

## MOMS on the Move: BC families supporting people with special needs

### **SPEAKING OUT: Reports from the front lines of BC's community living crisis**

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*October 2011*

*On Friday, October 14, MOMS was part of the BC Community Living Action Group delegation that finally got an audience with the minister responsible for community living (after six months of repeated requests!). We had the opportunity to share our concerns about the community living crisis and decided to let the voices of families and caregivers speak for themselves, by reading out a sampling from the hundreds of deeply disturbing emails that MOMS has received in the past 18 months.*

*MOMS urged the Minister to adopt the recommendations of the BC Community Living Action Group, including CLAG's calls for the BC government to:*

- 1. Immediately inject \$70 million to address the unfunded backlog of service needs from the past two years.*
- 2. Order a moratorium on CLBC's service redesign process, group home closures and service cuts.*
- 3. Order an external review of CLBC to investigate the very serious and systemic concerns.*
- 4. Establish an independent advocate to provide independent monitoring, oversight, advocacy and public reporting on behalf of adults with developmental disabilities in BC.*
- 5. Restore the commitment to supporting choice in service options and the meaningful inclusion of families and self advocates in planning and deciding how they will live their own lives.*

*To learn more about the community living crisis and the BC CLAG campaign, visit the [BC CLAG website](#).*

*We urge families, caregivers and concerned citizens to continue to urge Premier Christy Clark to start taking this crisis seriously by immediately agreeing to the BC CLAG recommendations. The new CLBC minister – the fourth minister in the past year!! – was unable to make any commitment.*

***Dawn & Cyndi, MOMS***

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### **Voices from the front lines**

*(Note: All names and identifying information has been deleted from the following email transcripts. We thank all the families and caregivers who have often taken significant risks in speaking out. Without your courage, we could not have helped to document the unfolding crisis. )*

We met with X's clbc facilitator... a lovely young woman... The facilitator was brutally honest. Said the only way X? could get housing support of any kind was if he was dying on the street. She referred X to a training program (with a waiting list)... Once upon a time - X was on a waiting list for group housing. Now there is nothing in his file to show that was ever so... We originally requested housing when he turned 19 (knowing it would be a wait). He turned 23 this past march.

I am a home share provider that supports your organization and all that you stand for 100%.  
Thank You.

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CLBC and the Provincial Government have stated on numerous occasions with regards to residents of BC group homes that "no one will be "forced" into new living arrangements." THAT IS A LIE. It is happening to residents all over British Columbia, including my brother. Decisions are being made and executed without ANY discussion with the families. Families are being "informed" as to what "IS" taking place. I find it ironic that an agency representing the Government is engaging in the WORST form of bullying, taking advantage of those who cannot fight for themselves, the mentally disabled. It is appalling that a party that runs on a "family first" platform is turning a blind eye to the families affected by these unjustified budget cuts while corporate salaries are increasing exponentially.

I am a mother of an adult who is considered Developmentally Delayed. She was forced from her home a year ago September. She was put in a home care situation that did not meet her needs. A year later, after much sadness, she is moving to a new home care situation. We are praying this works out. She has now been struck with a second blow. CLBC is cutting funding to the employment program she attends....

Yesterday in... I heard that the home next door to us was closing... I could tell this by the tears of the staff when they left the meeting. It is a two bed home with two extremely vulnerable obviously high needs teenagers. I am assuming as a former foster mom that they will be an extremely difficult placement. The house from what I can see has done a great job of support...  
**(Update 2 weeks later):** Dear Dawn... the situation continues to get worse in our province...the X closes in just over two weeks and guess what no placement.... the social worker from MCFD is calling staff to see if they will take one of them... a foster family came in the home to pick one of the kids but realized it would be too much for them... these boys have made great strides since being in support.. Now it seems like a puppy placement...

I live in...and my daughter will be 19 in November. She will miraculously be cured on her 19th birthday as all the help we are getting stops. Where do I go and on what day? I have lots to say!!!! I have been quiet since I was afraid if I spoke out I would jeopardize the help I get now - but I don't think they will stop anything in the next few months.

I'm forwarding this email to you in the hopes it may be of help holding CLBC accountable for the damage they continue to cause. The focus has been primarily on the closures of group homes but CLBC has hurt many individuals and their families with drastic cuts to their home based supports... Our situation has not improved and I am concerned for my son. I've contacted CLBC to see if my son, X, is on CLBC's waitlist. If he is not then CLBC is covering up the numbers of people who have asked for funding and just been outright refused. We are definitely still waiting for appropriate home based funding from CLBC. **FOLLOW UP EMAIL:** My family is not represented on the waitlist but we ARE still waiting for appropriate home based funding from CLBC to put our family back together.... Families should check if they are on the waitlist in case they assumed incorrectly like I did that we were on the list. I've included here some of my correspondence.

My name is X. and I have two mentally handicapped adult children ( 25 years old son and 20 years old daughter) living with me. I am 46, widowed and unemployed, struggling to meet ends. I have very little help from my family and sometimes I feel overwhelmed and stressed out trying to cope with raising and caring for my children. If something doesn't change, I am considering putting my 25 years old son in share housing. He has been in a waiting list for eight years now but it's very difficult to find and receive services.

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Our situation with my son X. has been horrific and we are only just beginning our recovery as a family. CLBC is promising only a three month placement in the home, after which no one is really saying where he'll be going. His placement is perfect for him. I only wish they'd stop messing with stuff that works.

Do you think they'd be interested in the story of what happens when an elderly parent goes into emergency care, leaving an adult with disabilities behind? I've been fighting to get my brother supports-- starting from a crisis situation--since August and (almost a year later) we're only now just starting to get supports on-line. I've been out of the workforce since October, trying to live between two cities and fighting social services for both my father and my brother's sake.

I am the mother of a 19 year old autistic son, ... My son will be graduating the end of June 2011. Here is the problem. X has been assessed thru CLBC and is been wait listed. He has in fact been wait listed for some years. As far as I know his assessment is 'incomplete.' X will be on his own effective July 1st. He cannot be left alone so this has necessitated me to stop working. My husband continues to work but money will be very tight. As you can see, this will create serious financial implications for my family. I must return to work and X must be able to access some programs for his social future. I am therefore requesting your help.

I am a 53 year old widow living in... with my 18 ½ year old daughter who has complex disabilities and medical issues including two life threatening. Over the past eight years, due to this severe regression and situation - this child/young adult and family have suffered from severe stress and been compromised continually by lack of support... This stress and compromise directly attributed to my husband's death 3 years ago... to pay for caregivers, food, medical items and transport for medical appointments in Vancouver when Government stonewalled requests from us for this – we ended up losing our business, our home, our vehicles, any retirement funding we had, I was forced to quit work as my daughter requires 24 hour arms length nursing awake care. In the past over 8 years I have not slept through all nights because she awakens every 2-3 hours for hours on time. We were forced into abject poverty while we spent everything on trying to assist our daughter... we lost everything earthly - plus our dignity. I beg from churches and organizations for food and supplies that are not covered by social assistance or medical care... I have been treated with continual disrespect, threats, and stonewalling from certain ministry departments while I am trying to assist and advocate my daughter's complex case.... I have been told that we are on a waitlist for funding for age 19, the current funding will end at transition... I have worked diligently to prepare, and two years ago submit, to CLBC a PLAN and budget...I ask for answers and am stonewalled or retaliation occurs.... I am only ONE person. **AND DUE TO THE LIFE THREATENING NATURE OF HER SITUATION - I AM NOT "ALLOWED" TO BE AWAY FROM HER FURTHER THAN 20 MINUTES AWAY -- 24/7 on call.** All this and without 8 hours uninterrupted sleep at night. I can't be expected to live the remainder of my life like this... **I don't want to throw my daughter or her life away. I don't want my family ripped apart any further by having her taken away to another city where I won't see her. I don't want to see her die prematurely. I love her, we have given everything to keep her safe and here in her community surrounded by friends and with me - her family. Can you help us? Please!**

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My son is now approaching the age of 21 and until recently my family was in such a state of crisis that I did not have the mental energy to answer my own telephone, let alone approach a problem as big as this one is. Almost a month ago now, my son was finally placed in a group home in.... This was done after considerable pressure was applied to the ...office of CLBC. During the advocacy process, my husband and I fought mental and physical breakdown to devote the kind of energy we didn't know that still possessed to a group of people who pay lip service to the claims on their own website. It almost tore our family apart. During this process, we were continuously lied to, offering us inappropriate home-share situations far from home, and even telling us that no resources actually existed in our own community. This just made us furious, as we had already determined for ourselves that a staffed home located in... had not just one vacancy, but two! We were treated as though our mental processes were somehow inadequate and they simply "knew better" what our son needed.... I am told that you are attempting to investigate situations like ours where family choice is not respected and the rights of the individuals don't seem to matter. Although our son is currently placed, CLBC has hung an axe over our heads, listing his funding as "temporary". It has been labeled a 3 month placement, with hints that he'll be heading back home at the end of June. Barring this, they are still trying to find a home-share placement for him, somewhere in the GVRD, when we've already identified the type of service he requires, which is 24-7 staffed...

We are not the only ones that have been treated with blatant disregard... Most of these families are afraid to speak out because of the intimidation factor. Oh yes, it's real. One family that I have known for many years receives 4 hours of respite care a week for their medically fragile son and has been warned that they could lose it if they speak out. He is diagnosed with Autism and Epilepsy. He suffers from seizures often, and last year, he was in a medically induced coma for two months... While their son is alive today, that life is so tenuous that the parents have moved their adult son into their own bed, where he sleeps between them every night. They awake at the smallest sound, terrified that he will die in their arms. If this sounds melodramatic to you, it is, but it is also the reality of their life. It's unacceptable that the only help they are given is a scant 4 hours a week, out of which, they are required to find the employee themselves, and pay WCB and CPP benefits, deduct taxes and basically run a small business, just so they can spend four hours devoting some time to their other children and each other. The answer they and others like them are given over and over is "theres' no money"

Group homes provide disabled people with a **HOME**. No matter what changes in the group home the people still have the same bricks and mortar and the same bedroom to sleep in every night. They feel settled and safe. Homestay provides a motel environment because every time there is a change in the status of the family who run the homestay home the disabled individual has to move. Homestay opens disabled individuals to increased stress due to family dynamics and the potential for abuse, as has already happened to my sister in the homestay environment.

Our 22 year old daughter X is one of the individuals who is being threatened with a move to a private shared care arrangement... A CLBC social worker visited her home last week and told her that she is once again being moved, this time to a private shared care arrangement. This move is not being done for her benefit but rather for the benefit of CLBC as they try to reduce the expenditures.

I am the owner of a group home...as well as a number of residential care homes. CLBC is proposing to cut our contract funds by 22%...per year. We will not be financially viable. This is not a negotiation. It is pure intimidation and bullying. We do not have the resources to fight this. Do you have any suggestions that may help us?

I work in a group home as a Community Living Support Worker and in the society I work for there has been announced one closure. We don't know yet when the home will be closed but

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once it does, the staff will be allowed to bump staff in other homes who can subsequently bump other staff in other homes, etc, etc. This concerns me as it will cause major stress on the individuals who live in the homes who thrive on routine.

I am writing on behalf of my daughter. I am a single mom with a son at home that needs help too. She is in a group home close to her family and the community where she grew up in. The group home is closing, they haven't sent a date yet. We were told either to put her in another group home which is about a 2 hour drive each way (remote community with an hour drive to the nearest city's centre...closeness to family is a high priority for X) or a home stay that is out in ... or .... If I kept her home they would only give me 4 hours a day for care. X is dependent on everyone to care for her needs. They say that they are closing because the government needs to find 5.7 million dollars in our community.

I am an ex group home worker. I have recently learned that two of the residents that I helped care for have been identified as candidates for pricare (home share). I think that pricare has it's place but I believe it's the absolute wrong way to go for these two. These two grew up at Woodlands and have been in a 24hr a day staffed group home ever since Woodlands shut down, they are both around 60 years old. They are both low functioning, non-verbal, and need help with every facet of their lives. Currently they are 4 living in the group home and they have all been together since birth. To separate them now would be extremely unfortunate and in my opinion mean. My biggest concern however is the level of care that they would receive in pricare. They are both up off and on during the night,(one is up more often then not) and require supervision at all times. I don't know how a pricare situation could provide this type of round the clock service and not burn out? The money the caregivers would be paid is not enough to allow both caregivers (assuming there are two in a normal family scenario) to devote all their time to these guys without having to have another job. How could this work??? I fear that their needs would not be met, or the caregivers would burn out, and what then? Being non-verbal, how could they let anyone know when their needs are not being met? How could the caregivers devote the required attention to these people? I am very fearful for them, I think it would take one phenomenal placement to come close to providing the care they need and deserve.

We had about a two hour meeting with...from CLBC in which we discussed the situation we are facing with the Group Home closure and the subsequent placement of X. Basically we got no commitment from them or any real indication of what is to come... but we did get the impression they think X. will be a good candidate for a "Home Share" and we held firm to our opinion the Home Share is just a new and fancy name for a Foster Home situation which we are adamantly opposed to. I told them I will fight them tooth and nail and if necessary go public with what is happening in this province.

I am the brother of a handicapped woman living successfully in a Group Home for about 20 years. All her success and happiness is now being put at risk by the thoughtless and heartless actions of this Liberal Government. I have written letters and contacted the media in order to raise awareness of this important issue.

**Letter from Vancouver service provider Sept 2010:** "CLBC is working with all service providers across the Province to review the services currently being provided to people with disabilities... A key outcome of this review for CLBC will be to identify savings in existing contracts to pay for services required for young people turning 19 years old, services for people in crisis and to pay for services for people who are on waitlists.... CLBC staff will be looking at all CLBC services and identifying those that may need

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further review... If CLBC would like to review the current level of service and the person's disability related needs, they would meet with the person and key members of their team (including family) and complete the Guide to Support Allocation. Some examples of possible changes to existing services might be: 1) Reducing the number of hours of service in the current home; 2) Changing staffed night supports to a roommate model. Some examples of different service models might be: 1) Having a live-in caregiver rather than staff on shifts; 2) Having a blend of staff on shifts with a live-in caregiver; 3) Moving to the home of a caregiver and receiving most care from that caregiver; 4) Moving to a home or apartment controlled by the person receiving service and receiving only the staffing supports necessary.

Hi Dawn: I can update you on the ...Society situation. We lost 11 Full Time Positions among our 6 group homes. 2.5 FTE positions were created for a net loss of 9.5 full time (40 hr) positions and changes to a number of workers' schedules. This results in decreased staffing levels and loss of community access time for our residents. Whether it also creates unsafe working conditions is yet to be determined. Our new schedule is due to kick in Nov. 15.

Many rumours are taking place around ...Group Home. An "assessor" attended the home and made allegations about who was already on their books for moving to "home share". Apparently one of the questions was which families are involved with these clients and the group home manager told him that all the clients had very involved families. His response was apparently "Oh S\_\_\_!"

My family has just recently gone thru a period of uncertainty (and still not comfortable with the outcome) with our bother, who lives in a group home in.... Community Living had been planning for a least two years in closing his home. We gathered together a concerned group of parents... and we exhausted ourselves with letters, telephone calls, doctors reports. Many of the help lines such as Jane Holland (I have a list) were either not able or were not in position to do much... In many cases they pretended to not be fully informed. Our group was relentless in our efforts (Pressure on the Minister and His deputy. It was pointless dealing with "heads" of CLBC. On the eve of closure we got a reprieve from the Minister. Today X. is still living in.... ---the services provided are somewhat diminished, but the staff are doing as best they can with cutbacks. ...The exposure of untruths in the process of CLBC programs over the past to close the successful homes does not paint a pretty picture for officials.

I am a recently laid off (effective Dec 1, 2010) supervisor of a residential home for 2 challenged adults. I have had a variety of experiences from 2 yrs ago having a visit from a CLBC manager who walked through our residence and only asked one question, "Do these individuals have parents or advocates?" We knew then there was a big plan.....To recently being present in a meeting where the CLBC representative asked us 'not to inform the parents' of the proposed cuts but that CLBC would inform them just before they would happen...In one home that has successfully run for over 12 years, with both individuals thriving, we have lost over 40hrs per week of community support worker and removal of the supervisor. These two adults are non-verbal, completely dependent for personal care but are thriving, happy individuals with full lives. Both have conditions that present the possibility of the transmission of infection disease and require stringent universal precautions to ensure they and others stay safe and healthy... Both walk, feed themselves and communicate in their own special way. CLBC has proposed that they individually be sent to 'live with a family.'

(CLBC) has stated that X. would not be eligible for a day program... X. is a 19 year old man. X has been diagnosed with severe developmentally disability. In addition X. has been diagnosed

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with autism, echolalia, obsessive compulsive disorder and depression. X. lives with his mother. His mother is a single parent and single caregiver. She has no support network... X's mother in 2009 was diagnosed with ... and she has.... She went thru three surgeries. (She) is very weak. She is on medication and single caregiver for X... He needs help with bathing, toilet, food, daily basic functioning and decision making. X. can't be left home alone because of his intellectual disability he is vulnerable to accidentally hurting himself or leave without notice. When X is bored he hurts himself! He doesn't hurt others. X needs routine, structure an active life which a day program can provide him. Since 2009 (X's mother) is unable to provide X's active life or structure. She struggles with meeting his basic needs of food, shelter, clothing, basic daily functioning. X is a very anxious & hyper adult. He mentally exhausts himself by counting or talking or obsessing about something. It's very demanding and exhausting to be X's daily caregiver. **CLBC reply:** CLBC maintains a Service Request Registry for supports when funds are not available to meet all support requests. CLBC's ability to provide the supports you have requested once this date is reached will depend on whether funds are available at that time.

As a way of introduction...I have a sister and a nephew ; both with mental and physical delays ; AND I am a caregiver...for my sister as well as a young man with profound down's syndrome/autism.. So as you probably know the GSA as been redone by CLBC as a means of this year's project to recover funds . Only a few of the caregivers in our area have had their GSA done so far....but it has literally meant a 50% reduction in fee for service for some who have had theirs done.

Hi there, I'm a frustrated service provider who is horrified at what I see happening to supports to adults with disabilities through CLBC. We've worked in this field for almost 20 years ... I'm so tired of having parents of adult children crying in our office or on the phone because of what is happening. I'm just wondering is there anything that can be done to speed up the process of dismantling CLBC?

I am a single mother of a now 19 year old daughter with Down syndrome. I applied for support to hire a one to one worker from CLBC well in advance of her 19th birthday (actually she was still 17) to be prepared for waitlists. I have asked for 40 hours a week and I am still waiting for approval. Last week when I called CLBC to advise them I am now in a crisis situation and have no one to assist looking after my daughter they advised they would set up an emergency meeting to get some funding, but that at best I would be lucky to get 12 hrs of care. I'm not sure how a person is expected to work and leave their children of young adults at home alone, but that is NOT an option for me. I guess I am expected to quit my job!!!! I am not aware of anyone else who can help me advocate and I have been told by many other struggling parents to just accept anything given to me and be thankful. This seems very unfortunate and a sad state for our citizens with special needs.... I will also forward this information to a few more parents, as I am aware of at least half a dozen other families who have been effected by cuts and underfunding of CLBC.

As you are now aware, people are reluctant to speak out about community living because they are being threatened with the denial of services for their family member. However, I met a woman whose son lives in a community living funded group home in... She (mom) is hopping mad, and may take a public stand.