

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

2007

Future tense

Gwen Lee wonders who will care for her son Geoffrey when she's gone. Hundreds of other aging parents in B.C. with developmentally disabled adult children face the same agonizing question.

by Cheryl Rossi, Vancouver Courier
Published: Friday, July 13, 2007

At 1 a.m. on March 11, 2005, Gwen Lee woke with what she thought was a severe asthma attack. She called 911. She had been through it before.

"This time I felt a pain. It started in my legs, so I never thought it was a heart attack," says Lee, 65. "When I laid down it started intensifying, and when it got to my chest, then I got worried."

Paramedics arrived. When she told them about the pain, one of the paramedics told Lee he needed to take her to the hospital so she could get checked out.

"I said, 'I can't. I'm alone with Geoffrey,'" she says, referring to her 36-year-old autistic and non-verbal son. But, luckily, her neighbour Myrtle saw the ambulance lights and came over.

When the paramedic told the neighbour he needed to take Lee, 82-year-old Myrtle said, "You take her right now. I'll stay with Geoffrey."

While the internist at Vancouver General Hospital was interviewing Lee, she suffered an angina attack.

"I was in the hospital for five days," she says. "Now if Myrtle hadn't come, I would be lying on the floor, and Geoffrey wouldn't know to call anybody."

Fears about such scenarios are common among the mostly single aging parents who care for mentally handicapped children, says Lee, president of the local Parent Support Group for Families of Mentally Handicapped Adults Society.

As parents worn out from decades of caring for their disabled sons and daughters experience health problems, they discover a new concern--finding stable housing for their children so they can live fulfilling lives long after their parents are gone.

In some cases, health problems magnified by financial strain lead to tragedy.

On Dec. 30, 2001, an upstanding Okanagan couple killed their 34-year-old disabled son and themselves with carbon monoxide poisoning. A back injury had forced the husband to quit his job. The couple requested an additional \$500 a month from the provincial government in addition to their son's \$750 disability cheque to help them care for him, but their repeated requests were denied.

No one in the Parent Support Group was surprised by the desperate act.

"Six years later everything is worse than ever," Lee says.

The Parent Support Group for Families of Mentally Handicapped Adults Society celebrated its 10th anniversary in June-10 long years of fighting for respite, financial assistance and basic services for their children. They're not convinced the housing the government funds will meet their children's needs, and in recent years they've focused on creating a choice of stable

housing options to protect their children's future as mature adults.

When 79-year-old George Soika sits with his eldest son, 56-year-old George Alexander, it's impossible not to notice the similarities between the two—thin hair, blue eyes, prominent ears and similar noses and frames.

"He's catching up to me," Soika quips after George Jr., who prefers to be called J.R., states his age. J.R. alternates between calling Soika "Dad" and "buddy pal."

Their new live-in caregiver Judy arrived three months ago, and before she came father and son were alone in their spacious rancher near Steveston.

"My biggest worry was what if I don't wake up in the morning. He wouldn't know what in the hell to do," Soika says. "Now, at least there's somebody else in the house that if something does happen—you know I'm not critically ill or something, I have my aches and pains and I hope to have a few years to go—but it is a comfort and I sleep a little better."

J.R. has phenylketonuria, or PKU, a rare genetic metabolic disorder that results in developmental delays and other neurological problems when treatment is not started within the first few weeks of life. J.R. was diagnosed when he was three-and-a-half years old. His enzyme deficiency means J.R. must avoid high-protein foods. He lives with life-threatening allergies, eczema, has had 70 per cent of his stomach removed, and needs to be told when to stop eating because he can't judge how full he is. He also suffers from osteoporosis and epilepsy.

"He understands everything," Soika says. "There may be a pregnant pause before he can talk, but that's his ailment."

Three weeks earlier at the annual general meeting of the parent support group, Soika stood up to thank the organizers of the group and representatives of the Mennonite Central Committee Supportive Care Services (MCC) for helping him secure a live-in caregiver.

"I have someone helping me with my son and we have someone living in, and it's given me a great, great peace of mind. I want to thank these people," he said, voice breaking as he choked back tears.

Prior to Judy's arrival, Soika had cared for J.R. as a single father since his son was 14.

He and his wife separated in 1959, partly because of the strain of trying to establish programs for J.R. and other disabled children. The two had started the Richmond Association for the Mentally Handicapped because few services existed then. With the help of association members, they established a school.

"Either myself or [my wife] would spend hours, hours on the phone with sobbing, hysterical parents," Soika said.

Since his school years ended, J.R. has attended a day program in Vancouver. In the early days when Soika drove him to his workshop, J.R. would often have seizures en route. Soika would detour straight to the hospital. He handled the problems mostly on his own, never leaving J.R. alone for more than 90 minutes.

Once when he was a teenager, J.R. spent an entire day waiting in the window for the HandyDart bus to transport him to his day program. The bus never arrived. Soika left him at quarter to seven in the morning and returned home after five to find him still wearing the heavy coat he'd put on that morning—even though it turned out to be a blistering day. The two apples in his pockets remained untouched. His face was burnt. (Soika emphasizes that HandyDart service is excellent now.)

J.R.'s dietary restrictions made Soika wary of handing his care to anyone else.

"At one of the respite places... I'm waiting for him to get ready and [the worker] says, 'Well we're just sitting down for lunch, would you like to join us?' I came and sat with him and here he's just going to go into a cheese sandwich. He's on a dairy-free diet for crying out loud. And that was the same place he would come home from with someone else's clothes."

Soika and his wife had two other sons. Their middle son, Gerry, was struck and killed by a car at the age of 16. His death occurred on the birthday of their youngest son, Jim. Soika and J.R. haven't seen Jim in more than a decade.

"Even when Jim was young he didn't want to have any relationship with J.R., absolutely none," Soika says.

Three times, Soika came close to long-term relationships with mothers of disabled children. "But they had as many suitcases, if not more, than I had," Soika says, and he felt he couldn't take on any more.

J.R.'s mother moved to Vancouver Island. Soika takes him to visit her in Port Hardy every summer and take advantage of the three-week break to travel the world and play and officiate tennis matches, one of his many sporting passions.

Soika, who worked at B.C. Tel for 40 years, said he received little support from the men around him. "Women will sister. Men don't brother," he says.

Soika met Lee when their sons were attending the same daycare. He started attending Parent Support Group meetings four years ago.

When he told Lee and the group's other key organizer, Janice Reithofer, that he was worried about J.R.'s future, the two women got the Mennonite Central Committee Supportive Care Services involved. The committee has provided services including homes and residential support to people in Abbotsford since 1974 and wants to offer services in Greater Vancouver.

"I was calling this mission impossible," Soika says.

An MCC facilitator visited the Soikas and developed a housing plan based on their needs. MCC submitted the plan for a 24-hour live-in caregiver to Community Living B.C., a Crown agency that delivers support and services to people with developmental disabilities, children with special needs and their families. The agency approved the plan, which was the first arrangement of this kind. (The government transferred responsibility for providing services to adults with developmental disabilities from the Ministry of Children and Family Development to Community Living B.C. two years ago.)

"It's hard to let go, so, of course, you monitor almost everything Judy does," he says.

"He's been doing it for 42 years so he cannot give it up," Judy adds.

Each month, J.R. receives \$906 in income assistance, of which \$716 goes towards Judy's position. If George put J.R. in a group home, it would cost the government an estimated \$100,000 a year.

Soika says that after he dies, he'd like another disabled adult to move in with J.R. and his caregiver. He plans to mortgage his house and buy a three-bedroom apartment.

"Before I conk out," he says.

Randy Furgason becomes weary explaining how the group home he needed for Sarah, his 24-year-old daughter, didn't work out. A month after attending the annual meeting of the Parent Support Group, the 55-year-old longshoreman is at home in the humble Hastings-Sunrise house he rents with Sarah-his "princess like the former duchess-and his 77-year-old mother Mavis. Sarah sits cross-legged on the couch, with Sunshine, the family's black Bichon next to her. Sarah's hair is thin, her eyes are close-set and her cheeks are round and full.

She was diagnosed with a brain tumour at age three. Following an emergency 10-hour surgery, she underwent 32 radiation treatments to her brain and spine to ensure the tumour didn't return. "That was the beginning of her nightmare, and it's never stopped," a wan Mavis says.

They've since discovered that the amount of radiation Sarah received was too much for her size. She stopped growing, and Furgason had to give her human growth hormone injections every day until she was 12. The radiation damaged her thyroid and pituitary function, affected her vision and gave her tinnitus and recruitment, which causes her to develop headaches in noisy environments. She developed a curvature in her spine and has compromised balance and coordination. Sarah has virtually no short-term memory and is developmentally delayed. Six years ago she developed seizures that make her space out for 30 to 45 seconds and leave her feeling disoriented for 10 to 15 minutes afterward, with blurry vision, a headache and fatigue. She's also hypoglycemic.

Furgason has spent his life attending medical appointments with Sarah. In the early years she needed to see a physiotherapist, an endocrinologist and an educational consultant.

Although his wife, Rose, didn't work outside the home until Sarah was in Grade 2, he always went to the appointments.

"I understood what the doctors were saying, and I found that if I had to rely on what Rose would tell me that the doctors had said, it wasn't as accurate and it wasn't as complete, so I went there myself to find out what was going on," he says.

Like Soika, Furgason's marriage didn't last. He and his wife split when Sarah was 12. The strain of dealing with his daughter's special needs contributed to an already troubled relationship.

Sarah attended a private Catholic elementary school on the East Side, completed Grades 8 and 9 at Lord Byng and graduated from a non-academic program at Gladstone secondary. "It was the proudest moment of my life to see her walk across that stage," Mavis says.

For a time, Mavis would take the bus with Sarah to school and drop her off at her classroom. When Furgason and Sarah lived in a basement suite near Trout Lake he couldn't afford a car so he'd bus down the Drive to his mother's seniors home with Sarah. Mavis would feed her breakfast before the HandyDart arrived to take her to school.

Seven years ago they moved in together so Mavis could help Furgason care for Sarah.

But two years ago, a serious downturn in Mavis's health meant they couldn't care for Sarah anymore.

"It became pretty obvious that we were in a crisis situation where I couldn't just leave Sarah on her own and my mom was no longer able to help out," Furgason says, his voice low and grave.

Sarah's short-term memory impairment means she can't cook or remember when to take her medication, let alone remember where to find her clothes. Furgason has put T-shirt, socks and underwear stickers on her dresser so she doesn't need to root through every drawer to find what she's looking for.

"Sometimes Sarah falls when she has a seizure, and she has fallen in the bathtub before and that's required medical attention," Furgason says. "How would Sarah respond in case of a fire or somebody trying to break into the house?"

Furgason told Community Living B.C. Sarah needed to move into a group home. In the meantime, the Parent Support Group and MCC devised a proposal that would see Sarah, a friend and two mentally handicapped men housed in a duplex with staff rotating between the two units. But when Community Living B.C. suddenly came up with two basement spaces in a group home, Sarah and her friend accepted the immediate solution and Sarah moved in April 2006. "We weren't given any other choices," Furgason says.

He and Sarah felt optimistic about the move. But one upstairs tenant who couldn't speak, write or use sign language would often wake up in the middle of the night and bang around. The tenant directly above Sarah's bedroom was a little person who got around on a noisy cart and enjoyed karaoke.

"She often has that cranked up too," Furgason says.

"At 6:30 in the morning," Mavis adds.

"I've asked her to turn that down so many times, too," Sarah says.

Sarah developed chronic headaches and aches and pains throughout her body that physicians were unable to diagnose. She hasn't lived at the home or attended her day program since February.

For more than half a century, mentally handicapped people were placed in large government-run residential institutions. In the early 1990s the provincial government closed the institutions and opened group homes with related support programs and services. Since 1997, no new group homes have been established in Vancouver because of their high capital and operating costs. Instead, the government encouraged home sharing where a developmentally disabled person lives with a non-disabled individual or family as a solution to parents who can no longer care for their children.

Lee, the president of the Parent Support Group, knows a family whose daughter went through four home sharing placements in one year.

"Quite a few people have been in crisis and the government has put them into care and it's never worked out," she says. "The foster care family has the option of saying sorry, I can't handle it."

Furgason won't place Sarah in foster care because of the lack of accountability. When Sarah was in the group home he could visit at any time, ask questions and have his concerns addressed by a higher authority. "I don't want Sarah buried in somebody's house, out of touch and out of sight."

Furgason finds it perplexing the government pays other families more than three times the benefits their children receive each month to care for them instead of providing better direct assistance to the families of the children in need.

Last November, Furgason attended a meeting about Community Living B.C.'s Residential Options Project, which was offering to meet with every person living in a group home by March 2007 to provide satisfactory living arrangements for people with developmental disabilities. He met twice with facilitators and hopes proper housing will be found for his daughter. Among other options, Community Living proposed moving people with developmental disabilities into apartments where a roommate would provide them with support in exchange for free rent.

"Who is going to work for nothing?" Furgason wonders.

The duplex proposal MCC submitted on behalf of four families was rejected once Sarah and her friend entered the group home. Now MCC is about to submit a similar proposal to Community Living B.C.

A Residential Options project manager told Furgason the annual budget of the group home Sarah lived in was \$400,000 to care for five people, so they're proposing an arrangement that would cost \$80,000 a year or less per person.

Furgason wants his only child to have a home that respects her need for quiet, where she can stay during the day if she's not feeling well and not have to attend her day program, which too often seems like a place for people with developmental disabilities to kill time.

In her school, day program and group home, Sarah's special needs often haven't been adequately met because the needs of the majority take precedence. And because Sarah and others with developmental disabilities usually cannot speak effectively for themselves, their often overburdened parents must do it for them.

"I'm frozen in time," Furgason says. "I look at the future and I don't see the day that I'll be able to retire and enjoy the time off that retirement gives one... I'll only be retiring from work."

Furgason's lack of means adds to his concerns about Sarah's future.

"I don't have the type of financial resources that would allow me to provide a comfortable long-term future for my daughter," he says. "It's worrisome to me that as the government reduces the resources available to families like myself, that my daughter's future could be restricted and diminished."

The Parent Support Group has proposed policy changes to representatives from various ministries to help the families manage, but Furgason's never seen the government act on their suggestions.

"The politicians tend to utilize whatever dirty laundry that they can in order to achieve their goal, which is to make them look good and make the other party look bad," Furgason says.

"It makes me feel like people just aren't aware of what it's like to be responsible for another person 24/7 for the foreseeable future, maybe until your last breath," he adds. "It really doesn't matter to the people in government, the people that hold the purse strings."

The purse strings for the day program Lee's autistic son Geoffrey attends have been yanked tighter and tighter.

At their modest Sunset home, Lee proudly displays the framed artwork her son created in his day program in 2003. But since Community Living B.C. clawed back money from agencies that provide day programs three years ago, many of the activities that helped her son flourish have been cut. Lee worries the lack of stimulation will cause her passive son to withdraw into his own world and lose the hard-won skills he's acquired.

While she fights to have Geoffrey transferred from his Vancouver day program to a more varied program in Burnaby, Lee continues her work with the Parent Support Group. It includes 75 mostly single-parent families and runs out of Lee's basement on membership fees. It started with five families in 1997. When they saw the government phasing out respite hostels where their children could sleep over, they fought the loss. Now the government affords them 28 days a year-two days a month and four holiday days-of respite. Parents arrange for someone they know to take care of their child for a day or night and pay a \$21.90 user fee each time.

Some of the members of the group receive help from their extended family. Lee's daughter Stephanie volunteers with the group, and Lee, her daughter and son go on outings together. But the members who've chosen to keep their sons and daughters at home feel punished for their devotion. While residents of group homes can have a worker stay with them while they're changing medications and can more easily access speech pathologists and a clothing allowance, parents who keep their children at home fight for every scrap of help they receive. They also suffer the indignity of having to visit the welfare income assistance office every year to maintain their children's disability benefits.

When Geoffrey first started receiving income assistance and needed a pair of rain boots, another parent told Lee he was entitled to a yearly \$500 clothing allowance. Lee asked about it at the income assistance office.

"The financial assistance worker turned and asked me, 'What are you doing with his money every month?'" Lee says. "That \$500 allowance was only available to people in group homes. That's when I realized that my son was treated differently because I was looking after him. I'm penalized... and I'm the one who's saving them money." (Such allowances are the norm now.)

She's asked for people with developmental disabilities to be given a special card, akin to a seniors card, to no avail.

In 2003, the Parent Support Group contacted Mennonite Central Committee Supportive Care Services about housing. The organization is developing individual housing plans for families and submitting them to Community Living B.C. The Parent Support Group wants to develop a "community village" where mentally handicapped adults could live, learn and socialize with friends, families and members of the community. The village could exist in a neighbourhood with 10 to 20 units where adults with mental handicaps could safely grow old. Some townhouses and duplexes could include assisted living spaces for aging parents who wish to continue living with their sons and daughters.

The Parent Support Group wants their children more involved with the broader community for two reasons: they want them to develop relationships with people who will care about them once their parents have passed on, and they realize they need members of the community at large to pressure the government to provide more support for their children because their own requests appear to fall on deaf ears.

"The developmental disabilities people, I call them the invisible people in our community because nobody realizes they exist," Lee says. For too long, parents have carried on quietly but it's time to make the public aware of their plight, she notes. "The politicians know all about us..."

Lee says the Parent Support Group wants the government to improve the quality of life for their sons and daughters.

"Not for us, we're past that," she says. "It's too late for us."

See related story "Survey says... one size doesn't fit all"

Survey says... one size doesn't fit all

Need for traditional group homes on the decline, says report

Cheryl Rossi, Vancouver Courier

Published: Friday, July 13, 2007

The Crown agency that helps people with developmental disabilities and their families profiled thousands of people living in group homes in the past year in a bid to provide them with the kind of housing they want.

Community Living B.C. completed profiles on 2,435 individuals living in group homes between September 2006 and March 2007.

"Increasingly, people are requesting and receiving individualized supports that meet their own unique needs and preferences," states the Community Living B.C. report about its Residential Options Project. "This is consistent with recent research that clearly demonstrates that 'one size fits all' is no longer an acceptable standard."

More people are living in staffed residential homes than ever before, with a 30 per cent increase since 1991, but the growth in popularity of group homes has slowed over the past several years.

And half of the people living in Community Living group homes in the past year were over 46 years of age, with the average age of residents at 45.

"Given that the average age of mortality for individuals served by [the agency] in 2006 was 51 years and that younger individuals and their families are typically choosing smaller, more person-centred living situations, this suggests that the need for traditional group homes of four to six people will diminish over time," the report states.

According to the report, those profiled show a growing interest in home ownership, sharing homes with individuals who do not have disabilities and "cluster apartments," in which residents live individually in apartments but share services.

"In 2007, 2,465 individuals with a developmental disability live with and receive support from a person or persons who are not disabled," Community Living's report states. (The figure does not include people who live with their families.) "Since 1991, the number of individuals using this type of support has increased by 387 per cent and continues to show steady growth (13 per cent since 2002)."

While those who participate in the Parent Support Group for Families of Mentally Handicapped Adults Society hope Community Living funds more individualized options, they wonder whether decreasing the number of group homes is driven by the government's desire to cut costs.

"What they've been trying to do is encourage staff in group homes or other organizations to take on [home sharing]," said Gwen Lee, president of the Parent Support Group and mother of a non-verbal autistic son. "For some people it does work--people who can talk, who can socialize, who don't mind change--but it's not meant for everybody. We realize it's a lot less money for them. But what's the point if it doesn't meet the individual's needs?"

Sally Greenwood, director of communications for Community Living B.C., said any money saved would be a bonus. "But the primary reason for doing it wasn't we've got to go out and close group homes because we've got to save money."

To encourage innovation among service providers, Community Living B.C. offered a grant for agencies that work with the developmentally disabled to propose expanding their living options or implement new residential services.

No service providers in Vancouver received the grant. Greenwood said the agency received limited applications from agencies in the Vancouver area--she wasn't sure why--and none of them met the grant requirements.

Developmentally disabled individuals have had problems moving from an unsuitable group home to a new home partly because of funding ties to service providers.

Of the 2,435 individuals who participated in the review, 170 wanted a different form of housing. Starting next spring, Community Living will work to make the funding of group homes more flexible to give individuals and families more choice in choosing housing options.

Will parents caring for their developmentally disabled adult children at home be consulted about the kind of help and housing for their children they'd prefer?

"Not at this point in time," Greenwood said. "That may be phase three or phase four."

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LETTERS TO THE EDITOR

Parents of handicapped adults story strikes chord

Vancouver Courier

Published: Friday, July 20, 2007

To the editor:

I want to thank Cheryl Rossi for bringing the plight of parents of mentally handicapped adults to the public's attention ("Future tense," July 13). My husband and I are the parents of a 32-year-old mentally and physically handicapped woman. After being on a wait list for seven years, she finally moved into a group home several years ago.

She would not do well in adult foster care. As a member of the Parent Support Group for Families of Mentally Handicapped Adults, I would like to commend Gwen Lee, Janice Reithofer and other members for working so hard on the dilemma faced by so many families needing help. There is a maxim that says, "a nation is judged by how it treats its most vulnerable citizens." Our sons and daughters are handicapped through no fault of their own but our society and our BC government are failing them badly. Families of mentally handicapped adults need hope, and must have the option to choose the type of care that best suits their particular needs.

Karen Menges, Vancouver

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To the editor:

I would like to thank Cheryl Rossi for her article on the Parent Support Group and parents who are looking after their adult disabled children at home. The article was well-written, well-researched and, unfortunately, all too true.

I was particularly impressed she chose to profile two single male parents. As one of the men said, "Women will sister, men don't." I have found this to be very true. For quite a few years, I was a single parent looking after my mental and physically disabled daughter while working full time. My life would have been more difficult were it not for the wonderful women in my life.

I am now remarried to a caring man who has willingly taken on the responsibility of having a child who we know will live with us for the remainder of her life. With the lack of government funding for residential options, we are aware it is unlikely she will have the opportunity to live apart from us. I am fortunate to have a husband and good women friends. Many others do not.

Roberta Bavis, Vancouver

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To the editor:

Re: "Future tense," July 13.

My heart ached when I read about the couple in Kelowna who killed their disabled son and themselves, after those hard-hearted tightwads in Victoria denied their request for financial assistance to help them care for him.

Just the day before, I had heard Finance Minister Carole Taylor proudly announcing that B.C. has a much bigger "surplus" than expected. I wonder how much money they "saved" by denying desperately needed help to those who are suffering, even as they gave themselves a 29 per cent pay raise.

What a despicable lack of values they have.

Tom Trueman, Vancouver

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Injustice shameful, story outstanding

Vancouver Courier

Published: Wednesday, July 25, 2007

To the editor:

This is to commend your Cheryl Rossi for her outstanding story "Future tense," July 13. It was very clearly explained to all of us the plight of older parents, caring 24/7 for their disabled adult children at home, and how these parents are penalized by not receiving the same support for their children as those in group homes.

It's heartbreaking and shameful to know that we as a society allow this injustice to happen.

Nina Pickburn, Vancouver

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Sent: March 22, 2007
To: BC FamilyNet Society
Subject: Funding for post-secondary education (Comments regarding Oct. 9 letter sent to MLA H. Oppal below)

As you know, different autistic individual has different needs. One thing in common is they need understanding from our families, our schools, government agencies, our society, etc. Without proper understanding, money would be spent in the wrong place.

Our universities have trained special need teachers. After I have shared my experience with a group of special education student teachers who were social workers or regular teachers prior to taking special education, I suspect their training is one-sided. I have the impression they are trained to deal with students with less ability to learn. This impression is further reinforced by my own dealing with my son's high school counselor. She told me the school is not a place to help autistic students who have achieved average to above average standing in schoolwork. She missed the social stress this group of students suffer each day in school. Many autistic students drop out from school not because of their lack of ability to learn but the inability to cope with the social stress.

At the college and university level, there are no bullying and no special education professors. Social stress does not decrease. The disability resource centres provide many accommodations, such as extra time and separate rooms for examination, note takers, etc. However, there are counselors who would not grant or recommend accommodations when they do not see physical disabilities. Parents of autistic students often have to intervene. Quite often, it is the beginning of another round of getting new medical letters, interviews, assessment, etc. Of course, there are counsellors who have more knowledge on Autism. Problems are easier to manage when the students are assigned to such counsellors. With the current advancement in communication, one would think the accommodations granted could be transmitted electronically to the professors. The students have to present the accommodation letters to the professors before or after classes in a line up with other fellow students. The student would explain or discuss his or her situation in public with the professors. My son finds this process very humiliating. When a student drives up to see the professor in a wheelchair, usually there are no questions asked. When an autistic student approaches the same professor with the same intent, the situation always carries some degree of surprise or suspicion. Unlike high schools, parents could only discuss their children's situation with the universities without their children's written permission. Direct discussion between parents and professors is rare.

Application for a student loan is also biased against students with disability. The application stands a better chance to success if the student lives on his or her own. Otherwise, parents' assets and income are used for calculation. Most students with disabilities live with their parents because there is a need to be cared for at home. Unfortunately, this need is overlooked.

Most scholarship application including scholarship for disable students insists on volunteering work or work involvement as a criteria. For autistic students who naturally do not have the ability to engage socially, are automatically disqualified from taking part in the process.

When my son graduated from high school, there were no counseling on continuing education or employment training for students with special needs. Today, he is approaching a similar milestone. Before April 2008 when he graduates from university (in the lower mainland), could he find the same guidance he needs? Housing and employment are pressing issues.

Over the years of caring for disabled children, many parents have missed many opportunities in their own lives, such as advancement in their careers, spending less time caring for other children in the same family, etc. I have to finance my other son, who lives away from his autistic brother. When I visited him in another province where he is doing his postgraduate studies last month, he casually said to me, "Dad, usually, parents would only kick out their bad children. I do well in school. I behave well. I am awarded many scholarships from universities. And, you kick me out of my home." When one's own family cannot understand the difficult situation at home, it is beyond hope that others would understand.

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Sent: October 9, 2006
To: Wally Oppal, MLA, Shirley Bond, MLA (Minister of Education)
Subject: New Funding for autistic students

Dear Hon. Oppal,
Please allow me to congratulate BC Government's latest funding for students with autism. The school districts will get \$16,000 per student per year.

Being a father of an adult autistic son, I know it first hand how difficult and almost impossible to get any services from

the school when my son was younger. With this new funding, the struggling families will get some extra help for their children's education.

My autistic son is currently attending university. He and his family are going through the same difficult and helpless situation as when he was in high school. This new funding will have no effect on any autistic student studying in post secondary institutions. I am asking our Government not to forget this group of special need students. Despite of their challenges, they have earned with great difficulty a place in our colleges and universities. Please provide this group of students with the necessary assistance.

Regards,
(name withheld)

Note: On Oct. 12 The Minister of Education replied to the above letter that the Ministry of Education is responsible for Kindergarten to Grade 12 and as this matter fell within the purview of the Ministry of Advanced Education, it was forwarded to Advanced Education for their consideration.

Sent: March 01, 2007
To: info@bcfamilynet.org
Subject: Re: Concerns CLBC

As a family model home provider I am concerned about the lack of support this new model provides. When our clients are ill we are to call into the office and whoever is on intake that day will hear our concern. The worker often will not know anything about our clients and worse, sometimes it takes days for a worker to return our calls. We as family model home providers feel vulnerable and out there on our own to deal with issues when they arise.

Another concern for many caregivers in our "family model home" is that we don't feel we have a voice to be HEARD and we feel we have to just keep working in hopes that issues work themselves out. We need a support network not only so we have someone to reach out to but also to have someone to go to so we can voice our complaints concerns and issues and feel that we have at LEAST BEEN heard. We are the FRONT Line workers out there. We live with our clients 24/7 and we have ABSOLUTELY NO ONE to turn too with this new model, no one to support us, no one to advocate for us--NOTHING. In my view this is WRONG and a HUGE HOLE in the entire program, which should have been dealt with first!! We have no one to call after hours or on weekends so we have to use our best judgment and make sometimes life and death decisions and pray to God we make the right choice. This issue is huge and needs to be addressed ASAP. If you think about the possibilities of anything going wrong before this issue is rectified, it is down right frightening.

Respectfully
Family Model Home Provider
(Interior, BC)

Sent: February 21, 2007
To: Maurine Karagianis , MCFD Oppostion Critic
Cc: BC FamilyNet Society
Subject: Community Living B.C. (CLBC)
Feb 21, 2007

I am a parent of a group home resident in B.C. Shortly after CLBC was created we began hearing rumors that group homes would be targeted for closure due to their high operating cost. For the parents of a very high need Down's syndrome daughter who had recently entered group home care, this "news" was very distressing to say the least.

We made numerous attempts to meet with our MLA's , Hon. John Les and Hon. Barry Penner, to express our concerns about group home closures and the impact that Liberal budget cuts were having on the agency and in their community. However, we were in effect ignored for over two years before we were finally granted a 30 min. audience in April 2006.

At the meeting we asked Mr. Les to discuss our concerns with Minister Mr. Hagen (MCFD) as soon as possible. We were given assurances that this would be done. Also, we were assured that the rumors of group home closures were unfounded and that "no group home would be closed".

Nearly a year later we have had no response from either MLA regarding our request to meet with the Minister of Children and Family Development to discuss our concerns. However in the past year CLBC after claiming there was not an extra dollar in its budget for programs, found \$ 1.7 million to conduct a Residential Options Review of the Province. The review, which I believe is not yet complete, was billed to group home residents and their family members as "driven by CLBC's desire to offer choices to group home residents". However it soon became apparent that this review was in fact driven by

cost cutting since the only options presented were those which involved a resident moving to a less costly form of care. We felt that the CLBC "team" that spoke to us was in effect there under false pretense. During the Residential Options Review presentation we were assured that absolutely that no one would be forced to leave their group home.

However, before the Residential Options Survey is even complete, CLBC has issued a draft Service Delivery Plan which indicates up to 100 group homes will be closed in B.C. Even more troubling is leaked information that a CLBC official made statements about closing every group home in B.C. It seems the cat is out of the bag. At this point in time, the assurances of "no group home closures" given by Mr. Les last April appear naïve at best. CLBC seems determined to create and perpetuate the myth that anyone in staffed residential care could be accommodated in some less costly setting, for example, Family Care. This is quite simply not true.

Closing group homes would be a disaster for residents who in effect typically do not have the capacity to make informed decisions about their own safety and wellbeing. Also, it would be a betrayal for their families who in many cases, struggled for years, to establish safe, stable and nurturing group homes where special needs family members would be able to interact with the community and have every opportunity to live fulfilled lives.

I sincerely hope that you can find a way to stop the regressive movement in CLBC/MCFD that seems intent on "experimenting" with the lives of B.C.'s most vulnerable and defenseless(and non-voting) citizens in order to save a few dollars.

I am also forwarding, via separate e-mail, a copy of a letter written to Minister Les and Minister Penner in April 2006. I have never received any response to this letter.

Thank you for taking the time to read about our concerns.

(name withheld)

Sent: Saturday, February 17, 2007 3:04 PM

To: M.Karagianis, MCFD Opposition Critic

Subject: Cuts to People with Disabilities (response to request for stories for govt.budget debates)

I was thrilled to get your e-mail. I now have an ear to voice my concern to. I am appalled at the Governments cruel cuts to People with Disabilities and to the front line staff who support these people in a variety of ways. Individuals cannot afford to pay for the podiatrist, optometrist and the dentist. These "perks" were taken away from them the first round of bargaining that the Gov't did with Social Service Sector 4 years ago. Individuals cannot afford to buy depends, creams and some medications that they require on a daily basis to live a "normal" life. These "perks" were taken away too. There are wait lists for day programs, work experiences, respite and home settings for these same individuals. People who turn 19 have no "new" money to access for any of the above and so they go from school full of promises to sit at home and waste away into depression and in some instances react in violence to their parents from frustration.

Individuals cannot afford to take a vacation as they have no money to go. These same individuals can't stay home from their day Program or work experience, as they do not have the staff at home during the day from 8-3pm to take care of them. Instead they go to these day activities and pass on their illness to everyone else and it just goes round and round. Someone is always sick and some staff is always away from being too ill to come to work. These staff members cannot afford to be away so much as they are not paid 100% for their days wage that too was taken away from them. There is no staff to relieve for holidays or sick time anyway as there is no way to hire staff with the qualifications needed to work in this field. No one stays if they do apply. This work is hard and thankless. The staff who have been in this field for more than 3 years are not here for the money, they stay because of the individuals. This is used against the staff when they want to stay home sick, take holidays or complain of the unsafe work or work load issues. The managers say, "think of the individuals - who will take care of them?"

The staff who take care of some of the most violent and fragile individuals of this province are not recognized as a "Profession" regardless of the education they have to have to work in this field. The individuals that the staff cares for are not recognized as being people. Someone has to stand up for them and I hope it is you. I speak up for all of those who afraid or unable to speak for them selves. Will you not stand and speak for me???

Louella Vincent

Sent: February 14, 2007 To: M.Karagianis , MCFD Oppostion Critic

Cc: info@bcfamilynet.org

Subject: clbc

M Karagianis;

I am a support worker in a group home where four individuals with complex disabilities live. Since CLBC has taken over from the Ministry I have witnessed the cuts to direct services to people with disabilities. All Agencies falling under the CSSEA umbrella have had to go through a very expensive accreditation process through CARF, (an American concept for service delivery standards), that has cost the Government and our Agencies incredible amounts of money as well as an outstanding amount of hours and energy to adhere to. None of this money was necessary to support people with disabilities at the same time as the cuts to services were being felt by the people supported and the people who support

them.

All of this has happened while CLBC has planned to close group homes across the province. We all know this is a money saving move rather than to benefit the individuals in care. Our agency supports individuals who are in their later years, and who have lived with roommates who are in many cases the only "family" they have and have experienced their lives with. The people who we support have in many cases, have no known family and so we are their advocates, as well as their support people. These people deserve to live their end years in their homes with their "families" the same as you and I.

The plan of CLBC is to move everyone in care into "family home provider" residences, in other words adult foster care. My question is "What happens to people when their failing health does not allow them to live with a family?"

We have just experienced one individual moving into a senior care facility, (in spite of our objections), and the impact that person is having on the other seniors she now lives with is unbelievable. The people we support have many behaviors and issues that do not easily allow them to live in the close quarters with frail elderly people, and the impact on that system will be unacceptable to most.

I implore you to question the mind set that would so impact so many people just for the sake of saving money at the same time that the Olympics is siphoning so much money out of our failing systems

Since I have worked in this career, I have felt the constant threats of closure, and cuts and changes in philosophy, and the people we support and the ones who support them have struggled to carry on in spite of all the turmoil that swirls around us. Please speak for us, and let us do our jobs in supporting people who we care for and give them piece of mind that they can live where they want, even if it isn't in CLBC plans. There have for far too long been too many people involved in their lives, who aren't involved in their lives.

Sincerely,
Support Worker

Sent: Tuesday, February 13, 2007 8:34 PM
To: M.Karagianis, MCFD Opposition Critic
Cc: info@bcfamilynet.org

Hello, I have a story to share with you regarding CLBC.

I am mom to a 4 1/2 year old son who has Down syndrome. Ever since he was born, I have been on the waitlist for respite services, but let me give you some details.

My son was born when we lived in Coquitlam, in 2002. At that time, we were put on 'the list' to receive respite services. During that time I suffered from severe post-partum depression, which was later diagnosed as clinical depression. I had suicidal thoughts and my family suffered because of my 'condition'. There was no help to be had except the usual drugs.

When my son was 2 1/2, we moved to Campbell River. I was immediately in touch with the CLBC offices to transfer the (unseen) services from Coquitlam. After playing phone tag, and waiting endlessly for someone to return my calls, I gave up as I found the battle added more stress to my already stressful life (which did not help the depression, which had lifted but always felt like it's just under the surface, ready to rupture again).

In September (approx) 2006, I picked up the phone to resume the battle for respite. At that time, and still currently, my husband and I have precious little time to re-connect and my marriage is suffering. My daughter (just turned 7) loses out for attention constantly because of the higher needs of my son.

After a time of phone tag, we finally had an appointment with an 'in-take facilitator' in Campbell River. She, however, was unable to make any decision. She was required to pass everything on to someone in Nanaimo, to have our case reviewed and decided upon. Sometime in October I received a call from Nanaimo that said, "so sorry, our budget for the fiscal year is used up, so we will have to wait and see in April. We MIGHT have it then. But the good news is, we've backdated you on the waitlist to when you first contacted us". (Two years prior when we first moved to Campbell River. And that doesn't take into account the 2 years in Coquitlam we never received services either.)

Later in November I received a letter from the CLBC office in Port Moody that required a phone call back by November 30. I phoned the person on the letter who returned my call a week later but I was out. I called again, waited 3 weeks and called again. I received her voice-mail, which was full, and not taking any messages, so I left a message with the phone operator. Another 3 weeks passed and still no response. I called again and again there was no 'space available' on her voicemail. Again, I dialed '0' for the receptionist and asked for her boss. After filling him in on the lack of response of the previous employee, he told I shouldn't have received this letter if I lived on Vancouver Island. I also expressed some of my frustration with the whole system regarding my wait for respite. He gave me the name of another person at CLBC in Nanaimo to call regarding the extensive waitlist time.

I called that person and he responded promptly (wow, first time for everything) and said he would look into it and get back to me soon. I waited almost a month and then called again. Finally in mid February 2007, I received a call letting me know

that some funding for self-directed respite has (suddenly) become available, and I would be receiving respite services. I was also informed that receiving the first cheque could take a bit longer than usual due to the move and disorganization of the Victoria office. (It's now mid-march and I'm still waiting).

In short, 4.5 years of waitlist, numerous phone calls, mostly unreturned, and untold frustration and stress. Why must parents/caregivers of people with special needs have to fight so much when our lives are stressful enough as it is??? If parents split up, or worse, become incapacitated themselves due to stress, does CLBC not realize that this would burden the system far more than if they could provide us with the right services WHEN WE NEED THEM? Also, there is a substantial lack of respite workers/homes available to us even if we do get respite services.

On a side note, there was another family that moved here in September of 2006 from Alberta. They received respite in December of the same year, while I was still on the waitlist. WHAT'S UP WITH THAT?

Signed,
A frustrated parent

Sent: February 14, 2007
To: info@bcfamilynet.org
Subject: Requested Comments

We are very thankful to have our son cared for in his own home and the partnership of family, micro-board and the contract funding support we receive. This all works to provide the best holistic and healthy environment for him and our family. The challenge is to be able to acquire quality caregivers when we are not at par with other funded agencies. We have not had an increase in our contract since it began in 1997. In fact we gave back 1% along with all the other care providers when we were asked to do so.

We do the best we can to provide consistent staffing for our son but becoming more difficult to attract people without the wage and benefits that are given in facilities. This model is an excellent One. We have had several students do their practicum training with us and they would like to work in these home environments but we are not able to offer what the public sector does.

Port Alberni, BC

Date: 1/26/2007
To: The Province Newspaper
Subject: Stanley Park

I am delighted about the millions of dollars thus far given to restore Stanley Park to its former grandeur. There are so many people concerned about the devastation of Stanley Park, that they have managed to raise all this money to put back what an act of nature has taken away. The coverage on the news and in the papers has been endless.

I am deeply saddened that the devastation on the Social Service Sector has gone largely un-noticed by those same people. The Government has taken 70 plus million dollars from some of the most vulnerable individuals in Society. This was dollars that were desperately needed to fund day programs, group homes, women's centers, child caring and senior services.

No one fund raised, no one wrote letters (except families, front line workers and a few recognized professionals) there was little newspaper coverage of this devastation that wrecked havoc on so many lives. It has been painfully quiet in comparison.

Where have we as a Society come to, when sisters, brothers, parents, grandparents and children can be so violated and we say nothing? We have millions of dollars to spend on everything but people. I am ashamed to say I live in British Columbia with those who say nothing to fight for the rights of those less able. It is time to stand up for those who can not stand up for themselves. Put back the money taken by an act of Government. Demand that the Government restore previous necessities of life for those less able than ourselves.

Louella Vincent

Jan. 5, 2007
BC FamilyNet received a copy of the following letter sent December 13, 2006 to:

Honourable Carole Taylor, Minister of Finance.

Re: Family Care Provider's Plight in BC

I received a request from you for feedback on budget issues. I completed the request online and was dismayed to find that I was given only 5 choices where some money could be "found" to address the priorities I identified. I did not agree with any

of these choices, but was forced to choose one in order to complete the survey. I am now taking this opportunity to write to you so that I can share some of my concerns about the lack of funding for supports and services for people with developmental disabilities. BC has experienced significant economic success as the surplus indicates however many people with developmental disabilities are not getting the support they need. I would like to tell you a little bit about the lives of a few of these people.

I have been a family care provider in supporting two ladies in my home. The two ladies I currently support have been living with me since 1999. One lady is 49 and the other will be 82 in January. I have taken them on vacations with them paying their own fare only. I have not charged for any caregiving or food when we have been away. If these gals are supported by someone else when they go away, they have to pay the caregivers way as well as some support time (usually shared with a group of clients). My people eat the same way as they always have, and we take them to appointments and drive them around with the cost of gas at \$1.00 per litre, etc. They are treated as family members.

I have just been given yet another contract at the same rate I have been paid for the past several years. This year, I am signing it under protest. I have been verbally protesting my contracts for years now, and have always had to suck it up, because "there is no money".

The 81 year old lady has many health issues, including Osteoporosis, GERD disease, Arthritis chronic pain from deteriorating disks in her spine, scoliosis, as well as other issues relating to age. This lady has communication difficulties and cannot be left alone. She uses a walker daily, and sometimes a wheel chair, depending on her mobility, which is very often impaired by pain. Because of this she is set up in a 4 day per week program with a trained one to one worker, and one day per week at a leisure days program, which is provided by another service provider. Since the one to one day program was instituted, I have been given \$750 per month to purchase this service. At 6 hours per day, not counting Statutory Holidays, when my lady is at home with me, this works out to \$7.51 per hour. The respite worker comes to our house, and takes our gal out into the community, and visits other people and programs during the day. They often go out for lunch or shopping. The caregiver is very sensitive to this lady's health and emotional needs and has been working for me since 1992, when she did similar work with a previous client of mine. About 2 years ago now, I raised the one to one's worker to \$60.00 per day. The worker pays for her own gas and food, and because of the increase in fuel and her other costs, I couldn't have her work for less. \$60.00 per day is very reasonable to get this quality of care for my lady. I have asked for the difference in my costs for this from this point on, not retroactively, and have been turned down. I just found out today that the company pays \$17.52 per hour plus benefits for respite care for other contractors doing the same work through the company.

I have taken them with me on a cruise to Alaska, 3 trips to Disneyland and other shorter trips. We take them camping with us in the summer. Neither one of my ladies visit their families for vacations. One went once for a cruise with Mom. The other, I have taken her and her family on a cruise, and over to Vancouver Island, and had them visit at home here with her sister several times.

It is difficult to go on a separate vacation, as I need to pay respite for someone else to look after them when we go away. Since 1996 I have had 3 vacations without my ladies, one 5 day, one 1 week and one 3 week vacation. If I don't take them with me, it costs me \$250.00 per weekend for someone to come in and look after them, plus food and gas for all of them. It costs me \$1,000.00 per week of care plus food and gas for them. This is true for many family care providers. Most jobs would cover at least a 2 week vacation period. That is 10 years without much in the way of holidays. I simply cannot afford to pay for a holiday plus respite and expenses. It is a long time when you support people 24 hours a day with only a six hour break on weekdays.

If we do not have respite, it makes us stale. Everyone needs a break sometime. We have our guys 24/7 except for day programs. We do have them 24/7 weekends and holidays. The younger lady visits her family overnight, very occasionally, the other never does. The younger lady has just been at home for the past 6 weeks recuperating from a total hysterectomy, necessitated by a growth in her abdomen. This lady has high emotional needs and severe anxiety. I had been turned down for any extra respite during this time. I have managed to get some extra mental health support for her through the years. After the recuperation, she had a very difficult time transitioning back to work at her regular day program. I ended up in Emergency myself, through a serious anxiety attack where my blood pressure was 196/106. This has never happened before, and after examination by my family doctor, it would appear that this was stress induced. Following my trip to the hospital, I was granted paid respite for my lady for 1 week.

My daughter moved into our basement suite in May of this year, leaving a funded vacancy at the group home she was living in previously. Her boyfriend of three years moved in in June of this year, and is a great addition to our family. He was supported in pri care previously. They pay us \$800.00 per month from their PWD benefits which were decreased from \$856.42 individually to \$1,469.06 as a couple, because someone has decided that two can live cheaper than one. This includes their utilities and food.

I do not expect to get any compensation for my daughter, and I have been turned down for any support for her boyfriend. He has epilepsy (with drop seizures) requiring him to wear a construction helmet so that he does not injure his head. I take him to doctor, dentist and other appointments, help him with his banking, and have arranged to get him a custom helmet that will not fall off during a seizure, and basically done life skills and whatever support he needs. We will continue to do this because he needs to have this done. His needs were considered serious enough to pay someone to look after him prior to him coming to live with us.

I have just celebrated my 62nd birthday. I have no pension, other than Canada Pension, no benefits of any kind, and am

going to have to work for much longer than the normal 65 years after which most people expect to retire. I volunteer countless hours and taxi people around at my expense, because I love these guys and just want to help them out.

The union that supports people with special needs was given a signing bonus of \$3,000, and has been receiving cost of living and other increases through the years since 1990, when I first started caregiving as a profession. They have extended medical, dental, eyeglass and other benefits for themselves and their families. We do not.

It makes me very angry when I hear of signing bonuses, cost of living increases, benefits, etc. I have lived in this province all my life, paid taxes, always supported my community and my government, and I love my work.

I really believe that if government expects us caregivers and the people we serve to live on less, and "find efficiencies" that government should be doing the same thing. After all, we are also responsible for the success of this province.

Perhaps MLAs could take a reduction in their salaries, like all of us in Community Living have had to do. According to STATS CAN, there has been a 21.5% cost of living increase that has never been addressed in my contract, which means that I am making 21.5% less than I was 5 years ago. Obviously Government has recognized the need for an increase in MLA's salaries. I feel like I have supported this province very well, and have always tried to be very professional in my work. I feel as if my work in giving direct care to people is certainly as important as MLA's work in running the government.

Perhaps specific lottery funds could be allocated to help fund Community Living BC. They are allocated to help fund amateur sports and other activities. It seems to me that it is an absolute travesty that persons with disabilities are being supported below the poverty line, especially when there are two living together and they have to endure a cut in their persons with disability benefits of almost \$250.00 per couple. Very many of these folks have to rely on the food bank and charity from others to survive. There are so many out there that are not connected to any support.

During the Interim Authority's duration, many efficiencies were found to save the government a considerable amount of money. I would like to know why that money was not put back into community living to address waitlists, rather than going into general revenue. I am totally ashamed to say that my government prioritized many "things", while taking little or no action to support the most vulnerable citizens in our society better.

I personally know a great many people with special needs, including my daughter, and I believe that this province is much richer for having their input into community. There must be some way to honour these proud citizens.

There are many of us family care providers throughout this province who provide excellent care to people who are mentally challenged. We provide a very valuable service to the individuals, their families and basically save the government a lot of money, because our guys are not supported in other, much more costly arrangements. It is time for us to be given a reasonable living wage, so that we are able to pay for some benefits for ourselves. Each one of us caregivers has a different, but similar story. This is mine.

Name withheld by request for confidentiality.

January 15, 2007

This letter is in reference to the **Direct Funding: Adult Respite Program**

We (parents) have been advocating for years for an adult respite program similar to the 'At Home' program for the clients under 19 years of age. We were so pleased and excited that CLBC had set up a program and they were inviting the Facilitators across British Columbia to put forth family's names to participate in the program. Our Facilitator asked us if we would participate and we agreed.

We received an information package. We read and discussed the information and were disappointed to realize that the process was so complex. Our first thought was not to participate. We did change our minds. We thought that this was an opportunity to give feed back and help to make this a program that would benefit many aging parents with sons and daughters living at home. So we continued with the process.

We started on our fact finding mission using the information entitled '**Adult Respite Direct Funding General Information for Families**' on page two under the topic '**What is your role as a family?**'

It states "It will be your responsibility to determine whether the provisions of the following legislation apply to whatever arrangements you make with caregivers:

- *Employment Standards Act
- *Workers Compensation Act
- *Human Rights Act
- *Income Tax Act
- *Canada Pension Act
- *Other relevant legislation

We checked with our local **banking institutions** about setting up a checking trust account in our son's name. We were told that we would need to present a document to the bank verifying that he was our son and that we were his legal guardians. We were also told that there would be service charges on this account. The charges varied from institution to institution. At a Credit Union, the fee would be \$.50 per check and at a bank, it would be \$3.00 per month. The legal fees for setting up a committee or proof of guardianship would be an added cost.

I continued to follow the directions and suggestions included in the package. I called **Revenue Canada** to get information regarding income tax for the respite providers. I was on the telephone for 45 minutes while people searched for information only to be referred to **INQUIRY BC**. I was told to ask to speak to a **'RULING OFFICER'** regarding **CPP** and **EI**. If he ruled that we would be responsible for CPP and EI then we would know that the respite provider would be taxed on the income. I spoke to a Ruling Officer, who told me that rulings are made on a case-by-case basis. We would have to continue with the application process, have a caregiver come in to provide respite for us and then call a 'Ruling Officer' to open a file. The Ruling Officer would set up a 20-minute interview with us and a 20-minute interview with the respite provider. There is a 60-day turn around time and we would be notified in due course of the ruling. There is no precedence set. Each case would be dealt with individually...in other words; each family would be required to follow the above procedure. Once a determination is made regarding the CPP and EI then Revenue Canada would know if the respite money is taxable income.

My next call was to **WCB** to get information about our responsibilities for coverage. This also got complicated. Each client would receive \$233.00 per month. If the family paid for respite in increments of **less than eight hours per week**, no WCB coverage is required. However, if the family had someone come in for a weekend to provide respite, coverage is required. The magic number is EIGHT HOURS PER WEEK. If you pay one or more individuals for more than 8 hours in a given week coverage is required. There is no way around this! Parents would be considered "employers".

My last call was to the **EMPLOYMENT STANDARDS** office. I explained the program and asked if parents would be considered "employers". The answer was very clear...YES; parents would be considered employers and would be required to act accordingly.

I understand that CLBC has an insurance policy that "**provides protection for you and your employees and contractors from liability claims up to @2 million...**" CLBC is very clear in the above statement that parents/families are employers. How many parents are going to follow through and get the above information? How many parents and families have already signed contracts with CLBC not understanding the possible legal repercussions? I believe that CLBC is placing parents and families in legal jeopardy.

After 5 hours on the telephone doing my due diligence according to the information package given to us we have decided that we do not want to be employers we just want to continue to be good parents to our son and all that entails. We are tired and stressed. We are REALLY tired and stressed and frustrated now that we have gotten all of the above information.

We think that CLBC needs to go back to the drawing board and come up with a less cumbersome process. It is our belief that CLBC is not looking after the needs of families. It is a bureaucracy that is in need of fixing. CLBC has broken a system that was working but was in need of fresh ideas and goals. I see the present system as being too heavy with the bureaucracy at the top and the Adults with Developmental Disabilities and their families at the bottom. Somewhere in the middle, our Social Workers (Facilitators and Analysts) have gotten lost. I do not care which way CLBC draws their pyramid...they need to put the Clients, their Families, the 'Social Workers' and Care Providers at the fore. This is where their focus needs to be. I am very disappointed in the direction that this new Authority has taken.

We have read with much concern, the draft proposal regarding the "PROPOSED SERVICE DELIVERY PLAN" that CLBC is considering. I refer to the following as taken from the draft proposal.

"Respite Care to a family or caregiver providing a service will be provided by a bargaining unit employee from a CSSEA member agency if the community has such an agency. Respite workers are subject to the ongoing approval of the individual(s), that person's family and/or the caregiver providing the service. A specific period of respite assignment, once approved, may only be terminated for cause or the early termination of the assignment.

The monthly allowance payable will be the standard monthly allowance paid for this type of service."

We have grave concerns about the abuse of power that CLBC appears to be displaying and the impact and the implications that the proposal will have on adults with developmental disabilities and their families. CLBC not only needs to hear the voice of the families. it needs to listen. We are not interested in the power struggles CLBC may be experiencing. We are interested in getting the best care for our children, be they 19 years of age or 59 years of age. We cannot do this alone. We need information, programs and people who **really care** about our children and will work with us to provide a better quality of life for them.

On a personal note, we want our son to enjoy a good quality of life and we want to be able to provide that for as long as we are able to. A genuine respite program that meets our son's and our needs would be a great help to us. We have decided that we will carry on as best we can and not participate in the Adult Respite Program in its present form. It is our hope that CLBC will revisit and revise the program guidelines and accept their responsibility for providing a much needed respite program for families in British Columbia.

Yours sincerely,

(name of parents withheld as requested)

Jan. 7, 2007:

Hello, I am a mother of a daughter who will be 18 in June of this year. I have been on income assistance in order to stay at home with her. I will be cut off in June and am wondering if there is any other help available for us as she will still be in my care. She attends high school but after that I do not know where she will be as far as programs for her. She was diagnosed with global development delay and needs supervision at all times. When in school she has a one on one caregiver. If you have any information for me I would greatly appreciate it. Just because she will be 18 does not mean her situation has changed any degree. Thank you very much.

Donna Nordin

[Apr - Dec 2006](#)

From: louella vincent

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*