



A DISCUSSION PAPER ON

Community Living

Exploring solutions



MARCH 2008



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Executive summary

In the 1980's British Columbia became one of the first provinces to close institutions housing people with developmental disabilities. Today there is a common vision shared by stakeholders in community living. As described by CLBC, it is a vision "of full citizenship in which people with developmental disabilities lead good lives, have rich relationships with friends and family, financial security, choices in how they live their lives, employment opportunities and are accepted and valued as citizens".

However, the community based resources and capacity to fulfill this vision are totally lacking.

The provincial authority provides support and services to only 28% of the 36,000 adult British Columbians with developmental disabilities. There are more than 1,300 eligible individuals on waitlists. These waitlists represent only families and individuals who have established eligibility for service. Many thousands of eligible individuals and families receive nothing. It's crucial the true needs of these people be assessed so that funding and resources can be put in place to meet those needs. For youth with developmental disabilities the system seems to collapse when they turn 19 and the ministry no longer has legal responsibility for them.

Despite a strong mandate and shared vision, the system is failing. Families, care providers, frontline workers, academics and advocates cite a litany of problems: a lack of choices, inadequate training and equipment, program closures, sudden and arbitrary transfer of adults in care and poor communication.

Parents and relatives complain they cannot get service or answers from the provincial authority or the ministry. Despite the addition of community councils, offices for quality service analysts and facilitators, CLBC remains distant from clients, families and care

providers. Adding to the problem is the current waitlist policy is complicated and not transparent.

There must be public accountability for the community living system. The province should introduce legislation guaranteeing entitlement of all individuals with developmental disabilities to the services and supports required for full participation in society. A thorough, independent review and assessment of CLBC is long overdue. Government is also less accountable because it has detached itself from direct service delivery. The Representative for Children and Youth needs to take on a greater role in providing oversight and demanding accountability. A Representative for Adults with Developmental Disabilities should be established as an independent officer of the legislature. Regional advocates could also assist individuals, families, and care providers to make the system more responsive.

The dream that the new organization could do more with less has proven false. There are long delays for services. Programs in many areas are bursting at the seams. More funding is urgently needed. Restoring the \$150 million cut from the budget in 2001 is not enough. A more realistic estimate to cover waitlists, crises and emergent care needs would be a budget of \$131 million over three years.

Funding must increase to meet population growth and an aging population and must be consistently distributed across the province.

There are significant differences in service needs based on geography and demographics that must be addressed. The province needs to initiate discussions with stakeholders in the sector, including unions and employers, to identify changes necessary to the current governance model of CLBC to ensure equitable services, as well as increased flexibility for individuals and consistency of care.

The promise of support and services in the community and real choices in housing and programming has also not been realized. Clients, their families, advocacy groups and workers are all looking for more variety in residential arrangements. Through the Residential Options Review process adult residents are being shuffled out of communal living arrangements and into private care. Group homes are being dismantled or transformed into unregulated residences narrowing the range of options.

The province needs to make a multi year investment in semi and independent living and develop a provincial network of houses with three or four self-contained units and apartment buildings where units can be grouped together. In some communities individuals capable of independent living could reside in apartments in different buildings within a relatively small area. Some group homes may be suitable for renovation or enlargement.

Properly resourced group homes are a good option but they are being ignored. We need a community living system that acknowledges the value of private and family care, as well as communal care in group homes, and semi and independent living.

Most care providers are supportive of expanding and transforming the system of residential settings. It's possible to create an innovative, flexible system of residential care

and program options that also provides stability and flexibility for workers too. These are not the models currently promoted by CLBC.

The sector needs staffing models for semi and independent living that respect family responsibilities and career aspirations. It also means integrating a wide variety of care providers into a network.

Across the sector workers are in short supply. Staff feel undervalued, under-equipped and are deeply concerned by the shortfalls, confusion and failures of the system. The community living sector is facing well documented recruitment and retention problems. The province must increase compensation for care providers and professionals in the community living sector.

Care providers recommend using the current CLBC service areas to establish a system that permits people to move between residential setting and between agencies without disruption. Portability of seniority and benefits would provide the flexibility needed to ensure consistent services and retain skilled staff.

Some agencies, facing prolonged vacancies have attempted to use the national temporary foreign worker program to fill the gap, applying to Services Canada for an exemption that will allow them to recruit in developing countries. Overseas recruitment should provide immigrants with Canadian citizenship and allow employers to assist them to achieve this status. Exploiting workers from developing countries should be rejected.

Consistent and improved training is also needed in the sector. Acute staffing shortages force agencies to knowingly hire under-skilled and unsuitable workers. Specific training is also needed for ageing clientele and mental health issues. CLBC and employers must also acknowledge this sector has a high degree of violence and take steps to reduce risk.

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Despite their frustration stakeholders believe it is possible to build a community living system that is inclusive, dynamic, responsible and responsive. A system that offers options, flexibility and security for individuals, families and workers.

Stakeholders we spoke with presented specific proposals. By the end of the current fiscal year CLBC will mark its third anniversary. This is the appropriate time to make needed improvements.



Summary of recommendations

1 Public Accountability

- (a) The Auditor-General should immediately undertake a comprehensive performance review and evaluation of the operation of Community Living BC.

2 Funding

- (a) The province must begin to provide regular annual budget increases to eliminate the current waitlists, address unmet need and growth in demand for services and to provide some contingency for crises. Funding must also be allocated to address specific needs including transportation, miscellaneous costs associated with day programs and professional services.
- (b) Substantial capital funds must be allocated to purchase equipment, retrofit existing group homes in the non-profit sector, and to establish a network of semi-independent and independent living settings.
- (c) The government must address poverty among adults with developmental disabilities, by significantly increasing social assistance funding, and eliminating differentials based on age.
- (d) Put a process in place to ensure funding is distributed fairly and proportionately across the province.
- (e) The province must increase compensation for care providers and professionals in the community living sector, and in the case of home share providers, should distinguish wage and benefit entitlements.

3 Governance and Regulation

- (a) Enact legislation guaranteeing entitlement of all individuals with developmental disabilities to the services and supports required for full participation in society.
- (b) The province must immediately initiate discussions with stakeholders in the community living sector to identify changes in governance necessary for CLBC to fulfill its provincial planning and oversight role.
- (c) Increase the accountability of CLBC through annual reports to the legislature, and give the Representative for Children and Youth a greater role to play in assessing the CLBC, and delay transfer of services to children.
- (d) Establish a Representative for Adults with Developmental Disabilities as an independent officer of the legislature and put in place regional advocates to work with families and adults who have developmental disabilities.
- (e) Increase standards for all residential settings, including home share, and increase the CLBC's capacity to monitor. Bring the assessment process back into the Ministry to ensure reliable external assessments of all residential settings.
- (f) Explore taking the accreditation process into government to ensure reliable and objective ongoing assessment of all residential settings.

4 Service Delivery

- (a) Stop the endless visioning, re-visioning and restructuring exercises at CLBC.
- (b) Develop and implement a multi-year plan for expansion of accommodation to create a genuine range of residential options for independent and semi-independent.
- (c) Acknowledge the value of group homes in the mix of residential options.
- (d) Build an integrated system of residential options from family home share to staffed independent living staffing, and provide more support, and skill development for home share providers.
- (e) Offer real options and respect and support choices made by adults with developmental disabilities.
- (f) Establish clear eligibility criteria for respite and relief care, based on the number of adults with developmental disability in the home and their degree of disability and take responsibility for recruitment away from already burdened family members and private home providers.
- (g) Revise the IQ-based eligibility threshold for entitlement to services and use an adaptive functioning test.
- (h) Restore case management at Community Living BC.
- (i) CLBC and the Ministry must establish a greater community presence, especially in small towns and rural or remote areas.
- (j) Increase staffing at Community Living BC, and improve communication with families of people with developmental disabilities, making sure entitlements, decision-making and waitlists for service are transparent and widely known.

- (k) Establish better communication and confirm responsibilities between the ministries, regional health authorities and CLBC.
- (l) Strengthen the process for joint assessment and planning to ensure a seamless transition from youth to adult services.

5 Staffing Issues

- (a) Reject use of the temporary foreign worker program, and encourage agencies to use existing immigration programs that offer Canadian citizenship.
- (b) Establish seniority and portability of benefits by geographic area to facilitate the best possible matching of residents and care providers and to permit a seamless transition through different care settings.
- (c) Ensure all care providers have appropriate and equivalent credentials, including those providing care in home share settings. Standardize training requirements and increase in-service training for all care providers, with a special emphasis on minimizing health and safety risks. Provide skills training for CLBC workers on working with special needs children. Ensure that care providers have knowledge of the resident's history of violence or abuse.
- (d) Increase training on crisis intervention, follow up on incident reports, and ensure information required to ensure the health and safety of both residents and care providers is provided.
- (e) Establish a labour adjustment and training agency under the joint direction of CSSEA, CLBC and the CSS Union Bargaining Association.



Introduction

At present as many as 36,000 adults, one percent of British Columbians, meet the current definition of developmentally disabled and may require some kind of support.

But are these British Columbians and their families getting the support and services they need? Is the current system incorporating the best practices and providing a range of real choices for adults with developmental disabilities and their families?

To find out, we organized a dialogue on community living involving care providers, advocates, academics and ministry representatives in May of 2007 at Simon Fraser University's Wosk Centre for Dialogue in Vancouver.

We followed this by talking to clients, family members, advocates, care providers, social workers, other ministry staff, staff at CLBC, academics and agencies. In all, we conducted taped interviews and several focus groups asking what works, what needs to be fixed, and what is required to ensure dignity, independence and support for people with developmental disabilities and their families. In total we engaged over 200 people from this sector. These conversations have informed this report.

Background

British Columbia began closing institutions housing people with developmental disabilities in the 1980s, one of the first provinces in Canada to take this step. For years advocates demanded the government replace institutional care with smaller settings.

They wanted a system of community-based programs that accommodated the specific needs of individuals and families. They wanted a system that enabled people with developmental disabilities to lead more independent and fulfilled lives. They were also clear that a move from institutional care was not merely an exercise in reducing costs. The move to community based services was intended to coincide with a commensurate increase in community funding and capacity.

Twenty years on, there is a common vision shared by stakeholders in community living. As described by CLBC, it is a vision "of full citizenship in which people with developmental disabilities lead good lives, have rich rela-

tionships with friends and family, financial security, choices in how they live their lives, employment opportunities and are accepted and valued as citizens".

What are lacking however are the community based resources and capacity to fulfill this vision.

In 2001, the government set up a long consultation process, at the end of which they created CLBC - an arms length crown corporation charged with "... responding to the life-long needs and goals of individuals and families by recognizing their abilities and contributions, sharing leadership with communities, and funding supports that honour individual choice."



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But the provincial authority was established on the faulty assumption that more and better services could be provided after funding was reduced by \$150 million. It's just not possible.

The universal sentiment we heard is that CLBC is failing to meet its objectives because it has been massively and tragically underfunded.

The provincial authority provides support and services to only 28% of the 36,000 adults who may meet the core definition of developmentally disabled. There are more than 1,300 individuals who are eligible but are waitlisted because there is no money for services for them.

And the waitlist represents only those families and individuals who have already established eligibility for service. Many thousands of individuals and families receive nothing at all.

CLBC acknowledges in their current service plan that "there are a significant number of vulnerable adults who have been identified who require supports and services but for whom no one ministry or authority has statutory or assigned responsibility. Addressing the needs of this vulnerable population is a government wide issue." There is no indication that CLBC or government is moving to fill this service void.

And the need for residential services is likely to grow quickly as aging parents of adult chil-

dren find they cannot cope with their children at home and urgently need alternatives. CLBC's Service Plan for 2007/08 also warns that as individuals with disabilities age their

need for service will increase; health problems occur up to 20 years earlier for people with developmental disabilities.

The provincial authority acknowledges there are several strategic issues that could have an adverse effect on capacity in the next few years. Most of

the issues relate to a lack of funds – and most are all too familiar to everyone involved in community living services:

- recruitment and retention – a labour shortage caused in large part by low compensation and benefits;
- cost pressures from service providers in the community;
- expanding eligibility criteria that might come from court rulings or public advocacy.

Families, care providers, frontline workers, academics and advocates cite a litany of other problems with the current service system: a lack of real choices; inconsistent or inadequate training; inadequate equipment, programs that close without notice; sudden and apparently arbitrary transfer of adults in care; and poor communication. Despite the strong mandate and the broadly shared vision the system is failing many individuals and their families.

“The provincial authority provides support and services to only 28% of the 36,000 adults who may meet the core definition of developmentally disabled.”

Improving the community living system

Despite their frustration with the current arrangements, stakeholders believe it is possible to build a community living system in B.C. that is inclusive, dynamic, responsible and responsive. A system that offers real options, flexibility and security for individuals, their families and for workers.

Stakeholders interviewed for this paper presented many very specific proposals. The suggestions that follow have been grouped into those dealing with public accountability, funding, governance and regulation, service delivery, and staffing.

1 Public Accountability

When Stan Hagen, then Minister for Children and Family Development, launched Community Living BC he promised families would have “choice, flexibility and input in designing the services they receive.” He assured the public CLBC was “ready to deliver stable, quality services now” and that “over time, it will implement a new service-delivery model that provides more services and delivery options, better supporting the hopes and dreams of individuals with developmental disabilities and their families.”

At least three independent “readiness assessments” were completed during the three years of planning that led to the establishment of the provincial authority. CLBC has now been up and running for three years, but there has been no independent assessment of its performance.

The authority conducts user surveys, but this presents a very incomplete picture as they only survey those who are already receiving service.

It is difficult to get a clear picture of the size of the waitlist or why it fluctuates. In March of 2006 the agency established that 3,200 people would need new or enhanced services over the next three year period. One year later the

CLBC revised the waitlist numbers without explanation, dropping 2,000 people waitlisted for services. The only reference to the significantly different waitlist was contained in a service plan comment that “collecting reliable information is challenging and management recognizes that waitlist data could be more robust.”

It is unclear how many people are entirely outside the system at this point and what would be required to really meet community needs.

It is also unclear whether the authority has accurately identified entitlement, service needs and the cost of meeting these needs in the coming years.

The demand for services will increase due to a number of factors including:

- the increased life expectancy of those with developmental disabilities;
- the incidence of health problems at a relatively early age in this population;
- the number of children reaching adulthood;
- the growth in autism spectrum disorder;
- the number of adult children now at home whose elderly parents will no longer be able to care for them because of their own illness or death.

There is no sign the authority has financial plans to meet these or the other cost pressures of recruitment and retention, community service providers, and changes in eligibility criteria.

But there are also questions about CLBC spending priorities. Many authority staff were

highly critical of funds spent on extensive office renovations at a time when budgets couldn't cover service needs. There were criticisms of the costly PARIS corporate information management system which is reported to be delayed and functioning below expectations.

Although service budgets were exhausted early in the year, there were funds available to increase senior management salaries. Community Living BC's CEO salary rose from \$104,000 for the 9 months reported in 2006 to \$194,000 for the 12 months reported in 2007. Other executive members at CLBC received similar wage hikes.

Provincial Government executive compensation guidelines require that compensation plans take into consideration the current fiscal and labour relations environment. The guidelines state there will be no new funding for compensation increases; they have to be managed via existing operational budgets and through workplace efficiency gains. This leaves stakeholders wondering if the pay raises came at the expense of service.

The number of CLBC employees with annual salaries above \$75,000 also jumped. The total cost of employees at this level surged from \$358,084 in 2006 to \$4,006,361 in 2007. It is unclear how this dramatic increase in management staffing aligns with CLBC's claim that they have reduced traditional management levels.

Although CLBC is a separate crown agency, the provincial government is responsible for reviewing and approving the authority's service plan, for monitoring its performance and ensuring that it delivers on its mandate. There must be some public accountability for the shortcomings of the current community living system. A thorough, independent review and assessment of CLBC is long overdue.

Legislated Entitlement

Legislation establishing CLBC says it was "to promote equitable access to community living support" and "assist adults with developmental disabilities to achieve maximum independence and live full lives in their communities." But advocates, families and caregivers say there's no teeth to it. They want an individual's entitlement to services enshrined in legislation.

There are few ways to hold the government accountable for the delivery of services. We need legislation to ensure the government does not abdicate its responsibilities through having a provincial authority deliver publicly funded services.

Recommendation: Enact legis-

lation guaranteeing entitlement of all individuals with developmental disabilities to the services and supports required for full participation in society.

Independent External Audit

The Auditor General is the independent legislative officer with the responsibility and authority to conduct audits that allow the public to know how well government and its agencies are managing their responsibilities and resources.

Performance audits conducted by the Auditor General examine whether money is being spent wisely. The Auditor General examines organizational and program elements of government performance, whether government is achieving results at a reasonable cost, and considers whether government managers are making the best use of public funds and adequately accounting for the prudent and effective management of the resources entrusted to them.

These are fair questions to ask of Community Living BC.

“It is unclear how this dramatic increase in management staffing aligns with CLBC's claim that they have reduced traditional management levels.”

It seems clear the provincial government itself has questions about CLBC operations to date. The Ministry of Children and Family Development (MCFD) recently cancelled plans to regionalize their non-aboriginal child welfare services, citing as their first consideration the “learned advantages and challenges of governance structures from our experience with CLBC.” The Ministry further identified the cost of governance structures such as CLBC and the concern that financial and human resources needed for service delivery would be diverted to structural uses.

The concerns which MCFD has identified are valid and should be reviewed by the Auditor General who has previously identified a need to examine the results as government divests more services to various agencies and authorities.

Given the lack of transparency regarding the real waitlist for services, the funding shortfalls and the size of the population receiving no support, the Auditor-General’s review should include a comprehensive analysis of funding and expenditures in this sector.

The Auditor General’s findings and recommendations should be used by the legislature to enable the provincial authority to fulfill its mandate.

Recommendation: The Auditor-General should immediately undertake a comprehensive performance review and evaluation of the operation of Community Living BC.

2 Funding

Inadequate funding is the cause of many of the systemic failures we see today in community living. Even before the new authority was formally set up, advocacy groups such as the BC Association for Community Living raised concerns that the budget allocated did “not allow for the proper implementation of Community Living BC.” The group also complained that the MCFD “retreated from many

of the original principles that drove this change.”

The premise that the new organization could do more with less has proven false.

More funding is urgently needed to achieve the vision of a support system where people with developmental disabilities lead good lives, have rich relationships with friends and family, have financial security and real choices in how they live their lives, enjoy employment opportunities and are accepted and valued as citizens.

There are long delays in diagnosis, required before entitlement to services can even be assessed. This is particularly true in rural and remote communities, and within the aboriginal community. According to one worker at the Victoria Native Friendship Centre, “We get referrals from other agencies, people who have disabilities but don’t have the diagnosis so it’s very hard to get services for them.

They are adults already and the government doesn’t spend money on people who are adults – it only happens when they are young, and even then there is a big wait list just to get in there to get a diagnosis.”

We heard of instances where individuals in BC waited as long as three years for assessment. And assessment is no guarantee of service. Once the services are identified clients and families are often told funding has been used up. In 2006 in some regions of the province, families were told by CLBC at the beginning of the fiscal year that they had no available funding for new waitlist requests other than health and safety emergency needs.

Quesnel parent Lynn LeBlanc says programs in the north are bursting at the seams. She has friends whose children are finishing high school but there are no services for them. Pitt Meadows parent Helen Stovell says, “I think the standard reply now to a family is “congratulations, your child has been deemed eligible for the waitlist!” “I know Community

“The premise that the new organization could do more with less has proven false.”

Living BC's intent was to provide proactive planning and services, and to provide services before a crisis occurs, but that's not the reality."

The government's response has been disappointing. In its report on 2008 budget consultations, the Finance and Government Services Committee acknowledged they had heard many submissions asking for additional resources for Community Living BC. Those presenting to the committee specified funding was needed to address waitlists, support respite care and child development programs.

But the Committee recommendation was an increase for the contracted community social services sector that would only cover inflation. This is not enough. Funding increases that only match inflation will not reduce the waitlist, nor address unmet needs in the community.

Increased Operating Budgets

Simply restoring the \$150 million cut from the budget in 2001 is not enough.

The provincial authority is low-balling its requests for additional funds. In 2006 they requested only \$54.8 million spread over a three year period to cover waitlists and \$10.3 million from the same budget line item to cover crises. A more realistic estimate to cover waitlists, crises and emergent care needs would be a total budget of \$131 million over three years.

According to their 2006/07 Annual Service Plan report CLBC currently provides services to 28% of the approx 36,000 adults who may meet the definition of developmental disability. The remainder or 72% of these individuals have not approached CLBC for services. CLBC acknowledges that as this group ages their needs will increase and some will seek services from CLBC. In the current environment these people will likely only add to already large groups of people on a waiting list for service. This is not acceptable. CLBC

must factor this population into their budget planning.

It is difficult to estimate the cost of providing services to these people and at what point they might require support. The current adult services budget of \$532 million provides support for 10,400 people. The current service plan proposes to increase the number of adults served to just over 11,050 by 2008/09. This will not even meet current waitlists! CLBC must begin to actively analyze the 72% of their target population not receiving service

and put in place the financial planning and resources necessary to meet this aspect of service demand.

Funds are also needed to match growth in the population. Analysts forecast the demand for community living services will

increase by 3.5 to 4 percent a year due to an ageing and increasing population.

And funds are required to match the separate pressures already identified by the CLBC that result from adults with developmental disabilities living longer, and ageing parents being unable to continue caring for their adult children. All these factors need to be calculated and included as annual increases in the CLBC budget over the next few years.

Workers also report a need for additional funds for educational and recreational programs and professional services like mental health. One mental health worker says, "we don't have the finances to do a lot of things, and a lot comes out of our own pockets instead of it being funded by the company... When we go to a matinee, the client will pay for his own ticket and I will pay for mine," she says.

A residential care worker from the Okanagan confirmed that while every effort is made at her group home to involve residents in community activities, there aren't enough staff to support them. "We have one gentleman who is 21 and likes to go to school ... He is missing

“We have one gentleman who is 21 and likes to go to school ... He is missing this opportunity because we cannot find staff to take him out.”

RESIDENT CARE WORKER, OKANAGAN

this opportunity because we cannot find staff to take him out.”

Recommendation: The province must begin to provide regular annual budget increases to eliminate the current waitlists, address unmet need and growth in demand for services and to provide some contingency for crises. Funding must also be allocated to address specific needs including transportation, miscellaneous costs associated with day programs and professional services.

Capital Funding

Many existing group homes need improvements, and renovations to make them more suitable for residents with high needs. Quesnel parent Rachel LeBlanc is one of several parents who said moving to a group home from home care improved the lives of their children, but she pointed out the group home is not wheelchair accessible. Other individuals expressed concerns about lack of equipment. One Employment Assistance Officer from the North says it’s a long frustrating process just to get medical equipment and “repairs are not done in a timely manner.”

With sufficient capital funds, it would be possible to quickly increase access to semi-independent living. Group homes operated by non-profit organizations, currently offering communal living opportunities could be converted to offer a small number of self-contained apartments clustered around communal areas. But it would require strong capital funding for a multi-year plan to develop independent and semi-independent living opportunities in communities across B.C.

Recommendation: Substantial capital funds must be allocated to purchase equipment, retrofit existing group homes in the non-profit sector, and to establish a network of semi-independent and independent living settings.

Addressing Poverty

The government must also take steps to end the poverty of adults with developmental disabilities who are living in our communities. Individuals under age 65 receive \$906.13 a month from the Ministry of Employment and

Income Assistance. Seniors receive more although it not clear what the rationale is for this differential. Income assistance rates are too low to realize the vision of dignity and independence for adults with developmental disabilities.

Recommendation: The government must address poverty among adults

with developmental disabilities, by significantly increasing social assistance funding, and eliminating differentials based on age.

Distribution of Funding

The distribution of funds is inconsistent across the province and while this is acknowledged in the CLBC annual report, no measures have been proposed to address this.

There is a widespread perception that white, middle and upper class families get a disproportionate share of the resources. Says Alanna Hendren, executive director of the Developmental Disabilities Association(DDA) “some people who have developmental disabilities who have really rich families are getting hundreds of thousands of dollars worth of service at the taxpayers’ expense, and then there are other people whose parents may have English as a second language, whose parents may be poor, whose parents may not be as sophisticated, who get nothing.”

Access to services also varies inexplicably from region to region. According to Hendren, “it is totally inequitable. Victoria and the south island have lots of funding. Vancouver and Richmond, where we have 18% of the population, we’ve got 10% of the funding.”

“It’s a long frustrating process just to get medical equipment and repairs are not done in a timely manner.”

EMPLOYMENT ASSISTANCE
OFFICER, NORTH

Evelyn Almassy, a former group home worker, says “in the Queen Charlotte Islands adults with developmental disabilities have no residential option at all except the hospital, which is already at capacity.”

Scarce funds means groups and programs compete with each other within the system. Some advocates, like Anita Dadson, president of BC FamilyNet, say whenever funding is cut or runs out, “special needs kids get cut first.” Others report programs for adults are now taking second place. Says Terry Schenkel of DDA, “Ten years ago, we used to see a lot of money put into developing new services, particularly for adults. We’ve now seen that shift – the money for new programs isn’t as readily available, we have to really fight to be able to get it, and the focus has shifted from adults to younger kids ... now we see one population have to sacrifice to another. There is more of a divide and conquer mentality where parents are fighting for their own particular sub-group.”

Recommendation: Put a process in place to ensure funding is distributed fairly and proportionately across the province.

Salaries

The community living sector is facing well documented recruitment and retention problems across the province.

Many parents understand the causes. Says parent Helen Stovell, “It’s not an attractive field for young people to go into anymore. It doesn’t pay enough, it doesn’t carry any prestige, so trying to find qualified caregivers is very challenging.” Says Alanna Hendren of DDA, “They are going to have to come to terms with the fact that our employees are not glorified babysitters. And not just anybody can do this, and not just anybody wants to do this.”

Had the provincial government not cancelled pay equity commitments to community social services sector at the beginning of their mandate, the wages of workers in this sector would have reached parity with community health workers by 2004.

Wage rates in community health itself were rolled back by 15% but there are still large pay gaps across a range of occupations in the two sectors. For example, residential care workers in community living, are paid \$17.56 the top rate, while in community health, equivalent work is paid \$20.98 – 24% gap.

A recent CSSEA newsletter indicates wage rates in the para-professional category are also uncompetitive. At April 2006, after wage increases and market adjustments, the wage rates for clinical counselors were still more than 18% behind the health sector, addictions counselors were 31% behind and physiotherapists were 17% the health sector.

“Our employees are not glorified babysitters. And not just anybody can do this, and not just anybody wants to do this.”

ALANNA HENDREN, DDA

Many workers are opting to work in extended care where they can make the same contribution at higher rates of compensation.

One residential care worker in North Okanagan says her group home did not have a problem with staffing in its first 10 years of operation. There was little turnover. “Now the big thing is casual workers, but we go through them very quickly. Five people were trained in one year, but they go through the training and orientation, and do not even work a shift – they find other jobs.”

Remuneration for the 1,500 private home providers is also problematic. Compensation is low and caregivers must provide 24 hour support, meals, transportation, household amenities, programming and respite or relief care. Home share providers, like group home workers report they pay out of their own pocket for field trips and incidentals because there is no money in the system to cover the

real needs of the individuals in their home. CLBC should ensure funds provided to those in private care come in two distinct funding “envelopes”, one for client support, and one for wage-benefit entitlements of the care providers.

Recommendation: The province must increase compensation for care providers and professionals in the community living sector, and in the case of home share providers, should distinguish wage and benefit entitlements.

3 Governance and Regulation

There was widespread agreement that structural changes may be needed to increase accountability in the system, and overcome the inability of family and relatives to get help or even get answers to their questions.

Changes to Governance Model

There are significant differences in service needs based on geography and demographics that must be addressed. Alanna Hendren of DDA says “different communities need to come up with different solutions and I think they need the freedom and authority to do that.” The governance model of CLBC, as it stands, does not all for this.

The province needs to initiate discussions with stakeholders in the sector, including unions and employers, to identify changes necessary to the current governance model of CLBC to bring greater equity to allocation of funds and help overcome the lack of accountability and lack of communication that many parents and families now experience. Changes are also needed to provide for increased flexibility for individuals and families, and ensure consistency of care.

The 17 community councils established by Community Living BC are not representative, or accessible to all stakeholders. These forums may actually use scarce human resources in the provincial authority, without increasing accountability, but if they are playing a larger role in decisions regarding funding they should be opened up to a wide range of stakeholders.

Recommendation: The province must immediately initiate discussions with stakeholders in the community living sector to identify changes in governance

necessary for CLBC to fulfill its provincial planning and oversight role.

Government Oversight

We repeatedly heard concerns about the lack of accountability by CLBC. There is also a sense that government itself is less accountable now because it has detached itself from direct service delivery to adults with developmental disabilities.

The Ministry of Children and Family Development should take a more active and direct role in the operation of CLBC. Given the troubled evolution of the provincial authority, the legislature should more closely scrutinize the CLBC, whose reports are currently buried in Ministry estimates.

One way to accomplish this is to ensure the Representative for Children and Youth, appointed by the legislative assembly, takes on a greater role in providing oversight and demanding accountability as CLBC assumes increased responsibility for providing services to children. At this point however, no transfer of additional responsibility to CLBC should occur until such time as the authority demonstrates an ability to manage the adult waitlists for services.

Recommendation: Increase the accountability of CLBC through annual reports to the legislature, and give the Representative for Children

“Different communities need to come up with different solutions and I think they need the freedom and authority to do that.”

ALANNA HENDREN,
DDA

and Youth a greater role to play in assessing the CLBC, and delay transfer of services to children.

Community-based Advocates

Parents told us of their frustration and exhaustion in dealing with Community Living BC, trying to get assessments, placements and other services for their children. Says Parent, Lynn Leblanc, “It took three years of constant phone calls, meetings and letters ... we basically had to be in a complete crisis situation before we received help ... We had to get just very, very angry and lost a lot of our dignity, you could say, before we got services.”

There are many offices around the province, but most have limited hours, and are called by names that leave their function largely obscure. Staff at CLBC indicate there are just not enough people to go around. It’s tough enough for families who have the energy and knowledge to advocate on behalf of their children. Many families don’t have the time, knowledge or stamina to get the support and services they need and are entitled to receive.

Many parents praised the helpfulness of the Advocate for Service Quality, but the current position is in Victoria and is answerable only to the minister. A Representative for Adults with Developmental Disabilities should be established as an independent officer of the legislature charged with working closely with the office of the Representative for Children and Youth.

Community-based advocates could also assist individuals, families, and care providers of all kinds to make the community living system more responsive. Workers pointed out that

confidentiality agreements often discourage them from raising concerns about poor quality care they see first hand. Whistleblower protection would help workers come forward, but a closer involvement by community-based advocates could also ensure that problems come to light and that across BC we provide high quality service for adults with developmental disabilities.

Recommendation: Establish a Representative for Adults with Developmental Disabilities as an independent officer of the legislature and put in place community-based advocates to work with families and adults who have developmental disabilities.

Residential Standards

The introduction of standards of care for home share arrangements is an important step. But it’s important to avoid elaborate standards with little or no enforcement. Only ongoing, regular inspection of all residential arrangements will ensure adults with

developmental disabilities are receiving appropriate care. There are not enough staff at CLBC to ensure this work is done. Without active monitoring the provincial authority cannot be certain that accommodations and programs are equivalent throughout the province, and that care-providers are receiving the support they need.

This is particularly important given the growing number of for-profit settings, home share arrangements and homes downgraded to unregulated community residences.

Individuals providing care in their home, and agencies providing care in communal, semi-independent or independent settings should all meet the same programming, accommoda-

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LYNN LEBLANC, PARENT

tion, health and safety standards and receive the equivalent support.

The people we interviewed say no one is paying attention to what is going on. Families need to know that their children and relatives are receiving care at the same high standard regardless of the setting. Many adults with developmental disabilities cannot advocate for themselves and without regular, external monitoring they may not receive adequate and appropriate housing and care.

Recommendation: Increase standards for all residential settings, including home share, and increase the CLBC's capacity to monitor. Bring the assessment process back into the Ministry to ensure reliable external assessments of all residential settings.

Residential Accreditation

CLBC is now involved in a lengthy accreditation process with the Commission on Accreditation of Rehabilitation Facilities (CARF) that will run to 2011. They have indicated that home sharing services will be part of the organizational review. Many care providers expressed support for the idea, but some questioned the appropriateness of using American standards developed to meet US funding requirements. Of greater concern were reports that the process is too "cozy" with one group home provider in a community assessing another. There are concerns that the process is little more than self-accreditation, heavy on paperwork and light on external objective assessment.

For example a group home worker in the interior says her group home went through accreditation "but it was more internal than double-checking by an external authority." Families want to see accredited and monitored home share arrangements to ensure consistent quality.

Recommendation: Explore taking the accreditation process into government to ensure reliable and objective ongoing assessment of all residential settings.

4 Service Delivery

The promise of support and services in the community for adults with development disabilities and real choice in housing and programming has not been realized. Instead of staged investments in a full range of family, communal, semi-independent and independent living options, CLBC is promoting the cheapest option – private home care.

Through the Residential Options Review process adult residents have been encouraged to dream about living independently, but instead are being shuffled out of communal living arrangements and into private care. Communal living in group homes is scorned, and as many homes as possible are being dismantled or transformed into unregulated residences narrowing the range of choices for adults.

According to BC Family Net the CLBC service plan shows the authority is not really concerned about choice. The stated target is to convince 400 individuals to "choose" to leave group homes for cheaper alternatives, and to encourage 70% of new clients to vote for alternatives to group homes that will be cheaper.

It seems as though all changes in the support system are based on squeezing cost savings that will stretch an inadequate annual budget.

Vision and Revision

Under immense cost pressures, CLBC's response is repeated attempts to reinvent itself, focusing efforts on surveys, advisory processes, committees and councils that are part of the quality service model. But stakeholders say this has led to confusion and disarray.

Parent Lynn LeBlanc says that despite three significant policy changes over three years, at considerable cost, nothing has changed, "They would change their name. They would present us with how it was all going to be much better for the families this way and in the meantime we had to start all over again with our request for services."

The CLBC draft handbook for home share providers appropriately warns "Visit the

(web) site often as things are always changing.” Workers at CLBC say they too are tired of being bombarded with seemingly endless changes to policies and procedures, constant re-branding and other unnecessary measures.

Recommendation: Stop the endless visioning, re-visioning and restructuring exercises at CLBC.

Multi-year Investment in Independent Living

Clients, their families, advocacy groups and workers are all looking for much more variety in residential arrangements.

Alanna Hendren of DDA, confirms flexibility and variety is needed. “Some people need to live by themselves, some people don’t need the level of support of a group home and are very happy in supportive living. For some people family life or proprietary care homes are the ideal answer ... But there is no “one size fits all” You really have to determine the residential model based on the needs and wishes of the individual and family.”

There is no shortage of group accommodation models to choose from. They are already in place in other jurisdictions where individuals can live in their own self-contained units with opportunities for socialization and with the ongoing supervision and support that gives them the privacy and dignity they want.

For example in Sweden over the course of a decade more than 14,000 people moved into semi-independent or independent living arrangements. They are now housed in group homes renovated for semi-independent living, expanded houses and apartment buildings like the one in Stockholm where two floors have been converted for more independent living.

BCs adults with developmental disabilities

should have similar opportunities. We should be developing a provincial network of houses with three or four self-contained units, apartment buildings where several units can be grouped together on a single floor.

In some communities individuals capable of independent living could reside in apartments in different buildings within a relatively small area with staff and day programs located nearby.

As mentioned, some existing group homes may be suitable for renovation or enlargement to replace individual rooms with individual flats.

Semi-independent and independent living arrangements do not necessarily require construction of special, purpose-built housing. However because many parts of BC are experiencing severe rental housing shortages it

will take a long term and strategic housing acquisition program, with the assistance of BC Housing and Canada Mortgage and Housing Corporation to build a coherent system.

BC has taken only the first step in the process of de-

institutionalization. We need to take the next steps on this road and make serious investments in semi-independent and independent living arrangements.

Recommendation: Develop and implement a multi-year plan for expansion of accommodation to create a genuine range of residential options for independent and semi-independent.

Group Homes

Many workers, clients and family members interviewed believe the value of communal living in group homes is being ignored even though group homes, properly resourced and staffed can be a good option for some adults with developmental disabilities.

“The CLBC draft handbook for home share providers appropriately warns ‘Visit the (web) site often as things are always changing.’”

Quesnel family member Rachel LeBlanc says there was an “absolute change” when her siblings, ages 21 and 23, went from home care to a group home. “They were regressing at home. Now they are more independent and happy in the group home, happy with the people who take care of them, happy with the programs.”

Helen Stovell, a Pitt Meadows parent agrees and says “CLBC right now is talking about things like the family care model. For my son and for a lot of people that have behavioural challenges, it is too hard for any one individual to do (that work) ... My son’s the type, he gets tired of the same people and he needs lots of variety.”

One residential care worker from the Interior recalls an individual who came to her group home weighing 115 lbs at 5’9. He was not receiving any treatment for his mental illness. “He was threatening to kill people and really suffering with delusions and hallucinations. At the group home, he started to receive meds, saw a psychiatrist and now he’s a healthy weight. His hygiene has improved. He goes to the movies with friends.”

Many individuals when interviewed through the residential options review chose group homes. But there are reports that parent’s and resident’s wishes are being ignored. Says Alanna Hendren: “We’re hearing from families that as much as they may demand a group home, or as much as an individual wants a group home, they are not being presented with that as an option ... plans indicate they are going to be put in proprietary care and that seems to be the only option that’s offered to families.”

Vancouver parent Joan Weatherby, whose daughter Janet has developmental disabilities argues it is important to respect the choices

made by individual residents. “I think a lot of the handicapped know what they want. They know whether they want to stay at home. A lot of them want to live on their own in a group home and they should be given that opportunity.”

In an integrated system of residential options, group homes could also provide transition housing for people about to make the shift from private or family care to semi-independent or independent living. Group home staff could link people to compatible small groups that are then prepared to move into accommodation in apartments that are grouped for semi-independent or independent living.

Recommendation: Acknowledge the value of group homes in the mix of residential options.

Build an Integrated Network of Residential Settings

We need a community living system that acknowledges the value of private and family care, as well as communal care in group homes, and semi and independent living.

Most care providers are very supportive of expanding and transforming the system of residential settings, but find it difficult to be enthusiastic about the

models promoted by CLBC.

On its website CLBC actively encourages agencies to reduce resident numbers in their group homes to 3 or under, as a way to get out from under the collective agreement, replacing workers with dependent contractors. Workers in the field are concerned CLBC intends to make sure almost all care providers in the province are dependent contractors.

The semi independent and independent living models presented by CLBC assume care providers will share their lives with one or

“I think a lot of the handicapped know what they want. They know whether they want to stay at home. A lot of them want to live on their own in a group home and they should be given that opportunity.”

JOAN WEATHERBY,
VANCOUVER PARENT

more clients, living 24 hours a day, 7 days a week in a home owned by the client, or in a residence or cluster of apartments owned by an agency. There is little interest in, or value placed on full-time trained staff, scheduled into residences to provide support and programs. What is presented is nothing more than homeshare with another name.

Many group home workers have already opted to take adults with development disabilities into their homes, providing care in a shared living arrangement. It exposes care providers to economic risk if the social and working relationship deteriorate. It could undermine the stability of support that all stakeholders want to see. For the client, family or micro-board it can add another level of responsibility for recruitment and monitoring.

Care providers believe it's possible to create an innovative, flexible system of residential and program options that also provides stability and flexibility for workers too. That means staffing models that respect family responsibilities, and career aspirations. It means acknowledging many qualified and compassionate care providers have interests outside their professional life.

It also means integrating a wide variety of care providers into a network.

If shared living is the only staffing model for semi and independent living, it could increase recruitment problems at a time when agencies across the province are having difficulty attracting skilled residential care workers into a predictable working environment with stable hours.

An integrated system of residential options and day programs would allow staff, like clients, to move seamlessly from one setting to another over their careers, increasing their experience, and stabilizing employment and care within a region.

Home share providers could use more support. They are encouraged to form networks with others in their community but receive little assistance to do so. The principal advice from CLBC is to rely on friends, family and neighbours not other care providers in the system.

More effort needs to be put into linking home-share providers and caregivers to other residential settings and day programs for adults with developmental disabilities.

Recommendation: Build an integrated system of residential options from family home share to staffed independent living staffing, and provide more support, and skill development for home share providers.

Options and Choices

Workers report that adults are being moved from residential settings without consent or

notice. One worker in the interior reported: "When one of the residents in our group home came back from his daily work program, all his stuff had been moved to another group home. He hadn't even been told."

Others expressed concerns that residents who opt for independent liv-

ing are not given the support they need to make this work. One worker in the North Okanagan reported a resident who was moved into an independent living situation didn't get enough transition planning, he was only given 8 hours a week in support. He called the group home after a couple of weeks to say "I don't have any food left - what do I do now?"

Workers in the north reported similar situations. Despite assurances that no one would be moved against their will, and despite interviews to determine what residents wanted, one worker in the north pointed out that a

“When one of the residents in our group home came back from his daily work program, all his stuff had been moved to another group home. He hadn't even been told.”

GROUP HOME WORKER, INTERIOR

group home resident was moved back to her former group home when she did not want to go. As a result her behavior deteriorated sharply.

Parents complained that even where there were openings in group homes these were shut in favour of home share arrangements although the adult had expressed a strong preference for staying in the group home. Those asking for their own home, or semi independent living, were also moved into home share arrangements.

Recommendation: Offer real options and respect and support choices made by adults with developmental disabilities.

Respite and Relief Care

We need to develop a capacity to predictably provide short-term respite and relief care as well as responding to emergencies that families experience and that may arise in home share situations.

It can't be something that may or may not be available after care providers are compensated. Responsibility for identifying suitable respite and relief care workers should not be left up to families themselves or the home share provider.

There are also concerns that not enough attention is being paid to qualifications for respite or relief workers. The draft CLBC home share handbook states it is the responsibility of the home share provider to ensure that a respite or relief worker has "appropriate" qualifications, although apart from a criminal record check this term is not defined.

The availability of respite and relief care now varies widely from area to area. Accessibility should be standardized. Pools of qualified respite care and relief caregivers should be established in communities, and schedules set up for respite care. We should continue to use

excess capacity in communal living settings and in group homes to permit short term respite placements for adults who usually live with their families.

Recommendation: Establish clear eligibility criteria for respite and relief care, based on the number of adults with developmental disability in the home and their degree of disability.

IQ Based Eligibility

People we interviewed say CLBC is overly reliant on IQ as a measure for establishing entitlement to services. At this point a developmental disability means sub-average intellectual functioning equivalent to an IQ of 70 or below, as well as impaired adaptive skills prior to age 18. But

critics say that test is preventing individuals in real need from getting assistance. Many of these people are ending up on the streets or in the correctional system.

One Penticton probation officer says, "A lot of our clients have fetal alcohol syndrome. They would actually test, on an IQ test, at or above 70, but their functioning is much lower. They often end up in our system over and over and over again."

A Guardianship worker is particularly concerned about youth who are left out. "I think using IQ is not very helpful. I mean we've all seen that movie "Rainman". Just because someone's IQ is in the brilliant range - well, the point is they can't function in their daily lives and they can't take care of themselves ... I think in some cases they should be looking at adaptive and cognitive abilities, and they need to look at dual diagnosis kids where they have some deficits and may have a life threatening issue."

Recommendation: Revise the IQ-based eligibility threshold for entitlement to services and use an adaptive functioning test.

“A lot of our clients have fetal alcohol syndrome. They would actually test, on an IQ test, at or above 70, but their functioning is much lower. They often end up in our system over and over and over again.”

PROBATION OFFICER, PENTICTON

Case Management

Many people we spoke with talked about the loss of case management and expressed concerns about the shift to quality service analysts and facilitators.

The loss of case management has also meant the loss of continuity and overall awareness and knowledge of a family's situation. "Families really liked the case management function," says Alanna Hendren. "Social workers who dealt with their file made them feel comfortable, even if they just talked over the phone. Just knowing someone was there who was familiar with their case, who could help them out was enough for families. And there is no case management and these families feel abandoned."

Young people are most affected, especially when they become adults and are no longer in care. "These young adults no longer have an ongoing social worker through CLBC," says one MCFD kinship worker. "and essentially that means if they run into problems they do not have that safety net or social worker to call." She adds, "It can be pretty challenging out there in the world. A young person or adult with developmental disabilities can easily fall prey to people who do not have compassion."

A ministry social worker agrees that case management is very important for young people. "If you have a youth who is high functioning, gravitating towards street culture, getting involved with drugs and living on the street, or living here and there – the parents can't manage them very well and it's really important for these youth to have case management where they have somebody they can contact; somebody that's available to them and has a plan to support them. That's what drops off when they become an adult."

The division of offices into quality service offices, satellite offices and community living centres is confusing for the public, adding

another level of administrative incoherence and reducing accessibility. Families and adults in the community don't know who or which office to call.

Recommendation: Restore case management at Community Living BC.

Community Presence

Parents and relatives complain they cannot get service or even get answers from the provincial authority or the ministry. Despite the addition of community councils and offices for quality service analysts and facilitators, CLBC remains distant from clients, their families, and care providers.

In communities such as Salmon Arm, the Community Living office is only open half a day and there is no official ministry presence. Workers in the interior report that since the formation of Community Living, and because there is no social worker present, clients are often unsure to whom they should talk. It's a maze for families.

Others commented on the over-reliance on phones. One mental health worker reported that Prince George uses a "service -centered model" where specific mental health case-loads have been set aside and mental health clients follow the same process as everyone else. "Before the caregivers could contact one person, the agencies could contact one person and now it's a 1-866 number. "We have some clients that aren't verbal so the phone system doesn't work. There is no personal contact any more, no face to face. They used to be able to drop in and see you. The 1-866 number is a real challenge for them. The process is very frustrating and inconsistent."

Staff at the provincial authority also report families feel they have been cut adrift. "Repeatedly, we hear the comment 'who do I call?', meaning 'who knows me?'" says an analyst at the authority. "For the people we support, the service providers and the fami-

“Repeatedly, we hear the comment ‘Who do I call?’ meaning ‘Who knows me?’”

STAFF, PROVINCIAL AUTHORITY

lies, the experience is a distinct severing of a once trusted and relied upon relationship.

Older parents are particularly distressed with the current situation. They fear they can't continue the level of advocacy needed to secure services. Comox parent Kaiva Carten says her son requires more attention now that he's 24 years old, but is still waiting for the additional services, "The problem is, I am close to retirement age. And the reality is I am not going to be able to continue this indefinitely."

A population of aging clients is rapidly going to present additional demands for services. There are parents in their 90's caring for their developmentally disabled children in their seventies. There are as many as 1,800 BC families where parents between ages 50 and 85 are at home with a developmentally disabled adult child. According to Terry Schenkel of DDA, "They are terrified. These are families that in the next ten years are going to die and they are leaving adult children behind, with no infrastructure to support them."

Recommendation: CLBC and the Ministry must establish a greater community presence, especially in small towns and rural or remote areas.

Communication

CLBC's failure to communicate effectively to parents and relatives contributes to a perception that services are rationed haphazardly; that a privileged few get support while others are left out in the cold. It's unclear how many of the 22,000 not on the waitlist are even aware they are entitled to services.

Many advocacy groups and workers within the sector reported they find the CLBC distant and unresponsive. "Calls are not being returned. No one is in the offices," says one social worker from Duncan. Families report that meetings happen, decisions are made, then plans change without warning.

Says Parent Lynn Leblanc, "Families should be able to see evidence that Community Living BC is doing something on their behalf. I felt like we were speaking into the air when

we went for a meeting or wrote a letter or made a phone call requesting help."

In response staff at CLBC report they are overworked and seriously under-resourced.

Adding to the problem is the current waitlist policy is complicated and not transparent. Many parents who have successfully obtained diagnosis and services for their children, say they had to learn how to work the system. It takes energy, persistence and know-how. Parent Lynn LeBlanc says it took three years of phone calls, meetings and letters to get help for her developmentally disabled children. "We were told what we were eligible for, but there was no money for it so then we were informed what the process was - to begin locally and then go through to Prince George, and then from Prince George we would probably have to take our case to Victoria."

The province has a responsibility to ensure people and families who need services have confidence the waitlist doesn't depend on where you live or who you know. Access to services shouldn't be based on a parent's energy level and ability to 'work the system'.

Recommendation: Increase staffing at Community Living BC, and improve communication with families of people with developmental disabilities, making sure entitlements, decision-making and waitlists for service are transparent and widely known.

Inter-agency Communication

Constant restructuring in government has led to disruption and confusion. There is poor communication between ministries themselves and between the Ministry of Children and Family Development, and CLBC.

A complicated Memorandum of Agreement has been negotiated between MCFD and CLBC. However, there continues to be confusion over roles and coverage is inadequate, especially in rural areas or outside of major urban centres. In the past, says one worker at the Ministry Office of the Guardian, a Community Living worker would get involved as soon as a child turned 18. There

would be joint appointments with ministry representatives. “The worker at Community Living BC would be responsible for really getting out there and trying to find appropriate long term resources, like where they would live. I’m finding now there is a lot of confusion – a lot of the workers don’t know what their role is or what they are supposed to be doing.” Says Lisa Harrison, an independent care provider in Courtenay, “There has been a major communications breakdown. As soon as that happened I saw crisis management rather than prevention.” Parents also complain about the lack of communication between regional health authorities outside the Lower Mainland and Community Living BC.

Recommendation: Establish better communication and confirm responsibilities between the ministries, regional health authorities and CLBC.

Youth to Adult Transition

For youth with developmental disabilities the system seems to collapse when they turn 19 and the ministry no longer has legal responsibility for them.

In the last three years more than 1,300 children with developmental disabilities turned 19 and left school. These young adults are often unsupported. One Ministry social worker characterized their situation this way, “A lot of our kids have special needs and are not able to live on their own without support. A lot of our kids have fetal alcohol syndrome and other needs and they fall between the cracks in terms of whether or not they are eligible for community living services. There are not many other services available to them. A lot of times they really crash when they leave our care.”

The recent case of the 19 year old Victoria man who had been in government care since the

age of 10 is a case in point. His former foster parent told the Victoria Times Colonist there was never a proper plan for his transition to adulthood and his first few placements failed. Without a place to live, the man ended up in the court system. CLBC told the court they had limited resources for him.

The BC Association for Community Living (BCACL) said this case is “all too typical” and stems from government’s failure to give CLBC enough money to properly care for people. In the absence of proper supports the BCACL says that this man will “go to jail; that’s where he’ll get his support.”

Workers in the system know that action is needed now to prevent these types of tragic situations from occurring. One Ministry worker suggests there be a system to “flag” youth when they turn 18. Others we interviewed suggested there be a “point person” in the transition stage, as well as an agreed-upon transition protocol between the MCFD and CLBC.

The people we spoke with say special attention must be given to the preferences of young people as they transition to adulthood. Laney Bryenton, Executive Director of the BCACL says kids leaving school want something different than they wanted 10 years ago. They are not interested in resi-

dential services per se, they are not interested in day programs, they are very interested in individualized service. But Bryenton says “we don’t have enough money to provide support necessary for early intervention for young children and their families or for those supports for adults ... and that’s a huge problem.”

Recommendation: Strengthen the process for joint assessment and planning to ensure a seamless transition from youth to adult services.

“There are not many other services available to them. At lot of times they really crash when they leave our care.”

MINISTRY SOCIAL WORKER

5 Staffing Issues

Community agencies are struggling to recruit and retain qualified staff. Residential care workers and professionals are leaving for similar but better paid work or are retiring. Positions are left unfilled for months and the lack of staff within residences is creating strong pressures on remaining staff. There is no backfill for vacations and illness. One worker in Victoria recently reported working 39 hours of overtime in one week. Staff at CLBC too report they are demoralized, and understaffed.

Across the sector workers are in short supply but the current staff feel undervalued, under-equipped and are deeply concerned by the shortfalls, confusion and failures of the system.

Recruit Citizens Not Servants

Some agencies, facing prolonged vacancies have recently attempted to use the national temporary foreign workers program to fill the gap, applying to Services Canada for an exemption that will allow them to recruit in developing countries. The workers coming in under this program can stay for up to two years. There are now more than 35,000 such temporary migrant workers in British Columbia who have only their entitlements under the collective agreement (where one is in place), must pay into national programs like EI, but are never entitled to draw. And can be sent back to their country of origin at any time.

Canada needs immigration to increase the labour pool but resorting to this mechanism can only increase instability, and will not permanently broaden the pool of qualified workers in community social services.

Overseas recruitment should provide immigrants with Canadian citizenship, and allow employers to assist them to achieve this status. Any program that exploits workers from low wage developing countries and creates a ghetto of temporary employees, barred from civic life and disconnected from our communities

should be rejected since it runs counter to the human values that inform community social services.

Recommendation: Reject use of the temporary foreign worker program, and encourage agencies to use existing immigration programs that attract new Canadian citizens.

Regionalize Seniority and Benefit Portability

Care providers recommend using the current CLBC service areas to establish a system that permits people to move from group homes to private care or to other independent or semi-independent living arrangements and to move across agencies without disruption or penalty. If seniority and benefits are portable, across settings and agencies this would provide the flexibility needed to ensure services are consistent, that highly skilled professionals are not lost if a working relationship is disrupted by their incompatibility with a client, or by a client deciding to move to a different residential setting.

Merging seniority lists presents some challenges for unions in the sector but there are clear benefits to creating broader career paths and the opportunities should help attract and retain workers.

Micro boards and adults with developmental disabilities are poorly placed to act as “employers” in semi-independent or independent living situations. The small groups of family and friends that form a non-profit society (board) to support a person with developmental disabilities should be able to focus on care, planning and support.

CLBC should act as the employer for all care providers in a region, including homeshare providers; their terms and conditions of employment to form part of the collective agreement. This would require legislative change and with the assistance of the bargaining agent CSSEA, can be responsible for ensuring the terms of the collective agreement are implemented, and can administer benefit programs.

Recommendation: Establish seniority and portability of benefits by geographic area to facilitate the best possible matching of residents and care providers and to permit a seamless transition through different care settings.

Training

Workers we talked with say there is no consistency in the level of training in the sector.

Because staff shortages are acute, many agencies are knowingly hiring workers who are unsuitable or under-skilled.

One group home worker says she knows of a client who only communicates by sign language but now has a caregiver who cannot communicate with him. “The position was open for two and a half months, and they just hired staff that has no experience with people with a mental handicap and doesn’t know how to sign. So he acts out, then starts getting PRNs. He is just acting out because he’s working with somebody that doesn’t understand him.”

One Counselor gives the example from one of the homes, where a young girl overdoses regularly and cuts her own arms. “The staff have to respond on the fly and they don’t have a background in psychology or clinical training. They are advised by a clinical counselor, but it’s an unreasonable expectation for them to deal with all this on a two year diploma, to cope with crisis, or deal with mental health issues or in-the-moment coping strategies.”

A group home supervisor in Williams Lake says it’s becoming increasingly challenging to find enough time to give the quality of care they have provided in the past. There’s more paper work. Fewer resources. Everything takes longer. “The psychologist that helps us

on the team has a much higher case load now and less time to work with us. The nurse that worked with us some of the time is gone; there’s been no one to replace her. The psychiatrist that the people we support are referred to comes from, I believe, Vancouver. So when things are happening for someone we need to wait and wait and wait.”

Commenting on the unrealistic pressures placed on the smaller number of staff she says,

“The biggest challenge is the expectation that you will do the work of a doctor, nurse, psychologist, psychiatrist, all the cleaning, medication, procurement and all the planning. We are expected to have many, many faces, and much, much knowledge.”

Residential care workers say staff also need specific training to deal with an ageing clientele, and with mental health issues. They suggest such training be offered in-house or

at local community colleges with assistance so care providers in all settings can complete courses.

Workers at Community Living BC itself say staff at the provincial authority need more training too especially those who are supposed to provide support for children with special needs. There were complaints that at the provincial authority there is more sermonizing and too little skill development.

The increasing variety of housing arrangements for adults with developmental disabilities should not mean a reduction in the quality of programming or housing. It was clear from interviews desperate families are sometimes relying on well-intentioned, but inadequately trained individuals. One parent reported hiring a person the family knew was not qualified simply because they couldn’t

“The position was open for two and a half months, and they just hired staff that has no experience with people with a mental handicap and doesn’t know how to sign. So he acts out, then starts getting PRNs. He is just acting out because he’s working with somebody that doesn’t understand him.”

GROUP HOME WORKER

find anyone with the proper credentials. The parent was shocked to discover her son was regularly over-powering the care provider and roughing him up.

All workers, including care providers in private homes, should have equivalent credentials. It appears from the CLBC home share providers' handbook that CPR, first aid and an adequate driver's license are all that will be required in a home share situation. But like workers in other residential settings, home share providers should be required to have training in proper lift procedures, communications, behaviour management and crisis intervention as well as monitoring and dispensing medications.

Consistency across settings should ensure a standard level and quality of care and to avoid problems of abuse and inappropriate care that have surfaced in other jurisdictions.

Recommendation: Ensure all care providers have appropriate and equivalent credentials, including those providing care in home share settings. Standardize training requirements and increase in-service training for all care providers, with a special emphasis on minimizing health and safety risks. Provide skills training for CLBC workers on working with special needs children. Ensure that care providers have knowledge of the resident's history of violence or abuse.

Health, Safety and Violence

Workers also report a lack of attention to health and safety. Assaults and other acts of violence seem to be viewed as just part of the job. One group home worker in the Okanagan says in one week he's been hit three times in the face by clients, but nothing is done to address it, "This one guy packs quite a wallop. I look at it - he's mentally challenged. Why he

hits is beyond me, but people working in this field, we have absolutely no rights. We do incident reports," he says "but they don't go anywhere. If anything, at times, the management will look at it to only see what we were doing to cause the situation."

Clients grab, scratch and punch staff. It gets reported to head office but nothing happens.

"You have to have a lot of patience," says one Coquitlam worker. "That behaviour is hard to deal with everyday."

CLBC and employers must acknowledge this sector has a high degree of violence and take steps to reduce risk. Incident reports must be handled immediately and meas-

ures required must be taken as soon as possible, to ensure the safety of both workers and clients.

Care providers expressed concerns they are not receiving information about a client's history of violence or abuse because of confidentiality requirements. But they need that information to ensure the safety of themselves and other clients, and to determine the care needs of the individual. Staff at CLBC report that under the new system they are not capturing client history either formally or informally. As a result they are not able to relay this information care providers.

There are no formal processes to ensure that as clients move from one care setting to another, the care providers themselves are included in discussions about day to day needs, issues or aspirations of the client with developmental disabilities. One community social worker says if a new client exhibits inappropriate sexual behaviours, for example it's critical they know about it at his residence. "Community Living BC says it is confidential but you need to know if you are going to be an appropriate and successful caregiver. You need to have the

“We do incident reports, but they don't go anywhere. If anything, at times, the management will look at it to only see what we were doing to cause the situation.”

GROUP HOME WORKER, OKANAGAN

information to ensure you don't set up your client by getting him a job at a day-care for example."

A residential care aide from the north agrees and says family home caregivers should be especially concerned because "we might be off-loading individuals to unsuspecting people who are just looking at it as a great way to possibly make some supplemental income, and they don't realize what they are getting in to."

Recommendation: Increase training on crisis intervention, follow up on incident reports, and ensure information required to ensure the health and safety of both residents and care providers is provided.

Labour Adjustment and Training

A centralized agency charged with training and labour adjustment could enhance skills across the province, provide regular upgrades, identify pending shortages and construct career ladders and smooth the transition of workers in the sector as adults with developmental disabilities

exercise their right during their lifetime to choose different residential options, or new service needs arise.

Workers in the community social services sector previously had access to the Health Labour Adjustment Agency (HLAA) in 1999, only to have the agency dismantled by government.

Establishing a training and labour adjustment agency for community social services alone could help ensure stability in the sector and continuity of care. If established under joint direction of CSSEA, CLBC and unions in the sector, the agency could take the lead in addressing the growing problems associated with recruitment and retention as the strong provincial job market and other factors encourage workers to drift into other sectors.

Recommendation: Establish a labour adjustment and training agency under the joint direction of CSSEA, CLBC and the CSS Union Bargaining Association.



Conclusion

Families appear to be headed for crisis unless there are real improvements to the system and a guarantee of dramatically increased funding by the provincial government. In many cases the crisis is already upon us, and clients and their families are paying a high price for government neglect and under funding.

The 29 recommendations in this report reflect the first-hand experience of the current system by the people who use, rely on, work in, and believe in community living for adults with developmental disabilities.

Together, these recommendations form a plan of action to fix a system badly in need of repair. We call on the provincial government to implement these recommendations immediately.