



# Alone and Afraid

*Lessons learned from the ordeal of a child with special needs and his family*

December 2018



REPRESENTATIVE FOR  
CHILDREN AND YOUTH



Dec. 10, 2018

The Honourable Darryl Plecas  
Speaker of the Legislative Assembly  
Suite 207, Parliament Buildings  
Victoria, B.C. V8V 1X4

Dear Mr. Speaker,

I have the honour of submitting the report *Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family* to the Legislative Assembly of British Columbia.

This report is prepared in accordance with Section 16 of the *Representative for Children and Youth Act*, which makes the Representative responsible for reporting on reviews and investigations of critical injuries and deaths of children receiving reviewable services.

Sincerely,



Dr. Jennifer Charlesworth  
Representative for Children and Youth

pc: Ms. Kate Ryan-Lloyd  
Acting Clerk and Clerk of Committees,  
Legislative Assembly of British Columbia

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*The Representative would also like to acknowledge the many other RCY staff who were involved in the planning, preparation and distribution of this report.*

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# Executive Summary

This is the story of one extremely vulnerable boy and what happened to him as he passed largely “unseen” through the very system designed to protect and support him. It is the personal story of Charlie and his family, but the Representative believes that telling it – and learning from it – can help improve outcomes for many other British Columbia children and their families in similar circumstances.

Charlie (a pseudonym used to protect his identity) was 12-years-old when he was removed from the care of his mother in January 2016, weighing just 65 pounds and suffering from signs of neglect so abhorrent that first responders who arrived at the home were traumatized. Charlie had endured years of malnutrition, inadequate and sporadic services to address his extreme special needs, and little education or socialization. Records show that he arrived at the hospital “*terrified, clinging to the paramedics.*”

The Representative is pleased to report that, nearly three years later, Charlie is doing well. He now lives in a foster home capable of providing the strong supports he needs, he is back in school, well nourished and healthy. He is described by those who know him best as affectionate, clever and observant.

This outcome is indeed fortunate considering the condition in which Charlie was found by police – naked and filthy, severely underweight, unable to walk, and living in a bedroom covered in garbage and feces. Charlie, a child with autism spectrum disorder who does not communicate verbally, had been screaming for a half-hour before police arrived at his Lower Mainland home.

Charlie had reached this shocking state despite his family being known to the Ministry of Children and Family Development (MCFD) since 2006, when police first alerted the ministry after visiting the home to investigate a loud argument between his parents. But despite eight formal reports to the ministry at different points in time from various sources concerned about his well-being, and despite four separate child protection assessments conducted by MCFD, no child protection social worker ever laid eyes on Charlie during a protection response until he was removed from his mother’s care more than nine years later.

The lack of eyes on Charlie by child protection workers is the most literal example of him going “unseen” by the system that was supposed to support and protect him. But even when Charlie was “seen” by social workers, medical and educational professionals, his needs often went unrecognized or unaddressed and these professionals did not consistently communicate effectively with one another about him. The child welfare system caught snippets of Charlie, but often failed to see him as a whole child beyond his severe special needs, and too often failed to see and address the needs of his vulnerable family.

Charlie was not yet five-years-old when doctors began to voice concerns that he was being neglected. Despite two lengthy hospitalizations, they were unable to determine a

medical reason for his failure to thrive, weight loss and inability to walk. Hospital staff also had concerns about his mother's delay in seeking medical attention and failure to follow through with medical appointments. After both stays in hospital, in 2008 and 2009, MCFD was prompted by the concerns of health professionals to open child protection investigations. But during neither investigation did ministry workers actually see Charlie before determining that he was not in need of protection.

During his hospital stays, Charlie received a plethora of services and attention and his condition improved as a result. But during the periods when he was back at home, he seemed to often fall off the radar of professionals and there was no follow-up when his mother did not follow through with requested testing or appointments for her son. A family doctor prescribed Charlie with anti-psychotic and anti-anxiety medication on more than one occasion without seeing Charlie based on the word of his mother alone.

Despite showing signs of significant developmental delay before he was three, Charlie was not diagnosed with autism spectrum disorder until well after his sixth birthday. That delay in assessment and diagnosis resulted in his family losing eligibility for \$22,000 in annual under-six autism funding and the early intervention services that money could have purchased – services that could have made a difference in his long-term development. Even after his diagnosis, Charlie's mother did not access the \$6,000 in annual funding available for children with autism over the age of six, yet this went unnoticed as MCFD had no mechanisms in place to flag the fact these funds weren't being accessed and trigger a follow-up with the family to find out why.

When Charlie was in school, he thrived, working with a one-on-one aide and following an Individual Education Plan (IEP), nevertheless his attendance dropped off soon after he was enrolled. Despite subsequent instances in which, first a school principal and, later, an income assistance worker, called MCFD with concerns that Charlie was not attending school, the ministry took no action, citing the fact that chronic absence from school is not considered a child protection concern under B.C. child welfare legislation. Charlie missed more than 100 days over two school years, yet between MCFD and his schools, they were unsuccessful in working with the family to address the barriers to his attendance. After his mother withdrew Charlie from public school altogether in 2011 to ostensibly homeschool him, neither MCFD nor his school district looked into whether he was, in fact, receiving a legitimate educational program.

Prior to Charlie's removal by MCFD in 2016, the needs of his family similarly went unseen. Charlie's mother lived in poverty, had little capacity to advocate for her children or herself and, as a result, she and her youngest son suffered. Voluntary MCFD and community services that sporadically helped the family were terminated when contract hours ran out or when Charlie's mother said she no longer required a service, regardless of the continuing needs of Charlie. And despite being a single mother with limited resources caring for two children, including one with extremely complex needs, Charlie's mother never once received respite services from MCFD. His mother was trying to cope with her own mental health and substance use issues, but her struggles seemed to go unnoticed and unsupported within the bigger context of the family.

From late 2011 after he was withdrawn from school to his removal in 2016, the family received no services even though MCFD had a Children and Youth with Special Needs (CYSN) file open on the family since 2008 and there were protection reports in 2014 and 2015. The family was, in effect, invisible to the system – a lengthy period of time when appropriate services likely would have had a significant positive impact on Charlie’s long-term development.

While the developmental, health and educational needs of Charlie and his family’s vulnerabilities often went unseen, so did Charlie’s heritage. Charlie’s father is of First Nations descent, but Charlie was never identified by MCFD as a First Nations child and so the ministry never made an effort to connect him to his extended family, community or culture. Even when the fact he has Indigenous roots was included in the court documentation that legally removed Charlie from his mother’s care, it was more than a year before his file was transferred to an Aboriginal guardianship office that was more likely to recognize and take advantage of the protective factors of culture to Charlie’s benefit.

The purpose of any RCY investigative report on an individual case is to identify systemic issues and make recommendations as to how those issues can be resolved. His identity is anonymized in this document, but Charlie’s story is a very real and personal one for his family, including those who were interviewed for this report. Although it was an extremely difficult process for them, Charlie’s family told RCY investigators that they felt the need to participate in the investigation to help prevent other families from enduring

*“Let’s not let this happen to the next child that’s going to be going through this, and the next family that has to go through this.”*

– Charlie’s father

a similar experience. The Representative sincerely thanks them for their participation, which has provided valuable insight into the issues that this report addresses.

The Representative also recognizes the immense challenges facing front-line social workers and team leaders in B.C., and believes their ability to conduct their duties is only as strong as the resources available to them, which includes staffing levels, training and policy to guide service delivery to vulnerable children. This report is not meant to cast blame on individual social workers or their supervisors, but to shine the light on the shortcomings of a system that obviously does not have the capacity to offer the depth of services and oversight that are required in such complex cases.

The Representative makes 11 recommendations in this report, led by the recommendation that MCFD undertake a comprehensive assessment of the needs of children and youth with special needs in B.C. and the capacity of the current CYSN division of MCFD to meet those needs. The ministry should examine funding, staffing levels and workloads, program delivery and wait times, identify necessary improvements to the system and take action so that children with special needs and their families can be consistently well-served.

While that comprehensive system review and overhaul is underway, the Representative recommends that MCFD take immediate steps to make things better for families such as Charlie’s – including providing respite within a reasonable time to families who need

it, eliminating the need for families to choose between respite and medical benefits, monitoring use of autism funding and following up with families who are not using it.

The Representative also recommends that MCFD take the lead in working with the ministries of Health and Education to develop an integrated service delivery model that enables information-sharing and offers the option for families to be provided with a case coordinator who would be responsible for navigating access to, and provision of, all necessary services to a child or youth with special needs. A case coordinator would likely have made a difference for Charlie and his family, as the lack of one consistently involved professional with a clear understanding and oversight of his file seemed to be a major reason that he and his family's lengthy history and various vulnerabilities never seemed to be fully considered.

The Representative also recommends that the Ministry of Health and MCFD develop a plan to ensure early identification, timely assessment, and appropriate and accessible supports for children under six with signs of developmental delay. She also recommends that the Ministry of Health incrementally decrease the wait times across B.C. for completed assessments of autism and complex behavioural developmental conditions.

The report calls on MCFD to ensure that all child protection workers receive mandatory training in working with children and youth with special needs, to ensure that children are seen by social workers during child protection assessments, and to ensure that child protection responses adhere to prescribed policy and timelines.

The Representative further recommends that MCFD and the Ministry of Education work together to develop a protocol to address unexplained school absences. In addition, the Representative calls on the Ministry of Education to create a system to flag when a child is not registered in an educational program, and to determine how many students with special needs designations are being homeschooled and whether school districts should be offering additional support and guidance to these students.

Finally, this report recommends MCFD ensure that identification and involvement of an Indigenous child or youth's family, community and culture is made at the first point of contact with any MCFD service and continues on an ongoing basis.

The Representative notes that while Charlie is now doing comparatively well, he and his family have been irrevocably impacted by the events that led to his removal. He no longer lives with his family and his mother is not in his life at all.

The fervent hope is that lessons can be learned from his story, so that the needs of other children such as Charlie and their families do not go unseen.

# Methodology

The *Representative for Children and Youth Act (RCY Act)* (see Appendix A) requires that MCFD and other public bodies report to the Representative on critical injuries and deaths of children who received a reviewable service from MCFD in the year prior to the critical injury or death.<sup>1</sup>

The Representative conducts an initial review of these reports to determine whether an injury or death of a child meets the criteria for a comprehensive review under the *RCY Act*. The comprehensive review assists in the determination of whether a full investigation is warranted.

The Representative conducted an initial review of the critical injury report for Charlie in January 2016 and subsequently completed a comprehensive review in April 2016. The comprehensive review found that Charlie's injury met the requirements for an investigation because the injury had been inflicted by another person and because a reviewable service and/or the policies and practices of a public body may have contributed to the injury.

“The primary purpose for reviewing injuries and deaths of children and youth who are in care or receiving Ministry services is to point the way to continuous improvements in policy and practice, so that future injuries or deaths can be prevented.”

– Hon. Ted. Hughes, in his 2006 *BC Children and Youth Review*

MCFD completed its own internal case review in January 2017. Under the *RCY Act*, the Representative was required to wait for MCFD to complete this internal review (to a maximum of 12 months from the date of the critical injury) before commencing an investigation. The RCY investigation focused on the time MCFD, as well as health and educational services, were involved with Charlie and his family prior to the injury, between 2008 and 2016.

In conducting the investigation, the Representative reviewed and analyzed documents from a variety of sources, including MCFD, hospitals, schools, police departments, government offices and non-profit organizations (see Appendix B). The Representative also conducted interviews with 44 individuals, including family members, who provided sworn evidence to RCY investigators (see Appendix C).

The Representative makes every attempt to include a child's family in the investigative process in order to obtain valuable information that may not be available in records and to provide an accurate reflection of the family's story, among other things. This is not always possible, however. In some cases, circumstances prevent meaningful participation by family members. In Charlie's case, his father, brother and other family members voluntarily participated in interviews. Other family members whom RCY investigators had hoped to interview for this investigation were unable to participate.

<sup>1</sup> Reviewable services are outlined in the *RCY Act* and include services or programs under the *Child, Family and Community Service Act* and the *Youth Justice Act*; mental health services for children; and addiction services for children.

RCY investigators made numerous attempts to contact Charlie's mother, beginning at the early stages of the investigation in June 2017. Those attempts were unsuccessful, but the Representative believed that the investigation could continue without her input. While the investigation progressed, investigators continued to look for Charlie's mother. In September 2018, RCY investigators met with her with the intention of gaining her perspective regarding Charlie, the circumstances leading up to Charlie's critical injury and her family's experience with supports and services available for Charlie. However, due to the state of her health and her current life circumstances, she was unable to provide any substantive information.

The Representative also makes every effort to understand the experience of the child who is the subject of an investigation. A member of RCY's team met with Charlie and directly observed and interacted with him on three occasions in different environments including his school and his foster home. Based on these observations as well as interactions and discussions with the supportive people (e.g., teachers, family, pediatrician, foster parent) in Charlie's life, the Representative decided not to interview Charlie due to his significant disability-related challenges and barriers. However, vital information about Charlie was obtained through interaction with him and speaking with his support people.

The Representative's Multidisciplinary Team (see Appendix D) met three times at various stages of the investigation to provide feedback to RCY investigators. RCY investigators also met with the First Nations community to which Charlie's paternal side of the family is connected, as well as the First Nations Health Authority and First Nations Health Council for their input. For the purpose of administrative fairness, organizations and individuals who provided evidence for this investigation, including Charlie's family, were offered an opportunity to review the draft report and provide feedback.

# Chronology

## Family Background

Charlie was born in March 2003 in B.C.'s Lower Mainland. He is of mixed heritage – French and Irish on his mother's side and Scottish and First Nations on his father's side. Charlie's paternal grandfather was registered with a First Nations<sup>2</sup> community in northwest B.C. Charlie's father became aware of his First Nations ancestry when he was a young teenager, through his own father's stories about relatives. Aside from this, Charlie's father was disconnected from his First Nations culture and community and this disconnection continued with Charlie and his brother.

As children, Charlie's parents were both witness to parental alcohol misuse and family violence, as well as the impacts of ongoing poverty. Neither parent was able to complete high school due to various barriers they faced.

Charlie's parents first met as children and reconnected in their teens and began dating. His father was 20 and his mother 18 when she became pregnant with Charlie's older brother in 1995. Although Charlie's father described their early relationship fondly – *"She loved me, and I loved her, it was a beautiful day"* – the couple began experiencing difficulties and they married in the summer of 2002 in an attempt to address those challenges. Charlie was born the following year. Charlie's father supported the family financially through work in the trades.

## 2003 to 2006: Charlie's Early Life

Charlie was born in a Lower Mainland hospital. His brother told RCY investigators about the first time he saw Charlie: *"He was beautiful. He had beautiful eyes; he still does. . . I was the first person he smiled to."* Family members described Charlie as a challenging baby who would only sleep when secured in a car seat. They told RCY investigators that a public health nurse visited the home once after Charlie's birth. Between May and December 2004, Charlie was seen three times at a walk-in clinic.

Charlie's arrival brought on financial strain for the family, which had already been struggling. The early conflict in his parents' relationship did not diminish after they were married, and Charlie was born. Charlie's father described their relationship at this time as *"toxic"* and a *"revolving door"* with his wife kicking him out of the house and then letting him back in. Along with the financial and relationship strain, the family also experienced housing instability during Charlie's formative years.

When Charlie was two-years-old, his father grew concerned that the boy's language development and walking were delayed. At this point, the family communicated with

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<sup>2</sup> Charlie's heritage is referred to in this report as "First Nations" or "Indigenous". "Aboriginal" is the official term in Canada and B.C. for First Nations, Inuit and Métis people. The term "Aboriginal" is used in this report only when it is embedded in the name of an agency or program.

Charlie by gesturing and talking to him, but he did not speak back. He also began eating rocks, dirt and toilet paper, which caused concern for some family members. Charlie's parents did not seek medical attention about these behaviours.

His family described the toddler Charlie as a “good eater” but in 2006, at age three, he began refusing to eat anything except chicken nuggets, Twinkies and soft drinks. Around this time, his maternal aunt, who had some experience working with young children, advised the mother that she thought Charlie was showing signs of being on the autism spectrum. Charlie's mother responded negatively, resulting in a conflict in the relationship with her sister.

## Autism Spectrum Disorder

Autism spectrum disorder (ASD) is characterized by persistent deficits in social communication and interaction and restricted, repetitive patterns of behaviours, interests, or activities. Individuals with ASD experience symptoms starting in early childhood that can cause significant impairment in day-to-day life. There is great variability in the severity and expression of symptoms in ASD.<sup>3</sup>

Charlie's parents had support from his paternal grandmother, who at times lived with them. His maternal grandparents also provided some financial assistance and child care. Family members told RCY investigators they felt they were “walking on eggshells” with Charlie's mother and that disagreeing with her meant risking not being involved with Charlie and his brother.

## 2006 to 2008: Initial Contacts with MCFD

MCFD first became aware of difficulties in the family home in the fall of 2006, when Charlie was three. On Sept. 22, Charlie's mother called police after a verbal conflict between the parents. When police arrived, Charlie's mother told them that the couple was in the midst of separating and that Charlie's father was no longer living in the home. She was crying and said that she wanted Charlie's father to leave, which he did shortly after police were called.

As there were children present, the police made a report to MCFD. A child protection social worker took the information and planned to offer support services to Charlie's mother. The child protection worker was unable to contact the family because there was

## Child Protection Social Worker

A child protection social worker receives, assesses and responds to reports concerning a child's safety. The worker can also provide families with support services and referrals.

no phone number on file. The child protection worker sent a letter to Charlie's mother asking her to call to “discuss possible support needs.” After receiving no response from Charlie's mother, the child protection worker consulted with her team leader. The team leader approved closing the file with no supports offered and no contact made with the family.

On May 5, 2007, when Charlie was four, police made a second report to MCFD. A concerned citizen contacted police after hearing a young child crying and screaming in the family's apartment. Records reviewed by RCY investigators indicated that the police officer

<sup>3</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (Arlington, VA: American Psychiatric Association, 2013).

who attended the home informed MCFD that she saw Charlie, his brother, his mother and his father, who was referred to as “*the boyfriend*” (however, the father told RCY investigators he was not present at the time). The officer told MCFD the family had informed her that Charlie cried all the time to get his own way and that this was his way of communicating. The child protection worker who received this second report determined that no further steps were necessary to assess the safety of Charlie and his brother as the police officer had not indicated any concerns for the children. Accordingly, Charlie, his brother and his parents were not seen nor contacted by MCFD and the file was closed.

RCY investigators learned that around this time, Charlie’s mother and father began using cocaine, leading to increased financial challenges, relationship conflict and struggles to parent. Investigators learned Charlie’s father quit using cocaine that same year, but Charlie’s mother continued to struggle with addiction. RCY investigators found no evidence that the various support services, medical professionals and MCFD workers involved with the family during the next several years were aware of any parental substance misuse.

## 2008: Charlie's First Hospitalization

In January 2008, Charlie’s parents took him to the doctor because he was bleeding from his mouth. The doctor determined that he had a dental infection but was also concerned about four-year-old Charlie’s development. This was the first time the doctor had seen Charlie, whose only previous health care interactions had been three visits to medical clinics. The doctor prescribed Charlie penicillin, referred him for an autism assessment and also to a dentist at BC Children’s Hospital (BCCH).<sup>4</sup>

The following month, Charlie’s parents brought him to a local hospital, concerned because he had not walked for several days. The hospital admitted Charlie due to bacteria in his blood from the dental infection that had yet to be treated. He weighed 37 pounds upon admission. This placed him in the 25th percentile, meaning that only 25 per cent of Charlie’s same-age peers weighed as much or less than he did.

Medical staff at the hospital noted concerns about signs of neglect, including Charlie’s severe dental decay, his parents’ lack of response to their son’s developmental delay and the time it took them to seek medical attention after he had stopped walking. Medical staff made a referral to the hospital social worker to become involved with the family.<sup>5</sup> This social worker reported these concerns to MCFD on Feb. 18, 2008, prompting a child protection investigation. A child protection worker was assigned to assess Charlie’s safety and determine whether he had been neglected. In her case notes, this social worker detailed factors that placed Charlie at a greater likelihood of harm, including that he was non-verbal with limited visibility in his community, and requested that the hospital

<sup>4</sup> An autism assessment is conducted by a specially trained pediatrician, psychologist, or psychiatrist who evaluates a child’s medical and developmental history and behaviours, social interactions and communication abilities using tools specially developed for ASD diagnosis. Children who are assessed as meeting criteria also receive comprehensive assessments from other professionals, such as speech language pathologists.

<sup>5</sup> The hospital social worker becomes involved in cases in which a doctor or nurse has a child protection concern or feels that a family needs additional support. The hospital social worker reports any concerns to MCFD and liaises with the MCFD child protection worker as necessary on a case-by-case basis.

## Neglect

Neglect is a form of maltreatment in which a caregiver fails to provide for a child's basic needs. *Physical neglect* is failing to provide food, clothing, shelter, and/or hygiene. When a caregiver allows chronic school absences, fails to enrol a school-age child in school or fails to attend to a child's special educational needs, this is characterized as *educational neglect*. *Emotional neglect* involves marked inattention to a child's need for affection, refusal or failure to provide necessary psychological care, spousal abuse in the child's presence and/or allowing a child to use drugs and/or alcohol. Finally, *medical neglect* is characterized by refusal or delay in seeking health care for a child who has a physical injury, illness or medical condition.<sup>7, 8</sup>

## Child Protection Investigation

The *Child, Family and Community Service Act* outlines circumstances when a child's need for protection must be investigated. These circumstances are listed in s.13 of the Act.

MCFD policy provides direction to social workers on how to conduct a child protection investigation, which is intended to be a timely response to concerns pertaining to the safety and well-being of a child. The investigation should focus on thoroughly gathering and assessing information about the concern and the risk of future harm to the child. Direct interviews with the child and family are essential to the process. Examples of child protection concerns include when a child has been, or is likely to be, physically or sexually abused or neglected. MCFD standards outline the steps involved in an investigation as well as the time frame for completion.<sup>9</sup>

delay his discharge until she could assess his safety.<sup>6</sup> The next day, the hospital completed a bone scan – as requested by the child protection worker – to ensure Charlie did not have any fractures. The scan revealed no concerns.

The child protection worker attended the hospital the next day to begin the investigation. Medical staff informed her that Charlie's legs were extremely swollen, which prevented him from walking, there was concern about his diet and nutrition, he was extremely thin and pale, he had numerous rotten teeth and there were concerns he may be on the autism spectrum.

The child protection worker interviewed Charlie's mother, who said it was challenging taking Charlie to medical appointments. She did not have a car and told the worker she did not want to take him on the bus as she felt judged when doing so. She said she had been unaware that she could get Charlie assessed for his developmental delays and she had limited understanding of the importance of nutrition. She said she was overwhelmed trying to meet Charlie's needs and willing to work with support services and accept help from MCFD.

As part of the investigation, the child protection worker reviewed the family's prior involvement with MCFD, spoke to professionals who had recently interacted

<sup>6</sup> Community visibility refers to a child being seen by people in the community who are not the child's family. Being visible in the community reduces the risk to vulnerable children who may be subjected to abuse or neglect.

<sup>7</sup> Tal Ben-Galim, Penelope T. Louis, & Angelo Giardino, "Neglect and Failure to Thrive," in *A Practical Guide to the Evaluation of Child Physical Abuse and Neglect, Second Edition*, eds. Angelo P. Giardino, Michelle Lyn, & Eileen R. Giardino (New York, Springer, 2010), 261-290.

<sup>8</sup> Eric J. Mash & David A. Wolfe, *Abnormal Child Psychology, Fourth Edition* (Belmont: Wadsworth, Cengage Learning, 2010), 435-437.

<sup>9</sup> Ministry of Children and Family Development, "Child and Family Development Service Standards," (Victoria, BC, Ministry of Children and Family Development), 59-62.

with the family and visited the family home, where she noted no concerns. The child protection worker did not see or interact with Charlie, nor did she interview Charlie's brother or father.

The worker determined that Charlie was safe with no immediate concerns. She contacted the hospital social worker to advise that Charlie could be discharged to his parents.

## Discharge Planning

During the 10 days Charlie was in hospital, a range of professionals and therapists worked with him including doctors, the hospital social worker, a physiotherapist, an occupational therapist, a dietician, a speech and language pathologist, a public health nurse and a teacher.<sup>10</sup> All of these professionals, along with the MCFD social worker and Charlie's parents, met for a discharge meeting before Charlie went home on Feb. 27, 2008.<sup>11</sup> Charlie was diagnosed with Henoch-Schonlein purpura (HSP) that had likely been caused by the infected abscess in his mouth.<sup>12</sup> He was also diagnosed with global developmental delay.<sup>13</sup>

During the discharge meeting, the child protection social worker advised other attendees that her investigation found Charlie was not in need of MCFD's protection, but rather that his family had "*slipped through the cracks in the community.*" She said upon discharge the family would now be connected to a multitude of services in the community. The teacher who worked with Charlie during his stay indicated that he would be of age to start Kindergarten that coming September and offered to accompany the parents and assist them in registering for school.

All those who attended the discharge meeting agreed that Charlie and his family required a coordinator to manage all aspects of his medical follow-up. Services to be provided included those of a community pediatrician and Nursing Support Services (arranged through the hospital), early intervention therapy services (arranged through the hospital and community agencies) and family outreach counsellor (through MCFD voluntary services).

<sup>10</sup> The hospital dietician was extremely concerned about Charlie's apparent malnutrition and worked on educating Charlie's parents regarding food choices and strategies to entice him to try foods other than the unhealthy choices he preferred.

<sup>11</sup> Discharge meetings are held in cases such as Charlie's that are complicated and when there is extensive community follow-up required.

<sup>12</sup> Henoch-Schonlein purpura is a disease involving inflammation of small blood vessels. It most commonly occurs in children. The inflammation causes blood vessels in the skin, intestines, kidneys, and joints to start leaking. This is a condition that usually lasts from four to six weeks but can reoccur. Joint inflammation involving pain and swelling occurs in three-quarters of cases but does not usually cause long-term joint problems.

<sup>13</sup> Global developmental delay refers to a condition in which a child under the age of five does not meet developmental milestones in several areas, such as learning and planning, vocabulary and grammar, and activities of daily living. Children with this diagnosis should be reassessed after age five.

Records from the meeting suggest that the hospital pediatrician who had treated him would assume the coordinator role and continue to see Charlie after discharge.<sup>14</sup> While this pediatrician did not attend the meeting, the intent that he was to coordinate

### Voluntary Support Services

If, at the end of a child protection investigation, the child protection worker concludes a child does not need protection, the worker's involvement will end, or the worker may refer the family to voluntary support services in the community and keep a file open for the purpose of providing services.<sup>15</sup>

was communicated to him through the discharge summary that he signed. However, it was unclear to RCY investigators if he agreed to take on the role of coordinator.

Charlie's parents expressed gratitude for all the people who had assisted them at the hospital. When speaking to RCY investigators, his father distinctly remembered the discharge meeting, saying: *"I felt really bad because it seemed like we were hurting him . . . we didn't do anything wrong."*

The family's MCFD file remained open after Charlie's discharge to provide voluntary support services. The child protection worker also referred them to a family outreach counsellor.<sup>16</sup>

## Post-Hospitalization Services in 2008 and the Deterioration of Charlie's Condition

The outreach counsellor began working with the family immediately after discharge. The counsellor met Charlie's mother in the home weekly for three months, focusing on achieving the goals of the referral set by the child protection worker, which included to help the family coordinate and access services and to assist with nutritious meal planning and parenting.

In initial meetings with the outreach counsellor, Charlie's mother said she wanted Charlie to be more involved in community activities and to attend school. Although Charlie's father was living in the home at the time, the counsellor had no interactions with him.

A Nursing Support Services (NSS) nurse visited Charlie and his mother two weeks after his discharge from the hospital on March 10, 2008, to assess whether he was eligible for the At Home Program.<sup>17</sup> The nurse interacted directly with Charlie in order to complete her assessment. Charlie was unable to walk at this time. The nurse offered the use of a wheelchair. His mother declined, saying she preferred to carry him.

<sup>14</sup> RCY investigators were told that pediatricians in B.C. generally do not function as primary care providers, except for those children with complex medical conditions.

<sup>15</sup> Ministry of Children and Family Development, "Child and Family Development Service Standards," (Victoria, BC, Ministry of Children and Family Development), 27-29.

<sup>16</sup> A community-based professional who provides supports, such as parent education, household management, building connections between families and community, support with navigating government systems (e.g., income assistance), and practical and emotional support for families and children with special needs.

<sup>17</sup> The At Home assessment is an assessment of the child's abilities in four functional categories of daily living (eating, dressing, toileting and washing).

## Nursing Support Services (NSS)

The NSS program assists parents and caregivers to help children with special health care needs (birth to age 19) lead active, healthy lives in their communities. NSS is free for eligible children and youth. The program is delivered province-wide with recipients determined by provincial eligibility criteria and guidelines. Nurses through NSS can become involved with families through three streams: conducting assessments for the At Home Program, providing direct care to eligible children, and supporting school staff to perform and provide health-related care for eligible children during the school day.<sup>18</sup>

## At Home Program

The At Home Program is intended to assist parents or guardians with some of the extraordinary costs of caring for a child with severe disabilities in the family home. It provides assistance in two main areas: respite benefits allow parents or guardians to access respite services; and medical benefits provide a range of basic, medically necessary items and services. A child may be eligible for both respite benefits and medical benefits, or a choice of one benefit. A regional committee reviews applications and assessments and makes eligibility recommendations.<sup>19</sup>

In her At Home Program assessment, the NSS nurse recommended Charlie be approved for both medical and respite benefits. The eligibility committee subsequently determined that Charlie was not eligible for both benefits because he was only rated as fully dependent in two categories of daily living and “*close to*” fully dependent in the remaining two categories. The committee informed his mother by letter that she would have to choose one or the other, adding that there was a wait list for respite. Charlie’s mother chose medical benefits, which covered his diapers, nutritional supplements and vitamins.

On March 11, 2008, Charlie had his first appointment with the community pediatrician. Three days later, he was seen at the BCCH dental clinic, where the majority of his baby teeth were extracted due to decay.

Additional services became involved with Charlie in April 2008, the second month following his hospital discharge. These included early intervention therapy from a community agency, comprised of occupational therapy, physiotherapy, and speech and language pathology.<sup>20</sup> Initially, the service providers were in the family home seeing Charlie every two weeks to establish a rapport and determine his needs. Often two therapists attended appointments as Charlie required substantial support and at times would hit therapists or his mother when he was frustrated.

The early intervention program physiotherapist referred the family to the program’s family support worker to help Charlie’s mother explore school and funding options, including applying for a child

disability benefit, and to help with Charlie leaving the house.<sup>21</sup> The family support worker maintained contact with Charlie’s mother throughout the summer of 2008.

<sup>18</sup> BC Children’s Hospital, “Nursing Support Services,” Public Health Services Authority, accessed October 31, 2018, <http://www.bcchildrens.ca/our-services/sunny-hill-health-centre/our-services/nursing-support>.

<sup>19</sup> Ministry of Children and Family Development, “At Home Program Guide,” (Ministry of Children and Family Development, October 2018), 4-5.

<sup>20</sup> MCFD funds early intervention programs and services that are provided by community agencies or health authorities.

<sup>21</sup> Tax-free income provided to families who care for a child under age 18 with a severe and prolonged impairment in physical or mental function. A medical practitioner must certify that a child has a severe and prolonged impairment. Charlie’s family did not receive this benefit.

The outreach counsellor met with Charlie's mother for multiple sessions between March and May 2008.<sup>22</sup> Her focus was to connect the family to community resources and to help Charlie's mother manage a recent break-up with his father, who had again left the home. During their final appointment, the family counsellor discussed nutrition with Charlie's mother, who said Charlie was now eating more types of food and pointed out that she had the *Canada Food Guide* posted in the kitchen. She added that she often talked with Charlie's pediatrician about his nutritional needs.<sup>23</sup> Charlie's mother told the outreach counsellor that she felt adequately supported and prepared for the counselling services to end. As a result, the outreach counsellor's file was closed at the end of May.

In June, the child protection worker contacted Charlie's mother about closing her MCFD file. The mother reported that things were going well, that she had a lot of community support, and that she did not require further assistance from MCFD. The child protection worker did not speak with the pediatrician or any of the involved support service providers before consulting with her team leader who approved closing the file. At the time of closure, the child protection worker had still never seen Charlie nor spoken to his father or brother. The worker sent a closing letter to the mother on June 16, 2008, telling her that she was *"doing an incredible job, a job that so many of us could never do, even with all the services you were lacking."* For the rest of summer 2008, the early intervention therapy services and family support worker remained involved with the family, primarily by phone.

In September 2008, Charlie's mother decided to wait another year to send him to Kindergarten as she felt he was not developmentally ready. Her family support worker was supportive of this decision.

In early October 2008, the NSS nurse checked in with Charlie's mother by phone. The mother advised the nurse that Charlie, now five, would not be attending school that year, but that he continued to receive services through the early intervention program and she was hoping to take Charlie to play groups.<sup>24</sup> That same month, Charlie's mother noticed he seemed to be experiencing pain in his hips and knees and was resistant to walking so, on Oct. 10, she took him to the same pediatrician he had seen at the hospital. The pediatrician determined Charlie was not in significant distress and advised his mother to give him Motrin for the pain.

In December 2008, the early intervention therapy team completed a progress report. The report indicated that, in the month prior, Charlie began to complain of pain in both his hips and knees and was unable to stand and walk. This was a marked difference from the summer, when Charlie was reported to be running and jumping. Charlie's mother reported to the team that this regression in walking and inability to stand was due to *"juvenile arthritis"* and Charlie began using a wheelchair that had been loaned to him by a community organization. RCY investigators could find no records or confirmation of a diagnosis of juvenile arthritis.

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<sup>22</sup> The outreach counsellor had a total of 10 visits with the family. She saw Charlie in nine of the 10 visits.

<sup>23</sup> Records examined by RCY investigators indicate that Charlie's mother had only spoken to the pediatrician once at the time of her final meeting with the family counsellor.

<sup>24</sup> RCY investigators found no evidence that Charlie's mother took him to any community play groups.

In the report, the therapy team indicated that Charlie's communication skills had improved and he was able to say 10 words, compared to only two when they began working with him the previous April. Despite this improvement, the early intervention team indicated that his skills in this area remained significantly delayed and disordered.

Also, in December 2008, the early intervention family support worker who had been working with Charlie's mother left her position. She left a note for the new worker, who had not yet been assigned, stating:

*"This is a single mom who tries hard to keep her family going. She just moved into a basement suite with her two sons . . . The little boy [Charlie] is awaiting an Autism assessment and he has another condition – early childhood arthritis. This is a mom who has no income and [no] help to care for this little boy and her son of 12. Please support this family with whatever you can."*

### Sunny Hill Health Centre

Sunny Hill provides specialized development and rehabilitation services for children and their families. Children who come to Sunny Hill range in age from birth to 19 years and often have complex medical, physical and developmental needs. Some of the children have conditions affecting physical, motor or sensory development or have acquired brain injury, prenatal exposure to alcohol or other drugs, cerebral palsy, or autism. The nature and complexity of their needs may make it difficult to find the support they need at home or in their community.<sup>25</sup>

A new early intervention family support worker was assigned in February 2009 but, for reasons RCY investigators were unable to determine, did not see the family until that summer.

Charlie's mother applied for income assistance for the first time in December 2008. Charlie's father had lost his job and was no longer able to pay the \$750 monthly rent for her and the children. Charlie's mother was unable to seek work due to his medical condition.

At the end of 2008, Charlie's mother learned that the Provincial Autism Resource Centre at Sunny Hill Health Centre for Children (Sunny Hill) would be conducting Charlie's awaited developmental assessment in early 2009, almost a year after the original referral date.

## January to April 2009: Charlie's Condition Further Deteriorates and He Attends Sunny Hill for Autism Assessment

The early intervention therapy team physiotherapist saw Charlie for the final time in January 2009 and noted that the boy had a swollen right foot and appeared *"thin and pale."* The physiotherapist recommended that Charlie's mother take him to a doctor. Following this meeting, in February 2009, the physiotherapist contacted the NSS nurse to report concerns about Charlie's condition and the fact that he hadn't received medical attention.

<sup>25</sup> Provincial Health Services Authority, "Sunny Hill Health Centre: About," Provincial Health Services Authority, accessed March 5, 2018, <http://www.bcchildrens.ca/our-services/sunny-hill-health-centre/about>.

The NSS nurse phoned the mother, who said that Charlie had not been walking for two months. Charlie's mother explained that she had left messages at the pediatrician's clinic but received no response. The nurse recommended Charlie's mother take him to a clinic and asked to come for a home visit to talk about support options. Charlie's mother said she did not require respite or additional support. She said she was planning on enrolling Charlie in Kindergarten and accepted help from the nurse in meeting with the school district.

Sunny Hill informed Charlie's mother by letter that her son's first appointment for an autism assessment would be March 13, 2009 (this appointment was later rescheduled for April 17). The letter included a parent questionnaire to provide doctors with further information about Charlie. His mother completed the questionnaire and, when asked to list her main concerns about her child, she wrote: *"everything."* When asked what she hoped to gain from the assessment, she wrote: *"To find out what is wrong with my child and show me how to fix it."*

On Feb. 26, 2009, the NSS nurse visited the family home and saw Charlie, who was in a wheelchair. The mother told the nurse that Charlie's feet were swollen, and he was unable to bear any weight. She said that she was doing her own physiotherapy on Charlie and that he had arthritis.<sup>26</sup> She also told the nurse that she had registered him for Kindergarten. The special needs coordinator from the school district and the NSS nurse visited the family's home together on March 4, at which time the special needs coordinator gathered information to assist the school in developing a plan to meet Charlie's needs.

On April 17, six-year-old Charlie visited Sunny Hill for his autism assessment. The developmental pediatrician noted that he was unable to physically assess Charlie due to his *"distress and combativeness."* He observed Charlie as *"a rather pale child, who appeared underweight."* Charlie was still in a wheelchair. The Sunny Hill pediatrician scheduled a second appointment for the following month in hopes Charlie's health would improve. He also advised the mother to reconnect with the community pediatrician.

On May 22, Charlie attended his second appointment at Sunny Hill. The pediatrician was once again unable to work with Charlie due to his level of distress. The pediatrician discussed his concerns regarding Charlie's chronic medical issues with his mother and told her that the boy required a *"coordinated course of action to address his needs,"* but that he did not feel Charlie was *"acutely unwell or requiring emergency room attention"* at that time. The Sunny Hill pediatrician noted that *"Charlie's mother was extremely fearful that her child would be removed from her, and [had] repeatedly expressed her concerns about her son's well-being."* After this appointment, the community pediatrician and the Sunny Hill pediatrician consulted and agreed on a planned admission to BC Children's Hospital (BCCH) to address Charlie's malnutrition and rule out any medical reason for his presentation.

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<sup>26</sup> RCY investigators could find no evidence of any training Charlie's mother received to provide him with physiotherapy.

## May 2009 to September 2009: Charlie's Second Hospitalization, Time at Sunny Hill and Completed Autism Assessment

On May 31, 2009, Charlie's mother brought him to Emergency at a local hospital because he was still not walking. Hospital chart notes indicate that he was admitted for "*failure to thrive, pain and swelling of both knees, inability to weight bear, [and] unexplained weight loss.*" After meeting Charlie and his mother, the hospital dietician noted that Charlie appeared malnourished and that his diet was clearly not meeting his nutritional

### Failure to Thrive

Failure to thrive is defined as the weight at which 95 per cent of same-age peers weigh more or as a significant slowing of weight gain.<sup>28</sup> Failure to thrive can be caused by parental neglect (also referred to as nonorganic failure to thrive), child behaviour (e.g. child is a "picky" eater), and/or child physiology (e.g. child requires a gastrostomy tube for feeding). A child is most at-risk for failure to thrive when two or more of these conditions are present.<sup>29</sup>

needs. He weighed 32 pounds and was in the third percentile for his age.<sup>27</sup> Just seven months earlier, he had weighed 38½ pounds. Hospital staff described Charlie as ". . . *very thin and malnourished looking . . . skin is very pale.*"

On June 5, Charlie was transferred to BCCH. There he was seen by a number of physicians who expressed concerns about neglect, his mother's ability to cope and her delay in seeking medical attention for Charlie. As a result, the Child Protection Service Unit (CPSU) at BCCH became involved and the CPSU hospital social worker contacted the MCFD child protection worker who had been involved with

the family in 2008 to inform her of the circumstances of Charlie's admission. Charlie's community physiotherapist also called the child protection worker to report that she had not been engaged with the family for some time and that, from November 2008 to her last visit with the family in January 2009, Charlie's mother would not allow her to treat him. The physiotherapist said she had suggested the mother seek medical attention for Charlie.

<sup>27</sup> This means that only three per cent of Charlie's same-age peers weighed the same or less than he did.

<sup>28</sup> Eric J. Mash & David A. Wolfe, *Abnormal Child Psychology, Fourth Edition* (Belmont: Wadsworth, Cengage Learning, 2010), 435-437.

<sup>29</sup> Christine Werkele & David A. Wolfe, "Child Maltreatment," in *Child Psychopathology* (New York: The Guilford Press, 2003), 632-686.

## BC Children's Hospital Child Protection Service Unit (CPSU)

The CPSU provides expert medical assessments for children in cases of suspected physical abuse, sexual abuse, emotional abuse and serious neglect. The unit is staffed by a multidisciplinary team consisting of pediatricians, social workers, clerical staff, a nurse, psychologists and a part-time psychiatrist. A referral from a physician, the police or MCFD is required to access this service. Before a clinical referral, the CPSU social worker gathers relevant information. During the clinic visit, specialists take a full medical and social history. The child is examined by the unit pediatrician and a medical report is prepared. The unit social worker provides crisis counselling to parents and may refer the child and family for appropriate services in the community. In the most serious cases, a child may be referred to one of the unit psychologists or the psychiatrist for further assessment. These professionals prepare a report with recommendations for ongoing treatment in the community.<sup>30</sup>

The child protection worker consulted with her team leader regarding the calls about Charlie and was directed to investigate his safety due to concerns that he was being deprived of health care, that his mother may be unable to care for him and that he may be experiencing neglect. The investigation was assigned to a different child protection worker in the local MCFD office. This worker phoned the CPSU hospital social worker, who informed her that Charlie was being fed through a nasogastric (NG) tube due to his extreme weight loss.<sup>31</sup> The hospital social worker added that a CPSU psychiatrist was planning to assess Charlie's mother for possible depression.

The CPSU pediatrician's overall assessment was that Charlie was a "very unwell" child, and that she was "very concerned about Charlie's condition on admission and the fact that he had not received medical care sooner." Following a meeting with Charlie's mother, the CPSU pediatrician wrote letters to a number of medical professionals involved in his care, including one to the MCFD child protection worker which stated:

*"In my opinion the mom should be given a chance to follow-up with recommendations and supports will definitely be needed. When Charlie is discharged, clear instructions need to be provided to the mother in writing. Close medical follow-up will be needed for some time to be certain that he progresses well. MCFD will hopefully provide support services."*

The CPSU pediatrician ended the letter by stating: "I would like to be notified again if the mother has any difficulty following through with medical recommendations."<sup>32</sup>

<sup>30</sup> Provincial Health Services Authority, "BC Children's Hospital Child Protection," accessed March 5, 2018, <http://www.bcchildrens.ca/our-services/support-services/child-protection>.

<sup>31</sup> A nasogastric tube (NG-tube) is a tube inserted into the nasal or oral passage down to the stomach to administer nutrition.

<sup>32</sup> The CPSU pediatrician was not notified when subsequent concerns were raised about medical follow-through.

On June 10, the CPSU psychiatrist met with Charlie's mother, who talked about the difficulties of being a single parent of a child with complex needs. She told the psychiatrist that she had a small budget, was frustrated and tired and had limited social connections. She expressed anger toward the medical system and the community pediatrician, whom she said had promised her that *"he would not let Charlie fall through the cracks anymore."* She also said she hadn't been persistent enough herself in seeking medical care for her son and added that she would be more assertive in seeking resources in the future.

The CPSU psychiatrist documented her initial impressions in a report to the CPSU pediatrician, saying that Charlie's mother appeared to be mildly, situationally depressed, which was related to being the primary parent to a child with multiple complex needs and having limited supports. The psychiatrist strongly recommended a case manager for Charlie's family as well as assistance with transportation to appointments and school, a dietician to improve Charlie's nutrition, and regular respite to allow Charlie's mother *"to have some time for herself away from the constant attention needed by a challenging child."* The CPSU hospital social worker informed the MCFD child protection worker that the psychiatrist had seen Charlie's mother. The only subsequent documentation on the MCFD file said that the mother was not depressed. The MCFD child protection worker was not copied on the psychiatrist's report.

The child protection social worker completed a home visit on June 11, 2009 and met with Charlie's mother, who had just moved into a new basement suite with Charlie and his brother. Charlie's mother told the worker that the medical system had failed her and that she was overwhelmed. Charlie was not present during this home visit, as he was still in hospital, and neither was his brother. The child protection worker discussed the reported protection concerns with Charlie's mother and offered services, which the mother said she did not require. The child protection worker informed Charlie's mother that MCFD would need to *"wait for medical evidence"* prior to concluding its investigation.

The child protection social worker received the CPSU pediatrician's report on June 23. As previously noted, this letter made clear the CPSU pediatrician's concerns regarding Charlie's condition, the lack of medical follow-up, the potential of neglect, and the need for ongoing monitoring and services to Charlie and his family. On this same date, Charlie was transferred from BCCH to Sunny Hill for further rehabilitation and assessment. Despite numerous specialists seeing Charlie while he had been at BCCH, there was still no underlying medical explanation for his osteopenia, failure to thrive, or inability to walk.<sup>33</sup>

Charlie's mother informed Sunny Hill that she had a new family doctor and provided consent for him to receive all medical documentation. This doctor was copied on all subsequent medical letters and reports from Sunny Hill. Charlie's mother stated that she did not want his father involved in Charlie's care and that there was no legal custody agreement in place.

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<sup>33</sup> Osteopenia refers to bone density that is lower than normal peak density but not low enough to be classified as osteoporosis.

Charlie remained an inpatient at Sunny Hill from June 23 to Sept. 14, 2009. While at Sunny Hill, he received a variety of rehabilitative therapy services and medical interventions. These included physician monitoring, ongoing testing to determine if there was a medical explanation for his failure to thrive, unexplained weight loss and osteopenia, physiotherapy, psychology services, speech and language pathology, occupational therapy and dietician services. In July 2009, Charlie had a procedure to insert a gastrostomy tube (G-tube) into his abdomen, as it was clear his diet still did not meet nutritional needs.<sup>34</sup> His mother received training on how to care for the G-tube, and NSS was enlisted to train support staff at his future school.

At Sunny Hill, Charlie was also formally diagnosed with autism on July 14, 2009. His assessment indicated that he developmentally functioned at the level of an 18- to 22-month-old. Charlie's assessment was sent to Community Living BC (CLBC) and, in early August 2009, he became eligible for autism funding.<sup>35</sup> A CLBC facilitator subsequently met with Charlie's mother at Sunny Hill to explain the autism funding program and have her sign the autism funding agreement. A wait list assessment was completed by the CLBC facilitator. It indicated that Charlie's disability-related support needs were significant and that he required a support person with him at all times when awake.<sup>36</sup>

### Community Living British Columbia (CLBC)

CLBC is a provincial Crown agency, mandated under the *Community Living Authority Act*. CLBC funds supports and services through service agencies for adults with developmental disabilities and their families. On July 1, 2005, responsibility to provide these services to children was transferred from MCFD to CLBC. On Oct. 31, 2009, responsibility to provide these services to children was transferred back to MCFD.

Charlie's mother was notified by letter on Aug. 27, 2009 that Charlie was now eligible for \$6,000 a year until he turned 19 to assist with the cost of purchasing autism intervention services such as behavioural supports, physical therapy, occupational therapy and speech and language therapy.

Following her meeting with Charlie's mother, the CLBC facilitator submitted a referral for a behavioural consultant.<sup>37</sup> The referral outlined Charlie's complex medical

and developmental needs, including his extreme rigidity around food, and noted that Charlie's behaviours had interfered with his rehabilitation as he refused to do exercises

<sup>34</sup> A gastrostomy tube is inserted in the abdomen and provides access for long-term administration of nutrition.

<sup>35</sup> The Children and Youth with Special Needs (CYSN) program provides funding for families of children with autism spectrum disorder to assist with the cost of purchasing eligible autism intervention services, as well as equipment and materials related to interventions. There are two funding streams: families of children with ASD under age six can access up to \$22,000 per year and families of children ages six to 19 can access up to \$6,000 per year.

<sup>36</sup> The disability-related support needs of the child/youth must be considered in relation to the expected support needs of same-age peers. The wait list assessment looks at the supports the child/youth requires specifically related to his/her disability.

<sup>37</sup> A behavioural consultant is a professional who conducts assessments, develops intervention plans, trains parents and behaviour interventionists, and monitors the implementation of intervention plans. A behavioural consultant has education and experience in ASD and Applied Behaviour Analysis and is a member of the Registered Autism Service Providers (RASP) network.

to strengthen his legs. The goals of the referral were to reduce the behaviours interfering with Charlie's therapy and to establish a communication system for Charlie.

When the MCFD child protection worker received Sunny Hill's confirmation of Charlie's autism diagnosis, she contacted his mother who said she was "shocked." The child protection worker's notes show she explained to the mother that *"there was no clear evidence showing that she caused his 'failure to thrive' . . . [but] if she [didn't] follow through with the recommendations, MCFD would be taking a more predominant role and may be more intrusive."*

The child protection worker recorded finding no evidence that he had been neglected or deprived of necessary health care or that his mother was unable to care for him. With her team leader's approval, she closed the investigation on Aug. 5, 2009, finding that *"Charlie [was] not in need of protection under the CFCS Act."* The MCFD file remained open for ongoing monitoring and voluntary support services. The investigating social worker did not see or interview Charlie, his father or his brother prior to closing the investigation. The worker made a referral for another family outreach counsellor once Charlie returned home to help educate his mother about his needs and help her with both coping skills and finding community supports.

Charlie's Sunny Hill pediatrician began planning for his discharge in August 2009 by making a referral to a community pediatrician. This referral indicated that Charlie had made gains while at Sunny Hill but that there was still no underlying diagnosis for his presentation. The Sunny Hill pediatrician contacted a pediatrician from the biochemical diseases department at BCCH, indicating he was worried that Charlie may not receive the medical follow-up he needed once discharged. He requested that this biochemical diseases pediatrician see Charlie while he was still an inpatient at Sunny Hill. As a result, Charlie received further tests in metabolics and genetics.

While at Sunny Hill, Charlie was re-assessed as eligible for full At Home Program benefits, including both medical and respite. On Sept. 11, 2009, his mother received a letter indicating he had been added to the wait list for respite benefits and continued to receive medical benefits. The Sunny Hill dietician requested that the medical benefits program pay for a monthly delivery of a G-tube nutritional supplement to the family and this was approved. The dietician indicated that Charlie had been growing well after the G-tube insertion and would require ongoing tube feeding as a supplement.

After being at Sunny Hill for more than two months, Charlie began staying at his home overnight and returning to the hospital during the day for therapy and nutritional monitoring in September 2009 – a process to help him prepare for discharge. The Sunny Hill social worker contacted the CLBC facilitator to explain that Sunny Hill would not discharge Charlie until he had a behavioural consultant. Despite a considerable wait list for these services, Charlie's case was prioritized, and a consultant was assigned the following day.

## September to November 2009: Charlie's Discharge from Sunny Hill, Transfer of Services from CLBC to MCFD

Charlie was discharged from Sunny Hill on Sept. 14, 2009 – 107 days after being admitted. The discharge meeting included his extensive Sunny Hill care team, the early intervention family support worker, his future community school team, his CLBC facilitator, and his mother and grandmother. The family support worker told RCY investigators this discharge meeting, held on Sept. 9, was extremely tense and that Charlie's mother *"was very difficult to work with."* The family support worker said it was clear from the meeting that the hospital had significant child protection concerns but no MCFD social worker was present for the meeting.

Charlie's discharge summary from Sunny Hill, dated Sept. 28, 2009, said: *"Despite the involvement of multiple specialists and numerous tests/imaging, no underlying diagnosis has been found for Charlie's condition."*<sup>38</sup> Medical team notes indicated it was *"possible that Charlie's presentation could be explained by a combination of autism spectrum disorder and malnutrition."* The MCFD child protection worker who carried the service file for the family was not copied on this document.

Promptly after the discharge, Charlie's mother began working with a private occupational therapist who received approval from the At Home medical benefits program to provide Charlie with 24 hours of occupational therapy over a six-month period. This therapy was to assist with skill development and to help his mother understand his sensory system in order to support Charlie tolerating other people. Charlie also began attending Kindergarten at a local school.

The CLBC-referred behavioural consultant made her first home visit soon after Charlie was discharged from Sunny Hill. The consultant also observed Charlie twice at his elementary school and noted that he was progressing well.

Charlie visited his new community pediatrician for the first time in early October 2009. The pediatrician noted that he shuffled on his bottom and used furniture to help him move around. That same month, a family outreach counsellor was assigned after a referral from the MCFD child protection worker. The counsellor had little success working with Charlie's mother, who cancelled four of the six scheduled in-home sessions. The counsellor, who had been keeping the ministry informed that Charlie's mother hadn't been engaging in services, eventually closed the file. The MCFD social worker did not follow up with Charlie's mother to find out why she had cancelled the meetings with the counsellor.

Charlie's first Kindergarten report card indicated that he had only attended school for eight partial days during the term, so no evaluation could be made. The following term, he missed two-thirds of the school days, although the teacher noted that he seemed to enjoy his class. Charlie had a one-to-one special education assistant and a school

<sup>38</sup> Specialists who saw Charlie include those working in genetics, metabolics, rheumatology, ophthalmology, cardiology, neurology, child protection services, gastroenterology and endocrinology.

physiotherapist. He was learning to use visual supports for communication and was working on walking, using furniture as a support. When upset or frustrated, Charlie would hit those who tried to help him, a behaviour his assistant was working with Charlie to modify. By early December 2009, professionals working with the family were expressing concerns to the MCFD child protection worker about Charlie's limited school attendance. The child protection worker visited the home, although RCY investigators could find no evidence that the worker addressed concerns about Charlie's school attendance with his mother.

In November 2009, Charlie's mother received a letter from MCFD indicating that CLBC Children's Services were being transferred to MCFD and would be renamed Children and Youth with Special Needs (CYSN). MCFD assigned Charlie's case to a CYSN worker. At the time his file was transferred to MCFD, Charlie had a wait list score of 86.7, which indicated he was rated as high priority for services. This rating was based on the Priority for Service Tool (PST) used by CLBC.

### Priority for Service Tool (PST) and Priority Score

At the time Charlie was initially assessed, the Priority for Service Tool assessed a family's support needs based on nine areas of consideration, plus one category for "other" considerations. The PST produced a numerical score (the priority score) that summarized the family's need for support. The PST was redesigned in 2017. The PST was, and still is, used when a family requests services or when their circumstances have changed. It is re-administered when the family's circumstances change. CYSN workers are required to offer to meet with families to discuss support needs and complete the PST based on this information. CYSN workers are not directed by policy to consult with other professionals, nor are they required to engage the child in the process. The priority score allows the support needs of one family to be compared to those of other families in their region, on a consistent basis. Families are prioritized as priority level one, two or three with level one families requiring the highest degree of support.

## 2010: Charlie's Family Moves to a New Community and Withdraws from Medical Services

On Jan. 26, 2010, Charlie saw an endocrinologist at BCCH who noted a significant weight gain. Charlie was now 49 pounds, compared to 32 pounds on his May 2009 admission to hospital. That same month, Charlie's behavioural consultant left her position, having provided the family with 36 hours of service from September to November 2009. Her replacement never met with Charlie's family and the family did not receive behavioural consultant services again until the following summer.

In February 2010, Charlie missed his second scheduled appointment with the community pediatrician. The pediatrician's office rescheduled the appointment for April 16 and notified Charlie's mother. Charlie did not attend the rescheduled appointment, either. The community pediatrician told RCY investigators that, looking back on the files now, it appeared as though he *"had been fired."* He had no further interactions with Charlie or his mother and he did not report the missed appointments to MCFD or other medical professionals as he believed Charlie was being followed by the CPSU at BCCH.

In early March 2010, when Charlie was seven, the family moved to a basement suite in a nearby community with more affordable housing – the seventh residence Charlie had lived in since birth. NSS was aware of the move and transferred the family's file. However, RCY investigators could not determine which of the other various service providers involved with the family knew about the move in advance.

Charlie and his mother attended a follow-up appointment with the pediatrician at the BCCH biochemical diseases department on March 12, 2010. The pediatrician concluded that the most likely cause of Charlie's osteopenia was nutritional deficiency. Charlie was now walking without difficulty.

The biochemical diseases pediatrician wrote to Charlie's community pediatrician, indicating that:

*"Because child neglect/abuse issues were raised in the past we should highlight that until the date of issue of this clinic letter, the mom did not do the recommended blood, urine and radiographic investigation from our service and did not do the blood investigations ordered by Endocrinology service."*

This letter was copied to 10 medical professionals, including the CPSU pediatrician at BCCH. MCFD and BCCH records show that the concerns were reported to the involved MCFD child protection worker by the CPSU social worker.

In the ensuing months, with her team leader's consent, the child protection worker closed the family's file. The last documentation on the child protection worker's file was a case note dated April 21, 2010, in which she called Charlie's mother and the number was not in service. The MCFD file remained open with no services or social worker monitoring until August 2010. RCY investigators could find no indication that the child protection worker and her team leader considered Sunny Hill and BCCH concerns of withdrawal from medical services, including the concerns from the biochemical diseases pediatrician, when determining the family's possible need for ongoing MCFD supervision prior to closing the file.

On March 26, 2010, Charlie's CYSN file was transferred to his new community. The transfer record indicated Charlie had received NSS services for the previous two years and that the involved nurse had expressed concern that, once the family moved, they *"might isolate themselves"* and would *"need help to manage their lives."* The transfer stated the family had limited support services and no family doctor. The transfer did not indicate that there had been past child protection concerns regarding Charlie, nor did it indicate his high CLBC priority score.

## Integration Support Teacher and Special Education Assistant

Integration support teachers provide support to school teams for students with special needs. They often help develop Individual Education Plans, adapt and modify instruction and materials, and help determine programming and placement of students with special needs. Integration support teachers can consult with classroom teachers and assist with transitions between schools. Special education assistants work with individual students or small groups of students in a school. They work with the classroom teacher to implement the strategies outlined in a student's IEP. Special education assistants can also utilize behaviour management techniques, help develop social skills, and provide personal care and physical assistance.<sup>39</sup>

Charlie started at his new school on March 30, 2010. He attended five days and was then absent for 28 days. At this school, he received the support of a special education assistant and an integration support teacher.

On April 30, 2010, the CYSN worker assigned to the family completed a home visit. Charlie's mother told the worker that her stress level was reduced, that she had family support and that she loved to care for Charlie. She said she had been taking him to their family doctor regularly, although RCY investigators found no evidence that the mother was taking Charlie to a physician during this period. The CYSN worker noted that *"her GP is monitoring the situation . . . Charlie is receiving Autism funding and Behavioural Support, but nothing else."*

The CYSN worker completed a PST assessment. Charlie's priority score was 53.3, relatively low compared to his 2009 score of 86.7.<sup>40</sup> The CYSN worker completed a Service Request and Support Plan and Charlie's mother indicated the family's top three needs were respite, a child and youth care worker and behavioural support. She rated respite as her highest need.

In May 2010, a new behavioural consultant was assigned to Charlie's file. After several weeks, the behavioural consultant was able to arrange a meeting with the mother and resumed services with her in July 2010. After Charlie returned to school in September 2010 for four hours a day, the behavioural consultant also observed him at school twice.

Charlie's school report card for December 2010 noted increasing his attendance as a continued goal and added: *"Charlie has come so far already. We can't wait to see what he can accomplish in the coming school term."*

## 2011: Charlie's Family Withdraws from School and Behavioural Support Services End

The behavioural consultant continued to work with Charlie, his mother and his school into the spring of 2011. By March, Charlie was attending school for the full day with the support of a full-time special education assistant, and the behavioural consultant's notes indicated that he displayed almost no behavioural challenges at school.

By April 2011, the behavioural consultant's contract hours had ended, and all of the service goals had been achieved. The consultant wrote a discharge report which was sent

<sup>39</sup> British Columbia. Ministry of Education. Special Education Services: A Manual of Policies, Procedures and Guidelines. Victoria, BC: Ministry of Education, 2011. Available from [https://www2.gov.bc.ca/assets/gov/education/administration/kindergarten-to-grade-12/inclusive/special\\_ed\\_policy\\_manual.pdf](https://www2.gov.bc.ca/assets/gov/education/administration/kindergarten-to-grade-12/inclusive/special_ed_policy_manual.pdf)

<sup>40</sup> Based on the region the family was residing in at this time, a priority score of 53.3 was considered low. RCY investigators could not determine whether the worker knew about Charlie's 2009 score.

to Charlie's CYSN social worker and shared with Charlie's mother. In May 2011, NSS services to the family also ended.

On June 15, Charlie's elementary school principal contacted MCFD, expressing concern about the boy's poor attendance. Although Charlie had worked up to spending some full days at school in March, by June he had only attended 95 out of 175 possible days of the school year, many of these partial days following phone call reminders to his mother. The principal told MCFD that there were many services and supports the school could provide to help address Charlie's autism and developmental needs. The principal explained that her school had been trying to work with Charlie's mother on strategies to help him return to school.

*"He has great capabilities. Though non-verbal, he has made great growth."*

– Charlie's school principal to MCFD in June 2011

The child protection worker who took the call summarized the principal's concerns as a report of parental neglect by not bringing Charlie to school. The report was sent to the local team and assigned to a child protection worker for a family development response assessment.<sup>41</sup> After the social worker had gathered information about the family's history with MCFD, she consulted with her team leader. They decided to respond by offering the mother voluntary support services rather than completing a family development

### Section 13 Child Protection Concern

The *Child, Family and Community Service Act* outlines circumstances when a child is in need of protection under section 13. The Director (MCFD or a Delegated Aboriginal Agency) is required to assess a child's need for protection when they receive a report containing one or more concerns listed in s.13 of the Act.

response assessment. The reason for this, as documented by the child protection worker, was that *"no significant child protection concerns were present; not attending school does not meet requirement for a section 13 concern."*

The team leader directed the child protection worker to contact Charlie's mother by phone, discuss the circumstance of the report and offer supports. During that call, Charlie's mother explained that he had experienced an outburst at school during

which he tried to hit his teacher. Since that incident, she said Charlie had panicked at the idea of going to school. She added that the teacher didn't understand why Charlie had responded aggressively and the school hadn't listened to her advice on how to manage Charlie's behaviour. Charlie's mother told the social worker that the new school year would be a fresh start and that she would contact her CYSN worker if she required special needs services. With her team leader's approval, the child protection worker closed the file.

On Sept. 20, 2011, the same child protection worker received a phone call from Charlie's mother. Although the file from June had since been closed, the social worker documented this conversation and placed her notes on the closed file. The worker noted that Charlie's

<sup>41</sup> A family development response assessment is an approach to child protection reports in which the risk of harm can be managed through the provision of intensive, time-limited support services. A family development response includes a strengths-based assessment of the family's ability to safely care for a child. It can include, with the family's consent, contact with collateral sources who are able to provide further information on family circumstances.

mother informed her that her son had attended school the first week but had a “*melt down*” during the second week. She told the social worker that since then she had been unable to get Charlie to return to school. Charlie’s mother said she had a meeting with the family’s CYSN worker and that she planned to withdraw Charlie from school and enrol him in a homeschool program. The social worker’s notes said Charlie’s mother “*wants to keep MCFD in the loop as she doesn’t want it to seem like she is neglecting her child.*”

A day later, Charlie’s principal called the CYSN worker to repeat her concern that Charlie’s mother had withdrawn him from school. The CYSN worker called Charlie’s mother to discuss the situation. Charlie’s mother explained that she was homeschooling her son and that she had spoken to a child protection worker who had agreed with this plan. The CYSN worker did not follow up with the child protection office regarding this matter.

The following week, the CYSN worker met with Charlie’s mother at her home and completed an updated PST. The CYSN worker noted that Charlie was home and “*playing in another room.*” RCY investigators could find no evidence that the CYSN worker saw Charlie during this visit. Charlie’s mother said that she wanted to work with her previous behavioural consultant and the CYSN worker said that he would complete another referral for this service to be put in place. Charlie’s mother said that her son was being homeschooled and that he seemed to be enjoying his schoolwork. She also told the CYSN worker that Charlie’s behaviours had become more challenging, which the worker reflected in an increased PST score (62.2) from this visit.<sup>42</sup> Following the visit, the CYSN worker made a new referral for behavioural support services, with a goal to address Charlie “*not wanting to attend school.*” Despite the referral, the family did not receive behavioural support due to the wait list for services and their low PST score.

Charlie’s mother officially withdrew him from school in October 2011, with the reason given in his permanent school record as “*unknown.*” Although the timeline is unclear, at some point after she withdrew Charlie, his father moved in again with the family for a short time.

## 2012 to 2013: Charlie and his Mother Alone with No Support Services, Medical Services or School Services

Due to the family’s considerable isolation and the lack of services involved with them, RCY investigators were unable to uncover many details about Charlie and his mother between 2012 and 2013. It appears their CYSN worker had no contact with the family during these two years.

On Jan. 20, 2012, Charlie’s mother received a phone call from a school district physiotherapist inquiring about his need for services. Charlie’s mother told the physiotherapist that he was being homeschooled and that the family had been under a lot of stress. She said Charlie was now walking on his tip-toes and did not need physiotherapy. The school physiotherapist nevertheless provided Charlie’s mother with a list of private physiotherapy services that she could access using her At Home funding.

<sup>42</sup> Based on the region the family was residing in at this time, a priority score of 62.2 was considered low priority for service.

At some point during the latter part of 2012, Charlie's father moved out of the family home for the final time. The parents' older son, now 17, left shortly after this due to an incident between him and his mother. There was no formal custody arrangement and Charlie's mother did not permit the father to see Charlie again. Charlie's father resumed paying monthly financial support after he moved out, which was dropped off at the mother's home by the older son. In addition to these monthly drop-offs, Charlie's brother tried to see Charlie at least once a week.

The only known contacts with services in 2013 occurred when Charlie's mother visited an income assistance office to complete an employment plan and when she went to their family doctor.<sup>43</sup> According to the doctor's notes, Charlie's mother "*represented*" him in July, reporting that the boy had "*social anxiety*" and could not attend the appointment. When she told the doctor about Charlie's frequent violent outbursts, she was prescribed 50 tablets of Ativan for him.<sup>44</sup>

## Prescribing

Prescribing for a patient solely on the basis of mailed or faxed information, or an electronic questionnaire, or counter-signing a prescription issued by another physician, without direct patient contact, is not an acceptable standard of medical practice. The provision of a prescription to a patient is a medical act. It is the result of a clinical decision made by a physician subsequent to a comprehensive evaluation of the patient by that same physician. This evaluation should be based on a face-to-face encounter with the patient, which includes the usual elements of clinical assessment such as the taking of a history, conducting a physical examination and any necessary investigations, and reaching a provisional diagnosis. Patient records should clearly reflect that the pertinent elements of the patient evaluation have been completed and documented. In situations where the patient is known to the physician, and where he or she has current knowledge of the patient's clinical status from previous encounters, a prescription may be provided on the basis of a more focused clinical evaluation.<sup>45</sup>

Members of the public who believe that a physician has not met a care standard (e.g., the physician provided inadequate treatment or care of a medical condition or the physician was inappropriate or unprofessional in conduct) can submit a complaint to the BC College of Physicians and Surgeons. The College investigates complaints submitted with a review of medical records, written statements, and interviews when required.<sup>46, 47</sup>

<sup>43</sup> An employment plan is mandatory for individuals receiving income assistance. It is a personalized plan that lists the steps you can take to find a job and is developed with an employment assistance worker.

<sup>44</sup> Ativan is a medication commonly used to treat the acute effects of anxiety disorders. Sedation is a common side effect.

<sup>45</sup> Professional Guideline – Prescribing Practices, Countersigning Prescriptions and Internet Prescribing, BC College of Physicians and Surgeons, <https://www.cpsbc.ca/files/pdf/PSG-Prescribing-Practices-Countersigning-Prescriptions-Internet-Prescribing.pdf>

<sup>46</sup> The College of Physicians and Surgeons regulates the practice of medicine under the authority of provincial law. All physicians who practise medicine in B.C. must be registrants of the College.

<sup>47</sup> College of Physicians and Surgeons of British Columbia, "File a complaint," last modified 2018, <https://www.cpsbc.ca/for-public/file-complaint>.

## 2014: Contact by CYSN and MCFD Child Protection

The family doctor wrote further prescriptions for citalopram<sup>48</sup> and quetiapine<sup>49</sup> for Charlie following a home visit in April 2014. In June 2014, the doctor wrote another prescription for Charlie for quetiapine and faxed it directly to the pharmacy without seeing Charlie.

The CYSN worker's third contact with Charlie's mother occurred on May 30, 2014. The worker attended the family home and reviewed the PST, which remained the same as the 2011 score – 62.2.<sup>50</sup> The CYSN worker documented having minimal contact with the family but noted that Charlie's mother said everything was going well and that she was still homeschooling Charlie. Charlie's mother requested a referral to behavioural support services and the CYSN worker completed this referral, indicating that the two priority areas to work on with Charlie were *“safety awareness and communication.”* RCY investigators could find no documentation that Charlie himself was seen by the CYSN worker during this visit.

The referral form indicated that families with priority service scores under 70 would only be eligible for group parent education through a community agency that specialized in providing services to children with special needs. The CYSN worker did not let Charlie's mother know that she was ineligible for behavioural consultant services. And she didn't receive group parent education, either, because the community agency was unable to make phone contact with Charlie's mother. The CYSN file remained open but inactive.

In late August 2014, MCFD received a report from an income assistance worker who was concerned about 11-year-old Charlie not being in school, as his mother had called the worker to ask for funding for homeschooling with Hooked on Phonics.<sup>51</sup> The child protection worker who took the report reviewed the family's prior involvement with MCFD and highlighted that the most recent report received on the family had also involved school attendance. The child protection worker consulted with her team leader, who indicated that no further action would be taken regarding the call as *“there [were] no section 13 concerns.”* The file was closed.

That same summer, Charlie's maternal aunt came to stay in the family home. She had a significant history of substance misuse and was preparing to enter a detox program. This aunt reintroduced Charlie's mother to a male friend, who soon moved into the home

<sup>48</sup> Citalopram is a medication commonly used to treat the symptoms of depression. Possible side effects include agitation, stomach aches, diarrhea, irritability, headaches, and sleep disturbance. In rare cases, increased thoughts of suicide can be a side effect.

<sup>49</sup> Quetiapine is a medication commonly used to treat psychotic symptoms. It is also sometimes used to manage aggressive behaviours. Common side effects include drowsiness, decreased appetite, weight gain, dizziness, dry mouth, congestion, blurred vision, muscle tightness and spasm, rolling eyes, restlessness, general motor slowing, tremor, and tenseness.

<sup>50</sup> Based on the region the family was residing in at this time, a priority score of 62.2 was considered low priority for service.

<sup>51</sup> Hooked on Phonics is a program that can be purchased online that is described as a method of teaching children to read through recognizing the sounds that letters make.

and became the mother's boyfriend. The aunt did not complete detox as she started using substances again. Charlie's mother and her sister fought over this and the sister did not return to the home after the detox attempt.

According to members of the family, once this man moved in, the behaviour of Charlie's mother changed significantly. Family members told RCY investigators that Charlie's room had always been cluttered and dirty compared to the rest of the home, which was tidy. But they said his room was now worse, covered with garbage and dirty diapers. Charlie's mother was sleeping more, losing weight, and exhibiting paranoid behaviour. Although Charlie's brother kept visiting, his mother stopped letting him see Charlie, always saying that Charlie was sleeping.

## 2015: Mother's Mental Health Declines and Police Make a Child Protection Report

In 2015, the family's situation deteriorated significantly. Charlie had not been at school for four years, since 2011, and still had no special needs or comprehensive medical services. Charlie's mother went to the family doctor on Jan. 9. Based on the mother's reports – and again without seeing Charlie – the doctor wrote him prescriptions with refills for Ritalin,<sup>52</sup> oxazepam<sup>53</sup> and valproic acid.<sup>54</sup> RCY investigators could find no records to indicate why the doctor prescribed these drugs.

In early 2015, those who knew Charlie's mother also began to notice a change in her behaviours. She appeared to have lost a lot of weight, was often heard fighting with her boyfriend, and frequently left her residence without Charlie. When concerned family members asked Charlie's mother about her weight loss, she told them that she had breast cancer and that a doctor was providing chemotherapy in her home, an explanation she also repeated to other people she knew. RCY investigators could find no records indicating Charlie's mother received any cancer-related diagnosis or treatment.

In the summer of 2015, Charlie's brother was hospitalized after he was hit by a car. His mother visited the hospital and family members described her as exhibiting odd behaviour including talking to herself. They also continued to be surprised by how much weight she had lost. She explained that she had just finished a round of chemotherapy.

Neighbours and family members noticed the mother's mental health had significantly deteriorated by the fall of 2015. Charlie was last seen by neighbours in the late summer of 2015 and this was also the last time the landlord was in the family's suite. The landlord

<sup>52</sup> Ritalin is a medication used to treat the symptoms of ADHD. Side effects can include loss of appetite, insomnia, dizziness, rebound phenomenon (worsening of symptoms when medication wears off), irritability, sadness, moodiness, agitation, and growth problems.

<sup>53</sup> Oxazepam is a medication commonly used to treat symptoms associated with anxiety disorders. Side effects include sedation, drowsiness, and decreased mental acuity.

<sup>54</sup> Valproic acid is most commonly used as an anti-seizure medication. Common side effects include diarrhea, dizziness, hair loss, blurred vision, tinnitus (ringing in the ears), unsteadiness, and weight changes.

did not see Charlie or his room because Charlie's mother said it would "*set him off.*" One neighbour later reported to police that she knew something was seriously wrong when Charlie's mother started asking people if they heard voices in her vents and telling people that she was being recorded.

Charlie's maternal grandfather passed away on Nov. 13, 2015. This was a difficult time for Charlie's mother as she and her father had been extremely close. Family described both maternal grandparents as frequent providers of financial and care support for Charlie and his mother, and that they were Charlie's "*comfort people.*"

When family members told Charlie's mother that her father was dying, she refused to go to the hospital and she did not attend his funeral. Relatives visited her home after her father died. Charlie remained in his room during this visit. The mother was described to RCY investigators as looking ". . . *horrible . . . she looked really gaunt and skinny . . . talking a mile a minute.*" Charlie's mother accused a family member of spying on her and placing a camera in her home. Some family members suspected that the mother was using substances, due to her behaviour and dramatically altered physical appearance.

On Nov. 22, 2015, MCFD's Centralized Screening Unit received a child protection report on the family – the seventh such report since Charlie's birth.<sup>55</sup> Police reported receiving a call from Charlie's mother saying that she was hearing voices, and that people were in her backyard and listening to her through the stove vents. Police found that the home was clean and that there were no concerns with Charlie's mother, indicating that she was able speak coherently and was not agitated. The police informed MCFD that Charlie's mother told them that he had autism and that he was sleeping at the time. The police did not see Charlie or his room. Police had no concerns that Charlie's mother was an immediate risk to herself or others and concluded their involvement.<sup>56</sup>

The child protection worker who received the report from police completed a brief initial review of the family's history with MCFD but did not indicate that there was an open CYSN file (with no services being provided). The report was forwarded to the family's local MCFD child protection office. The following morning, the file was reviewed and assigned to a child protection worker there. The worker completed a screening assessment, which indicated there were allegations that "*the parent [was] unable or unwilling to care and had not made adequate provision for child's care*" and that a protection response was required.<sup>57</sup>

<sup>55</sup> MCFD has implemented Provincial Centralized Screening for child protection that provides service across the province. The objectives of Provincial Centralized Screening are to (i) meet the needs of children and families in the screening process; (ii) improve consistency and efficiency of screening; (iii) expand screening coverage to 24 hours per day, seven days per week; and (iv) free up time for teams to use other resources for community- and family-based services.

<sup>56</sup> Had Charlie's mother been considered an immediate risk to herself or others, police may have apprehended her under the *Mental Health Act* to take her to a hospital for a mental health assessment.

<sup>57</sup> A protection response occurs when there is an allegation of a s.13 concern. A screening assessment determines whether a s.13 report requires a protection or non-protection response. For those concerns that are screened in as needing a protection response, the screening assessment determines the response priority.

The child protection worker consulted with her team leader and planned to commence a child protection response with a five-day response priority.<sup>58</sup> The child protection social worker completed a detailed review of the family's history with MCFD, which indicated that there was an open CYSN file and outlined all of the previous child protection reports. The worker then documented a plan in her case notes to *“connect with the mother, conduct a home visit, interview the children, meet with the mother's boyfriend, develop a safety plan if needed, offer supports, conduct collateral checks and consult with the team leader.”* She did not contact CYSN at this time.

Over the next four weeks, starting on Nov. 24, 2015, the child protection worker made six unsuccessful attempts to contact the mother by phone. The worker left for a two-week vacation on Dec. 16, 2015 and the file was not covered by another colleague.

## January 2016: Charlie is Removed from his Mother's Care by MCFD

On Jan. 5, 2016, Charlie's brother brought his mother the monthly support money from his father. He recalled that his mother was clearly paranoid, thinking a nail in her bathroom was a camera being used to spy on her. Charlie's brother left the home after an argument with his mother and did not see Charlie or his room.

Late the following evening, the family doctor visited Charlie's mother at the request of his maternal grandmother. Charlie was in his room and his mother told the doctor that her son was sleeping. The doctor suspected that Charlie's mother may have been using substances as she was exhibiting bizarre behaviour including talking to herself and telling him that she was being spied on. Charlie's mother denied substance use and indicated that she was exhausted. She told the doctor that Charlie had recently head-butted her and knocked out two of her teeth. The doctor wrote Charlie and his mother prescriptions for antidepressants and left a note for his assistant to call MCFD, telling her the family needed a *“referral to social services to help [Charlie] socialize and improve [his] education”* and that Charlie's mother needed *“respite to help her recover from all the stress.”*

The assistant contacted MCFD Centralized Screening the next day and sent a referral letter to Charlie's CYSN worker. Centralized Screening sent the record of the call to the child protection worker who had the open file on the family from November 2015. The child protection worker again attempted to contact the mother by phone but was unsuccessful.

The child protection worker visited the home on Jan. 11, 2016 – 45 days after MCFD had received the original report in November 2015. Charlie's mother invited the child protection worker into her home. The worker's case notes from the visit documented that the home was *“clean and tidy [with] no safety concerns observed.”* She did not see Charlie's room. The child protection worker discussed the concerns arising from the November 2015 report with Charlie's mother, who indicated that she was overwhelmed, having

<sup>58</sup> When a child protection concern is found to require a protection response, the response time is determined to be either 24 hours or five days based on an initial assessment. This means that the family must either be contacted within 24 hours or five days of receipt of the report.

challenges with Charlie, and that both she and Charlie had recently been prescribed antidepressants. The mother stated that she had no other mental health concerns. The child protection worker did not ask the mother about the voices she had reported hearing in the vents that prompted the police visit.

The mother told the child protection worker that Charlie was being homeschooled with Hooked on Phonics. She said Charlie was reading online, playing games, counting and saying “Mom.” She also said that he had picked up on sign language and was learning at his own comfort level. Charlie was home during this visit but, when the child protection worker asked to see him, his mother said that he was sleeping and that seeing a stranger would upset him. The social worker agreed, did not see Charlie and made no arrangements with the mother to see him at another time.

Before the social worker left the residence, she asked Charlie’s mother to provide the names of individuals who could comment on how Charlie and his mother were doing. She provided the names of her mother, the family doctor and her boyfriend. The child protection worker did not contact these people for follow-up. Charlie’s mother told the child protection worker that she needed support and respite care and that they had been on a respite wait list for six years. When the worker returned to her office, she emailed the CYSN worker saying she had visited the family and that they required support. The child protection worker and CYSN worker planned to visit the family together.

On Jan. 20, 2016, 54 days after the child protection report by the police, MCFD Centralized Screening received another report expressing concern for Charlie and his mother. A concerned citizen had seen Charlie’s mother outside her residence late the previous night talking to herself, appearing to be confused and hallucinating. The caller had concerns for Charlie, considering his mother’s state, his autism and his medical needs and stated that Charlie had been left home alone. The Centralized Screening social worker then followed up with the police, who said that they would visit the family residence to check on the well-being of Charlie and his mother.

When the police arrived at the residence, they heard screaming from inside the suite. They knocked on the door and Charlie answered. He was covered in what appeared to be sores, dirt and small bruise-like marks. Charlie was naked, smelled of feces and was noted by the officers to be in distress. In their notes, police described Charlie as also appearing emaciated with “*his bones protruding all over [his] body.*” Charlie’s mother was not home and there were no other adults present. Although the rest of the residence appeared tidy, Charlie’s room was in a “*state of filth,*” with a strong smell of urine and feces, a floor “*covered in garbage and soiled diapers, [and] dried fecal matter observed all over the room and smeared on the floor and bed.*” While police were in the home, the mother’s boyfriend returned. When police questioned him about Charlie’s condition and the state of his room, the boyfriend replied: “*That is how he lives.*”

Police contacted MCFD while still at Charlie's home and explained the situation and the boy's condition. They were advised to contact paramedics and transport Charlie to the hospital where an on-call child protection worker would meet them.

When the child protection worker attended the hospital, he was told that Charlie appeared to be suffering from severe neglect. The social worker consulted with his team leader and they decided to remove Charlie from his mother's care because Charlie was *"in need of protection due to serious concerns of neglect."*

## 2016 to the Present Day: Charlie after the Critical Injury

Charlie remained in hospital on the pediatric ward for six weeks after his admission in January 2016. He was diagnosed with social neglect, failure to thrive and tooth decay at the time of discharge. Charlie weighed 65 pounds when he was admitted to hospital in January at age 12, significantly less than the average weight considered healthy for a male his age, which is roughly 100 pounds.

As Charlie was unable to walk when he arrived at hospital, medical staff on the pediatric unit put a mattress on the floor to avoid any risk of him falling and breaking his already weakened bones. RCY investigators were told by a number of professionals involved with Charlie while he was hospitalized that the only two words he said were *"home"* and *"Mom"* and he repeated those words. RCY investigators were further told that

*"It was hard to see him. He was like a feral child. That's the way I would describe him. He couldn't walk. He kept saying 'Mom' and 'home' which was really hard because he obviously wanted his mother . . . and he had obviously been neglected for a very long time."*

– Hospital social worker

several professionals who saw Charlie at hospital were emotionally impacted and traumatized by his physical state. When he was first admitted, the only foods Charlie would eat were McDonald's chicken nuggets and Twinkies.

Charlie underwent several medical tests and treatments while in hospital. All his teeth were removed because they were rotten. He received a bone scan and was found to have severe osteopenia resulting

from nutritional deficiency. His vitamin D levels were extremely low, leading to concern from medical staff about when he had last been in the sun.

The police commenced an investigation on Jan. 21, 2016 into Charlie's mother for failure to provide the necessities of life.<sup>59</sup> Police searched the family residence on Jan. 22 and documented that the first thing noticed by officers when the door to the suite was opened was that *"the smell was putrid and overpowering."* Police documentation further noted Charlie's bed was covered in used diapers and the floor was covered in garbage with a large brown stain. A letter was found on the kitchen counter written by the child protection worker who had been involved with the family in 2009 indicating the *"investigation found that Charlie was not in need of protection."*

<sup>59</sup> According to s.215 of the *Criminal Code of Canada*, an offence is committed if an individual fails to provide those things necessary to preserve life, such as food, shelter, medical attention and protection from harm to a person under his or her charge.

When police interviewed the mother's boyfriend, he said he had never seen Charlie's room. He added that the mother's mental health had been declining and she had been paranoid and talking to herself. He denied that he and Charlie's mother had been using substances.

Charlie's mother told police that she thought they were meeting with her to perform an exorcism because she was possessed by her grandfather whom she believed had harmed her in the past. The police detained her under the *Mental Health Act* and transported her to the local hospital.<sup>60</sup> Charlie's mother was assessed by a psychiatrist. Hospital records described her as "*paranoid, grandiose and delusional.*" She tested positive for methamphetamines and was kept on the psychiatric ward for a week due to "*drug-induced psychosis.*"<sup>61</sup>

On Jan. 22, Charlie's father spoke to a social worker at MCFD. He said that Charlie's paternal grandmother had informed him Charlie had been brought into care. Charlie's father informed the social worker that he had not seen Charlie for about 3½ years. He said that he had not spoken to Charlie's mother since August of the previous year when their elder son had been hit by a car.

In subsequent conversations in March 2016, Charlie's father informed the MCFD social worker that he was First Nations and connected to a community in northwest B.C. Upon learning this, the MCFD social worker notified the First Nation by phone about Charlie's removal and subsequently faxed the First Nation court documents.

In July 2016, court documents pertaining to MCFD's application for Charlie to remain in the temporary care of MCFD were served to the First Nation. Although Charlie had been identified as an Aboriginal child, his file was not transferred to an MCFD Aboriginal office.

The MCFD social worker responsible for Charlie's file met with his mother on Feb. 2, 2016 on the hospital psychiatric ward. The social worker's case notes from this meeting indicate that Charlie's mother was unsure why MCFD had become involved and she appeared "*shocked*" when the social worker informed her that Charlie had been removed from her care. The social worker noted that Charlie's mother did not seem to understand what had happened. She acknowledged that she was provided "*white papers*" which the social worker indicated in her notes were court documents outlining the reasons for Charlie's removal. Charlie's mother told the social worker that she had been struggling "*forever.*" She denied that she had ever used substances and could not explain why crystal meth was found in her system.

Several individuals, including medical professionals, neighbours and family members, were interviewed by police as part of their investigation. The file was concluded after the investigating officer and his supervisor consulted with Crown Counsel and determined

<sup>60</sup> Under B.C.'s *Mental Health Act*, a person can be "*certified,*" meaning that the person is detained in a hospital or other mental health facility.

<sup>61</sup> Drug-induced psychosis is a diagnosis that refers to a person experiencing psychotic symptoms, such as hallucinations (i.e., hearing, seeing, feeling, smelling things that are not real) or delusions (i.e., believing things to be true that are not real) as the result of substance use.

that Charlie's mother would not be charged due to the overall circumstances of the case and the mother's mental state. The investigating officer offered the following opinion in his concluding report:

*“After reviewing the relevant medical history, it is reasonable to conclude that [Charlie's mother] was never truly capable of caring for a severely autistic child suffering from numerous other complex medical issues. The failure to provide adequate care for [Charlie] and his resulting failure to thrive cannot be attributed to [his mother] alone. Starting at the age of five and throughout [Charlie's] life, medical professionals, health care providers and social services [MCFD] were well aware of significant health concerns . . . Despite these serious re-occurring health complications, [Charlie] was not removed from [his mother's] care.”*

Charlie was discharged from hospital on March 8, 2016, six weeks after he was admitted. He was placed in a specialized resource that MCFD had created for him, referred to as a therapeutic home. Before his discharge, the agency staff members who were going to be primarily working with Charlie began going to the hospital to visit him and receive training, including how to feed him through his G-tube.

When Charlie arrived at his new home, he was only able to walk short distances and was unable to use the toilet, feed himself or dress himself. Once there, he received occupational therapy, behavioural support services, speech and language therapy, physiotherapy and life skills support. About a month after arriving at the therapeutic home, he began walking without difficulty. Charlie's primary caregiver focused on building a relationship and trust with him. The staff at the home developed a nutritional plan for Charlie and he was soon eating a variety of food and gaining weight. As soon as he had stabilized in his new placement, Charlie's father, brother and paternal grandmother were able to visit him in the therapeutic home.

On June 21, 2016, a meeting was held at Charlie's future school, to ensure a multi-disciplinary wraparound approach to supporting his transition back to school. Participants included his social worker, a front-line worker from the therapeutic home and several school district staff.

Team members discussed Charlie's various developmental needs, his strengths and areas for growth. Plans were made to facilitate a gradual transition to school and ensure consistent school support including intensive speech-language support in combination with a pictorial communications system, access to a quiet work space at school and completion of required assessments.

Arrangements were made for a teacher and district education assistant to visit the therapeutic home to meet Charlie and facilitate his return to school. As part of this planning, later that summer Charlie's primary caregiver started familiarizing him with the school. This caregiver told RCY investigators that he took Charlie to his school during the summer break and, once school started in September 2016, Charlie gradually started attending with the caregiver. Within a month, he attended his first full school day.

When Charlie was discharged from the hospital, he also was assigned a community pediatrician who had been involved in his care while he was in hospital in January 2016. This pediatrician's October 2016 records indicated that Charlie now weighed 91 pounds and was eating "a wide variety of foods." On the pediatrician's recommendation, a surgeon removed Charlie's G-tube in November 2016. By February 2017, a year after Charlie's hospitalization, he weighed 98½ pounds. The pediatrician told RCY investigators that Charlie was thriving in his new environment, saying: "He is getting proper nutrition, he's happy, he's walking, he's not in diapers anymore . . . he has made lots of progress." The pediatrician still follows Charlie closely.

In January 2017, during a family group conference meeting,<sup>62</sup> Charlie's father, brother, paternal grandmother and paternal relatives created a family plan through which Charlie could be placed in their care. The plan was presented to MCFD and included several tasks that required completion over a six- to 12-month period in order to allow the family to care for Charlie. At the time of this meeting, Charlie's father was visiting him two to three times a week and he had strong support from his family.

On June 30, 2017, Charlie moved from his therapeutic home to a family care foster home with a single caregiver who specializes in working with children who have complex developmental needs. This move included a nearly two-month gentle transition plan involving both homes and Charlie's MCFD team. A detailed discharge report, written by the therapeutic home program manager, outlined all of Charlie's areas of need when he arrived at the resource and the progress he had made by the time he was discharged. Domains that were covered in the discharge summary in which Charlie made substantial gains included communication, life skills, social development, school placement, community involvement, sensory integration and safety:

*"[Charlie] has shown the ability to learn many new skills in the year he was residing at the [therapeutic home] . . . [Charlie] thrived in an environment that was set up for his needs and that provided structure and predictability. [Charlie] has developed many positive relationships and learned to express his needs and wants in an environment where he felt safe. [Charlie] progressed in all areas and appeared to be ready for a less intensive placement. [Charlie] will continue with his programming and speech therapy in his new placement. A two-month transition plan was carefully planned out to ensure [Charlie's] programming was transferred over to his new foster placement and will continue to develop his daily functional skills . . . Further recommendations were made under each domain to ensure ongoing service is provided to best support [Charlie] in achieving the highest level of independence."*

<sup>62</sup> The family group conference (FGC) is a process of collaborative planning in situations where decisions need to be made for children or youth. It is a formal meeting where members of a child or youth's immediate family come together with extended kin and members of the child's community who are, or might be, involved to develop a plan for the child.

Charlie's family care foster home does not have built-in supports and services like those in the therapeutic home. He receives supports and services through school and through contracts set up by his guardianship social worker for services such as speech and language therapy.<sup>63</sup> Charlie attends high school under an IEP and takes the bus from his foster home to school. He is in a specialized program for students with disabilities requiring substantial support and has the full-time support of a special education assistant. The family foster home is not in the same catchment area as the school Charlie attended when he was at the therapeutic home, but his social worker and the school district worked together to ensure that Charlie's school situation was not disrupted, and he could remain at the same school he had attended the previous year and where he has positive connections.

In the fall of 2017, Charlie's father and his family met with the MCFD social worker to say that the level of care Charlie required was far higher than they would be able to provide and that they no longer wished to proceed with the plan to have Charlie returned to their care. They said that Charlie was happy and making significant progress in care and they were pleased with the care he was receiving. Charlie's father, brother and paternal grandmother continue to visit Charlie in his current home whenever they are able.

Charlie was seen by his community pediatrician on Nov. 15, 2017. At this visit, he weighed 110 pounds. The pediatrician documented that his eating, toileting and self-care had improved significantly and that he used a "*shower mister to shower as he does not like the feel of water on his body.*" The pediatrician made a referral to the dental clinic at BCCH to determine next steps for Charlie as he may need dentures or dental implants because he currently has no teeth.

In December 2017, an order was made by the Provincial Court to place Charlie in the care of MCFD until he is 19. Both Charlie's father and Charlie's First Nation consented to this order.

In July 2018, Charlie's file was transferred to an Aboriginal guardianship team to provide him with services to support his cultural connection and to conduct further permanency planning. The new social worker responsible for Charlie's care made a referral to the Roots program, which explores a child's cultural connections and extended family for the purpose of permanency planning.<sup>64</sup>

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<sup>63</sup> A guardianship social worker is a professional who is responsible for the day-to-day guardianship decisions for a child in care.

<sup>64</sup> Permanency planning is developing a permanent connection to a significant person or persons who can provide children with the stability and continuity they need to develop into healthy, secure adults. Wherever possible, kinship ties and a child or youth's attachment to extended family are preserved. For Indigenous children and youth, these connections include permanent ties to their Aboriginal community to promote cultural continuity.

# Key Events in Charlie's Story

Legend:

Health
MCFD
School
Police
Other

SEEN



2003    2004    2005    2006    2007    2008    2009    2010

NOT SEEN





**January**  
Police attend family home and find Charlie alone in a state of extreme neglect. Paramedics transport him to hospital.

**January**  
MCFD receives another report of concern about Charlie (**child protection report No. 8**). Charlie formally removed from his mother's care by MCFD (**child protection response No. 4**).

The removal marks first time Charlie is seen as part of an MCFD child protection response.

**January**  
Charlie's third hospitalization, for failure to thrive resulting from severe neglect, begins.

**March**  
Charlie discharged from hospital into therapeutic home.

**June**  
Charlie moves from his therapeutic home to a family care foster home.

**September**  
Charlie returns to school for the first time in five years.

**December**  
Charlie placed in the permanent care of MCFD.

**December**  
Charlie continues to thrive with proper supports and medical care.

2011

**June**  
School principal calls MCFD, concerned over Charlie's lack of school attendance (**child protection report No. 5**). MCFD calls Charlie's mother to offer voluntary services.

2012

**October**  
Charlie's mother withdraws him from school.

Charlie is disconnected from both school and community services at this point.

2013

**August**  
Income Assistance worker calls MCFD, concerned that Charlie is not in school and his mother is requesting funding for Hooked on Phonics. MCFD closes the file without contacting the family (**child protection report No. 6**).

2015

**November**  
Charlie's maternal grandfather dies.

**November**  
Police receive call from Charlie's mother, who is acting paranoid and delusional. Police attend home. Police make report to MCFD (**child protection report No. 7**).

2016

**November**  
MCFD initiates family development response assessment (**child protection response No. 3**).

2017

2018

# Findings and Analysis

## Child Protection

**Finding:** *MCFD did not meet key child protection standards, including seeing Charlie and interviewing others in his family; did not always communicate effectively or heed the advice of health and education officials; closed investigations without sufficient information to safely do so; and did not adequately consider the vulnerability of Charlie and his family due to his special needs. As a result, Charlie was left at considerable risk which contributed significantly to his critical injury.*

In B.C., MCFD is responsible for the delivery of child welfare services. The *CFCS Act* is the legislation that covers the safety and well-being of children, including providing support services to children and families, defining when a child needs protection and providing authority for social workers to intervene to protect children. The Act outlines broad guiding principles that inform MCFD policies, standards and directives.

In Charlie's case, there were multiple instances when MCFD's responses did not adhere to the guiding principles of the Act and when his safety and well-being were not treated as the paramount consideration.

### CFCS Act Guiding Principles

This Act must be interpreted and administered so that the safety and well-being of children are the paramount considerations and in accordance with the following principles:

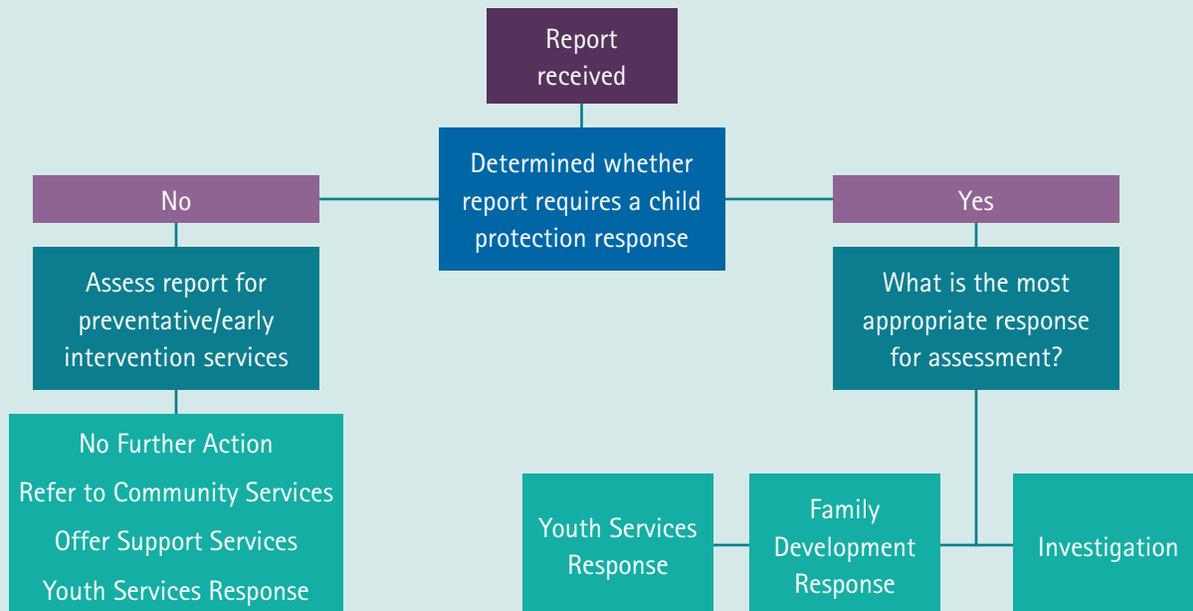
- (a) children are entitled to be protected from abuse, neglect and harm or threat of harm;
- (b) a family is the preferred environment for the care and upbringing of children and the responsibility for the protection of children rests primarily with the parents;
- (c) if, with available support services, a family can provide a safe and nurturing environment for a child, support services should be provided;
- (d) the child's views should be taken into account when decisions relating to a child are made;
- (e) kinship ties and a child's attachment to the extended family should be preserved if possible;
- (f) the cultural identity of aboriginal children should be preserved;
- (g) decisions relating to children should be made and implemented in a timely manner.

MCFD received eight distinct reports regarding Charlie's safety and well-being between 2006 and his removal in January 2016.<sup>65</sup> The ministry determined that four of the eight reports warranted a child protection response. MCFD determined that the four

<sup>65</sup> This total does not include the numerous calls of concern made from community service providers to MCFD that were not treated as individual child protection reports.

other reports did not meet the threshold for a child protection response.<sup>66</sup> The ministry responded to these four other reports by either making a phone call to Charlie's mother and offering support services or closing the file with no follow-up.

### Child Protection Report Pathway



**Child Protection Report** – When MCFD receives a report (in-person, via phone or in writing) from the community with concerns regarding a child's safety or well-being.

### Child Protection Responses

**Investigation** – A pathway to assessing reports of child protection concerns that involve severe physical abuse, sexual abuse or severe neglect, when the parent(s) are unable to participate in collaborative assessment and planning and when there is an open case on a family where at least one child/youth is out of the home due to protection concerns.

**Family Development Response** – Primary pathway for assessing reports containing child protection concerns when the circumstances do not involve severe physical abuse, sexual abuse or severe neglect and when the parent(s) are able and willing to participate in a collaborative assessment.

**Youth Services Response** – A response to a youth in need of assistance that involves screening, assessment and short-term planning and utilization of youth support services. A youth response may also provide a comprehensive longer-term service plan for a youth receiving services for mental health or services through a youth agreement.

<sup>66</sup> The four reports that did not meet the threshold for child protection investigation were reports received in 2006 and 2007 that pertained to police attendance at the family home due to conflict between Charlie's parents, a report about concerns regarding his school attendance and a report with concerns that Charlie's mother was looking for funding for Hooked on Phonics and that he was not in school.

In assessing the eight child protection reports and conducting the three child protection responses that preceded Charlie's removal, and also during periods when Charlie and his family were receiving voluntary services from the ministry, the Representative finds that MCFD did not take sufficient action to protect Charlie in a number of areas, including:

- Compliance with ministry standards – most importantly the need to see a child who is the subject of a child protection response, the need to gather all pertinent information about the child's situation and the need to respond to child protection reports within prescribed time frames
- Communication with health professionals and others outside MCFD, including educators, who were working with Charlie and who expressed serious concerns about his well-being
- Decisions to close child protection files without sufficient information and termination of other services when Charlie and his family were still in need of help
- Consideration of Charlie's extreme vulnerability due to his special needs and the pressures on his family as they attempted to address those needs.

### Compliance with Ministry Standards

Seeing the child is fundamental to any child protection response. Yet, in the three responses conducted prior to the removal of Charlie from his mother's care in 2016, investigating child protection workers never laid eyes on Charlie.<sup>67</sup>

RCY investigators were unable to determine why child protection workers in 2008 and 2009 did not see Charlie during investigations into his safety. In an interview, the worker involved in the 2008 investigation could not recall why she hadn't seen him, although she cited the fact that she was only working part-time at the MCFD office and juggling competing responsibilities while also feeling pressure to close files. Despite not seeing Charlie, the worker wrote to his mother upon closing the file on June 16, 2008, telling her that she was *“doing an incredible job, a job that so many of us could never do . . .”*

The investigating social worker in 2009 did not see or interview Charlie during her home visit as he was hospitalized at the time to receive assessment and treatment for his failure to thrive and unexplained weight loss. She also did not see him during the length of time he was in the hospital. The worker's case notes from that investigation show that interviews with the children in the home were not conducted *“due to the child protection concerns being about Charlie and his undiagnosed ailments.”*

The MCFD child protection worker in the 2015/16 response also visited the home but did not see Charlie as his mother told the worker that her son was sleeping. The worker did not press the issue and could not recall when asked by RCY investigators whether she had planned to see Charlie at a later date.

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<sup>67</sup> The child protection social worker in 2009 saw Charlie twice when she was providing voluntary services but not as part of a child protection investigation.

It is evident to the Representative, through interviews conducted for this report, that the child protection workers tasked with assessing Charlie's safety did not, at the time, fully understand the negative impact of failing to see him.

Not laying eyes on the child who was the subject of a protection response was the most obvious example of social workers' lack of adherence to standards in Charlie's case. But standards also called for social workers to interview other family members who might have shed light on Charlie's need for protection, particularly considering that he is non-verbal.

Social workers in the 2008, 2009 and 2015/16 responses did not interview Charlie's father, older brother or grandparents. Nor did they interview the boyfriend of Charlie's mother, who was living in the home during the 2015/16 response. Child protection workers interviewed only Charlie's mother.

Had the child protection worker in 2008 interviewed Charlie's brother, who was 13-years-old at the time and had a close relationship with Charlie, he might have been able to provide relevant information about his brother's safety and their mother's capacity to meet Charlie's special needs. In retrospect, this child protection worker told RCY investigators that she should have conducted interviews with Charlie's brother and father to gain a better understanding of the family and adequately assess Charlie's safety.

The investigating child protection worker in 2009 told RCY investigators that, in hindsight, she could not believe that she had not interviewed Charlie's brother as this could have provided her with a "better picture" of what was going on in the family. The decision not to interview Charlie's brother was made in consultation with her team leader, who was unable to explain the rationale to RCY investigators. The child protection worker told RCY investigators that she couldn't recall why she hadn't interviewed Charlie's father, who was living in the home at the time, nor did her case notes provide a reason for this decision.

The failure to interview Charlie's brother, father and other involved family members including grandparents was a contravention of policy. Such interviews might have provided more information about Charlie's well-being. For example, social workers might have learned more about his mother's challenges, including her mental health and substance use issues and the impact they may have had on her ability to parent.

*"Charlie was extremely vulnerable. He was non-verbal. At the point of the intervention, he was not in community eyes and that is where I feel that, if I were to repeat this case again, connecting with [Charlie's brother] and perhaps the grandma and the dad would have been more critical."*

– Child protection worker who investigated in 2008

Another key child protection standard is the requirement to adhere to the response time assigned to a file once it has been determined that a child protection response is required – either within 24 hours or within five days.

The November 2015 report about Charlie – when police called with concerns that his mother was paranoid and delusional – was assigned a five-day response. The child protection worker assigned to the file tried to reach Charlie's mother six times by phone without success and it was 45 days before the worker made an unannounced visit to the home.

MCFD policy calls for a child protection response to be completed within 30 days of a report being received. If a response is not completed within 30 days, a supervisor's approval for an extension and a plan for completion must be documented. In the 2015/16 response, the team leader was not consulted about the delay and an extension was not requested by the child protection worker.

At the time of Charlie's removal, following an eighth child protection report, the third child protection response had been open for 54 days (24 days overdue), and the child protection worker on that file still had not assessed Charlie's immediate safety because she had not seen him.

The inability of the child protection worker to meet mandated timelines in 2015/16 was due to multiple factors, including her extremely high caseload and the fact there was no coverage for her when she took scheduled vacation.<sup>68</sup> Team leader oversight of the file was also noticeably missing as the team leader was unaware the file had not been responded to. MCFD confirmed that, in fact, there is no mechanism in place to alert team leaders in such cases where child protection assessments are not meeting required response time frames.

*"We're constantly prioritizing and then reprioritizing. You have a plan to go out to see a family and then something more pressing comes in. Those kinds of scenarios are happening on a daily basis. When you look back in hindsight, we should have gotten out there earlier."*

– MCFD team leader for the 2015 response to report about Charlie

A number of MCFD staff interviewed told RCY investigators that a report with a five-day response priority was unlikely to be responded to within that time frame. As the team leader involved in the case in 2015/16 stated: *"The caseloads in the community are very high and they are very complex."* She told RCY investigators that for her team, which includes experienced staff, *"it is almost impossible"* to respond to files set for five-day responses. She said files with 24-hour response times come in daily and must be responded to immediately.

### Thin Front Line

In October 2015, the Representative highlighted the issue of high caseloads in MCFD offices in the report *Thin Front Line: MCFD staffing crunch leaves social workers over-burdened, B.C. children under-protected*. The report found a dramatic mismatch between the expectations placed on child protection workers and the number of staff available to do the work. Despite the demands and complexity of the job increasing in recent years, there were fewer front-line child protection workers in B.C. in 2015 than there had been in 2002. As a result, timelines set out in child protection standards routinely went unmet and children and youth were too often left in unsafe situations while social workers were increasingly disillusioned and burned out.

<sup>68</sup> MCFD estimates that average caseload for child protection workers in the office responsible for Charlie's file in 2015 was 39 cases.

MCFD policies and standards require child protection workers to review a family's prior history with the ministry when conducting a protection assessment. This did not occur during the 2009 child protection response involving Charlie, which should have included reviewing information about Charlie's 2008 hospitalization.

The social worker who took the initial 2009 call had also been the investigating social worker in 2008. She told RCY investigators that she had made clear to the newly assigned social worker and team leader that the previous concerns had been serious: *"I clearly documented the concerns so that it wouldn't get lost. I made sure it was really clear what the concerns were. I couldn't believe that things had fallen apart. His needs were significant."*

When interviewed by RCY investigators, the investigating child protection worker in 2009 acknowledged that she had not thoroughly reviewed and considered the information about Charlie's 2008 hospitalization in assessing his need for protection.

## Communication and Coordination with Health, Education and Other Professionals

Professionals working in health care, education and the community expressed serious concerns about Charlie's well-being on several occasions between the first child protection investigation involving the family in 2008 and Charlie's removal from his mother's care in 2016. The Representative finds that a lack of appropriate responses by MCFD to these concerns of involved professionals working in other sectors contributed to Charlie's critical injury.

In early 2008, medical professionals began raising the possibility that Charlie was being neglected. Those concerns were relayed to the hospital social worker, who reported them to MCFD, prompting the first child protection investigation into the family. But by the end of Charlie's prolonged hospitalization in 2009, with doctors still unable to detect any underlying medical reasons for his failure to thrive, inability to walk and osteopenia, MCFD closed its second child protection investigation regarding Charlie, citing no child protection concerns.

This was the first in a number of instances in which Charlie's unexplained medical condition should have prompted more scrutiny by MCFD. Instead, the ministry and others involved with Charlie often seemed to rely predominantly on information from the mother. For example, in December 2008, the early intervention family support worker who had been working with Charlie's mother stated in a note left for the worker who would be replacing her that Charlie had *"early childhood arthritis,"* apparently taking his mother's word for this although no such diagnosis had been made.

In May 2009, Charlie's mother brought him to a local hospital because he was still not walking. He was admitted for *"failure to thrive, pain and swelling of both knees, inability to weight bear, [and] unexplained weight loss."* The hospital dietician noted that Charlie appeared malnourished and that his diet was clearly not meeting his nutritional needs – he had lost more than six pounds in the previous seven months. After Charlie was transferred to BCCH, a number of physicians there expressed concerns about neglect, his mother's ability to cope and her delay in seeking medical attention for Charlie. This prompted MCFD's second child protection investigation into Charlie's well-being.

During this hospitalization, Charlie's community physiotherapist called the MCFD child protection worker to report that Charlie's mother would not allow her to treat him. The CPSU hospital social worker also informed the child protection worker that Charlie was being fed through a nasogastric tube due to his extreme weight loss. The hospital social worker also told the MCFD social worker that a CPSU psychiatrist was planning to assess Charlie's mother for possible depression.

The CPSU pediatrician's assessment was that Charlie was a *"very unwell"* child, and that she was *"very concerned about Charlie's condition on admission and the fact that he had not received medical care sooner."* She recommended that Charlie's mother be *"given a chance to follow-up with recommendations"* but noted that *"supports will definitely be needed . . . Close medical follow-up will be needed for some time to be certain that he progressed well. MCFD will hopefully provide support services."* The CPSU pediatrician also asked to be notified if the mother had *"any difficulty following through with medical recommendations."*

These concerns should have alerted MCFD to be more vigilant in assessing whether Charlie was in need of protection. And indeed, in June 2009, the child protection worker indicated that medical opinions were raising concerns about his safety when she informed Charlie's mother that MCFD would need to *"wait for medical evidence"* prior to concluding its investigation. However, despite receiving the CPSU pediatrician's concerns and with still no underlying cause detected for his medical condition, the MCFD social worker, with her team leader's approval, closed the child protection investigation in August 2009 that had resulted from Charlie's hospitalization. The social worker found no evidence that Charlie had been neglected or deprived of necessary health care or that his mother was unable to care for him, noting that *"Charlie [was] not in need of protection under the CFCS Act."*

*"I guess it feels like there's blame attached to the neglect, like it's something that she did to the child . . . by saying that there was not neglect was more trying to honour her struggles and how hard she tried to meet the needs of her child, more than perhaps an accurate reflection of what was there."*

– Social worker who investigated in 2009

The Representative finds it difficult to reconcile that assessment with the medical information and concerns of medical professionals that were being presented to MCFD.

One significant opportunity to connect with health officials was missed when the ministry child protection worker did not attend Charlie's discharge meeting from Sunny Hill on Sept. 9, 2009, despite the fact the ministry still had a file open on the family to provide services.

Service providers who attended the meeting told RCY investigators that they were surprised no child protection worker was present because it was apparent to them that the Sunny Hill medical team was concerned about neglect. The family support worker told RCY investigators this discharge meeting was extremely tense and that Charlie's mother *"was very difficult to work with."* The family support worker said it was clear from the meeting that the hospital had significant child protection concerns.

The MCFD child protection worker had ongoing communication with Sunny Hill during Charlie's hospitalization and would have been aware of the nature of the hospital's concerns.

RCY investigators reviewed the child protection worker's case notes detailing a call from the Sunny Hill social worker the day after the meeting: *“medical overview: we don't know what's wrong with him. Has autism. Unsure why osteopenia/fractures. Still assessing/testing.”* Given this lack of information about what was *“wrong”* with Charlie, the discharge meeting was a significant missed opportunity for both MCFD and Sunny Hill to communicate directly about concerns regarding Charlie and further plans for him.

The Representative concludes that the serious nature of medical professionals' concerns regarding Charlie's health were not properly understood or considered by the ministry. For example, the MCFD social worker believed that Charlie's autism was the cause for his medical concerns and closed the child protection investigation, concluding that Charlie was not in need of protection. However, Sunny Hill staff were confounded that, at the time of Charlie's discharge, they could find no underlying diagnosis for his medical presentation, citing: *“Since hospitalization Charlie has been seen by numerous specialties (Genetics, Metabolics, Rheumatology, Ophthalmology, Cardiology, Child Protective Services, Gastroenterology, Endocrinology). However, no underlying diagnosis has been found at this point.”*

The child protection worker was not copied on the Sunny Hill discharge summary dated Sept. 28, 2009, which indicated that *“no underlying diagnosis has been found at this time . . . it is possible that [Charlie's presentation] could be explained by a combination of autism spectrum disorder and malnutrition. Overall it seems that Charlie is improving with proper nutrition and therapy.”*

Another example of lack of MCFD action on the advice of medical experts came after Charlie and his mother attended a follow-up appointment with the pediatrician at the BCCH biochemical diseases department in March 2010. The pediatrician concluded that the most likely cause of Charlie's osteopenia was nutritional deficiency. In a letter to Charlie's community pediatrician, he noted that *“the mom did not do the recommended blood, urine and radiographic investigation from our service and did not do the blood investigations ordered by Endocrinology service.”*

This letter was copied to 10 medical professionals, including the CPSU pediatrician at BCCH. MCFD and BCCH records show that the concerns were reported to the MCFD child protection worker by the CPSU social worker. Nevertheless, in the ensuing months, and with her team leader's consent, the child protection worker closed the family's file.

RCY investigators could find no indication that the child protection worker and her team leader considered BCCH's concerns of withdrawal from medical services, including the concerns from the biochemical diseases pediatrician, when determining the family's possible need for ongoing MCFD supervision and support prior to closing the file.

Despite the continued absence of underlying medical reasons for Charlie's condition and the consistent concerns about his well-being on the part of medical professionals, the possibility that Charlie was being neglected was ruled out by MCFD and its child protection investigations were closed prematurely.

## Other Missed Opportunities

MCFD missed other opportunities in which it was provided with information about Charlie and his family that should have caused concern for his welfare but did not, including:

- By early December 2009, professionals working with the family were expressing concerns to the MCFD child protection worker about Charlie's limited school attendance. These continued until Charlie's mother withdrew him from school in 2011 but were never acted on by MCFD, which consistently cited the fact that school attendance is not a child protection concern under the *CFCS Act*. (These instances are examined in detail in the Education finding section that follows.)
- In March 2010, Charlie's CYSN file was transferred to his new community. The transfer record indicated Charlie had received NSS services for the previous two years and that the involved nurse had expressed concern that, once the family moved, they "*might isolate themselves*" and would "*need help to manage their lives.*" The transfer stated the family had limited support services and no family doctor. The transfer did not indicate that there had been past child protection concerns regarding Charlie, nor did it indicate his high CLBC priority score. Concerns on the transfer record do not appear to have prompted any action on the part of MCFD as Charlie and his mother were not involved with services and had no contact with their CYSN worker in 2012 and 2013.
- In late August 2014, MCFD received a report from an income assistance worker who was concerned about 11-year-old Charlie not being in school, as his mother had called the worker to ask for funding for homeschooling with Hooked on Phonics. The child protection worker consulted with her team leader, who indicated that no further action would be taken regarding the call as "*there [were] no section 13 concerns.*" This call should have raised serious concerns about Charlie's vulnerability as a child with significant special needs and whether his right to an education was being upheld. However, MCFD closed the file.

## Closure of Files and Time-Limited Services

In the three child protection responses that preceded Charlie's removal from his mother's care, MCFD social workers, with the approval of their supervisors, closed Charlie's file without sufficient information to safely do so. MCFD also closed its files prematurely during responses to earlier child protection reports regarding Charlie while other voluntary services to the family were terminated without proper consideration of whether they were still required.

The first MCFD contact with the family came in the fall of 2006 when Charlie was three. Charlie's mother called the police after a verbal conflict with his father. The child protection worker planned to offer support services to Charlie's mother. After multiple unsuccessful attempts to contact her, the child protection worker closed the file with no support services offered.

For a variety of reasons, the families that MCFD works with are not always easily reached. Although the MCFD worker attempted to contact the mother without success, it would have been prudent for the worker to keep the file open and continue to try to contact her or other people who may have known the family prior to closing the file with no support services offered.

In May 2007, when Charlie was four, police made a second report to MCFD as a concerned citizen had heard a young child crying and screaming in the family's apartment. A police officer visited the home, met the mother, Charlie's brother and Charlie. The police officer then reported the incident to MCFD. The MCFD worker who received this second report determined that no further steps were necessary to assess Charlie's safety because the officer had not indicated any concerns for the children and the file was closed.

In this incidence, MCFD relied on police to share any concerns for the children, rather than completing its own assessment of relevant information, which should have included interviewing all relevant family members to assess Charlie's safety and offering support services to the family. Charlie's father told RCY investigators that he was never contacted about this 2007 MCFD report and that their family could have benefited from supports at the time. Rather than offering supports, MCFD closed the file without sufficient information.

In February 2008, after MCFD investigated child protection concerns related to Charlie's hospitalization, the child protection worker determined that Charlie was safe and kept the MCFD file open to provide family outreach counselling through an MCFD-contracted agency. However, the file was closed three months later as Charlie's mother reported that she did not require further assistance from MCFD.

This illustrates a lack of adequate, fully informed decision making. Rather than re-assessing whether contracted services should remain involved to support Charlie's needs, the MCFD worker closed the file, taking the mother's word that additional services weren't required.

The child protection worker who investigated the 2008 report closed Charlie's file after determining that he was not in need of protection. The worker told RCY investigators that she felt making a determination that Charlie needed protection would be blaming his mother for something that was due more to a lack of services than neglect. This worker told RCY investigators that, in hindsight, she now believes Charlie was neglected. However, at the time, she believed his hospitalization and subsequent discharge planning and connection to services would be adequate to reduce risk.

This child protection worker also told RCY investigators that, at the time, there was pressure on workers in the office to close files. RCY investigators found records indicating that *"due to work load and staffing issues"* the Community Service Manager responsible for this office was allowing some Comprehensive Risk Assessments to go uncompleted *"to allow files to be closed in a timely manner."*

In Charlie's case, because the investigation found he was not in need of protection, there was no requirement for this risk assessment to be completed. The child protection worker documented in her case notes that she did not complete a risk assessment but told RCY investigators that, in hindsight, doing so would have been "very useful" in her work with the family.

When Charlie was hospitalized in 2009, the medical community reported to MCFD similar concerns about neglect and the mother's delay in seeking medical attention for Charlie. The MCFD worker investigated and closed the investigation in August but left the MCFD file open for support services through contracted agencies.

It is noted in the records that MCFD told Charlie's mother that it would be taking a more predominant role and more intrusive measures if she did not follow-through on

### Practice Consideration

During a number of investigations conducted by RCY since its inception in 2007, social workers have expressed concern about feeling pressure to close files. The Representative notes that there is value in keeping some files open when there are unexplained risks or when there are multiple professionals involved – both of which were the case with Charlie – in order to facilitate helpful monitoring, case coordination and rapid system response when there is a subsequent report, risk or need.

recommendations by professionals, yet no one paid attention to whether Charlie's mother followed through with support services and recommendations by medical professionals.

This is an example of a closure of a child protection assessment without sufficient information. The MCFD worker closed the investigation and kept the file open to offer support services but did not check to see if the support services were meeting Charlie's and his mother's needs.

### Other Missed Opportunities

RCY investigators found other examples of termination of services when Charlie and his family were still in need of help, including:

- In October 2009, Charlie's mother was referred to a family outreach counsellor by MCFD. The family outreach counsellor, who had been keeping the ministry informed that Charlie's mother hadn't been engaging in services, eventually closed the file. The MCFD social worker did not follow up with Charlie's mother or family members to explore if she still needed help following the termination of the family outreach counsellor services. The family outreach counsellor closed the file because the mother was not engaging in services. However, this did not mean that the mother no longer needed help and support.
- Charlie was connected to a behavioural consultant and to NSS. These two services were in place for about a year and they appeared to be effective in supporting Charlie and his mother's needs and goals. Unfortunately, both of these services ended at the same time, either due to contract hours being complete or the specific goals of the contract being complete. These services ended about the same time that Charlie's mother withdrew Charlie from school. Given this scenario, service providers should have been prompted to re-assess whether a renewal of the behavioural consultant's contract hours and involvement of NSS should continue.

## Consideration of Charlie and his Family's Vulnerability due to his Special Needs

The Representative is concerned that child protection workers in B.C. do not always have the training or resources necessary to assess the safety and well-being of children and youth with special needs. RCY investigators interviewed a number of child protection workers and team leaders during this investigation and all were asked if they had received such training. The responses indicated that there is a lack of specific training in this area and that there is no training regarding alternative ways to communicate with a child who is non-verbal.

The Representative concludes that a lack of understanding on the part of social workers and their supervisors about the severity of Charlie's special needs contributed to his critical injuries. Social workers didn't place enough importance on laying eyes on Charlie or on trying to interact with him, perhaps due to the fact he was non-verbal, and they didn't feel he would be able to communicate about his situation. However, the fact he was unable to speak for himself, coupled with his lack of visibility in the community, should have prompted social workers to ensure that they saw him during these investigations.

The Representative finds it extremely troubling that Charlie was only seen during a child protection response when the circumstances grew so dire that police had to be called to check on his welfare. In addition to the fact that seeing a child is a policy requirement during a child protection investigation, observing Charlie and his interactions with his mother would no doubt have shed more light on his needs and the challenges his mother faced related to his disabilities.

*“When kids are non-verbal and they're not expressing themselves, that doesn't mean they don't understand. We never really know for sure just how much of what we say to kids they can understand . . . We talk to them and wonder if they understand more than they seem to . . .”*

– Pediatrician at BCCH

The struggles of Charlie's mother to deal with his special needs should have been obvious to MCFD. In an interview with the investigating child protection worker in 2008, Charlie's mother, said it was challenging taking him to medical appointments.

She told the worker that she did not want to take him on the bus because she felt judged when doing so. She acknowledged that she was overwhelmed trying to meet Charlie's needs and was asking for help from MCFD.

In a June 10, 2009 appointment with the CPSU psychiatrist, Charlie's mother shared how difficult it was to be a single parent of a child with complex needs with limited means and few social connections. The CPSU psychiatrist believed that Charlie's mother was mildly, situationally depressed – a condition related to being the primary parent to a child with multiple complex needs and having limited supports. The psychiatrist strongly recommended a case manager for Charlie's family as well as assistance with transportation to appointments and school, a dietician to improve Charlie's nutrition, and regular respite to allow Charlie's mother *“to have some time for herself away from the constant attention needed by a challenging child.”*

However, this psychiatrist's report never reached the MCFD child protection worker, whose only note on file about the mother's meeting with the psychiatrist was that Charlie's mother was not depressed. Charlie never received a case manager, assistance with transportation to appointments and school, the services of a dietician or respite care.

The November 2015 child protection report about Charlie was coded by MCFD for a five-day response time. The Representative questions whether Charlie's significant special needs were fully considered by the ministry in arriving at this decision. Police attended the family home after Charlie's mother reported that she was paranoid, believing she was being spied on and hearing voices coming from vents. Police reported to MCFD that Charlie's mother indicated he had special needs which the Representative believes should have prompted consideration of a 24-hour response time. Regardless of the coding, the report was not responded to for 45 days, an outcome that led to Charlie's critical injury.

### Child Protection Responses: Requirements Versus Performance

#### Seeing the child and all other vulnerable children in the home

	Yes	No	Partially	Comments
First child protection response		✓		Charlie and his brother were not seen
Second child protection response		✓		Charlie and his brother were not seen
Third child protection response		✓		Charlie was not seen (his brother no longer lived in the home)

#### Interviewing the child and all other vulnerable children in the home, where developmentally appropriate and with supports if necessary

First child protection response		✓		Charlie and his brother were not interviewed
Second child protection response		✓		Charlie and his brother were not interviewed
Third child protection response		✓		Charlie was not interviewed (his brother no longer lived in the home)

#### Directly observing the child's living situation

First child protection response			✓	Part of Charlie's home was viewed, but not his room
Second child protection response			✓	Part of Charlie's home was viewed, but not his room
Third child protection response			✓	Part of Charlie's home was viewed, but not his room

#### Seeing and interviewing the parent

First child protection response			✓	Mother was interviewed; father was not
Second child protection response			✓	Mother was interviewed; father was not
Third child protection response	✓			

#### Completion of investigation within 30 days

First child protection response	✓			
Second child protection response		✓		
Third child protection response		✓		Response was not completed

## Culture, Family and Community

**Finding:** *Contrary to policy, MCFD did not identify and document Charlie's First Nations ancestry during the family's involvement with MCFD. This did not happen until after Charlie came into the care of the ministry, resulting in MCFD not involving his Nation in planning for his care, in child protection responses or in supporting Charlie and his family to learn about their culture.*

### Grand Chief Ed John on the Importance of Documenting Indigenous Identity

Clearly documenting Indigenous identity is a critical part of ensuring that children and families have access to relevant services, including culturally relevant approaches and materials. The current practice of gathering this information in B.C. is reliant on self-identification and having a social worker document the identification. The current practice results in a high level of under-reporting for Indigenous children currently engaged in the child welfare system, including Indigenous children in care. It also leads to inaccuracies in data when it comes to analysis and monitoring of program impacts.

– Grand Chief Ed John, *Indigenous Resilience, Connectedness and Reunification, from Root Causes to Root Solutions* (November 2016)

### UNCRC Article 8 (Preservation of identity)

Children have the right to an identity – an official record of who they are. Governments should respect children's right to a name, a nationality and family ties.

The *CFCS Act* requires that Indigenous children receiving services under the Act be connected to their culture in a meaningful and consistent way.<sup>69</sup> MCFD Child and Family Development Service Standards in place between 2003 and 2012 stated that “to preserve and promote a child's Aboriginal heritage and connection to his or her Aboriginal community, the following must be involved in all significant decisions when determining the child's Aboriginal connections, heritage and descent, and when assessing, planning and providing services for the child:

- *the child*
- *the child's family*
- *the child's extended family*
- *the child's Aboriginal community*
- *the identified delegated agency and any other community agencies involved with the child and family, and*
- *any significant people identified by the child and his or her family or Aboriginal community.”*

<sup>69</sup> According to *CFCS Act* section 2(f) the cultural identity of Aboriginal children should be preserved. Section 3(b) states that Aboriginal people should be involved in the planning and delivery of services to Aboriginal families and their children. Additionally, section 3(c) directs that services should be planned and provided in ways that are sensitive to their needs and the cultural, racial and religious heritage. Finally, section 4(2) notes that if the child is an Aboriginal child, the importance of preserving the child's cultural identity must be considered in determining the child's best interest.

This standard acknowledged the importance of promoting and maintaining a child's Aboriginal heritage and connections with his or her Aboriginal community. Involving the Aboriginal child's family, extended family, community and others acknowledges their traditional responsibilities and roles in identifying resources for the child and in ensuring that services are sensitive to, and build on, the strengths of the child, family, extended family and Aboriginal community.

The standards required MCFD to involve the child's Aboriginal community from initial contact and throughout the period of involvement with the child and family in order to:

- identify the strengths within the Aboriginal community and heritage of the child and family
- identify extended family members
- identify, plan and deliver services that are culturally appropriate and accessible
- provide information to help strengthen and support the Aboriginal child's home and in turn help ensure his or her safety and well-being
- participate in the development and implementation of plans of care that will preserve the child's cultural identity
- ensure that review processes are sensitive to cultural perspectives and are carried out in ways that are culturally appropriate
- identify and develop an appropriate out-of-care living arrangement for the child, and reunify Aboriginal children who have been removed from their homes and communities with their extended families and communities.

MCFD has clear practice standards in place around identifying and documenting a child's Indigenous ancestry and involving the child's family and community from initial contact with MCFD throughout the period of involvement with any MCFD services including child welfare, CYSN, Child and Youth Mental Health and youth justice. The standards recognize the importance of viewing the child as a whole by requiring the involvement of the child's family, extended family, Indigenous community and other significant people in the child's life in decisions and planning for the child.

These things did not happen in Charlie's case. In 2008, Charlie's mother described his ancestry as Aboriginal to a service provider who in turn informed the child protection worker involved with the family. The social worker recorded this in her case notes but did not enter it in the MCFD case management information system, as required by MCFD Service Standards. Although Charlie's family interacted with numerous MCFD staff from child protection and CYSN, none of them made further inquiries about his culture or community. In fact, Charlie was not identified by ministry staff as being First Nations until after he was removed from his mother's care in 2016.

While, the Representative does not know how identification and involvement of Charlie's community might have changed his outcomes, proper identification of Indigenous ancestry is a crucial part of MCFD's work with Indigenous children and families and this work

## U.S. Federal Child Welfare Legislation

In the U.S., federal child welfare protections for Indigenous children have existed under the federal *Indian Child Welfare Act* since 1978. The Act has provisions for the rights and responsibilities of Indigenous parents, cultural protections, administrative concerns and guidelines for the “active” participation of tribal communities.<sup>70</sup> Active participation requires that child welfare service providers not only identify the challenges a family faces and provide solutions, but also requires that affirmative, active, thorough and timely efforts are made with the intention of keeping an Indigenous child with family. The cultural protections include culturally appropriate services, provisions to maintain cultural connections, kinship care, customary care or custom adoption and post-adoption agreements.

of Indigenous children. Charlie’s nation was not involved in any of MCFD’s child protection investigations concerning his family because Charlie had not been identified as Indigenous in the first place.

The Representative is of the view that identification of a child’s culture and community is also critical when working with children with special needs and their families. The Representative encourages MCFD to consider how to ensure that it provides culturally

needs be rigorous, beginning at first point of contact with any MCFD service.

Proper identification of Indigenous ancestry and community is what enables MCFD to involve Indigenous communities in planning for their children and enables the ministry to work toward the goals identified in the standard. For example, MCFD child protection standards state that “*family and Aboriginal communities should be involved during the investigation process.*”<sup>71</sup> The importance of involving Indigenous communities during child protection investigations should not be understated. Indigenous communities are integral in working with families to develop less disruptive measures to the removal

responsive and safe services specifically for Indigenous children with special needs and that staff have appropriate training in this respect. Proper identification of Indigenous ancestry is very important, especially given that the intersection of being Indigenous and having special needs made Charlie even more vulnerable to discrimination, oppression and marginalization.

In addition, involving an Indigenous community in planning for services for a child with special needs may provide a different way of looking at disability.

## Culture as a Protective Factor

*“Traditional Indigenous cultural practices help children to grow into active contributors to family, community and societal life. Children have access to a wide network of support, and through a collective community approach, Indigenous people work together to ensure their children are safe and happy. In doing so, children are given opportunities to explore the world, develop their independence and, hence, build their capacity to make responsible decisions that help them throughout their journey to adulthood.”*

– Lohar, Butera and Kennedy, 2014

<sup>70</sup> Active efforts must be undertaken to provide remedial services after an investigation and before a decision is made to place the child out of the home. Active efforts must also be provided after the child has been removed in order to prevent the breakup of the family by working towards reunification. National Indian Child Welfare Association, “A Guide to Compliance with the Indian Child Welfare Act”, accessed 2018, <https://www.nicwa.org/wp-content/uploads/2018/01/Guide-to-ICWA-Compliance-2018.pdf>

<sup>71</sup> Ministry of Children and Family Development, “Child and Family Development Service Standards,” (Victoria, BC, Ministry of Children and Family Development), 15-18.

*“Disabilities within Aboriginal communities tend to be considered special gifts or powers which enable people to communicate with the spiritual world. Such an understanding and perspective on disabilities is quite contrary to the western perception of a disability where it is viewed as a deficit.”* – Dion, J. *Falling Through the Cracks: Canadian Indigenous Children with Disabilities*, 2017.

In addition, before his removal, Charlie and his family received services from an MCFD office where they lived. It wasn't until more than a year after Charlie was removed and his Indigenous ancestry was identified that his file was transferred to an Aboriginal team that specializes in working with Indigenous children, youth and families to provide culturally appropriate services and supports to children.

## Charlie's Nation

Charlie's father was not connected to his culture or community and, as a result, Charlie wasn't connected, either. RCY investigators met with representatives from the nation who indicated that this would not have been a barrier to them being involved and that they wished they had known more about the family's circumstances sooner, so they could have helped. Representatives of the First Nation said they were unaware of how grave the circumstances had been for Charlie prior to his removal. They said they supported

### Practice Consideration

Representatives of Charlie's First Nation told RCY investigators that they would have exercised their legislative ability as a designate to advocate for Charlie had they been aware of his circumstances and they would have liked to be more involved in cultural planning for him once he came into care.<sup>72</sup> The *CFCS Act* places legislative responsibility on individual First Nations to be third-parties to all court proceedings involving their children. Social workers should be mindful of this and genuinely invite Indigenous communities to the table, including the use of collaborative or shared planning and decision-making, mediation, family case planning and traditional decision-making in cases involving Indigenous children.

MCFD's decision to remove Charlie because it was in his best interest to receive the proper care and services he needed. The First Nation told RCY investigators that it intends to support Charlie and his family in learning about their culture.

The Representative recognizes that there can be challenges associated with identification and involvement of Indigenous communities in planning services for children. For example, Charlie was raised by his non-Indigenous mother, his father was not connected to his nation and his nation was geographically far away from where Charlie and his family live. The Representative also recognizes the impact of

colonization on Indigenous children and families resulting in the multi-generational loss of culture and many Indigenous people living far away from their communities. Despite these challenges, the Representative urges government to ensure that identification and involvement of Indigenous communities in planning for the care of their children and in protecting their cultural identity is prioritized in practice.

<sup>72</sup> A cultural plan is a framework for developing an action plan that describes how a child's connection to their Indigenous community is promoted and preserved.

In November 2016, Grand Chief Ed John, in the capacity of special advisor to MCFD, released a report with 85 recommendations directed to a variety of agencies and organizations including MCFD, B.C.'s Delegated Aboriginal Agencies, First Nations leadership and the federal government.

One of Grand Chief John's areas of consideration was the existing policy framework at MCFD. He noted that the stage has been set through Canadian Human Rights Tribunal decisions, the Truth and Reconciliation Commission's final report and numerous reports from the Representative's Office and others to develop a comprehensive Indigenous child welfare policy framework that will support reconciliation and resilience of Indigenous families and communities.

The Representative is supportive of Grand Chief John's recommendation for the adoption of a clear and overarching Indigenous child welfare policy framework in B.C. Included in this framework should be a requirement for MCFD staff to identify a child's family, extended family and community and to document it and help to support access to culturally relevant approaches and materials regardless of which service stream they are in contact with (e.g., early years, adoption, child and family services, special needs, guardianship and permanency services, mental health and substance use services). In Charlie's case, MCFD workers only documented his Indigenous ancestry when he came into MCFD care. The Representative believes that exploration of Indigenous ancestry needs to occur as early as possible when an Indigenous child and family come into contact with MCFD as culturally relevant approaches and materials can be beneficial to children in all areas of MCFD service provision, not just guardianship and permanency planning services.

## Special Needs Supports and Services

**Finding:** *The complex, overburdened and under-resourced Children and Youth with Special Needs system was not responsive enough to the needs of Charlie and his family, which resulted in a lack of necessary supports and services and contributed to his critical injury.*

Under MCFD's CYSN program, support services for families of children with special needs may include, but are not limited to, in-home family support, respite care, parenting programs, preventative and support service programs, and payments to parents to assist in purchasing support services (such as autism funding).<sup>73</sup> CYSN service delivery is complicated by the fact that some services are provided by MCFD, some are provided by health authorities and others are provided by contractors hired by government or by families using government funding. Further, some CYSN programs (e.g., At Home medical benefits, autism funding) are managed provincially, while others (e.g., At Home respite benefits) are managed by regional service delivery areas (see Table 1 for examples).

<sup>73</sup> *CFCS Act, Statutes of B.C. 1996, c. 46.* [http://www.bclaws.ca/civix/document/id/complete/statreg/96046\\_01](http://www.bclaws.ca/civix/document/id/complete/statreg/96046_01)

Table 1 – Comparison of CYSN Program Components

	At Home respite benefits	At Home medical benefits	Autism funding
Eligibility <sup>74</sup>	Initial assessment by a professional (NSS). Access to services is determined by Priority Service Tool (PST) score. Clinical judgement of relevant factors may be considered.	Initial assessment by a professional (NSS). Access to services is automatic with confirmation of dependency in three or four areas of daily living.	Initial assessment by a professional (e.g., psychologist). Access to services is automatic with diagnosis.
Program Description	Provides money that families use to hire respite provider. Families are responsible for finding and hiring care providers.	Provides medically necessary supplies to the family.	Provides money that families use to hire behaviour consultants, buy equipment and materials to support interventions. Families are responsible for finding and hiring professionals.
Program Administration	Regional SDAs	Provincial	Provincial
Wait list	Long wait list (length of wait depends on PST score and number of other families waiting for service in an SDA)	No wait list	No wait list

## High Caseloads

CYSN services are delivered out of local MCFD offices by CYSN social workers who are assigned to families. A CYSN case file remains open until the family chooses to close the file or the child turns 19 years of age. Family can re-engage the CYSN social worker at any time. CYSN social workers are responsible for intake, determining eligibility, helping families connect to supports, assessing priority for services and meeting with families. They are supervised by team leaders who provide clinical consultation and support.

When CYSN services were returned to MCFD from CLBC in 2009, as is mentioned in the Representative's report *Update: System of Services for Children and Youth with Special Needs (September 2010)*, there was hope that MCFD's service delivery model would provide more support to families and caregivers of children with disabilities who required assistance in planning, implementing and coordinating the various services for which they were deemed eligible.<sup>75</sup> However, the Representative is concerned that caseloads across the province for CYSN social workers remain unacceptably high, resulting in many families not receiving the assistance and support they require.

In 2010, Charlie's CYSN social worker had a caseload of about 120 families. It is important to note that some families may have more than one child eligible for CYSN services, so it is likely that a caseload of 120 families could involve even more than that number of children. Charlie's CYSN social worker was described by management as

<sup>74</sup> Access to services is dependent on proof of B.C. residency and age.

<sup>75</sup> *Update: Systems of services for children and youth with special needs*, RCYBC (September 2010): 6-7.

dedicated, compassionate and experienced, but the reality of a caseload of this volume is that, no matter the skill or passion of the worker, many families will likely not receive the attention or assistance that they need. MCFD confirmed that the average CYSN social worker caseload in B.C. in 2018 was 131 families.

## Service Prioritization

To triage such unmanageable caseloads, CYSN social workers prioritize their files for families requesting services as priority level one, two or three. CYSN social workers meet with families and complete the PST. This tool quantifies a family's need for service across many domains (e.g. family's disability-related supports, parent stress, parent health) and how functionality in these domains affects the family's ability to meet the disability-related needs of their child/children.

A family's priority determines the role and responsibility of their CYSN worker. The PST further serves to determine a family's place on the wait list for At Home Program respite benefits. Families with a high PST score are placed higher on the list and are more likely to receive respite funding.

However, the version of the PST used for Charlie's family was unreliable and CYSN social workers were not provided with a standardized set of instructions on how to administer the tool. This meant that different CYSN social workers might gather information in different ways (e.g., formal interview, informal discussion with family members, reading the questions to families and recording responses verbatim). Therefore, the amount and quality of information gathered by different CYSN social workers using the same PST tool could be vastly different. Scoring was also difficult for CYSN social workers. *A Guide to the Priority Service Tool* was provided with explanations and examples to help workers fill out the PST. However, these were not exhaustive, nor were they concrete or easy to apply.<sup>76</sup> All of these factors meant that two CYSN social workers could administer the tool to the same family at the same time and give that family two very different scores.

Charlie's PST scores did not accurately reflect the impact of his disability-specific support needs, nor did they reflect his family's overall need for services. In Charlie's case, the subjective variation in PST scoring can be seen over time. In 2009, when his services transferred from CLBC to CYSN, Charlie had a PST score of 86.7 (out of 111 points) which meant that he was a priority one candidate for services according to policy.

By 2010, Charlie's PST score was a low 53.3, even though his available supports had significantly decreased, and his situation had not improved. His subsequent scores in 2011 and 2014 were both 62.2, despite changes in the family's circumstances between those years.

Problems with the PST had been evident since 2009, however it continued to be used as the key tool to determine eligibility for different levels of service. The Representative

<sup>76</sup> Ministry of Children and Family Development, "Revising the PST – Discussion and Rationale," (Province of British Columbia, 2018).

acknowledges that in 2017, MCFD revised the PST and embedded it within the CYSN Consolidated Assessment Tool (C-CAT).

### PST Scores – How They Determine Services

As previously mentioned, the PST is used to categorize a family as being priority one, two or three, and this priority level determines the intensity of service the family receives. Clinical judgment may also be taken into consideration.

Policy directs CYSN social workers to meet with, and become most intensively involved with, priority one families. These are families who were described to RCY investigators as “*in crisis or on the verge of crisis.*” According to CYSN policy, a priority one family is a family who:

- Exhibits a high need for support and assistance because they are receiving services through an urgent or emergency request
- Frequently experiences stress and challenges that impact their ability to meet their child’s needs
- Has limited capacity to implement service plans and access community services
- Is involved with child welfare and there is a protection concern
- Is at risk of placing their child in care without additional services and support
- Has a child who is not participating in an education program or going to school
- Has one or both parents with a disability or a mental health challenge that may impact their capacity to meet their child’s needs.

CYSN social workers are required to offer to meet with priority one families every three months, visit the child or children at least once a year, proactively support planning, re-administer a PST as necessary, proactively help the family address any barriers they are facing, and take the lead in service coordination.<sup>77</sup> CYSN team leaders provide comprehensive clinical consultation and support for CYSN social workers related to priority one families.

Priority two families are defined as families that exhibit a moderate need for support. Policy directs CYSN social workers to offer to meet with priority two families every six to nine months to review their support plan and assist in a variety of other ways.

Priority three families are those who are determined to have a lower need for support. CYSN workers are directed to meet with priority three families within one year to review their need for services. A support plan is developed if a priority three family requests it or if a CYSN worker deems a plan is required. CYSN workers are directed to offer to meet with priority three families annually. Consultation with team leaders regarding priority two and priority three families occurs less frequently than for priority one families.

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<sup>77</sup> Policy dictates that it is necessary to re-administer the PST when a family wait-listed for a service notifies their CYSN worker that their needs have changed significantly, when a family requests new or enhanced support services or when a family requests At Home respite benefits.

The Representative was surprised to learn that Charlie's family was never assessed as a priority one, given the high need for support identified during his two significant hospitalizations, the challenges his parents faced in meeting his needs and in following through with appointments and plans, the family's involvement with child welfare, the documented concerns with school attendance, his subsequent withdrawal from school and his mother's mental health challenges. Charlie's family clearly met the CYSN policy definition of a priority one family.

Because the family was never deemed priority one, Charlie's CYSN social worker was not expected to help proactively address barriers to participating in services or take the lead in service coordination. Nevertheless, as a priority two or three family, Charlie and his mother should have been offered an in-person consultation by their CYSN social worker annually. However, records indicate that between 2011 and 2014, there was no in-person contact. Heavy caseloads would appear to be the biggest reason for this. Charlie's CYSN social worker told RCY investigators that even meeting with families once a year was not achievable and that team leaders were aware of this situation.

Children and youth with special needs, particularly those with complex needs and those from vulnerable populations, require timely, appropriate and responsive supports. CYSN social workers are hampered by high caseloads and overly restrictive prioritization policies and assessment tools. Had the caseload of Charlie's CYSN social worker been lower, he may have been able to exercise clinical judgment in determining when and how to interact with Charlie and his family, and there could have been different outcomes for Charlie.

## At Home Program

CYSN's At Home Program recognizes that raising a child with special needs may come with extraordinary personal and financial costs. The At Home Program provides medical and respite benefits to eligible families. To be eligible for benefits, a child or youth must be assessed as dependent in at least three out of four areas of daily living (eating, toileting, dressing, washing), have a palliative condition, be eligible for NSS Direct Care, or have a diagnosis of Duchenne muscular dystrophy or spinal atrophy type 2.<sup>78</sup>

The medical benefits program provides a range of basic, medically necessary services, such as equipment, therapies and transportation. Once a child is eligible for the medical benefits program, the B.C. Medical Services Plan provides enhanced coverage. A health professional must recommend a service in writing and there are limits to the amount of funding provided for different services.

The At Home Program respite benefit provides up to \$2,800 per year for families to choose respite services in their home or another location.<sup>79</sup> Respite benefits are managed locally, through MCFD offices, rather than provincially. Families are often placed on a wait list for respite services and their position on the wait list is determined, in large part, by a family's PST score. Once approved for respite benefits, families may receive

<sup>78</sup> Ministry of Children and Family Development, "At Home Program Guide," (Ministry of Children and Family Development, October 2018), 5.

<sup>79</sup> The amount a family receives is based on an income test.

direct monthly payments, or they can be reimbursed for respite expenses. Families are responsible for arranging respite care, paying caregivers, managing their respite budget, and providing a record of respite expenditures.<sup>80</sup>

### Choice Between Medical and Respite Benefits

NSS is contracted by MCFD to evaluate children and youth who are potentially eligible for respite and/or medical benefits. Results of NSS assessments are submitted to regionally based eligibility committees. The eligibility committees determine whether a family is eligible for both respite and medical benefits, a choice of one, or neither. Families of children determined by both NSS assessment and the regional eligibility committee as dependent in three out of four activities of daily living are offered a choice between respite and medical benefits, whereas families of children and youth assessed as dependent in all four activities of daily living are eligible for both respite and medical

*“Most families choose medical benefits because they are immediately available . . . there is no wait list, where there is for respite, and medical supplies are more important.”*

– Nurse who conducted Charlie’s At Home assessment

benefits. When faced with having to make the choice, most parents choose medical benefits over respite because medical benefits are provided to families immediately whereas families are typically wait-listed for respite service, often for long periods of time.<sup>81</sup>

Charlie was assessed by NSS in March 2008. Although Charlie’s scores on the assessment indicated that he was partially independent in some domains (and therefore eligible for a choice between respite and medical benefits),

the nurse recommended to the eligibility committee that he be approved for both respite and medical benefits. In making this recommendation, the nurse took into consideration Charlie’s communication difficulties, his behaviour challenges and his mother’s exhaustion. The nurse noted that medical benefits would help pay for diapers and therapies and that the respite benefit would provide Charlie’s mother with a necessary break from his constant care needs and the ability to spend some time with Charlie’s older brother. However, at that time, the eligibility committee offered the family a choice between the two and Charlie’s mother chose medical benefits. As part of his admission to Sunny Hill in 2009, Charlie was re-assessed as eligible for both respite and medical benefits. He was placed on the wait list for respite benefits at that time and he continued to receive the same medical benefits as before.

The Representative believes that asking vulnerable families with few resources, such as Charlie’s, to choose between respite and medical benefits is unfair. When faced with the choice of accessing medically necessary services versus respite services, families may feel forced to choose medical benefits.

<sup>80</sup> Ministry of Children and Family Development, “At Home Program Guide,” (Ministry of Children and Family Development, October 2018), 6.

<sup>81</sup> Ministry of Children and Family Development, “At Home Program Guide,” (Ministry of Children and Family Development, October 2018), 8.

## Respite Benefits

Respite care is a vital support for families of children and youth with special needs and temporarily relieves parents of the stress of meeting the needs of their children. Respite services are provided through either contracted providers or funding directly to families to purchase the respite services that best meet their needs. Direct-funded respite provides funds for families to pay for a qualified care provider to look after a child with special needs for a short period of time (e.g., overnight or a weekend).<sup>82</sup> Families may also be eligible for respite through a contracted agency, although wait lists exist for this option as well.

High demand for respite services in B.C. has resulted in significant wait times across the province and the necessity to prioritize families for available funds. A family's place on the wait list is based mostly on their PST score.

The benefits of respite care have been demonstrated in many research studies. One review determined that respite reduced parental stress.<sup>83</sup> Another study showed that

*“Respite is probably the thing that families ask for the most because the child with special needs can have a real impact on the overall family functioning . . . many of the children don't sleep through the night or they're not in school full days. So the parents just absolutely need a break.”*

– CYSN Director of Operations

parents reported less psychological distress and children were less likely to be found in need of child protection services when respite was provided.<sup>84</sup>

Charlie's mother identified her need for respite support to her CYSN social worker in May 2010 and again in May 2014. But when Charlie was removed and placed in ministry care six years after the first request, his mother had still not received any respite support. Every day, Charlie's mother had to ensure his diapers were changed, provide nutrition through his G-tube, and work to meet his dietary restrictions. Charlie had an aversion to running water and avoided baths and brushing

his teeth. He often hit and kicked his mother when she attempted to brush his teeth. He was confused between days and nights, requiring his mother to be awake with him almost 24 hours. Charlie's mother told professionals that she could not take him out in the community due to his behaviours, meaning both she and Charlie were at home, all the time, without support. Charlie's mother was struggling financially and had little time to care for herself or Charlie's brother. The Representative believes respite would have provided relief for Charlie's mother and would have been a protective factor for Charlie as another person would have regularly interacted with him and his mother.

<sup>82</sup> Ministry of Children and Family Development, “At Home Program Guide,” (Ministry of Children and Family Development, October 2018), 8.

<sup>83</sup> Perle Slavik Cowen and David A. Reed, “Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families,” *Public Health Nursing*, 19, 4 (2002): 272-283.

<sup>84</sup> Julie A. Strunk, “Respite care for families of special needs children: A systematic review,” *Journal of Developmental and Physical Disabilities*, 22, 6 (December 2010): 615-630.

## The Importance of Early Intervention

While he was in the hospital in 2016, professionals determined that Charlie had a high need for intensive supports due to his complex diagnoses and experience of trauma. As a result, he was placed in a specialized resource that MCFD had created for him, referred to as a therapeutic home. This placement provided Charlie with the intense support he needed, developed a comprehensive plan of care and, ultimately, allowed Charlie to be successfully "stepped down" into a family-style foster home. Fifteen months after he was placed in the therapeutic home, Charlie moved to his new foster home with a single caregiver who specializes in working with children who have complex developmental needs. The Representative commends the caregivers at the therapeutic home for their exemplary work in supporting Charlie and also recognizes the high level of care that Charlie receives in his current foster home. However, the Representative is troubled that Charlie did not receive appropriate and timely early interventions that may have reduced his suffering from profound neglect, changed his developmental trajectory and reduced his need for such intensive supports later on.

Early intervention services could have positively influenced Charlie's development. They may have also significantly reduced the cost of supporting Charlie after his removal. For example, RCY investigators calculated that, at a rate of \$2,800 annually, the total cost of providing respite services to Charlie's family would have been \$16,800 from the time he was determined eligible in September 2009 until he was removed in January 2016. Similarly, Charlie was deemed eligible for autism funding in 2009. Had his mother been supported to access this funding between 2009 and his removal in 2016, the total cost would have equaled \$30,000 (\$6,000 per year for five years). In contrast, MCFD paid \$41,004 per month for 15 months, plus the cost of extra staffing required to care for Charlie in the therapeutic home and address his complex special needs. Charlie's case highlights the important role that early interventions and supports can play in not only improving the outcomes for children with disabilities but also reducing the long-term cost to government of supporting children and youth such as Charlie.

## Respite Wait Times

Respite benefits are in such high demand that often the families of children such as Charlie are required to wait many years for service. Some families do not receive respite before their child turns 19, when they are no longer eligible through MCFD. MCFD's *At Home Program Guide* states that families may be wait-listed for the respite benefit and directs families to their local MCFD office for more specific inquiries.<sup>85</sup>

<sup>85</sup> Ministry of Children and Family Development, "At Home Program Guide," (Ministry of Children and Family Development, October 2018), 8.

RCY investigators were informed by MCFD that it does not centrally track the number of B.C. families waiting for respite services or the length of time they have been waiting. The extensive wait lists for respite are regionally managed by each service delivery area in the province on separate spreadsheets. Without any provincial oversight, it is impossible for MCFD to know how effective and accessible this program is or to determine the amount of funding that would be necessary to adequately support this program.

RCY investigators were advised by a CYSN staff member that, in the area where Charlie resided, it was “*not unusual for families to wait five years on the respite wait list.*”

## Respite Funding

When services for children and youth with special needs were transferred back to MCFD from CLBC in 2009, total budgets allocated to each service delivery area were based on the historical amounts provided by CLBC. Each service delivery area determines the allocation of family supports, such as the At Home respite benefit.

Overall provincial funding for direct-funded respite has increased from \$1.5 million in 2007/08 to \$7.6 million in 2017/18 to support more families, although that is still a relatively modest amount and does not meet needs. The basic amount of respite funding of up to \$2,800 provided annually to each family has not increased since the program was developed in 1989 and lengthy wait lists persist.<sup>86</sup> Families today receive fewer hours of respite because the cost of hiring respite workers has increased while the funding has remained steady.<sup>87</sup>

## Autism Funding

MCFD funds two programs to support families of children and youth with autism: Autism Funding Under Age 6 and Autism Funding Ages 6 to 18. The primary intent of the program for children under six is to assist families with the cost of purchasing intervention services to promote communication, social-emotional development, pre-academic skills and functional life skills development. Under-six funding can also be used for parent training and some travel costs associated with training, equipment and materials related to autism intervention, as well as computers or touch-screen tablets. Families of children under six are eligible for \$22,000 per year under this program.

Past their sixth birthday, children and youth with autism are eligible for \$6,000 per year to supplement school-based interventions. Up to 20 per cent of the annual funding may be used to purchase training, travel and equipment related to autism intervention.<sup>88</sup> In the 2017/18 fiscal year, MCFD provided \$83,854,342 in autism funding to B.C. families.

<sup>86</sup> An income test is applied to families who are eligible for respite services to determine how much they will receive – between \$2,400 and \$2,800 per year.

<sup>87</sup> Funding for other sources of respite, such as contracted respite, have increased from \$2.9 million in 2007/08 to \$16.9 million in 2017/18.

<sup>88</sup> Ministry of Children and Family Development, *A Parent's Handbook: Your Guide to Autism Programs* (Victoria: Ministry of Children and Family Development, 2017), 17-19.

## The Auton Decision

In *Auton v Attorney General of B.C.*, parents of autistic infants brought forward a lawsuit against the provincial government. The parents argued that by failing to provide funding for an intensive early behavioural intervention (the Lovaas Autism Treatment), the provincial government violated their equality rights (s.15) under the *Canadian Charter of Rights and Freedoms*. The parents experienced frustration in accessing government services for their children. Social workers were unavailable or unable to explain the available services or criteria for the available services. Benefits were promised, never delivered or abruptly terminated. Families encountered wait lists for up to two years to access treatment facilities. Due to the lack of available services, the parents had paid for the costly Lovaas treatment themselves and saw significant improvements in their children's conditions. When the parents could no longer bear the expense of the therapy, they sought help from the provincial government without success. At the hearing, the provincial government rejected the treatment as a medically necessary service. However, the Supreme Court of British Columbia found that the provincial government failed to provide effective treatments for autism and discriminated against the parents by failing to accommodate their disadvantaged position by not providing effective autism treatment. This decision was later reversed by the Supreme Court of Canada. This lawsuit led to many changes in B.C., including the advent of individualized funding for autism treatment, which had previously not existed.

<sup>90</sup> *Auton v AGBC*, 2000 BCSC 1142

<sup>91</sup> *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982 (UK)*, 1982, c 11.

Students with autism are also eligible for special education services through their school district or school authority, such as additional staff (e.g., special education assistant), specialized learning materials, physical accommodations or equipment, and assessments to enable them to meet their educational and social needs. Many students with autism work with therapists, such as speech/language pathologists or occupational therapists, and some school districts employ behaviour consultants. Students with autism are entitled to an IEP that outlines educational goals, strategies to achieve those goals, and measures to track progress.<sup>89</sup>

Accessing and using autism funding is complicated, time-consuming, and almost completely up to family members to manage. Many families have difficulty managing the interviewing, hiring, scheduling, paying and billing that is required to access services for their child. Some families likely also struggle with the paperwork each of these things requires. It is important to understand that these tasks are in addition to the tremendous challenges parents already experience caring for children with special needs. From initial concern, to participating in intervention, the onus for initiating, monitoring, and continuing services is on parents. Ultimately, using autism funding is akin to running a small business and some families, such as Charlie's, require much more support and guidance to manage this system than what is currently provided.

<sup>89</sup> Ministry of Education, *Special Education Services: A Manual of Policies, Procedures, and Guidelines*, (Victoria: B.C., Ministry of Education, 2016), 12.

*“When my son was diagnosed at age five, I was so tired and overwhelmed that without autism funding I’m not sure I would have tried behavioural therapies because I really didn’t believe they would help. Then, in one year we saw such progress and it was such a relief. But I know other parents who are overwhelmed figuring out the invoicing system and who fail to remember to fill out forms and renew every year. I know of kids who need support and assistance, but their parents don’t access autism funding because the system is too much for them. They aren’t really up to hiring and overseeing therapists, and they are so tired . . . It seems to me that many parents use this funding wisely but that the most vulnerable kids often have the most challenged families who are the least likely to sit down and do the paperwork needed to access those funds. There needs to be more support and outreach [but not more paperwork] for those families and those very vulnerable children.”*

– Parent advocate

## Practice Consideration

CYSN provides voluntary support programs to promote healthy development of children and youth with special needs, maximize quality of life and assist families in their role as primary caregivers. However, the responsibility for accessing and managing services is usually placed on parents. The Representative recognizes that some families have the capacity to meet the disability-related needs of their children, navigate systems of support, and independently manage service providers. However, some families clearly require support. These are often the most vulnerable families who, as a result, may miss services and supports. The Representative believes MCFD should provide a choice for families between managing supports on their own or choosing a case-managed option, in which a third party would coordinate and manage services for the child and family. This case-managed option already exists on a limited scale in B.C. Families can sign a request for service provision with a community agency and have that agency manage their autism or respite funding. For example, families can take their respite funding to an agency and ask that agency to find and pay respite caregivers. This is offered by some agencies and may not be available in all communities.

Although Charlie was immediately eligible for \$6,000 a year in autism funding once he was diagnosed, his mother never accessed this funding. This is not unusual, as MCFD figures show. In fiscal years 2014/15 and 2015/16, 3,376 families were eligible for under-six autism funding but only 3,275 claimed it within two fiscal years, meaning about three per cent did not. During the same period, 19,656 families were eligible for six-to-18 funding, but only 9,122 families claimed it within two fiscal years, meaning nearly 14 per cent did not.

There may be a variety of reasons for eligible families not accessing autism funding. Some families may not require it. Others may not access it to avoid contact with MCFD. However, the Representative believes it possible that many of these families do not access their funding because finding and gaining access to services is a challenge and, overall, the process is too onerous.

Charlie’s case demonstrates that some families need much more support than they currently receive. The Representative understands that there are many families of children with special needs who do not require a high level of CYSN worker support – their children are safe, involved in their communities, and their families are able to navigate complex systems to meet their needs. However, Charlie’s mother clearly required more intensive support from a CYSN social worker with the time and ability to assess and respond to the family’s needs.

## UNCRC – Children with Disabilities

**Article 23:** *Children who have any kind of disability have the right to special care and support, as well as all the rights in the Convention, so that they can live full and independent lives.*

### Practice Consideration

The Representative believes that MCFD would benefit from identifying a single point of accountability and responsibility for CYSN services. This could be done through the creation of a Provincial Director for Children and Youth with Special Needs, a move that would demonstrate MCFD's commitment to prioritizing this program area.

The Representative acknowledges work undertaken by the ministry in this area to date. In response to previous recommendations made by the RCY and recommendations by the BC Coroners Service following inquests into the death of Robert Robinson and Angie Robinson, MCFD has created new CYSN policies, developed training for new CYSN staff, and amended the PST tool. The Representative is encouraged by these improvements and is pleased that the C-CAT now provides a consolidated assessment of a family's needs. However, much more work is needed to address the broader challenges children with special needs and their families experience in accessing supports and services.

## Education

**Finding:** *There is a lack of clarity and coordination between MCFD and schools in responding to concerning school absences and withdrawals and working with families to address barriers and to promote school attendance. The Ministry of Education and the school district do not have adequate systems in place to flag when a child is withdrawn from school and does not subsequently register in an educational program. This left Charlie, a child with significant special needs and vulnerabilities, isolated in an unsafe environment where he received little in the way of educational programming for more than five years.*

### Right to Education

The *UN Convention on the Rights of the Child* states that children have a right to an education.

Article 24 of the *UN Convention on the Rights of Persons with Disabilities* says: "States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong."

In B.C., the *School Act* requires children to enrol in an educational program every year starting in the year they turn five, unless the child's parent defers enrolment to the following year.<sup>90</sup>

Students with special needs who are enrolled in B.C. schools are entitled to have "equitable access to learning, opportunities for achievement, and

*the pursuit of excellence in all aspects of their educational programs.*"<sup>91</sup> As a result, children with special needs often receive additional support and accommodations to enable them to access and participate in school programs. These additional supports may include staff, specialized learning materials, physical accommodation equipment, and assessments.

<sup>90</sup> Section 3(1), 3(2) of the *School Act*

<sup>91</sup> British Columbia, *Special Education Services: A Manual of Policies, Procedures and Guidelines*, (April 2016): 1.

## Individual Education Plan

An IEP is a documented plan developed for a student with special needs that describes individualized goals, adaptations, modifications and the services to be provided, and includes measures for tracking achievement. An IEP must have one or more of the following:

- the goals or outcomes set for that student for that school year where they are different from the learning outcomes set out in an applicable educational program guide; or
- a list of the support services required to achieve goals established for the student; or
- a list of the adaptations to educational materials, instructional strategies or assessment methods.

Students may qualify for special needs funding if they have been assessed and identified as having a Ministry of Education-funded designation and have an IEP in place.

As an alternative to a school-based educational program, a child can be registered with a public or independent school for homeschooling, where the parent provides the child with an educational program. There are three options for home-based schooling in B.C.: public school distributed learning, independent

school distributed learning and traditional homeschooling. These options are compared in the table below.

### Home-Based Learning Program Options in B.C.<sup>92</sup>

	Traditional homeschooling	Public school distributed learning	Independent school distributed learning
Must meet the learning outcomes of the B.C. curriculum	No	Yes	Yes
Learning must be supervised by a B.C. teacher	No	Yes	Yes
Students must use district- or school-approved resources	No	Yes	Yes
Student progress must be evaluated by a teacher and report cards are prepared by a teacher 3 times a year	No	Yes	Yes
Must participate in provincial testing (provincial exams and Foundation Skills Assessments)	No	Yes	Yes
Religious texts/resources may be used	Yes	No	Yes
Status of student with school	Registered	Enrolled	Enrolled

Distributed learning programs are government funded and offered through some public schools and independent schools. When enrolled in distributed learning, students are supported by a B.C. certified teacher who is responsible for supervising the program and evaluating progress. For students with special needs who are enrolled in distributed

<sup>92</sup> Ministry of Education, "Homeschooling," Government of British Columbia, retrieved from <https://www2.gov.bc.ca/gov/content/education-training/ways-to-learn/homeschooling>

learning programs, the school board or authority administering the program is responsible for developing IEPs and also receives any supplemental funding connected to the students' designation. As such, the board or authority is also responsible for providing and/or coordinating supplemental services to support children's success in their educational program.<sup>93</sup>

Traditional homeschooling is an alternative approach to education that exists outside of the B.C. education system. Parents who choose the traditional homeschooling option are required to register their child on an annual basis but are not required to meet any provincial standards or to deliver provincial curriculum. Rather, they take on the considerable responsibility for their child's entire educational program including curriculum, learning materials and evaluations. Parents who choose to homeschool also take on the responsibility for providing any special needs supports their child may require.

### Charlie's School Attendance

The school district that Charlie attended has policies and practices regarding attendance. When a student is absent, policy requires a teacher to report the absence to the school office. Principals and school counsellors review student attendance data and follow up with parents/guardians when they notice considerable unexplained absences. The district has staff and programs in place to support attendance. Child care and youth workers, school counsellors, principals, vice-principals and classroom teachers all work together as a school-based team to address attendance concerns, encourage improved attendance and communicate with students and parents. If attendance does not improve, or the school does not receive information from parents explaining the student absences, the response escalates.

In situations when the school is unsuccessful in working with parents, the principal will contact MCFD and engage district student support services to ensure that the student is being case-managed. According to the district, the concern is that if a student is not attending school regularly, he or she could be at-risk and there could be a child protection issue requiring the involvement of MCFD.

In Charlie's case, school attendance was a problem from the very beginning. In 2009, professionals involved with the family began informing the involved MCFD worker about concerns regarding Charlie's school attendance.

Charlie started at a new school in March 2010. He attended five days and was then absent for 28 days. Gradually, with the support of the school and a behavioural consultant, Charlie began attending school for full days and, by March 2011, was attending regularly with almost no behavioural concerns. In fact, according to school staff and administration, Charlie was making great progress. However, when Charlie's behavioural consultant's contract ended the next month, his mother stopped bringing

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<sup>93</sup> Ministry of Education, "Distributed Learning – Requirements and Guidelines for Students with Special Needs," last updated January 2014, <https://www2.gov.bc.ca/gov/content/education-training/administration/legislation-policy/public-schools/distributed-learning-requirements-and-guidelines-for-students-with-special-needs>.

him to school, saying that he did not want to go and that the school did not listen to her about managing his behaviour.

In June 2011, the principal at Charlie's school contacted MCFD to report concerns about his attendance. While the social worker did contact Charlie's mother to discuss the situation and offer supports, the report was closed because "*no significant child protection concerns were present; not attending school does not meet requirement for a section 13 concern.*" This meant that a fulsome assessment of the challenges the family faced in getting Charlie to school was not done. It was also a missed opportunity for MCFD to provide support to the family to help ensure Charlie's continued success at school.

In September 2011, Charlie's mother contacted a child protection worker to explain that she was having difficulty getting Charlie to school and planned to withdraw him and enrol him in a homeschool program. Charlie's mother told the social worker that she was calling because she didn't want MCFD to think that she was neglecting her child in withdrawing him from school. The social worker recorded this information but took no further action. Given the history of child protection investigations that were focused on neglect and lack of follow-through by Charlie's parents, the Representative believes that MCFD should have been more concerned about his mother's decision to withdraw him from school as well as whether she was able to provide him with an education.

On Sept. 21, 2011, the school principal called Charlie's CYSN worker to express concern that Charlie was being withdrawn from school. The CYSN worker responded to this report by meeting with Charlie's mother, who informed him that she had chosen to homeschool her son and that a child protection worker agreed with her plan. The CYSN worker did not find this choice to be unusual for a parent with Charlie's level of needs and did not ask for details about the mother's plans to homeschool Charlie or if he was registered as a homeschooler.

Charlie's mother withdrew him from school in October 2011. School records indicate the reason for his withdrawal as "*unknown.*" The school district explained to RCY investigators that Charlie experienced significant attendance challenges resulting in his mother's decision to homeschool him. Although records from earlier that year indicate that the school had attempted to support Charlie and his mother with attendance, it is unclear to the Representative what specific steps the school took in that regard.

## Ontario's Approach to School Attendance

In contrast to B.C., Ontario has a more rigorous process for working with students and families to encourage school attendance. Under the Ontario *Education Act*, the parent or guardian is required to ensure their child attends school. The principal of every elementary and secondary school is required to report the names, ages and residences of all children of compulsory school age who have not attended school to the school attendance counsellor. The attendance counsellor is required to inquire into every case of failure to attend school and has powers under the *Education Act* to encourage attendance. To assist in resolving attendance problems, the counsellor may visit schools to meet with students and staff, visit homes to meet with families, work with school board support staff and community agencies, investigate when students move or run away, provide long-term counselling to students who are habitually absent, and help students and parents who are requesting homeschooling or alternative programming.

Reports to MCFD regarding Charlie's school attendance and withdrawal were made on a number of occasions. The principal made two calls to MCFD expressing concerns about Charlie's attendance and withdrawal and there were additional calls with concerns from an income assistance worker and Charlie's mother. None of those calls resulted in substantive follow-up by the ministry.<sup>94</sup>

When a school has concerns about a child's attendance and has not been able to work successfully with the parents or guardian, practice is to make a report to MCFD. Importantly, however, the *CFCS Act* does not include educational neglect

as a child protection concern. Therefore, MCFD is unlikely to conduct a child protection investigation in response to a report about school attendance unless there are other protection issues. RCY investigators requested information from MCFD on the number of reports it receives about school attendance but MCFD does not track this data.

The Representative has observed inconsistency in MCFD practice around how it responds to reports about concerning school attendance and withdrawals. The Representative is concerned that there is a lack of clarity in MCFD about the role it can play in responding to concerns about school attendance and a concerning disconnect between the policies and practices of schools in reporting concerns to MCFD and in MCFD responding to those concerns, which can leave children like Charlie not properly supported and at risk.

School personnel told RCY investigators they feel discouraged when they report a concern to MCFD involving a child's declining school attendance and MCFD closes its file without assessment and without considering whether the family requires support. Schools will make reports to MCFD when they are of the view that the student and the student's family require a level of support that the school district is unable to provide or that there may be a child protection concern. MCFD does have the ability to provide supports and services to families voluntarily.<sup>95</sup> This was minimally done in June 2011 when the child protection worker contacted Charlie's mother by phone to ask her if she needed supports.

<sup>94</sup> Section 16(3)(b) of the *CFCS Act*

<sup>95</sup> Section 16(2) (a) and (b) of the *CFCS Act* indicate that the Director (MCFD) may offer supports services and agreements to the child or family or refer the child and family to a community agency.

## Requirement to Register in an Educational Program

Section 12 of the *School Act* provides parents with the right to educate their children at home or elsewhere but requires homeschooled children to be registered by Sept. 30 of each year with their catchment area school, or the public or independent school of their choice. It is an offence under the *School Act* to fail to register a child who is homeschooled.

In order to homeschool a child, a parent must register the child with a school. The principal of a public school is required to then register any homeschooled child and report this registration to the Ministry of Education. Additionally, the school principal must offer to the homeschooled child or the parents free of charge evaluation and assessment services to determine the child's educational progress in relation to students of similar age and ability and the loan of educational resource materials that are authorized and recommended by the Minister of Education and which, in the school board's opinion, are sufficient to enable the child to pursue an educational program.<sup>96</sup> The parent is not obligated to accept these services.

Charlie was withdrawn from school in October 2011 to be homeschooled. It is unclear if the school district ever informed Charlie's mother about the requirement to register him annually as a homeschooler. No one from the school followed up with Charlie's mother when he wasn't registered as a homeschooler in the 2011/12 school year or in subsequent school years. In early 2012, the school district missed an opportunity to ensure that Charlie was registered and receiving an education when a district physiotherapist called Charlie's mother to inquire about his need for services. Charlie's mother told the physiotherapist that he was being homeschooled and that he did not need any physiotherapy. The

physiotherapist accepted the mother's word and there was no follow-up.

### Investigation by Superintendent Order

The Ministerial Order *Investigation by Superintendent Order* requires a superintendent to investigate a report that a child is not registered in an educational program.<sup>97</sup> If the superintendent determines that a child is not registered in accordance with the *School Act*, the superintendent must advise the parent of the obligation to register. If the parent refuses to register the child, the superintendent is required to inform the police. The Ministerial Order also requires a superintendent to investigate a report that a registered homeschooled child is not receiving an educational program and discuss this with the parent. If the superintendent believes that a child is not receiving an educational program and is in need of protection, the superintendent must report to MCFD. Neither of these processes were followed in Charlie's case.

Despite children having a right to receive an education and despite there being a legal requirement for school-age children to be enrolled in an educational program or registered as a homeschooler (and provided with an educational program by the parent) both the district and the Ministry of Education confirmed that they do not track when students are not registered. The Ministry of Education confirmed to RCY investigators that it has a student information system that may have the capability to create an alert to indicate when a student is not registered

in an educational program. The Representative believes the ministry should utilize this technology to ensure appropriate follow-up with families in these cases.

<sup>96</sup> Section 3 School Regulation

<sup>97</sup> *Investigation by Superintendent Order* Ministerial Order 151/89 s.1

*“When I read back on his previous file, I have to admit, I said, how did this happen? . . . There were red flags there . . . I know the way the system is set up is that there’s balances and checks put in place. So if a child doesn’t come back to school the next year, you get a hold of education services . . . So my initial reaction was, how did this happen?”*

– Teacher at Charlie’s 2016/17 school

In discussing Charlie’s case with RCY investigators, one experienced CYSN supervisor said she felt the mother’s lack of connection to an official homeschooling program at this time should have been a “red flag” for the worker to follow up with the school and that the CYSN worker likely “took the parent’s word too much.” However, she explained that in the context of caseloads, which for many CYSN workers includes more than 150 files, workers are extremely limited in their ability to do that level of follow-up.

Charlie was not enrolled in an educational program or registered as a homeschooler between October 2011 and September 2016 and no one seemed to notice, including the school, the school district, the Ministry of Education, and MCFD.

## Concerns about Charlie's Educational Program at Home

MCFD missed an opportunity to see Charlie and assess whether he was receiving an education at home. In August 2014, MCFD received a report from an income assistance worker who was concerned that Charlie was not receiving an educational program after his mother requested funding to buy Hooked on Phonics to homeschool the 11-year-old.

The child protection social worker consulted with her team leader. They determined that no further action would be taken regarding the call as “there [were] no section 13 concerns.” The child protection worker didn’t ask whether Charlie was enrolled in distributed learning or if he was registered as a homeschooler. RCY investigators interviewed an MCFD senior management staff member and asked what level of assessment they would expect for this type of call. She said that the social worker should have discussed the concern with the parent, assessed the parent’s stress level and support system, and contacted the school district for its views on the matter. Her expectation was that the social worker would have considered Charlie’s visibility in the community, his medical issues and his special needs and would have contacted his doctor and the CYSN worker. The social worker did not see Charlie or take any of these steps.

If this information did not result in an assessment by MCFD into whether Charlie was receiving an education at home, it is clear to the Representative that there is a barrier to MCFD intervening in such cases. The Representative is concerned that the barrier may be legislative because in B.C. educational neglect is not grounds for protection under the *CFCS Act* and that MCFD does not have any policy or guidelines for staff on how to respond to and assess a report about the educational program a child is receiving at home or about concerning school attendance or concerning withdrawals.

## Educational Neglect

Educational neglect can be conceptualized as parental failure to meet a child's basic needs in a way that results in current or future harm.<sup>98</sup> It can have detrimental impacts on child development, including cognition and academics.<sup>99</sup> For example, an Ontario study found that, the vast majority of children involved in educational neglect investigations had at least one reported child functioning concern (e.g., behaviour problems, depression, ADHD, developmental delay, etc.). As well, almost all caregivers involved in educational neglect investigations had at least one risk factor (i.e., mental health challenge, physical health challenge, few social supports, substance misuse, social assistance receipt, or lack of money for basic necessities within the previous six months).<sup>100</sup>

B.C.'s *CFCS Act* does not explicitly include educational neglect as a child protection concern. Further, educational neglect is not a concept that has been considered in depth in B.C.'s child protection case law.

Educational neglect is explicitly included as a child protection concern in the child welfare legislation of both Quebec and New Brunswick.<sup>101</sup> While not specifically mentioning educational neglect, Alberta, Nova Scotia and Newfoundland and Labrador include deprivation of cognitive

stimulation and/or cognitive neglect as child protection concerns in their legislation.

The Representative is mindful of not wanting to create additional grounds for the removal of children from their parents' care and particularly of not wanting to create additional grounds for removal of Indigenous children or children with special needs, who may have very real challenges with regular school participation. That being said, the Representative is deeply concerned about the possibility that children such as Charlie may go without receiving an education for lengthy periods of time because of a lack of co-ordination and communication between schools and MCFD when it comes to working with families to support children's education.

## Homeschooling Children with Special Needs

Under the *School Act*, homeschooling is the full responsibility of the parent and is not overseen by a B.C. certified teacher. There is no requirement for a parent to demonstrate that they have capacity to educate a child, or for homeschool programs to meet provincial standards or deliver B.C. curriculum. There is no authority for a school, school board, or the Ministry of Education to approve or supervise the educational program. Consequently, homeschooled children are not eligible to receive a B.C. Dogwood Graduation Certificate.

<sup>98</sup> Melissa Van Wert, Barbara Fallon, Nico Trocmé, and Delphine Collin Vézina, "Educational neglect: Understanding 20 years of child welfare," *Child Abuse & Neglect*, 75 (January 2018): 51.

<sup>99</sup> Melissa Van Wert, Barbara Fallon, Nico Trocmé, and Delphine Collin Vézina, "Educational neglect: Understanding 20 years of child welfare," *Child Abuse & Neglect*, 75 (January 2018): 51.

<sup>100</sup> Christine Wekerle and David A. Wolfe, "Child maltreatment," in *Child Psychopathology, Second Edition* (New York: The Guilford Press, 2003), 640.

<sup>101</sup> Quebec Protection Act, *R.S.Q., c. P-34.1* ("*YPA*") includes failing to take the necessary steps to provide a child with schooling in its definition of "neglect" [s.38(b)(1)(iii)]. The *YPA* further notes that the security or development of a child may be considered in danger where the child is of school age and does not attend school, or is frequently absent without reason [s.38.1(b)]. New Brunswick's *Family Services Act, S.N.B. 1980, c. F-2.2* states that the security or development of a child may be in danger when the child is in the care of a person who neglects or refuses to ensure that the child attends school [s.31(1)(k)].

The Ministry of Education's funding policy does not provide supplementary funding for homeschooled students with special needs, as it does for students with designated special needs who are enrolled in schools. Public schools receive \$250 for each registered homeschooled child, and an independent school authority can receive \$175 for each registered homeschooled child. These funds are intended to support the provision of materials and resources to homeschooling parents and also to support evaluation and assessment services.

In 2017/2018, a total of 2,259 B.C. students were registered as homeschooled.<sup>102</sup> The Ministry of Education does not track how many registered homeschool students have special needs. Because there is no oversight of homeschooling, when Charlie was withdrawn from school to be homeschooled, he was effectively cut off from the school system and the special needs supports embedded within that system. For a child diagnosed with autism, individual funding decreases from \$22,000 to \$6,000 per year when the child reaches school-age because autism supports are embedded in the school system. Therefore, a decision to withdraw a child from school means that the student doesn't receive the autism supports embedded in the system and receives \$16,000 less per year in direct funding than a pre-school-age child. Given that was Charlie's situation, the Representative believes that MCFD and the school should both have questioned how Charlie's mother was going to meet his special needs as a homeschooler. It is also unclear to the Representative whether the school encouraged Charlie's mother to register him in distributed learning, where he would have received more support.

*"If he was going to school, he would not have been in that situation . . . he would have been red-flagged."*

– Pediatrician discussing Charlie's state in 2016

The Representative acknowledges that parents may choose to educate their children at home for a variety of reasons and that those parents may welcome the opportunity to direct their children's education without state involvement.

However, the Representative also believes that there should be greater oversight of students with special needs who are homeschooled to ensure that their parents are well supported in meeting their educational goals.

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<sup>102</sup> The Ministry of Education has data on students with special needs who are enrolled in a distributed learning program.

## Health and Early Years Services

**Finding:** *Charlie showed clear signs of developmental delay in the early years but was not identified by either the health care system or MCFD, in part because the family had limited contact with these systems, and in part because these systems do not have sufficient programs in place to serve hard-to-reach families. There was also unreasonable delay between the time of referral and Charlie's autism assessment given the importance of early intervention in improving outcomes.*

### Limited Early Contact with Primary Health Services

Early in his life, Charlie displayed behaviours suggesting he should be screened for autism and developmental delay. At age three, his father was concerned that he was not speaking and, when he was four, police attended the home after receiving a report that there was a child constantly crying in the apartment. Charlie's family said crying was a main form of communication for him.

Despite the early years being a critical time when wellness checks and developmental monitoring and screening are very important, Charlie had limited contact with the

health system prior to 2008, when he was already almost five.

#### Children with Disabilities – *UNCRC* Article 23<sup>103</sup>

According to *UNCRC* Article 23, Charlie had the right to special care, support and education for his disability. The adults and professionals in his life were responsible for recognizing situations of vulnerability, protection, resiliency and empowerment. The special care and support that he could have received for his disability included access to health care, screening and supports for his suspected developmental delays.

Charlie had limited access to health care in the early years when he could have been screened and supported for autism and his other special needs. His mother told professionals that she was a single parent living in poverty, and she struggled with her own chronic

illnesses including mental health and substance use challenges. She experienced barriers to accessing health services for herself and Charlie including transportation, stigma and the fear of Charlie being removed from her care.

Between May and December 2004, Charlie was seen three times at a walk-in clinic. At one visit, health records indicate that Charlie was flagged by the physician as having “*symptoms concerning nutrition, metabolism and development*” but RCY investigators found no evidence of a referral for a developmental assessment. When Charlie was nearly five, he was seen by a doctor for a dental infection. This doctor, who had never seen Charlie before, was extremely concerned with his development and made an immediate referral for an autism assessment.

MCFD and health authorities have joint responsibility to provide early years services to families. MCFD funds a range of universal and enhanced early years supports in key areas including child care, enhanced eligibility-based services for children and youth

<sup>103</sup> UNICEF, “Convention on the Rights of the Child,” UNICEF, <https://www.unicef.org/crc/>.

*“I am also worried about the age Charlie received his diagnosis of autism spectrum disorder. By the accounts of his developmental level, parental concern should have aroused much sooner than the age of six.”*

– Pediatrician who reviewed Charlie’s medical history in 2016

with mental health concerns or special needs and early childhood development or family support.

Physicians in B.C. can carry out developmental monitoring during wellness visits with infants and young children. During these wellness checks, physicians gather information about a child’s physical and behavioural development

and can refer to other specialists if concerns are expressed or evident. Developmental monitoring is dependent upon a physician’s clinical judgment to determine whether infants and young children are meeting milestones. Importantly, physicians rely on a child’s parents to schedule wellness visits, bring children to appointments, and identify any concerns regarding their child’s development. Like many families, Charlie’s family did not have a family doctor in the early years and so Charlie did not have a physician who monitored his development.

Developmental screening is another way to detect variances (i.e., a difference between expected norms and what is actually occurring) in development of infants and young children. However, B.C. aligns with the recommendation of the Canadian Task Force on Preventative Health Care (CTFPHC) that developmental screening tools should not be administered universally. Rather, developmental monitoring should be conducted with all infants and children. Developmental monitoring is conducted at wellness checks with family physicians, whereas developmental screening is undertaken by public health nurses at immunization appointments until 18 months of age. The next regular immunization appointment after these doesn’t occur until a child is five-years-old. Like many families who choose not to immunize their children, Charlie was not immunized as an infant and therefore his development was not screened by public health.

### MCFD Early Years Policy and Programs

MCFD early years services cuts across numerous government ministries, health authorities, school districts, Indigenous governments, municipalities and community organizations that share roles and responsibilities for providing supports to families. MCFD’s early years services (e.g. family support programs) are delivered entirely through contracted organizations with the goals of connecting families to the services that they need, providing them with effective social supports and networks and ultimately supporting wellness for children and families.<sup>104</sup> For example, child development centres are funded by MCFD to provide community-based, accessible, inclusive and strength-based services to children and their families and serve to provide families (who are either self-referred or referred by a health professional) access to professionals with expertise in child development, and who can provide developmental screening, consultation, and recommendations for healthy development.

<sup>104</sup> Ministry of Children and Family Development, “Early Years Policy and Programs,” (Ministry of Children and Family Development, June 2018), 1-12.

MCFD provides early years services between the ages of zero and six. The goals of these services are to: support the well-being of children and families; serve as barrier-free access point, particularly for families facing acute or chronic vulnerabilities; and, provide clear pathways to enhanced supports and services including Infant Mental Health and CYSN programs.

Because there are no universal touchpoints offered to families between the ages of 18 months and school entry (age five), MCFD plays an important role in filling the gap in early years services including family supports, early intervention, Child and Youth Mental Health and CYSN services. MCFD's early years framework was developed in June 2018 and focusses on five key areas of service including family navigation, supporting families, providing non-child care early learning, promoting community belonging and supporting Indigenous cultural, language revitalization and cultural competency. MCFD currently spends \$200 million a year on early supports for children and families.<sup>105</sup>

Family members expressed concerns about Charlie's development at age two. Other than being referred to an early intervention family support worker, Charlie received limited supports from MCFD early years in the form of family education, developmental screening and tools to assess and promote the healthy development of a child presenting with atypical behaviours.

## Developmental Monitoring and Screening

Primary health care providers, in partnership with parents, are responsible for developmental monitoring and screening to determine whether infants and young children are on track to meet developmental milestones. *Developmental monitoring* is an ongoing process in which primary care professionals use clinical judgement and elicit parental concerns to determine whether a child may need additional assessment or support.<sup>106</sup> *Developmental screening* is a point-in-time overview that uses standardized tools to help determine whether infants and young children are meeting milestones in the same way as their age-matched peers.<sup>107</sup> Developmental screening tools do not diagnose; rather, these tools suggest that referral for formal assessment may be warranted. The Canadian Task Force on Preventative Health recommends developmental screening when parents express concerns about development or when developmental monitoring suggests an infant or young child is at risk for delay.<sup>108</sup>

<sup>105</sup> Ministry of Children and Family Development, "Early Years Policy and Programs," (Ministry of Children and Family Development, June 2018), 1-12.

<sup>106</sup> U.S. Department of Health and Human Services & U.S. Department of Education, "Birth to 5: Watch Me Thrive! A Primary Care Provider's Guide for Developmental and Behavioural Screening," (U.S. Department of Health and Human Services & U.S. Department of Education, March 2014), 3

<sup>107</sup> U.S. Department of Health and Human Services & U.S. Department of Education, "Birth to 5: Watch Me Thrive! A Primary Care Provider's Guide for Developmental and Behavioural Screening," (U.S. Department of Health and Human Services & U.S. Department of Education, March 2014), 3

<sup>108</sup> Canadian Task Force on Preventative Health Care, "Recommendations on screening for developmental delay," *Canadian Medical Association Journal*, 188, 8 (May 2016): 584.

In B.C., early identification of young children displaying signs of autism or other neurodevelopmental disorders is a process that is heavily reliant on – and driven by – the child’s parent. A parent must have some knowledge of typical child development, know who to ask for help, and be able to access health care providers who can confirm concerns. A child’s parent may avoid identifying signs of variances in development due to stigma associated with disability. In Charlie’s case, his mother would have had to take him to immunization appointments, a child development centre or to a doctor and articulate concerns related to developmental delay to a professional who would have had to make a referral for assessment.

The Healthy Start Initiative: Provincial Perinatal, Child and Family Public Health Services standards provide high-level guidance to support the provision of effective public health services during pregnancy and the early years of a child’s life. Although the intent of the standards is to reduce inequities and promote health through the provision of both universal (population level) and enhanced services (more intensive interventions for families who may be experiencing vulnerabilities), gaps remain in the ability to identify and provide enhanced services to families (such as Charlie’s) who may experience barriers to accessing

### Social Determinants of Health

The Ministry of Health uses the following criteria to identify vulnerable populations or those in need of enhanced services:<sup>109</sup>

- Income and Social Status
- Social Support Networks
- Education and Literacy
- Employment/Working Conditions
- Social Environments
- Physical Environments
- Personal Health Practices and Coping Skills
- Healthy Child Development
- Biology and Genetic Endowment
- Health Services
- Gender
- Culture

or utilizing public health or primary health care services. For example, families may be unable to access a public health nurse who can help to identify vulnerable families who may benefit from more intensive follow-up, including referrals to specialists when children are between eight weeks and two years of age. In addition, many families are not connected to a family physician who can provide primary health care. The Representative is encouraged that the Ministry of Health is looking to expand its service delivery standards to age six, as the early years represents a unique period when the social determinants of health can have a significant impact on a family’s access to, and utilization of, health services.

A child’s early years represent a critical time in development. Intervening early and often can help to minimize or decrease the impact of neurodevelopmental disorders and prevent harmful experiences.<sup>110</sup> Therefore, health professionals (funded by MCFD and the Ministry of Health) play a crucial role in promoting healthy development of children through identifying parents and children who may be considered at-risk, providing support and direction for families to access intervention and treatment and adequately supporting parents.<sup>111</sup>

<sup>109</sup> Ministry of Health, “Healthy Start Initiative: Provincial, Perinatal, Child and Family Public Health Services,” (Ministry of Health, April 2013).

<sup>110</sup> Neurodevelopmental disorders are those, such as autism or intellectual disabilities, with onset early in development (i.e., before school age) and are characterized by impairment in personal, social, academic, or occupational functioning. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (Arlington, VA: American Psychiatric Publishing, 2013), 31.

<sup>111</sup> Royal College of Physicians and Surgeons of Canada, “Royal College Position Statement: Early Childhood Development,” last update June 2014.

## Birth to Age Three

The first few years of life (between birth and age three) is a period of rapid brain development. The brain is extremely plastic or flexible during this period, meaning that it is susceptible to the influence of both positive and negative environmental factors. Research shows that 90 per cent of a child's brain is developed by age five, before many children have any access to formal education.<sup>112</sup> As the brain becomes more mature, it becomes less adaptable and capable of re-organizing to new or unexpected challenges.<sup>113</sup> Given this, it is crucial to capitalize on the opportunity to provide meaningful supports and interventions during this critical period of time in order to influence a child's brain development and potential outcomes.

## Early Identification in Other Jurisdictions

Research suggests that conducting developmental monitoring and screening increases the chances that potential developmental delay is recognized and responded to appropriately.<sup>114</sup> The Canadian Task Force on Preventative Health recommends ongoing developmental monitoring at wellness checks.<sup>115</sup> The American Academy of Pediatrics (AAP) recommends developmental screening tools be administered at nine-, 18-, and 30-months or when parents identify concerns. The AAP also recommends an autism-specific screening tool be administered at 18-months.<sup>116</sup> In Ontario, the 18-month well-baby visit has been enhanced to include physician-prompted health supervision and evidence-informed suggestions, screening for parental morbidities (such as mental health concerns, abuse, substance misuse, physical illness), promotion of early literacy and information about community-based early childhood development resources. This strategically timed "enhanced" well-baby visit is conducted at this point because, apart from illness-related visits, the 18-month visit may be the last time a child and family see their primary physician until the child is four-years-old or starts school.

<sup>112</sup> Hutchison P Chair, "Inquiry into improving child health outcomes and preventing child abuse, with a focus on pre-conception until three years of age," (New Zealand House of Representatives, Wellington (NZ): 2013). Available: <http://media.nzherald.co.nz/webcontent/document/pdf/201347/Full-report-text1.pdf>

<sup>113</sup> Centre on the Developing Child, "In Brief: The Science of Early Childhood Development," retrieved from <https://developingchild.harvard.edu/resources/inbrief-science-of-ecc/>

<sup>114</sup> Brian Barger, Catherine Rice, Rebecca Wolf, & Andrew Roach, "Better together: Developmental screening and monitoring best identify children who need early intervention," *Disability and Health Journal*, 11 (2018): 423.

<sup>115</sup> Canadian Task Force on Preventative Health Care, "Recommendations on screening for developmental delay," *Canadian Medical Association Journal*, 188, 8 (May 2016): 584.

<sup>116</sup> American Academy of Pediatrics, "Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening," available from <http://pediatrics.aappublications.org/content/pediatrics/118/1/405.full.pdf>.

There is a tremendous opportunity for primary care providers (pediatricians, family physicians, health nurses) to positively impact outcomes through physician-prompted regular contact and developmental monitoring with children and families in the early years. In fact, the Early Years Task Force of the Canadian Pediatric Society has suggested that governments and child-focused organizations promote and support initiatives to determine whether there is a need for regularly scheduled well-child visits between the ages of 18 months and four years. B.C.'s health care system could be strengthened by proactively monitoring the development of children and families and increasing the frequency of access points for referral connections, particularly when there are concerns of possible developmental delay. The Representative encourages the Ministry of Health to review its current system of developmental monitoring to ensure that the system of services provided is available and accessible to all vulnerable families and children with signs of developmental delays.

### Promising Practice: Support for School Success (SD 39)

In School District 39 (Vancouver), a partnership between Vancouver Coastal Health, the Provincial Health Services Authority (RICHER team) and Ray-Cam Co-operative Community Centre has created a program that provides safe and accessible health screening to children who are at risk of significant developmental challenges at school-entry age in Vancouver's Downtown Eastside. Children are referred through a variety of means (child care providers, health professionals, community agencies, and self-referral) to take part in a one-day screening event held at Ray-Cam. A multidisciplinary team (dental, vision, hearing, occupational therapist, speech language therapist, nurse practitioner, public health nurse, pediatrician and developmental pediatrician) along with parents/guardians walk through a comprehensive screening process using the Ages and Stages Questionnaire and other specialized screening tools. If concerns arise during the screening, the pediatricians are on hand to perform more comprehensive evaluations and, in some cases, can provide a diagnosis. At the end of the screening process, families are provided a summary of the findings, and are connected with a medical professional who supports the family in follow-up appointments, if required. The school district also receives a copy of the report, which allows the district to mobilize support services for the child prior to Kindergarten entry. Children and families are provided food, bus tickets, summer program information and gift bags. The screening occurs bi-weekly in the spring over seven to eight sessions and families receive all multidisciplinary services on the same day.<sup>117</sup>

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<sup>117</sup> Provincial Office for the Early Years, "Early years in BC school districts: A scan of promising practices," retrieved from [https://www2.gov.bc.ca/assets/gov/family-and-social-support/child-care/early\\_years\\_in\\_sd\\_promising\\_practices.pdf](https://www2.gov.bc.ca/assets/gov/family-and-social-support/child-care/early_years_in_sd_promising_practices.pdf)

The Representative observed that lack of access to primary health care practitioners became a barrier to early identification and assessment of Charlie's developmental needs and delays. In considering other ways in which families such as Charlie's might have been seen and supported, the Representative has identified several promising practices:

### Practice Consideration

The type of innovative service delivery shown by School District 39 and its health and community partners can reach families who may otherwise have limited access to health care services. The Representative believes these types of services should be available prior to school entry in all communities across B.C. The Representative encourages the Ministry of Health to continue to fund and support innovative approaches and promising practices that increase the accessibility of developmental monitoring and supports for vulnerable families and communities.

### Practice Consideration

The Nurse-Family Partnership is a free public health program for women having their first baby. Each regional health authority runs a Nurse-Family Partnership program, so it is available across B.C. Women enrolled in the program are visited by a public health nurse starting in pregnancy until their child turns two. Mothers and nurses work together to determine a visiting schedule that works for mothers, but nurses are available to meet with mothers as often as every one-to-two weeks. Nurses who have specialized education work with mothers to

- ensure a healthy pregnancy
- prepare for childbirth
- enhance nutrition
- encourage exercise
- promote child development
- plan for the future, and
- facilitate access to community resources.

First-time mothers are eligible for the program if they enroll prior to their 29th week of pregnancy, are age 19 or under or are age 20 to 24 and experience social, financial, and/or housing challenges. For example, a young mother who is a single parent, stopped her education before the end of Grade 12 or who is homeless would be eligible for the program. The Nurse-Family Partnership is available in 54 communities in B.C. across four regional health authorities (Vancouver Coastal, Fraser Health, Island Health, Interior Health).

The Representative believes the Nurse–Family Partnership could be expanded to provide supports to vulnerable families of children with developmental disabilities. Key strengths of the Nurse–Family Partnership model, such as connecting with families in their homes and flexible schedules for home visits based on the child and family’s needs could be considered in the expansion of services. When Charlie and his mother were connected to Nursing Support Services, they engaged with their nurse and connected with other support services. In a similar way, the Nurse–Family Partnership might have provided support and facilitated connections to early identification and interventions before Charlie was five-years-old.

## Early Assessment/Intervention in the U.S.

In the U.S., children under the age of three with suspected or confirmed developmental-behavioural problems are referred to a state’s early childhood intervention program as mandated by the federal *Individuals with Disabilities Education Act*. The early intervention professional then evaluates to see if the child qualifies for early intervention services and what type(s) of services are best. Children older than three can receive developmental-behavioural evaluations to determine if they are eligible for special education services through the U.S. public school system. U.S. schools are required to complete the evaluation within 60 days of the parent signing a consent form for an evaluation. Follow-up by professionals is then individualized according to the type and level of concern, and can include one or a combination of the following: referral for developmental or behavioural evaluation; referral for early intervention or special education services; referral to an early prevention program (such as Head Start); enhanced developmental monitoring and repeat developmental-behavioural screening; and, more frequent follow-ups to help assure prompt referral to appropriate services.<sup>118</sup>

family’s social circumstances and the clinician’s response to them. For example, families who may be experiencing extreme stress can easily become isolated and marginalized, making it more challenging for these families to access health services. Successful social pediatric initiatives often involve leveraging enduring supportive relationships in order to alter the trajectory for vulnerable children and families and working in partnership with other community-based organizations.

<sup>118</sup> *Individuals with Disabilities Education Act*, retrieved from <https://sites.ed.gov/idea/>

<sup>119</sup> Nick Spencer, Concha Colomer, Garth Alperstein, Paul Bouvier, Julia Colomer, Olivier Duperrex et al., “Social Pediatrics,” *Journal of Epidemiology and Community Health*, 59, 2(2005): 106-108.

<sup>120</sup> Gilles Julien, *A Different Kind of Care: The Social Pediatrics Approach*, (Montreal, QC, McGill Queen’s University Press, 2004): 71

In B.C., there is no legislation that mandates timely assessment/evaluation in the early years and families experience much longer wait times (more than a year in most areas of the province) for assessments for autism and/or complex behavioural and developmental conditions.

## The Role of Social Pediatrics in Increasing Service Access

Social pediatrics is an approach to child health that focuses on the child, in illness and in health, within the context of their society, environment, school and family.<sup>119</sup> Social pediatrics is meant to complement existing health services in order to provide care to those who are most vulnerable – in particular, “*children who are experiencing extreme difficulty on the physical, social and psychological levels as well as families experiencing an alarming level of stress.*”<sup>120</sup> It is an approach that recognizes that the complexities related to accessing health services are further compounded by a

Charlie's family experienced barriers to accessing services. Those barriers included a lack of enduring supportive relationships, challenges attending appointments outside of Charlie's home and neighbourhood, lack of referral and long wait times for assessment of suspected developmental delays. A social pediatrics approach to early identification and intervention might have reduced those barriers to services.

## Long Wait Times for Assessments

Research suggests that early identification of autism is especially important as interventions are most effective at a young age. Effective autism interventions are those that start early, are intensive (i.e., at least 25 hours per week), have a low student-to-teacher ratio, have consistent structure, include family members and peers, generalize skills to different contexts and utilize ongoing assessments.<sup>121</sup> In B.C., a formal diagnosis of autism is required for children and their families to access autism supports through MCFD and the Ministry of Education.

## BCAAN and CDBC Assessments

The PHSA oversees the BC Autism Assessment Network (BCAAN) that provides diagnostic assessments for those with suspected autism and the Complex Developmental and Behavioural Conditions program (CDBC) that provides assessments for those with suspected complex developmental and behavioural conditions.<sup>122</sup> Assessments are carried out by clinics in regional health authorities. Referrals to BCAAN and CDBC must be made by a physician. A BCAAN assessment is carried out by one to four trained clinicians whereas CDBC assessments usually require at least three trained clinicians. The presentation of children assessed through CDBC is usually very complex and eligible children often come from vulnerable families.

The average wait time for an autism assessment through BCAAN is 55 weeks and the wait times for CDBC assessments are even longer (68.2 weeks).<sup>123</sup> Wait times for both types of assessments vary across health authorities. Currently, the Northern Health Authority has the longest wait for a BCAAN assessment (62.1 weeks) and Island Health has the shortest (46.2 weeks). There are currently 2,806 eligible children waiting for a BCAAN assessment and 39 per cent (1,122 children) of those are in the

<sup>121</sup> Eric J. Mash & David A. Wolfe, *Abnormal Child Psychology (4th Ed.)* (Belmont: Wadsworth, Cengage Learning, (2010), 299-334.

<sup>122</sup> Complex Developmental Behavioural Conditions (CDBC) provides diagnostic assessment services for children and youth who have significant difficulties in multiple areas of function. For example, children and youth with suspected intellectual disability or prenatal alcohol exposure would complete a CDBC assessment. Referral sources are the same as those for BCAAN assessments and wait times are as long or longer than those for BCAAN.

<sup>123</sup> Wait times for CDBC assessment range from 53.2 weeks (Interior Health) to 76.1 weeks (Island Health).

Fraser Health authority.<sup>124,125</sup> Although Northern Health has the longest wait times for BCAAN assessment, it has the lowest number of eligible children waiting for assessment (155 children or five per cent of the total).<sup>126</sup> Families can choose to pay for a private assessment, rather than waiting for a BCAAN assessment. While wait times for private assessments may be shorter (around two to three months) than those for publicly funded assessments, the cost for a private assessment is usually between \$3,000 and \$4,000 and thus out of reach for many families.

When Charlie was referred for autism assessment in 2008, he could have been eligible for \$22,000 per year through the under-six program. By the time he was diagnosed, he had turned six and was eligible for only \$6,000 per year under the ages six-to-18 programming. During the time between referral and diagnosis, Charlie was not eligible for autism services through MCFD (although he did access some early interventions). This was a critical time in Charlie's life when the involvement of intensive autism-specific supports and services could have positively impacted the trajectory of his development.

## Barriers to Accessing Autism Funding

When Charlie was determined eligible for autism funding in 2009, his mother received an in-person orientation on how to manage the funding. She also received the resource handbook provided to all families eligible for this funding, *A Parent's Handbook: Your Guide to Autism Programs*. This is a 40-page comprehensive document with information about autism, how to obtain an assessment and diagnosis, funding options, community resources and parental responsibilities. Although this document is intended to assist parents, it can be overwhelming. The handbook begins with what to do if a parent suspects their child may have autism and outlines the following steps for parents to take:

- Review early indicators of autism
- Make an appointment to discuss concerns with a physician
- If the physician does not make a referral for autism assessment, parents are directed to continue monitoring their child's development and return to their physician if concerns persist
- If the child's physician makes a referral for assessment, parents are responsible for attending the assessment with their child
- For children not diagnosed with autism, parents are again directed to continue monitoring their child's development and return to their physician if concerns persist
- For children diagnosed with autism, parents are directed to then contact their local MCFD office.

<sup>124</sup> The total number of eligible children waiting for a BCAAN assessment has increased from 2,378 in the 2012/2013 fiscal year. In October 2018, the Ministry of Health approved additional funding of \$1.2 million for 2018/19 to complete more than 400 additional autism assessments.

<sup>125</sup> The total number of eligible children waiting for CDBC assessment is 1,230. Northern Health has the smallest number of eligible children waiting for a CDBC assessment (195 or 16 per cent) and Island Health has the most (289 or 24 per cent).

<sup>126</sup> Information provided by PHSA to the Representative

Charlie is a child who needs supports for communication, engaging in social activities and adaptive functioning. This was clear even before he received a formal diagnosis.

### Practice Consideration

The Representative encourages the Ministry of Health to embed health services within community programs to strengthen relationships between health practitioners and community agencies, as well as other government service providers, and explore all resources to support children and their families while they wait for assessment and diagnosis.

Although autism funding was unavailable to him until he was diagnosed, RCY investigators could not find any evidence that the health practitioners involved with Charlie suggested any other, more informal, supports in the interim. Such supports could have been valuable to Charlie's development and could have also helped Charlie's mother who may have had a chance to talk with experienced and caring professionals, such as early childhood educators. Charlie's mother may also have connected with other parents and had the opportunity to compare Charlie's behaviour and skills with those of other children.

## Case Coordination

**Finding:** *The lack of a coordinated and integrated approach to the provision of services and supports to Charlie and his family contributed to his critical injury. The health system, medical system, education system and the child- and family-serving system often failed to provide the right supports and services to this family at the right times. Although multiple professionals were involved, no one ensured that this child received the continuity of care that was required to meet his complex needs and ensure his health and well-being.*

The Representative is concerned about the level and integration of services Charlie received from several government agencies. It is troubling that a child significantly impacted by disability and unable to speak for himself received what were often substandard responses and services. If anything, the level of service to Charlie, and the response to his needs and safety, should have been amplified due to his level of vulnerability. No one professional had an overall impression of Charlie, the services provided to his family, or the gaps in those services. Therefore, professionals had a limited understanding of the ways in which Charlie's disability- and family-related needs impacted his safety and his ability to thrive.

Charlie and his mother needed one professional to work intensively with the family, as well as professionals across various sectors. Further, this professional could have supported Charlie and his mother together, recognizing that in supporting Charlie's mother she would be better equipped to support Charlie. Charlie's mother expressed multiple times that she needed support to overcome poverty-related barriers, that she needed respite to rest and recharge, and the CPSU psychiatrist identified mental health supports as important for Charlie's mother. A professional such as this might well have bridged the gaps that existed and changed the outcome of Charlie's story.

## Multiple Service Systems and Providers

Charlie and his mother faced numerous significant challenges and required services from various government ministries (MCFD, Education, Health, Social Development and Income Assistance) as well as health authorities and contracted community agencies. RCY investigators met with 38 different professionals who had been involved

*“That’s one of the problems in the community – no one has the overall picture. Everyone has their little puzzle pieces. At Sunny Hill, we meet every week. I can tell you immediately if things are not coming together. Whereas in the community, you don’t have that advantage, and people are busy and have large caseloads. I think things can fall apart sometimes.”*

– Hospital social worker

with the family. Each service provider required intake, forms, and appointments; Charlie’s mother would have had to explain his history, diagnoses and current service needs multiple times.

Charlie’s mother told multiple professionals that she was a single mother of a child with complex care needs, that she struggled financially and that she had a limited social support network. She was clearly struggling

to care for Charlie by herself and needed someone to help coordinate services and supports. Like many other parents caring for children with complex needs, Charlie’s mother could have used support filling out forms, applying for services, making appointments, getting to appointments, and finding, scheduling and paying service providers. She needed someone able to provide updates and coordinate with other service providers.

Charlie’s mother relied on service providers from across government and communities to work together in support of his health and development. Unfortunately, the social services

*“If it were a perfect world, there would be somebody to coordinate all of this stuff and help parents wade their way through all of that. Because these families have a lot more to deal with than you or I do. And it’s hard to be a parent at the best of times . . . The parents are always looked at it as though somehow, they did something wrong or they’re lacking . . . But no, I think it’s supports [that] are lacking.”*

– Early intervention therapies family support worker

sector is not designed to provide services in an integrated, collaborative manner. The system is not set up to enable information-sharing between service providers so that they have access to critical details about a child’s well-being and about other care, treatment and therapy the child is receiving.

The Representative identified three main areas in Charlie’s case that were barriers to collaboration: communication challenges, siloed service provision and short-term, time-

limited supports. These are barriers that a case coordinator could have helped to overcome.

## Barriers to Communication

When Charlie and his mother had face-to-face contact with professionals, and when those professionals were connected, Charlie thrived. When Charlie was hospitalized, he and his mother had daily contact with health practitioners and social workers. In school, Charlie was involved with teachers, support staff and therapists who collaborated to support his learning. When he was placed in the therapeutic home and there was a clear treatment plan, and a coordinated multi-disciplinary approach, he rapidly progressed in many different ways.

In contrast, during many times in his life, the community-based health practitioners he was to receive care from were spread out geographically. Unlike in-patient health professionals or those working in a school, community professionals do not have the chance to communicate face-to-face and rely on less direct forms of communication. In Charlie's case, these forms of communication often broke down. For example, he was assigned a community pediatrician upon discharge from Sunny Hill. This pediatrician relied on other professionals to include him on communications, such as lab reports and appointment summaries, in order to stay informed of Charlie's status. When this communication stopped, and Charlie's mother stopped bringing Charlie for appointments, the pediatrician assumed he was no longer responsible for Charlie's health care. No other health professional, MCFD social worker or educator noticed that Charlie was not seeing a pediatrician. Further, the CPSU pediatrician wrote to many other professionals, including the MCFD social worker, that she was to be informed if Charlie's mother did not follow through on medical recommendations. None of the professionals who received the letter communicated Charlie's missed appointments to the CPSU pediatrician.

Frequent staff changes and reliance on phone calls or letters for communication provided further barriers to communication. There was no professional who knew all the others assigned to support Charlie and no one who facilitated communication between professionals. Because of this, Charlie was often withdrawn from services and isolated in his home.

## System Siloes

The Representative observed situations where professionals worked in silos to Charlie's detriment. For example, when Charlie's mother withdrew him from school in 2011, educators expressed concern to MCFD, assuming that it would work with Charlie's family. However, MCFD determined that a full investigation into those concerns was not required and instead offered the family services over the phone. The ministries that Charlie and his mother interacted with the most – MCFD, Education and Health – did not have a mandate to work with Charlie and his mother to address one of their most pressing needs: poverty and associated housing instability and transportation barriers. Charlie's mother expressed to many service providers from these ministries that poverty related obstacles hindered her ability to follow medical recommendations and disrupted Charlie's school attendance. However, these ministries did not have the mandate to work with Charlie's mother to address poverty. Similarly, these ministries consistently

overlooked the mental health-related needs of Charlie's mother. In not adequately considering her reports of exhaustion and depression, ministries missed valuable opportunities to support this family and strengthen the capacity of Charlie's mother to meet his complex needs.

### Promising Practices: Services to Adults with Developmental Disabilities program (STADD)

STADD is a partnership among schools and school districts, MCFD, DAAs, CLBC, WorkBC Employment Service Centres, SDSI, health authorities, the Public Guardian and Trustee and various community organizations. STADD is a program available in an increasing number of B.C. communities designed to assist with transition planning for eligible youth with special needs and their families. STADD supports are available to youth ages 16 to 24 who are eligible for CLBC services and supports because of a developmental disability, or who meet CLBC eligibility requirements for the Personal Supports Initiative. STADD provides eligible individuals and families the service of a STADD navigator. The navigator works to make sure individuals and families have the support of teams made up of representatives of different ministries, agencies and service providers, for a "one-government" approach to service delivery. Individuals, families and community partners, including MCFD staff, utilize a secure online tool to promote a one-government approach by sharing information, assessment results and planning goals.

A case coordinator who could work with various ministries, rather than within a silo, could have facilitated access to and engagement with services for Charlie and his mother. One example of a program that works across government ministries and is available to eligible youth with special needs and their families (for youth ages 16 to 24) is the Services to Adults with Developmental Disabilities program (STADD) (see text box).

### Time-limited Supports

Although Charlie received some beneficial supports, more often than not these were provided on short-term contracts. The termination of these supports contributed to Charlie's isolation. For example, a family outreach counsellor successfully supported Charlie's mother but was only contracted to do so for April and May 2008. In December 2008, a family support worker

who had been working with Charlie's mother left her position. A new family support worker wasn't assigned until three months later and this worker did not see the family until the following summer, leaving Charlie's mother without support for six months. Charlie's behaviour consultant's contract ended after 11 months of service – 96 total hours – when his initial goals were completed. However, compared to other children his age, Charlie still had many skills to work on. Upon discharge from Sunny Hill, Charlie was assigned a private occupational therapist. The At Home Program funded this therapist to work with Charlie – a child whose mobility consisted of scooting on his bum and furniture-walking – for a total of 24 hours over a six-month period. A case coordinator could have noted the detrimental effect of short-term services and gaps when providers were unavailable and facilitated more comprehensive and long-term supports.

## The Role of a Case Coordinator

Service integration is especially important for a child with complex medical and developmental needs such as Charlie. Charlie and his mother would have benefited from a case coordinator to ensure that he received the continuity of care and supports that he needed throughout his life. A case coordinator would have been responsible

### Promising practice: Nursing Support Services

In fact, Charlie's NSS nurse sometimes acted as a case coordinator. Although it was not her role, the NSS nurse worked well with others who were involved with Charlie and his mother. For example, when Charlie's physiotherapist had concerns that the mother was not seeking appropriate medical attention for Charlie in 2009, the physiotherapist reported concerns to the NSS nurse. The nurse quickly phoned Charlie's mother to check in and offer supports. The NSS nurse took the time to develop rapport with Charlie's mother and met with her at the family home, instead of requiring her to take long trips on transit to meet with the nurse at an office.

This nurse also highlighted the importance of acceptance for Charlie's mother. She felt it was important *"not to judge [Charlie's mother]. To see that she really was trying to do what she felt was best for her son, but not knowing how to do it."*

for helping Charlie and his family access required services, coordinate multiple supports and ensure that services were available at the right time and the right intensity based on his changing needs.

Research shows that children with disabilities are one of the most marginalized and excluded groups of children and may experience a widespread violation of their rights. Children with disabilities face increased discrimination due to society's lack of understanding of disability.<sup>127</sup> Therefore, it is important for government

agencies to recognize the barriers faced by children and youth with disabilities and the fact that they are human beings with rights who are entitled to be treated equitably and with dignity.

### Rights of Children with Disabilities – *UNCRC Article 2 (Non-discrimination)*

*The Convention applies to all children, whatever their race, religion or abilities; whatever they think or say, whatever type of family they come from. It doesn't matter where children live, what language they speak, what their parents do, whether they are boys or girls, what their culture is, whether they have a disability or whether they are rich or poor. No child should be treated unfairly on any basis.*

### *UNCRPD Article 7 (Children with disabilities)*

*Ensures the full enjoyment of all human rights and fundamental freedoms on an equal basis with all other children.*

<sup>127</sup> UNICEF, "Children and young people with disabilities fact sheet," (UNICEF, May 2013), 4.

# Recommendations

## Recommendation 1

That MCFD undertake a comprehensive assessment of the actual need for CYSN services across B.C. and the capacity of the current system to meet those needs. This assessment to examine funding, staffing levels and workloads, program delivery and wait times. Findings to be used to inform comprehensive service improvements so all eligible children with special needs and their families receive culturally respectful, appropriate and timely services and supports.

MCFD to complete the comprehensive assessment and plan by the fall of 2019, seek necessary funding enhancements and begin implementation of changes by April 2020.

## Recommendation 2

Pending completion of the comprehensive assessment, that MCFD take immediate steps to improve the current accessibility of CYSN services and supports by providing respite within a reasonable period of time, eliminating the need to choose between medical and respite benefits, and monitoring and ensuring follow-up with families not using autism funding.

## Recommendation 3

That MCFD take the lead in working with the Ministry of Health and the Ministry of Education to develop an integrated service delivery model that enables appropriate information-sharing between service providers. This model would ensure that children and youth receiving special needs services through MCFD can be supported by a case coordinator who is responsible for navigating access to, and provision of, all necessary services. The case coordinator to remain assigned to the child to ensure appropriate services and facilitate successful transition to adulthood.

MCFD to lead development of a comprehensive plan by the fall of 2019 and seek funding and begin implementation of the plan by April 2020.

## Recommendation 4

That MCFD ensure its children and youth with special needs training is mandatory for child protection staff.

MCFD to ensure that all child protection social workers complete training by April 2020.

### Recommendation 5

That MCFD take steps to support child protection social workers to adhere to policy on response times to child protection reports and ensure children are seen during child protection investigations. This should include consideration of additional staffing, training and resources. MCFD to track adherence to these policies.

MCFD to begin implementation of these changes by April 2019.

### Recommendation 6

That MCFD and the Ministry of Education develop practice guidelines and a joint protocol to address concerns of unexplained school absences and withdrawals with the view to supporting children, youth and families and addressing barriers to school participation. MCFD and the Ministry of Education to conduct this work in consultation with advocates/stakeholders from the Indigenous and special needs communities.

MCFD and the Ministry of Education to complete this work by May 2019.

### Recommendation 7

That the Ministry of Education establish mechanisms to enable local school districts to identify and do timely follow up when a school-age student is not registered in an educational program.

Ministry of Education to complete this work by September 2020.

### Recommendation 8

That the Ministry of Education determine how many students with special needs designations are being homeschooled and conduct a review to determine whether school districts should be offering additional support and guidance to these students.

Ministry of Education to complete this work by September 2020.

### Recommendation 9

That MCFD ensure identification and involvement of an Indigenous child or youth's family, community and culture at the first point of contact with any MCFD service and continue this involvement on an ongoing basis. This should include, in consultation with Indigenous stakeholders and communities, the creation of guidelines for social workers working with Indigenous families, including resources to help them do this work.

MCFD to complete this work by May 2019.

### Recommendation 10

That the Ministry of Health and MCFD develop a plan to ensure early identification, timely assessment and appropriate and accessible supports for children under six-years-old with signs of developmental delay.

Plan to be developed by April 1, 2020 with implementation to begin immediately thereafter.

### Recommendation 11

That the Ministry of Health take steps to incrementally decrease the wait times to three months for completed assessments of autism and complex behavioural developmental conditions across the province.

Wait times to be reduced to nine months by Sept. 30, 2019; to six months by Sept. 30, 2020; and to three months by Sept. 30, 2021.

# Appendix A: Sections 11, 12 and 16 of RCY Act

## Part 4 – Reviews and Investigations of Critical Injuries and Deaths

### Section 11 – Reviews of critical injuries and deaths

- (1) After a public body responsible for the provision of a reviewable service becomes aware of a critical injury or death of a child who was receiving, or whose family was receiving, the reviewable service at the time of, or in the year previous to, the critical injury or death, the public body must provide information respecting the critical injury or death to the representative for review under subsection (3).
- (2) For the purposes of subsection (1), the public body may compile the information relating to one or more critical injuries or deaths and provide that information to the representative in time intervals agreed to between the public body and the representative.
- (3) The representative may conduct a review for the purpose of identifying and analyzing recurring circumstances or trends to improve the effectiveness and responsiveness of a reviewable service or to inform improvements to broader public policy initiatives.

### Section 12 – Investigations of critical injuries and deaths

- (1) The representative may investigate the critical injury or death of a child if, after the completion of a review of the critical injury or death of the child under section 11, the representative determines that
  - (a) a reviewable service, or the policies or practices of a public body or director, may have contributed to the critical injury or death, and
  - (b) the critical injury or death
    - (i) was, or may have been, due to one or more of the circumstances set out in section 13 (1) of the *Child, Family and Community Service Act*,
    - (ii) occurred, in the opinion of the representative, in unusual or suspicious circumstances, or
    - (iii) was, or may have been, self-inflicted or inflicted by another person.
- (2) The standing committee may refer to the representative for investigation the critical injury or death of a child.
- (3) After receiving a referral under subsection (2), the representative
  - (a) may investigate the critical injury or death of the child, and
  - (b) if the representative decides not to investigate, must provide to the standing committee a report of the reasons the representative did not investigate.

### Section 16 – Reports after reviews and investigations

- (1) The representative may aggregate and analyze the information received from the reviews and investigations conducted under sections 11 and 12 and produce a report of the aggregated and analyzed information that does not contain information in individually identifiable form.

- (2) The representative must provide a report made under subsection (1) to the following:
  - (a) the standing committee;
  - (b) the public body, or the director, responsible for the provision of a reviewable service that is a subject of the report;
  - (c) any other public body, director or person that the representative considers appropriate.
- (3) After an investigation of the critical injury or death of a child under section 12, the representative must make a report on the individual critical injury or death of the child.
- (4) A report made under subsection (3) must contain the representative's reasons for undertaking the investigation and may contain the following:
  - (a) recommendations for
    - (i) the public body, or the director, responsible for the provision of a reviewable service that is a subject of the report, or
    - (ii) any other public body, director or person that the representative considers appropriate;
  - (b) personal information, if, in the opinion of the representative,
    - (i) the disclosure is necessary to support the findings and recommendations contained in the report, and
    - (ii) the public interest in the disclosure outweighs the privacy interests of the individual whose personal information is disclosed in the report;
  - (c) any other matters the representative considers relevant.
- (5) A report made under subsection (3) may be provided to any person that the representative considers appropriate and must be provided to
  - (a) the standing committee,
  - (b) the public body, or the director, responsible for the provision of a reviewable service that is a subject of the report, and
  - (c) the public body, or the director, that is a subject of recommendations in the report, if not already provided the report under paragraph (b).

# Appendix B: Documents Reviewed During the Representative's Investigation

## Medical Records

- Nursing Support Services records
- Hospital records
- Community physician records
- Medical Service Plan records for Charlie and his mother
- PharmaCare Dispensing records for Charlie and his mother

## Ministry of Education Records

- Charlie's school records from two schools

## MCFD Records

- Family Service file
- Children and Youth with Special Needs Family Service file
- Community Living BC file
- Charlie's Child Service file
- Charlie's Autism file
- Charlie's Child At Home file
- Charlie's Medical Benefits file
- Charlie's Critical Incident file, 2016
- Case Review, 2017

## Ministry of Social Development and Poverty Reduction

- Employment and Assistance file for Charlie's mother

## Police Records

- Records from two policy agencies

## Community Agency

- Charlie's Therapeutic Home records
- Behavioural Support Records
- Early Intervention Therapy Services records
- Records from two community agencies

### Standards and Policy

- British Columbia Ministry of Children and Family Development (2003). Child and Family Service Standards
- British Columbia Ministry of Children and Family Development (2009). Children and Youth with Special Needs Service Delivery Policies:
  - Eligibility for Autism Programs Policy
  - Eligibility for CYSN Support Services - Interim Policy
  - Eligibility for the At Home Program Policy
  - Service Planning Policy
  - Service Prioritization Policy
  - Use of Respite Funding
- British Columbia Ministry of Children and Family Development (2012). Child Safety and Family Support Policies
- British Columbia Ministry of Children and Family Development (2012). Collaborative Practice between Children and Youth with Special Needs and Child Welfare Workers
- British Columbia Ministry of Education (January 2014). Distributed Learning-Requirements and Guidelines for Students with Special Needs
- British Columbia Ministry of Education (April 2016). Special Education Services: A Manual of Policies, Procedures and Guidelines

### Legislation

- *Child, Family and Community Service Act* (1996). Victoria, B.C. Queen's Printer
- *Indian Child Welfare Act* (1978). United States.
- *Individuals with Disabilities Education Act* (1975). United States.
- *Representative for Children and Youth Act* (2006). Victoria, B.C. Queen's Printer
- *School Act* (1996). Victoria, B.C. Queen's Printer
- *Education Act* (1990). Ontario, Canada.
- *New Brunswick Family Services Act* (1980). Government of New Brunswick.

## Appendix C: Interviews Conducted During the Representative's Investigation

- Family Members (4)
- First Nation (1)
- Medical Service Providers (12)
- MCFD Staff (19)
- Community Agency service providers (5)
- School staff (2)
- Police (1)

Total: 44 individuals interviewed

## Appendix D: Multidisciplinary Team Members

**Catherine Jayne Nash** – Catherine has worked in the child protection field for more than two decades as a lawyer, on commissions and inquiries, and as a front-line worker. She currently lives in Victoria and is the mother of two children, including a 14-year-old son with extensive special needs.

**Dr. Jonathan Down** – Dr. Down is the Developmental Pediatrician for Vancouver Island Health Authority (VIHA), based at the Queen Alexandra Centre for Children's Health in Victoria. He is a Clinical Assistant Professor in the Faculty of Medicine at UBC and a member of the Division of Developmental Pediatrics at BCCH. He is an Affiliate Assistant Professor in the Island Medical Program at the University of Victoria.

Dr. Down's clinical interests have focused on children with prenatal alcohol exposure (FASD), and autism spectrum disorder. More recently, clinical and research interests have expanded to include adults with prenatal alcohol exposure and individuals with fragile X syndrome and developmental coordination disorder (DCD). He is President of the Whitecrow Village FASD Society and a board member of Inclusion BC.

**Dr. Rachelle Hole** – Dr. Hole is the co-director of the Centre for Inclusion and Citizenship (CIC), the only university-based research centre in Canada with a dedicated focus on intellectual disability policy and practice. Rachelle is also a member of the UBC Institute for Community Engaged Research (ICER) and the leader of the social inclusion and equity research cluster. She is also an associated health researcher of the Collaborative REsearch Team to study psychosocial issues in bipolar disorder.

**Faith Bodnar** - Prior to holding the position of Executive Director of Inclusion BC for nine years, Faith was the Executive Director of the Saskatchewan Association for Community Living for eight years. Over her career, she has worked locally, provincially and nationally with families, people with intellectual disabilities, agencies and government to advance full citizenship and human rights for all people.

**Grand Chief Doug Kelly** – Grand Chief Kelly is a founding member, elected Tribal Chief, and President of the Stó:lō Tribal Council, and was appointed Chair of the First Nations Health Council in June 2010. He has more than 25 years of leadership experience including four terms as Chief of Soowahlie, eight years as Tribal Chief & officer for the Stó:lō Tribal Council, and key leadership positions with the First Nations Summit Political Executive, founding Chair of the BC First Nations Fisheries Council, and the BC Treaty Commission. Doug is married, with a blended family of six adult children, He resides on the Soowahlie Indian Reserve located near Cultus Lake. The First Nations Health Council is responsible for overseeing the design of and transition to a new First Nations health governance structure as well as overseeing the delivery of health action items identified in the Tripartite First Nations Health Plan.

**Dr. Shannon McDonald** – Dr. McDonald is proudly Métis/Anishinabe with deep roots in the Red River Valley of Manitoba and is the Deputy Chief Medical Officer at the First Nations Health Authority. Dr. McDonald is a trained physician, with post-graduate medical training in community medicine and psychiatry and has worked for more than 20 years in the area of First Nations and Aboriginal health. Dr. McDonald has extensive experience both in the federal and provincial government contexts – most recently for five years as the Executive Director of Aboriginal Health at the B.C. Ministry of Health. As an influential leader, Dr. McDonald was recently awarded B.C.’s Physician Champions of Change award by the Doctors of BC for her leadership and advocacy for physician services in B.C.’s rural and remote First Nations communities.

# Appendix E: Priority for Service Tool

	Priority Level One	Priority Level Two	Priority Level Three
Family Characteristics	<ul style="list-style-type: none"> <li>• PST Scores:<sup>128</sup> 76-111</li> <li>• Family has a high need for support and assistance or is requesting services through an urgent or emergency service request as demonstrated by one or more of the following:               <ol style="list-style-type: none"> <li>i. Family frequently experiences stress and challenges that impact ability to meet their child's needs</li> <li>ii. Family has limited capacity to meet their child's needs</li> <li>iii. Family is currently involved with child welfare and there is a protection concern</li> <li>iv. Child or youth is not participating in an educational program/school</li> <li>v. Parent(s) has a disability and/or mental health challenge that impacts their capacity to meet their child's needs</li> </ol> </li> </ul>	<ul style="list-style-type: none"> <li>• PST Scores: 50-75</li> <li>• Moderate need for support and assistance as demonstrated by one or more of the following:               <ol style="list-style-type: none"> <li>i. Family experiences occasional stress and challenges that impact ability to meet their child's needs</li> <li>ii. Family has a weaker support network that may not be consistently available to them</li> </ol> </li> </ul>	<ul style="list-style-type: none"> <li>• PST Scores: &gt; 50</li> <li>• Low need for support and assistance as demonstrated by one or more of the following:               <ol style="list-style-type: none"> <li>i. Family is coping well and meeting their child's disability-related needs</li> <li>ii. Family has capacity to implement service plans and access community service independently</li> <li>iii. Family implements service plans and follows-through with advice</li> </ol> </li> </ul>

<sup>128</sup> These scores reflect those from the PST in use at the time Charlie was being evaluated by the tool. The PST underwent revision between 2015 and 2017 and was embedded within the CCAT. There is a new scoring rubric in the revised PST.

	Priority Level One	Priority Level Two	Priority Level Three
Timelines	<ul style="list-style-type: none"> <li>Initially contact the family within one week. The team leader must be consulted within one week of this meeting</li> <li>Within one month of initial contact provide the support plan</li> <li>Offer to meet with the family every three months<sup>129</sup> and consult with team leader every three months</li> <li>Visit<sup>130</sup> children at least once per year</li> </ul>	<ul style="list-style-type: none"> <li>Initially contact the family within one month. The team leader must be consulted within one month of this meeting</li> <li>Within one month of initial contact provide the support plan</li> <li>Offer to meet with the family every six to nine months<sup>131</sup> and consult with team leader every six months</li> <li>Wherever possible, meetings with the family include the child</li> </ul>	<ul style="list-style-type: none"> <li>Once Level 3 is determined, contact the family and child within one year</li> </ul>

<sup>129</sup> If the CYSN worker is unable to meet every three months, the team leader must be advised and the reason(s) must be documented.

<sup>130</sup> A visit requires CYSN workers to see the child in person and must be conducted even if another MCFD worker (e.g. child protection worker). If the CYSN worker cannot complete an annual visit, the team leader must be consulted, and a plan made to visit the child. If a plan cannot be made and the annual visit does not occur, the reason(s) documented.

<sup>131</sup> If the CYSN worker is unable to meet every three months, the team leader must be advised and the reason(s) must be documented.

	Priority Level One	Priority Level Two	Priority Level Three
Actions	<ul style="list-style-type: none"> <li>• Take a lead role in service coordination</li> <li>• Create a support plan</li> <li>• Pro-actively help the family address any barriers to support</li> <li>• Consult with team leader to determine the appropriateness of Integrated Case Management Meetings</li> <li>• Re-administer the PST<sup>132</sup></li> <li>• Reassess Priority Response Level if the family's situation changes</li> <li>• Recognize the cultural, legal, historical uniqueness of Indigenous people in working with families</li> </ul>	<ul style="list-style-type: none"> <li>• Share case management responsibilities with the family; assist with service coordination</li> <li>• Create and review a support plan</li> <li>• Support the family to address any barriers</li> <li>• Re-administer the PST<sup>133</sup></li> <li>• Reassess Priority Response Level if the family's situation changes</li> <li>• Provide new or enhanced services, as available</li> <li>• Refer to other community and government supports and services</li> <li>• Recognize the cultural, legal, historical uniqueness of Indigenous people in working with families</li> </ul>	<ul style="list-style-type: none"> <li>• If requested, develop a support plan with the family</li> <li>• Re-administer the PST<sup>134</sup></li> <li>• Reassess Priority Response Level if the family's situation changes</li> <li>• Provide current contact information and update information about family circumstances</li> <li>• Initiate requests for services, as they become available</li> <li>• Recognize the cultural, legal, historical uniqueness of Indigenous people in working with families</li> </ul>

<sup>132</sup> The Service Prioritization Policy outlines the times when the PST must be re-administered.

<sup>133</sup> The Service Prioritization Policy outlines the times when the PST must be re-administered.

<sup>134</sup> The Service Prioritization Policy outlines the times when the PST must be re-administered.

## Appendix F: MCFD-funded Programs and Services for Children and Youth with Special Needs in B.C.

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Foundational Programs</b>				
Infant Development program (IDP)		Children 0-3 <sup>135</sup> years who are residents of B.C., are at risk of developmental delay, are delayed in one or more areas of development (e.g., speech, gross motor skills, etc.), or are diagnosed with a disability/medical condition	IDP Consultants located in contracted service agencies such as Child Development Centres  MCFD also funds five regional advisors situated across the province	IDP consultants create an individual plan that outlines developmental goals for children and programs and services that will be provided to meet goals. When possible and appropriate, the plan includes goals of other involved professionals to provide one integrated plan for the family. IDP consultants provide home visits, developmental screening, and referrals to community supports/services, as well as other CYSN supports/services (e.g. EIT)

<sup>135</sup> IDP services can last longer than three years, depending on key transitions, such as preschool entry or a lack of other services in the community.

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Foundational Programs</b>				
Aboriginal Infant Development program (AIDP)		<p>Children ages 0-5<sup>136</sup> who are delayed in one or more skill areas or are at risk of delay</p> <p>Families in need of support or education to enhance parenting skills and capacity, as well as young/teen parents, and mothers with post-partum depression or caregiver mental health issues. Participation is voluntary</p>	<p>There is a Provincial Advisor for AIDP who serves to strengthen the capacity of Aboriginal Infant Development Programs and to support the AIDP consultants located in contracted agencies around the province</p> <p>Provincial Advisor services are provided through the BC Association of Aboriginal Friendship Centres</p> <p>AIDP Consultant services provided through contracted agencies</p> <p>MCFD also funds five regional AIDP advisors situated across the province</p>	<p>AIDP provides culturally relevant supports and services to families of children up to the age of school entry who have – or are at risk of – developmental delays. AIDP consultants directly support families and children by offering:</p> <ul style="list-style-type: none"> <li>• home visits, playgroups, parent education opportunities, parent support groups, and cultural activities, networking of parents</li> <li>• assistance in planning family activities to encourage healthy development of their child</li> <li>• a variety of online resources</li> <li>• screening and assessment that is culturally sensitive and meaningful</li> <li>• referrals and information about other health, social and community services</li> </ul>
Supported Child Development (SCD)		<p>Children ages 0-19 who have a documented delay or disability<sup>137</sup> and have a documented need for extra support in a child care setting due to the developmental delay or disability. Children and families can be referred by a professional or can self-refer</p>	<p>Community agencies are contracted to provide SCD consultants</p> <p>SCD programs authorize extra staffing support SCD Workers. SCD workers work in child care programs providing extra staffing support to ensure a child's inclusion</p> <p>MCFD also funds five regional advisors situated across the province</p>	<p>SCD is a community-based program that offers a range of consulting and support services to children, families and child-care centres, so that children with extra support needs can participate in fully inclusive child care settings</p> <p>SCD facilitates a child's participation in child care settings that assist the child to reach developmental goals and milestones. The program provides training, support and consultation to children, families and child-care staff</p>

<sup>136</sup> AIDP services children up to age six in communities where other services are not available.

<sup>137</sup> Documentation may be in the form of a letter, report, or assessment from a family physician, medical specialist, pediatrician, diagnostic team or clinic, speech-language pathologist, physiotherapist, occupational therapist, registered psychologist, early childhood educator, infant development consultant, public health nurse, or other related professional. If documentation is unavailable, the SCD consultant may complete a developmental screening/assessment to determine eligibility.

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Foundational Programs</b>				
Aboriginal Supported Child Development (ASCD)		Aboriginal children ages 0-12 <sup>138</sup> and their families, both on- and off-reserve, who require extra support due to developmental delays, including communication, speech and language delays, fine motor and gross motor delays, cognitive delays, social/emotional/behavioural delays. Children do not need a diagnosis to access ASCD	Community agencies contract with MCFD to provide ASCD  There is a provincial advisor for ASCD working from the BC Association of Aboriginal Friendship Centres who contributes to the overall coordination, training, resources, and support for ASCD. MCFD also funds five regional advisors situated across the province	Children are supported within the context of their families, extended families, communities, and culture. ASCD works to recreate the strong traditional systems of caring for children that Indigenous communities historically had in place  ASCD helps families of children with extra support needs access inclusive child care. The ASCD program promotes the development of children alongside their peers and allows parents/caregivers to participate in the workforce and pursue their training or education  Services can include: <ul style="list-style-type: none"> <li>• assistance in finding childcare</li> <li>• individual planning</li> <li>• extra staffing support in childcare programs</li> <li>• training and support for families and childcare providers</li> <li>• assistance accessing other community services</li> <li>• developmental screening and assessments at the request of the family</li> </ul> Support may take place in a variety of settings: <ul style="list-style-type: none"> <li>• Preschool</li> <li>• Aboriginal Head Start programs</li> <li>• Childcare programs</li> <li>• After school care programs</li> </ul>

<sup>138</sup> In some communities, children are eligible up to 19 years of age.

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Foundational Programs</b>				
Early Intervention Therapies (EIT)		<p>Infants and young children up to school entry who have, or are at risk for a developmental delay or disability</p> <p>Parents, physicians and community members can refer</p>	<p>Contracted with community-based organizations, including health authorities</p> <p>Professionals can include:</p> <ul style="list-style-type: none"> <li>• SLP</li> <li>• OT</li> <li>• PT</li> <li>• Family support professionals</li> </ul>	<p>EIT provides OT, PT, SLP and family support services to optimize children's growth and development and to support their families and communities</p> <p>Family support professionals assist families to acquire parenting, child development, and advocacy skills, and address factors which may affect their capacity to care for their child</p> <p>EIT therapists provide:</p> <ul style="list-style-type: none"> <li>• screening</li> <li>• referral</li> <li>• assessment</li> <li>• family education and support</li> <li>• service planning</li> <li>• direct therapeutic intervention</li> <li>• consultation</li> <li>• monitoring</li> <li>• transition planning to school and/or other services</li> <li>• training of community members</li> </ul>
School-Aged Therapy program (SAT)		<p>Children and youth who have – or are at risk for – a developmental delay or disability and display a demonstrated need have access to SAT services from school entry until school exit. Anyone can refer a child or youth to the SAT program</p>	<p>Professionals can include:</p> <ul style="list-style-type: none"> <li>• OT</li> <li>• PT</li> </ul>	<p>SAT provides occupational therapy and physiotherapy services to assist children and youth with special needs in meeting their educational goals and to help them achieve their highest level of independent functioning within their home, school and community settings</p>

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Specialized Provincial Services</b>				
Autism Funding Program		Children and youth who have been diagnosed with ASD (BCAAN or private assessment)	CYSN social worker facilitates eligibility review and initiates the service request to the program  The Autism Funding Program staff facilitate payments on eligible expenses	The program assists parents with purchasing eligible intervention services for their child or youth who has been diagnosed with ASD. MCFD provides two autism funding programs: <ul style="list-style-type: none"> <li>• Under Age 6 (\$22,000 per year)</li> <li>• Ages 6-18 (\$6,000 per year)</li> </ul>
At Home program (AHP) medical benefits program including School Ages Extended Therapy (SAET) benefit		Children and youth ages 0-17 living with a parent/guardian or with an Extended Family Program caregiver who are: <ul style="list-style-type: none"> <li>• Assessed as dependent in at least 3 of 4 activities of daily living (eating, dressing, toileting, washing),<sup>139</sup> or</li> <li>• have a palliative condition, or</li> <li>• are eligible for NSS direct nursing care, or</li> <li>• are diagnosed with a degenerative condition (Duchenne muscular dystrophy, spinal muscular atrophy type 2)</li> </ul>	Specialized Provincial Services AHP medical benefits staff facilitates payments or supplies based on eligible expenses  CYSN Worker offers support and referrals to other supports	Medical benefits available to an eligible child or youth may include the following: <ul style="list-style-type: none"> <li>• medical equipment</li> <li>• biomedical equipment</li> <li>• medical supplies</li> <li>• orthotics and splints</li> <li>• audiology equipment and supplies</li> <li>• School-Age extended therapies (if the child is eligible for medical benefits and school-age)</li> <li>• Dental, orthodontic and optical coverage</li> <li>• Medical transportation</li> <li>• Medical Services Plan coverage</li> <li>• Medications and PharmaCare</li> </ul>

<sup>139</sup> Children and youth assessed as dependent in three out of four activities of daily living are eligible for a choice of AHP medical benefits of AHP respite benefits whereas children and youth assessed as dependent in four out of four activities of daily living are eligible for both AHP medical benefits and AHP respite benefits (although families are still subject to wait lists for respite benefits).

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Specialized Provincial Services</b>				
Provincial Deaf and Hard of Hearing Services		<p>Children and youth who are deaf or hard of hearing or deaf-blind</p> <p>PDHHS contracts for specialized early intervention services for children who are blind or partially sighted</p>	Provides direct and contracted services	<p>Direct Services:</p> <ul style="list-style-type: none"> <li>• Consultative services to MCFD workers and community partners regarding accessibility and meeting the needs of families with deaf, hard of hearing, and deaf-blind members; and</li> <li>• Family and community services include services to support family attachment, and services to support youth transition. Victory Hill Residential Program, a home-like residence for deaf and hard of hearing students who must live away from home to attend the provincial school for the deaf</li> <li>• Contracted services include:               <ul style="list-style-type: none"> <li>- specialized early intervention services</li> <li>- summer camp</li> <li>- youth developmental health and addiction services for deaf people, family and community development</li> <li>- interpreter/intervenor services</li> </ul> </li> </ul>

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Specialized Provincial Services</b>				
Provincial Outreach and Professional Support		Children with complex developmental and/or neuromotor disabilities are referred by a physician or community rehabilitation professional	Predominately OT, PT and SLP	<p>MCFD contracts with Sunny Hill Health Centre for Children to deliver provincial outreach services, which include:</p> <ul style="list-style-type: none"> <li>prescription and fitting of customized assistive devices, including mobility devices (e.g. wheelchairs)</li> <li>complex feeding and nutritional assessment</li> <li>professional support services for community-based therapists to develop and increase community skills and knowledge in order to better serve children and youth with complex needs</li> </ul>
Community Brain Injury Program (CBIPCY)		<p>The program accepts referrals (from parents, community/medical professionals) within 12 months post-injury for those without third-party funding<sup>140</sup> and who:</p> <ul style="list-style-type: none"> <li>• Are diagnosed with acquired brain injury from falls, tumors, infections, strokes and other causes.</li> <li>• Need rehabilitation and support services</li> </ul>	<p>The ministry contracts with B.C. Centre for Ability (BCCFA) to coordinate and fund short-term (6 months), acute rehabilitation services for children and youth returning to their communities following discharge from hospital after an acquired brain injury</p> <p>BCCFA contracts with local service providers to provide intensive community-based rehabilitation throughout the province</p> <p>CBIPCY Coordinator/ social worker</p> <p>PT OT SLP psychology neuropsychology</p>	<p>CBIPCY provides:</p> <ul style="list-style-type: none"> <li>• Acute rehabilitation: short-term (up to 6 months), rehabilitation and support to assist the child or youth as they transition from hospital or rehabilitation centre to home, school, and community. Services are provided in the child/youth's home community. Services provided can include PT, OT, SLP, psychology, social work, rehabilitation assistance services and neuropsychology assessment.</li> <li>• Service coordination: CBIPCY assigns a coordinator to each child/youth receiving acute rehabilitation services to ensure coordinated and quality services to meet the identified needs of the child/youth and the family</li> </ul>

<sup>140</sup> That is, the individual is not in receipt of duplicate funding through sources such as ICBC, Victim Assistance or other private insurance coverage.

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Specialized Provincial Services</b>				
AHP respite benefits		<p>Children and youth ages 0-19 living with a parent/guardian or with an Extended Family Program caregiver who are:</p> <ul style="list-style-type: none"> <li>• assessed by NSS as dependent in at least 3 of 4 activities of daily living (eating, dressing, toileting, washing), or</li> <li>• have a palliative condition, or</li> <li>• are eligible for NSS respite care, or</li> <li>• are diagnosed with a degenerative condition (Duchenne muscular dystrophy, spinal muscular atrophy type 2)</li> </ul>	CYSN social worker determines priority for service, administers payments, and meets periodically with families	Respite benefits provide funding to purchase respite care for eligible children and youth. Families may choose the type of respite services that best suit their needs, either in their home or at another location. Respite benefits of up to \$2,800 per year may be available dependent on family income

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Specialized Provincial Services</b>				
Family Support Services (FSS)		<p>Children and youth with confirmed:</p> <ul style="list-style-type: none"> <li>• Intellectual disability</li> <li>• Children under age five diagnosed with global developmental delay</li> <li>• Children and youth diagnosed with unspecified intellectual disability may be eligible</li> <li>• Children and youth eligible for autism funding are eligible for FSS</li> <li>• Children and youth eligible for the AHP are eligible for FSS</li> </ul>	CYSN social worker and contracted program staff	<p>Support services include a range of programs intended to support parents to care for their child or youth with special needs in the home, including:</p> <ul style="list-style-type: none"> <li>• Respite (direct funded, contracted respite, respite relief)</li> <li>• Child &amp; youth care worker/behaviour supports who provide direct goal-oriented assistance to a child and/or family</li> <li>• Homemaker/Home Support services that provide direct child care and household management services, and/or training in these areas, by trained personnel on a short term, on-going, intermittent or as-needed basis</li> <li>• Parenting supports, including services to assist parents and/or children to develop skills and access information and community programs</li> <li>• Professional supports – Contract for specialized support services to be provided for specified periods of time by qualified professionals</li> </ul>

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Specialized Provincial Services</b>				
FASD Key Worker and Parent Support		<p>Eligibility without an assessment: parents may self-refer to the program without an assessment, or at any point during the assessment process. Key worker services are not restricted to families of children and youth who qualify for or complete an assessment</p> <p>Eligibility following an assessment: the program is most likely to be of continuing benefit after assessment if the child or youth receives one of the following FASD diagnoses from the Canadian Guidelines for Diagnosis:<sup>141</sup></p> <ul style="list-style-type: none"> <li>• Fetal alcohol syndrome (with confirmed maternal alcohol exposure)</li> <li>• Fetal alcohol syndrome (without confirmed maternal alcohol exposure)</li> <li>• Partial fetal alcohol syndrome (with confirmed maternal alcohol exposure)</li> <li>• Alcohol related neurodevelopmental disorder (with confirmed maternal alcohol exposure)</li> </ul>	<p>Services are provided through contracted community agencies</p> <p>Key Workers deliver the services</p>	<p>Key Workers</p> <ul style="list-style-type: none"> <li>• use family-centered and culturally safe frameworks of practice</li> <li>• build on families' strengths</li> <li>• are a community resource on FASD</li> <li>• develop and strengthen community networks</li> </ul> <p>Specific roles of Key Workers include:</p> <ul style="list-style-type: none"> <li>• finding ways that parents, family members, caregivers, and service providers can adapt the child's environment</li> <li>• give emotional and practical support to families along with education and information tailored specifically to their needs</li> <li>• refer families to resources such as training, support groups, or mentoring programs</li> </ul>

<sup>141</sup> MCFD's "Key Worker and Parent Support Program Standards" outline eligibility for the program using the 2005 FASD Canadian Guidelines for Diagnosis. The Canadian Guidelines were updated in 2016, however, this change has not been reflected in the MCFD program standards.

	Referral Source	Eligibility	Service Provider(s)	Program Description
<b>Specialized Provincial Services</b>				
		<p>Occasionally, a child or youth may have received a diagnosis following the University of Washington FASD diagnostic process (4-digit code). The following additional diagnoses indicate that a child/youth would benefit from the Key Worker program:</p> <ul style="list-style-type: none"> <li>• Atypical fetal alcohol syndrome and/or</li> <li>• Static encephalopathy, alcohol exposed.</li> </ul> <p>Similar neurodevelopmental conditions: an assessment report may indicate that although a child does not have confirmed FASD, he or she has similar needs and challenges to those of children with FASD and would benefit from the Key Worker program. These children are eligible.</p>		
Microboard services		Those children who are eligible for FSS are eligible for microboard services.	Individuals with a relationship to the child and their family (often other family members or friends).	A microboard is a small group of people who join together as a non-profit society (in accordance with the <i>Society Act</i> ) to address a child's support needs.

# Contact Information

## Representative for Children and Youth

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B.C.'s Representative  
for Children and Youth  
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