

MOMS on the MOVE: BC Families supporting people with special needs

BRIEF to the Select Standing Committee on Finance and Government Services

Presented by: Dawn Steele, MOMS coordinator, September 15, 2011

About us: Founded in 2001, we've become BC's largest, all-volunteer parent network supporting families of individuals with special needs through information exchange, support and advocacy.

Key message: Government claims unprecedented spending to support children & youth with special needs, adults with developmental disabilities and families. Yet since we started MOMS, families around BC have reported an erosion of supports, growing waitlists, reduced standards and no accountability.

This places a crushing burden on families, and is taking a significant human and economic toll:

- Parents, usually mothers, forced to abandon careers or fulltime work.
- Young families with crushing debt, single parents forced into poverty, aging parents in crisis.
- Reduced economic contribution from parents and young adults failed by the school system.
- More families, children and adults in crisis & relying on costly emergency services.
- Fighting for services and administering funding is a major stress for already-stressed families

These problems can be resolved, if the political will exists to address: 1) Funding and 2) Accountability.

Part 1: Budget history & funding recommendations

Lifetime supports are funded through MSD/CLBC, Education, MCFD, and Health ministries. The budget story is that **funding has failed to keep pace with costs and the demands of a growing population.**

Our children have been asked to tighten their belts for a decade, in good times and bad. If the Premier is serious about listening and putting families first, that requires a major shift in spending priorities.

1. EDUCATION: Special education grants have been cut as the number of special needs students grew.

- Total enrolment, students with special needs [in 2001/02](#) was 48,766. [In 2010/11](#), it was 50,987
- [Total special education grants in 2001/02](#): \$444 million. [Total grants in 2010/11](#): \$383 million
- Teacher salaries (the bulk of special education costs) grew by 27% in the past decade.

The result: Significantly less funding to accommodate students with special needs, a massive erosion of supports for the most vulnerable students in our public schools, and serious lifetime cost implications.

RECOMMENDATION #1: *An additional \$110 million in special education grants to restore per student funding to 2001 levels in real dollars. Distribute this based on enrolment of all designated students and index future grants to teacher compensation. Provide a further \$5 million annually for capacity building in special education, and establish a stakeholder council to work with the Minister to identify priorities.*

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2. COMMUNITY LIVING: Funding was alternately cut and raised, with a net increase erased by inflation. The number of adults requiring support has grown and will continue growing while budgets are frozen.

- Provincial operating budget for community living in [2002/03 was \\$577 million](#). For [2011/12 it is \\$681 million](#), an 18% increase. Factoring in inflation leaves a flat budget in real dollar terms.
- In 2001/02, community living served 8,000 adults. By 201/11, [CLBC provided some services to 13,416](#) adults (up 68%).
- Applying very conservative incidence rates (1.05%) to [BC population estimates](#), 37,400 BC adults were eligible for CLBC services in 2010, a 17% increase over the number eligible a decade earlier. **The vast majority of these are supported entirely or partially by their families.**
- CLBC's budget has been [frozen from 2010 to 2014](#), despite a [5% annual increase](#) in the number of adults requiring CLBC-funded support. This means less funding & less support per adult.

The result: With a growing backlog of unfunded new adults, CLBC can either turn its back, reduce standards or rob Peter to pay Paul. Waitlists and efforts to cut service costs have fuelled a growing crisis.

RECOMMENDATION #2: *We support BC CLAG's recommendation for an immediate \$70 million budget lift, plus a further \$35 million for each of the next two years, to address the backlog of demand and stop cuts and group home closures that are pushing vulnerable adults and their families into crisis.*

UPDATE: Yesterday the Minister announced \$6 million in one-time funding for community living and \$2.9 million in previously-budgeted funds for young adults in crisis who don't meet CLBC's criteria.

While it's a positive gesture, it's like throwing a cup of tea to douse a raging kitchen fire.

Based on CLBC's average costs, this can serve 120 clients for one year – 1/10th of the unfunded backlog of 1,400 new clients since 2010. Feedback from our families suggests much of this may be intended for emergency supports to families who've complained publicly via the media. While we're happy for those families, that would be shockingly unfair. It promotes a squeaky wheel system where those who make noise or wield political clout get preferential access while CLBC robs "Peter to pay Paul" to crisis manages other needs. It's a recipe for disaster.

3. MCFD: Budget analysis is impossible, as the children & youth with special needs (CYSN) budget has been restructured and shifted between ministries so often. A decade ago, MCFD promised to improve data management but still cannot say how many children are eligible, how many get services, what are the waitlists or outcomes. In this data void, official communications include wildly inaccurate assertions:

- [A May 2011 announcement](#) claimed total CYSN spending now exceeds \$600 million
- [An August 2011 announcement](#) claimed spending for school-age CYSN alone is \$858 million.
 - However, an independent study ([BCACDI, Dec. 2010](#)) reports that three ministries (MCFD, Health and Education) now spend just \$525 million for all CYSN programs.
- [An April 2011 announcement](#) claimed MCFD's autism budget of \$42 million was 10 times the 2001 budget of \$4.1 million.
 - But this [Times Colonist report](#) shows the 2001 autism budget was \$19M, not \$4.1M.

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- MCFD says it now serves 7,000 children with Autism (vs. a few hundred in 2001). That indicates a dramatic drop in funding per child (\$42 million/7,000 = \$6,000 per child), far less than the \$40,000 cost of a typical autism intensive early intervention program, as promised in 2001.

RECOMMENDATION #3: Give MCFD one year to establish a data management system to support accountability, evaluation and effective management of services for children and youth with special needs. Provide targeted funding for this and other reforms set out by the Children's Representative.

4. HEALTH: This ministry funds the autism diagnosis program (BCAAN). Without a diagnosis, children cannot access autism funding. Families recently reported that waitlists for diagnosis are growing again.

- In 2003, BC set 3-6 month target for an autism diagnosis, a target that was initially being met.
- [By 2008, however, some families were waiting 8 months](#) just to start the first step and BCAAN's program director acknowledged that funding was inadequate to keep up with demand.
- Last month, [families reported](#) waiting over a year for diagnosis. Officials claim that average waits have improved, but median wait times are now longer than 2008, and similar to a decade ago.
- A [2010 Health Ministry briefing note](#) admitted wait times for autism diagnosis were too long. The memo discussed plans to merge BCAAN with a new autism centre, despite advice that this would worsen delays in autism diagnosis.

RECOMMENDATION #4: Increase the BCAAN budget immediately to eliminate the backlog of requests and meet the target of no more than 6 months wait to complete a full autism diagnosis. Urge the ministers responsible to abandon any plans to integrate BCAAN with the proposed autism centre.

Part 2: Accountability & gaps

Since 2008, the Representative for Children & Youth has echoed families' concerns ([2008 Monitoring Brief](#), [Nov 2008 Update](#), [Sep 2010 Update](#) and her [June 2011 report – Isolated and Invisible](#)): A complex, fragmented system; eligibility criteria that ignore need; problematic wait times and access barriers; lack of case management support for families; and insufficient accountability or attention to outcomes.

After 3 more years of restructuring, her latest report shows little progress on key issues.

This should be no surprise because THERE IS NO PLAN! There is no vision of what BC hopes to achieve with the \$5-600 million spent annually on CYSN services. No needs assessment, no stakeholder consultation, no clear objectives, no priorities, no meaningful performance targets, no performance monitoring and reporting system! Without this, there's no accountability and spending isn't effective.

- BC still has no comprehensive early intervention plan for preschoolers with special needs. We have ad hoc fringe services, gaps and overlaps, but no basic core.
 - EIBI programs that provided intensive intervention for autism to several hundred children were closed in 2009. The alternatives offer significantly less. Are they effective? Who knows!
 - Eligibility still unresolved. Many children excluded by diagnostic criteria that ignore need.

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- Long waitlists or rationing for key programs, e.g. Supported Child Development, without which our children can't even access regular daycare, preschool & after-school programs.
- No framework for evaluating and prioritizing proposed initiatives, so funding may be poorly spent.
 - The BCACDI report found CYSN resources scattered across over 90 programs.
 - In 2008, BC approved a [cross-ministry integration framework](#) to improve coordination for CYSN services, but after 3 years, nothing has changed on the front lines.
 - Each new ad hoc announcement complicates an already fragmented and complex system.
 - (E.g. no rationale for the Province's \$20 million offer to help build a lavish private project to house existing autism services, when families stress program gaps as their top priority.)
- Poor communication, no consultation to identify issues & support effective planning or allocation.
 - BCACDI called for a needs assessment before spending \$20 million on an autism centre. MOMS and others supported that call, but the Minister insists there's no need.
 - Rationing of critical supports means children end up in costly care arrangements.
- No accountability: After a decade of promises, MCFD still has no performance reporting framework.
 - Issues include serious concerns about standards/quality of care for children in care.
 - No evaluation of the effectiveness of ongoing programs and ad hoc initiatives.
- Accountability has also deteriorated at the Education Ministry:
 - In 2002, the Education Ministry stopped tracking grad rates, the only outcome previously tracked for 17,000 students who generate \$290 million (92%) of special education grants.
 - [The latest ministry report](#) on outcomes for special needs students was 2006: 5 years ago.
- With growing waitlists, erosion of core services and complaints of mismanagement at CLBC, families have lost confidence that CLBC and the Minister can assure the safety of vulnerable adults.
 - For over a year, MOMS, individual families, community groups and media have been reporting disturbing complaints about CLBC's treatment of adults and families. CLBC and the Minister have spent a year trying to ignore the problem and yesterday's announcement reflects a continuing failure to understand the seriousness of the systemic crisis. MOMS strongly supports CLAG's call for establishment of an independent adult Representative.

RECOMMENDATION #5: *We urge the appointment of an external expert to work with the Ministers responsible, the Children's Representative and stakeholders to undertake a broad needs assessment and help the province develop a comprehensive vision, objectives and prioritized action plan that provides clear direction, coordination, prioritization, streamlining and accountability for the government-wide, life-long system of services and supports for children, youth and adults with special needs.)*

Thank you for listening. **We trust that you will support the Premier's commitment to put families first by re-ordering budget priorities to simply restore what has been lost.** This is not much to ask and we urge you to bear in mind that these supports represent an ongoing moral societal obligation that exists independently of where we are in the economic cycle.