the basics of life that we take for granted. Put back the \$150 million that was taken out of the Social Service Sector. Get rid of the Wage Grid that ensures NO Employer can attract employees or retain them. There is no stability, no growth and no ability to retain staff with this Wage Grid. There are Employers that offer their employees \$50.00 gift certificates for each new person than bring in.

Ensure that all individuals with disabilities have the ability to afford the medications they need; trained staff to assist them, give some time to hear the concerns of the families of people with individuals with disabilities. Listen to the people of this great Province when they tell enough is enough.

We do not accept that we do not matter. We do matter, we are important and we are worth ensuring a quality of life that reflects those facts. I await your timely response.

Louella Vincent, Surrey, B.C.

(Premier's response to above letter)

From: OfficeofthePremier, Office PREM:EX

Date: 10/24/06

To: Louella Vincent

Subject: RE: Something good

Thank you for your e-mail regarding Persons with Disabilities.

I can assure you that this government is working hard to provide support to those British Columbians who need it most. Currently, Persons with Disabilities receive the highest rate of assistance available in BC and the third highest among Canadian provinces.

I will share your correspondence with the Minister of Employment and Income Assistance, the Honourable Claude Richmond, for his review. I know that he, and his staff, will give your comments every consideration.

Again, thank you for writing. I appreciate your taking the time to share your views with me.

cc: Honourable Claude Richmond

To: Hon. Tom Christensen; Hon. Linda Reid

Sent: Sunday, October 22, 2006 7:20 PM

Subject: My Experience with CLBC

I write this email after great consideration, having decided that I need to tell my story about my experience with CLBC.

On Oct 3, I had a crisis with my son and called CLBC at 4:40 pm. The office was closed and the answering service never came on. I double checked the phone number and still no answer. I checked CLBC's website, called the Vancouver number and was told the number had changed. I called the new number and talked to two people before being put to the MCFD nightline.

The reason for the call was my 6 year old son with autism was on the roof again. (I have 3 sons, 2 of them on the autism spectrum, the third with special needs, and it's impossible to watch all 3 at once, especially when trying to cook dinner, etc. Lately, he has taken to climbing on the roof whenever I don't pay attention to him) I was anxious and needed to let CLBC know about my concerns. What I thought was a call for support, turned into two weeks of stress and no supports.

When I explained my situation to the night person at MCFD on Oct 3, she said I sounded stressed. I was stressed. I just spent 20 minutes trying to leave a message and I wasn't happy. She also wanted to know why I couldn't put my son in his room, to which I replied have you ever raised children with autism? The conversation ended with a promise to send my concerns to CLBC the next day.

On Oct 4, I got a phone call from a CLBC facilitator. He came to my house on Oct 6 and spent time going over a plan for what support I needed. We agreed that what I needed was respite/child care worker to come into the home to help me out during the difficult hours. He left indicating that he would submit this as an urgent/emergency request for support.

That afternoon, I received a phone call from MCFD wondering how my son was. I said he was standing next to me. She then asked if I could assure her that he would not go on the roof. I told her I couldn't and asked her who she was. She gave me her first name and said she was from MCFD child protection. I freaked, thinking they could take my children away. I didn't handle the phone call well and told her to contact the facilitator and the team leader that knew me at CLBC because they knew our situation and I was trying to get more help. I contacted a lawyer and he figured I had nothing to worry about. I also called the facilitator about the child protection call and he thought that this would make my case stronger. On Friday, I tried calling the child protection person back. I left a message indicating that I was calmer and could she call me back. She never did.

On Oct 10 I called the facilitator to ask where my request stood. He later called back and asked to set up a meeting, which we did for Oct 11.

On Oct 11, he advised that I was declined emergency services. I wasn't happy that in rejecting the request, the CLBC analyst suggested that I use my autism therapy funding to pay for a child care worker (that is not permitted under the autism therapy program). The analyst also felt I wasn't utilizing my existing services appropriately and that because I'm a student and not working outside the home, I should be able to do housework while my children are at school.

I asked the CLBC facilitator for a response in writing explaining why the analyst rejected my request. On Friday, Oct 13 I hadn't heard anything so I called CLBC and was advised that the facilitator was away until Monday. I then phoned the analysts supervisor and left a message. My phone call was returned by the analyst who had rejected my request. We had a lengthy conversation. I asked for a letter explaining why I was turned down. He wouldn't answer me. He referred to my existing services. I explained I was only getting SCD (which allow my sons in home childcare support) for 15 hours a week, though I could receive 20 hours. I only required 15 hours and wasn't going to take more than I needed because I knew there were many other families on the waitlist. The analyst told me to apply for those 5 hours. I told him, even if I did apply it could be a year before I received them and that didn't help me in the interim.

The analyst also alluded that I could use my autism therapy dollars. I told him that my contract stated that I couldn't use autism dollars to purchase childcare. He told me I could use the \$\$'s for a behaviour interventionist. I replied that I would then be doing therapy and not childcare and it was childcare that I needed, not intervention. I also told him that I couldn't use SCD funding for intervention or Autism \$\$'s for child care.

The analyst also told me that CLBC doesn't supply emergency funding. I asked if I could quote him and he didn't reply. He said MCFD told me I could get emergency funding from them. I said what MCFD told me is if I needed a break because I couldn't cope that they would send someone over so that I could get out. I was also told that MCFD doesn't advertise this because if everyone knew about it, their budget would be blown (my words).

I told the analyst that CLBC should not be telling families to use their autism therapy dollars to fund child care. I had heard before from other families that CLBC was suggesting this and had previously reported this concern to CLBC managers.

The analyst wouldn't reply when I asked again for a letter about why he refused me emergency funding. He said he wanted to sit down with me and go over what services I have and come up with a plan. I explained that I understand very well how the system worked and that when I had needed emergency funding before, I could call up the team leader and explain the situation (e.g. having to call the police because my son ran off) and if there was some funding available, they would help me. Now that I am asking CLBC for help and I am getting the run-around.

I agreed to a meeting on Tuesday October 17.

Also, on Oct 13, Child Protection went to my oldest son's school to question him about our family. They then came to my house and because I wasn't home, the social worker left a message saying to contact her ASAP. I freaked. My oldest son has an anxiety disorder and I was extremely concerned about the impact of this on him. I called the school and was very upset because the school is aware of his disorder and didn't protect my son and a complete stranger was asking him questions about our family.

I also contact the lawyer who advised that I get in touch with the social worker and that he would also do the same. I contacted the social worker and agreed to meet her on Tuesday. I then called the CLBC facilitator and advised that I was inviting the MCFD social worker to our meeting.

On Oct 17 the social worker arrived at 10:00. We discussed our families case, what services we were getting and what I needed. I showed her where my son got access to the roof and what we have done to ensure that he can't get access. I can't guarantee that he won't get access, but now that it is raining he is less likely to go on the roof.

The meeting with CLBC and MCFD was very difficult for me as a person and a parent and here is my recollection of how it went.

The analyst controlled the meeting. He starting by questioning me about how I spend my autism funding. He drilled me about the funding and where it was spent to the point where it was uncomfortable for me. He kept combining the funding for both sons and I had to keep insisting that each child's money be discussed separately before he finally consented. The questioning went on and on and it felt like he was looking for any fault in my spending of the autism funding.

He then started on the SCD hours, questioned me about how I used the hours. Again this went on, with him insisting that I wasn't utilizing them effectively and that I should be using the 20 hours when I only needed 15. At one point I finally said to him, "this is the 4th time I am saying this, SCD hours are to be used for when I work and for when I am studying, I cannot apply for hours I don't need." I also stated that "this is the fourth time I am telling you what my contract says I can spend the money on, either you are not listening or you are not hearing me". I also told him that I have to supplement the SCD dollars because I only get \$12 per hour. He then started trying to argue that the funding paid \$15/hour instead of what I was actually getting.

During all this, he didn't seem to have any concern about my oldest son's needs. I explained that I needed to be there for him just like I needed to be there for his brothers who have autism. I explained that my oldest has an anxiety disorder and that his needs were just as important. He asked me if my oldest was designated as special needs and I said he was. He then suggested that I request SCD funding for the oldest and use that to cover my needs. I was appalled, I even asked him if he wanted me to lie. My oldest son doesn't need support in a child care setting, nor I am prepared to lie to get funding that I don't require. I made this very clear. What I require is a helper that can come into the home and help during the most trying times of the day. The analyst indicated that he would be looking into SCD.

The analyst also indicated that I wasn't using my respite hours appropriately. He had a spread sheet showing that I used 4 hours in April, nothing in May or June and 95 hours (I think) in July. He failed to mention that the agency that provides the respite couldn't supply me with anyone that was able to support my family during that time.

It felt like he was trying to make out that I didn't need the support that I was asking for or that he was trying to trip me up into admitting that I wasn't using the hours that I was already getting.

He then asked the social worker what services Child Protection had to offer this family. The reply was nothing. The file is closed because there is no apprehension issues here. What this family needs is respite and that is your (CLBC's) department.

The analyst also asked about the behaviour plan to be put into place for my younger son to keep him off the roof. I told him that once I had funding, my consultant would provide the plan and it would be implemented. The analyst asked to see the plan, and asked if he could speak to my consultant. I said he could speak to my consultant if he was prepared to pay the fee, because I wasn't going to waste my child's funding to brief him on the behaviour plan. I did indicate that I would provide the plan when I got the funding.

The meeting concluded 90 minutes later with the analyst advising he would check into SCD and get back to me. He also suggested that maybe I would be better off with direct funding. I said I had been told by a CLBC manager that direct funding would not be available for children until this fall. He claimed direct funding had been available for a year. Who am I supposed to believe?

I advised the analyst that I want all correspondence in writing. He agreed. I advised the CLBC staff that I felt like I was

being dissected. I didn't feel like I was being supported by the analyst. My feeling is that he believes I was mis-spending my existing funding. I feel violated by the very people that are supposed to be there to help me.

I understand that there is a complaints process to follow with CLBC. But I don't want this swept under the carpet so that CLBC can continue to allude families to believing that they are doing a great job. CLBC came into my home as strangers. I felt like I was under interrogation about my funding. I felt that CLBC was asking me to violate my contracts and to lie to obtain more funding from another source. Twice I have spoken to CLBC about the autism funding issue, as other parents have told me that they were advised they could purchase respite with autism funding. I feel scared for the families that are duped into using money for which it is not intended. What's going to happen when they are interrogated and it's found that they did spend the money incorrectly?

CLBC has caused me significant stress these last two weeks. I looked for them for help and I was put under a microscope in my own home. So much for CLBC being about families, it is about gate keeping the money. Will I get any extra funding? I have no idea. The intent of this email is to advise you what happened to me. If it happened to me and I feel confident that I am fairly well informed, then what is happening to families that don't understand the system and are relying on CLBC?

Cyndi Gerlach

Received: October 11, 2006

To: info@bcfamilynet.org

Subject: Frustrated mom

Hello,

I have three sons who are intellectually disabled. I had a very hurtful day today while trying to even get anyone to admit my third son has needs. My first son was only diagnosed as mild-moderately intellectually disabled just in January of this year after much effort on my part to get the assessments he needed to label him as such. I am part of the Black hole group as your web sight calls it. My oldest son finally is in a special education program associated with North Island Distance Education School. Is there not a more practical way to get our children what they deserve for education? There are thousands of children falling through the cracks it is deplorable that this is allowed to go on. All children are sent to us from a loving God, as parents some of us feel absolutely responsible to God for the care of each child. I don't want more red tape, these are unique conditions we find our children in we need unique solutions. Who says we each need a special day or time for an assessment. Get the qualified person's and a classroom full of kids present tasks, get the doctor to go around and make note about each child, but get them assessed. Everyone knows that a child's greatest chance for learning is when they are between the ages of birth and 6, so why do I keep getting told that we must wait, they are not old enough for the assessments. We are missing such a great chance of helping our children. I am sorry, but I have been crying most of the afternoon. I hate how complacent many things have become. There are no ethics, or morals I hate it. HELP HELP HELP!

Received: Oct. 7, 2006

To: Government Finance Committee

Copy to BC FamilyNet Society

Subject: Select Standing Committee on Finance- Urgent funding needed!

To Whom it may concern:

I am writing the Select Standing Committee on Finance this e-mail to URGENTLY request that MCFD continue to support families, children, and adults in our province with special needs by allocating another \$75 Million dollars into this budget. Do you realize there are 3,150 adults with special needs on waitlists that have been identified as requiring some kind of supports through CLBC between April 1,2006 and March 31, 2009??? This waitlist does not include children, or those currently receiving some kind of funding supports. Every year there are more children, and thus adults, that require support, and this Ministry is simply not providing enough funding to meet the needs.

My son turns 19 years old on Dec. 31st of this year. We have spent the last 5 years putting together a proposal for funding supports to begin Jan.1/07. We have been told that we will receive this funding to support our son. What about the other 3,150 people in desperate need of service??? Or those who have an IQ above 70, but who cannot function in society without support?? Right now our government has a surplus of funds. RIGHT NOW is the time this Ministry needs to speak up and advocate for these vulnerable British Columbia Citizens. As a parent, I can tell you, we who have disabled children or adult children do not ask for something we do not need! Listen to what people are telling you, look at the numbers, and do the right thing by being their advocates. Tomorrow you could have a family member that is disabled, you never know, it is

not something we ask for!

Think about it.

Thank you so much for listening to my concerns and taking the time to address them. I look forward to your response.

Parent from Quesnel, B.C.

Received: September 18, 2006

Subject: FamilyNet Update: Current Issues/Upcoming Meetings

To: BC Family Net Society

I am the mother of a child with Autism Spectrum Disorder, other developmental challenges, behavior disorders (A.D.H.D., O.D.D., vestibular disorder, etc.) and Diabetes. I agree with all the concerns expressed in the email I received on August 22, 2006. I currently receive Autism funding for my son and the service of a Life skills worker once a week.

In addition to the concerns stated in the update, I also believe that the amount of funding families receive for their Autistic children above age six is not near enough to continue the progress they have achieved. With the current funding as it is allocated quarterly and the time frame that it has to be spent, hinders therapy and access to tools and resources that families can provide for the children.

In particular, I send my son to a Life Skills Coach (the only therapy he gets) one hour once a week. This helps with some issues but other therapies are needed. We started at twice weekly, scaled back to once a week and now may have to scale back to once every two weeks so I can keep affording what little he has and possibly get some occupational therapy items to practice fine motor skills at home. Why does it seem that when a child makes progress the bureaucrats pull the rug out from under their feet? They do not understand that without therapy, our children no longer progress but regress and are harder to manage. How can they expect our children to become functional members of society to the best of their abilities when their abilities rely on therapy? The current program keeps parents like me at home with their children. I am always on call to pick my son up from school and keeping him home the next day at the request of the school so they can debrief the episode. He attends part time as there is not enough E.A support. I can't imagine how anyone with a job outside the home can manage without losing their job due to frequent calls to leave work and pick up their child. It's difficult enough staying at home on income assistance and trying to develop a home based business, while providing in home care for my son, who most do not understand, and his two younger siblings.

I can only speak for myself but, I'm sure there are other parents that live month to month and often fall short financially each month just to cover the basics, never mind trying to allocate extra resources for special needs. In less than 3 years I've moved myself and my boys 3 times. Each time I've had to leave a home, my son's outbursts have played a part in the reason for being asked to leave. Each landlord however, has given a positive reference so that we will not have a problem finding a new place to live. No one wants to say they asked someone to leave due to their disabilities, so they keep my son's behavior under wraps. I do however notify the next landlord that my son is special needs and that they will hear him hit the walls and scream. You can never truly prepare anyone for what is to come. During difficult adjustment times, I live each day praying that the landlord will not evict us and will continue understanding that my son has disabilities that cannot be cured and that he is a good boy. Medication helps Band-Aid some behaviors but we live with children whose disabilities are life long.

If I had the finances to renovate my home to accommodate my son's disabilities life may be a bit easier. It is so amazing how our life affects others outside our home. The likelihood that the police will appear at my door also looms over us as neighbors who do not understand or know what is going on can only imagine from what they hear. I cannot imagine what my son's emotional state would be like if he ever was taken to jail. The police have been called in the past and requested ambulance assistance. He was taken to the emergency dept. at BC Children's Hospital and left in a room with a pad on the floor for psychiatric assessment and until I arrived to be with him. A security guard was posted outside the room.

In the last two weeks, my son has had a few meltdowns adjusting to the routine change of back to school. During one episode hands full of hair were ripped from my scalp, my head, face and arms bruised while he screams profanity at the top of his lungs while I do my best to contain and calm him. My son is approximately 6' 2" tall, 220 pounds at age 14. I am almost 5' 5" tall. I don't know anyone that I could pay enough to endure what I do to care for my son. Please add these concerns for required therapy at any age, to your list when presenting to the CLBC, MCFD and other agencies. My wish is for my son to eventually be independent and live in a place of his own. I know that with multiple disabilities, he will need support but who will help him if ever I'm not there? I do not want him to fall through the cracks and end up homeless or in jail because he didn't get the help he needed. I'll be here for him as long as I can but therapy needs to be a part of his life as a child and into adulthood whether at home or on his own.

If you feel you need to use my name please contact me anytime. I hope this small look at our lives is helpful in understanding that therapy helps a child become a more functional adult.

Best regards,
(name withheld)

Received: September 15, 2006
Subject: BC FamilyNet Alert to Families: CLBCReview of Staffed Homes

My concerns about the CLBC Group Homes Review:

- ** Any kind of move for a person who is handicapped with developmental disabilities (HDD) is difficult for them. My family member, for example, is blind so changes in the physical layout are not a simple matter for him. But also changes in physical place are difficult. Changes in personnel are difficult. Then factor in his being a senior as well.
- ** I am concerned because supposing he were moved out of his group home to place A, and A did not work out. What happens then? Will a place in the group home be kept during a trial period? Or would my brother be moved to Place B? and then maybe the place B people decide not to do pri-care anymore, so he is on to Place C. This could go on and on. I see no means of making it otherwise. He is 63. He could get lucky and find someone who is going to keep him in their home until he dies - but the odds are pretty low.
- ** My mother was promised (when my brother was moved into the community from the infamous Woodland's) that he would remain in this group home for the rest of his life. The promise is being broken. I think that things should be "grandfathered" for people like my brother whose parents were given what amounts to (or should) a covenant regarding care.
- ** Once out in a pri-care situation - who is going to monitor this? We are told that whatever-they-are- calling-social-workers- nowadays will have fifty (50!) pri-care situations to monitor? How good, and effective, is that level of monitoring going to be - especially for people who are blind, disabled, and can't speak for themselves, who can't go out to get help or make a phone call if they are being maltreated?
- ** Concern that the whole system of care for people with DDs is becoming a corporately motivated system, instead of a socially caring motivated system.
- ** Are these people doing pri-care — will they all be trained in handling various behaviours such as outbursts? Will they be informed in advance of behaviours requiring management, or will it just be a surprise (in the same sense that Woodland's would not release medical records when people were moved into the community). I can imagine innocent couples just freaking out when they are surprised by aggressive behaviours. And then the poor resident being bounced out p.d.q. We have a good system set up; it works well. If it ain't broke...
- ** If this pri-care experiment does not work out - are there any guarantees that the CLBC will take the placed people back? I'm not seeing that kind of assurance. And once they are "out there" they are very very very vulnerable.
- ** I see the CLBC and the BC Government in general, basically trying to treat these most vulnerable of our citizens as if they are basically just like regular folks. As if they do not need, from time to time, special services in regard to their disabilities.
- ** The no-assigned-social-workers and the call centre system is very impersonal, and very difficult for even the most gifted & typical of people. This new system sounds very not-user-friendly for people with developmental disabilities, never mind physical handicaps.
- ** Concern about the independence and objectivity of those who will "identify" those who should be moved out of group homes.
- ** Concern about the process of screening those who apply to do pri-care, and their motivations as well.
- ** Given the current prices of \$1500/month per person in pri-care, big concerns about people getting good food, proper medical attention in a timely fashion; the pri care people having the means (vehicles) etc. to move about people with disabilities; having the time/energy to get people out of the house for exercise and outings; having the funds to pay for admissions to things like swimming etc.
- ** Concern about burnout in the pri-care providers - and the moving about of their clients that would result if they become incapable of providing care. I believe that the care should come to the people like my brother who are in group homes -- that they ought not to be moved around like chess pieces in their home life; they need stability more than the average bear, given their disabilities.
- ** Concern about beds in group homes now not being filled so that those homes may become untenable, and have to close when they get down to one or two individuals - so the decision will be made by default. Unfair.
- ** Given the tumultuous history in recent years of the Ministry - and given the point directly above - that this latest endeavour is just the first step in many re-alignments, restructurings, downsizing of services, and what seems to amount to at times a "washing our hands of" the people with DDs in this province.

There's more - but that's it for now.
(name withheld by request)

Received: September 06, 2006
Subject: Re: Feedback now posted on our Website (responses to FamilyNet current issues update)

Thanks for all your work.

Here is another one...

I coached an athlete every spring for 7 years. This year his caregivers changed and he was not allowed to continue. I talked with many people but was unable to get the athlete back. He is unable to advocate for himself and I am concerned. On June 6, 2006 I filed a complaint. The complaint resolution policy states that "...all concerns expressed about service delivery will be reviewed as quickly as possible. The total length of time from receipt of a complaint to its resolution through the four steps will be no longer than 30 days". Currently it has been 90 days and there is no sign of it being resolved now or in the near future.

I am not confident that Community Living will ensure that those without a voice are provided with quality service.

Kelly Megyesi
Vernon BC

Received: August 21, 2006
Subject: IQ 70 (Response to FamilyNet Update: Current Issues/Upcoming Meetings)

As a parent of a 20 year old who has an IQ of 78 and a diagnosis of Autism I have been writing, phoning and e-mailing all who I can about our desperate situation. Over the past year he has become more frustrated, stressed and angry about his life in the community, where he has been called freak, mental retard etc. His anger has destroyed our home - chairs, walls, trees, bicycles etc. He has hit his parents, carried weapons, called the Police without good reason and is using lots of emergency resources when they are needed elsewhere. He has been taken to the hospital by the police as well as us and no one has been able to help. We are told to wait until October 26 to see a psychiatrist. He is a danger to himself and others yet Mental Health refuses us service and CLBC refuses to help. We have psychologists, doctors and behaviour consultants all stating his adaptive functioning and lack of executive functioning overrides any IQ level and state freely he needs support to live in the community. If they are the experts why is CLBC not listening. I have gone to see the Minister of Health, George Abbott and will be meeting with him again in September. Our son knows he needs help, especially with his anger and impulsivity. I cannot even begin to tell you how the inaction of all the social services to help has affected our family - we are prisoners in our own home. Add my name on the list of people angry about this IQ being used. I am next looking to go to the media about our situation. I won't be going away until we find help. Finally I would like to say that people like our son and others could contribute to society if they received help and without it, it will cost the taxpayer in jails, victim services etc. etc.

(name withheld)

Received: August 22, 2006
Subject: Response to BC Family Net Society 'Current Issues' discussion.

I have operated a family care home for 27 years.

The last 7 years have been directionless. ('World wars' are completed in less time).

Primary concerns. (briefly).

1. Poor morale amongst social workers (worst in 30 years), and the Ministry in general.
2. Apparent neglect of wage increase issues for non-union staff.
3. Apparent complete lack of monitoring.
(Accreditation doesn't count, - it is an expensive bureaucratic process having little to do with real lives of real people).
4. The incredible length of time, energy and money taken up with a process that is still confused and to date doesn't appear to offer much to a disabled person that wasn't available at the start of the process.

I am well aware that many good hearted and committed people have of course spent much time and energy attempting to develop a new model. Unfortunately it must be said that to date their efforts have not born fruit and the result is a rise in cynicism and frustration; not a good sign.

Manager, Family Care Home.

Received: August 22, 2006

Subject: FamilyNet Current Issues Update

There needs to be collaboration across all Government Ministries in terms of providing adequate supports for children, youth, young adults and their families. A thorough examination of the secondary disabilities that occur when adequate supports are not provided to support children, youth and young adults who have a need for extra support is well documented in the literature. One only needs to conduct an examination across ALL Government Ministries including corrections wherein it will be found that the cost to the taxpayer and Society is far greater. Yes, we need to get a handle on crime and we can start by providing adequate community supports so that the children of this Province, who are our future, will not be at risk for institutionalization in other settings at a cost far greater!!!! Pay now or pay MORE later!!!! We don't need to spend any more money on reviews, that money has been spent time and time again -- what a waste of money that could be better spent on supports!!!!

Joyce Preston said it years ago, "It's Not Good Enough" - her report is there for all to see along with numerous other reports. It's time for a change and the citizens of this Province have to simply speak up and say "it's not good enough", quit wasting precious time, and help children, youth, young adults and others who need supports NOW!!!!

This Government always finds a way to come up with money for other priorities. It's time that children, youth and young adults who require extra supports became a priority in this Province. There needs to be a focus on the next 20 years as opposed to the next election!

I want a Government run by Politicians who dare to be different! If this Government continues to do what it has always done, it will always get what it has always had. If there is no change....there is no change!

-from a parent

Received August 21, 2006:

Subject: FamilyNet Update: Current Issues/Upcoming Meetings

Re mental health

The loss of CLBC case management for all but especially for individuals with complex needs (mental health issues and/or challenging behaviours) is an area that needs further highlighting in your list below. I work for one of the mental health support teams (see ages 14 and up) and our ability to do our mandated work (of assessment and treatment recommendations) is being overwhelmed by a huge increase in calls to our team about clients in crisis (the 5 Provincial Mental Health Support Teams have never been funded to allow for crisis response and have not had budget increases since they were begun in 1992). Placement break downs, 'knee jerk' inappropriate placements with inadequate preparation or sharing of vital information, poor communication amongst CLBC between different cities, lack of any adequate crisis respite in almost all locations, lack of any comprehensive approach to crisis, increased++ response time and red tape to get any recommendations in place (Facilitator has to do a plan then give it to the analyst who then has to apply for funds- takes weeks-which is not helpful anytime but worse when someone is dealing with Mental health issues or medication changes).

The loss of continuity and lack of case management is potentially dangerous for many of these high needs individuals and is resulting in increased huge demands on the families (if involved) and the rest of the community supports who are trying to shore everything up and will result in negative response from the general community when individuals with complex high needs are not supported in a safe way.

- name withheld

Received August 22, 2006

Subject: FamilyNet Update: Current Issues/Upcoming Meetings

I agree with all the points you have made. The Black Hole at 19 is especially concerning to me! I was wondering if you/we could add something about "seniors", there seems to be no services for our individuals when they reach the time in their life to slow down and enjoy some different activities. I have tried on many occasions to have our individuals access the services available to seniors who are "typical" for lack of a better word and they are NOT accepting of most of our individuals. Thank you.

- Louella Vincent, Envision Society for Choice and Inclusion

Received: August 21, 2006

Subject: Under 70 1Q cut off (Response to FamilyNet Current Issues Update)

I am in complete agreement with all concerns as identified by Family Net Update: Current Issues/upcoming Meetings.

Our daughter now 24 yrs. old was cut off by Community Living when she turned 19. She has had a High-Functioning/ADHD/Anxiety-Depression Diagnosis since the age of 14 -- diagnosis done as an in-patient at B.C. Children's Hospital (a refinement of all previous diagnoses applied to her since the age of 3 by specialists)

She currently receives a Disability Check from the B.C. government. Period. End of assistance

Number of Self-Harm Incidences requiring Emergency Room admissions with or without the assistance of ambulance personnel -- can no longer remember the total -- usually once a year.

- name withheld

Received: August 22, 2006

Subject: How to Administer a Government entity (Response to BC FamilyNet Society Current Issues Update)

To Whomever.

My brother had been in institutions, including the infamous Woodlands, for 74 of his 85 years. PRACL (service provider) was his last and most dignified resting place for the last 19 years of his life. Even in that haven, the only time any controversy about care was raised was when the Welfare Department tried to dazzle everyone with its brilliance, eg: a young man of considerable agitation and difficult handling, was placed as a roommate of this old gentle soul, on the absurd comparison that they had both come to Powell River from Glendale (institution). It was not long until a near-tragedy happened, and thanks only to the vigilance and professional care of PRACL, the scalding my brother received was soon resolved. Then several years later, a great issue, approximating the Lumber Dispute, arose over his ability to chew his food. Again the matter was resolved quietly as it had been intended by PRACL- a blender.

To give the government department some credit, I have no doubt that the personnel do the best they can under trying circumstances, but like a ship, the crew have to know what's happening and where the vessel is bound. When an incident occurs, is it not possible to render the conclusion about what happened and to fix the problem immediately. But no; children still are abused while in government's care, and Seniors in need of care cannot be provided with the appropriate care we have paid taxes, fought a war to defend and for what.

Studies are not needed. Everything the B.C.Government touches becomes a study. Nothing has improved and desperately needed care facilities are sadly, and critically inadequate and in most cases, unsuitable. I'll be the first to commend the government department involved for any job well done, but they have to do something to earn that accolade. In the meantime, if you want to study a perfect domain, if PRACL does it, do it, if they say don't do it, forget it.

Lorne Hardy

Received: August 23, 2006

Subject: FamilyNet Update: Current Issues/Upcoming Meetings

Thank you for consolidating these key current issues and concerns. I agree with **each and every issue** listed below. As far as CLBC is concerned, I feel that my family no longer has an ongoing relationship with anyone in a "social services/worker" type of role. I feel we have become a file somewhere and I'm not even sure where.

I do have an additional concern. I feel we need to mitigate risk by having an independent body that handles complaints and performs audits on CLBC, group homes, and service providers. (There is Licensing but they are only concerned about whether a service is being performed according to licensing regulations.) We need an independent QA/QC/Auditing body that is legally sanctioned to take action when inappropriate levels of services are being delivered and to investigate when complaints are filed.

I know this would be expensive but ... I wonder what the responses would be like if a comprehensive survey were to be sent to families about the restructuring and the outcomes to-date of CLBC et al. And wouldn't it be grand if this survey were to be repeated every 2 - 3 years. These survey results would represent a true "report card" of the success of the CLBC/MCFD model.

I understand that once the document is complete, you plan to meet with the stakeholders in an effort to find solutions to these complex problems. Your efforts are valued and appreciated. Again, thank you.

Received: Wednesday, August 23, 2006

Subject: FamilyNet Current Issues Update

I also have come across some annoying encounters with the New CLBC. We put in the 3rd time application for individual funding for my daughter, the last 2 times denied. The date we met with our social worker was around March 2006 and my social worker told me my daughter is on her top case. Now it is up to the so-called analyst to decide.

I have not heard from them and this is almost the end of August. I made a phone call to my social worker to find out what is wrong. These new breed CLBC Analysts sent 2 very important letters to the wrong address.

I talked to the person who denied our funding and who doesn't seem to know we had applied every year for 6 years since 2000. Didn't see my doctor's note. Doesn't seem to know anything about my daughter. She said everything now starts from scratch and that horrifies me.

It seems these new breed Analysts do not have to communicate with your social worker. Even if your social worker thinks you are urgent or her top priority, when the case goes to the Analyst, it is a completely different case. They have no idea who you are, never met you, have no feeling towards you, don't know your age, your health issue. My Analyst didn't even know my daughter was on the waiting list for 6 years until I pointed out to her. How disgusting and maddening that can be. And yet she has the power to fail or pass anyone.

We are to them just a figure, not human, that's why they can carelessly send out 2 important letters to the wrong address and don't bother to call. It is really a shame that we have to deal with this so called New group of CLBC Analysts. I might have to wait til I drop dead.

[BC FamilyNet Society August 21, 2006 Current Issues Update](#)

At our August 11 Board meeting, BC FamilyNet reviewed key current issues and concerns in community living being raised by families and self advocates. We invite comments and further feedback on the following summary. We will fine-tune this list and use it to brief CLBC, the new Deputy Minister, the new Opposition MCFD critic and other community organizations in a series of meetings that we hope to arrange this Fall, to help promote solutions.

Please comment on whether you agree or disagree with these concerns and/or have further concerns or success stories to share. Many of these are chronic, long-term issues that relate directly to underfunding and budget cuts, and that remain unresolved by ongoing restructuring. Some concerns also stem directly from the ongoing challenges of restructuring, and from unrealistic expectations about the extent to which "innovative" new structures and approaches can compensate for underfunding.

Key current issues identified at our Aug 11 meeting (not in order of importance) include:

Children's services: ongoing confusion and conflicting reports about how responsibility for children's services is and will be split between CLBC and MCFD and how this might impact future services.

IQ 70 eligibility criteria: Anger and dismay over the Province's efforts to continue using IQ of 70 as the eligibility cut-off for adult Community Living services. The Courts recently rejected CLBC's unwritten policy of refusing services to anyone with IQ over 70, after a legal challenge by a Victoria family. MCFD used this as a rough guideline for many years, but there was enough flexibility before the budget cuts to make exceptions, which is no longer happening. The Province has been widely criticized for appealing the court ruling. Clearly there are more reasonable approaches (e.g. those used in managing children's special needs services and determining eligibility for federal tax credits) which do not unfairly discriminate against certain disabilities (Aspergers and FAS, in particular), and which the BC public would accept as affordable, given our massive provincial fiscal surpluses and the consequences to individuals and society of failing to support critical needs.

This issue relates to broader ongoing concerns about entitlement and the lack of clarity in defining expectations of just what it is that community living is expected to deliver and to whom.

CLBC staff roles: CLBC is currently implementing its new operational model, replacing the traditional social worker liaison role with a new system of facilitators and analysts, while closing some regional offices and opening new ones. The transition and/or new system appears to be posing many problems for families and self advocates. Complaints include:

- not knowing who to deal with at CLBC when issues arise;
- loss of continuity & understanding in client/staff relationships
- staff unclear about their new roles and/or new CLBC policies and procedures
- staff not responsive, calls not returned
- reports of poor staff morale/ "cold" attitude
- new "facilitator/planner" was too busy with transition challenges to attend planning meeting
- self-advocates on very tight budgets must call long distance (or navigate Access BC) to reach CLBC offices.

An ongoing complaint is that assurances from the Minister and/or top CLBC management often don't match the reality that families and self-advocates face in dealing with the new bureaucracy. This has been conveyed to CLBC repeatedly and the failure to resolve it erodes credibility and trust.

Group home review: Concern that CLBC staff are doing this review, despite assurances from CLBC management that it would be done independently. Parents and self-advocates say they don't trust that the outcome of this residential needs assessment will be fair and impartial unless it is conducted by a neutral and independent group with no stake in the budget implications of any final reports or recommendations. CLBC's mandate requires it to cut costs to meet its budgetary restrictions, and it has identified group homes as a key target for cost-cutting, so families feel an internal review cannot be impartial and that the process could result in manipulation of vulnerable individuals against their own best interests. It is a major concern to many families that CLBC has repeatedly failed to demonstrate a commitment to group homes as a legitimate and appropriate community living option for many adults.

Family Independence Fund: Concerns that serious shortcomings in the handling of the first \$20 million Community Living Restructuring Fund not be repeated. Some of those concerns are mentioned in a November 2005 evaluation report prepared by the fund's coordinator. Also questions about whether financing costly renovations for individual private homeowners is the best use of scarce community living dollars, compared to, for example, addressing waitlists for respite and other services and programs that help other families besides homeowners to support their adult sons and daughters at home. Also concern that the previous fund's focus on homeownership unfairly left out renters/low-income families with equal or greater needs.

Complaints handling: Responsiveness of current mechanisms for addressing complaints and concerns. It's not clear how indicative this feedback is or whether these are isolated cases, so feedback either way would be welcomed.

Black hole at 19: Lack of services for individuals turning 19 remains a major problem, given CLBC's serious budgetary limitations. One success story is the innovative solution put together by a group of highly committed and resourceful parents on the North Shore, with much help from MLAs, CLBC and the Ministry. This appears to have inspired the allocation of a \$300,000 CLBC grant to fund innovative alternatives to meet the needs of other individuals turning 19. However, counting on families around the province to repeat the exceptional North Shore example seems unrealistic in most cases, so the \$300,000 grant was seen as woefully inadequate to even begin to address this major issue. MCFD's and CLBC's credibility is seriously at stake here, given the repeated insistence that bringing adults and children together under CLBC's new service delivery model (despite vigorous opposition from some groups) would resolve this long-standing complaint from families.

Unrealistic reliance on community supports: CLBC's new service model also attempts to address inadequate funding via unrealistic expectations that other community groups and resources will step in to fill gaps. The experiences of families and self-advocates indicate this isn't happening and it simply won't happen, no matter how much we wish it would, because other groups and community organizations have their own mandates and priorities and are already stretched to the limit as well, so people will instead fall through the gaps.

Community inclusion: Our Board was reminded that community living is in theory supposed to be about community inclusion. But chronic underfunding, budget cuts and the ongoing challenges of restructuring have kept the focus on trying to maintain/provide the bare essentials needed to keep body and soul together. Meaningful community inclusion is rarely even on the agenda for some agencies, for CLBC and even for advocacy groups like ours, it was acknowledged. This represents a massive, glaring systemic failure that demands attention from all partners.

Access to services: Given budget cuts and growing demands on the system, it's no surprise to hear reports that access to certain services is increasingly difficult, from crisis intervention dollars, to residential placements, to mental health to funding for replacement wheelchairs. Despite CLBC's repeated promises and hefty investments in new data systems, we still can't get any clear data on waitlists, so it's hard to say just how bad things are. After five years of restructuring, it's no longer reasonable to ask families to "give it more time" to work out the kinks.

It's hard to generalize, of course, but CLBC faces growing skepticism as families and self-advocates face new challenges and frustrations linked to the new service model and its implementation, while seeing little or no resolution of the same old problems, and indeed an intensification of those problems in some cases.

Woodlands compensation: We're hearing expressions of anger and dismay over the inadequacy of the government's latest proposal to compensate victims. This is adding to the anxiety, frustration and disillusionment that some self-advocates and their families are currently feeling.

Staffing: The ability to attract and retain qualified staffing on current budgets, especially in non-union situations, is making it extremely difficult for many families, microboards and service providers to provide the care, therapies and support needed for both adults and children.

Consistency: As MCFD welcomes its 10th minister in 10 years, along with a brand-new Deputy and also a brand new Opposition Critic, there is also inevitable frustration about the repeated setbacks and enormous energy wasted on repeatedly bringing new players and leaders up to speed, only to have them vanish before anything can be resolved.

Community response: In contrast to the unrelenting frustration over community living services and the challenges facing the new CLBC bureaucracy as it starts to implement the new service model, we have been hearing more optimism about the prospects for unity and cooperation in our wider community in terms of coming together to press for solutions. BC FamilyNet has always kept the doors open to working with all families and individuals, groups, service providers and government to help resolve common concerns and will continue to pursue opportunities in this regard.

Please share any thoughts and comments you may have on the above at your earliest convenience. In responding, please also indicate whether we have your permission to share your feedback in meetings with government, CLBC, Opposition critic, media etc, and if so, whether or not we should use your name.
BC FamilyNet Society

e-mail: info@bcfamilynet.org
website: www.bcfamilynet.org

Letter from a parent sent April 24, 2006 to Lois Hollsted, Chair, CLBC

Dear Lois

I have two boys who are on the Autism Spectrum. My older son turns 19 in August and my younger son will turn 14 in the next few days. Both boys have IQs over 70.

We moved to Richmond from Vancouver two years ago and my boys' files stayed in Vancouver due to extenuating circumstances regarding my younger son. Now there is confusion as to where the files for my boys will reside. It has been suggested that my younger son's file will be transferred to Richmond and my older son's file will stay in Vancouver. How does this benefit my family?

In the meantime, my younger son's Extended Autism Contract needs to be renewed at the end of this month. Hopefully, his contract will not "fall through the cracks". Needless to say I have left a voice message with our Social Worker in the Vancouver office regarding my son's contract. It will be interesting to see who eventually calls me back. I realize this issue is strictly short term and will eventually be resolved hopefully with a minimum of disruption and angst on anyone's part. But it does illustrate a point that the transitions are not all smooth sailing and seamless.

From a longer term perspective, I do not like the CLBC model of operation. My life is so busy with my boys as it is without adding an additional responsibility onto my shoulders of coming up with a "plan" in conjunction with a CLBC worker. I am also concerned that this "plan" will be unnecessarily intrusive into our private lives and allow for what I consider to be inappropriate scrutiny of us as a family - in effect, a violation of our privacy.

Furthermore, the whole idea of putting CLBC into place was to ensure a seamless transition from childhood into adulthood. Well, my boys are going to be unceremoniously dumped from the system when they turn 19 whether they are with MCFD or CLBC. So where's the benefit to my family?

Further to this point, there is a concern that our children's Extended Autism funding will be cut long before they turn 19 because the budget just won't be able to support them and/or CLBC's mandate does not include people with IQs over 70.

I am also concerned with the idea that we will not have an assigned worker from a CLBC office. One day I could be talking to one person and the next day another person. When a family is in crisis mode, they cannot be expected to continually bring different CLBC staff up-to-date. It just adds too much stress to what can already be an extremely challenging situation when you have to cover the same ground over and over again. I cannot even begin to imagine what it will be like for families where English is a second language.

I look forward to hearing from you regarding my concerns.

Sincerely yours,

Received April 2, 2006:

Re: CLBC Service Model

There are many positive aspects to the new service delivery model under Community Living BC but many of these changes will require funding in order to become reality. My first concern is not so much with service delivery but the transformation process and CLBC's commitment to extra staffing during this time. I am hoping CLBC honors their commitment to beef up staff as we are run off our feet responding to crisis and new service requests (for which there is no money). There are individuals wanting to make new life plans, move, etc, but are being told they can't because of lack of funds. Once again we are back to financial based decision making under health and safety criteria.

There are many experienced and educated caregivers supporting individuals within CLBC however, there are also many under trained caregivers, afterall, training has not been made available to this group yet we are leaving them in charge to care for vulnerable adults. A grouphome operator without a degree or specialized training should not be allowed to make decisions independently. Some of the problems I have seen of late are, lack of knowledge of mental illness, lack of knowledge of proper procedure with regard to psychotropic medication, doctor shopping, lack of knowledge as to what constitutes abusive behaviour by staff, conflictual relationships with adults in the home, yelling at adults in the home. Without the monitoring function by social workers adults are going to be abused to a greater degree because there are people in jobs of responsibility who lack the appropriate education and training.

My last point concerns case management. Some areas throughout the province will continue to perform case management because there are situations too complicated to be left without the extra support of a social worker hence, CLBC will be a two-tiered system consisting of those we plan for and those we case manage. Why didn't we leave the system alone and

use the millions of dollars wasted to improve service delivery and the range of services. Why is the hiring of a communications specialist priority over service at this time?

Please post and exclude my name. Thank you.

Sent: Thursday, March 09, 2006 2:03 PM

Subject: CLBC news release 3 year service plan

While I will admit to not reading the entire plan, I have a real concern about the group home review and plans for lower-cost alternative residential settings.

I have 30 years experience assisting people with disabilities and their families with advocacy and services. I also have a sister who is mentally challenged. There seems to be a real push to take people out of group homes and to set them up in smaller homes with 1-2 people. If the individuals in question have families who are very involved and if they themselves are able to report abuse and or neglect, these settings often work just fine. However, the chance that the individual will be neglected or at least not supported in a way we would expect, is much higher when there are fewer people (staff, family, friends, supervisors, medical supports, etc.) coming and going in the home. I have a number of examples where people have been hurt or neglected in these settings. Licensing requires certain safe guards that I believe are necessary to protect people who are totally dependent upon staff for their safety and well being. The smaller 1-2 person home does not require licensing and fewer people are coming and going in the home. This can be a recipe for disaster.

Again, I support person-centered planning and if a smaller setting is safe and appropriate, I support such a service. However, it has been my experience that people are often moved out of their safe and appropriate group homes just to free up space for others.

(Name omitted as requested by sender)

Sent: March 6, 2006 9:45 PM

Subject: Re: FW: CLBC \$1.7mil.plan-Move people out of group homes/New Service Plan

Hello,

My reaction to the CLBC's plan to move people out of group homes is horror. My daughter just moved into a group home that is licensed and she is doing very well. Everything is charted and documented. To think that she might be moved out into a private setting with others who may or may not be eligible to care for her concerns me deeply.

In my daughter's case she needs 24/7 support with qualified staff and she is getting that now. To move her would be a crime. She would not be receiving the best of care, in my opinion. In the group home she is living in, the staff comes and goes, there is no risk of burnout nor any health and safety risks in the home. From what I see, Pricare does carry risks, it is the individual's needs that must be addressed, not the monetary issues.

If I understand this correctly, those individuals who are happy with their service will not be moved? Is that correct?

Please feel free to forward my comments to whomever you feel appropriate.

Christette Cromarty

Sent: Friday, March 03, 2006 4:52 PM

Subject: this government will nickle and dime us to death

Have you ever thought that the \$1.7 million might be better spent - saving children in risk or enhancing the life of challenged adults and seniors with 1-1 staff.

This constant pursuit of "less costly options" to well run group homes will result not in enhanced services to individuals but more clients living in the basement of a home and trimmed up when the social worker arrives. Those individuals will not have a steady home and will be used as contracts to be bought and sold.

Very sad.

Clients in care in my organization are monitored and served well by loving caregivers. The government/public/friends/family has as much access and oversight that they desire.

I don't think we will know how bad this plan is until we have a tragedy.

*Jack Bennest
Oliver*

Sent: Sunday, March 05, 2006 12:06 PM

Subject: re group home review - my comments

Why is this government intent on causing upheaval for persons with disabilities and their families? (Rhetorical question).

It's about time those in Victoria thought about the impact of their decisions and began to develop some compassion and respect for clients and their families. So many of us have worked long and hard, with incredible opposition and personal stress, to find secure, safe and livable homes for our disabled children.

Give families some credit for thinking of their children's best interests. I know of no one with a mentally challenged child (adult or child) who would not want them to live an independent life if they were capable of such and could do so safely. The truth is, our children have high needs. It is extremely cruel to clients and their families to continue to hang this cloud of 're-evaluation and possible diminished service' over their heads.

My autistic son is an adult and well settled in a group home. Were he to be housed in a lesser environment I am sure he would end up on the streets or worse. My son does the best he can but he will always need this 24-hour staffed environment. The fact that he has three other autistic men living in the house means that he is with his peers and, like many young men, is sharing a home accommodation - thus there is normalization within the safety net. I have done the best I can as a parent. These constant threats are distressing and cruel. Should my son be moved at the Ministry's whim, I would hold any of those involved with that move personally responsible, over both short and long term, for his comfort and his safety.

*Pauline Barratt
Vancouver*