

Evaluating Your Current Experience with CLBC

The BC Association for Community Living (BCACL) wanted to know how some of the key areas in the transformation of Community Living British Columbia (CLBC) are affecting self advocates, children and youth with special needs and their families.

We conducted this survey, for seven days, between April 7 and April 15, 2008. The survey was available through our website and e-mailed to individuals, families and member organizations across the province. Meant to be easily accessible, the survey consisted of 12 short questions, with room for comments.

The survey was distributed through Survey Monkey, an online survey host. While many respondents answered the questions online, many self advocates printed the survey and returned a hard copy. Those responses were also included in this report.

We asked questions related to the key structural elements that were part of the original vision for CLBC:

- Providing a seamless lifelong system of support for children and youth with special needs, adults with developmental disabilities and their families.
- Providing individualized services and individualized funding.
- Increasing decision-making by people with developmental disabilities.
- Offering individualized planning supports, in a way that separates the function of approving funding.

BCACL is a federation working with partners to build community and to enhance the lives of children, youth and adults with developmental disabilities and their families by supporting abilities, promoting action and advancing rights, responsibilities and social justice. BCACL's vision is: *"Inspiring a world where everyone belongs."*



**British Columbia
Association for
Community Living**

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Questions 1 – 3:

Who Did We Hear From?

- 594 respondents
- 72% family members
- 17% self advocates
- 11% others

Respondents were (or had a family member) within a broad age range:

- 9% over 50 years
- 14% between 36 and 50 years
- 34% between 20 and 35 years
- 22% between 13 and 19 years
- 15% between 7 and 12 years
- 6% under 6 years

Respondents by region:

- 46% - Lower Mainland
- 22% - Vancouver Island/Sunshine Coast
- 18% - Interior/Kootenays
- 14% - Northern BC

Question 4

I/my family member, receive(s) the appropriate community living supports when needed.

Strongly Disagree	Disagree	Agree	Strongly Agree
21.3%	31.5%	39.2%	7.9%

Respondents noted the following concerns in their comments:

- long waitlists
- no funding
- no or poor transition planning for youth turning 19
- refusal of CLBC to provide supports based on I.Q. over 70 and/or for individuals who have FASD or Autism

“I feel that I have good supports.”

“Even with strong advocacy, we were unable to get the support we believe we need. Our daughter needs 24/7 care but we’ve chosen to keep her at home saving CLBC and government thousands of dollars a year. They should want to help us so we can continue to do that job.”

Question 5

My/my family member’s services are individualized to meet my/their/our needs.

Strongly Disagree	Disagree	Agree	Strongly Agree
17.7%	29.0%	44.5%	8.8%

Just over one-half of people reported that their services are individualized to meet their needs. Many people commented that this was due to the hard work of their family, microboard and personal support networks.

“Yes, CLBC was responsive and supportive of addressing individual need and committed to ensuring that the services my family members ultimately received were person-centred.”

Reasons given for why services are not individualized included, lack of financial resources available at CLBC, CLBC not having enough staff to make this happen, and long waitlists.

“. . . we are getting there. It is a process and takes a lot of advocating, energy, letter writing and meetings. We have learned to ‘beg’ . . . this is hard for us as parents, but we have learned that one has to do whatever one can to make an impression on those holding the purse strings.”

Question 6

Key decisions about what supports and services I/my family member receive(s) are made by me, my family and/or my advocate.

Strongly Disagree	Disagree	Agree	Strongly Agree
15.8%	17.2%	50.6%	16.5%

Sixty-seven per cent indicated they are making key decisions about what supports and services they receive.

“We have a wonderful facilitator and analyst in our community who truly care about their clients and families. This makes it easier to discuss needs and try to work out ways to meet those needs.”

“Most decisions are made by my mom, some are made by me.”

Other comments reflected that while respondents can choose the supports they need and want; they are not made available because of limited resources.

Question 7

Key decisions about how and from whom I/my family member receive(s) supports and services are made by me, my family and/or my advocate.

Strongly Disagree	Disagree	Agree	Strongly Agree
13.8%	18.8%	50.6%	16.8%

Similarly, 67 per cent believe they make decisions about who provides their services and how they are delivered.

“This is at my insistence – I am an extremely strong advocate out of necessity.”

The majority of comments received were from the group of respondents who said they did not make these key decisions and suggested it was because CLBC made the decisions for them, or the decisions were made within available resources.

“Decisions are limited by lack of resources, options and funding.”

Some commented that even when they have received funding and want to make this decision about who will provide the supports, it is difficult to find and hire qualified staff.

“Making the decision is not hard for us . . . finding a speech therapist is impossible.”

Question 8

I support the vision of participating in mainstream/generic community activities (i.e., recreation centre, local pool etc.), events and groups.

Strongly Disagree	Disagree	Agree	Strongly Agree
3.1%	4.7%	50.1%	42.1%

Nine out of every 10 people (92.2 per cent) who participated in the survey support the vision of participating in mainstream or generic, community-based activities.

“I believe people with disabilities have talents and gifts to offer our communities. The more integrated we become, the more everybody benefits as a whole.”

However, the vast majority of comments indicated that much work needs to be done to educate the generic community service providers on welcoming, valuing and including people with developmental disabilities into mainstream activities.

“We work extremely hard to remind others that generic services and supports are ideal – it would seem that policies and confused people stand in the way of integration.”

Many people commented that while accessing typical supports is important, there is value in segregated programs as well.

“But not to the exclusion of activities held in the person’s immediate and longest term community – the disability community.”

Question 9

The CLBC facilitator helps me/my family to find and engage in mainstream/generic community activities (i.e., recreation centre, local pool etc.), events and groups.

Strongly Disagree	Disagree	Agree	Strongly Agree
33.2%	37.3%	24.8%	4.8%

In contrast to question eight, while 92.2 per cent believe in this vision, only 29.6 per cent report their facilitator is helping them to make this happen.

The most repeated comments provided, indicated that people do not know who their facilitator is or what they do, and that they have never heard from one and don’t know how to get one.

“I’ve read of facilitators – but do not know who this person is. I don’t think they make themselves a known person in the community. They do not contact families to keep in touch, and do not attend meetings I’m involved with.”

Others commented on the inability of the facilitator to do this because of their lack of training, awareness, access to funding, and overwhelming case loads.

“The facilitator tries, but they have such huge case loads and crisis to deal with, it is hard for them to focus on this piece of work for clients.”

Question 10

If adequately funded, I believe CLBC will achieve its vision over time.

Strongly Disagree	Disagree	Agree	Strongly Agree
10.7%	19.6%	50.1%	19.5%

Seven out of 10 people surveyed, agreed or strongly agreed that if adequately funded, CLBC will achieve its vision over time.

“CLBC had a vision that was appropriate and was created by the individuals who would be stakeholders.”

The themes that emerged in the comments indicated that increased funding, changes in policy, and more trained staff are needed to make this happen.

“It’s not always about the money. I think the employees should come and live with and take care of our kids for a week so they can truly experience what it is like.”

“If there are sufficient changes to policy and procedures, in addition to adequate funding.”

“I am very concerned that the system is not working and that some individuals are not getting the support they need, even when they are in crisis it seems to be a question of whether they will get support or not. It never used to be a questioned – it just happened.”

Question 11

I believe that, over the long-term, the separation of the roles of facilitator (the person who helps develop individualized plans) and the analyst (the person responsible for funding the plans) will serve people with disabilities and their families better.

Strongly Disagree	Disagree	Agree	Strongly Agree
27.9%	26.6%	36.3%	9.2%

The complexity of this question is reflected in the range of comments provided.

Respondents commented, that they did not understand the different roles, and that they miss having one person to contact at CLBC, that more levels of staff just add to the bureaucracy and that it doesn't matter who is making the decision because there is no money anyway.

"Separating roles has lead to delays in responding, confusion about how decisions are made, less collaboration, communication and accountability."

"A great idea – it just hasn't worked! The analysts have all the control – no money, no planning. No planning unless there are funds available. No planning unless someone can assist you – for free. Families are now begging for help like never before from anyone they can find. Many families won't go back to the facilitator – the time spent is upsetting and useless."

Question 12

I believe that Community Living BC should provide a seamless system of support for children and youth with special needs, adults with developmental disabilities and their families throughout their lifespan.

Strongly Disagree	Disagree	Agree	Strongly Agree
3.7%	3.5%	29.7%	63.2%

"That would be a dream come true!"

While 92.9 per cent agreed with this statement, the majority of comments indicated there is great distress and concern about children and youth with special needs transitioning to the adult system of support when they turn 19.

"This is the biggest problem in the current system – the virtual abandonment of families when their children turn 19."

"We have just gone through, without a doubt, one of the worst experiences of our lives just dealing with our son transitioning from child to adult services. I don't think they could have been more inept, inefficient, and inconsiderate or made a family feel more confused, and hopeless, with no control over our lives than they had. There was no communication at all for months, only to leave us with no respite or support services of any kind with absolutely no communication what-so-ever to let us know what was going on. We couldn't even get the local facilitator on the phone for any explanations either, for over a month."

Disclaimer – We have summarized the comments provided to each of the survey questions in broad terms to best reflect both the majority and range of comments provided. We acknowledge that CLBC is still in a period of change and individuals and families have a variety of experiences. The average number of comments provided for each question was 215. If you would like to view the full results of the survey please contact BCACL.

What We Have Learned

There is an overwhelming agreement (92.9 per cent) that CLBC should provide one seamless system of supports for children and youth with special needs and adults with developmental disabilities, across their lifespan.

While 70 per cent of the participants who answered the survey still believe the vision of CLBC can be achieved over time and with adequate funding, there are still many operational obstacles and attitudes that stand in the way of this becoming a reality.

Two-thirds of the respondents agree they are making decisions about the type of supports and services, how it is provided and who provides them.

What appears to be particularly problematic is the development of the facilitator and analyst roles CLBC has created as the way to ensure that individualized planning supports are provided independently from the decision-making process to approve funding.

Major Themes

From the nearly 2000 comments provided, we were able to pull out the following themes:

- The transition from childhood to adult services is leaving people in crisis and without needed supports. Transition planning is not often happening, and when it does happen, long waitlists and lack of funding prevent services from being provided when the child turns 19 years old.
- Individuals who have an I.Q. above 70, or who have FASD and/or Autism are denied supports from CLBC because of the current eligibility criteria.
- Lack of funding and long waitlists are preventing supports and services from being individualized. In some situations where plans are approved and funding is available, the supports can still not be individualized because trained staff is hard to find and hire at the offered wage, or group programs are the only option offered.
- Individuals and families are confused and frustrated with the separation of roles for facilitators and analysts. Overwhelmingly, we heard that families don't know who to contact at CLBC, calls are not returned, someone different answers the phone every time they call, and no one at CLBC knows who makes decisions.

A few comments serve to remind us all about our collective responsibility to continue to build communities where everyone belongs. In response to the question asking about participation in generic/community based activities, we heard:

"I appreciate the rationale behind participation . . . but only if it doesn't affect, harm or frighten non-challenged children."

Next Steps

Annual General Meeting and Conference — BCACL travelled to the communities of Nanaimo, Cranbrook, Terrace and Kelowna in May to report on the initial survey responses and to gather additional information from self advocates and family members to add to the original data. Members of the BCACL Board of Directors will facilitate a workshop at the BCACL AGM and conference on June 12. The workshop, entitled CLBC: On the Road to Success?, will report back on the initial online survey and the additional information learned at regional meetings.

Final Report — A final report, compiling all the information gathered from the online survey in April, the regional meetings in May, and the provincial workshop in June, will be distributed and posted on our website in the fall.

inspiring a world where everyone belongs