REPRESENTATIVE FOR
CHILDREN AND YOUTH

Monitoring Brief

System of Services for Children and Youth with Special Needs

February 26, 2008

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1. Introduction

Section 6(b) of the *Representative for Children and Youth Act* makes the Representative responsible for monitoring, reviewing, auditing and conducting research on the provision of a designated service, making recommendations to improve the effectiveness and responsiveness of that service and commenting publicly on any of these functions. A Monitoring Brief makes information available to the public on the responsiveness and effectiveness of a particular aspect of the child and youth serving system. It identifies, where appropriate, the Representative's specific issues of concern, and makes recommendations related to services designed to promote the health, development and well-being of children and youth.

This Brief focuses on the accountabilities of the Ministry of Children and Family Development (MCFD) and Community Living BC (CLBC) with respect to the delivery of services to children and youth with special needs (CYSN).[1] The Representative's observations and recommendations stem from a review of the system of support and are also informed by her advocacy work.

The Representative wants to support MCFD and CLBC to succeed in building a strong and effective system of support for children and youth with special needs and their families or caregivers. The intent of this Brief is to highlight key areas of concern as well as to present some recommendations for action. A particular focus of our advocacy and monitoring work has been on CYSN where child protection and guardianship concerns arise.

The Representative is conducting research and a more detailed examination of the health and well-being of children and youth with special needs as part of our overall Service Plan.

2. Background

- Prior to July 1, 2005 community living services for children and adults were provided by MCFD. On October 29, 2002 the *Community Services Interim Authorities Act* (Bill 65) passed. The interim authority for CLBC was formed on November 13, 2002.
- In June 2004, a "Children's Agreement" was reached between MCFD and the interim authority for CLBC. The Agreement outlined the proposed system of service delivery for children and youth with special needs in BC.
- The *Community Living Authority Act* was passed on October 6, 2004. CLBC was created as a Crown agency effective July 1, 2005.

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[1] Children and youth with special needs refers to "those children and youth between birth and 19 years of age who require additional education, medical/health and social/environmental support, beyond that required by children in general to enhance or improve their health, development, quality of life, and community integration." Definition is taken from MCFD, MoH, and MoEd Cross-Ministry CYSN Framework for Action.

- CLBC was created to provide residential and non-residential family support services to children and adults with developmental disabilities and their families.
- On June 30, 2005 the Minister of MCFD (Stan Hagen) spoke to the rationale for CLBCs creation:

> *People with developmental disabilities and their families told us they needed more choice, flexibility and input in designing the services they receive – and we've responded. Community Living BC is ready to deliver stable, quality services now, through the same staff and locations as in the past. 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.*[2]
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> *To ensure stability for families of children and youth with special needs, the ministry will retain policy, budget and contract responsibility, while staff transferring to CLBC will continue to be the primary contact for these families. Families will continue to receive the same service from the same staff in the same location; the only difference is that these staff will now work for CLBC.*
>
> *The long-term vision, which will be achieved over the next year, is to see CLBC deliver services to children with developmental disabilities into adulthood.*[3]

- During 2005/2006, MCFD and CLBC worked under a Memorandum of Understanding (MOU) regarding the temporary provision of some children's services by CLBC on behalf of MCFD and planned for the implementation of the "Children's Agreement".
- In April 2006, CLBC and MCFD agreed not to implement the "Children's Agreement" due to concerns about possible service fragmentation, confusion for families and lack of planning coordination. While the term of the MOU was not extended beyond March 31, 2007, MCFD and CLBC continue to work within the spirit and structure outlined in the MOU.
- CLBC has agreed to remain the single point of contact for some specific services to children and youth with special needs until a long-term agreement can be reached. CLBC provides support services and/or connects families to services for children who have an Autism Spectrum Disorder (ASD) diagnosis, are eligible for the At Home Program,[4] or have a developmental disability as defined by CLBC. In the area of children and youth with special needs, MCFD is responsible for the delivery of intervention services and programs regionally and provincially. They also share responsibility with CLBC for the delivery of the At Home and Autism Funding Programs.[5]

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[2] June 30, 2005 MCFD News Release 2005CFD0011-000636.

[3] June 30, 2005 MCFD News Release 2005CFD0011-000636.

[4] As identified by the At Home Program Guide, to qualify for At Home Program Benefits a child must be:
- age 18 or younger for respite benefits
- age 17 or younger for medical benefits
- a resident of BC
- living at home with a parent or guardian
- assessed as dependent in at least three of four areas of daily living (eating, dressing, toileting, washing)

[5] CLBC website http://www.communitylivingbc.ca/policies_and_publications/publications.htm.

- In their cross-ministry work on children and youth with special needs, the ministries of Children and Family Development, Health, and Education have identified that approximately 5.65% of BC's children and youth have significant special needs, a percentage that equates to approximately 52,000 individuals.[6] Improvements in diagnosis and assessments, increased public awareness of special needs, and advances in medical science and technology[7] have all served to increase demand for services.
- As of February 12, 2008, 9,610 children and families were either receiving or waiting for CLBC services.[8] MCFD reports that it serves approximately 20,000 children and youth with special needs.[9, 10]
- The past three years have been spent building a Crown agency service model. The Representative recognizes that stronger service planning is a priority for CLBC and MCFD.

3. Key Concerns

This section identifies issues that have come to the attention of the Representative's office through its advocacy and monitoring functions.

- Families and caregivers have difficulty understanding and navigating the complex, fragmented service delivery system.
- Eligibility criteria for some services are not based on children's functional needs and may exclude those requiring service.
- Wait times are problematic. From assessments to intervention services, there are access issues.
- Support is lacking for families and caregivers who require or desire assistance in planning for, implementing and coordinating the variety of services and supports available to them.
- When there is a need for an out-of-home placement, there is confusion about roles and responsibilities and how MCFD and CLBC staff should work together – particularly when it is unclear whether the need is based on the requirement for support to the parent, the child or both.
- There is insufficient public accountability and measurement of child and youth outcomes. At present, with respect to CLBC and MCFD services to children and youth with special needs, it is not possible to decipher who is getting what service(s), by whom, at what cost and with what outcome.

3.1. Preliminary Analysis

The Preliminary Analysis focuses on the responsiveness of the system. The effectiveness of the system cannot be fully assessed due to lack of reliable data. To illustrate some of the systemic service responsiveness

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[6] Prevalence data obtained from Cross-Ministry CYSN Framework for Action.
[7] CYSN service pressures as identified by MCFD.
[8] CLBC, Policy and Program Development.
[9] MCFD, Children and Youth with Special Needs, Policy / Provincial Operations.
[10] The Representative cannot independently report that these numbers are accurate.

difficulties facing children and youth with special needs and their families or caregivers, this Brief uses examples from situations where the Representative has been asked to provide advocacy support.

In this Brief, "responsiveness" refers to the degree that services to children and youth with special needs respond to their needs and are accessible. Services should be available to those who need them and should improve and support health, development and well-being of children. Services must be available and understandable to families and caregivers. They must create the supports and interventions required to help bring about positive outcomes for children and youth with special needs. Services should also reduce vulnerabilities for children and youth who are not living with their parents or families and help them transition into adulthood.

3.1.1. Eligibility

Eligibility for some services requires a diagnosis – in particular for services and supports for Autism Spectrum Disorder (ASD), Fetal Alcohol Spectrum Disorder (FASD) and CLBC services for children and youth with a developmental disability. This diagnostically driven approach to eligibility excludes many children and youth with comparable needs but who do not meet the diagnostic requirements from accessing services.

Government is engaged in a Cross-Ministry CYSN Framework for Action process. This is a collaboration between MCFD and the ministries of Health and Education. Led by MCFD, the Framework for Action creates a vision for a common system for children and youth with special needs that delivers "optimal development, health, well-being and achievement for children and youth with special needs". One of the guiding principles of the Framework is the creation and provision of functionally based services rather than diagnostically driven ones. This work is promising but is at a preliminary stage at this time and has not yet been implemented into MCFD program areas or into CLBC.

The *Community Living Authority Act* (i.e. services delivered by CLBC only) is designed to enable the delivery support and services to children and adults with developmental disabilities, and to support families in caring for the developmentally disabled. Access to supports and services depends on meeting the *Act*'s eligibility requirements. The key eligibility requirement is the definition of "developmental disability" which is set out as follows in s. 1 of the *Act:*

> "**developmental disability**" means significantly impaired intellectual functioning that
>
> (a) manifests before the age of 18 years,
>
> (b) exists concurrently with impaired adaptive functioning, and
>
> (c) meets other prescribed criteria

Section 29(2)(c) of the *Act* authorizes the Lieutenant Governor in Council to pass a regulation "prescribing additional criteria" for the purpose of defining "developmental disability". While Cabinet has passed a

Community Living Authority Regulation, B.C. Reg. 231/2005 (as amended), that Regulation does not add any other criteria to the definition of "developmental disability".

The wording of the definition of "developmental disability" naturally requires an examination of what the term "significantly impaired intellectual functioning" means. CLBC currently interprets eligibility criteria based on the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) criteria for mental retardation:

- Significantly subaverage intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test.
- Concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
- The onset is before age 18 years.[11]

The IQ test has been a barrier to service for children and adolescents with developmental disabilities. IQ scores are only partial indicators of intellect and are even less helpful in assessing the development of children or their level of functioning. Determining whether a child has a "significant" impairment in intellectual functioning should be open to a broader and more flexible assessment that is not contingent upon an IQ test.

Using IQ to determine eligibility has been scrutinized by the courts in BC. In *Fahlman v. Community Living British Columbia*, 2007 BCCA 15, the guardian of a disabled 19-year-old adult challenged a CLBC decision excluding him from eligibility because his IQ measured 79. The British Columbia Court of Appeal held that it was not within CLBC's jurisdiction to use policy to create an "unlegislated criterion" for determining eligibility. The Court rejected the argument that the legislation intended to incorporate a standard set out for "mental retardation" in the DSM-IV. As noted by the Court "the legislature decided against imposing an IQ criterion due to community concerns with a rigid guideline and the need for flexibility". The Court's judgment outlines the legal framework which CLBC is required to function within:

> In my view, the *Act* clearly grants to CLBC discretion in determining eligibility for adult services. As is evident from para. 37 of the chambers judge's reasons, CLBC recognized in Supreme Court its "wide ranging discretion with respect to the provision of the benefits it is authorized to administer". Whether an applicant has "significantly impaired intellectual functioning" so as to have a "developmental disability" and therefore warrant "community living support" appears to be a discretionary decision. Application of the statutory criteria does not necessarily yield an incontrovertible result. CLBC's duty to satisfy itself as to the presence of a qualifying impairment is to be exercised on the facts of each case.

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[11] *Diagnostic and Statistical Manual of Mental Disorders, fourth Edition.* Copyright 1994 *American Psychiatric Association* accessed from http://www.behavenet.com/capsules/disorders/mentretard.htm

> In the instant case, had the legislature intended IQ to be partially determinative of "significantly impaired intellectual functioning" and, therefore, "developmental disability", it could have invoked s. 29 of the *Act*. Namely, the Lieutenant Governor in Council could have specifically prescribed the IQ threshold as an additional criterion "for the purpose of paragraph (c) of the definition of 'developmental disability' in section 1". Instead, the legislature seemed reticent to impose rigid rules. Until the legislature decides to impose such rules, the *Act* as it currently reads confers discretion on CLBC to determine whether an applicant has "significantly impaired intellectual functioning" so as to be developmentally disabled and thus eligible for "community living support". In exercising its discretion, CLBC is to consider fully the facts, circumstances and merits of each application. The IQ policy precludes such consideration and application thereof gives rise to a fettering of discretion.

Fahlman was 19 years old. As such, his case did not address the issues around the diagnosis of significant impaired intellectual functioning for children and adolescents. It is obvious, however, that the legislation is such that if IQ tests cannot even be "partially determinative" for adults, the same is true for children and adolescents. However, Mr. Fahlman's situation is one that deserves close attention as he is one of a group of individuals who face eligibility barriers.

Despite *Fahlman* (which was decided January 9, 2007), the previous *Eligibility Policy* continues. As CLBC states:

> In assessing the elements of developmental disability, registered or certified psychologists apply the "Diagnostic Criteria for Mental Retardation" including the criteria for age of onset, intellectual functioning and adaptive behavior as cited in the DSM IV.[12]

CLBC's reliance on the DSM-IV's "mental retardation" diagnosis is explained by CLBC as a matter of government strategic policy direction. However, the *Act* requires CLBC to determine eligibility according to the statutory requirement. While the Government may step in and pass "prescribed criteria" in the way of regulations, it has not done so. The Representative is not aware of any statutory or regulatory amendment since *Fahlman* that would authorize the IQ policy necessarily implicit in the "mental retardation" test. CLBC's own policy states that "as of the date of this policy, no further criteria have been prescribed".[13]
In the absence of such regulations, CLBC has the legal responsibility to apply the legislation in accordance with the judgment in *Fahlman*.

The very purpose of the supports in CLBC for children and adolescents must be to reduce their vulnerability to further impairments, promote their best opportunities for healthy and safe development, and to support their inclusion in society. The Representative urges that MCFD proceed more quickly to addressing eligibility and that a child-focus be brought to the issues of service responsiveness.

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[12] Community Living British Columbia. (December 2006) *Eligibility for CLBC Supports and Services Policy.* Accessed from http://www.communitylivingbc.ca/policies_and_publications/policies.htm.

[13] Ibid.

Advocacy Case

A child diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and Fetal Alcohol Spectrum Disorder (FASD) lives with her grandparents under the Ministry of Employment and Income Assistance's (MEIA) "child in the home of a relative" (CIHR) program. The family applied for CLBC but was denied service as the child has an IQ over 70 (73). The family is not receiving any services from MCFD and is unaware of the potential services available to meet their needs. The only support the family has in addition to CIHR is through the child's school – two hours of teachers' aid assistance per week.

Advocacy Case

A 15-year-old Aboriginal youth requires services, including an out-of-home placement and counselling. He was required to move from his home community to another community approximately 500 kilometres away. At the time, MCFD was providing service and requested services from CLBC based on the outcome of a forensic assessment that concluded that the youth's IQ was under 70. CLBC challenged the assessment, questioning whether the testing was valid. Another assessment was done. The adolescent was left in limbo. The second assessment confirmed the 70 IQ. At that point there continued to be ongoing challenges regarding who (MCFD or CLBC) would cover the costs of the placement for this youth with multiple needs (i.e. special needs, anti-social behaviour, etc.). The placement of the youth was "temporary" and efforts were supposed to have been made to secure a more long-term placement. This did not occur. When CLBC accepted responsibility for service, it decided the youth was required to move to a new placement in another community. The progress the youth was making in his established treatment plan would certainly be interrupted. A caregiver in the youth's home community came forward with an alternative proposal but CLBC refused to consider it stating that the youth was required to relocate in order to access the available resources. With extensive advocacy by the Representative (RCY), CLBC agreed to explore the caregiver's proposal and eventually agreed to fund it.

Advocacy Case

A 17-year-old youth has been diagnosed with Pervasive Developmental Disorder, low adaptive functioning, severe attachment disorder, conduct disorder and ADHD. Although the youth tested below 70 IQ in the past, he recently had another assessment and scored an IQ in the mid 70's. Based on this assessment, the youth has been deemed ineligible for CLBC services. The youth is currently living in a CLBC home. MCFD purchases the home from CLBC for approximately $8000/month as MCFD does not have an appropriate placement for the youth. The youth's former foster family had given their notice when the youth assaulted their 6-year-old grandson. The youth is currently doing well in the CLBC placement according to the MCFD social worker. The social worker has brought this case to the attention of the RCY as the social worker is concerned for the youth's transition out of care at age 19. The youth does not qualify for CLBC adult services and the social worker and forensic assessments concur that he will not be able to function on his own. He requires support and is at risk of harm to himself and /or the community if not supported.

3.1.2. Wait Times

- Timely and appropriate access to service is a key component of service responsiveness and is particularly important for vulnerable families. Wait times or delays may occur at initial intake and screening; at the time of assessment and/or confirming diagnosis; in the planning stage; and when accessing intervention, services and supports. Some services for children and youth with special needs have no wait times, such as nursing support services, Autism individualized funding programs[14], and provincial outreach and professional support services. Others do have wait times, such as infant development programs and early intervention therapies.
- Both CLBC and MCFD have waitlist data but data cannot be compiled to provide an accurate and comprehensive picture of wait times across the spectrum of CYSN services.
- Wait time information is important because it may influence a family's or caregiver's choice of service support. For example, if a child is eligible for either respite or medical benefits, the latter may be chosen due to the waitlists for respite. These choices are influenced by community wait times and not by considering which services best meet the needs of the child or the family.
- CLBC reports that pressure for services increases most in those areas of population growth. Thus, wait times exist for family support and behavioural support services in the Interior, Fraser, Vancouver Coastal and Vancouver Island regions.[15, 16]
- Waitlist data is not necessarily an indicator of inappropriate wait times for services due to inconsistent waitlisting practices at the service provider level and the lack of actual wait time data available. Waitlist information for MCFD contracted services is managed mainly by the service providers within regions. There is no rigorous data collection standard. Some communities never waitlist for certain programs while others do. It is not always possible to determine whether the lack of a waitlist means service needs are met or whether the service does not exist in the particular area.
- In November 2007, CLBC implemented a Waitlist Policy to ensure that service decisions are made in a consistent and fair way. They are also in the process of implementing a provincial waitlist for children and youth services. As the waitlist will initially be populated with historical data, accurate waitlist information will not be immediate. For MCFD, additional reporting cycles are required to obtain more seasonal data to draw reliable conclusions about pressure areas. MCFD is in the process of developing consensus about waitlist definitions as well as a consistent reporting mechanism for their Supported Child Development, Infant Development, Early Intervention Infant Therapy and School-Aged Therapies Programs.[17] The Representative supports efforts by MCFD (via its work with the cross-ministry collaboration) through UBC's Department of Pediatrics to determine evidence-based wait times for CYSN services.

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[14] For children and youth eligible for Autism services, there are no waitlists for accessing individualized funding programs. However, children may have to wait to access the Autism EIBI programs.

[15] MCFD, Children and Youth with Special Needs, Policy / Provincial Operations and MCFD, Regional Council Support Team.

[16] CLBC, Community Planning and Development.

[17] MCFD, Regional Council Support Team and CLBC, Policy and Program Development.

- Access to assessment services – in particular for families seeking services and support for ASD and FASD – fall under the mandate of the Provincial Health Services Authority (PHSA) as opposed to either MCFD or CLBC. ASD assessment services are provided via the BC Autism Assessment Network and FASD assessment services are provided via the Complex Developmental Behavioural Conditions (CDBC) Network. Wait times associated with these assessments obviously impact accessibility to services and supports.

3.1.3. Accessibility

The ease with which families or caregivers in need can access services is another key component of service responsiveness. Unfortunately, the service delivery system can be rather intricate. Parents are often required to understand a variety of complex service information in order to identify, access and make informed choices about the services that best address their needs and eligibility criteria.

- Families of children with special needs are challenged with navigating a complex system of family support and intervention. Some services, such as family support services, are accessed via CLBC while others are accessed through MCFD, such as nursing support services. Different services have different eligibility criteria – some are open to self-referral and generally accessible, while others are determined by the child's age, severity of disability or diagnosis. In some cases, such as within the Medical Benefits program or Autism services, a choice must be made regarding which service best meet the needs of the family and child. Parents and caregivers may not have all of the information required to make a fully informed decision.

- Given the continuum of services available for children and youth with special needs, there is no single information source for parents and caregivers seeking to access all the information they need. Parents and caregivers must go to multiple information sources to determine what services and supports are available, how they work together, and how to access them. To take an example, certain web sites and documents will refer to the individual support plan, the individualized family support plan and the Behavioural Plan of Intervention. However, there is no single place that describes all three plans, their purposes, and how they inter-relate. Families that are already vulnerable or are not experienced in self advocacy would have little success figuring out what services would best suit the needs of their child and how to access those services.

- RCY advocacy cases demonstrate that CLBC services are not accessible in most First Nations communities. While CLBC is in the process of developing an Aboriginal service strategy[18] and MCFD is focusing on building Aboriginal service provider capacity for children and youth with special needs[19], there is currently no systematic effort to reach Aboriginal children and families. Also, there is lack of clarity with respect to who has the obligation to fund or deliver services on reserve.

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[18] CLBC, Policy and Program Development.

[19] MCFD, Children and Youth with Special Needs, Policy / Provincial Operations.

3.1.4. Service Integration

Families with children and youth with special needs often require supports and interventions from a variety of providers. It is important that service delivery is coordinated and integrated to ensure that the most suitable services are received at the most appropriate time. Interventions and supports must work in conjunction with each other to maximize benefits. Disparate service delivery policies and accountabilities should not impede families' abilities to access services in a timely fashion.

The Representative's advocacy cases suggest that for the adolescent special needs population, the impact of inappropriate eligibility criteria, accessibility barriers, and other systemic difficulties may not support good outcomes for this vulnerable population. For example, the special needs adolescent may develop secondary mental health issues and be at greater risk of social exclusion and exposure to street life (i.e. drug use, homelessness, risk of injury). With more support, outcomes for adolescents and adults between the ages of 16-24 years of age can be improved overall. This is particularly the case where the families have other challenges including socio-economic disadvantage, family breakdown, or where the adolescent is not living with his or her parents. CLBC and MCFD have not developed systemic approaches to support adolescents during this crucial transition when their health, safety and well-being can take a dramatic downturn. The Representative is especially concerned that the system is not supporting adolescents for the transition out of care.

A prudent parent would not send a developmentally disabled 19 year old out to fend for him/herself – particularly when it is known that he or she will not be able to seek service or care independently.

To reduce vulnerability during the transition to adulthood, the Representative believes there is a need to extend CYSN services and the advocacy and support of her office up to age 24 years. This matter was raised by the Child and Youth Officer, Jane Morley QC, in her 2006 report *A Bridge to Adulthood*. This continues to be a significant issue[20] in the Representative's work today.

For children in care, collaboration between MCFD and CLBC varies between regions and is often not reflected in the planning for the child. Children may be placed in foster care and caregivers may express concern about intellectual impairment and behaviour issues arising from poor functioning. These issues are often "shelved" until narrower concerns are addressed. Better planning for the assessment and support for CYSN is required for those in the child protection system. Children may be returned to a family placement from the care system with identified behaviour issues and intellectual delays, realities which were not accounted for in the transition planning process. CLBC services are "voluntary", meaning the onus is on the family to initiate access to services. More dramatically, children may be placed into care voluntarily through special needs agreements or involuntarily when the CLBC supports are not available or offered in a timely or responsive fashion.

CLBC and MCFD do realize the need for better defined roles and responsibilities; operational concerns are the purview of an MCFD and CLBC Joint Management Committee. However, there is no evidence that progress has

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[20] September 2006. *A Bridge to Adulthood: Maximizing the Independence of Youth in Care with Fetal Alcohol Spectrum Disorder.* Prepared by the Child and Youth Officer of British Columbia.

been made to clarify roles and responsibilities for children's services. A new CLBC and MCFD Working Group committee has been initiated and charged with recommending an appropriate division of roles and responsibilities between CLBC and MCFD for services to children and youth with special needs. The Representative encourages and supports the collaborative work between CLBC and MCFD to resolve the issues identified by the parties and those further raised by this Monitoring Brief.[21]

- Issues regarding the lack of supports to manage the variety of services available as well as those around MCFD and CLBC's ability to work in an integrated fashion have been raised many times. There are few supports available for parents and caregivers who cannot meet the complex system expectations or who do not wish to manage the spectrum of services on their own.
- There is no one individual who has the responsibility for helping parents and caregivers to maneuver the intricacies of the service delivery system. CLBC's model of support promotes family and caregiver choice, flexibility and innovation. This model works well for some but does not meet the needs of those who require intensive and ongoing assistance in coordinating or managing services and supports. CLBC has developed approximately 150 "facilitator"[22] roles (approximately half of whom deal with children and families) throughout the province to assist parents and caregivers. Despite this, families are still having a difficult time navigating the complexity of services. For example, parents and caregivers involved in advocacy cases often experience an endless cycle of referrals as opposed to having one individual provide them the necessary information and help them understand what services and supports are available to them.
- In July 2007, CLBC implemented changes to the facilitator role to address the lack of support concerns. The role of the facilitator is to provide information, outreach and support to children and youth with special needs and to their families. Supports can include short term problem solving, assistance with service coordination, and time-limited and goal-focused supports in response to an identified issue. The July 2007 changes were designed by CLBC to allow families and caregivers to work with one facilitator on an ongoing basis rather than working with a new facilitator each time the family connects with CLBC. CLBC is currently revising their Individual and Family Support Policy to further clarify the facilitator role.[23] The Representative will be monitoring this closely to determine if it is an effective response for vulnerable families and caregivers who have found the system difficult to navigate.

  Many MCFD programs have family support components that include case coordination. However, families can still face issues coordinating multiple workers and their advice and demands.[24] The exception to this is MCFD's implementation of "key workers" to provide support to families and caregivers with children with FASD and, in some regions, to families and caregivers with children with complex developmental behavioural conditions. The role of the key worker is not to provide case management support but to enable parents and caregivers by providing education and training to families and by assisting them

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[21] CLBC, Policy and Program Development.
[22] CLBC, Policy and Program Development.
[23] CLBC, Policy and Program Development.
[24] MCFD, Children and Youth with Special Needs, Policy / Provincial Operations.

to access available supports and services for as long as they are required. Regions have implemented the role to best fit the needs of their communities (e.g. Vancouver Coastal has a heavy emphasis on the Aboriginal community) and MCFD has developed standards in addition to providing provincial training for key workers and their supervisors. As the key worker program role is fairly new, it is undergoing a series of external evaluations. Early reports to date indicate an overwhelmingly positive response from families.[25]

Advocacy Case

A 2-month-old First Nations infant was removed from the reserve and placed into the care of MCFD due to protection concerns. The infant was placed in three foster homes within a three-month period. While in the third foster home, the infant received severe head trauma from Shaken Baby Syndrome. As a result, the infant suffers from brain injury and has seizure activity, severe motor skill impairment, vision loss, and a risk of lung infection / pneumonia. Subsequently, the infant was placed in a level 3 foster home where he remained in care of MCFD until he was returned to his parents under a supervision order (SO). The Representative's office was contacted by MCFD and the First Nation to provide advocacy support services to ensure the infant receives the necessary support services he needs. During the supervision order, the parents received respite support on a weekly basis from MCFD. The parents were informed that once the SO ended, respite could be provided under a support services agreement (this agreement is voluntary, with conditions, and involves the continued involvement of a MCFD social worker). While the parents receive some supports, the Representative's office has advocated that such resources are not sufficient to meet the high-level needs of the infant, such as medication adjustments, and assistance for travel to access specialized care. MCFD initially had difficulty connecting the family with CLBC as it is a voluntary service and thus requires parents or caregivers to take the initiative to access services and conduct follow up. The parents were unaware of how CLBC operated and were unable to navigate the system on their own. To facilitate the parents connecting with CLBC, MCFD staff directly assisted the parents in the completion of required documentation. The Representative's office attended meetings with CLBC and MCFD to ensure the parents understood what was required and why. Through the assistance of the RCY and MCFD, the family has made contact with a CLBC facilitator and are currently developing an individualized support plan. The family has been approved for the At Home benefits program but is waiting to be considered for the waitlist for direct funded respite. With the SO ending and the respite services waitlist, there was a potential gap in service for the infant. The RCY appreciated MCFD's offer to commit to providing ongoing respite services twice a month until the family could access them from CLBC. There are no commitments with respect to ongoing supports from MCFD once the family is fully engaged with CLBC. Direct funded respite from CLBC will not be available until the new fiscal year and, even when the family can access CLBC respite, the respite available is not guaranteed and will be significantly reduced. Until CLBC respite services are confirmed, MCFD will continue to provide respite services (two weekends per month vs. four weekends per month during the SO).

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[25] MCFD, Children and Youth with Special Needs, Policy / Provincial Operations.

As previously mentioned, the lack of clarity between CLBC and MCFD regarding service delivery roles is pronounced when a child or youth who is eligible for CLBC services requires an out-of-home placement. There is confusion between whether the placement stems from the needs of the child or youth or from the parent's or caregiver's. A new version of the Children's Field Service Protocol is currently being prepared. The intent of the Protocol is to provide clarity with respect to mandates and joint responsibilities and to outline the ways in which both organizations should work together to provide integrated services at the operational level.[26] The protocol, however, identifies roles and responsibilities by mandates. It does not address how CLBC and MCFD staff are to resolve disputes about who has the primary mandate and responsibility for the child. For example, how to resolve conflicting opinions as to whether a resource requirement is due to a parent's capacity to address his or her child's complex medical or behavioural needs versus a parent's ability to provide a safe environment that is not specific to the child's disability is not expressed explicitly. Practical policies, clear standards and effective, timely mechanisms to resolve service disputes are required.

Advocacy Case

A mother requested suitable placement support for her son diagnosed with Asperger's Syndrome and Obsessive Compulsive Disorder. The CLBC facilitator explained to the mother that her request for residential support services fell under the responsibility of MCFD. The MCFD social worker advocated for a long-term CLBC bed and a placement that offered a more structured environment for the client. MCFD facilitated a special needs agreement to address the immediate needs of the mother and the risk to her son. The RCY facilitated communications between MCFD and CLBC to secure an appropriate placement for the child. A temporary placement for the child was secured by MCFD, however, a long-term placement was still being negotiated between MCFD and CLBC. Unfortunately, the temporary placement did not adequately meet the child's special needs as the child was not taking his medication on a consistent basis and was using alcohol and drugs. In addition the mother had specifically requested a two-bed resource for the child yet despite this he was placed in a four-bed resource. Unfortunately the MCFD placement fell through within a four-day period as the client was remanded in youth custody for stealing a vehicle. At that point, MCFD and CLBC had not come to an agreement as to whose responsibility it was to provide the long-term placement.

3.2. Effectiveness

The *Community Living Authority Act* (CLAA) lays out the powers, functions and duties of CLBC.[27] While CLBC is not a Ministry of Government, it is not independent of Government. Many of CLBC's functions are subject to Ministerial approval and direction.

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[26] CLBC, Children's Field Service Protocol between Community Living British Columbia and Ministry of Children and Family Development. Draft. Jan 14, 2007.

[27] CLBC is a Crown Corporation.

CLBC is responsible for responding to Government's broad strategic goals such as Great Goal 3, "to build the best system of support in Canada for persons with disabilities, those with special needs, children at risk and seniors" as well as for adhering to applicable legislation and regulations such as *CLAA* and the *Budget Transparency and Accountability Act*. The Minister's accountability levers for CLBC include identifying provincial standards for CLBC to adhere to, developing an annual Shareholders' Letter of Expectations, providing a funding letter during budget time, and, whenever necessary, developing a Minister's Letters of Direction.[28]

CLBC and MCFD are currently looking at a number of mechanisms to improve current accountabilities and move to a more structured and accountable framework. The Representative supports an appropriate accountability framework, as it is pivotal to evaluating the responsiveness and effectiveness of the system.

3.2.1. Mandates

- CLBC is authorized by the *CLAA* to "manage the delivery of community living support and administrative services, including, without limitation, developing policies, setting priorities and allocating resources, in accordance with its service plan, budget plan and capital plan." This responsibility is subject to any "Provincial standards established by the Minister": (s. 11). CLBC's duty to develop a service plan is also subject to Ministerial override or change before it is approved.

- The Minister has issued a Letter of Expectations to the CLBC chair to help define the respective roles and responsibilities and to help inform CLBC's Service Plans and Annual Service Plan reports.

- The *CLAA* makes clear that while the Minister may have ultimate authority to establish standards, this power does not abrogate CLBC's responsibility to develop policy and set priorities in the absence of Ministerial direction.

3.2.2. Provincial Standards

- Since CLBC's inception, the Minister has not articulated new provincial standards, though MCFD is considering provincial standards for those areas not covered by service level agreements or Memoranda of Understanding.[29]

- Similar to other MCFD services, contracted service providers who receive $500,000 or more of funding from government are required to be accredited and thus adhere to service standards. Service standards exist for some but not all children and youth services. Standards may not be explicit but are considered by MCFD to be captured within policy. The Representative does not consider this to be an adequate approach.

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[28] Written instructions to CLBC from the Minister. A Letter of Direction may be written at any time.

[29] MCFD, Integrated Policy and Legislation.

3.2.3. Reporting

Reporting is the cornerstone of public accountability. Reporting enables government to inform the public how many children and youth with special needs are being served by government, in what ways and at what cost. It also is the mechanism by which government can evaluate the effectiveness and the strengths of the service delivery system.

- There is very limited reporting on services for children and youth with special needs by both MCFD and CLBC. Neither MCFD nor CLBC are measuring service effectiveness. Their service data cannot be reconciled to obtain a comprehensive picture of how many children and youth are served, at what cost and with what outcomes. CLBC and MCFD are aware of this problem and are taking steps to implement technology to better capture utilization, financial and effectiveness data. CLBC is currently working toward implementing a client management system and a contract management system as is MCFD. In this regard, BC has an opportunity to become a leader internationally in client outcome and decision support data. The Representative reminds the parties that public interest in knowing who is served and to what end is a matter of pressing importance.
- As noted previously, there are wait times for both MCFD and CLBC services. However, currently there is no central client waiting list registry for all services. CLBC is in the process of compiling a provincial waitlist for their children's services which is expected to be operational in fiscal 2008/09. MCFD's waitlists are handled in a variety of ways depending on service or program type.[30] There is agency aggregate data available for some services, but not all. There is also difficulty in aggregating and interpreting waitlists across CLBC and MCFD.
- CLBC's reporting framework as identified in the 2007/08 – 2009/10 Service Plan[31] is based on the quantity of activities performed rather than the result of those services on recipients. MCFD's reporting capacity for children and youth with special needs differs among programs. Currently there is no capacity to determine the effectiveness of programs and services provided to children and youth with special needs and their families. CLBC and MCFD have initiated a project to develop a performance management framework to identify appropriate effectiveness measures to include in CLBC's 2009 /2010 Service Plan.[32]
- There does not seem to be any monitoring and reporting on adherence to standards from CLBC to MCFD. This is a particularly important area to address as the Minister's authority to ensure that CLBC is meeting its obligations is through defining provincial standards, monitoring adherence to those standards, and public reporting on such matters. CLBC reports that the Ministry has not developed any provincial standards for CYSN services – only for services related to children in care and residential services.

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[30] MCFD, Children and Youth with Special Needs, Policy / Provincial Operations.

[31] CLBC, 2007/08–2009 /10 Service Plan.

[32] CLBC, Strategic Planning and MCFD, Integrated Policy and Legislation.

4. Recommendations

The Representative believes the service responsiveness and accountability issues identified in this Brief require resolution. At present it is not possible for the RCY to evaluate service effectiveness as it is unclear who is being served. The Representative recognizes that MCFD and CLBC have identified many of these same issues in the past three years and have been working to resolve them. However, the Representative recommends that this work be given greater priority by both organisations.

Government accountability to the public must increase so that the public is aware of who is served, where, when, with what resources, and to what effect. In September 2004, CLBC commissioned a report *An Operational Examination of the Community Living Service Delivery Model*[33] in which some of the issues identified above were mentioned. It emphasized the need for a document defining the service delivery model in very operational terms, including roles, responsibilities, reporting relationships, linkages and limitations on Authority and the consideration with respect to the need for some case management functions for some individuals or at-risk families of children with developmental disabilities. The Representative endorses this recommendation. Although CLBC has done much to develop its service delivery model and operational policies, roles and responsibilities, further documentation and clarification on these areas from MCFD and CLBC is required.

The Representative's office has discussed these matters with CLBC and MCFD. The Representative believes that resolution of many of these issues is overdue and can be achieved in a short time, but she recognizes that substantial strengthening of the system of supports requires work into the long term.

The Representative has attached an outline of recommendations for resolution by CLBC and MCFD. The Representative will report again in late summer 2008 on the progress made by MCFD and CLBC on the issue identified.

The Representative's office is available to assist MCFD and CLBC in bringing a child and youth focus to the resolution of these important matters.

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[33] CLBC. *Consultant's Report: An Operational Examination of the Community Living Service Delivery Model.* September 30, 2004. Fred Milowsky.

	Recommended Outcomes	
Concern Identified	**Short Term** **(4–6 months)**	**Long Term** **(18 months – 2 years)** (Demonstrate progress towards completion)
Responsiveness	Families and caregivers can readily obtain information on any aspect of the service delivery system for children and youth with special needs, regardless of point of contact.	Families and caregivers can readily understand and navigate the system of services.
	Aboriginal communities are aware of and involved in the planning and delivery of services to Aboriginal children and youth with special needs.	Aboriginal children and youth have access to the same range and level of services as other children in BC.
	Families and caregivers receive support when needed to plan, implement and manage services and supports to their children over time.	
	Services to children and youth with special needs serves children and youth from birth to age 24. (To be implemented as soon as practicable given the regulatory and legislative regime.)	
	RCY provides advocacy services for children and youth and their families from birth to age 24. (To be implemented as soon as practicable given the regulatory and legislative regime.)	
	Eligibility for children and youth services is child-development centered and based on functioning.	
		Collection and measurement of wait time data is consistent and standardized across MCFD and CLBC services and supports.
		Wait times for services are consistent with evidence-based wait times for services to children and youth with special needs.
	Access to services is not delayed or disrupted by disputes regarding mandates or jurisdictions.	
	Strategic and operational roles, responsibilities, relationships, and accountabilities for services for children and youth with special needs are clearly articulated and documented publicly.	Services for children and youth with special needs have a strong quality assurance process that includes auditing against standards, ongoing monitoring and evaluation.
Effectiveness		Public accountability and reporting include number of children served, how they are served, at what cost, and with what outcome.
		Integrated decision support tools enable case coordination across organizations and capture CYSN data to support contract management, service utilization, effectiveness and wait times management.

Appendix 1 – CLBC and MCFD Children and Youth with Special Needs Service Responsibilities

Children and Youth with Special Needs[34]
Services – Ministry of Children and Family Development (www.mcf.gov.bc.ca/spec_needs/index)

- **Infant Development Program**: provides home-based services for infants up to age three who are at risk of developmental delay, or who have a developmental delay.
- **Aboriginal Infant Development Program**: provides support to families of infants up to age three who are at risk for or have been diagnosed with developmental delays. In Aboriginal communities where no other services exist, children up to age six can be included.
- **Supported Child Development**: provides the additional supports children with special needs require to participate in preschool and child care settings.
- **Aboriginal Supported Child Development**: provides culturally appropriate support services in child care centres, or home or community environments, to children with special needs.
- **Early Intervention Therapy**: provides a network of services for early intervention and support to children with special needs and their families, including physiotherapy, occupational therapy and speech-language pathology services.
- **School-Aged Therapy**: provides occupational therapy and physiotherapy services to school-aged children with special needs.
- **Key Worker and Parent Support**: supports families of children and youth with Fetal Alcohol Spectrum Disorder (FASD) and similar neurological conditions through the provision of a specialized key worker and various parent support mechanisms.
- **Nursing Support Services**: supports children and youth with special health care needs and their parents by providing comprehensive nursing services in their home, school and child care settings.
- **Provincial Services for the Deaf and Hard of Hearing**: provides a range of direct and contracted services to clients for children who have hearing or vision loss.
- **Early Intensive Behavioural Intervention**: provides up to 20 hours per week of intensive multi-disciplinary treatment and intervention for children under age six diagnosed with Autism Spectrum Disorder, provided through three agencies in seven communities.
- **Community Brain Injury Program**: plans, co-ordinates and funds short-term, acute rehabilitation services for children and youth with acquired brain injuries.
- **Provincial Outreach and Professional Supports**: provides provincial outreach services (customized assistive devices, complex feeding and nutritional assessment, psychology assessment or consultation) and professional support for community-based therapists.
- Chil**dren in Care**: guardianship and residential services for children with special needs.

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[34] British Columbia MCFD. (January 2007), *Children and Youth with Special Needs.* [Fact Sheet]

- **Children in Care Medical Benefits**: provides essential medical equipment and supplies for children in care with special needs and optical dental benefits for all children in care.
- **Post-adoption Assistance Program**: offers financial assistance and/or access to other support services to some families who adopt or have adopted children with special service and/or placement needs.

Services - Community Living BC (www.communitylivingbc.ca/what_we_do/support_for_children)

- **Supports for Families with Children and Youth with Special Needs**: helps families with a range of community-based services including respite, parent support groups, parent skills training, homemaker/home support, child and youth care workers, counselling, life skills and organised activities.
- **Residential Services**: guardianship and residential services for children with special needs

Services – MCFD and CLBC Joint Responsibility

- **At Home Program (www.mcf.gov.bc.ca/at_home/index)**
  Provides medical and respite benefits to assist parents in caring for children with severe disabilities at home.
  - **Eligibility**: is established through a community-based eligibility committee that is coordinated by CLBC.
  - **Respite**: CLBC provides eligible families with $2,400-$2,800 per year to purchase the respite that best meets their needs.
  - **Medical Benefits**: MCFD provides eligible children with essential medical supplies, medical equipment, medical transportation, therapies, orthotics, dental, optical and PharmaCare benefits.
- **Autism Funding (www.mcf.gov.bc.ca/autism/index.htm)**
  - **Eligibility**: is confirmed by CLBC facilitators who also assist families with intake, information, funding agreements and renewals.
  - **Toll-Free Information Line**: is provided by MCFD Autism Funds Processing Unit staff who respond to inquiries regarding eligible expenses and parental responsibilities associated with funding agreements.
  - **Funding Agreement Processing, Payments to Families and Service Providers, and Financial Reconciliation**: is provided by MCFD Autism Funds Processing Unit staff who make payments to families and/or service providers.
  - **Autism Funding**: Under Age 6 provides families of children with Autism Spectrum Disorder under age 6 with up to $20,000 per year in direct funding to assist with the cost of purchasing Autism intervention services. An invoice payment option is also available.
  - **Autism Funding**: Ages 6-18 provides families of children with Autism Spectrum Disorder ages 6 through 18 with up to $6,000 per year to assist with the cost of purchasing out-of-school Autism intervention services. This funding is in addition to the educational program and special education services provided through school boards. An invoice payment option is also available.

Funds Administered through Foundations:

- **FASD Action Fund (www.victoriafoundation.bc.ca/programs/FASD/FASDMain.htm)**: Administered through the Victoria Foundation, this $10 million fund promotes prevention, public education, and parent and caregiver education and will support demonstration projects intended to focus on improving outcomes for children and youth with FASD through peer support, social and life skills development, transition supports and school-based initiatives.
- **Children and Youth With Special Needs Supports Fund and Family Independence Fund (www.vancouverfoundation.bc.ca/grants/grantingareas.htm#htm)**: Administered in a coordinated manner by the Vancouver Foundation. Grants are provided to families of children with special needs and adults and children with developmental disabilities to assist them to buy equipment, convert vehicles and renovate homes to support their son or daughter to remain at home and gain greater access to their communities.

Appendix 2 – Glossary

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CDBC	Complex Developmental Behavioural Condition
CIHR	Child In Home of Relative
CLAA	Community Living Authority Act
CLBC	Community Living BC
CYSN	Children and Youth with Special Needs
DSM	Diagnostic and Statistical Manual of Mental Disorders
EIBI	Early Intensive Behavioural Intervention
FASD	Fetal Alcohol Syndrome
HA	Health Authority
MCFD	Ministry of Children and Family Development
MOH	Ministry of Health
MOU	Memorandum of Understanding
PHSA	Provincial Health Services Authority
RCY	Representative for Children and Youth
SO	Supervision Order
UBC	University of British Columbia

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