Supports and Systems to Respond to Complex Needs Among Children and Youth in Ontario



Policy Brief

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Issue: How can systems best support children with complex behavioural and mental health needs to improve health, social, and other developmental outcomes, and reduce harm?

Background: In Ontario, there is growing concern about the inadequate supports for children and youth with complex needs – defined as multiple diagnoses or behavioural problems spanning multiple service sectors, which are anticipated to have long-term consequences. These children often face exclusion from services due to various barriers, including the complexity of their conditions and broader systemic issues. The lack of coordination across systems further complicates the situation, leading to a fragmented care landscape for these children and their families.

Objective: This report provides an overview and synthesis of the available literature relevant to complex mental health and behavioural needs among children and youth from a transdisciplinary perspective. The primary aim is to inform the development of evidence-based, cross-sector solutions to support optimal development and health equity for children and their families.

Key Findings: Overall, findings from the literature revealed that multiple initiatives to support children and youth with complex needs do exist at the local level across Ontario; however, the province is still lacking a well-coordinated or integrated approach across child-serving public sectors (health, education, social services, youth justice). As a result, children and families with complex needs continue to experience challenges in accessing and receiving appropriate services and supports, resulting in inadequate treatment and care. Another theme from the literature is the need for improved coordination and collaboration across systems and services. There is support for a systems of care approach to improve the quality and consistency of care for children and youth with complex needs; however, the lack of strong evidence and guidance around systems of care has limited its implementation thus far in Canada.

Policy Implications: Because of the complexity of their multiple challenges (i.e. behavioural, emotional, mental health, developmental, educational), it is clear that a "one size fits all" approach will not be enough to meet the needs of these children and families, as no single sector or agency has the necessary capacity to address these challenges effectively. There is a need for integrated solutions that break down existing silos and work towards a more holistic, whole systems approach—in which all child-serving systems collaborate and acknowledge their shared responsibility to not only meet the needs of these children but to help prevent them before they escalate and reach the point of crisis.

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Supports and Systems to Respond to Complex Needs Among Children and Youth in Ontario

1.0 Introduction

1.1 Overview of the Issue

In recent decades, researchers, service providers and professionals across public sectors in Ontario have expressed concern over the inadequacy of systems to support children and youth with complex mental health, behavioural, developmental and other needs (referred to in this brief simply as "complex needs") – broadly defined as children who experience multiple or co-occurring diagnoses or behavioural problems that cross multiple service sectors (see Section 4.3 for further discussion around terminology and definitions). As an example, this may include a child with a developmental condition such as autism or Attention Deficit Hyperactivity Disorder (ADHD) along with a co-occurring mental health condition such as anxiety or depression. Moreover, for many children, the complexity of their circumstances can be partially attributed to systemic barriers and social exclusions - which lead to inequities in access to needed supports and further complicate the risk of experiencing ongoing challenges.

The lack of support for these children has been identified across several sectors – including health and medicine, social services, education and child welfare. In each of these systems, children with the highest level of need are often the least likely to have their needs met. It should also be noted that the issue is not limited to Ontario, but has been identified in many jurisdictions across Canada and other countries, particularly within the child welfare sector. For example, recent reports from child welfare advocates in New Brunswick have identified an increase in the complexity of mental health issues among children and youth coming into care, which makes it increasingly difficult to find placements for these children that can adequately respond to their needs (Donkin, 2022). Similarly, up to half of children in foster care in the United Kingdom are reported to have complex mental health needs, and the majority of these needs are not being met (Ferguson, 2022).

There are several reasons why children with complex needs are frequently identified in Ontario but are not provided with adequate supports. First, due to the complexity of their intersecting conditions, children and youth with complex needs are often excluded or denied access to existing services. For instance, they may not meet the specific age or diagnostic criteria that would make them eligible for certain services, such as mental health, developmental, or disability services. Others may be ineligible due to prior histories or behaviours or may be hesitant to engage with services based on historical or past experiences of trauma – particularly for First Nations, Métis and Inuit peoples (Klassman et al., 2024). Another reason why children and families may not be receiving services is because of challenges and barriers in access or a lack of resources and capacity among service providers. Finally, the lack of evidence and guidance for both families and practitioners in this space has hindered the development and implementation of appropriate system responses. There is currently no clear pathway that informs the approach of service providers or professionals working with children with complex needs in Ontario and many families have difficulty navigating different systems themselves.

These challenges are made more difficult by the lack of coordination across systems in how children and youth with complex needs are assessed and treated in Ontario. Parents of children with complex needs currently face a fractured landscape in which they must seek out or get referrals for multiple services from multiple organizations – often navigating different or even inconsistent plans

of care through each service (Complex Mental Health Needs Collaboration Table, 2022; Van den Steene et al., 2019). Researchers have referred to this as a "hot potato" situation, meaning that families end up being tossed around from service to service to try to address specific aspects of their child's challenges rather than being offered a single, integrated system or care plan (Coneybeare & Cagas, 2022).

Ultimately, the lack of clarity and responsibility for providing effective care to a child with complex needs at a systems level can mean that children end up falling through the cracks with nowhere to

go for support. In the absence of a coordinated approach with well-defined guidelines for how to intervene, many children end up being referred to child protective services, seeking emergency or crisis services, or diverted into the justice system rather than receiving the supports they need to optimize health, developmental, social, educational and other outcomes (Becken, 2023). This places greater burden on these sectors which don't have the capacity or resources to provide appropriate care, leading to a crisis situation in the province that must be addressed. The Ontario Association of Children's Aid Societies (OACAS, 2023) has noted that while the Ontario government has taken steps to improve access to mental health supports and services, critical gaps remain for those children and youth with increasingly complex mental health needs. There is an urgent need for a more efficient and effective system in Ontario that recognizes and addresses complex mental health needs among children and youth as well as the needs of their caregivers.



1.2 Why is the Issue Important

The issue of how to respond to complex mental health needs among children and youth is important for several reasons. First, children with complex mental health and behavioural needs have been described as one of the most vulnerable population groups in need of services through Canada's health and social care systems (Canadian Home Care Association, 2016). The lack of a whole systems approach to meet these needs means that an already vulnerable population is at even greater risk of negative outcomes. For instance, because their care needs are more complex and optimal care requires coordination between sectors or providers (i.e. medical, educational, and social services), children with complex needs are at higher risk of inadequate treatment (including poorer quality of care and greater dissatisfaction with care), more persistent symptoms and complications from illness, greater functional impairment, and higher service use throughout the life course – all of which increase the cost of health and other service resources (Paton & Hiscock, 2019; Sirotich & Durbin, 2014).

The issue of inadequate and uncoordinated services for people with complex needs is even more important for children and youth, who stand to benefit the most from improved care responses because of their age and the potential for years gained in quality of life (Paton & Hiscock, 2019). Moreover, evidence from developmental science suggests that there are critical developmental periods during which health and social interventions have the greatest likelihood of changing a

child's trajectory – including early childhood and early adolescence. Without effective interventions, children with complex mental health needs will miss these key windows of opportunity to optimize positive outcomes.

Another reason why the issue is important is that the vulnerabilities and challenges facing children and youth with complex health needs intersect with other systemic factors that place some children at greater risk of negative health, developmental, social, educational, and other outcomes. For example, Indigenous and racialized children in Canada already experience marginalization and discrimination in their past and current experiences, which creates barriers in access to services. For Indigenous children with complex mental health needs, these challenges and barriers are amplified even further.

In addition to the impact on children and youth, the issue of how to respond to complex needs must also be considered at the level of the family. Parents and caregivers of children with complex mental health needs often experience continuous demands beyond their emotional, physical, or financial capabilities. Combined with a lack of adequate supports and resources for families, the added stress on caregivers may increase the risk of harm for children, creating an unsafe environment in the home which may ultimately lead to involvement in the child protection system.

Finally, this issue is especially important in the wake of the COVID-19 pandemic, which made it even more difficult for children and families to access needed health, mental health and social services. The breakdown in services during the pandemic resulted in an increase in demand without adequate resources to meet the level of need, resulting in long wait times and ongoing challenges in access (e.g. Kourgiantakis et al., 2023). Evidence on increased stress, mental health problems and unmet caregiving needs associated with the COVID-19 pandemic among parents, combined with scarce resources and supports for families, has intensified challenges for parents and caregivers in supporting the complex needs of their children (Roos et al., 2021). According to the Knowledge Institute on Child and Youth Mental Health and Addictions in Canada, the number of children and youth with complex mental health needs increased throughout the pandemic and their needs have become more acute (Knowledge Institute on Child and Youth Mental Health and Addictions, n.d.).

2.0 Aims and Objectives

2.1 Overview and Scope

This report was developed to provide an overview and synthesis of the available literature relevant to complex mental health needs among children and youth from a transdisciplinary perspective. First, an overview of the current context around complex needs in Ontario is provided, including definitions and understandings of complex needs and what the issue means for children and their families. Findings from the literature in Canada and other jurisdictions are summarized, including a review of existing models and approaches to address complex mental health needs and any evidence of their impact, as well as evidence on the challenges and barriers to accessing needed services. Finally, implications of the findings for policy and practice, as well as remaining limitations and future research needs are discussed.

This report aims to build on a larger body of literature which has laid a foundation for our current understanding of complex needs. This includes theoretical frameworks, models, and early interventions and pilot studies that have contributed to the research and knowledge base around the issue. However, given the scope and objectives of this report, a thorough discussion of the history and development of research on children and youth with complex needs is not covered.

2.2 Objectives

By providing an objective summary and analysis of any available interventions and approaches to support children with complex mental health needs, this report aims to inform the development of evidence-based, cross-sectoral solutions to support optimal development and health equity for children and their families in Canada.

More specific objectives of this policy brief are:

- To identify needs, challenges, and vulnerabilities among children with complex mental health and behavioural diagnoses in Canada as well as existing gaps in knowledge around how to address these needs at a systems level
- To examine the literature on opportunities to strengthen supports for children with complex mental health care needs through early prevention and intervention strategies and any evidence of their effectiveness in reducing negative outcomes and improving developmental trajectories
- To provide transdisciplinary perspectives on the issue of how systems (health, social, educational) can best support children with complex needs and develop insights to inform future policy and practice

2.3 Research Questions

The primary research question guiding this policy brief is how systems can best support children with complex behavioural and mental health needs to improve health, social, developmental and other outcomes and reduce harm.

This main question led to several specific research questions to explore the issue from various perspectives:

- Based on the available literature, what can we learn from existing approaches to support children with complex needs and how can we use this knowledge (or lack or information) to help inform or accelerate future efforts and interventions?
 - What models or approaches have already been implemented in Ontario or other jurisdictions and is there any evidence of their impact?
 - O Which interventions have the greatest likelihood of changing a child's trajectory and when should they occur to be most effective? What are the consequences when these opportunities to intervene are missed?
 - What are the barriers and challenges that prevent children and families from accessing supports and services?
 - What other factors might play a role in the impact of interventions for individual children or families?
- What approaches or factors should be considered to support children from racialized and Indigenous families, who may be at greater risk of vulnerability due to historical and structural inequities and reduced access to existing supports and services? Are there any examples of culturally based programs?

3.0 Methods

A scan of the literature was conducted from December 2023 to January 2024 to determine the breadth of information available and to identify and synthesize literature relevant to the issue of systems to respond to complex mental and behavioural health needs among children and youth.

Various search engines, research portals, and institution-specific websites were utilized for the collection of relevant data. Two main data sources were selected: 1) peer-reviewed journals found in electronic databases; and 2) internet-based grey literature, including published reports, websites of relevant organizations or groups; working papers; presentations or webinars; and government publications and legislation.

Sources were included in the literature review if they were found to contain variables of interest and keywords relevant to the research question and objectives. A hand search of reference lists from relevant studies was also used to supplement searches. Data sources were limited to those published in English. In addition, in order to gather the most current information, the search was largely focused on data sources published after the year 2000, or within the last five years for policy-relevant information. However, some sources published prior to 2000 were also included where they provided relevant background or evidence. Finally, the search was focused on results specific to the Ontario context, however, given the limited amount of research published in Canada on the topic, we included sources from other jurisdictions (i.e. the United States, United Kingdom, and Australia) where relevant.

A list of the primary keywords and search terms used in the literature scan are provided below. Throughout the search process, some keywords were added, deleted, or modified as needed to enhance the search strategy or supplement initial sources found. It should be noted that sources specific to complex medical needs among children and youth were excluded from the results except where information was needed for comparative purposes (i.e. discussing differences between children with complex medical care needs and their treatment versus children with complex mental health needs). Further discussion on the definitions considered in this report is provided in Section 4.3.

Main Keywords:¹ Complex needs, mental health, behaviour, children, Indigenous, child welfare, health care, supports, services, systems, Ontario, Canada

4.0 Background

4.1 Overview of Complex Needs among Children and Families

In order to develop effective solutions to address complex mental health needs among children and youth, it is necessary to understand what it means for children and their families to have complex needs and how the issue impacts their lives.

As mentioned in Section 1.1, individuals with complex needs generally refers to those who experience difficulties in several domains and engage in high levels of service use from multiple sectors or systems – including health, mental health, developmental, behavioural, social and educational supports. It is important to note that the complexity of the issue lies not in the children

¹ Note that additional keywords relevant to the literature review topic (e.g. socioeconomic status) may not be listed here, including terms that were found to be embedded within the primary search terms.

and youth themselves or their condition(s), but in the challenge of coordinating all of the necessary services across different sectors and providers to meet these needs – most of which have historically lacked integration in Canada (Burnside, 2012; Van den Steene et al., 2019). This challenge is deepened by the observation that most children with complex needs will require long-term supports – often throughout their entire life. In other words, complex needs are not easily or quickly resolved but are more ongoing.

Research suggests that children and youth experiencing multiple complex needs are at higher risk of negative outcomes in different life domains. These challenges can impact their functioning at home, school, and in the community, jeopardizing their overall development and well-being (e.g. Knowledge Institute on Child and Youth Mental Health and Addictions, n.d.; Van den Steene et al., 2019). According to Dowse et al. (2014), there is emerging evidence that young people with complex needs are also more likely to become involved with the police and criminal justice system – both as victims and offenders.

Parents and caregivers of children with complex needs are also at risk of negative outcomes beyond the impact of managing their child's symptoms. For example, the process of finding appropriate

supports, navigating various systems, waiting for appointments, and completing often arduous application processes to determine eligibility for services can be very stressful (Complex Mental Health Needs Collaboration Table, 2022). In addition, there is a reported shortage of qualified respite workers who can provide direct in-home supports for children and families with complex needs in Ontario, meaning that parents and caregivers are likely to take on more of this responsibility themselves, leading to caregiver burnout (Complex Mental Health Needs Collaboration Table, 2022). When parents are exposed to these stressors, this can not only affect their own mental health and well-being, but it can also further increase the risk of negative outcomes for their children, as research has shown a negative association between parent's anxiety and household stress and child mental health, behavioural and psychological development (e.g. Fields et al., 2021; Păsărelu et al., 2022). There is also a direct financial impact on families when using many of these services which can further add to parental stress.



4.2 Factors Related to Complex Needs

The challenge of responding to complex needs among children and youth can be further complicated by other factors, including family characteristics and broader environmental, social and structural factors. Indeed, some researchers describe the issue of complex needs among children and youth as one that occurs not at the level of the child but at the family level. For example, van Assen et al. (2020) use the term "families experiencing complex and multiple problems" to refer to families with an accumulation of problems in different domains, including factors both within and outside the family.

Family level characteristics that might affect the family's ability to access and coordinate services for their child include literacy or language barriers, life events and stressors, health and well-being of parents and other family members, and their ability to cope (MCCSS, 2024). Other family factors that could directly impact the child's functioning include parental substance use, family violence, and parent mental health issues (Burnside, 2012). Many of these factors have been well-recognized in studies demonstrating the lasting impact of adverse childhood experiences (ACEs) on various aspects of health and well-being. For example, research shows that children who are exposed to multiple adverse factors in their home environments (e.g. abuse, maltreatment, exposure to violence, household dysfunction) have a greater risk of a wide range of negative developmental outcomes, including behavioural problems, low social competency, cognitive delays, and lower educational achievement; and these effects continue into adulthood, increasing the risk of negative health behaviours and premature mortality (van Assen et al., 2020; Felitti et al., 1998; Anda et al., 2006; Brown et al., 2009).

At a broader level, the social determinants of health, which refers to the social and economic factors that influence people's health – including socioeconomic status, housing, transportation and geographic area, food security, gender, race, education level and employment – are also important considerations for children and youth with complex needs as these factors can intersect to further complicate and sustain their care needs and increase the likelihood of outcomes such as involvement in the child welfare and youth justice sectors (Knowledge Institute on Child and Youth Mental Health and Addictions, n.d.; van Assen et al., 2020). Indeed, administrative data from Alberta, Canada on service use patterns among youth with complex service needs shows that those youth who used more services generally had lower socioeconomic status and higher rates of high school incompletion (Izakian et al., 2019). These external factors can also affect parents' ability to manage their child's needs in either a positive (i.e. through the availability of social supports) or negative (i.e. through the strain caused by competing demands of work) way (MCCSS, 2024).

Some researchers have described the issue of complex needs as related to social vulnerability and marginalization, "particularly the multiple interlocking experiences and factors that span health and social issues" (Dowse et al., 2014, p.174). For example, according to Baldry & Dowse (2013), the key to understanding complex needs is conceptualizing the issue as an interaction of risk factors and experiences which serve to increase vulnerability for experiencing additional needs. Rather than focusing on the issue of complex needs as an individualized problem, this notion considers the social and structural factors that contribute to the development and maintenance of these needs. The experience of complex needs is described by these researchers as "a dynamic, interactive, and multidimensional concept, which is created and sustained by social arrangements and systems." (Baldry & Dowse, 2013, pg. 224). The web of disadvantageous factors that combine to create complex needs is illustrated in Figure 1.

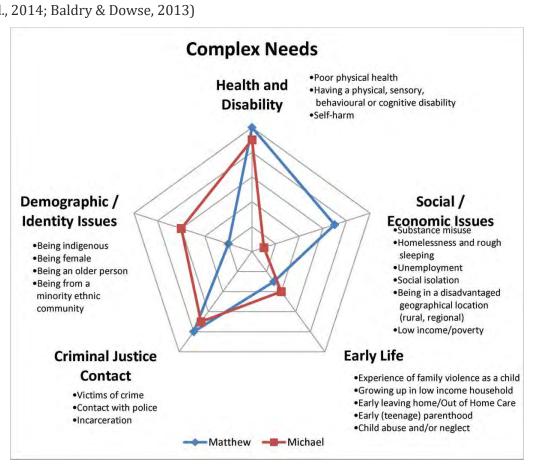


Figure 1: Interlocking nature of factors associated with complex needs (Source: Dowse et al., 2014; Baldry & Dowse, 2013)

Note: the blue and red lines illustrate two examples of case studies of young people whose experiences have been mapped onto the framework diagram.

4.3 Definitions of Complex Needs

Challenges with definition

Understanding the issue of complex needs among children and youth is made more difficult by the lack of a clear and consistent definition of the term "complex needs" – as noted by Hnatko (2016), most definitions have been "ambiguous, context dependent, and subjective". Some of the most common terms used in the literature –all of which generally describe the same concept with some variations, include: complex needs, complex care needs, complex mental health needs, multiple complex needs, extensive needs, special needs, and high needs.

According to Baldry & Dowse (2013), the absence of agreed upon terminology reflects the limitations of a historically medical approach to categorizing health problems as a single or dual diagnosis or co-morbidities – an approach that does not adequately capture complex problems and their interactions. This approach also tends to locate identifiers of risk for these diagnoses within the individual person or body rather than in broader social and institutional arrangements and fails to recognize the role of social determinants and inequities in health, including racism, sexism, and social class. For example, the issue of complex needs often occurs within a historical and societal

context of discrimination, exclusion, and neglect for some populations – all of which can intersect to further complicate an individual's needs and challenges and affect their ability to navigate a path forward.

Another challenge with identifying children and youth with complex needs is that their underlying symptoms do not necessarily fit into pre-defined diagnostic categories or criteria. For instance, many of the behavioural, emotional, psychiatric, cognitive, developmental, or relational difficulties experienced by children and youth with complex needs may be manifestations of multiple conditions, individual traits, or their family and social environments (Hnatko, 2016). As a result, the population of children with complex needs has been described as one that is unified *not by their diagnosis*, *but by the high level of their needs* (Complex Mental Health Needs Collaboration Table, 2022, p.5).

Finally, researchers have also noted that the issue of complex needs is somewhat subjective and is often dependent on those doing the defining. For example, children and youth themselves generally don't identify as "complex"; the term is applied by others (Hnatko, 2016). Determining how "complex" a child's needs are can depend on the skill level and resources of professionals and caregivers (Burnside, 2012; Van den Steene et al., 2019). For instance, if the needs are considered to be beyond their own ability to manage, they may be seen as more complex.

Box 1: Understanding Complex Needs: An Alternate Perspective

The term can also be understood by defining it as what it does not mean. As an example, the issue of complex needs in this report is different from definitions used in medicine and health care to describe children with medical complexity. In the health care domain, children with complex needs are those who have chronic conditions and high health needs requiring specialized care (see the detailed definition below). While many of the experiences related to service use and access and the impact of these challenges for children and families with complex medical needs are similar to those discussed in this report, it is important to note that children with medical complexity are not included in the definition used in this report.

Definition of complex medical needs from Cohen et al. (2023):

"Children with medical complexity (CMC) have been defined as those with complex chronic conditions requiring specialized care, with substantial health care needs, functional limitations, and high health resource utilization. CMC and their families interact with multiple services along the care continuum and often experience substantial gaps in care due to poor care coordination, disjointed services, multiple prolonged and potentially preventable hospitalizations, receiving care from multiple clinicians, higher risk of medication order errors, and extraordinary stress on parents and caregivers. The consequences include social isolation, poor caregiver health, fragmentation between family caregivers and health care professionals, and profound financial and social hardships."

Examples of relevant definitions and conceptualizations

Despite the difficulties in defining the concept of complex mental health needs, some relevant definitions from the literature are summarized below to better illustrate the issue.

- A simple definition provided by the Knowledge Institute on Child and Youth Mental Health
 and Addictions (n.d.) is children and youth who experience "significant, multiple, rare or
 persistent mental health challenges that can impact their functioning at home, at school and
 in the community" and who may have other conditions or challenges requiring additional
 services.
- Similarly, the definition of children and youth with multiple and/or complex needs provided by the Ontario government (MCCSS, 2024) is a subset of children and youth with special needs who require multiple specialized services due to the depth and breadth of their needs. These children may also experience challenges in other areas of development (i.e. intellectual, physical, emotional, social, behavioural) requiring services from multiple sectors or professionals, and are likely to have ongoing service needs. Other governmental ministries and departments in provinces other than Ontario have also published definitions of children with complex needs (or other similar terms), as shown in Appendix A.
- Outside of Canada, other definitions also focus on the service needs of children with complex needs. For example, researchers from Australia have referred to complex care needs as "those resulting from one or more conditions which require access to multiple health and social support services" (Paton & Hiscock, 2019).
- Another international definition of 'multiple and complex needs in children and youth' was
 developed by a cross-sector panel of experts using Delphi method (Van den Steene et al.,
 2019). The study was based on the recognition of the need for an agreed-upon definition of
 multiple complex needs endorsed by experts in the fields involved in the care of this
 population, with the ultimate aim of optimizing their care delivery. Rather than focusing on
 the need for services, the final definition below highlights the mismatch between the level of
 need and the actual services or care they receive:

"Children and adolescents with profound and interacting needs in the context of issues on several life domains (family context, functioning and integration in society) as well as psychiatric problems. The extent of their needs exceeds the capacity (expertise and resources) of existing services and sequential interventions lead to discontinuous care delivery. As such, existing services do not adequately meet the needs of these youths and their families. Cross-sector, integrated and assertive care delivery is necessary for safeguarding the wellbeing, development and societal integration of these young people." (p. 63)

- Some definitions refer to complex needs as a combination of health and social care needs that require integration of health and social services.
 - For example, Kuluski et al. (2017) define complex care needs as those that result from "multiple concurrent chronic conditions, functional and cognitive impairments, mental health challenges and social vulnerability." (pg. 1).
 - Others focus more heavily on the social needs rather than mental health needs, such
 as the definition of complex needs in an Ontario-based study as "highly persistent
 needs experienced simultaneously in two or more areas of life, such as housing,
 income, emotional/behavioural, legal, family, safety and educational/vocational"

(Wallace et al., 2015, p. 53). This study further notes that these needs may place the child or youth at risk of placement outside the home, such as in child welfare, residential treatment, health care, or in the justice system.

Baldry & Dowse (2013, p. 223) describe the concept as not just a list of needs or challenges, but as "a three-dimensional web of factors, elements, and circumstances that interact simultaneously and across time." The interaction between these factors is said to have a cumulative or compounding effect, such that each one enhances the effects of the others. As these effects accumulate, their breadth and depth expand, resulting in a total impact that is much greater than the sum of its parts.

While each of these definitions varies slightly in their conceptualization and scope, there are some commonalities which together form the basis of the definition that has been applied in this report:

"Complex needs" are characterized by the presence of <u>multiple</u> diagnoses or behavioural problems, which are anticipated to have <u>long-term</u> consequences and necessitate engagement with <u>multiple</u> service sectors. Importantly, these complex needs may be further complicated by systemic barriers to supports and services that are associated with the social exclusion of specific populations.

4.4 Context in Ontario

Another issue that comes with the absence of a common or standardized definition of complex needs is that it is extremely difficult to estimate the number of children and youth in Ontario or other jurisdictions with complex needs. Even when data is available, it is usually based on the prevalence of only one aspect or condition among multiple needs – for example, several studies and data sources from Ontario have reported on the prevalence of behavioural problems or of mental health disorders overall, or rates of depression and anxiety specifically among children and youth compared to adults (e.g. Children's Mental Health Ontario, 2020; Kourgiantakis et al., 2023). Moreover, the lack of integration across service sectors involved in working with children and youth with complex needs can mean that any statistics or observations on this population are also siloed and may reflect only the methods and definitions used by the sector collecting the data (Burnside, 2012).

Without accurate estimates of the number of children and youth with complex needs, it is even more challenging to ensure adequate resources and supports are available to respond to their needs. For example, child welfare professionals need to know how many youth in the system have complex needs in order to advocate for more resources to support additional placement options for these youth (Burnside, 2012).

Some estimates of the rate of children and youth in Canada with complex needs have been reported in the literature; however, as noted by Burnside (2012), the actual rates of complex needs among children and youth are likely underestimated.

• Research from Ontario indicates that at least 10% of children and youth seeking assistance from mental health services have increased complexity (Billawala et al., 2018). For example, a study of families (with children aged 4-17 years) recruited from 15 children's mental health agencies in Ontario examined help-seeking efforts across sectors (mental health, education, medical, child welfare, juvenile justice) over time (Reid et al., 2011). Results showed that virtually all families were involved with multiple sectors in the previous year and almost one in five (17%) had been involved with mental health services for more than

- one year. A smaller percentage (11%) of families had more intense patterns of help-seeking where they were simultaneously involved with multiple agencies and were also seeking additional help from new agencies. These families were shown to have children with greater impairments and had a longer duration of help seeking over time.
- An earlier report from 2012 reported that the number of youth with complex needs in Manitoba was estimated to be about 10% of the overall youth population across several studies (Burnside, 2012).
- More recently, a survey from Prince Edward Island showed that more than 1 in 6 children in the province (17% of children under age 18) have complex needs, defined as experiencing a functional limitation due to a physical, developmental, behavioural or emotional condition lasting at least 12 months; and at least two related health consequences² (Department of Health and Wellness, 2023). Findings also showed that the majority of children with complex needs (84%) experienced difficulties accessing needed health services in the last year; and almost all caregivers (97%) expressed a desire for additional supports.

The prevalence of complex needs is also higher among certain sub-populations of children and youth, including those involved in the child welfare system and Indigenous children. For example:

Complex needs among children and youth in care:

- In Ontario, there has been a decline in the overall number of children in care in recent years, but the proportion of children and youth in care with high or complex needs has reportedly increased (Becken, 2023). Childrens aid societies in Ontario have reported that at any given time, they have several children or youth with high needs for whom they can't find appropriate placements, and who don't have access to other systems and supports that could help respond to their needs (Becken, 2023).
- The higher rate of complex needs among children and youth in the child welfare system has also been reported in other provinces. For example, in Manitoba, Burnside (2012) estimated that because those with complex needs are overrepresented in the child welfare population, it is likely that the prevalence of complex needs among children and youth in care is significantly greater than the rate observed in the community.

Complex needs among Indigenous and racialized children and youth

• Research indicates that Indigenous youth are not only at higher risk than non-Indigenous youth to experience complex needs, but the associated challenges of having complex mental health needs including experiences of marginalization are also intensified for Indigenous youth (Dowse et al., 2014). This greater risk is due to a number of factors stemming from the historical effects of colonialism and systemic discrimination against Indigenous peoples in Canada. The ongoing effects of intergenerational trauma resulting from these experiences has led to an increased risk of mental and physical health problems among Indigenous populations (Toombs et al., 2023). These effects can be understood within the broader context of Indigenous social determinants of health. For instance, research has shown that experiences of racism and discrimination such as attending residential schools are associated with factors such as lower socioeconomic status, disrupted educational and

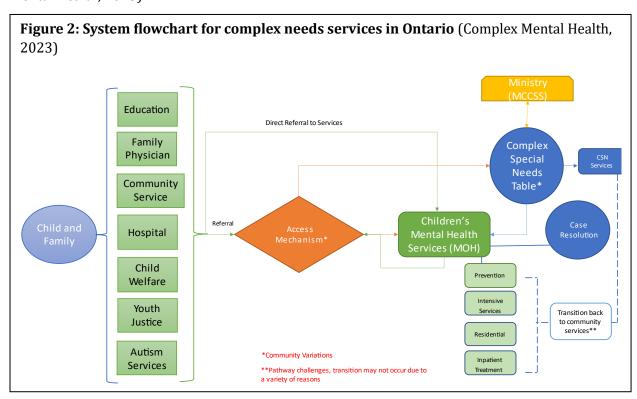
² Health consequences related to a physical, developmental, behavioural or emotional condition include: use of need for prescribed medicine or supplements; frequent or ongoing use or need for medical care, mental health services, or extra educational supports; and use or need for therapies.

- employment outcomes, greater exposure to adverse childhood experiences, food insecurity and housing insecurity all of which contribute to continued health disparities for Indigenous peoples (Toombs et al., 2023). Moreover, as discussed in Section 4.2, many of these factors that are more likely to be experienced by Indigenous children and youth are also associated with an increased likelihood of having complex mental health needs.
- Higher rates of complex mental health and developmental needs have also been reported among Indigenous children and youth living in areas of high opioid use. Data shows higher rates of opioid-related harm including overdose deaths among Indigenous populations in Canada, which again relates to the historical and structural factors that contribute to disparities in health service access and effectiveness for Indigenous peoples (Carrière et al., 2022; Chiefs of Ontario & ODPRN, 2023). The disproportionate impact of the opioid crisis on Indigenous communities including the effects on mental health and behavioural outcomes for children and youth is a pressing public health concern requiring more effective prevention and harm reduction strategies (Sansone et al., 2022).
 - E.g. In Ontario, data from 13 First Nations has shown a higher rate of prenatal opioid exposure among First Nations babies compared to all babies in the province (10.2% vs. 1.7%) as well as a higher likelihood of neonatal abstinence syndrome (4.2% of First Nations babies vs. 0.5% of all babies) (Kerpan et al., 2023)
 - O While research on the developmental effects of opioid exposure on Indigenous children is scarce, some evidence suggests that it can impact children's physical, social, mental, emotional, and spiritual well-being. First Nations participants from a qualitative research study in Ontario reported that while some children with prenatal opioid exposure appear to have no developmental delays, the long-term effects may not emerge until they are older (Kerpan et al., 2023). This study also highlighted the importance of understanding the effects of opioids on child health and development from a holistic perspective that considers the combined effects of substance exposure with other social and environmental factors for Indigenous children and youth.
- As noted by researchers such as Ineese-Nash (2022), Indigenous communities also face significant challenges in accessing culturally appropriate and effective treatments or supports for mental health problems, which has increased the rates of poor mental health functioning, substance use and suicide prevalence among Indigenous youth even further. The complex nature of mental health needs among many Indigenous children and youth also means that their needs are not easily addressed in mainstream systems and services, highlighting the need for more effective strategies and treatments that respond to the unique experiences, histories and cultures of Indigenous populations (Ineese-Nash, 2022).
- Similarly, research from Canada also shows that Black children and youth experience greater challenges in accessing mental health care services, and that those who are unable to access or receive treatment have a higher likelihood of negative outcomes such as difficulties in school, family conflict, and involvement with the justice system (Fante-Coleman & Jackson-Best, 2020). Evidence from a scoping review identified barriers in access to mental health services at multiple levels of care for Black children and youth, including longer wait times, referral delays, geographical and financial challenges, lack of funding for culturally responsive services, racism and discrimination by practitioners, a lack of Black mental health professionals, and perceived stigma (Fante-Coleman & Jackson-Best, 2020).

5.0 Services and Programs for Children with Complex Needs

5.1 Overview of Services in Ontario

In Ontario, families who have concerns about their child experiencing complex or challenging mental health needs may be able to access or engage with several different systems, depending on the nature of the child's challenges and the specific mechanisms or pathways available in their local area or region. When determining which services or systems to engage with, families may first have contact with an access mechanism or service in which an initial assessment is done and referrals are made to the appropriate services based on the need(s) identified (see Figure 2). For example, the initial contact may be with a child welfare agency, schools, a community-based organization, or a family physician, who may then direct families to other agencies, to mental health services, or to the Complex Special Needs table (Complex Mental Health, 2023). However, it is important to note that there is a great deal of variation in how these processes are organized and accessed across the province, depending on the region and the population or demographic needs of the area. The configuration of services also varies, meaning that there are local variations in how services present, in addition to variation in the types of needs that are referred to each system (Complex Mental Health, 2023).



In Ontario, some the main systems relevant to children and youth with complex mental health needs are described in Table 1. For children and youth with any mental health issues, there are a number of other programs and services available at the local level across the province, including counselling and therapy, crisis support services, virtual or phone services, brief interventions and more intensive treatment services – which are coordinated by designated lead agencies and community partners who are responsible for planning and delivering children's mental health services in each region (Ministry of Health, 2023).

It should be noted that child mental health services in Ontario cross multiple sectors. At the local level, service provision is primarily the responsibility of the Ministry of Children, Community and Social Services (MCCSS), which develops and implements relevant policies and oversees funding and delivery of services by mental health agencies across the province (Duncan et al., 2018). However, child and youth mental health services are also provided by the Ministry of Health (MOH) and Ministry of Education (MOE) in healthcare (primary care and hospitals) and school settings, respectively. This system has been described as fragmented, as Ontario has not yet developed an integrated care model that would coordinate child and youth mental health services across each of these government ministries (Duncan et al., 2018).

Table 1: Specific services and systems for children and youth with complex needs in Ontario

Name	Target Population	Description of Services	Funding Source/ Ministry
Complex Special Needs ³	Provides additional services to children/youth with complex special needs whose complexity of need is beyond the capacity of the family and service system to address.	Children/youth receive an individualized service plan, reviewed annually, which may include out-of-home placements, in-home respite, behaviour management or other services to support the child, youth, and their family. Services are evidence-informed and outcomes focused; and must fall within MCCSS's mandate.	MCCSS
Ontario Autism Program	Provides support to families of children and youth up to age 18 who have been diagnosed with autism spectrum disorder (ASD) by a qualified professional.	Available services include family services (i.e. supports for parents and caregivers, such as mentoring, workshops and consultations), early years programs (for children aged 12-48 months old), core clinical services (i.e. applied behaviour analysis, speechlanguage pathology, occupational therapy, mental health services), an entry to school program (focusing on developing school readiness skills and providing transition supports) and urgent response services (time limited service that addresses a specific need to prevent further escalation).	MCCSS
Secure Treatment Program ⁴	The program is for children and youth aged 12 to 17 years who are at risk of self-harm or harm to others.	A live-in treatment option which provides intensive care for children and youth experiencing acute and complex mental health and/or addictions challenges.	МОН

³ https://www.ontario.ca/document/mccss-service-objectives-children-special-needs/services-delivered-csn-individualized

⁴ https://news.ontario.ca/en/release/60491/ontario-supporting-children-and-youth-with-complex-mental-health-and-addictions-needs

In addition to these main systems, children with complex mental health needs may require or be able to access additional supports through other services that are available to children and families with complex or special health needs, such as home care or respite services. Some of these services are described below:

- Home care services: Ontario has 14 Home and Community Care Support Services organizations (called Community Care Access Centres, or CCACs) that help to coordinate access to in-home and community-based care for people with complex or chronic conditions that require extra care or support in their home, school, or community (Ministry of Health, 2024). Typically, a case manager or care coordinator will assess the individual's needs and determine which services they may be eligible for or provide referrals and information to other organizations. Available services in the home may include services from health care professionals (e.g. physiotherapy, speech-language pathology, nursing care); personal support services (i.e. daily living activities); and homemaking services (e.g. housecleaning, shopping, banking). A number of additional services may be available through community based organizations.
- School-based services: Children with complex or special needs in Ontario may be eligible for services from school health professionals under the suite of home care and community services. These services are aimed at children and youth with complex health problems or disabilities who require medical and/or rehabilitative assistance to allow them to participate in school safely (Home and Community Care Support Services, n.d.). Other special education programs and services may be available through school boards, including programs for students with ASD⁵.
- Developmental services: Children who have a developmental disability or are at risk of developmental delay are eligible for services through the provincial Infant and Child Development Program from birth up to school entry (kindergarten or grade one). There are currently 49 centres across Ontario funded by the MCCSS which primarily provide home-based services including information and early intervention services to promote the child's development and wellbeing. Other early childhood developmental programs funded by the government of Ontario include Healthy Babies Healthy Children and programs through EarlyON child and family centres across the province, which offer free programs for families with children up to age six.
- Respite care: Out-of-home respite care services are available for some children and youth with multiple special needs due to a physical or developmental disability who require continuous care (24 hours a day). The service provides funding for temporary relief from

⁵ Information on supports for students with Autism Spectrum Disorder are available on the Government of Ontario's website https://www.ontario.ca/page/support-students-autism

⁶ More information available on the website for the Ontario Association for Infant and Child Development https://www.oaicd.ca/

- the daily demands of caring for the child, with the aim or reducing the likelihood of a long-term placement or the risk of harm to the child or family.
- Services for Indigenous populations: First Nations individuals who live both on and offreserve are eligible for CCAC services in Ontario. However, CCAC services must determine
 whether similar services are available in the First Nations community and attempt to
 coordinate with and complement those services rather than duplicate them. A CCAC may
 enter into a formal agreement with First Nations groups or organizations to ensure effective
 communication and linkages between service providers working with First Nations
 communities (Canadian Home Care Association, 2016). The federal government also
 provides funding for home and community care services to Indigenous peoples living in
 First Nations and Inuit communities through the First Nations and Inuit Home and
 Community Care (FNIHCC) program.⁷

5.2 Examples of Specific Programs and Models in Ontario

This section describes some examples of specific programs or models of service delivery that may be relevant for children and youth with complex needs across Ontario. However, evidence from evaluations of the impact of any of these programs is not available.

Coordinated Service Planning (CSP)

In 2014, Ontario's Special Needs Strategy was jointly introduced by the Ministries of Education, Health, and Children, Community and Social Services⁸. These ministries committed to working together along with families, communities and service providers to improve outcomes for children and youth with special needs, including those with complex mental health needs. One of the key initiatives of the strategy was the implementation of coordinated service planning, in which a dedicated coordinator would work with families with children with complex needs to help connect them to appropriate services and supports and develop a holistic, coordinated service plan that responds to their individual needs and goals (Ministry of Education, 2024). The information in the service plan can be shared with all relevant providers (i.e. educators, health professionals, and other service providers working with the child), making the process more efficient and consistent for both families and service providers. Importantly, coordinated service planning goes beyond communication and collaboration between service providers and systems; rather, it involves actual integration of practice and service delivery within a single plan of care (MCCSS, 2024, part 2). CSP services are available in 34 different geographical areas of the province, each with its own coordinating agency. For example, KidsInclusive is the coordinating agency for children and youth with multiple and/or complex needs and their families in the areas of Kingston, Frontenac, Lennox & Addington, and Lanark, Leeds & Granville.

Figure 3 shows the steps involved in the CSP process. Additional information about CSP is provided in Table 2.

⁷ The program is available for First Nations and Inuit people of all ages who: a) live in a First Nations reserve or community North of 60 or an Inuit community; b) have disabilities, chronic or acute illnesses, or are elderly; and c) have undergone a formal assessment of continuing care service needs and have been determined to require one or more services (source: <u>Government of Canada</u>)

⁸ At that time, what is now MCCSS was divided into two separate ministries – the Ministry of Children and Youth Services and the Ministry of Community and Social Services.

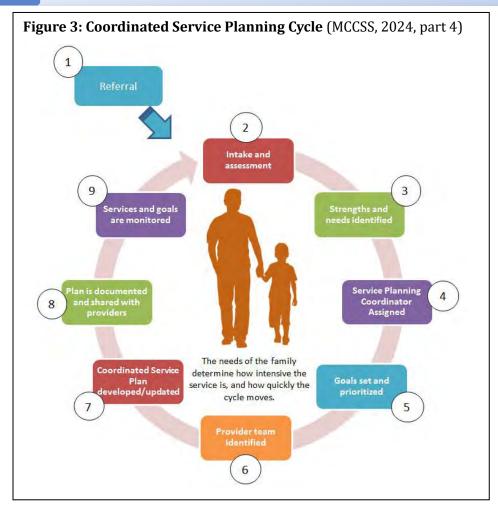


Table 2: Details on Coordinated Service Planning in Ontario

Table 2. Details on coordinated Service Flamming in Ortanio				
Principles	 CSP aims to be a supportive, proactive, responsive, and child, youth and family-oriented service. Active participation - Families and children/youth are actively engaged in the entire process and work together with service providers to make informed decisions about the planning and delivery of their services Seamless information sharing – information about a family's needs is shared between providers so families themselves don't need to repeat information Diversity – the CSP process aims to be inclusive, accessible, and culturally appropriate, and respect the diverse needs of each child, youth and family, including those of Indigenous children and families 			
Target population	The overall target population for Coordinated Service Planning is families of children and youth with multiple and/or complex special needs whose need for service coordination goes beyond the scope of inter-professional collaboration to address and who would benefit from the added support provided by Coordinated Service Planning. This could be due to the breadth and cross-sectoral nature of a child/youth's service needs and/or potential challenges in coordinating services because of factors affecting the whole family.			
Eligibility	Children and youth under age 18, and young people between the ages of 18-21 who remain in school, are eligible for CSP. A diagnosis is not required.			

Referral process	Referrals to CSP can be made at any point a child/youth's needs are recognized to be multiple and/or complex. Decisions around whether a family should receive CSP will be made by the Coordinating Agency or service provider with input from the family, based on an assessment of whether the service will be beneficial to a child/youth and family. Families can also self-refer. Referrals to CSP should be made in parallel to referrals to other services; being referred to CSP should not prevent a family from accessing other appropriate services.
Supports and (i.e. time-limited supports from the service planning coordinator); intermitt services offered Based on the assessment process, a family may be offered either brief support (i.e. time-limited supports from the service planning coordinator); intermitt support (more intensive level of support during transitions with less intensi other times); or continuous support.	
Participants	CSP participants are agencies/district school boards that provide services and/or supports to children and youth with special needs and that are expected to participate in Coordinated Service Planning. This may include children's agencies or treatment centres, autism intervention program agencies, local CCACs, developmental service agencies and local school boards. Examples of service providers that may be included in the CSP team are: speech and language therapists; behavioural therapists; occupational therapists, special education teachers, social workers, and healthcare coordinators.

Child and Parent Resource Institute (CPRI)

CPRI is operated by the Government of Ontario and located in London, Ontario. CPRI offers trauma-informed, highly specialized programs and services for children and youth up to age 18 with "complex combinations of special needs, including developmental disabilities, autism, and severe behavioural, emotional and mental health challenges" (MCCSS, 2023). Services offered include assessments and consultations, treatment and intervention services (including inpatient and outpatient services), as well as research, education and training opportunities. All services are voluntary although referrals to CPRI must be made through a local access agency. As part of the research program, CPRI also developed a set of assessment tools called interRAI which are now used in the intake process at CPRI as well as by other organizations and services in Ontario and internationally (MCCSS, 2022).

Specific services provided by CPRI include the following:

- Inpatient services short-term interdisciplinary services for children and youth aged 6-18 years with co-occurring developmental and mental health challenges or complex medical challenges. There are six inpatient units serving different groups of children and youth depending on their unique needs.
- General Clinical Services for children and youth with significantly complex emotional or behavioural needs, which may include consultations and assessments
- Homeshare a specialized family placement program for children and youth with complex multiple disabilities who cannot live at home. Placements are generally full-time and longterm, and may continue into adulthood.

- Other specialized services specific to diagnoses include:
 - Attachment Consultation and Education Service for children and youth with an attachment disorder
 - Brake Shop program for children and youth with neurological or disinhibition disorders such as Tourette syndrome and other tic disorders, obsessive-compulsive disorder, and attention-deficit/hyperactivity disorder
 - Dual diagnosis behaviour and anxiety clinic for children and youth who have an intellectual disability along with severe psychiatric or behavioural concerns
 - Interdisciplinary Autism Services for children and youth with suspected or confirmed ASD
 - Mood and Anxiety clinic for children and youth with a mood or anxiety disorder

Extensive Needs Service

The Extensive Needs Service is a new multi-disciplinary treatment program that aims to support over 1,000 children with complex behavioural, developmental, medical, social and mental health care needs in Ontario each year. More specifically, the target population for the service is children and youth up to age 17 who have been previously excluded from care or whose needs are not being met through existing services (CHEO, n.d.). The service was introduced in 2023 as a pilot program with funding from the Ontario government and is being delivered by three children's hospitals in the province - Holland Bloorview, the Children's Hospital of Eastern Ontario and McMaster Children's Hospital. The service aims to transform the way systems respond to children and youth with complex needs by reducing barriers and connecting them with the right services and supports through a wraparound model. Families who are eligible for the program will be connected to a team of professionals including physicians as well as social workers and behavioural consultants who work together to provide individualized supports based on each child's needs (Canadian Press, 2023; Holland Bloorview Kids Rehabilitation Hospital, 2023). The approach is multidisciplinary and offers timely and evidence-based assessments and interventions such as mental health treatments, counselling, behaviour therapy, and skills-building interventions. The program is still in development as a three-year proof-of-concept program and hospital leads are actively working with community partners to expand the service.

Community Consultation and Assessment Service (CCAAS)

CCAAS is a free provincial resource for service providers who work with children and youth with complex mental health needs (i.e. mental health challenges that impact more than one setting, such as home, school, or community) and their families in Ontario. The service is designed to support the management of complex mental health cases by providing a multidisciplinary consultation service for service providers as well as assessment services for families. CCAAS is made up of a team of professionals with different backgrounds and expertise, including professionals representing psychology, psychiatry, speech pathology, occupational therapy and family systems services. The team can help to provide clarification around diagnoses and guidance for treatment planning and intervention strategies that support the child's unique needs. Referrals for cases are made by children's mental health agencies, case managers, child protection agencies, or school boards; and assessments typically take place at the site in York Hills; though the number of agencies across Ontario as well as the use of virtual services has expanded (York Hills Centre for Children, Youth and Families, 2022).

Lakehead Public Schools Collaborative Pediatric Clinic - Thunder Bay

There is a shortage of pediatricians in Northern Ontario, leading to prolonged wait times for children and families. To address some of the barriers in access to needed services, especially for marginalized children, the Lakehead Public Schools Collaborative Pediatric Clinic was developed to serve children who are struggling in school because of medical, behavioural, developmental or mental health challenges (Bakovic & Probizanski, 2023). The clinic offers a direct pathway for families to access a team of professionals in a shorter time frame, and follows a collaborative approach in which the school board works with parents, pediatricians and psychologists to develop a plan of care that will address the student's needs and challenges. This approach aims to improve on traditional models of care in which the burden is placed on parents to navigate separate systems, requiring parents or caregivers to be knowledgeable enough to understand and relay information between each system (i.e. between doctors and educators).

Importantly, rather than focusing on the child's challenges, the Lakehead model takes a strengths-based approach to identify the student's strengths in a variety of domains using an inventory that is completed by all participants; and strategies to improve the child's functioning are developed based on those strengths.

The program currently works with 4-6 students per month and research is ongoing to evaluate outcomes associated with the program such as student functioning at school and parent satisfaction.

Lumenus – Toronto

Lumenus is a community-based agency that offers a range of mental health, developmental, autism and early years intervention services for children, youth and families with complex needs across Toronto. The aim of Lumenus is to provide a single circle of care and support through a collaborative and integrated approach. They also work in partnership with other community partners, organizations and service providers to help families navigate different systems and reduce access barriers to care.

The <u>Complex Special Needs Team</u> at Lumenus offers information and referrals to community services as well as a congregate care access point mechanism for children and youth with complex/multiple needs who require "specialized integrated cross-sector services and supports". Children and youth under age 18 may be eligible for this service if they have a documented intellectual disability, and at least one additional complex special need. The family must also have no child protection concerns and have exhausted all other available community services and supports. Other programs and services offered at Lumenus include: urgent response services, child welfare wraparound services to keep families together, individual and family counselling, respite services, and services provided through the Ontario Autism Program. Services offered in partnership with local school boards include school-based mental health counselling for students aged 12-18 years; and a series of therapeutic day programs with an academic component (Lumenus, n.d.).

Lumenus also offers the "Whatever it Takes" program which serves children and youth up to age 18 with complex clinical needs that cross various sectors (i.e. health services, education, youth justice, child welfare, and children's mental health). The program "facilitates the collaboration of service providers to respond to children and youth whose needs surpass the ability and capacity of any one service provider or service sector, closing the gaps and enhancing the circle of support and service."

6.0 Findings from the Literature

Results from the literature review are highlighted in this section. This includes any evidence on specific programs, interventions or approaches to respond to complex needs among children and youth and their impact, with a focus on any cultural programs relevant to Indigenous populations; as well as any other findings from individual studies or review studies on the characteristics or service use patterns of children and youth with complex needs. Finally, much of the literature focuses on the remaining challenges and barriers experienced by children and families with complex needs; therefore, findings about these challenges from the perspectives of both families and service providers are also discussed.

6.1 Evidence on Wraparound Programs

The WrapAround model has been commonly used in social services research and practice in Canada and the US beginning in the 1980s-1990s and has now become a model for an approach to serve

children and youth with complex needs (Wallace et al., 2015; CSCN, 2024). Its popularity has grown alongside the increased interest and support for a broader "systems of care" approach to the management of care services for children and youth with complex behavioural and health needs (Graaf et al., 2021) (see Section 7.1 for further discussion of the systems of care approach). WrapAround itself is not a set of services, but refers to a process for meeting complex needs of children, youth and families by integrating multiples systems together into a single plan of care (Healthy Child Manitoba, 2013). It involves a collaborative process that aims to provide coordinated and individualized care and supports to meet the unique needs of children and their families who are involved with multiple systems, providing an alternative to traditional treatment and service models which are restricted to specific categories of services and needs. In the WrapAround, services and supports are "wrapped

Box 2: Key Features of the WrapAround Model

- Team-based involves service providers, families, community and members of their social support network who work collaboratively
- Strengths-based recognizes the assets, skills and capacities of the individual/family
- Family-driven the family directs the plan and are involved in each step; ensuring children and caregivers voices are respected
- Individualized responds to the particular needs of the child and family in a customized plan
- Culturally competent supports respects the values, preferences, beliefs and identities of children and families
- Community-based utilizes the 'natural resources' available to families in the community and within their existing networks and is often driven by volunteers
- Unconditional supports are continued until the team agrees the process is no longer needed
- Outcome-based goals of the process are tied to measurable outcomes and progress is monitored

Sources: CSCN, 2024; Graaf et al;. 2021; Healthy Child Manitoba, 2013

around" the child or youth and their family/caregiver, so that the child and family are at the centre of the plan (Healthy Child Manitoba, 2013). The process typically does not have a set timeframe, and may last as long as it takes to meet the needs of the individual and their family; as determined by the team through regular monitoring of the process and progress (CSCN, 2024; Dowse et al., 2014). Some of the key features of the WrapAround model are listed in Box 2.

In Canada, the model (known as Wrap Canada) has been developed and refined by the Canadian Wraparound Training Institute to provide a standardized training approach and certification system to support communities to implement the process at the local level with trained facilitators (Debicki & Wrap Canada, 2014). There are several agencies across Ontario offering a WrapAround program. For example, in Hamilton, Ontario, Shalem mental health network partners with the Catholic Children's Aid Society of Hamilton to provide WrapAround supports to approximately 12-15 families each year (Shalem Mental Health Network, 2024).

Outside of Ontario, WrapAround has also been promoted by the government of Manitoba as part of the province's protocol to promote optimal outcomes for children and youth with severe or chronic emotional and behavioural disorders (EBD) who require supports from multiple systems or services (Healthy Child Manitoba, 2013). The protocol represents an agreement between various departments and agencies in Manitoba who provide support to children, youth and caregivers (i.e. education, health, and family services). However, according to Bartlett (2015), a comprehensive plan to guide the implementation of the protocol was not developed, and the province's previous protocol from 1995 that mandated the coordination of supports for children and youth with EBD through a system of care was not realized in practice.

In the youth justice sector in Canada, the WrapAround model has also been used as a crime prevention approach for youth aged 13-24 dealing with multiple complex emotional and/or behavioural problems whose needs have not been addressed by other services, and who are at risk of involvement with the law (Public Safety Canada, 2021). A total of 18 organizations between 2007-2021 were supported by Public Safety Canada's National Crime Prevention Strategy to implement a WrapAround program.⁹

According to Wallace et al. (2015), WrapAround has a strong evidence base as an effective and costeffective approach for responding to children with complex needs and has been cited as a best practice in several settings, including child mental health, child welfare, and youth justice. However, most research has focused on models and programs in the United States; there is limited research



examining Canadian programs and their unique elements (Wallace et al., 2015; Bartlett & Freeze, 2018). In addition, much of the literature on WrapAround has focused on defining and measuring outcomes; there is still a lack of conclusive evidence around its effectiveness. For example, a 2017 meta-analysis of 206 publications on WrapAround found that only 60% (n=123) of publications were empirical studies, and most of the controlled studies (experimental or quasiexperimental; n=22) provided either positive or mixed evidence of effectiveness (Schurer Coldiron et al., 2017). Similarly, a 2021 systematic review and meta-analysis of WrapAround care coordination for children and youth with serious emotional disorders found small positive effects of the model on a range of behavioural health

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⁹ Only 1 program was still being implemented by the year 2021

outcomes (Olson et al., 2021). However, many of the studies showed mixed findings or methodological weaknesses which limited the ability to make strong conclusions; highlighting the need for more research using rigorous study designs.

Other research has indicated that adherence to the principles of the WrapAround process is key for achieving better outcomes for children and youth, as higher fidelity to the process has been shown to be associated with improvements in behaviour and child functioning as well as higher caregiver satisfaction with the child's progress (Bruns et al., 2005). Given that stronger implementation of the key WrapAround principles has been shown to have greater benefits, some research from Canada has examined the circumstances or settings that can promote the implementation of the WrapAround process. For example:

- A program evaluation was conducted after a one-year pilot program of WrapAround in Hamilton, Ontario, in which twelve families experiencing multiple, complex problems participated (Wallace et al., 2015). The results of the pilot study showed benefits for children and families, including significant increases in adult resilience and in overall family functioning, and families reported satisfaction with the supports they received through the program. Additional positive feedback collected through qualitative research methods indicated that the WrapAround model can be successful implemented through a community-based, volunteer-driven process, as this allows communities and families to have greater ownership and control over the process. However, some barriers to success of the program were also observed related to long-term sustainability, including challenges gaining credibility and recognition, sustaining the volunteer base, and maintaining funding.
- A qualitative case study examined the characteristics of three community schools in Manitoba that would support the implementation of the WrapAround process for children with complex mental health needs in school settings, such as those with emotional and behavioural disorders (EBD) (Bartlett & Freeze, 2018). In Manitoba, schools participating in the provincial Community Schools program are located in socio-economically disadvantaged areas that receive additional funding to provide a comprehensive range of supports within the school setting such as nutrition services, health and mental health services, early childhood education programs, parent education, and mentoring programs. In other words, the school becomes the primary hub for service provision (Bartlett, 2015). Findings from interviews with school staff, parents, and partnering services within the three community schools showed that the schools do engage in practices that align with the principles of the WrapAround model (as summarized in Box 1) and have existing broadbased partnerships at the local level. According to the authors, these findings indicate that community schools would be well-equipped to successfully lead the implementation of the WrapAround model and may represent an ideal setting for the provision of integrated supports for children and youth with complex mental health needs.

6.2 Evidence on Programs for Indigenous Populations

Programs to support Indigenous children and youth with complex mental health and behavioural needs are limited; however, the following examples provide some information and insights on cultural approaches or models of service delivery that may be effective among Indigenous populations. The examples include a program focused on children with complex health care needs, a school-based health care model, a mental health model, and a multimodal service model.

Niniijaanis Nide Program (My Child, My Heart) - Manitoba

The Niniijaanis Nide Program aims to support families of children (up to age 18) with complex care needs¹⁰ living on reserve to ensure they can access services within their own community, without delay or denial (Canadian Home Care Association, 2017;

Cram, 2017). It was developed in 2015 as a pilot project by the Pinaymootang First Nation with funding from Health Canada's Health Service Integration Fund, and received funding through the government's Jordan's Principle fund starting in 2017. The name "My Child, My Heart" was chosen to represent the strengths of children and families rather than using labels such as having special or complex needs (Cram, 2017).



The program team includes a case manager and three child

development workers who work together to provide coordinated and responsive supports in a culturally sensitive and safe space. This includes basic care and support services to address health and social needs (i.e. referrals to child and family services, education, social assistance, and health and home care programs) as well as specific activities to meet each child and family's goals (i.e. skill building activities, educational workshops, behaviour management programs). Evaluations of goals and outcomes are done at regular intervals throughout the program. As of 2017, 25 children with complex needs had been enrolled in the program¹¹ and initial evaluations showed many benefits of the program for children, their families and the community as a whole. Some of the positive impacts observed include increased independence and socialization as well as reduced problematic behaviours among children; improved coping skills, reduced stress, and increased sense of support and trust in the system for parents and caregivers; and overall improvements in timely access to care, greater capacity at the local level and stronger integration of existing services (Canadian Home Care Association, 2017). Service providers were also unanimous that without the program, children with complex care needs living on the Pinaymootang First Nation reserve would not be able to access the services needed to meet their needs and would be unable to remain in the community (Indigenous Services Canada, 2019). Key factors found to contribute to the program's success included: a community governance structure, community consultation, interagency collaboration, multidisciplinary teams, strong leadership and infrastructure, and staff education (Indigenous Services Canada, 2019).

Ngaramadshi Space (NS) - Australia

A program offered at a specialized behavioural school in Sydney, Australia called Ngaramadshi Space (NS) is a school-based health care model for students with externalizing behaviour problems that is grounded in an Aboriginal framework. The NS model is a unique example of school-based health care as it represents a holistic and multidisciplinary approach to care that integrates the health, education and social care sectors. The goal of the model was to address the physical health, mental health, educational and social needs of children and their families through a multidisciplinary clinic with a team that includes pediatricians, nurses, social workers, school counsellors, and therapists. Importantly, NS was developed in consultation with the local Aboriginal

¹⁰ The program is aimed at children with special healthcare needs with multiple and overlapping diagnoses that create functional limitations.

¹¹ By 2019, the program was serving approximately 60 children (Indigenous Services Canada, 2019)

community, emphasizing the importance of collaboration between the health and education systems to understand the diverse needs of children and family from a holistic perspective.

The NS model was piloted between 2016 and 2019 and more formal evaluations are underway using mixed methods study designs. While specific outcomes for children and youth enrolled in the program are not yet available, some initial findings related to the overall model of care show that it was effective in engaging communities through active community participation in the development of the model. The NS model was also found to achieve greater coordination and collaboration across sectors, although this took years of communication and relationship development to build trust (Rungan et al., 2023).

Building our Bundle - Canada

Researchers from Ontario conducted a project to develop a theoretical basis for an approach to mental health service delivery for Indigenous youth in remote First Nations communities in Northern Canada (Ineese-Nash et al., 2022). The project involved a systematic literature review of existing mental health strategies to support Indigenous mental health (i.e., Indigenous healing programs, Child and Youth Care (CYC) approaches; and Dialectical Behaviour Therapy (DBT)); community consultations with practitioners; and a pilot test of the approach that emerged from these findings in an online therapeutic setting. Results from the literature review pointed to the value of a braided approach to mental health support for Indigenous youth, which recognizes and integrates Indigenous and non-Indigenous perspectives and modalities, allowing for culture to be included in mental health services in a safe and meaningful way. The researchers then applied the principles of a braided approach (i.e. culture, interconnection, relationality, self-discovery, holism, balance restoration, and context specificity) into a six-week pilot program to support Indigenous youth in developing mental health skills that could help them cope during the COVID-19 pandemic. Specifically, the program aimed to teach DBT skills in a culturally responsive manner by embedding traditional Indigenous practices and teaching into the DBT skills training. Findings showed that integrated and innovative approaches can be valuable and even necessary to appropriately address the complex mental health needs of Indigenous youth. According to the researchers: "The integration of practical DBT skills held within the context of Indigenous teachings, worldviews, and experiences allowed for flexibility in working with Indigenous youth, as the non-Indigenous interventions were tailored to reflect the specific context of the participants and facilitators alike. Taking an integrative and flexible stance allowed for open reflection, introspection, modeling, and reciprocal learning, which transmuted potential conflict or tension into collaborative and mutual understanding." (Ineese-Nash et al., 2022, p. 51).

HealthWISE - Australia

HealthWISE is a non-profit organization established in 2015 that provides multimodal services that incorporate a range of interdisciplinary health professionals to support Aboriginal and Torres Strait Islander peoples in rural and remote areas of New South Wales and Queensland, Australia. The organization delivers social and emotional wellbeing support, mental health services, and care coordination for people with complex and severe mental health issues, as well as other Aboriginal health and allied health services. Importantly, the organization has recognized the need for strong cultural governance of these services and has partnered with a number of community-based Aboriginal Medical Services teams to provide mental health and other services. Lessons learned in

¹² Information about services offered by HealthWISE is available on their website https://healthwise.org.au/

the development of HealthWISE have pointed to the importance of community partnerships and codesign of programs to respond to local needs. In addition, self-determination and empowerment were found to be important elements of the approach to service delivery, as clients were more likely to continue with services towards recovery when they were able to self-refer and determine which treatment method is most suited to their own needs (Smith et al., 2020).

The example of HealthWISE provides one possible holistic model of service delivery to support multiple and varied health and mental health care needs of Indigenous communities at every stage of life. However, it should be noted that the services are not specifically targeted at children and youth with complex needs.

6.3 Other Relevant Findings from Research Articles

Findings from Ontario:

As described in Section 5.1, children and youth in Ontario experiencing complex mental health challenges may be referred to the provincial Complex Special Needs (CSN) program that provides specialized funding for families with extensive resource needs. However, not all families who are eligible for this funding actually receive support; the provincial government determines which families have the greatest need and allocates the limited funding accordingly (Billawala et al., 2018). According to Billawala et al., (2018), there is a gap in our knowledge of which families are referred to additional funding for CSN services in Ontario, which would help to inform provincial policy decisions around service allocation. To address this gap, the researchers used data from 1,020 male children in Southwestern Ontario who were seeking mental health services to compare those who were referred for additional CSN funding and those who were not referred and identify risk factors associated with CSN referrals. Of the four risk factors examined, results showed that children identified as having difficulties completing daily activities of living and those with impairments in family functioning were more likely to be referred to CSN services, while those with a physical or medical condition and mental illness comorbidity were not more likely to be referred. According to the study authors, these findings indicate the need for comprehensive assessments of children and youth with complex needs that consider factors beyond specific diagnoses, particularly family level factors.

Findings from Canada:

Researchers in Manitoba analyzed data from the provincial child welfare database between 2009-2010 to quantify and describe the characteristics of youth in care with complex needs (Burnside, 2012). Initial findings revealed many gaps in the data that limited the ability to understand reasons for admission to care and challenges in meeting care needs. Therefore, analyses were limited to youth who were referred for potential placement in a resident care facility or group home, as these youth are most likely to have multiple and complex needs requiring specialized supports. Among those referred who had information filled in on "risk issues" (i.e. antecedent issues that can contribute to a child's admission into care or consequence issues that can result from adverse childhood experiences) (n=289 children), the average number of 'issues' identified was 8.4 per child, demonstrating that multiple challenges were common. The most common issue identified among those children referred for residential placement was behaviour issues (93% of the sample). Other common challenges in the sample included emotional issues (79%), mental health issues (15%), ADHD (14%), and FASD (25%). Among children who also had linked educational data available, results showed that children with multiple and complex needs had a high rate of school

changes and were at risk of not completing high school. For example, in September 2010, 30% of 14-17 year olds were not in school and over 14% were in a grade that was not consistent with their chronological age. The findings from this analysis were consistent with other provincial studies. For example, a complex case committee that reviews high risk complex cases among children and youth in care in Winnipeg also found that most youth identified as having complex needs experienced a multitude of issues, including mental health issues (14 of 44 cases), cognitive functioning issues (11 cases), FASD (6 cases) and risky behaviours (15 cases) (Burnside, 2012).

Findings from international or review studies of intervention approaches:

A recent systematic review commissioned by the province of Ontario (Schutte et al., 2023) compared the design and implementation of **secure treatment programs** for children and youth with complex mental health and behavioural concerns¹³ in Canada to similar jurisdictions¹⁴ and examined the evidence for the effectiveness of these programs. Findings from the study will be used to inform the development of a framework for secure treatment in Ontario. As mentioned in Section 5.1, children and youth in Ontario with complex mental health challenges may be referred to a secure treatment program if they are at risk of harming themselves or others.

- The review found that mental health treatment programs for children and youth in secure settings are highly variable across jurisdictions in terms of their client profiles, types of treatments and services provided, lengths of stay, and discharge procedures.
- However, most programs showed similarities in their governance, definitions, designs, and
 intended outcomes. For example, most programs target clients with serious and complex
 mental health concerns who are at high risk of self-harm or harm to others; provide
 intensive treatment to address these needs across multiple life domains (i.e. health,
 education, living situation, family and social relationships) and reduce the risk of harm; and
 implement a range of security measures.
- Evidence on treatment programs provided in secure settings indicates that by removing clients from their usual environment and providing treatment in a controlled setting only until they show improvement generally leads to short-term improvements in mental health and behavioural outcomes, but these improvements are not sustained once they return to the same environments that may have contributed to their concerns in the first place.
- These findings indicate the need for a more comprehensive approach to address complex and severe needs that takes social and environmental determinants of mental health into account, which could allow these clients to "achieve and maintain improvements in their mental health and wellbeing both in and beyond secure settings" (p.10).

Another systematic review of **home-visiting interventions** for families experiencing complex and multiple problems (defined in the study as an accumulation of adverse factors in different life domains such as parenting, mental health, poverty, housing) looked at out-of-home placement rates and child outcomes following intervention (van Assen et al., 2020). Home-visiting interventions are

¹³ The review focused on children and youth with complex needs who have serious mental health concerns and are at high risk of harming themselves and/or others. However, the authors noted that there are no consistent terms used to refer to these programs, and there is a lack of clear and measurable definitions around client profiles (e.g. what constitutes serious and complex mental health concerns or behaviours that place themselves or others at significant risk).

¹⁴ Other jurisdictions included in the review were Australia, Belgium, New Zealand, the Netherlands, England and Wales, Scotland, and the United States.

a common approach to meet the complex care needs of families because care is provided in the family's home environment, rather than requiring the family to coordinate with multiple services outside of the home. As home visiting interventions can vary in their scope of activities, this review focused on those that provide a comprehensive set of care activities across multiple domains.¹⁵

- Results showed that children participating in home-visiting interventions showed
 improvement on several outcomes, including moderate decreases in emotional and
 behavioural problems and a reduction in stressful events in the year following the
 intervention; however, many children still experience problems at the end of the
 intervention.
- In addition, a considerable proportion of children still experienced out-of-home placements in the year following the intervention placement rates increased significantly in the year after case closure (from 7.5% to 24.3%) such that rates were no different at one-year follow up between children in home-visiting programs and those receiving treatment as usual services.
- These findings suggest that longer-term solutions or approaches to respond to families and children with complex needs are needed.

6.4 Evidence on Challenges and Barriers

As discussed throughout this report, there are several barriers and challenges in Ontario that prevent children and youth with complex mental health needs from accessing the services and supports they need in a timely and efficient manner. Indeed, much of the literature around the issue of children experiencing complex needs focuses on identifying and highlighting these challenges in order to understand ways of improving service delivery.

General findings:

A rapid evidence assessment of the literature on service barriers and best practices for engaging with young people aged 10-25 years experiencing complex needs¹⁶ was conducted to inform the development of an accessible practice framework for service providers in Australia (Klassman et al., 2024). Results were summarized from 18 papers, all of which used qualitative or mixed methods designs to examine perspectives of either young people, service providers, or a mix of perspectives. Some of the barriers to



service engagement identified in the study are summarized in Table 3. Overall, young people with complex needs experienced difficulties navigating and accessing services, and their challenges were further compounded by the nature and structure of service systems, which were not seen as responsive or conducive to their needs.

¹⁵ Studies included in the review were mostly based in the United States, with other interventions included from the Netherlands, Finland, Belgium, and the United Kingdom.

¹⁶ Defined as having co-occurring difficulties including: physical or psychological health problems, drug and alcohol issues, poverty, precarious housing or homelessness, child maltreatment and exposure to family violence, justice system involvement, which may require supports from multiple service providers

Table 3: Barriers to service engagement for young people with complex needs (Klassman et al., 2024)

Level	Barrier	Description
Individual level (young person and	Characteristics of young people	Barriers to accessing or receiving services were reported due to the complexity of young people's individual needs as well as negative perceptions, stereotypes, and discrimination against young people with complex needs, which can lead to fear and mistrust of services
practitioner)	Difficulties navigating service systems	Systems were seen as overwhelming, complex and confusing
	Nature of the service system	Services were described as inconsistent and disjointed; as well as crisis-driven and reactive
	Interagency collaboration	Inadequate collaboration and communication between agencies or services was commonly reported as a barrier
Service and system level	Transitions across services	A lack of continuity of care was identified as a barrier for future service engagement. Transitions between services were also poorly planned, leading to further disengagement
	Resource issues	Staffing and resource issues included a lack of cultural training or awareness and a shortage of funding for services

Findings on service providers' perspectives:

A qualitative study from Toronto, Ontario examined the perspectives of 24 health and social care providers to try to understand what supports are needed to promote optimal care in the community for people with complex needs (characterized by significant health and social challenges) and what barriers exist that prevent optimal care for this population. Findings from the study revealed several themes (Kuluski et al., 2017). First, participants agreed that building a strong, trusting relationship between care providers and recipients (as well as their family) is essential. Providers also identified tangible components of care that they saw as necessary to support complex care needs of patients, including: comprehensive assessment of their needs (including social determinants of health and other non-medical factors) and their capacity to make decisions; building an appropriate team to provide coordinated services; and early and proactive care planning. Finally, some of the remaining barriers that limit the ability to provide these components included: multiple access issues, such as geographic barriers or strict eligibility criteria; a lack of early intervention opportunities; and administrative or structural boundaries that limit the ability of care providers to respond to patients needs. While this study is more relevant to patients with complex care needs in the medical system and is not focused on children and youth, the findings still provide some insights that may be relevant to supporting the complex mental health needs of children and youth, such as the importance of proactive care, of empowering patients with complex needs, and the need for strong therapeutic relationships as the foundation of care.

A similar study from Australia examined the perspectives of 30 health professionals¹⁷ managing the care of children with complex mental health conditions through semi-structured interviews to identify barriers and enablers to an optimal care model (Paton & Hiscock, 2019). Clinicians identified the lack of continuity of services during the transition from child and adolescent services to adult services as the most compromised area of care for children with complex mental health needs. Other barriers to optimal care that were identified included: systemic and structural issues related to the healthcare system in Australia; reduced funding for mental health services; lack of integration between sectors; and challenges with navigating the system for both families and clinicians. Some factors that were seen to enable or improve access to care included: the ability of parents and families to advocate for care and the availability of universal health insurance. Overall,



participants emphasized the importance of empowering parents to manage and support their children as key to improving outcomes for children and youth with complex mental health needs. Other elements of optimal care identified by participants were: greater cooperation between providers through multidisciplinary teams; integration and co-location of services; strengthening knowledge of healthcare providers through training, and strengthening education systems where children spend most of their time.

Findings on parents' perspectives:

While most research on children with complex needs considers the experiences and challenges of children themselves, it is also important to understand the experiences of parents and caregivers who are responsible for managing the challenges experienced by their children with complex mental health needs. A qualitative study from Alberta examined experiences with accessing services of parents of children aged 6 to 17 years with complex mental health needs (Leung et al., 2021). Findings from interviews with parents revealed three key themes:

- 1) Fragmented services parents reported a lack of collaboration between healthcare providers across sectors (i.e. schools and community services), difficulty finding information related to mental health services, and gaps in patient-centered care.
- 2) Challenges navigating complex systems parents experienced barriers in accessing and receiving care (e.g. long wait times, geographical barriers), a lack of continuity of care and a lack of resources at the community level.
- 3) Distress parents reported experiencing emotional challenges related to the difficulties of navigating the fragmented healthcare system, the financial burden of paying for services, and felt stigma due to their child's behaviour, all of which contributed to stress.

Parents in the study also reported the need to self-advocate for their child's care, meaning that parents themselves faced the burden of having to play a navigator role in identifying and accessing appropriate care services. These findings highlight the need for greater coordination of care across

 $^{^{17}}$ Participants included 13 pediatricians, 10 child and adolescent psychiatrists, 6 psychologists and 1 health system professional from another background

sectors and the benefits of a care manager or navigator to support parents and families through the process in a more centralized approach.

7.0 Implications for Policy and Practice

After reviewing the literature on the issue of how to respond to children and youth with complex mental health and behavioural needs, several strategies and approaches emerged as possible ways to promote or enable greater access to the services and supports that these children need. Some of these proposed strategies from the literature are summarized in this section. First, strategies for system level changes to improve the ways systems respond to children and youth with complex needs are discussed. Next, implications for service providers, including the need for education and training and the importance of building trust and relationships are considered, followed by implications for parents and caregivers. Finally, any additional strategies that have emerged from the literature are presented.

7.1 Implications for System Level Responses

Systems of care approach

The most commonly cited model for responding to children with complex health and mental health needs in the literature is a systems of care approach, which was originally defined as: "a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents" (Stroul & Friedman, 1986, p. iv).

The key features of a system of care are very similar to the WrapAround model (discussed in Section 6.1). For example, it involves the integration of services across multiple child-serving agencies; it should be child and family-centered; it is based within the community; and it can be individualized to meet the unique needs of each child or youth and family (Garland et al., 2001).

A systems of care approach may address many of the challenges currently experienced by children and youth whose complex needs cross multiple sectors. As stated by Hornberger et al., ""it is clear that no one system or agency has the mandate, resources, or reach to address both the complex and urgent needs of our most vulnerable children and families and the social and economic conditions that exacerbate these needs" (cited in Burnside, 2012, p. 13). This has also been echoed by experts on the Complex Mental Health Needs Collaboration Table (2022) in Ontario, who noted that experience has shown no single discipline can effectively address complex needs; rather, children and youth with complex needs require collaboration from an integrated care team covering multiple disciplines.



Rather than each sector working in silos, researchers have emphasized the need for multidisciplinary solutions where different service providers work together as critical for providing optimal care to children and youth with complex needs. For example, research from Australian clinicians (Paton & Hiscock, 2019) identified systems of care that focus on "streamlined, coordinated services and cooperation between parents, health, disability and education sectors" as a key component in improving outcomes for children with complex mental health conditions. Research from Atlantic Canada has also pointed to the need for multi-level coordinated services as part of a system of care to respond to young people with complex needs (Ungar et al., 2014). In this study, six principles for more responsive service

Box 3: Principles of good service delivery for young people with complex needs

According to Ungar et al (2014), services that are more responsive to youth with complex needs are those that are:

- 1. Multi-level and ecologically complex in their delivery
- 2. Coordinated
- 3. Continuous over time
- 4. Negotiated with users to match their culture and context
- 5. Provided along a continuum from least to most intrusive
- 6. Effective, as demonstrated by practice or evidence-based treatments

delivery for this population were identified, as listed in Box 3.

In the United States, the systems of care framework has already guided child mental health services for decades, and almost every state in the country has received federal funding to establish systems of care at the state or local level (Graaf et al., 2021). A 2012 article reported that the principles of a systems of care approach have been "successful in transforming the field of children's mental health and facilitating the integration of child-serving systems. This approach has achieved positive outcomes at the child and family, practice and system levels, and numerous articles have been published using data collected from system of care communities, demonstrating the effectiveness of this framework." (Miller et al., 2012, p.566). More recently, Graaf et al. (2021) reported that multiple published evaluations of these publicly funded systems of care have shown improvements among children and youth in classroom, home, and community functioning, including decreases in school-based discipline, reduced contact with the law and the child welfare system, better grades, as well as lower caregiver strain and greater social support for families.

However, the same model has not developed as quickly in Canada. A 2022 report from a group of leaders from mental health agencies¹⁸ in Ontario outlined a shared vision for advancing a coordinated system of care for children and youth mental health in the province (School and Community System of Care Collaborative, 2022). The report acknowledges that Ontario does already have many of the foundational elements for an integrated system of care, but many barriers have prevented service providers from achieving the level of sustained collaboration needed to build a responsive system of care thus far. Furthermore, the pressures of the COVID-19 pandemic have only amplified the gaps and inconsistencies in existing service delivery. The report aims to provide guidance on key resources and tools that can enable the actual implementation of a system of care in the province. However, establishing these guiding principles is only the first step towards

¹⁸ Partners included the Child and Youth Mental Health Lead Agency Consortium (LAC), School Mental Health Ontario, the Knowledge Institute for Child and Youth Mental Health, and Children's Mental Health Ontario, with representation from the Ministry of Health, Ministry of Education, and children and families.

the 'aspiration' of a system of care in which schools and community-based mental health organizations work together to meet the mental health needs of children and youth; the authors note that moving from the concept of a system of care to an actual plan of action will require strong cross-sector collaboration.

A systems of care model has also been supported by Canadian parents of children with complex mental health care needs. For example, in the qualitative study from Alberta by Leung et al. (2021), parents were asked what their ideal vision of a healthcare system that works to meet the needs of them and their child would look like. Responses consistently highlighted the need for well-coordinated care using a team approach in which a multi-disciplinary team works collaboratively across sectors and disciplines to enhance communication and continuity of care.

Early intervention and assessments

Sources within the literature have noted the need for timely intervention and assessments in order to get children experiencing complex challenges the appropriate supports before their issues worsen and reach a crisis state.

According to the Ontario Association of Childrens Aid Societies, it is always preferable to keep children with complex needs at home in the family setting for as long as possible rather than placing them in out-of-home care. It is essential that community-based resources are available and accessible so that families can stay together while receiving essential supports, without needing to seek treatment from child protection services (e.g. Becken, 2023).

In addition to community-based resources, another component of an early intervention approach is conducting a comprehensive needs assessment to determine which resources would be most appropriate for each child or youth with complex needs. However, as discussed by Burnside (2012), it can be difficult to determine the best time for this assessment to take place. "Assessment is the hallmark activity that needs to guide appropriate placement and service plans. For youth with complex needs who enter the system in adolescence, the timing of assessment is at the point of entry, but for youth who have been involved with the system (often child welfare) for a long period of time, guidelines need to be established as to when and how such youth become part of an assessment process to ensure that their needs are identified and addressed at an early stage." (pg. 57).

The need for guidance on conducting assessments has also been identified by other researchers such as Hnatko (2016),



who calls for developing "integrated and agreed principles upon which we can objectively identify need and levels of care across all invested in children's mental (developmental) health".

In their study of care providers for people with complex care needs in Toronto, Kuluski et al. (2017) noted that in addition to a comprehensive assessment of the patient's needs (i.e. physical and mental health status, social context, and other factors that affect behaviour), care providers should also assess an individual's ability or capacity to make decisions about their care.

Participants in the study also pointed to the importance of early intervention and the impact of missed opportunities to intervene. For example, if an appropriate assessment is conducted at the first contact with the patient, then a care plan can be developed at that point and potentially avoid negative outcomes in the future. The authors further emphasized that an appropriate risk assessment for people with complex needs must also include non-medical (i.e. social) factors. According to the authors, "Ignoring social risk factors ha[s] real implications, as noted by the participants in our study, who indicated that overlooking social needs may culminate into a missed opportunity to mitigate a medical crisis later on." (Kuluski et al., 2017, p.8).

School-based interventions

There are many examples within the literature on the importance of schools as a setting or point of contact for interventions that could help support children and youth with complex needs. There are several reasons why schools may be an effective way of reaching these youth: students already spend the majority of their time at school; it is a familiar and safe environment; and interventions offered through schools may be less stigmatizing than services from other sectors or agencies (e.g. mental health organizations) (Ungar et al., 2014; Izakian et al., 2019; Burnside, 2012). Some

researchers suggest that schools may be more accessible and inclusive settings for the provision of integrated supports for children and youth with mental health needs, compared to health settings where services tend to be fragmented and less accessible (Bartlett & Freeze, 2018). In addition, schools often have a team of professionals (ie. teachers, counsellors, school psychologists) who can help identify mental health problems among students and refer students to appropriate services.



The role of schools must be considered in strategies to respond to children with complex needs as the challenges these children experience can affect their behaviour and performance at school. For example, many youth with complex needs are suspended from school because of behaviour problems and it can be difficult for them to return; or they may experience other disruptions that prevent them from attending school consistently such as changes in placements (Burnside). For these youth, alternative education strategies may be needed to keep them engaged with their education, such as mobile school programs (Burnside, 2012).

According to Burnside (2012), more opportunities to bring treatments and interventions into the school environment are needed. Schools should also be provided with appropriate information and resources to enhance their capacity to support students with complex needs.

Additional supports during transitions

As children with complex needs tend to experience chronic or ongoing challenges as they age and grow into adulthood, it is important to ensure continuity of services and supports during this transition. According to Izakian et al. (2019), the transition from child to adult services is particularly challenging as it involves multiple changes in supports (i.e. educational, health care,

disability, income, justice, and/or child welfare supports), and these changes are critical for youth with complex service needs.

This is especially important for children and youth in out-of-home care (i.e. foster care). The transition out of care when youth reach the age of majority is often extremely challenging for any young person involved in the child welfare system (e.g. see Sansone et al., 2020 for more discussion), but it can be even more difficult for those experiencing multiple complex mental health and behavioural challenges. For example, evidence from the United Kingdom suggests that young people with multiple and complex needs are more likely to struggle during the process of leaving care and are at greater risk of becoming homeless or involved in the correctional system (Stein, 2012). A qualitative study conducted among people working in organizations involved with youth leaving care in Australia identified similar challenges for young people with complex needs (Malvaso et al., 2016). For example, participants noted challenges with the availability and accessibility of services for youth transitioning from care; challenges with engaging youth with complex needs, and difficulties maintaining strong connections and relationships. Ongoing contact and support as well as greater flexibility in service delivery were identified as strategies to enhance service engagement for this population.

Children and youth with complex needs may experience other transitions as well, such as transitions between schools or placements in the child welfare system. As discussed by Burnside (2012), relational models of care are critical to supporting children and youth with complex needs, particularly during periods of change; as these placement disruptions affect the relationships and trust that children and youth may have built with different service providers. Therefore, strategies are needed to help strengthen these relationships and ensure that youth with complex needs remain connected to at least one supportive adult who can guide them through transitions. Strategies to minimize placement breakdowns and keep youth engaged in school are also important.

7.2 Implications for Service Providers

Education and training of service providers

In order for systems of care to be implemented and delivered effectively, service providers across systems working with children and youth with complex needs must have adequate training and knowledge. As noted by Paton & Hiscock (2019) in their study of Australian clinicians' perspectives on optimal care for children with complex mental health needs: "Underpinning coordination and multidisciplinary solutions is the need for strengthening workforce knowledge through improved workforce planning, succession planning and specific training for treating complex mental health conditions." (pg. 12).

Experts in Ontario have also cited the need for better training of service providers. For example, in a study on secure treatment programs commissioned by the Ontario Ministry of Health (Schutte et al., 2023), the researchers noted that the range of complex needs across domains presented by children and youth in these programs necessitates ongoing professional development for service providers, which would allow them to continuously develop the necessary skills and knowledge to deliver safe and effective treatment. The report from the provincial Complex Mental Health Needs Collaboration Table (2022) also noted that the lack of early access to trained clinicians for families with complex needs means that families are left without the proper skills and supports that could prevent their issues from escalating to a crisis situation. According to the group of experts in Ontario: "Existing

academic programs for those in the mental health sector (e.g., social work) do not include adequate training to allow clinicians to work effectively and confidently with children and youth with complex needs. This is further exacerbated by the lack of integration or inclusion of Indigenous and other forms of culturally congruent content in the mainstream service delivery when that is needed." (pg. 9).

Finally, as noted in Section 7.3, parents and caregivers have identified the need for more support in navigating existing services for their children with complex needs. Therefore, besides training in how to prevent and treat complex mental health and behavioural conditions in children and youth, service providers also need to develop a strong understanding and awareness of existing resources and supports in the local community that families may be able to access and benefit from.

Cultural training and awareness

Importantly, service providers should receive training in cultural safety to enhance their awareness and understanding of the unique needs and histories of children and youth with different cultural backgrounds as well as their own personal and systemic biases and privileges. This should include self-reflection and learning to better understand factors that serve as barriers to care and ways to

engage with children and families from diverse backgrounds in respectful and culturally appropriate ways. Ultimately, training in cultural safety should strive to address the inherent power imbalances in the healthcare system and equip healthcare providers for service delivery that is anti-racist and anti-discriminatory (Public Health Agency of Canada, 2023; Baba, 2013). Additional information on cultural safety, including relevant terms and their meanings within the health system, can be found in Appendix B (Additional Resources).



Not only do all families need access to evidence-based services provided by highly skilled professionals to meet their needs, but there is an additional need for Indigenous and other racialized groups to be able to access services that align with their culture and traditional practices and beliefs. This may include having access to a cultural expert as part of a child or young person's multidisciplinary care team or offering a separate stream of services and interventions to support the linguistic and cultural needs of Indigenous and other marginalized populations (Complex Mental Health Needs Collaboration Table, 2022).

The need for cultural training, including trauma-informed care, has been identified for service providers working with children and families experiencing a range of complex challenges. For example:

Researchers and community partners studying prenatal opioid exposure in 13 First Nations
communities in Ontario reported that ongoing education and training on the impacts of POE
is critical for anyone interacting with children with POE, including service providers,
educators and parents. As children exposed to opioids are more likely to experience a
variety of health, developmental, behavioural, emotional and mental health challenges, it is
important to understand and support their needs using a trauma-informed approach
(Kerpan et al., 2023).

Some practical guidance for practitioners working with families experiencing multiple
complex needs has been developed by Emerging Minds, an organization that works to
promote evidence-based practice and policy to support child and youth mental health in
Australia. The practice paper provides tips for service providers to better understand the
families they work with and their unique needs, including gaining knowledge through
cultural competence training (see Appendix B).

Relational approach

Consistent with frameworks on person and family centered care in health, research has also identified the importance of strong, trusting relationships with service providers for children and youth with complex needs. For example:

- Findings from focus group research with care providers in Toronto highlighted quality of care and the way in which it is delivered as a key part of better care for patients with complex needs (Kuluski et al., 2017). Participants in the study stated that establishing a strong therapeutic relationship with patients as well as with their family and support network is integral to their care. However, care providers also recognized that building trust with patients requires a significant amount of time, which is challenging to achieve.
- Results from the rapid review of evidence on barriers and facilitators for service
 engagement among young people with complex needs by Klassman et al. (2024) showed
 that several studies reference 'relational approaches to service delivery' as a strategy to
 enhance service engagement. Most of the research on relationships with practitioners
 focused on building trust as a means of encouraging sustained engagement with services, as
 practitioners who are able to maintain and honour confidentiality are more likely to retain
 young people with complex needs as clients. Besides trust, respect, openness, empathy and
 warmth were also identified as key relational elements that facilitate service engagement.
- As discussed by Malvaso et al. (2016) in their study of youth leaving out-of-home care, developing a supportive relationship with service providers can be especially difficult for children and youth with complex needs, who may be disengaged or resistant to receiving services based on their previous experiences; However, these researchers state that building those relationships can promote significant benefits and success, particularly for young people who are transitioning into adulthood and need ongoing support. For instance, if youth temporarily disengage from services, they are more likely to return and re-engage with service providers if they have developed a trusting relationship and confidence in them.
- Finally, in qualitative research among mental health practitioners (Indigenous and non-Indigenous) who work with Indigenous youth in Canada, practitioners described the importance developing effective therapeutic relationships with youth through authentic mutual understanding and trust-building. Intentional authenticity and self-disclosure on the part of practitioners was reported to be foundational to building genuine relationships with Indigenous youth (Ineese-Nash et al., 2022).

Person-centered approach

Research also shows that a critical part of a child or youth-centered approach to care delivery for children with complex needs is allowing them to be involved in decision making around their own care or case management (e.g. Malvaso et al., 2016). For example, in the study of youth leaving care, findings showed that "Effective case management was believed to be achieved through fostering a

sense of empowerment in young people as well as advocating for and on behalf of the young person." (Malvaso et al., 2016, pg. 139). Empowerment over their own choices was noted to be especially important for young people in care, who are often deprived of opportunities to make decisions for themselves. However, the authors cautioned that balance is needed between respecting young people's autonomy while also ensuring that services and decisions are still in their best interests. When a young person is not able or capable of making decisions in their own best interest, service providers should be willing to advocate on their behalf.

The importance of advocacy has also been noted in a review by Klassman et al. (2024), who found that several studies have emphasized the need for practitioners to act as advocates for young people with complex needs, or for another trusted individual or mentor to act on their behalf. According to Klassman et al. (2024), the use of a mentor or advocate may be especially important for young people from Indigenous or refugee backgrounds, who may face communication or cultural barriers. When someone else is able to act on their behalf and communicate their needs effectively, their

concerns are more likely to be addressed appropriately.

Overall, findings in this section indicate that to maintain engagement, services for young people with complex needs should aim to be: flexible yet consistent and reliable; supportive and youth-centered; authentic; friendly and non-judgmental, and should incorporate informal, creative strategies and activities (Malvaso et al., 2016; Ineese-Nash et al., 2022).



7.3 Implications for Parents and Caregivers

While system level change is clearly needed to improve outcomes for children and families experiencing complex needs in Ontario, changing the ways in which systems and services respond to children and youth with complex needs can take a long time. For example, the foundational resource on strengthening Ontario's mental health system of care for children and youth people published in 2022 (the "Right time, right care" report, available online; see also Appendix B) was in development for almost a decade. In New Brunswick, the provincial government committed in 2013 to building a "centre of excellence" that would provide a range of services for children and youth with complex mental health and behavioural needs, but by 2022, there was still no update on the promised centre (Donkin, 2022).

Therefore, until further steps are taken to achieve system change, short-term solutions are needed to help families who require support now. One approach that has been identified as beneficial for parents and caregivers is empowering them to advocate for the services they need for their child. According to Paton & Hiscock (2019), given the complexity of the current healthcare system, it is even more important for parents and caregivers to be informed and capable to ensure optimal care. The authors reported that: "In an environment where healthcare funding is limited and children require support in multiple settings, empowering parents to manage their children within the healthcare, disability and education systems was identified as key to improving outcomes for children with complex needs" (pg. 10).

The role of parents and family members is especially valuable considering that they have the greatest experience and contact with their child and knowledge of their needs. Therefore, it is important to not only empower parents to advocate on their child's behalf but also to empower them as caregivers themselves. As discussed by Paton & Hiscock (2019), when parents have adequate resources and tools to support their children, the overall capacity to effectively respond to the child's needs is enhanced. However, it is important to recognize that this strategy is not feasible for all families; many parents and caregivers experiencing multiple complex challenges – including their own past or current challenges as well as those of their child – do not have the capacity to engage in effective advocacy efforts. This is especially important for parents and caregivers with mental health challenges, prior experiences of trauma, and experiences of discrimination and marginalization (i.e., Indigenous and racialized populations) – who face additional barriers that may prevent them from realizing the role of empowered advocate for their child.

A couple of strategies to support parents and families in their role as advocates and care providers from the literature include peer support networks and care coordinators or navigators.

- Some studies suggest that parents can benefit from peer-to-peer support networks as a supplement to the supports offered by professionals; however, the evidence on the specific benefits or outcomes associated with peer support are inconclusive (Paton & Hiscock, 2019; Niela-Vilén et al., 2014). For example, review studies of peer support for parents of children with complex medical conditions or disabilities have found consistent qualitative evidence that peer support is perceived as beneficial and valuable for parents, but it is unclear whether these benefits are measurable in terms of quantitative outcomes (e.g. Shilling et al., 2013; Sartore et al., 2021).
- Based on qualitative research with parents of children with complex mental health needs in Alberta, Leung et al. (2021) argue for a more centralized system led by a care navigator who can facilitate and support parents' navigations across different services and disciplines. This could be a facilitator, case manager, or resource worker who serves as a single point of contact for all aspects of the child's care. Families with experience navigating the mental health and addiction system in Toronto, Ontario have also identified the need for a navigating service that would respond to their needs. For example, families in focus group research identified three features of an ideal navigating service: a) *engagement* a navigator who remains engaged with the family throughout the entire care process; b) *resource matching* a navigator who understands the differences between resources in order to make individualized recommendations; and c) *compassionate persistence* a navigator who will continue to pursue other alternatives if the first recommendations are not helpful (Markoulakis et al., 2016).
- Care manager programs have been shown to be effective within the healthcare system as measured by patient outcomes and cost effectiveness (e.g. Holst et al., 2018). An example of a care navigator program in Ontario that has shown benefits is the Family Navigation Project at Sunnybrook Health Sciences Centre, which has served youth aged 11-29 years old with mental health and/or addiction issues and their families since 2013. The project offers a free service to help families navigate and access appropriate supports, resources and treatment options that best suit their needs. Feedback from families has been positive, with findings from a pilot survey indicating high satisfaction with the process (Markoulakis et al., 2016). However, further research would be needed to assess the impact of care navigator programs on parents and families with children experiencing multiple or complex challenges.

7.4 Multi-level Strategies

Overall, research indicates that multiple strategies are needed at the systems level, practitioner level, and family level to promote positive outcomes for children and youth with complex needs. This section summarizes findings from selected reviews on best practices for service delivery to support children and youth with complex needs from a multi-system perspective.

After reviewing the evidence on service engagement for young people with complex needs, Klassman et al. (2024) identified a number of strategies at both the practitioner level and the system level to facilitate service engagement. Most of these strategies, which are listed in Table 4, have already been discussed throughout Section 7 of this report. Overall, a common thread between the strategies was the "importance of creating a service environment that is structured around the needs of young people rather than one which requires vulnerable young people to adapt to services." According to the authors, this will require a "fundamental shift" in the way services are organized to ensure that youth with complex needs can access the services they need without falling through the cracks.

Table 4: Summary of strategies to enhance service engagement among youth with complex needs (Klassman et al., 2024)

Level	Approach	Description		
Service and system level	Structural approaches	Services need to be accessible and offer flexible opportunities for engagement (e.g. more flexible opening times)		
	Collaborative approaches	Services and systems must work together to effectively address the needs of young people; through improved communication and information sharing and more integrated or centralized systems		
	Staff training and support	Staff must be trained in different aspects of service provision for young people with complex needs, especially those of different cultural backgrounds		
Individual level (practitioner and youth)	Relational approaches	Building trust and respect between practitioners and young people		
	Practical approaches	Action-oriented practices and outreach to engage young people; addressing immediate and practical needs first before referrals to further services		
	Empowerment approaches	Involve young people in decision-making processers or act as an advocate on their behalf		

In British Columbia, the Office of the Representative for Children and Youth (RCY) commissioned a literature review to inform the province's proposed plan to develop a new service system to support children and youth with "support needs" (i.e., physical and/or developmental disability, emotional disturbance or mental health concern) (Mirenda, 2023). The purpose of the review was to identify the key components of effective service delivery systems or models for children with support needs and their families, with a focus on specific components needed to address mental health needs and the needs of Indigenous children and families. While these findings are not necessarily specific to children with multiple complex needs as defined in this report, the results (summarized in Table 5)

may still be relevant to this report, particularly because they focus on additional supports for Indigenous families.

Table 5: Summary of key components for effective service delivery for children and youth with support needs (Source: Mirenda, 2023)

Category	Component	Description
General components for effective service delivery	Provision of family- centered care	All reviewed articles identified family-centered care as a critical component of service delivery. This includes: Encouraging parent/caregiver decision-making, building on child and family strengths, respecting each family's abilities and diverse values or cultures, and encouraging the involvement of all family members
	Cross-sector collaboration and connections to community networks	61% of studies identified the importance of collaboration across government departments/ministries and/or with community networks. This may include co-locating services in a central location, establishing a common database to support communication and team-based planning.
	Coordination of services across therapies	57% of studies mentioned the need for intra-agency care coordination, which may be achieved by assigning a care coordinator or navigator or a small team.
	Sufficient funding and resources	57% of studies specifically emphasized the importance of adequate and equitable funding for service provision; while 35% of studies identified the need for sufficient resources such as technology equipment, or administrative support.
	Services customized to meet individual needs	42% of studies identified the availability of individualized services as a key component of effective service delivery, focusing on adequate intensity of services (i.e. service hours and duration) and quality of services (i.e. how well the supports match the child's needs).
	Staff training	43% of studies identified the importance of staff training when new changes are made to a service delivery model; as well as ongoing training in antiracist, culturally safe, and trauma-informed practice.
Additional Components related to mental health	Wraparound services	79% of studies on mental health delivery mentioned the Wraparound process, focusing on the authentic and measurable elements of the Wraparound model (as described in Section 6.1).
	Ease of referral and access	57% of mental-health focused studies identified the importance of an easy referral process and easy or quick access to mental health services.

Additional components for services for Indigenous children and families	Two-eyed seeing	87% of Indigenous-focused research studies emphasized the importance of embedding Indigenous culture, values and practices into service delivery for Indigenous children and families with support needs, highlighting the 'two-eyed seeing' approach which incorporates the strengths of both Indigenous and Western ways of knowing. This may include providing Indigenous-run services or recruiting Indigenous service providers; allowing sufficient time to build trust and relationships with Indigenous families; involving Elders and traditional healers, and integrating traditional healing practices
	Support the whole family	67% of Indigenous-focused studies identified the need to provide supports to the whole family, not just the child or youth with support needs, as a way of acknowledging the key role that families play in Indigenous identity and connecting to culture and kinship

8.0 Summary and Conclusions

8.1 Summary of Findings

This report summarized the available literature on systems and approaches to respond to complex mental health and behavioural needs among children and youth. Overall, findings from the literature revealed that multiple initiatives to support children and youth with complex needs do exist at the local level across Ontario; however, the province is still lacking a well-coordinated or integrated approach that could help break down many of the barriers that children and families experience in accessing appropriate services. In addition, most of the existing services in Ontario are delivered through the health and social services systems; there are still gaps in involvement from other sectors, such as education and youth justice.

As discussed in Section 5, children and families experiencing complex needs may be able to access different systems for support; although the specific services or programs that are available to them can depend on a number of factors, including the family's circumstances, the child's specific challenges or diagnosis, the region they live in, their age, and the risk of harm to themselves or others. There are also local variations in how these different systems operate and the types of services they provide. While this variation can be a strength because it provides many opportunities and pathways for families to engage with different services, it can also create more confusion and stress for families when they are faced with navigating each of these different pathways and service structures on their own (Complex Mental Health, 2023).

Indeed, one of the most common themes from the literature reviewed in this report is that children and families with complex needs continue to experience challenges in accessing and receiving appropriate services and supports, resulting in inadequate treatment and care. The fragmented nature of existing care services in Ontario means that even when individual services provide high-quality care, children experiencing complex challenges that cross multiple service sectors are still left with unmet needs.

Because of the complexity of their multiple challenges (i.e. behavioural, emotional, mental health, developmental, educational), it is clear that a "one size fits all" approach will not be enough to meet the needs of these children and families, as no single sector or agency has the necessary capacity to address these challenges effectively. The multiple, often-changing needs of these children and youth require cross-sector solutions (see Van den Steene et al., 2019). Furthermore, research suggests that rather than requiring children and youth to try to fit their needs into existing systems, services should be flexible and adapt to the complex and unique needs of children and youth themselves to provide the greatest benefit (Klassman et al., 2024).

Another theme from the literature is the need for improved coordination and collaboration across systems and services. This coordination needs to take place at multiple levels, including between

different service providers involved in the child's care and between the various systems the child interacts with throughout their life. Moreover, as discussed in Section 7.1, it can be especially challenging for children with complex needs who reach the age of majority and need to transition to adult services; pointing again to the importance of continuity of care and coordination of services over time.



There appears to be support among practitioners and families for a systems of care approach, such

as the WrapAround model of integrated services (described in Section 6.1), as a way to improve the quality and consistency of care and promote better outcomes for children and youth with complex needs (Burnside, 2012). This approach goes beyond communication and coordination of services across sectors and involves the actual integration of services into a single plan of care. However, researchers have noted that there are still challenges with the practical implementation of this model, especially in Canada where guidance around systems of care is not yet fully developed and evidence is still limited (Bartlett, 2015).

8.2 Limitations of the Evidence

After reviewing the available literature on supports for children, youth and families with complex needs, several gaps and challenges with existing research were identified.

First, as discussed in Section 4.3, there are ongoing challenges with defining the issue of complex needs and the population who experience complexity. Studies have shown that the term 'complexity' or 'complex needs' is often subjective and dependent on the context, the time, and the perspective of the individual or service, making it difficult to define in any consistent way (e.g. Klassman et al., 2024). Without a clear understanding of the actual experiences of children and youth with complex needs, it is even more difficult for practitioners and policymakers to respond effectively to these needs. As noted by Van den Steene et al. (2019), a common definition would not only lead to more effective responses for children and youth with complex needs and their families, but it would also help to improve communication and coordination between service professionals, inform policymakers in determining priorities and allocating resources, and contribute to research and data collection. According to Dowse et al. (2014, p. 181): "The challenge for policymakers is to enact strategies that enable shared recognition and understanding of the nature of complex needs in young people, including common criteria and terminology to identify this group."

Another major limitation is the overall lack of research and evidence that could help inform responses to children and youth with complex needs. Most of the literature relevant to the issue of "complex needs" among children and youth focuses on those with medical complexity and responses within the health care sector; there is less literature relevant to the issue of complex needs as defined in this report (i.e. children and youth with multiple, co-occurring mental health and behavioural challenges). There is also a lack of research in the Canadian context, as well as a lack of research specific to certain populations of children and youth in families that tend to be overrepresented in the health, mental health, and child welfare systems – specifically those from Black, Indigenous, and other racialized backgrounds.

Given the complexity of the issue and its relevance across multiple systems and sectors, it is difficult to evaluate the overall impact of any interventions or programs that aim to support people experiencing a combination of mental health, behavioural, social, or other challenges. As noted by Ungar et al. (2014), it is harder to determine effect sizes of interventions for complex cases because there are so many factors that can affect outcomes. The effects of interventions can also vary depending on the outcome that is being assessed. For example, interventions may appear to have little or no effect on outcomes associated with the child or youth's disorder (i.e. behaviour or mental health symptoms), while at the same time they can have a positive impact on aspects of functioning, such as promoting resilience, self-efficacy and overall-well-being. Because these two dimensions of health interact, interventions that positively affect well-being can actually lead to changes in other outcomes as well (Ungar et al., 2014).

In addition, as discussed by researchers such as Graaf et al. (2021), there are added barriers that can prevent the use of evidence-based treatments in actual practice for children's services. For example, many treatments target only one or two specific diagnoses and are not well suited for children with multiple medical, developmental and behavioural challenges. According to Graaf et al., research-supported treatments (or evidence-based practices) are typically not designed to fit into interdisciplinary team-based approaches such as the systems of care model. Despite the fact that one of the key principles of the WrapAround model is the use of evidence-informed practices, there is still little guidance as to how to select or implement evidence-based treatments or interventions. As stated by Ungar et al. (2014, p. 690), there is a need "to introduce more complexity into treatment protocols to see how EBT (evidence-based treatment) can be useful for clients with complex needs that span multiple ecological levels."

Finally, as noted in Section 4.4, another limitation of the available evidence is that any data on prevalence or outcomes for children and youth with complex needs may be specific only to the sector that is collecting the information (i.e. health, mental health, child welfare), which limits comprehensive understandings of complex needs.

8.3 Future Directions

Future research needs

To overcome some of the limitations of the available literature, there is a clear need for more research to understand how systems can respond more effectively to complex needs among children, youth and families in Ontario.

Some specific areas for further research noted in the literature include:

• **Data collection and monitoring** – researchers in Ontario have identified the need for enhanced collection and analysis of data to identify, understand and address complex needs

among patients in the mental health sector (Sirotich & Durbin, 2014). According to Klassman et al. (2024), system-wide prevention for people with complex needs is hindered by siloed data collection and information systems. The lack of information sharing and collaboration between services and agencies serves as a barrier to service engagement for young people and families. Researchers (Klassman et al., 2024; Malvaso et al., 2016; Malvaso et al., 2022) have recommended that three types of indicators should be routinely collected and linked to better understand the needs of children and youth with complex health and social challenges and improve service delivery at a system level: a) process indicators to measure agency activities (e.g. information on number of clients and services provided); b) indicators that measure referrals to specialized services and subsequent engagement with those services; and c) child and family well-being outcomes across multiple domains.

- More longitudinal studies to examine pathways of service use and trajectories for children and youth with complex needs. According to Garland et al. (2001), a better understanding of longitudinal patterns of service needs and utilization across multiple sectors may provide insights into effective points of intervention. These critical points for decision and referral are often complicated for children and youth with complex needs due to limits on the availability and scope of services provided by different systems (Ungar et al., 2014). Therefore, more evidence and guidance is needed to identify appropriate targets for preventive interventions and to facilitate more adaptive pathways of service use (Garland et al., 2001).
- More research on culturally relevant approaches and interventions to support the
 complex needs of Indigenous children and youth researchers have noted the need for
 more effective strategies to respond to the unique experiences and histories of Indigenous
 children and families experiencing complex mental health and behavioural challenges, as
 mainstream systems may not be accessible or appropriate for Indigenous populations who
 have experienced trauma and discrimination in the past.

Finally, as shown in the literature on the benefits of empowering children and youth with complex needs to actively participate in their own care planning, it is important for future research to involve and engage children, youth and families. Children and families experiencing multiple complex challenges may have valuable insights that can help to better define the issue as well as effective responses to address it.

Future innovations

The need for more research to inform evidence-based practices and guidelines is especially important given the complexity that would be involved with restructuring existing service delivery models or implementing broad, system-level changes. As discussed by researchers such as Paton & Hiscock (2019), future work should explore the best ways to restructure systems and services, including studies to develop, implement and evaluate the effectiveness and cost-effectiveness of approaches such as integrated care models on outcomes such as access to services and child and family mental health and well-being.

Another area of focus for future study is finding new ways to address individual needs and challenges among children at an earlier stage – that is, before they become more acute and reach a crisis state. A more upstream approach to understanding and addressing complex needs would look

at the macro level factors and structures that affect health and well-being, such as the social determinants of health discussed in Section 4.2.

However, implementing system-level change and addressing the root cases of complex needs would require time; thus other strategies to improve care access and delivery are needed in the short-term. According to Paton & Hiscock (2019), empowering parents and families to better understand and advocate for the services they need may have the greatest impact in the short term, although this may not be feasible or realistic for all parents and families experiencing complex challenges. Another short-term strategy to address the lack of culturally respectful and appropriate services in existing systems would involve locating more services in culturally-embedded and trusted community-based organizations. In line with some of the examples of programs for Indigenous populations in Section 6.2, this would help to expand the reach of available services and provide more comprehensive and holistic supports to all children and families experiencing complex needs.

8.4 Conclusion and Policy Implications

Findings from this report have shown that even though children and youth with complex needs are often identified in Ontario and researchers, practitioners, and child welfare advocates are increasingly recognizing the many challenges and barriers this population experiences in accessing needed services and supports, there is still no clear path forward. Service providers across systems that work with children and youth lack the necessary resources to respond to complex needs in an

integrated and coordinated way; and policymakers lack the necessary evidence and guidance to inform system level changes that could improve outcomes for children and youth with complex needs. Without sufficient research showing what the long-term trajectories look like for children and youth with complex needs and how their outcomes are impacted by different prevention and intervention approaches, policymakers and practitioners will not be able to help these children in ways that can change their trajectories and optimize health and well-being outcomes.



It is clear that finding a solution to these questions around how to best support children and youth with complex needs is not simple or straightforward; indeed, the inherent complexity of challenges experienced by children and youth with multiple issues requires change at multiple levels. For instance, as indicated by the definition of complex needs offered in Section 4.3 (pg. 10) and throughout this report, the issue is not additive but multiplicative – involving multiple diagnoses or behavioural problems, which are mismatched to a fragmented system of services, within a context of societal level marginalization stemming from systemic factors that serve as barriers to families who are navigating this system. As summarized by Dowse et al. (2014, p. 181):

"Envisioning a comprehensive response will mean addressing a range of matters at the level of systems and practices in individual and family support programs, service system cohesion, and overarching policy direction. Responses across all levels will need to recognise and explicitly address the fact that rather than simply co-occurring, complex needs are pervasive and interlocking and must be addressed in concert rather than in isolation from each other."

More simply stated, "It is time to consider complex solutions for complex circumstances." (Ineese-Nash et al., 2022, p. 52).

A common theme that has been repeated throughout this report is that we cannot rely on one system or sector for a solution to the issue of how to respond to children and youth with complex needs. In order to tackle the issue effectively, we need to break down existing silos between the various groups, sectors, departments, and ministries and work towards a more holistic, whole systems approach. In an integrated model of service delivery, all services must be accessible to all children and youth with complex needs through multiple points of entry, regardless of the individual system in which their needs are identified – known as a "no wrong door" policy (Miller et al., 2012; Mirenda, 2023).

In Ontario, researchers and advocates have called for a full system redesign – or at least a common provincial direction to care for children and youth with complex needs (Becken, 2023; Burnside, 2012). Moving forward, this could involve more cross-ministerial partnerships as well as greater sharing of resources and budgets across the network of organizations and service providers responsible supporting children and youth with complex needs (Burnside, 2012; OACAS, 2023). It should also involve more proactive strategies that could help to prevent or address the health, mental health and social care needs of children and youth before they escalate and reach the point of crisis. As discussed by researchers such as Burnside (2012) and Kuluksi et al. (2017), our current systems are oriented more towards acute care and reactive response, which actually creates more strain on resources and can leave children and youth with nowhere to go for support. Ultimately, the best interests of children themselves is the highest priority, and all child-serving systems must collaborate and acknowledge their shared responsibility to meet their needs (Mirenda, 2023).

Visions for system redesign around responding to complex mental health needs among children and youth in Ontario might benefit from looking to other parallel sectors and issues where recent strides have been made. As a primary example, the health care system was historically not set up to meet the needs of children with medical complexity, but there has been a considerable movement around ways to better mobilize health care resources to meet these complex medical needs and improve the delivery of care. The growing awareness and attention to the issue of complex medical needs among children and youth may provide some insights into best practices and potential next steps that could be applied to the issue of complex mental health and behavioural needs.

Ontario has taken steps to address mental health and behavioural problems among children and youth. This includes investments into the province's mental health and addictions strategy, a joint publication outlining a vision for strengthening mental health supports for children and young people through a system of care (the "Right time, right care" report; see Appendix B), and the coordination of a provincial collaboration table on complex mental health needs, which published a set of recommendations for change in 2022. Putting these strategies and recommendations into action will be essential for transformative change to occur.

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Appendix A - Provincial Definitions of Complex Needs

Most provincial and territorial governments do not have a specific definition of children with complex needs. However, some ministries, organizations, and initiatives across Canada have provided various definitions as follows:

Source: Canadian Home Care Association https://cdnhomecare.ca/wp-content/uploads/2020/02/CHCA-Children-with-Complex-Care-Needs.pdf

Province/ Territory	Source	Term	Definition
remulty			
Alberta			There is no specific definition for children with complex care needs used in Alberta
British Columbia	B.C. Cross- Ministry Framework for Action	Children and youth with special needs	Children and youth up to 19 years of age who need significant additional educational, medical/health and social/environmental support—beyond that required by children in general—to improve their health, development, learning, quality of life, participation and community inclusion.
Manitoba			Provincially, Manitoba does not have a definition that describes and identifies children with complex care needs.
	The Winnipeg Regional Health Authority (WRHA)	Children with complex needs	include those who require a network of health, education, social and other services in their homes and communities. The children in this population have a wide range of physical/medical and developmental needs. These children are often chronically ill, medically fragile and dependent on technology.
New Brunswick	Department of Social Development	Children with complex care needs	Children/youth who present with one or more highly complex behavioural, emotional, mental health, addictions or physical challenges; who are involved with at least 2 departments and for which their need for services is outside of the respective departments' mandate, requiring an exception to standards or policies.
Newfoundland and Labrador	Department of Health and Community Services	Children with complex care needs	Those with highly complex behavioural, emotional or medical needs
Northwest Territories			There is no specific definition for children with complex care needs used in the NWT.
Nova Scotia			In the absence of a provincial definition for children with complex care needs, variation

			exists in the identification of these children across provincial programming and services
Nunavut			A definition specific to the identification of children with complex care needs was not identified for Nunavut
Ontario	Special Needs Strategy	children and youth with multiple and/or complex special needs	Children and youth with multiple and/or complex special needs are a sub-set of children and youth with special needs. These children require multiple specialized services (e.g. rehabilitation services, autism services, developmental services, and/or respite supports) due to the depth and breadth of their needs. They may experience challenges related to multiple areas of their development, including their physical, communication, intellectual, emotional, social, and/or behavioural development and require services from multiple sectors and/or professionals.
PEI	Department of Health and Wellness	children with complex care needs	Children and youth up to the age of 18 years (and their families) who have or are at increased risk for chronic physical, developmental, behavioural or emotional conditions. Multiple services are required to address these interrelated needs, which have a functional impact beyond that experienced by children generally.
Quebec			A provincial definition identifying children with complex care needs is not available
Saskatchewan			The Ministry of Social Services does not have a formal definition of children with complex care needs.
Yukon			The Yukon does not apply a specific definition to children with complex care needs.

Appendix B - Additional Resources

Australia: Promising Practice Guide: Improving the Social and Emotional Wellbeing of Young Aboriginal and Torres Strait Islander People with Severe and Complex Mental Health Needs

• Source: Smith J, Christie B, Tari-Keresztes N, Gupta H, Stephens D, Wallace T, Caton-Graham P. *Promising Practice Guide: Improving the social and emotional wellbeing of young Aboriginal and Torres Strait Islander people with severe and complex mental health needs.*Darwin: Menzies School of Health Research; 2020.

The Menzies School of Health Research was commissed by Orygen, a youth mental health organization in Australia, to identify and document promising practices aimed at improving the social and emotional well-being of young Aboriginal and Torres Strait Islander people with severe and complex mental health needs. The resulting 'promising practice guide' synthesized the emerging evidence base on the topic and outlined several strategies for service providers, commissioners and policymakers. The following list highlights some of these strategies; the complete list can be found here: <a href="https://www.orygen.org.au/About/Service-Development/Youth-Enhanced-Services-National-Programs/Primary-Health-Network-resources/Improving-the-social-and-emotional-wellbeing-of-yo/orygen-Practice-Guide-to-improve-the-social-and-em.aspx?ext="mailto:mai

Overall, multi-faceted programs and services involving a holistic outlook, multi-disciplinary teams, a life-course approach, and commitment to integrated service delivery demonstrate promising outcomes.

Strategies for Service Strategies for **Strategies for Commissioners Providers Policymakers** Provide a culturally safe Develop guidelines to Use promising practice models environment and emerging evaluation expand and support the workforce to better meet evidence as the basis to Demonstrate flexibility. adaptability and opencommission new services the needs of young focused on improving the **Aboriginal and Torres** mindedness SEWB of young Aboriginal and Strait Islander people Adopt strengths-based and place-based Torres Strait Islander people with complex mental Provide adequate resources health needs approaches and supports to staff and Involve young and older Adopt gender-sensitive community members working **Aboriginal and Torres** and person-centered with Aboriginal and Torres Strait Islander people in approaches Strait Islander people the design and Ensure well-developed Prioritize funds for programs implementation of co-design approaches led by Aboriginal and Torres policies that affect them are followed and engage Strait Islander staff Acknowledge a local Elders coordinated multi-policy Adopt flexible and longer-term Use peer-led funding models and ensure approach is required to approaches and programs are funded to address the social intergenerational emotional and mental undertake monitoring and mentoring health needs of young evaluation activities Aboriginal and Torres Encourage co-design Strait Islander people approaches; support collaborations and partnerships

Canada: Right time, right care: Strengthening Ontario's mental health and addictions system of care for children and young people

• Source: School and Community System of Care Collaborative. (2022). *Right time, right care:* Strengthening Ontario's mental health and addictions system of care for children and young people. https://smho-smso.ca/wp-content/uploads/2022/04/report-right-time-right-care.pdf

School Mental Health Ontario, along with The Lead Agency Consortium, the Knowledge Institute on Child and Youth Mental Health and Addictions and Children's Mental Health Ontario have partnered to develop a collective vision for how schools and community-based child and youth mental health organizations can collaborate to provide a coordinated, responsive system of care. Aimed at meeting the mental health needs of Ontario's children and youth.

The document describes four common foundations of a system of care and sets them within our current context. It also outlines the aspirational roles and responsibilities for partners, as well as the importance of pathways to, from and through mental health services, especially for clients accessing these services. Finally, key implementation factors and how they can guide the system of care framework from concept to action are explained.

Each section contains additional resources and links that may be useful. Some examples of practical tools from the field are also provided in Appendix B of the report – including tools to assess readiness for collaboration; tools to understand the environment; tools to assist with working collaboratively; tools to assist with communication; tools to support developing an equitable system of care; and tools to assist with implementing evidence-informed services and practices.

United States: CALOCUS-CASII Assessment Tool

- Sources: American Academy of Child & Adolescent Psychiatry. CALOCUS-CASII.
 https://www.aacap.org/AACAP/Member Resources/Practice Information/CALOCUS CASII

 https://www.aacap.org/AACAP/Member Resources/Practice Information/CALOCUS CASII
- Using the CALOCUS-CASII for QI Assessment: Quick information guide.
 https://ocfs.ny.gov/main/policies/external/2022/inf/22-OCFS-INF-09-CALOCUS-CASII.pdf

The Child and Adolescent Level of Care/Service Intensity Utilization System (CALOCUS-CASII) is a standardized and validated assessment tool that can be used to determine the appropriate level of service intensity needed by a child or youth (aged 6-18 years) and their family. The tool can be used by various service providers (i.e. primary care providers, mental health care professionals, care coordinators, social workers) and is applicable to children and youth in a variety of settings. For example, it can be used to determine appropriate placements for children and youth involved in the child welfare system or juvenile justice system; or to assess needs of children and youth with complex needs including mental health disorders, substance use disorders, and medical or developmental concerns. The tool was developed under a systems of care approach that emphasizes family-centred care, strengths-based approaches, culturally sensitive services, wraparound service planning, and the use of home and community-based supports over clinical or out-of-home placements. Service intensity is assessed across six dimensions: risk of harm; functional status; co-occurrence of conditions; recovery environment; resiliency and response to services; and engagement in services. While CALOCUS-CASII can be useful as a decision-support tool and can help promote communication between providers and systems, it is not meant to provide a clinical diagnosis or specific care plan.

Canada: Common Definitions on Cultural Safety

 Source: Public Health Agency of Canada (2023). Common definitions on cultural safety: Chief Public Health Officer Health Professional Forum. Government of Canada. https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/chief-public-health-officer-health-professional-forum-common-definitions-cultural-safety/definitions-en2.pdf

The Chief Public Health Officer (CPHO) Health Professional Forum (formed in 2018) brings together 19 national health organizations to collaboration on public health issues. The Forum's Indigenous Health Sub-Group was formed to advance Indigenous cultural competence, awareness, safety and humility among health professionals. The Sub-Group developed definitions of these and other relevant terms (provided at the link above), as well as a figure to illustrate the continuous process by which cultural awareness, competence and sensitivity lead to cultural safety (see image below). The figure also shows how anti-racism, cultural humility, and trauma-informed care can influence or change our understanding of cultural safety.

