Key Components of Effective Service Delivery for Children and Youth with Support Needs and Their Families:

A Research Review and Analysis

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HISTORY AND INTRODUCTION

In October 2021, British Columbia's Ministry of Children and Family Development (MCFD) announced a plan to establish a new service system, based on its Children and Youth with Support Needs (CYSN) Framework, through the implementation of new one-stop "family connection hubs" – now known as Family Connections Centres (FCCs) – over a three-year period from 2022 to 2025.[1] The plan was aligned with previous reports and recommendations by the Office of the Representative for Children and Youth (RCY) and the Select Standing Committee on Children and Youth (SSCCY). It was also informed by a community consultation process conducted in 2019; a review of academic literature; and input from researchers at CanChild, an international organization focused on improving the lives of CYSN and their families.

The stated intention of the new framework was to address many of the service gaps and inequities that are, unfortunately, inherent in the current system. Specifically, the framework aimed to provide community-based, accessible services and supports based on a child or youth's functional abilities and needs, irrespective of diagnosis. The plan also included the proposed elimination of individualized funding for children diagnosed with autism spectrum disorder (ASD).

As noted previously, RCY has a long history of concern about the quality and quantity of current services provided to CYSN and their families, as reflected in multiple reports, including:

1. *Isolated and Invisible: When Children with Special Needs are Seen but Not Seen (2011)*
2. *Who Protected Him?: How B.C.'s Child Welfare System Failed One if Its Most Vulnerable Children (2013)*
3. *Who Cares?: B.C. Children with Complex Medical, Psychological, and Developmental Needs and Their Families Deserve Better (2014)*
4. *Alone and Afraid: Lessons Learned from the Ordeal of a Child with Special Needs and His Family (2018)*
5. *Left Out: Children and Youth with Special Needs in the Pandemic (2020)*
6. *Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and Their Families (2021)*
7. *Beyond Compliance: Ensuring Quality in Care Planning (2022).*

Following MCFD's 2021 announcement, considerable concern was expressed by Indigenous leaders and community representatives, by parents/caregivers – both as individuals and as members of numerous disability advocacy groups – and by numerous community and professional organizations regarding (a) the process by which MCFD developed the new framework and (b) the types, quality and quantity of services that were to be available through the framework. In particular, there was widespread concern about the lack of consultation by MCFD with key groups in the sector regarding potential solutions to deficiencies in the current system and to the proposed elimination of individualized funding for children with ASD.

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[1] BC Gov News, October 27, 2021; https://news.gov.bc.ca/releases/2021CFD0067-002047

On Nov. 25, 2022, numerous advocacy efforts related to these concerns culminated in an announcement by government to "pause" provincial implementation of the proposed CYSN framework.[2] This announcement, made by the Premier, promised continuation of individualized funding for CYSN with autism for all current and newly diagnosed children. It also promised a co-designed engagement process to inform the path to build a better system of supports in partnership with Indigenous communities, and interim investments for currently underserved populations. Subsequently, the Premier and the Minister of Children and Family Development committed to engage in "deeper consultation with parents and caregivers, First Nations, Indigenous peoples, communities, experts and practitioners, and other stakeholders with lived experience." [3] However, despite the "pause" announcement, the original plan to establish four FCCs was maintained, albeit as "pilot" sites to be evaluated rather than as "early implementation" sites.[2] Thus, in January 2023, MCFD announced that FCCs would open in spring 2023 in four B.C. communities – Central Okanagan/Kelowna, Haida Gwaii/Prince Rupert, Terrace/Kitimat and Bulkley Valley/Stikine – and would offer "therapies, interventions, supports, and services to CYSN and their families based on their unique needs, regardless of whether they have a diagnosis." [4]

Although government's November 2022 announcement was welcomed by many in the disability sector,[2] several concerns remain. First, although the announcement promised an evaluation plan for the four pilot FCCs, neither an evaluation plan or specific performance measures have been provided to date. Second, and more importantly, questions remain about MCFD's plan to "build a better system of supports for children and youth with support needs."[3] Specifically, the extent to which the system of supports will be based on research about effective service delivery models for CYSN is unknown. To address this issue, RCY commissioned a literature search and review to examine three related questions:

(a) What are the key components of effective, family-centred service delivery systems for CYSN and their families, in general?;

(b) What additional components, if any, are required to address the mental health needs of CYSN and their families?; and

(c) What additional components, if any, are required for effective service delivery to Indigenous CYSN and their families?

A previous version of this report was shared with key government officials in mid-January 2023. RCY believes that this information can be useful to MCFD as it conducts the promised evaluation of the four pilot sites and as it develops new plans for service system transformation based on a forthcoming public consultation process that was part of the November 2022 announcement.[2]

Finally, this report was commissioned by the Representative in order to provide valuable information to MCFD as it moves forward with re-imagining the CYSN framework, and to the FCCs as they pilot and evaluate the effectiveness and impact of a new model of service. However, RCY firmly believes that B.C.'s improved CYSN service delivery system must be truly co-designed with Indigenous leadership, families, advocates and community partners.

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[2] BC Gov News, November 25, 2022; https://news.gov.bc.ca/releases/2022PREM0095-001797

[3] Mandate letter to Minister Mitzi Dean, December 7, 2022; https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/premier-cabinet-mlas/minister-letter/cfd_-_dean.pdf

[4] BC Gov News, January 5, 2023; https://news.gov.bc.ca/releases/2023CFD0001-000002

METHOD

A literature search was conducted via the UBC library system using the Academic Search Complete, PsycInfo, and CINAHL databases.[5] All searches were confined to peer-reviewed journal articles written in English and published since 2000. After a title and abstract scan to determine general appropriateness, this resulted in 88 general studies, 45 mental health studies, and 27 Indigenous studies that were then reviewed against the inclusion criteria:

- either, a review of research about effective service delivery for a specific population (e.g., Indigenous youth with mental health challenges); ***or***
- both,
  (a) a description of a service delivery system/model/program designed for children and/or youth with some type of support need (e.g., physical and/or developmental disability, emotional disturbance/mental health concern); ***and***
  (b) interview, survey, or focus group data gathered from one or more relevant groups about the key components of the system/model/program.

In the end, a total of 50 studies – 22 general service delivery, 13 mental health and 15 Indigenous – met the inclusion criteria and were reviewed in detail. Numerous countries were represented in the eligible studies, including Canada, the United States, Australia, New Zealand, the United Kingdom, Wales, India, Norway and Belgium.

Inductive thematic analysis was used to identify key service delivery components, and the results were then aggregated across studies. In this summary, the most commonly identified components are summarized for general service delivery (i.e., across all three categories) and compared to publicly available MCFD documents describing the proposed CYSN framework and FCCs.[6] Similar summaries and comparisons are also provided for additional components identified as key for mental health and Indigenous service delivery. The summaries and comparisons were supplemented by secondary literature searches on specific topics, including family-centred care, intervention intensity, intervention quality, support for families who speak a primary language other than English (i.e., immigrant families), dual diagnosis, needs assessment, family mental health, and respite care.

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[5] Search terms for the first question (general service delivery) included *service, delivery, model, disabled/disability/disabilities, rehabilitation, children, youth, adolescents, teens, hub, spoke, individualized, block, mixed, hybrid, funding* and various combinations of these (e.g., *service delivery, hub and spoke*). Search terms for the second question included all of the above plus *mental, health, emotional, disturbance* and combinations. Search terms for the final question included the general terms plus *Indigenous, Aboriginal, American Indian, First Nations, Metis, Inuit,* and combinations.

[6] During the current "pause," government has not been specific about the status of the CYSN framework as announced in 2022 and whether it is being set aside or re-worked.

KEY COMPONENTS FOR EFFECTIVE CYSN SERVICE DELIVERY: GENERAL

Six key components for effective service delivery in general were mentioned in 20 or more of the 50 research studies that were reviewed. They include:

1. Provision of family-centred care;
2. Cross-sector collaboration and connections to community networks and resources;
3. Coordination of services across therapies;
4. Sufficient, accountable funding, equitable funding allocation, and sufficient resources;
5. Services customized to meet individual needs (intensity, quality); and
6. Staff training related to the service delivery model.

Provision of Family-Centred Care

All of the articles reviewed, including those specific to mental health or Indigenous families, identified family-centred care as a critical component of any service delivery system for CYSN. Researchers at CanChild/McMaster University noted that family-centred services are based on three basic premises, each of which translates to specific service provider behaviours (Rosenbaum et al., 1998). The first premise is that *"parents know their children best and want the best for their children"* (p. 5). For service providers, this means encouraging parent/caregiver decision-making based on appropriately presented information, in the context of clearly defined child and family needs, and built upon child and family strengths. The service provider-parent/caregiver relationship should be collaborative, and services should be accessible with respect to both location and a communication style that respects each family's abilities to understand and absorb information and advice. The second premise is that *"families are different and unique"* (p. 6). This requires service providers to recognize and accept the diversity of values and cultures found in multi-ethnic and Indigenous communities, listen carefully to what parents/caregivers are saying, and trust their observations about their child. The third premise is that *"optimal child functioning occurs within a supportive family and community context: the child is affected by the stress and coping of other family members"* (p. 6). Thus, the needs of all family members should be considered, and the involvement of all family members should be supported and encouraged.

These three premises and associated behaviours have been reflected in numerous research studies over the past 20-plus years, including in four recent research reviews conducted from different perspectives. Xu et al. (2022) examined research on the barriers and facilitators of service access for *immigrant families* in the U.S. They identified several service facilitators that correspond to Rosenbaum et al.'s (1998) premises for family-centered care:

(a) establish communication and trust, using interpreters whenever possible;

(b) treat parents/caregivers with compassion, patience, and respect;

(c) understand families' cultural values and customs, particularly with regard to child development and care; and

(d) provide integrated, "one-stop" access to services.

Other studies of immigrant family needs have emphasized the importance of:

(a) understanding that a collaborative model of decision-making may be unfamiliar to families who view professionals as "experts";

(b) providing care coordination; and

(c) supporting family-level needs by providing, for example, respite care and family mental health supports/counseling (Fong et al., 2021; King et al., 2015; Nicholas et al., 2017; Stewart et al., 2006).

McCalman et al. (2017) examined the literature on family-centred care for *Indigenous children and families* in Australia, Canada, New Zealand, and the U.S. They identified key components that resonate with Rosenbaum et al.'s premises:

(a) support family wellness behaviour and self-care;

(b) increase parent/caregiver knowledge;

(c) encourage families to access clinical services for themselves and their child;

(d) promote cultural/community connectedness; and

(e) advocate for the social determinants of health.

Of note is that fact that four of these five components are family- rather than exclusively child-focused, in line with the pivotal role of families in Indigenous culture.[7]

Woody et al. (2019) reviewed the research on family-centred care for *youth and young adults with serious mental illness or complex mental health needs* in six countries. Key family-centred practices included:

(a) multiagency collaboration with educational, vocational, and housing support in addition to mental health care (i.e., wraparound supports);

(b) consumer and family collaboration in care planning;

(c) intensive case management, including provision of specialist interventions or linkages with services related to co-occurring conditions (e.g., substance abuse); and

(d) service integration through the continuum of care, including transition planning. Here, the key components of family-centred care were focused primarily on youth/young adults, although family counseling/therapy supports were also included in 39 per cent of the studies reviewed.

Finally, McCarthy and Guerin (2022) analyzed the research from nine countries on *family-centred services for young children with disabilities* and identified five practices that were common:

(a) multidisciplinary service coordination;

(b) collaborative care planning and goal setting;

(c) providing both centre- and home-based intervention;

(d) providing family education/coaching; and

(e) imparting specific information about external resources.

These components echo many of those in the other reviews, with a balance between child- and family-focused supports.

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[7] National Collaborating Centre for Aboriginal Health (2015). *Family is the Focus – Proceedings Summary*. Prince George, BC: Author.

Despite the evidence supporting the application of family-centred care, numerous family, service provider, and organizational barriers may impede its use. Research has sought to identify implementation barriers from the perspectives of parents/caregivers; two of the most recent and comprehensive studies were conducted in Ontario by the CanChild research team that was mentioned previously (Phoenix et al., 2020a, b). They identified three types of barriers that may limit participation in family-centred services: those related to family structure and composition, those related to family health, and those related to the service delivery system itself. Family structural factors may include:

(a) the number of parents/caregivers involved in care (i.e., two- vs. lone-parent/caregiver households);
(b) parent/caregiver age;
(c) the number of children living in the household;
(d) family financial status;
(e) the availability of transportation to and from appointments; and
(f) parents'/caregivers' employment status and needs.

Family health barriers may include the complexity of the child's health needs and those of siblings, and parents'/caregivers' own mental health challenges. Finally, service delivery barriers may include:

(a) restrictive eligibility requirements;
(b) the need to schedule and navigate multiple appointments in multiple locations;
(c) long wait lists for service; and
(d) frequent staff/therapist turnover.

In response, the authors of these two studies recommended care coordination by a key worker or system navigator – including counselling and other mental health supports for parents/caregivers – and addressing structural barriers by, for example, providing travel supports (e.g., taxi vouchers, volunteer drivers); providing therapy services in family homes or at daycare; providing services outside of traditional working hours for families who work full time; and offering joint appointments with more than one discipline present. Studies such as these that focus on barriers and associated solutions provide essential information that can help to resolve discrepancies between family-centred *policies* and "on the ground" *practices*, or what some have referred to as implementation lag.

Family-Centred Care in the MCFD Proposal. Multiple documents created by MCFD that were available to the public prior to the November 2022 "pause" announcement refer to *policies* for the availability of "family-centred approaches/care/services/solutions" at the FCCs that were to be located in 45 communities across the province to provide CYSN services.[8,9,10,11] From these documents, it appeared that several of the key components of family-centred care were to be available within the proposed new

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[8] *Children and Youth with Special Needs Service Framework and Service Descriptions:* https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-support-needs/1_cysn_service_framework.pdf

[9] *Family Connections Centres: Service Expectations & Descriptions:* https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-support-needs/2_cysn_framework_-_family_connections_centres.pdf

[10] *Disability Services: Service Expectations & Descriptions:* https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-support-needs/3_cysn_framework_-_disabilityservices.pdf

[11] *Children and Youth with Support Needs: Appendix A, B, & C, Glossary and Bibliography:* https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-support-needs/5_cysn_framework_-_appendices_glossary_bibliography.pdf

system, which was “designed to make it easier for families to navigate and access services for children and youth with support needs in a way that best meets their unique needs.”[9] A wide array of supports were to be provided by “one-stop centres”[9] that offer multidisciplinary care coordination and family collaboration in goal-setting and care planning. There was also mention of family support workers who would “help identify and remove barriers to accessing and receiving services,” including access to local transportation; service coordination with the ministry’s Child and Youth Mental Health (CYMH) teams and Specialized Homes and Support Services (SHSS) programs; and engagement options such as virtual services, supports from FCC outreach teams, and in-home services, in addition to in-person supports at the FCC.[9]

In contrast, several components that were identified as important in the family-centred care research were designed to be subject to eligibility requirements through a component of the framework called Disability Services. These included, for example, family counselling and education, family respite care, cross-sector planning and care coordination, and planning for the transition to adulthood.[10] Aside from requirements in the FCC pilot site Requests for Proposals (RFPs) for descriptions of “how diverse cultures are reflected in materials” and “how your organization will ensure services are accessible for English Language Learners and their families,” [12] there was no mention of specific supports for immigrant families, or for staff training specifically designed to increase cross-cultural understandings. Finally, the extent to which therapy services that are individualized with regard to both intensity and quality and specialist services for CYSN who require extraordinary supports would be made available was also unclear. These and other limitations to family-centred *practices* – not simply *policies* – will be discussed further in upcoming sections of this report.

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[12] Ministry of Children and Family Development, Request for Proposals (RFP) – Children and Youth with Support Needs for Kelowna, Appendix G: Cultural Safety Plan template

Unanswered Questions. It seems clear that several key elements of family-centred care were not evident in the original CYSN framework and FCC proposals; thus, challenges remain. Operators of the four pilot FCCs need to be aware of these challenges and plan to address them as they roll out services. Furthermore, as government fulfills the Premier's commitment to "engage in deeper consultation with parents/caregivers, Indigenous Peoples, communities, experts and practitioners, and other stakeholders with lived experience to understand how the system can be transformed and how to build a better system of supports,"[2] questions such as the following must be addressed:

- The use of "eligibility" requirements for Disability Services does not fit into a framework that purports to offer integrated, "one-stop," family-centred care. All families should have access to supports such as family counselling and education, family respite care, cross-sector planning and care coordination, and planning for the transition to adulthood. Will the pilot FCCs be required to limit access to these services only to eligible CYSN and families? How will the transformed CYSN system address this concern in the future?
- What specific family-centred accommodations will be required in the pilot FCCs to support Indigenous, culturally diverse and immigrant families?
- Typically, a plan to evaluate the outcomes of a pilot project is formulated in advance of initiation of the project, so that implementation sites are aware of the measurement benchmarks in advance. However, RCY has recently been advised by MCFD that an evaluation plan for the pilot FCCs is currently in development and is being recalibrated with reporting requirements on children and youth outcomes including measurement of developmental goals, social inclusion, empowerment and family inclusion. As this is still in development, questions remain about how services offered at the pilot FCCs will be evaluated. Specifically, will the evaluation include the Measure of Processes of Care (MPOC) as described in a previous MCFD document,[11] despite the fact that this measure has been found to over-simplify the elements of family-centred care and lack clinical utility as an outcome measure (McCarthy & Guerin, 2022)? What other measures and processes will be used to determine CYSN goal attainment, social inclusion and family empowerment?

Cross-Sector Collaboration and Connections to Community Networks and Resources

The importance of cross-sector collaboration across government departments or ministries and/or of community network collaboration was specifically identified in 61 per cent of the research studies reviewed, although this was alluded to in virtually all of them. Cross-sector and community network collaboration was accomplished, in some cases, by co-locating services (e.g., health, social services, education, housing) in a central location like a community hub. In other cases, a common database was established to support communication and planning across sectors and networks for the children and families who were served. In yet other cases, this component was identified by one or more parties (e.g., parents/caregivers, service providers) as important, but no specifics were provided about how it was accomplished. Regardless, the rationale for this element is simple: CYSN and their families face multiple challenges over the lifespan of the child/youth, and no one sector or community network can address all of them. Most CYSN require one or more types of targeted therapy support (e.g., speech, occupational and physiotherapy) in addition to support for behavioural/mental health, educational, and/or health challenges. Most also require community-based supports such as after-school daycare and recreation programs. In the mental health area, this is one component of a common team-based planning process called "Wraparound" that is "child- and family-centered, builds on child and family strengths, …is culturally relevant, flexible, and [is] … *developed and implemented based on an inter-agency, community-based, collaborative process"* (Winters & Metz, 2009, p. 138-139; italics are mine). In addition, families of CYSN require services such as those related to mental health/addiction, positive caregiving, medical/health challenges and respite. They may require supports related to employment, housing, counselling, and poverty reduction, among others. In particular, 10 out of 15 Indigenous studies (67 per cent) identified the importance of providing services to the whole family, not just the child/youth with support needs. Again, this requires coordinated planning, execution and resource sharing both within and across public sectors and community resources.

Cross-Sector Collaboration and Community Connections in the MCFD Proposal. Publicly available MCFD documents related to the original CYSN framework referred to "support planning" by "primary support coordinators" who would be located at the FCCs. However, the scope of support planning was to depend on a child's/youth's eligibility for Disability Services, as noted previously.[10] To determine eligibility, the framework proposed to use a number of reliable and valid assessment instruments that were designed to identify functional delays, inform program planning, and monitor individual progress – but not to determine resource needs or service eligibility. Eligibility criteria included (a) moderate or significant limitations in adaptive functioning **and** (b) a prolonged disability that impacts the child or youth's activities in areas such as daily activities (e.g., toileting, bathing, feeding, dressing), mobility, and social engagement and inclusion. Children deemed ***ineligible*** for Disability Services were to be assigned a primary support coordinator within the FCC, who would coordinate goal-focused therapy services at the FCC. Thus, it appeared that *children and youth with less than moderate or significant limitations in adaptive functioning might not be provided with cross-sector support planning for services outside of the FCC.* These children and youth might include, for example, those without a specific disability diagnosis (e.g., undiagnosed fetal alcohol spectrum disorder (FASD)); more able children/youth on the autism spectrum; and those with disabilities that might have a less-than-moderate impact on their daily activities, mobility, or social engagement/inclusion, such as dyslexia, attention deficit hyperactivity disorder (ADHD), and mild intellectual disability.

Children identified as ***eligible*** for Disability Services were to be assigned a CYSN worker in the FCC community or catchment area who would develop an "integrated support plan … to guide service delivery on behalf of the child or youth and their family"[11] (p. 7). CYSN workers were expected to "refer families to community supports outside of Disability Services as appropriate" and "engage in coordinated support planning with professionals within the FCC and outside the FCC (e.g., school-based team)"[10] (p. 15). Although this sounds like a provision for cross-sector and community-based planning, other documents call this into question. For example, a publicly available MCFD document described a shared Information Management and Information Technology (IMIT) system in which support plans would be embedded and populated, but also specified that *"the full plan will be visible to the child or youth, family and the primary support coordinator"* [11] (p. 10). Thus, this does not appear to be an information platform that will support cross-sector planning and coordination. In fact, there was no specific mention of either community networking or cross-sector collaboration with other ministries in the development or execution of the support plan. In the weighted criteria for adjudication of the RFPs that were issued in May 2022 for the four pilot FCCs, applicants' approach to "Connection to and understanding of community" accounted for 6.5 per cent of the total points assigned[13] (p. 22). However, aside from "connection" and "understanding," there was no *requirement* in the RFP that the FCCs demonstrate a *plan* for cross-ministry or community partnerships, collaboration, or service delivery. There was also no indication that provisions were made for cross-ministry resource-sharing, information-sharing or funding allocation.

Unanswered Questions. Most often, CYSN and their families require support from two or more providers of health, education, social/support needs, and mental health and addictions services. Thus, family-centred support planning requires coordination and information-sharing across government and community sectors for *all* families. During the pilot FCC roll out and as part of the system transformation process that was promised by the Premier, questions such as the following must be addressed:

- How will planning for a transformed system of supports involve collaboration between the Ministries of Children and Family Development, Health, Education and Child Care, Mental Health and Addictions, Social Development and Poverty Reduction, Housing, and Indigenous Relations and Reconciliation?
- What provisions will be in place to guarantee ongoing engagement in cross-sector/ministry care coordination for *all* families within the transformed system?
- How will the principles and intentions of Jordan's Principle be upheld in the transformed system?
- How will the IMIT system support cross-sector and cross-ministry information-sharing, planning, and coordination?
- What provisions will be made for cross-ministry resource sharing or funding allocation?

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[13] Ministry of Children and Family Development, Request for Proposals (RFP) – Children and Youth with Support Needs for Kelowna

Coordination of Services Across Therapies

This component is related to the cross-sector collaboration component discussed previously, but refers to the need for *intra-* rather than *inter*-agency coordination and was specifically mentioned in 57 per cent of the studies reviewed. Intra-agency coordination is required across speech-language, occupational and physio therapies; supports for children/youth with behavioural challenges; supports from infant development and supported child development consultants; and supports from mental health professionals. In the research literature, care coordination is typically carried out either by one individual (most often a nurse or social worker) or by a small team of people, depending on the size of the organization. Care coordinators are often referred to as "key workers," "navigators," or "case managers," among other terms. The literature on this topic stresses that care coordinators should have expertise that goes beyond assessment, planning, implementation and evaluation, including:

- Analytical thinking, family-centered planning, organizing and coordinating;
- Communication, engagement, building partnerships, teamwork and cooperation;
- Problem solving, judgement and conflict management;
- Continuous learning, flexibility, innovation and knowledge transfer; and
- Empowering others and cultural competency[14] (pp. 13-14).

Coordination of Services Across Therapies in the MCFD Proposal. In the current system, care coordination is limited, dispersed, and quite variable across B.C. for families of children with support needs. However, as noted in the cross-sector collaboration section, all children and families who receive services at one of the pilot FCCs will be assigned a care coordinator who will either be a CYSN worker or a member of the FCC therapy team, depending on the extent of a child's support needs. This might be sufficient for children with limited support needs who live in a community where all therapy services are available at an FCC that serves a well-defined geographic area. However, in rural and remote communities, many therapy services are now and most likely will continue to be offered outside of a pilot FCC; for example, families in the Kootenay region currently access speech-language therapy services at local health units. In situations like this, cross-sector coordination (i.e., between the MCFD-funded FCC and the Ministry of Health-funded health unit) will be required but will only be available to children who are eligible for Disability Services, as noted previously. Thus, although care coordination for therapy supports will be included at the pilot FCCs, the extent to which *adequate* coordination will meet the needs of all CYSN and their families is likely to be quite variable.

Unanswered Questions. Operators of the four pilot FCCs will need to ensure coordination of therapy services for ***all*** children and families. This will require consideration of questions such as:

- How will therapy care coordination be available in communities where some therapy supports are available at locations other than the FCC?
- What provisions will be made to minimize the travel burden for families who live at a distance from the FCC and/or satellite therapy sites?

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[14] MCFD Strategic Policy, Research and Engagement team, *Research Brief: Case Coordination for Children and Youth with Special Needs*, November 27, 2020.

Sufficient, Accountable Funding, Equitable Funding Allocation and Sufficient Resources

It seems obvious that adequate service provision to CYSN and their families is dependent on adequate and equitable funding, among other factors. Indeed, this component was specifically emphasized in 57 per cent of the studies reviewed although, like the cross-sector requirement discussed previously, it was an implicit assumption in all of them. Related to this was the need for sufficient resources (e.g., technology, administrative support, equipment), which was specifically identified in 35 per cent of studies. In this regard, several funding models were represented in the research review; the most prevalent were block funding, funding for hub and spoke models, and individualized (aka direct) funding. It is important to note that *no one funding model has been shown to be superior to the others; all have the potential to support effective service delivery, all other components being equal.*

Block funding occurs when funds are allocated to a centre (e.g., a health care, rehabilitation, or child development centre) which, in turn, provides services; currently, this is the prevalent model in B.C. for most CYSN and their families, especially for children under age six. Funding for *hub and spoke* services is similar, except that each primary centre (the “hub”) is affiliated with two or more secondary centres (the “spokes”) and funding is distributed proportionately. This model has primarily been used in the delivery of health care, wherein a “hub” hospital in a central/urban location delivers more costly, time-consuming, specialized services. With support from experts at the hub, affiliated “spoke” hospitals or clinics provide screening, support and basic health services in remote/rural communities or via a satellite/telehealth network. *Individualized or direct funding* involves payments that are made directly to people with support needs or their families, based on assessment of a person’s unmet needs of specific types. This funding model was the specific focus of much of the research from Australia, which adopted the National Disability Insurance Scheme (NDIS) in 2013 to provide individualized funding (IF) to citizens with permanent and significant disabilities that prevent them from doing everyday things by themselves. In Australia, IF funds can be used to purchase early intervention supports for young children (under age seven) as well as supports and services that are not otherwise funded, for citizens under age 65 in 15 support categories (e.g., assistance with daily life, assistive technology, coordination of supports, finding and keeping a job, improved relationships, improved health and well-being, improved learning).[15] This is the model currently used in B. C. in the Autism Funding Program (AFP) to support children on the autism spectrum up to age 18[16] and in the At Home Program (AHP) to support children with severe disabilities who live at home and are assessed as dependent in at least three of four functional activities of daily living (eating, dressing, toileting and washing).[17]

Funding and Resource Allocation in the MCFD Proposal. The “paused” FCC provincial roll-out was based on a “cost pass through plus service fee model.”[13] Within this model, MCFD planned to provide funding to the FCCs, which would then act as community service “hubs.” Currently, the four pilot FCCs will operate under this model and will be responsible for planning, coordinating, delivering and evaluating all CYSN services that they are contracted to provide.

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[15] National Disability Insurance Scheme website; https://www.ndis.gov.au/

[16] Autism Funding Program (AFP): https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/autism-spectrum-disorder/autism-funding

[17] At Home Program (AHP): https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/complex-health-needs/at-home-program

In the original framework, MCFD planned to support FCCs using funds from several existing sources:

(a) funds that are assigned to the AFP and the AHP;

(b) funds that are assigned to a key worker program for children with diagnosed or suspected FASD, and

(c) funds that are provided to Child Development Centres (CDCs) across the province.

By MCFD estimates in March 2022, *approximately 24,000-plus children and youth are currently enrolled in the AFP* and *4,700-plus children with significant, complex health disabilities are currently enrolled in the AHP*.[18] All of these children were meant to transition to the FCCs by 2025, along with all CYSN currently served at the CDCs and an *estimated 8,300-plus additional CYSN who are not currently receiving MCFD services but would be eligible for them in the new framework*.[19] However, in the 2022 Budget, no new funding was allocated for the 8,300 additional children during the three-year budget cycle to 2025.[20] Furthermore, following the November 2022 announcement that the millions of dollars currently allocated to the AFP will be maintained in that program indefinitely and will likely increase due to the ongoing inclusion of newly diagnosed cases, those funds are obviously no longer available to support a transformed service delivery system.

In addition, it is important to emphasize that the current CYSN budget does not take into account either existing AFP and AHP funding shortfalls, existing service wait lists at the current CDCs or the lengthy wait lists for diagnostic services available through the health authorities (which have the effect of avoiding or delaying service costs). For example, the School-Age Extended Therapy Service that is part of the AHP sets a maximum of $80/hr for therapy services, but private practice speech-language pathologists (SLPs), occupational therapists (OTs) and physiotherapists (PTs) in B.C. charge ~$125/hr or more. This forces many families to forego essential therapies for their children because they simply cannot afford to "top up" the maximum hourly rate.[21] Regarding wait lists, in 2019 the BC Association for Child Development and Intervention (BCACDI) provided data to the Select Standing Committee on Children and Youth regarding this issue as it pertains to early intervention supports for children under age six at the CDCs. According to this report, the average wait time was, for example, 335 days for speech-language therapy in northern B.C., 180 days for occupational therapy in the Vancouver Coastal region, and 151 days for physiotherapy in the Fraser region.[22] Across the province, the average wait time for speech-language therapy was six months, with waits up to 17 months reported in multiple communities.[23] Thus, during the critical time period that brain science tells us is most likely to significantly impact the trajectory of a child's development, families of young children were waiting up to one year for their child to receive essential therapy supports at the CDCs in 2019; this situation was exacerbated greatly with the onset of COVID-19 in 2020.[24] To compensate, some CDCs have advised the Representative that they have

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[18] *Services for Children and Youth with Support Needs (CYSN) Case Data and Trends:* https://mcfd.gov.bc.ca/reporting/services/children-and-youth-with-support-needs/case-data-and-trends

[19] *Addendum #4 – Questions & Answers, RFP #ON-003774, Children and Youth with Support Needs for Kelowna,* MCFD, June 23, 2022

[20] Budget 2022, Stronger Together: https://www.bcbudget.gov.bc.ca/2022/default.htm

[21] Personal communication, Brenda Lenahan, BC Complex Kids Network, Oct. 31, 2022

[22] BCACDI submission to the Select Standing Committee on Children and Youth, 2019, https://www.leg.bc.ca/content/CommitteeDocuments/41st-parliament/4th-session/cay/submissions/1012-05167.pdf

[23] Health Sciences Association, *Improve Access to Critical Services Provided by Child Development Centres;* https://hsabc.org/sites/default/files/uploads/CL%20Backgrounder%20CDCs%202021.pdf

[24] Representative for Children and Youth (2020). *Left Out: Children and Youth with Special Needs in the Pandemic;* https://rcybc.ca/wp-content/uploads/2020/12/CYSN_Report.pdf

no choice but to offer "watered-down" supports that lack the necessary intensity for effective outcomes. Currently, it is common to observe strategies such as group therapy for a child who requires one-to-one support; a consultative approach to services when an intensive approach is more appropriate; service rationing, whereby a child receives therapy support for a short period of time (e.g., eight weeks) and is then placed back on a wait list until another therapy "slot" is available; and downloading substantial responsibility for intervention onto parents/caregivers who are already overwhelmed with the responsibility of raising their child with disabilities. The bottom line is that funding for the current system is grossly inadequate and will be even more so when an additional 8,300-plus children are eligible for CYSN services.

Unanswered Questions. Without a substantial infusion of new funding, wait lists will be even longer, service quality will be even more compromised, and CYSN and their families will suffer as a result. Perhaps the most important question to be addressed is this one:

- What is the ministry's plan for additional funding, both interim and long-term, to address current funding shortfalls, existing service wait lists, existing service inadequacies (i.e., intensity of service) and the influx of additional CYSN under a future transformed system?

Services Customized to Meet Individual Needs (Intensity, Quality)

Twenty-one of 50 studies (42 per cent) specifically identified the availability of individualized services as a key component of an effective CYSN model, with emphasis on the importance of adequate service intensity and quality. *Intensity* is conceptualized as a function of both service hours per week and service duration; for example, intensity would be identical for a child who receives one hour of therapy per week for 50 weeks and a child who receives two hours of therapy per week for 25 weeks. *Quality* refers to the extent to which there is a "match" between a child or youth's needs and the type(s) of support offered. For example, it is well established that young children with significant speech delays benefit from early access to augmentative communication supports in addition to conventional speech therapy (Light et al., 2019), so adequate service provision would include both.

Intensity. Research on intensity has focused primarily on early intervention therapy services (e.g., from speech-language pathologists and occupational or physio therapists), as well as supports from developmental specialists (in B.C., these include behaviour analysts/consultants and infant development consultants). Numerous research studies examining the relationship between intensity and child outcomes have shown a positive association; that is, *higher intensity intervention equals better child outcomes*. For example, studies have shown this association for:

- Young children with a *developmental delay but no formal diagnosis* who received multidisciplinary therapy services (e.g., speech-language, occupational, and/or physio therapy) and/or developmental specialist supports (McManus et al., 2019; Richardson et al., 2020; Woodman et al., 2018);
- Young children with *autism* who received early intensive behavioural intervention (EIBI) based on the principles of applied behaviour analysis (e.g., Lovaas, 1987; Luiselli et al., 2000; Makrygianni & Reed, 2010; Perry et al., 2011; Virues-Ortega, 2011);

- Young children with *Down syndrome* who received speech-language (Yoder et al., 2014), physiotherapy (Mahoney et al., 2001), or multidisciplinary therapy services (Woodman et al., 2018);
- Young children with *cerebral palsy or other motor delays* who received physiotherapy (Mahoney et al., 2001) or multidisciplinary therapy services (Woodman et al., 2018);
- Young children who were either *pre-term or experienced birth asphyxia* and received home-based services similar to the infant development program in B.C. (Wallander et al. 2014);
- Young children with *speech sound disorder* who received speech-language services (Allen, 2013);
- Young and school-age children with *cleft palate both with and without cleft lip* who received speech-language therapy (Aligheri et al., 2021); and
- School-age children with *developmental language disorder* who received speech-language services (Calder et al., 2021).

In most of the aforementioned studies, child outcomes were measured after one to two years of therapy support. However, in a few studies, outcomes were measured over longer time periods. For example, Clark et al. (2018) found better school-age outcomes for children with autism who received early intervention over a longer period of time (i.e., starting at age 30 months vs. age 42 months); and Farnsworth et al. (2021) found better Kindergarten reading performance for children with a wide range of disabilities who received higher intensity early intervention services. Overall, while some studies have failed to find an intensity effect (e.g., Rogers et al., 2021), the bulk of research has established that children and families who receive more hours of service and/or receive services of longer duration show more progress in child and family outcomes (James, 2022).

Quality. Intensity is not the only factor that matters; many hours of low quality service are likely to yield no better (or worse) outcomes than fewer hours of high quality service. Unfortunately, the impact of service quality on CYSN has been examined less often than intensity, probably because quality is much more difficult to measure. However, there are a few exceptions, both related to services designed for young children with autism. In a Swedish study examining the outcomes of an EIBI program, Långh et al. (2021) found a positive association between intervention quality and children's language and learning skill outcomes. Similarly, Zitter et al. (2021) assessed the quality of delivery of the Early Start Denver Model (ESDM) for young children with autism and found that children whose therapists received higher scores exhibited more appropriate and more frequent learning responses. Studies such as these suggest that intervention quality plays as important a role in achieving optimal child outcomes as does intensity.

Service Intensity and Quality in the MCFD Proposal. In the research on key components for effective service delivery, several factors were identified that contribute to the availability of intervention supports that are of sufficient intensity and quality. Here, "sufficiency" is not a single amount of service (e.g., all children require X hours of Y therapy per week for Z months), nor is it a single indicator of quality. Rather "sufficiency" is appropriately determined on an individual basis, depending on child and family need. Thus, some type of assessment is first required in order to determine appropriate service type (i.e., for ***this*** child and ***this*** family, what type(s) of service support is/are needed?) and intensity (i.e., for ***this*** child and ***this*** family, how many hours per week/month will be required?). Following assessment, the system then requires: (a) a therapy workforce of the *appropriate size* to deliver services without the need for lengthy wait times; and (b) a therapy workforce with *appropriate education and experience* to support the clients who are served.

In the four pilot FCCs, clinical assessments to determine the type and amount of each service will be conducted by therapy staff, "using a variety of assessment approaches and tools" [9] (p. 7). Decisions about therapy types(s) and amount(s) will then be based on "the clinical judgement of professionals within the centre" (p. 8) and will, of necessity, be constrained by workforce availability. Thus, a child who is found to require one hour/week of individual speech-language therapy, one hour/week of individual occupational therapy, and ongoing support from a behaviour analyst to remediate distressed behaviour will not receive those supports if sufficient staff are not available to deliver them. This is alluded to in a statement describing service planning for children who are eligible for Disability Services: "The CYSN worker will prioritize services for the family *within the context of available resources and information gathered in the PST* (Prioritization for Services Tool)" [10] (p. 5; italics mine). In addition, in the pilot site RFPs issued in May 2022, alternatives to 1:1 therapy supports were explicitly encouraged in a section entitled Caseloads: "The Contractor will provide or deliver … the Services as described in the Contract … *with the aim for cases per therapist to align with a shift away from the concept of 1:1 intervention as the only option through maintaining caseload numbers* as per relevant professional practice guidelines …" [13] (p. 6; italics mine). A website search failed to locate "relevant professional practice guidelines" for therapy caseloads for any of the therapy professions in B.C. However, Therapy BC provides a series of workload management tools on its website[25] for use across the professions, suggesting that caseload concerns in B.C. are ubiquitous. The RFPs also encouraged *"utilization of 'behaviour interventionists' and 'therapy assistants' and the use of the Transdisciplinary Models [sic] and group programs"*[13] (p. 6; italics mine) as alternatives to 1:1 therapies. Basically, what this means is that staff with less training and less experience than professional therapists, most of whom have graduate degrees, will provide at least some of the support services that are required. How therapy service quality will be maintained at the pilot FCCs under these circumstances is unclear.

Three recent surveys conducted in B.C. are also illuminating with regard to current service intensity and quality. These surveys provide relevant information that should be considered during the forthcoming consultative process related to planning a transformed service system. The first, conducted by Down Syndrome BC, focused on parents'/caregivers' experiences with the current MCFD service delivery system[26] and found that:

- Around 34 per cent of 75 respondents reported that they *waited more than three months* to access speech therapy and/occupational therapy services for their child;
- 83 per cent indicated that *service intensity was inadequate*, even when it became available; specifically,
    - 76 per cent answered "no" for speech therapy adequacy;
    - 67 per cent answered "no" for occupational therapy adequacy;
    - 67 per cent answered "no" for physiotherapy adequacy; and
- Regarding service quality, 62 per cent of respondents of children ages 0 to 5 and 77 per cent of school-age children said *services currently available through the public system are only adequate or poor*.

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[25] Therapy BC Workload Management; https://therapybc.ca/workload-management/

[26] *Understanding Common Experiences for Families of Individuals with Down Syndrome in British Columbia: Access to Services and Support;* https://static1.squarespace.com/static/5f91ec6bf050df2a75b0ce91/t/6334c611d9865c4a3b57665f/1664402961853/Access+to+Survey+Report+FINAL.pdf

The implications of these results are that parents/caregivers of children with Down syndrome believe that: (a) the current therapy workforce is inadequate, resulting in long wait lists and insufficient therapy intensity; and (b) the current quality of public system therapy services for children with Down syndrome is marginal, at best.

A second survey was conducted by the Autism Society of BC[27] and was completed by 1,563 parents/caregivers, 96 per cent of whom reported that they currently receive AFP funds. This survey focused primarily on respondents' opinions about the new CYSN framework and proposed FCC model as described in public documents circulated by MCFD, and found that:

- Only four per cent of respondents (and only two per cent of Indigenous respondents) supported the FCCs as a sole service delivery model; the other 96 per cent (98 per cent Indigenous) *wanted individualized funding (IF) for autism to remain as at least an option*;
- More than half (52 per cent) expressed *concern about current workforce adequacy* at the FCCs (e.g., "It is already very hard to find therapists …, usually they have a very long waiting list. It took us a year to find one SLP; how can the government guarantee our child can receive the service?");
- 68 per cent of respondents expressed *concern about the needs assessment process* that will determine service eligibility at pilot FCCs;
- 73 per cent of respondents were *concerned about adequate service intensity* at the FCCs; and
- 71 per cent of respondents were *concerned about the quality of services* that would be available at the FCCs (e.g., "Too many children to serve; [and] not enough funding, therapists or physical spaces to provide adequate and meaningful therapy services").

The take-home message from this survey was that parents/caregivers of children/youth with autism across the province had significant concerns about both service intensity and quality, based on their experiences with the current public system. These survey results and accompanying advocacy contributed to the November 2022 government announcement that individualized funding for autism services would be maintained. The survey also highlighted the critical need for strategies aimed at recruitment and retention of SLPs, OTs, PTs, BCBAs, infant development consultants, and other therapy staff, to address staff shortfalls across the system.

Where will these additional professionals come from? Prior to government's November 2022 announcement, one source of additional staffing might have been private practice therapists listed on the Registry of Autism Service Providers (RASP), who are funded through the AFP. MCFD likely assumed that the majority of these individuals would simply shift their employment to join an FCC when the AFP was discontinued in 2025; however, now that the AFP has been retained, this is no longer an option and will likely create a competitive marketplace between FCCs and AFP-funded families for already scarcely available professionals. In fact, results of a third survey, conducted prior to the "pause" announcement, by researchers at Simon Fraser University (SFU) in collaboration with ACT-Autism Community Training, suggest that this was *never* a viable option.[28] This survey was designed to (a) assess the availability of RASP professionals to provide services and supports within the FCCs; and (b) evaluate

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[27] *Parent and Caregiver Perspectives on the Family Connections Centres: Autism BC Survey Results:* https://www.autismbc.ca/fccreport/

[28] *Implementing the Family Connections Centres in British Columbia: Perspectives of Professionals on the Registry of Autism Service Providers* (Fong, Iarocci, & Pugh, 2022); https://www.actcommunity.ca/wp-content/uploads/2022/09/RASP-Perspectives-2022.pdf

the perspectives of RASP professionals regarding plans to end the AFP. Respondents were 485 BCBAs/behaviour consultants, SLPs, OTs, and PTs who work with children with autism; 68 per cent reported that they also work with children with ADHD, 49 per cent with children with Down syndrome, and 45 per cent with children with FASD. Among other things, results indicated that:

- *Current wait lists* for the services provided by respondents ranged from 2.6 months (PTs) to six months (SLPs);
- 37 per cent of respondents reported that they were unlikely/very unlikely to work for an FCC and an additional 42 per cent responded that they did not have enough information to decide; thus, *79 per cent had no plans prior to the pause announcement to work at an FCC*;
- 63 per cent *disagreed/strongly disagreed that adequate levels of high quality therapy* would be available to all children with a range of neurodevelopmental and physical conditions at the FCCs; and
- 75 per cent of respondents *agreed/strongly agreed that the quality of care at the FCCs would be compromised*.

The survey report concluded that: “It is difficult to see how it is possible for this initiative, which entails a radical restructuring of therapy and supports for an undetermined number of developmentally disabled children, can be successful given the shortage of sufficient staff, the absence of committed funding, the lack of a detailed implementation plan, and widespread opposition from clinicians” (p. 24).

Unanswered Questions. Regardless of the design of a transformed CYSN system, the first priority for families is that their child or youth receive quality services of sufficient intensity (i.e., frequency, duration). This requires sufficient funding, as noted in the previous section, and a workforce of adequate size with adequate training. Several questions remain:

- How will the pilot FCCs recruit qualified staff to fulfill their mandate to provide “one-stop” services of sufficient intensity and quality?
- In a transformed system, how will MCFD ensure that therapy supports will be of *sufficient intensity* to meet the individual needs of CYSN?
- In a transformed system, how will MCFD ensure that therapy supports will be of *sufficient quality* to meet the individual needs of CYSN?
- Given current therapy workforce shortages, how will MCFD ensure that the workforce in a transformed system will be adequate to meet the needs of CYSN and their families?
- Since progress during an intervention plan is directly associated with adequate service intensity and quality, lack of progress often indicates a need for more and/or different services. How will children’s progress during intervention be evaluated on an ongoing basis?

Staff Training Related to the Model

Twenty-two studies (43 per cent) identified staff training as an essential component whenever substantial changes are made to an existing service delivery model. This component will be especially important at the four pilot FCCs, all of which will provide services and supports to some CYSN that are new to the operators. From an administrative perspective, training will be required to teach staff how to use new information-sharing technologies (e.g., the IMIT system) and other planning systems. Staff will also require ongoing training in the provision of anti-racism, culturally safe, and trauma-informed practices. Therapists who are expected to work with therapy assistants and have no experience doing so will need to familiarize themselves with strategies to train, mentor, supervise and evaluate their performance. Training must also be available for staff who have little or no experience with the specific challenges and learning needs of CYSN who are newly eligible for services at a pilot FCC. For example, therapists at an FCC that previously supported children up to age six will now be expected to support older CYSN as well. And, needless to say, a 10-year-old child with cerebral palsy has dramatically different therapy needs than a 10-year-old child with FASD, mental health concerns, or…any other disability that can be named. Care coordinators will require training related to their record-keeping responsibilities, administration and scoring of the assessment tools that will be used to determine Disability Services eligibility (assuming this requirement is maintained), and the interpersonal aspects of their role. In particular, one of the key skills required of care coordinators is cultural competency,[14] particularly when supporting new and first-generation immigrant families. Such families may harbour feelings of shame or guilt on behalf of their disabled child, may be uncomfortable when asked to collaborate with service providers who they perceive as experts, and/or may be reluctant to participate in therapy interventions (Fellin et al., 2013; Fong et al., 2021; Nicholas et al., 2017; Xu et al., 2022). Care coordinators who aspire to offer family-centred care will require training about these and other cultural differences (e.g., the secondary role of women as decision-makers in some cultures) and how to accommodate them. Conversely, families of CYSN will also benefit from training on care coordination that is aimed at orienting them to the various parameters involved (e.g., their role and the role of the care coordinator, key members of their child's care team, goal-setting within the care plan; Ufer et al., 2018).

Staff Training in the MCFD Proposal. Aside from staff training related to anti-racism, culturally safety, and trauma-informed practices, there was no specific provision for staff training in the RFPs,[13] nor was staff training mentioned specifically in the weighted criteria used to adjudicate the RFPs. Presumably, training was subsumed under the approach for "Culturally Safe and Trauma-Informed" services (weight: 4.5 per cent) and perhaps under "Staffing Model" (weight: 6 per cent). However, in the RFP for Kelowna, the largest city in the B.C. Interior, the ministry-assigned benchmark cost allocated for staff training was $1,100 per month for all of the staff at the successful agency (Appendix F)[29] – hardly sufficient to accomplish the broad training needs that will be essential at the FCC located there. Given this, either (a) staff training is likely to be inadequate; or (b) time for staff training will be eked out of funds and staff time that should be devoted to the delivery of services to CYSN and their families. Neither option reflects the importance of staff training that was prevalent in the research on service delivery. In the end, this is likely to result in the delivery of generic rather than individualized and tailored service supports to a wide range of CYSN.

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[29] Ministry of Children and Family Development, Request for Proposals (RFP) – Children and Youth with Support Needs for Kelowna, Appendix F: Payment template.

Unanswered Questions. The pilot FCCs are faced with multiple tasks, all of which are supposed to be accomplished by spring 2023. These tasks will require training of new and existing staff to ensure their ability to support CYSN with a wide range of needs and across a wide age range (0-18). Questions to be addressed include:

- How will the training needs of FCC staff be assessed and costed?
- How will the FCCs secure and allocate adequate funding for staff training? Who will deliver this training? How will it be delivered to meet the spring 2023 timeline?
- What training will be provided to ensure that staff are familiar with the specific learning needs of CYSN across the range of age and ability?
- What training will be required to ensure that staff can understand and support new and first-generation immigrant families whose child-rearing practices may not align with mainstream Canadian values and practices?
- What training will be provided to support anti-racism, cultural safety and trauma-informed care, particularly for Indigenous and new immigrant families?
- How will staff training be evaluated on an ongoing basis so that adjustments can be made if it is found to be lacking?

ADDITIONAL KEY COMPONENTS FOR EFFECTIVE CYSN SERVICES RELATED TO MENTAL HEALTH

RCY has a long history of concern about the availability and quality (or lack thereof) of mental health services for children and youth in B.C., as reflected in multiple reports:

1. *Still Waiting: First-Hand Experiences with Youth Mental Health Services in B.C.* (2013)
2. *Paige's Story: Abuse, Indifference and a Young Life Discarded* (2015)
3. *A Tragedy in Waiting: How B.C.'s Mental Health System Failed One First Nations Youth* (2016)
4. *Missing Pieces: Joshua's Story* (2017)
5. *Broken Promises: Alex's Story* (2017)
6. *Time to Listen: Youth Voices on Substance Use* (2018)
7. *Detained: Rights of Children and Youth Under the Mental Health Act* (2021), *and*
8. *Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families* (2021).

Two additional components were identified as key components for effective mental health service delivery in the 14 research studies on that topic included in this review: Wraparound services and ease of referral and access. Both components are discussed in this section.

Wraparound

This component was mentioned in the previous section on Cross-Sector Collaboration and Connections to Community Resources but will be reviewed in more detail here because it was mentioned in 79 per cent of the studies on mental health service delivery included in this review. Wraparound is an intensive, structured process that convenes a team of youth, parents/caregivers, and family members, along with professionals and natural supports relevant to a youth with mental health needs and their family. This "Wraparound team" develops, implements, and monitors success of an individualized plan of care based on the youth's and family's underlying needs and perspective. A Wraparound care coordinator with a low caseload (e.g., eight to 12 families at a time) facilitates this process and directs its four phases: engagement, plan development, implementation and transition. Within these four phases, evidence-informed elements of Wraparound are undertaken, including:

(a) engaging the youth and family,
(b) identifying and overcoming barriers,
(c) building team morale and cohesion,
(d) selecting, implementing, and monitoring evidence-based strategies and services,
(e) identifying and engaging social supports for the youth and family, and
(f) using routine monitoring of outcomes and processes to direct changes to the plan of care and to facilitate transition.

It is important to emphasize that Wrapround is neither an ideal nor a concept; it is a *service delivery process*. Thus, simply calling something "wraparound" is insufficient; true Wraparound supports have several key elements that can be observed and measured with instruments such as the Wrapround Fidelity Index (Bruns, Suter, & Leverentz-Brady, 2008). Authentic Wraparound services include family voice and choice, natural supports, and collaboration; and are community-based, culturally competent, strengths-based, persistent, and outcomes-based (Pullman, Bruns, & Sather, 2013). In a recent meta-analysis of 17 research studies on Wraparound, Olson et al. (2021) found that this approach, which is currently implemented in most of the U.S., is "associated with small but significant positive effects on a range of behavioral health outcomes while also serving as a less expensive alternative to [treatment as usual]" (p. 1363). The importance of Wraparound was also underlined in an article that examined factors that contributed to family involvement in mental health treatment and care (Mayberry & Heflinger, 2012). The authors found that "when children were served in ways that demonstrated higher access to an array of service, higher levels of service coordination, more individualized service delivery and with a long-term perspective on treatment needs and goals, their families were more likely to be involved in treatment" (p. 271).

Family mental health supports. Family-level mental health supports are also important. Numerous studies have documented the impact of raising a child or youth with support needs on family stress and mental health. In a review of research across 11 countries, Scherer et al. (2019) found consistent increases in anxiety and depression for parents/caregivers of children with intellectual/developmental disabilities (IDD), especially those with more severely disabled children and those with lower household incomes. A more recent review of research across 13 countries found similar results, in addition to significantly increased parent/caregiver stress (Rydzewska et al., 2021). Overall, the evidence of health and well-being disparity in parents/caregivers of CYSN is irrefutable, indicating the need for supports and interventions that can ameliorate stress and support overall health, mental health, and well-being (Bourke-Taylor et al., 2021).

Wraparound in the MCFD Proposal. It is important to first contextualize the current service delivery system in B.C. for CYSN who require mental health supports. In the 2021/22 fiscal year, 29,966 children and youth received mental health services through MCFD's CYMH programs.[30] On average, these individuals waited 68 days from the time of referral to first service, with a range of 29 days (northwest region) to 143 days (north central region).[31] The three most frequent presenting issues were fears or anxieties (70.3 per cent), depressed mood (48.2 per cent), and suicidal thoughts (25.3 per cent).[30] These statistics do not identify children and youth with co-occurring mental health concerns and IDD, whose estimated prevalence in B.C. was 39 per cent (i.e., 3,575 individuals) in 2017[32] and has certainly increased since that time as a result of the COVID-19 pandemic.[24] Individuals with such "dual diagnoses" typically present with complex and persistent externalizing behaviours such as aggression, self-injury and property destruction and/or with psychiatric disorders that include depression, anxiety and substance abuse disorders (Constantino et al. 2020). Currently, dually diagnosed youth between ages 14 and 19 with "severe" mental health or behavioural challenges can access multidisciplinary supports from

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[30] https://mcfd.gov.bc.ca/reporting/services/child-and-youth-mental-health/case-data-and-trends, November 23, 2002

[31] https://mcfd.gov.bc.ca/reporting/services/child-and-youth-mental-health/performance-indicators, November 23, 2022

[32] Byrne, C., Hurley, A., & James, R. (2007). *Planning guidelines for mental health and addiction services for children, youth and adults with developmental disability*. Victoria, BC: Mental Health and Addictions Branch. https://www.health.gov.bc.ca/library/publications/year/2007/MHA_Developmental_Disability_Planning_Guidelines.pdf

Developmental Disabilities Mental Health Services (DDMHS) in the five health regions.[33] However, families of children and youth under age 14 and those with "less-than-severe" behavioural concerns must navigate a patchwork of services offered through the Ministries of Health, Mental Health and Addictions, and MCFD, as there is no coherent service delivery pathway designed to support them.

A 2019 plan entitled *A Pathway to Hope* developed by MMHA identified the establishment of Integrated Child and Youth (ICY) teams in school districts across the province as a "priority action."[34] From the description provided, these teams will be modelled after the Wraparound process. The RFPs for the pilot FCCs stated that,

> "Clinical mental health professionals providing service to children and youth out of the FCC will work as part of a collaborative team that includes staff at the FCC, the local *integrated child and youth team* (italics mine), and other teams in the community. Services may be delivered onsite, through outreach, virtual and/or via outbound support."[13] (p. 8).

From this description, it appeared that provisions had been made for staff from local integrated child and youth teams (ICYs) and/or MCFD's Child and Youth Mental Health teams to work within the FCCs to deliver mental health services. However, no mention of the CYSN framework or of collaboration with MCFD service providers (e.g., social workers, child care workers) was evident in a subsequent 2021 *A Pathway to Hope Progress Report*,[35] which stated that the ICY teams would "work … closely with schools, early years services, and primary care" (i.e., through the Ministries of Education and Health) and would include core team members consisting of "child and youth mental health clinicians, youth substance use clinicians, education counsellors, youth and family peer support workers, Indigenous positions, and ICY Program Leaders" (p. 7). The Progress Report also stated that ICY teams would be established in a total of only 20 (out of 60) school districts by the end of 2024 (p. 8). This means that ICY teams will not be available in the vast majority of communities until after 2024. Moreover, an ICY team is currently established in only one of the four FCC pilot sites.[36] There is also no mention of services that will be available to CYSN with dual diagnoses, who are perhaps the most underserved group at the current time. Altogether, it appears that there is no coherent plan between MCFD, MMHA or any other ministry for the delivery of coordinated, integrated, Wraparound mental health services for CYSN across the province.

Family mental health supports. As noted previously, family-level supports aimed at decreased parent/caregiver stress and enhancing mental health and well-being are also key components of a family-centred service delivery system such as the one envisioned by MCFD. However, a full suite of supports (which includes support planning, respite care, parenting and professional supports, youth transition planning, and supports for children and youth in care) will only be available to families at the pilot FCCs whose children/youth are eligible for Disability Services, as described in the section on cross-sector collaboration. This is deeply problematic, as numerous studies have demonstrated the positive impact

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[33] Representative for Children and Youth (2021). *Excluded; Increasing Understanding, Support, and Inclusion of Children with FASD and Their Families*. https://rcybc.ca/wp-content/uploads/2021/06/RCY-FASD_Report_FINAL_REVISED_21-JUNE-2021_Web.pdf

[34] *A Pathway to Hope: A Roadmap for Making Mental Health and Addictions Care Better for People in British Columbia*; https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/initiatives-plans-strategies/mental-health-and-addictions-strategy/bcmentalhealthroadmap_2019web-5.pdf

[35] *A Pathway to Hope Progress Report*; https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/ministries/mental-health-addictions/pathway_to_hope_update_report_final.pdf

[36] An ICY site has been established in the Coast Mountain school district; https://www2.gov.bc.ca/gov/content/governments/about-the-bc-government/mental-health-and-addictions-strategy/integrated-child-youth-teams

of both parent/caregiver-focused interventions (Bourke-Taylor et al., 2021) and general family supports on family mental health.

Respite care is a prime example of a family-level support that should be available to all (Robertson et al. 2011) – but in the pilot FCCs, only those families whose children have moderate to severe support needs are currently eligible for it. Respite care involves the temporary care of an individual with a disability for the purpose of providing relief to the parent/caregiver. It can be either formal (i.e., provided by licensed, trained providers) or informal (i.e., provided by relatives or family friends). Typically, families use respite care either to respond to family crises or emergencies or to enable participation in routine activities without caregiving responsibility for the disabled child. The research on respite care in general has shown numerous benefits. For example:

- *At-risk families of children with developmental disabilities* experienced decreased parent/caregiver stress following respite, resulting in a decreased risk for the development of dysfunctional parental/caregiver behaviour (Cowen & Reed, 2002);
- *Immigrant mothers in Canada* endorsed even short-term respite care as important: “Yes, you’re alone, but you can get a friend to sit … for two hours, just go and do what you like … You’ll feel good … You come back and you can face anything then … for [your] sanity” (South Asian woman, Stewart et al., 2006, p. 336);
- *Single mothers of children with autism*, most of whom were at risk for clinical depression, experienced more positive appraisals of daily events and had fewer depressive symptoms following respite (Dyches et al., 2016);
- Respite was directly associated with marital quality for *parents/caregivers of children with autism* and indirectly associated with marital quality for *parent/caregivers of children with Down syndrome*, with reduced individual stress (Easler et al., 2022);
- *Foster, adoptive, and kinship parents/caregivers caring for a child involved in the child welfare system* reported that family stability was better after they began to receive respite care and that such care positively impacted their lives (Madden et al. 2016);
- *Parents/caregivers of children with complex medical needs* reported significant emotional and physical relief among the entire family, including siblings, with many parents/caregivers describing respite as an essential service (Edelstein et al., 2016; Welsh et al., 2014);
- *Parents/caregivers and siblings of children with severe and challenging behaviours* reported substantive benefits for the children, their siblings, and themselves: “The stress level builds up and builds up and you just explode. It did when I first started respite – then it started to go down” (McConkey et al. 2013, p. 280);
- For *siblings*, respite care ameliorated some of the negative impacts and promoted many of the positive impacts of having a disabled brother or sister (Welch et al. 2012, 2014). For example, one parent noted: “ … without regular breaks, I am sure the entire family would find the day-to-day stress impossible to cope with, and I am certain the other children would end up with ‘issues’ if they never had the chance to be put first” (Welch et al., 2012, p. 455);
- Parents/caregivers reported that respite care provided an opportunity for their *disabled youth* to develop independence and their own interests: “Respite is good for … just doing all that stuff that children do, or teenagers do, without their mother around” (Welsh et al., 2014, p. 101).

In contrast to these and other reports, a family that now relies on one weekend per month of respite to maintain family equilibrium may not be eligible because their child is deemed ineligible. While a child may not have moderate to significant functional needs, their *family's* needs may be significant due to factors such as income or housing insecurity; mental health or substance use support needs; newcomer status; and/or isolation or disconnection from extended family members, cultural supports, and or community relationships. In the absence of respite supports, the vulnerability of families with such challenges is heightened considerably and places them and their children at risk. In short, the notion that assessing the *child's* functional needs to determine if their *family* requires respite care is simply nonsensical. For example, a child might have fewer functional needs at least in part *because* their family has access to respite – so denying that access could then result in increased need. The same logic applies to the other supports in the Disability Services cluster – parenting supports (e.g., counselling, parent/caregiver education, transportation assistance), specialist professional services, and planning for youth transitioning to adult services. In a system committed to service quality, why should these services be provided only to eligible CYSN, when they are designed primarily to support both CYSN *and their families*?

Unanswered Questions. The January 2023 announcement of the four pilot FCC operators referred to the availability of a "wraparound care plan, which could include behaviour supports, physiotherapy, speech and occupational therapy, inclusive child care supports, child and youth care workers, family support, and education, as well as other important supports." [4] However, as noted previously, true Wraparound is more than an array of services; it is a specific *process* of service delivery that requires staff training and support as well as adequate funding. Thus, questions remain about the availability of authentic Wraparound services in the pilot FCCs and in a transformed CYSN system of the future:

- What arrangements will be made between MCFD, MMHA, MoH, health authorities and other ministries for the delivery of coordinated, integrated, Wraparound mental health services across the province?
- Will family-focused mental health supports such as respite care and parent/caregiver education/counselling be available to all families or will the current, restrictive eligibility requirements be maintained?
- Will planning for the transition to adult services be available to all CYSN and their families or will the current, restrictive eligibility requirements be maintained?
- How will CYSN with co-occurring neurodevelopmental and mental health conditions or with dual diagnoses across the age range be supported in the four pilot FCCs and in the future?
- How will the effectiveness of mental health services for both CYSN and their families be evaluated?
- How will the mental health services offered at the pilot FCCs be evaluated with regard to both integrity with Wraparound principles and meaningful outcomes for CYSN and their families?

Ease of Referral and Access

More than half of the mental health-focused studies reviewed (57 per cent) also identified the importance of an easy referral process and easy/immediate access to mental health services, given that the need for such services is often urgent. Examples of this urgency in B.C. include:

- Between 2020 and September 2022, 72 children and youth under age 19 died from illicit drug toxicity;[37]
- Between 2019 and December 2021, 62 children and youth under age 19 died from suicide;[38] and
- In the decade from 2008/09 to 2017/18, 17,054 children and youth under age 19 were involuntarily admitted to hospital for mental health treatment and an additional 13,241 were admitted voluntarily.[39]

These statistics reinforce the urgency of what some research refers to as a "no wrong door" policy wherein "services must be available to all youth, regardless of the particular system in which their needs are identified" (Miller et al., 2012, p. 573). In order to achieve this, all "child-serving systems" – youth justice, mental health, child welfare/protection, disability services and supports, and education – must collaborate and share responsibility for these services.

Ease of Referral and Access in the MCFD Proposal. An MCFD document describing FCC services states that "Mental health *supports* are provided as part of Family Supports, Behaviour Supports, and Education Services offered by [FCC] staff" and that "Clinical Mental Health *Services may be available for eligible* children and youth at the centre"[9] (p. 11; italics mine). The distinction made between *supports* and *services* is unclear; however, it seems that access to professional mental health *services* will be subject to eligibility criteria – perhaps those used to determine if a child qualifies for Disability Services, which are quite restrictive. Thus, it is questionable whether ease of referral and access in line with a "no wrong door" policy at the four FCCs will be available for CYSN with mental health concerns and/or dual diagnoses.

Unanswered Questions. Moving forward, during the pilot FCC roll-out and as part of the system transformation process, questions such as the following must be addressed:

- What specific provisions will be made at the pilot FCCs to implement a "no wrong door" mental health policy?
- How will ease of access to mental health services be ensured in a transformed system of care in the future?

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[37] BC Coroners Service, *Illicit Drug Toxicity Deaths in BC*, January 1, 2012 – September 30, 2022 https://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/coroners-service/statistical/illicit-drug.pdf

[38] BC Coroners Service, *Suicide Knowledge Update*, December 2021; https://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/coroners-service/statistical/suicide_knowledge_update.pdf

[39] Representative for Children and Youth (2021). *Detained: Rights of Children Under the Mental Health Act*; https://rcybc.ca/wp-content/uploads/2021/01/RCY_Detained-Jan2021.FINAL_.pdf

ADDITIONAL KEY COMPONENTS FOR EFFECTIVE CYSN SERVICES FOR INDIGENOUS CHILDREN AND FAMILIES

RCY has a long history of concern about the services provided to First Nations, Métis, Inuit and Urban Indigenous children and youth in B.C., as reflected in multiple reports, some of which also addressed mental health concerns and were referenced in the previous section. These reports include:

1. *Paige's Story: Abuse, Indifference and a Young Life Discarded* (2015);
2. *A Tragedy in Waiting: How B.C.'s Mental Health System Failed One First Nations Youth* (2016);
3. *Broken Promises: Alex's Story* (2017);
4. *Alone and Afraid: Lessons Learned from the Ordeal of a Child with Special Needs and His Family* (2018);
5. *Caught in the Middle* (2019);
6. *Invisible Children: A Descriptive Analysis of Injury and Death Reports for Métis Children and Youth in British Columbia, 2015 to 2017* (2020):
7. *Illuminating Service Experience: A Descriptive Analysis of Injury and Death Reports for First Nations Children and Youth in B.C., 2015 to 2017* (2020);
8. *Skye's Legacy: A Focus on Belonging* (2021); and
9. *At a Crossroads: The Roadmap from Fiscal Discrimination to Equity in Indigenous Child Welfare* (2022).

In addition to the key components identified in previous sections of this review, two additional components for effective service delivery to Indigenous CYSN and their families were identified in more than half of the 15 Indigenous-focussed research studies that were reviewed.

Embed Indigenous Culture, Values, and Practices; "Two-Eyed Seeing"

Thirteen of 15 studies (87 per cent) emphasized the importance of embedding Indigenous culture, values and practices in the delivery of services to Indigenous CYSN and their families. In this regard, some studies explicitly identified an approach called "Two-Eyed Seeing" that was created by honoured Mi'kmaq Elders Albert and Murdena Marshall. This approach is based on the idea that "one can learn to take the perspective of seeing from one eye the strengths of Indigenous ways of knowing, and from the other eye, the strengths of Western ways of knowing, and to use both of these perspectives for the benefit of those being served" (Hutt-MacLeod et al., 2019, p. 43). Many elements were included as examples of the principle of embedding Indigenous ways of knowing, being, and doing in service delivery, including:

- Providing Indigenous-run services or, at a minimum, recruiting Indigenous professionals as paid service providers (i.e., executive leaders, managers, administrative staff, therapists, etc.);
- Allowing sufficient time to build trust and establish relationships with Indigenous families prior to conducting assessments and/or developing treatment plans;
- Involving Elders/knowledge keepers and traditional healers in setting goals and providing intervention supports; and

- Integrating traditional medicines, ceremonies, smudging, and other Indigenous practices into treatment plans.

These elements are in addition to ongoing staff training on anti-racism, cultural safety and humility, trauma-informed practice and reconciliation practices. The literature on this topic emphasizes that the "embedding actions" should be substantive rather than simply performative and, in a mainstream system, should be components of service delivery for all CYSN and families, not just those who are Indigenous.

Embedding Indigenous Culture, Values and Practices in the MCFD Proposal. Appendix G of the RFPs for the pilot FCCs required anti-racism and Indigenous cultural safety plans as part of the application.[12] In the anti-racism plan, applicants were asked to describe, for example:

(a) how the organization plans to reduce biases and discrimination within CYSN services accessed by Indigenous, Black and People of Colour (IBPOC) communities;

(b) policies that support the hiring and retention of IBPOC staff; and

(c) how the organization will enable and respond to feedback from IBPOC families about barriers to accessing services.

In the cultural safety plan, applicants were asked to describe, for example:

(a) the types of relationships already established with Indigenous and First Nations communities;

(b) the organization's ongoing and planned activities related to staff knowledge and understanding of racism, colonization and reconciliation;

(c) practices that reflect the organization's Indigenous cultural competence; and

(d) policies that support the hiring and retention of Indigenous employees and/or Elder/knowledge keeper positions.

Thus, there was a focus in the RFP on Indigenous-focused policies, procedures, staff training and hiring practices. However, there was no evidence of *provision for Two-Eyed Seeing or for meaningfully embedding Indigenous culture, values, and practices in the delivery of services*.

Six months after MCFD announced the now-paused framework, the First Nations Leadership Council (FNLC) wrote to MCFD Minister Mitzi Dean,[40] calling the model "potentially racist and discriminatory" and demanded "that if, as you say, you are 'committed to building a better future for families and children and youth with special needs,' you must stop the planned roll-out of your planned "hub" model … Such a system will never come into being by causing trauma and conflict, or the violation of basic human rights standards of Indigenous peoples …" Seven months later, having had no meaningful response from MCFD to the FNLC's letter, the Union of BC Indian Chiefs (UBCIC) issued a resolution[41] noting that "efforts by MCFD to further centralize and control services for First Nations children is a continuation of the colonial practices that have proved harmful to our children, youth and families" (p. 2). They called for continuation of "the current service and funding model for children and youth with disabilities that includes individualized funding supports" while the FCCs are explored as

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[40] First Nations Leadership Council letter, Nov. 19, 2021; https://www.actcommunity.ca/wp-content/uploads/2021/11/Letter-to-Minister-Dean-from-First-Nations-Leadership-Council-002.pdf

[41] Union of BC Indian Chiefs Resolution No. 2022-24, June 2-3, 2022; https://assets.nationbuilder.com/ubcic/pages/4608/attachments/original/1663187481/UBCIC_CC06_22_Resolution2022-24_CYSNFunding.pdf?1663187481

"part of expansion of existing services rather than replacing existing services." The fundamental reasons for these two outright rejections? The FNLC letter described the FCC model as "removing existing opportunities for individualized, culturally appropriate, or diverse community integrated services, and replacing it with the expectation that Indigenous children and families seek out services through … MCFD controlled 'hubs.' First Nations feel vulnerable to having child protection reports and removals whenever they attend to your office or 'hubs'… Hub models have failed and traumatized our people [and] are not rights compliant …" (p. 2).

Following these scathing reviews, MCFD announced a series of engagement sessions with First Nation, Métis and Urban Indigenous service providers and communities and rights' holders on the best path forward for services for Indigenous children and youth with support needs."[42] The sessions commenced in November 2022 and include sharing circles, surveys and interviews that are being led by an Indigenous consulting group. Results of this consultative process are pending and a "restructured engagement approach with First Nations and partners" is scheduled to take place in early 2023.[43]

Unanswered Questions. The overwhelmingly negative reaction of the FNLC to the planned provincial roll-out of FCCs undoubtedly played an important role in the November 2022 "pause" announcement. As planning for a transformed system moves forward, fundamental questions such as the following must be addressed:

- How will MCFD work with First Nations, Métis, Inuit and Urban Indigenous leaders regarding the design and governance of CYSN services?
- To what extent will services for Indigenous CYSN be designed and administered in Indigenous communities and by Indigenous staff?
- What specific provisions will be made for Two-Eyed Seeing and for meaningfully embedding Indigenous culture, values and practices in the delivery of services for all CYSN and their families, both in the pilot FCCs and in a transformed CYSN system?

Support the Whole Family

Indigenous families are pivotal to the well-being of Indigenous communities and to their culture and survival.[7] Thus, it is not surprising that 10 of 15 Indigenous studies (67 per cent) emphasized the need to provide supports for the whole family, not just the child or youth with support needs. This component was described to some extent in the general service delivery section but bears repeating here because it was so prevalent in the Indigenous literature. For example, in a study that focused on the Aboriginal Infant Development Program (AIDP) in B.C., a service provider described how families' initial engagement in the program was frequently fostered by a pragmatic approach focused on addressing family social determinants of health and well-being, especially food and housing security (Ball, 2005). As one AIDP worker reflected: "Does the child really need to learn this puzzle right now or do I need to look at the fact that mom is barely feeding herself?" (Gerlach, 2017, p. 1768). By offering supports for the family as a whole, service providers acknowledge the pivotal role that families play in defining Indigenous identity and a sense of connectedness to kinship and culture.

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[42] CYSN Engagement Updates; https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/cysn-engagement-updates

Support for the Whole Family in the MCFD Proposal. Two types of family support will be provided in the four pilot FCCs. The first type, available to all families who receive services, will be delivered by "family support workers" and is designed to "assist families experiencing vulnerabilities to access the culturally safe help and services they need when they need it. Family support workers help identify and remove barriers to accessing and receiving services …[and] may also be involved in coordinating and delivering other services"[9] (p. 10). However, as noted in a previous section, the type(s) of supports that will be available and the extent to which cross-ministry collaboration will be involved are both unclear. For example, if a family requires support related to housing, or food insecurity, or employment, it is not clear if the family support worker will be able to provide assistance in these domains.

As it now stands, a second cluster of supports will be provided by the pilot FCCs only to those families whose children are eligible for Disability Services.[10] As a reminder, these are children and youth with moderate or significant limitations in adaptive functioning and a prolonged disability that impacts their participation in activities of daily living (e.g., eating, dressing), mobility, and/or social engagement and inclusion; thus, children who have relatively "mild" disabilities may not be eligible. Those who *are* eligible can receive support planning from a CYSN worker, respite care, parenting supports (e.g., counselling, parent/caregiver education, transportation assistance), specialist professional services (e.g., for distressed behaviour), and planning for youth transitioning to adult services.

As noted in previous sections of this report, there are several problems with the Disability Services approach, not just for Indigenous families but for *all* families connected to an FCC. The first pertains to how Disability Service eligibility will be determined at the four pilot FCC sites. The assessment tools that will be used for this purpose include:

(a) the Pediatric Evaluation of Disability Inventory-Computer Adaptive Test (PEDI-CAT) for children with physical support needs;

(b) the Vineland Adaptive Behaviour Scales-3rd edition (VABS-3) for children with behavioural or cognitive support needs;

(c) the Gross Motor Function Classification System (GMFCS) to determine if a child requires assistive technology or wheeled mobility; and

(d) a Prioritization for Services Tool developed by MCFD.[10]

The first three tools are reliable and valid instruments that were designed to identify functional delays, inform program planning, and monitor individual progress – *but not to determine resource needs or service eligibility*. Furthermore, these measures were all designed to measure adaptive behaviour in a North American context, so some items on them may not be appropriate for Indigenous CYSN or those from other cultural/ethnic groups (see Berg et al., 2016). The VABS-3 has been translated into U.S. Spanish;[43] the PEDI-CAT is available in French Canadian, U.S. Spanish, Brazilian Portuguese, Danish, Dutch, German, Italian, Norwegian and Swedish;[44] and the GMFCS is available in 14 languages, including traditional Chinese.[45] With this exception, versions of the assessment tools in the dominant minority languages in B.C. (Punjabi, Cantonese, Mandarin)[46] and in Indigenous languages are not available.

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[43] See https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Adaptive/Vineland-Adaptive-Behavior-Scales-%7C-Third-Edition/p/100001622.html

[44] See Administration and Versions: https://www.pedicat.com/about/

[45] See https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r

[46] Statistics Canada. *Table 98-10-0216-01 Knowledge of languages by age and gender: Canada, provinces and territories, census divisions and census subdivisions* DOI: https://doi.org/10.25318/9810021601-eng

In addition, both the PEDI-CAT and the VABS-3 have been found to have what is called a "floor effect" when used with children and youth with a wide range of support needs (Corderio et al., 2020; Milne et al., 2019; Pasternak et al., 2016). This means that some parts of the measure are less accurate because there are insufficient items at the lower end (i.e., the "floor") of the measure. The result of a floor effect is that *the scores obtained for young children and for individuals with significant functional needs may result in an over-estimation of their ability and an under-estimation of their support needs*. In addition, neither of these two measures results in an automatic "threshold" score that can be used to indicate service eligibility. Thus, a decision will be made to deem children/youth who score below an arbitrary threshold (i.e., below X score) as eligible for Disability Services (because the children have "more severe" functional limitations) and those who score above that threshold as ineligible. Lower threshold scores will result in fewer children and families being eligible for Disability Services; conversely, higher scores will increase eligibility. Because these tools were never intended to be used for this purpose, it will be up to MCFD to set the thresholds; however, there is a clear risk to setting them low, as this will render more CYSN as ineligible. In general, the eligibility approach is antithetical to both Jordan's Principle and MCFD's *Aboriginal Policy and Practice Framework in British Columbia* (2015),[47] which emphasizes inclusivity and equitable access to services and supports for Indigenous families; and to the service delivery principle of substantive equality as set out in the recently amended *Child, Family and Community Service Act*.[48] In the broader sense, it is also contrary to the basic principles reflective of family-centred care for *all* families of CYSN.

Unanswered Questions. Support for the whole family emerged from the research review as a key component for effective service delivery to Indigenous CYSN; however, it is also a key element of family-centred care in general. As the pilot FCCs address this concern and planning for a transformed system commences, the following questions are outstanding:

- What specific provisions will be made at the pilot FCCs to recognize the central role of family and kinship supports in Indigenous communities?
- To what extent and how will family support workers at the FCCs provide assistance to Indigenous and other families who require supports related to the social determinants of health (e.g., housing, food insecurity, employment)?
- Will the pilot FCCs be required to use the PEDI-CAT, VABS-3, and GMFCS to assess eligibility for Disability Services, despite the inappropriateness of the use of these tools for this purpose?
    - If so, how will the tools be administered to families whose primary language is not English?
    - How will Indigenous and other diverse cultural expectations and behaviours be accommodated in scoring parents'/caregivers' responses on these measures?
    - What threshold score(s) on the PEDI-CAT and VABS-3 will be used to determine eligibility for services?
    - How often will Disability Service eligibility and support needs be re-assessed?
    - If a child improves, will Disability Services be terminated and, if so, when and how?

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[47] See https://www2.gov.bc.ca/assets/gov/family-and-social-supports/indigenous-cfd/abframework.pdf

[48] See https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96046_01#section3

CONCLUSION

This review draws on academic and grey literature as well as available documentation about the CYSN framework as announced in October 2021 and the current FCC pilots. RCY acknowledges a limitation of this work is a lack of engagement with organizations and individuals involved in the support needs sector.

Child Development Centres, Aboriginal Friendship Centres, other community-based agencies, Indigenous leaders and communities, families, ministry CYSN field staff, and advocates hold immense expertise with regard to what is required to deliver effective child- and family-centred services in this province. It is our hope that this review can be used to support consultation and planning between government and those organizations and individuals, as plans for an improved and inclusive CYSN delivery service are developed and finalized.

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