Cross Sector Approaches to Serving Children and Youth with Complex Needs

Findings from a Scoping Review and Environmental Scan

Prepared by

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For

Calgary and Area, Bow River and Central East RCSDs

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Acknowledgements

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Executive Summary

As is the case elsewhere, many children and youth in Alberta have special needs for a range of types of supports and services from social, educational and health providers. Within those special needs groups, there are also children and youth with more complex needs for services from multiple providers across two or more sectors that elevate the challenge for effective responses. There are consistent reports that this group of children and youth with more complex needs has increased in both numbers and severity of needs in recent decades.

Calgary and Area, Bow River and Central East RCSDs have collaborated on a cross-sector regional service model to plan for and support children and youth with complex needs in their regions since 2014/2015. The increased prevalence of children and youth with a range of complex needs and the complexity of their circumstances that has been documented elsewhere has been observed here as well. In the spirit of continued learning and improvement of services for these children and youth, the partners initiated a scoping review of the topic which included systematic searches of the scientific and grey literatures and a rapid environmental scan of current practices for children and youth in major western countries and in Canadian jurisdictions. The purpose of the review was:

> ***To gather information on best or promising practices related to cross-sector approaches for addressing the needs of children and youth with complex needs aimed at informing the development of an evidence-informed and sustainable model for the work of the Tri-Region RCSDs in this area.***

Scoping review methods were used to locate, systematically select and review approximately 70 peer-reviewed articles from seven scientific literature databases and approximately 84 grey literature documents or links on related policy and practice from the internet for Western countries and Canadian provinces for the years 2012 through 2020. Thirteen colleagues from other provinces were contacted briefly for further nomination of materials in their jurisdictions. In addition, two focus groups with six managers from other RCSDs, two interviews of policy-level key informants, and one interview with a very experienced front-line provider were held to deepen contextual understanding.

Key Findings

- There was a noted separation of most of the literature by the primary type of complex needs that children and youth presented with, particularly in the grey literature, reflective of the typical structure of the service system.

- The three types were children and youth discussed in the literature were those with:
    - **Complex Healthcare Needs**
    - **Complex Social Services Needs, and,**
    - **Complex Learning Needs**

- Approaches to serving children and youth with ***complex health care needs*** (estimated prevalence .4 – 2% and rising) are advancing quickly with proposed definitions, and major recent recommendations from the American Pediatric Association, the Canadian Association of Paediatric Health Centres and evaluation of a few models. Key issues for this group include out-of-home care, lack of data and service gaps (mental health and education).

- There are, as yet, no standard definitions for children and youth with ***complex social care needs,*** (estimated prevalence 1% and rising), but many emphasize that these children and youth are best understood as living in complex circumstances. Cross-sector/collaborative models have a long history with 'wraparound' approaches most studied to date. Many service reviews have been conducted and key issues remain including the need for prevention/early intervention, Indigenous disproportionality, out-of-home care; service gaps (mental health and education), metro-centric approaches and lack of data.

- No standard definitions were found for children and youth with ***complex learning needs*** either (prevalence .4 – 1% and rising), and many definitions are still based on diagnoses. There were fewer models found for this group, but those found were relatively well evaluated. Key issues for this group are problematic processes regarding eligibility for services based on diagnosis, lack of commensurate funding, out-of-home care, service gaps (early identification and intervention) and lack of data.

- Five 'big picture' themes were found that cut across these subgroups of children and youth with complex needs. They were:
    - The issues associated with complex needs and complex service delivery are very similar across these groups of children and youth. Each child or youth is unique in presentation and needs, but the similarities, including population prevalence, and impacts of their conditions and life circumstances on them and their families, are striking.
    - Authors of documents for all groups across all countries expressed concern about the ability to plan for effective and comprehensive system- and local-level service responses to children and youth with complex needs when definitions are diverse, and data are unavailable or piecemeal.
    - Service model concepts and related terms are mostly used without definition, sometimes interchangeably and other times with enormous diversity of implied meaning.
    - Collaboration/coordination/integration approaches are considered essential and a 'normative good' for children and youth with complex needs.
    - There is a broader knowledge base beginning to emerge that considers the full range of children and youth with complex needs, and relevant policy and practice approaches to serve them more effectively and ultimately to improve outcomes.

- Alberta has at least a 20-year history of policy and practice to best serve these children and youth. When RCSDs were formed in 2013, Calgary and Area continued with the former provincial approach to children and youth with complex needs in partnership with Bow River and Central East RCSDs, which included system reviews of services for systematically nominated children/youth (broadly defined), a special funding pool, and the addition of the CONeX program in 2017. The approach includes most components found in leading practices across the three subgroups of children and youth with complex needs found in the literature reviewed.

- Recommendations from the literature for policy and practice fell into four groups: attributes of a system (policy level); attributes of a system (regional level), families, and funding. Considerations for future work are provided.

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1. Introduction and Background

> *"…a unified vision for services for youth with complex needs is required. One of the main goals of a unified vision is to address the issues of system fragmentation, "siloism", service gaps and a lack of service coordination throughout the system, especially across service sectors."*[1 p.122]

As is the case elsewhere, many children and youth in Alberta have special needs for a range of types of supports and services from social, education and health providers. Within those special needs groups, there are also children and youth with more complex needs for services from multiple providers across sectors that elevate the challenge for effective responses. There are consistent reports that this group of children and youth have increased in both numbers and severity of conditions and needs, at least in developed countries in recent decades. However, data on these children are non-existent at worst and patchy at best, making it difficult to assemble a clear and comprehensive picture of needs to guide policy and service planning.

Calgary and Area, Bow River and Central East RCSDs (Regional Collaborative Service Delivery)[1] have collaborated on a cross-sector regional service model to support children and youth with complex needs since 2014/2015. The increased prevalence of children and youth with a range of complex needs and the complexity of their circumstances that has been documented elsewhere has been observed here as well. In the spirit of continued learning and improvement of services for these children and youth, the partners initiated a scoping review of the topic which included systematic searches of the scientific and grey literatures and a rapid environmental scan of current practices for children and youth in major western countries and in Canadian jurisdictions. The purpose of the review was:

> ***To gather information on best or promising practices related to cross-sector approaches for addressing the needs of children and youth with complex needs aimed at informing the development of an evidence-informed and sustainable model for the work of the Tri-Region RCSDs in this area.***

2. Review Methods in Brief

A rapid scoping review method was used for the literature reviews. Levac et al. (2010) offer several definitions of scoping reviews for which the following best fit our aims: *"Scoping studies are concerned with contextualizing knowledge in terms of identifying the current state of understanding; identifying the sorts of things we know and do not know; and then setting this within policy and practice contexts".* [2 p.2] The method has six stages: setting the research question(s); searching for relevant studies (or documents

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[1] RCSD is a provincial program, funded from 2013 to 2020, and championed by the ministries of Children's Services, Community and Social Services, Education and Health, and further supported by Alberta Health Services, school authorities, interested First Nations and community organizations. Cross-ministry partners in 17 RCSD regions were charged with working together to ensure children, youth and their families had the supports and services needed to be healthy, resilient, and successful in school, at home and in their community.

in the case of grey literature); selecting the studies/documents; charting the data; and collating, summarizing and reporting the results.

Our working definition for the project for ‘children and youth with complex and/or intensive support needs’ (from the RCSD Handbook) are those children and youth who:

“require significant extraordinary care, due to the severity of their impairments, and require services from more than one service sector. Those who require such services may include children and youth:

- ***with multiple impairments, complex mental health and health issues, and/or severe behavioural needs;***
- ***for whom all currently available resources have been utilized with limited success;***
- ***who require fiscal and human resources that strain the capacity of any one service sector; and/or***
- ***for whom there are questions about the safety of the child or youth, their family[2], or the public.”***

Because there are no standard terms for this very specialized population of interest or their level of need, or indeed even the cross-sectoral approaches in literature databases of interest, we considered it necessary to use systematic and comprehensive search methods, guided by a professional librarian (full details of methods available upon request). By consensus we developed a lengthy set of search terms, related to the population (including the age range) and the ‘cross-sector approach’ and ran them in seven databases covering multiple relevant disciplines (health [2], education, sociology, psychology, social work and allied health) adjusting terms as necessary for each database. Initial searches focused on English-language materials from the past decade; the date range was reduced to the past seven years when the initial yield was considered too large to be feasible to review in the timeline.

Seventy peer-reviewed articles were selected from 1374 total abstracts by consensus for relevance using standard criteria; and 84 grey literature items were found in two grey literature databases and Google and Google Scholar online searches. Items were limited to major Western countries (US, Canada, UK, New Zealand, EU and Australia) for maximum applicability to our Alberta context and to the child/youth/young adult age range.

The scoping review was characterized as ‘rapid’ because the timeframe (end of March to mid-May 2020) put constraints on the degree to which the collection, collation and review of materials could be comprehensive. As such, we are confident that the broad findings are reflective of the comprehensively sourced materials at hand, but that some of the more specific information should be considered examples or instances – rather than an exhaustive tabulation of all policies, models or practices. It is important to note as well, that while some of the materials also included information about single sector collaborative or integrative approaches as well as individual-level ‘clinical’ interventions, our priority was to extract information about ***cross-sector approaches*** to the organization or delivery of services (at either regional

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[2] Throughout this report wherever the term ‘family’ is used it refers to close relatives by any of birth, marriage, adoption, kinship or fostering. Whenever the term ‘parent’ is used it refers to guardians/carers of all types, including by birth, marriage, kinship or fostering

or policy levels, or both). Information on evidence-based clinical interventions was also found but is not included in this report.

In addition to the literature review, we used rapid environmental scan methods to locate additional core content and to provide important context for the findings. The environmental scan methods included extracting information from the 2018/19 annual reports of all RCSDs in Alberta, and systematically searching government websites for five international jurisdictions (US, UK, EU, Australia and New Zealand) and 10 provinces in Canada. Thirteen colleagues in six larger provinces were contacted by email with brief questions about relevant provincial developments to ensure that important content was not missed. To ensure understanding of the Alberta context, we held two digital focus groups with six managers of other RCSDs plus two one-on-one teleconference interviews with policy-level key informants, and one interview with a very experienced front-line provider, using specific semi-structured interview questions for each type of respondent. Content from all materials was read in date order and notes taken. In keeping with the scoping review approach, information derived from the peer-reviewed and grey literature was integrated in the report.

3. Findings

3.1 Who are our Children and Youth with Complex Needs?

There was consistency across both the peer-reviewed and grey literature in that children and youth with complex needs were defined and discussed from the perspective of the service delivery system. That is, they were covered as subgroups based on which sector provided oversight for services or supports. This was true even though the searches were specifically designed to locate *cross-sector* approaches. These subgroup separations were especially marked in the grey literature where children and youth with complex needs were discussed in the contexts of:

- health services as a subset of a group of children and youth with special health care needs;
- education as part of a subset of children and youth with special learning needs; and;
- child and family services as part of a subset of children and youth with social/human services support needs.

Disability-related services also came up, but more for the first two groups. While attendance to specialized needs by sector and provider-type has undoubtedly arisen for practical and even important administrative reasons, case stories and descriptions are unequivocal that these children have needs that span the sectors (indeed that is one of their defining features), and comprehensive, whole population approaches to describing and planning for their service and support needs are rare. Many authors raised issues about the impact of these historically narrower approaches on the efficiency, quality, and most notably equity of services. Despite this being the overarching characteristic of the literature reviewed, there has been some evolution in approaches to defining children and youth with *special needs overall* and the smaller subset with *complex* needs.[3]

Because so much of the literature on children and youth with complex needs is divided according to these service-oriented groupings, it was necessary in this report to discuss the literature separately at least initially. As such the findings are organized by sections for each subgroup. Each of **three sections** includes a story illustrative of that subgroup, definitions, prevalence estimates where reported, care concerns and recommendations, key issues, service organization models (including principles and components where reported), as well as general evidence for the effectiveness of the models for the particular group of children and youth. The **fourth section** of the Findings covers the smaller set of literature that discussed more ‘integrated’ and specifically more ‘cross-sector’ approaches to *any or all* of these children and youth. However, a clear distinction between single and cross-sector models is also somewhat artificial as these approaches really span a continuum from lesser to greater degrees of cross sectoral connection and they also vary by level of activity (services or policy level). The **fifth section** describes the Tri-Region RCSD approach in light of the broader provincial context and includes a comparison of the components of the Tri-Region RCSD approach with the components of models found in the literature. The report concludes with a summary of key messages and considerations for future work.

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[3] Although terms vary enormously, the terms ‘special needs’ and ‘complex needs’ are used throughout the report to refer to the broader groups and the narrower group of children of focus in this review, respectively

3.2 Children and Youth with Complex Healthcare Needs

ONE CHILD'S STORY[4] - MICAELA

Micaela was born with a rare metabolic disorder which requires her to have continuous feeding day and night through a tube into her stomach and with a pump system. If there is a pump failure, or vomiting, there is only a 30-minute reserve of blood sugar in her bloodstream to sustain her life. When this happens, she needs immediate nutrition into her bloodstream through an intravenous line. So, since birth she has needed to be constantly monitored and has had frequent hospitalizations. This is an extremely rare genetic condition that is constantly life threatening.

Micaela was otherwise a normally developing child until age 13 years when, unrelated to the metabolic disorder, she was diagnosed with a brain and nervous system infection. This illness began with distorted vision, confusion, and uncontrolled movements. Her immune system overreacted causing paralysis. Micaela was "locked in", unable to move or respond. She was six weeks in intensive care and eight months in hospital. It was necessary for her father to leave his job for six months during this time to share in the family's care needs, including caring for a younger sibling. When Micaela got home from hospital, she was unable to swallow or talk, was severely brain injured, blind and totally paralyzed. At that point her breathing was stopping 700 times per night due to the brain injury.

Micaela is now 25 years old. Her medical needs remain complex and 24/7 care is still required. As just one example, every night she must be repositioned for comfort approximately four times. She is slowly regaining some movement and has recovered most of her cognitive abilities but has far to go to achieve her learning potential and social independence. As Micaela was unable to attend regular school, the family paid for a limited amount of expensive specialized tutoring. Micaela had to relearn all academics to the age of 13 and onward. Academic achievement is a high priority for a future of independence but there are no current supports for her to continue her education. Micaela also suffers from traumatic stress after all that has happened to her and this sometimes makes her noncompliant with needed care. Most of the personal care has been provided by family, with some aide assistance.

Micaela continues to "camp out" in the family room next to the kitchen in the family's two- story home. Costs to renovate for more private and appropriate function are prohibitive for the family. One parent must always be present, so a second income has not been available to help pay for the expensive equipment needed e.g. a medical bed, lifts, an accessible van, wheelchairs, and ongoing rehabilitation costs and supplies. Navigating a fragmented system for Micaela's needs has been an exhausting and often fruitless effort for the family. There are serious concerns about ongoing costs associated with rehabilitation as well as future care for Micaela when her parents can no longer provide the current level of support.

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[4] The four children's stories in this document are short adaptations of the stories of real children/youth available in public documents and/or used with permission. All names are changed except for the first story which is the young woman's real name, used with her and her family's permission

The recent literature on services for children and youth with special healthcare needs reveals substantial advancement of recommendations for practice improvement, including specific work on defining and describing the overall population of interest as well as the child and youth with complex needs subgroup. It is self-evident that most of the literature on this group comes from, and emphasizes, the health sector.

Terms and Definitions

Table 1 summarizes the definitions and descriptions from the set of articles and documents that focused primarily on this group of children and youth and includes estimates of prevalence reported in the articles. Unlike the other groups, the overall definition for the special needs group (Table 1) has reasonable consensus; it is endorsed by the American Pediatric Association and is frequency cited in recent articles. In their recent guideline *'Management of Medically Complex Children and Youth Through the Continuum of Care'* (2018), the Canadian Association of Pediatric Health Centres (CAPHC) acknowledged the broader definition and the four component framework, but concluded that there is no consensus definition for the children and youth with complex needs subgroup as yet[3].

Table 1 – Broader Group Terms, Definitions and Prevalence

Term/Acronym	Consensus Definition	Prevalence Estimates
Children with Special Healthcare Needs (CSHCN)[4-7]	Those with increased risk of a chronic physical, developmental, behavioural or emotional condition and require health care and related services of a type or amount beyond that which is required by children generally[4].	13 – 18%[4] 6.3% [5] ** 15 – 20%[6] ***

**of all children in the US
**children in the US between the ages of 5 and 15 years with 1 or more disability
*** children in the US birth to age 17 years

No standard definition was found in the review for the group with complex needs. Kuo et al. (2016) summarize the current situation: *"no consensus yet exists on recognizing complexity on the population level, multiples tools, such as a diagnosis classification scheme and a questionnaire may be needed to recognize the multiple attributes of complexity."* [7 p. e2] As shown in Table 2, authors have used a variety of terms for these children and many have also provided descriptions and examples.

Table 2 – Narrower Group Terms, Definitions and Prevalence

Term/Acronym	Definition	Descriptions/Examples/Diagnoses	Prevalence Estimates
Children with Medical Complexity (CMC)[4,7]	Children with medical fragility and intensive care needs	Children with congenital or acquired multi-system disease, severe neurological conditions with marked functional impairment and/or technology dependence for activities of daily living plus need for highly skilled providers.	.4%[4]

		Complex, chronic medical conditions and/or needs/complex medical or complex health conditions, medically complex children. Medically extreme/catastrophic conditions expected to be lifelong and progressive and to require extensive services (e.g. quadriplegia, cystic fibrosis) Neurological impairments, multiple congenital anomalies, complex cardiac conditions, severe autism	
Children with Medical Complexity (CMC)[8]	Children with medical complexity have at least one of four features.	1. Technology dependence or are users of high intensity care (e.g. mechanical ventilation, IV administration, tube feeding etc.) 2. Fragility i.e. severe or life-threatening disease 3. Chronicity – conditions expected to last at least 6 months 4. Complexity – multiple healthcare providers in at least 3 locations (e.g. home, school, hospital, clinic) Examples are severe congenital anomalies, acquired brain injuries	
Children with Disabilities[5]	A subset of children with special health care needs with more complex conditions, functional impairments, technology dependence and recurrent hospitalizations	Not able to care for themselves Require care from primary care, specialists and subspecialists, nurses, pharmacists, nutritionists, equipment, and community providers.	1% [5,7]
Medically Complex Children and Youth[3]	Children/youth who share four characteristics	1. Chronic condition(s) – diagnosed or unknown but suspected; severe and/or associated with medical fragility 2. Functional limitations – severe; often associated with technology dependence 3. Health care use – high resource use; necessitating involvement of multiple service providers 4. Needs – substantial family-identified service needs; significant impact on family (e.g. financial burden)	.67% [3]
Children with Complex Care Needs[9]	Multidimensional health and social care* needs in the presence of a recognized medical condition	Disability, chronic illness Three conceptual aspects: needs are heterogeneous and substantial; individual and contextualized; continuing and dynamic	

*note educational needs not mentioned

Two authors in this set of literature have proposed frameworks to guide conceptual understanding of this group. Cohen et al. (2011) describe a definitional framework, that was also included in the 2018 CAPHC guideline,[3] for these children and youth that has four domains: chronic conditions, needs, functional limitations, and health care use.[4] Notably, the needs domain includes the significant impacts on family and their requirements. Kingsnorth et al. (2013) also lists a different set of similar features (shown in Table 2).[8] A next stage of operationalization of this definition is proposed in the form of a checklist.[3]

In their review on this topic, the Canadian Foundation for Health Improvement (CFHI) assert that there is no single profile or set of diagnoses that will work for this heterogenous group. They warn that diagnosis is not a reliable indicator of need, and favour a 'breadth and depth'-based definition: *"Care needs become complex by virtue of their breadth and depth. Breadth of these needs is characterized by multiple needs for care in diverse areas of functioning that require comprehensive and coordinated care across multiple sectors and services. Depth of these needs is characterized by their intensity and/or frequency and their chronic and often lifelong nature that must be supported by people and/or resources (e.g., technology) to optimize functioning and fulfillment of youth and adult roles. A person's complex needs fluctuate over time."* [10 p.5] They relate the concept of functioning in the definition back to the World Health Organization's International Framework of Functioning, Disability and Health.[11] Other authors favour the link to the WHO Framework as well.[7,12]

In terms of overall observations about definitional issues for this group, it is noteworthy that the broader special needs group includes mental health (behavioural/emotional conditions), but there is little mention of concurrent mental health needs of the complex needs group. Most of the needs listed are viewed as medical, with only minor reference to other needs that would reflect a whole of child perspective. Finally, the language in these descriptions reflects the dramatic nature of the circumstances of these children (extreme, intense, catastrophic, severe) but tends to be deficit focused; not acknowledging the potential of these children to participate, contribute and their entitlement to a quality of life that others enjoy.

Prevalence and Impact

The increasing prevalence of these children and youth is attributed to greater survival of infants born early or at term with life-threatening conditions. Reports note up to a tripling of prevalence in the past 50 years.[4,5,9,13] In terms of availability of prevalence data, the United States is an apparent exception in having conducted population-based nationwide cross-sectional surveys going back to 2001 (which are now annual) on the broader group (children and youth with special health care needs). These surveys document the prevalence of 16 common health conditions and 14 functional limitations as well as types of services used.[4] Within the increase in overall special needs, both the complexity and type of needs are reported to have increased with emotional and behavioural needs having increased at a faster rate than other types.[6] A concerning proportion of these children and youth also have adverse childhood experiences which are known to have impacts on both mental and physical health throughout the lifespan.[6]

Authors note that while the complex needs subgroup is very small (.4 - 1%), various analyses in the US have shown that they account for 11 to 33% of healthcare costs and 24% of pediatric hospital discharges.[4,5,7] A Canadian blog from the Queen's School of Rehabilitation Therapy posts the prevalence of children with high levels of medical complexity or complex disabilities in Ontario as .5 to 2% of children, however these children require up to one third of all spending for children.[14]

Care Concerns and Recommendations

Authors of papers in this group are unanimous in outlining increasing concerns about the inadequacy of care, fragmented services, unmet needs and personal and financial burdens on families. Calls for coordinated approaches to care have been loud and clear.[3,5,6,7] Bethell et al. (2014) outline serious access and care quality concerns that disproportionately impact these children and youth due to their additional need and vulnerability.[6] In a comprehensive literature review, Brenner et al (2018) outline the practical and economic burden that increasingly has fallen on the shoulders of families given that social and community supports have not kept pace with the medical advances that have improved survival.[9] These authors describe a *"stark lack of integrated systems"* and a general lack of interagency collaboration, planning and coordination. They also report marked geographic variability, which raises issues of equity. In 2011 it was estimated that only 14% of American families with children and youth with complex needs were receiving a coordinated model of care.[5] Recent comprehensive surveys of care conditions for children and youth with complex needs in 30 European countries have documented similar inadequacies across a long list of aspects of care.[15,16] Similar issues are outlined by Canadian authors. For example, CAPHC (2018) describe the situation in Canada as highly variable, with only *"pockets of good practice"*.[3] The Ontario Association of Community Care Access Centres (2013) enumerated a long list of service problems related to a lack of coordination and integration, describing *"an intimidating array of narrowly construed programs and eligibility criteria"* across three public sectors. [13 p.1] In their 2014 report, the CFHI concluded: *"to set the stage for real transformative change… it is critical that all of the ministries involved in providing services and supports to this population work together to improve the overall collaboration of the service providers, communities and clients/families."* [10 p.8]

Recommendations for change are extensive and examples from this set of papers are: [3,4,5,7,9,10,13,17]

- Systems-level reform for a shared vision for inter-agency, multidisciplinary approaches
- Regulation and training
- Case management and navigation
- Articulation of roles and responsibilities
- Alternative payment/funding models that incent care coordination (US and Canada)
- Options for funding to follow the person
- Simplification of processes and eligibility for benefits
- Flexible provider roles and care in place
- Care coordination across sectors
- Better financial and social supports for parents
- Funding to support alternatives to in-person service delivery
- Funding to support infrastructure to build model systems of care with the full range of health, education and social services and family partnerships
- Funding levels to meet needs, including increasing needs
- Home care and tele-home care
- Youth facilitators/peer support
- Sustained linkages through regular communication

Key Issues

Among the broader care issues discussed in this group of documents, there were some particularly vexing specific issues expressed. The first of these was the issue of **out-of-home care** for children and youth with complex needs. In the US a goal of zero outside of home care had been set as a health goal in 2010[5]. This goal was considered unachievable by several authors/organizations for this group of children and youth. A statement from the American Pediatric Association published in 2014 that indicated that care should be provided in home for the vast majority of these children and youth (including special education) was amended in 2016 after input from the Council on Children with Disabilities to call for the availability of alternative community-based non-congregate settings such as with families with the capacity to provide the necessary care.[18,19] This indicates a shift to a more nuanced conversation than the previous dichotomy of some institutional care vs. no institutional care. In Canada, a public hearing about children and youth with complex needs aging out of paediatric care noted that there was currently a 20-year waiting list for residential care and some parents were in desperate need in this respect.[20]

A second issue was the stark **lack of data** for planning and resource allocation on a total population needs-basis. Even in the US where survey data have been available for a decade, there is concern about the lack of longitudinal data to understand and document outcomes over time. [e.g.6]

Third, in terms of types of specific **service gaps**, several authors have identified high unmet needs for mental health services. A National Academy of Sciences Report (2016) reported that many children and youth with complex medical needs have serious **mental health-related needs** (post traumatic and ongoing stress) that are going unrecognized and undertreated.[21] The same report documented insufficient attention to the **education needs** of these children/youth citing low expectations and high drop-out rates.

Service Models

Several service organization and delivery models were mentioned in the papers reviewed for this subgroup of children and youth with complex needs. The models listed in Table 3 are based on information provided in the papers which was not consistent across sources; more complete information would require more focused searches and direct contact with authors and/or programs. Several models (i.e. co-management, accountable care organizations, and chronic care model) were mentioned in name only without further detail by Murphy et al. (2011)[5] so they are not listed. Bethell et al. (2014) describe the application of a theory-based approach called the life course approach for the *broader group* of children with special health care needs that includes a set of service principles that would apply to the more complex group as well.[6] An (2014) notes that family-professional collaboration supersedes specific approaches as a 'given' best and essential practice in this realm.[17]

Finally, though not a service model, one example of a disability supports policy that includes explicit recognition of the needs of this group of children and youth was found on the Quebec government website. It provides disability supports to families at two levels of severity with a higher level of support for *"parents who assume extraordinary responsibilities in administering special care or who must be constantly present for children under 18 who have severe and multiple disabilities that prevent them from carrying out his or her life habits or whose medical condition requires complex medical care at home."*[22]

Table 3 – Service Models Noted by Authors for Children and Youth with Complex Health Service Needs

Name and Location	Service or Structural Components/Features	Principles	Sectors/Levels/General Comments
The Health Home Approach (aka Medical Home Model)[5] USA	Single locus of overall responsibility Roles and expectations explicit Care coordinator/key worker/case manager Family support groups Psychoeducation Respite care Insurance and financing Early/continuous screening and referral Care plan templates Explicit support for transitions of all types Quality improvement I and performance measurement	Family-professional-community partnership Easy to use supports Cultural competence Enhancing family capacity Addresses multiple domains	Mostly health, local level – also includes the idea of the 'health neighborhood' which are other services in the community that support the child/youth
Complex Care for Kids Ontario (CCKO)[3] Ontario, CANADA	Care coordinator/key worker/case manager Shared care summary and plan Measurable outcomes	Child, youth, family-centred Integrated Coordinated Collaborative Continuous Seamless Accessible Empowering Equity Flexibility	Also includes a strategy for the province and associated toolkits
Integrated Complex Care Models (ICCM)[8] 2012) Toronto, CANADA	Keyworker dyads Single care plan Systematic communications mechanisms Interprofessional assessments Information sharing Family involvement Central management of all appointments IT infrastructure		Partnership between acute rehabilitation and community care Connections to education and social services by health but not cross-sector overall

*these items may have been expressed explicitly as principles or just implied

Kingsnorth at al. (2012) characterize the current state of practice as being focused mostly on care coordination of multiple providers in different places and care structures and there is a lack of information on the actual process of integration.[8] In their study of the ICCM model implementation process, the authors identified enablers as staff dedication, leadership, communication, use of an electronic care plan and barriers as assumptions about other organizations, different organizational structures and information systems, limited participation of some players (e.g. primary care), fee-for-service payment systems.[8]

Effectiveness

Evidence for effectiveness[5] of these approaches is relatively early stage and sparse but authors characterize it as mounting, including evidence for cost-effectiveness.[8] Some other documented outcomes of these approaches include reductions in acute care events such as admissions and emergency room visits[5] as well as health improvements for the child/youth and service satisfaction for the family.[21] One cross-sector collaborative model aimed at improving youth to adult transitions found that families had half the likelihood of cutting back or stopping work because of their young adult's health issues.[5]

Summary

The concerns about the current state of care for this group of children and youth with complex needs are universal in this literature including from documents from the US, Canada and Europe. Care coordination models have advanced substantially in conceptualization but are as yet not available to the majority of these children and youth in any jurisdiction. Despite strong messages about the importance of addressing the needs of these children and youth in other domains than health, the literature on this subgroup of children and youth with complex needs was notably health sector led and dominated; some consultation processes with listed stakeholders that revealed a lack of key provider sectors like education.

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[5] Effectiveness is defined as the association between the intervention and outcomes (which can include a range of child/youth, family, and health system outcomes)

3.3 Children and Youth with Complex Social Care Needs

ONE CHILD'S STORY – ASIM

Asim is a 14-year-old boy who experienced childhood trauma from time spent in a refugee camp. He speaks only some English and has a moderate intellectual disability. He requires one on one support in a specialized school setting and regular therapy for his history of trauma, and benefits from structure and routine. He has been attending school with less and less consistency and has recently started to run away and use drugs, with increasing frequency and advancing from cannabis to more dangerous street drugs. He hears voices and has suicidal thoughts but has not been cooperative with a full psychiatric assessment. He is on prescription medications for attention issues and psychotic symptoms. He is frequently ill with common viruses but is otherwise physically healthy and strong. Asim has had difficulties connecting with peers in a positive way and is now becoming involved in gang activities which as resulted in interactions with law enforcement on several occasions. He has no positive, adult relationships. He was apprehended into care because his parents have been unable to manage his behaviour and there have been allegations of emotional and physical abuse. His tendency to run away has led to multiple group home placements breaking down and an increase in couch surfing and street life.

The recent literature on services for children and youth with (primarily) special social services care needs includes articles focused on the children and youth but also on the families as a whole; and the information here was drawn from both.

Terms and Definitions

No standard definition for this group of children and youth (or families) was found in the set of materials reviewed, either for the broader special needs or the narrower complex needs group. While no definition is provided for the broader group, most articles imply that this group is comprised of children/youth in families with some involvement with social care programs including income support, child welfare and often the justice system. Mitchell (2011) laments that a long history of single disorder and single setting interventions has hampered acknowledgement of complexity beyond diagnostic categories[23]; even so the articles were replete with a variety of terms and lengthy descriptions of these children/youth as well (Table 4). Contemporary descriptions attempt to incorporate the range of known risk factors and combinations of health and social needs (including basic needs such as housing, food and safety) that elevate risk for the children or youth in the family context.[24] One UK study showed that the typical family served had five or more disadvantages.[24]

In keeping with better understanding of the social determinants of health, there has also been a movement away from expressing these risk characteristics as being attributes of the person and toward expressing them as attributes of the environment or context; hence the emergence of terms like 'complex environments' and 'complex circumstances'.[1,24] Even so, descriptions containing long lists of deficits or problems are unavoidable given the serious disadvantages faced by these children and families. Authors in this set of documents also acknowledge the breadth and depth features of complexity and attribute that concept to a 2004 publication by UK social care researcher Jennifer Rankin.[24] In this category there is also an emphasis on functioning and needs oriented definitions, (not just diagnoses) as well as not just multiple issues but the interaction among issues.[1]

In a very recent publication, a research group from Belgium used a cross-sector stakeholder Delphi process to try to produce a consensus definition. Their definition in Table 5 (see [25]) emphasizes the severity of inter-related problems in multiple domains; and includes both depth (severity) and breadth (many different needs). They acknowledge that their definition is preliminary and needs further international validation, and that physical health problems were left out of the final version.

Table 4 – Broader Group Terms, Definitions and Prevalence

Term/Acronym	Implied Definition	Prevalence Estimates
Children with Special Social Care Needs	All children in families receiving some type of social care services	

Table 5 – Narrower Group Terms, Definitions and Prevalence

Term/Acronym	Informal or Preliminary Definitions Descriptions/Examples/Diagnoses	Prevalence Estimates
Youth with Multiple and Complex Needs (YMCN)[23]	Children and youth with mental health, substance use problems, periods of homelessness and offending behaviour. Socioeconomic hardship, learning difficulties, disconnection from education, training and employment opportunities, family breakdown, lack of supportive relationships, gender and cultural minority status	50% of children/youth in child welfare have mental health problems; 70% of children/youth in juvenile justice have a diagnosable disorder[26]
Youth/Young Adults with Complex Needs (YCN) **Service Gap Youth/Young Adults[27]**	Youth/young adults with co-occurring substance use and mental health issues (including personality, social or psychological problems) and physical impairments. Social conditions include unemployment, insecure income and housing, involvement with child protection services, forensic services and sometimes issues of safety to others. Needs cannot not be met by one agency.	
Children with Disabilities in Out-of-Home Care[28]	Children and youth involved with child protection, youth justice, health and mental health services, foster care support, residential care facilities and other agencies with disability and extreme and complex behaviours.	

Children with Complex Needs (CCN)[29]	Children and youth with emotional, behavioural or mental health difficulties involved in several sectors and at risk of institutional placement	
Children with Complex Behavioural Health Needs and their Families / Serious Emotional and Behavioural Disorders (SEBD)[30]	Children and youth with the most serious and complex needs consume 40-70% of child-serving resources; a lot in congregate and institutional settings	10% of all children/youth with mental health-related needs
Dually Involved Youth or Crossover Youth[31]	Youth involved with both child welfare and juvenile justice, many in congregate care.	
Youth with Severe and Complex Behaviour YSCB[32]	Students with severe behavioural disabilities/challenging behaviours *"a spectrum of antisocial, aggressive, dishonest, delinquent, defiant and disruptive behaviors. These behaviors may vary from none to severe, and may have the following consequences for the child/young person and those around him/her: stress, distress and concern to adult care givers and authority figures; threats to the physical safety of the young people involved and their peers; disruption of the home, school or other environments; and involvement of the criminal justice system".*	
Youth with Multiple and Complex Needs[33]	Combination of psychiatric problems and family instability/lack of safety, abuse and neglect common, multiple out-of-home placements and requiring child welfare and mental health services.	
Youth with Severe, Persistent and Complex Mental Illness[34]	Youth with impaired functioning in multiple settings over time – impairment due to disengagement from educational, occupational, social and family networks plus comorbidities including intellectual or other developmental disability, substance use and physical health problems. May have social exclusion, abuse, trauma, homelessness or criminal justice system involvement. Diagnostically severe mood/anxiety disorders, treatment refractory psychosis, eating disorders, post-traumatic stress disorder, disruptive behavioural disorders and often severe and recurrent self-injury. Multiple agency involvement including health (including hospitalizations) education/vocational, housing, juvenile justice and transition support.	
Children and Youth with Complex Support Needs[35]	Children and youth with *"difficulties that can arise from an interplay of developmental, cognitive, psychosocial, physical impairment and/or health conditions with adverse life experiences such as substance misuse, a history of violence and trauma, cultural and intergenerational disadvantage, criminal justice contact, disrupted education and poverty."*	

Children and Youth with Multiple and Complex Needs[25]	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. Includes physical and mental health problems, social exclusion, education issues and for some, justice involvement. Cross-sector, integrated and assertive care delivery is necessary for safeguarding the wellbeing, development and societal integration of these young people.	
Families with Multiple and Complex Needs[24,36,37]	Other terms: families with high and complex needs, families with entrenched disadvantages, vulnerable families, troubled families; families living on complex circumstances, multiple disadvantage, multiple disabilities, multiple adversities, multiple impairments, high support needs, dual diagnosis and complex health needs.	
Youth with Multiple and Complex Needs[38]	Young adults with mental illness, substance use, intellectual impairment, acquired brain injury and forensic involvement posing a risk to themselves and the community	
Youth with Complex Needs[1,39]	Children and youth with mental health issues, disabilities including cognitive impairment, significant health concerns, Fetal Alcohol Spectrum Disorders (FASD), behavioural issues, addictions issues, juvenile justice involvement, attachment disorders and unresolved trauma. *"Exhibits challenging and/or risk-taking behaviors of such intensity, frequency and duration that they place themselves or others are serious risk of harm, and/or; has mental health presentations which impair their ability to participate in an ordinary life and which reduce access to services, activities, experiences, and/or; has a disability with high level challenging behaviors or complex health issues, which are life threatening or require continuous monitoring and intervention."**	1 – 3%
Children and Youth with Severe to Profound Emotional and Behavioural Disorders (SPEB)[40,41]	The child/youth is a danger to self and/or others and their actions are marked by impulsive, aggressive and violent behaviour; their behaviour is chronic – the disorder is persistent over a lengthy period of time; their behaviour is pervasive and consistent- the disorder negatively affects all the child/youth's living environments including home, school and community; the child/youth requires or is already receiving a combination of statutory and non-statutory services from authorities and agencies including education, mental health and/or justice systems. Profoundly emotionally/behaviourally disordered.	
Children with Complex Medical, Psychological and Developmental Needs[42]	Children/youth *"requiring the highest level of services and supports. From early childhood trauma, including severe abuse and neglect, to physical and developmental disabilities, to assault and self-harm – these are children who have survived horrific circumstances and need a carefully planned continuum of*	

	services and a placement that is properly equipped with thoroughly trained caregivers so that they can heal and grow". Persons up to age 19, who have serious emotional, mental health, developmental or behavioural needs that persist, cause functional impairment in the home, school and/or community, involve multiple sectors/child-serving systems; and require specialized treatment or service planning that is integrated.	
Saskatchewan 2020 Intersectoral Partnership[43]	For children/youth vulnerable to crime, violence, school absenteeism, disruptive behaviour and substance use	

*Attributed to the Dept. of Community Services in Australia (2006)

Prevalence and Impact

Prevalence/incidence data were not commonly reported in the documents found for this group of children and youth with complex needs; those that were reported were generated from service groups rather than the total population. However, crude estimates are similar to the previous group in a range around 1%. Observations from service settings or for related conditions suggest increasing service presentations for the broader group. For example, Healthy Child Manitoba (2017) reports a doubling of children/youth in care in Manitoba over the past 20 years, with strong concerns expressed that most of these children/youth are Indigenous. They also report that the numbers served by disability services has also increased and that some mental disorders (e.g. conduct disorders) are also on the rise.[44] A more recent study, also from Manitoba (the Manitoba Centre for Health Policy) examined a cohort of children born in 1994 to adulthood and quantified the overlap between the children taken into care and those ever accused of a crime as a youth (more than 1/3)[45]. The analysis also showed that two-thirds of these youth did not graduate high school. In terms of impact, information is copious on costs to society and poor outcomes, but most telling is that no fewer than eight Child Advocate, Coroner's or special review reports came up in our grey literature search that have been published in Canadian provinces in the last eight years that have examined the worse kinds of outcomes: deaths in care including suicides, tasering of young children, and/or assaults by youth with complex needs on members of the public.

Care Concerns and Recommendations

Authors of papers in this group are unanimous in outlining increasing concerns about inadequate care for this group of children/youth and the urgent need for more and better coordination/integration approaches at all levels. Several authors of major reviews note that issues raised up to a decade earlier with systems remain largely unaddressed (e.g. Manitoba CA 2012). General recommendations for change are also extensive for this group of children and youth with complex needs and examples from this set of papers are: [1,24,25,28,29,31,32,39,42,46-50]

- Whole family, whole systems and whole of government approaches
- Cross-department and cross-Ministry governance and accountability
- Cross-sector, integrated and assertive care delivery

- Integration of all of health, mental health, education, recreation, childcare, early intervention, prevention and developmental services based on need
- Single point of entry
- Information sharing, joint records
- Collaborative, multi-faceted, multi-system, and well-structured
- Family centred; strengths and capability-based
- Culturally responsive and empowering particularly for Indigenous children/youth
- Trauma-informed, relational and family preserving approaches
- Early, systematic and consistent screening and assessment
- Collaborative case conferencing
- Prevention and early intervention
- Wider range of higher quality placement options
- Inclusion of the voices of those with lived experience
- Better data/information overall
- Address human resources issues including training, recruitment, retention
- Better licensing and oversight of the quality of residential care
- Better understanding of services by all stakeholders
- Measurement and evaluation

Van den Steene and colleagues (2019) wrote *"no single agency or sector has all the resources, mandate, or reach to address both the personal needs of these vulnerable children and young people and their families and at the same time the social and economic factors that aggravate the complexity of these needs".* [25 *pp.60-61*] Some authors have characterized the child welfare system (in the US) as the de facto public behavioural health care system (i.e. mental heath system)[46] and the Child and Youth Advocate in New Brunswick urged that we must *"stop letting the youth criminal justice system pick up the pieces and be a stop-gap measure or solution to our historical failings in the area of child and youth mental health services….when we make the youth criminal justice system our default solution for children with complex needs, we are deliberately placing young, vulnerable children directly in harm's way. The approach is so fundamentally contrary to Canadian values that the average Canadian would be amazed to learn that it happens as routinely as it does."*[48]. Wright et al. (2017) write that there are few requirements in the US for the two service systems commonly involved with these children and youth (child welfare and juvenile justice) and that their philosophies are often diametrically opposed (juvenile justice is oriented to rehabilitation and child welfare is oriented to care and protection).[31] Nearly every document concludes that cross-sector, integrated and assertive care delivery is necessary, if not critical. Some authors argue that communication and coordination approaches across services or sectors are not enough; that services (especially child welfare, juvenile justice and mental health/addictions) need to be more extensively integrated to improve outcomes[1].

Key Issues

Several key issues stood out in the literature for this group of children and youth with complex needs. The first was a strong message that there is now a comprehensive understanding of the risk factors leading to the complex circumstances and conditions for these children/youth, and the protective factors that can enhance their resiliency. Furthermore, there is a growing and rich set of effective interventions such that **prevention and early intervention** is increasingly possible, yet these approaches are still not sufficiently used.[23,24,29]

While concerns for equitable service delivery were expressed for all children and youth with complex needs, a second very strong theme in this set of literature was the disproportionate impact of risk circumstances as well as inadequate services and supports for **Indigenous children and youth with complex needs** and strong concerns about the need to address inequities on every front.[1,39,40,42,44,47,51] A 2017 report by the McGill University Faculty of Law on *Indigenous Children with Disabilities* acknowledges the different world view of disabilities that Indigenous peoples hold, as well as the service fragmentation disparities and lack of access that these children/youth face, which is further exacerbated by jurisdictional and political disputes. While some progress is noted to have been made by the authors, their view is that circumstances are still particularly bad for Indigenous children or youth with disabilities.[52] While this review did not draw materials from academic law disciplines more broadly, this article has strong implied messages about fragmentation across regulations/legislation and protective behaviours of government ministries and departments around mandates and funding responsibility that can fail these children/youth and even harm them. The importance of policy-level oversight of cross-sectoral work to ensure equity of service delivery across regions was also underscored in other documents.

A third issue was the dynamic tension between the need for some **out-of-home residential options** for extraordinary situations alongside an imperative to avoid congregate/institutional placements due to their potential harmful effects.[30,34,42,47,48,51] There is some sense in the discourse that there is a shift away from seeking an end to congregate care completely to making substantive and meaningful improvements in quality for the small amount of congregate care that is necessary.

A fourth key issue was some **specific gaps in care**, including the expressed concern that attention to the **educational needs**, particularly for children and youth with complex needs in care, has been lacking and that educational outcomes are very poor. [29,42,47,53] A second care gap identified repeatedly was the marked lack of access to and availability of **mental health and substance use services** for these children and youth with the greatest needs in these areas.[53]

Concern about **'metro-centric'** approaches not fitting rural contexts was a fifth key issue. Elevated challenges in navigating inter-agency and inter-professional connections across large geographical areas, and with recruitment and retention of skilled personnel were noted in these settings, necessitating flexibility in approaches used.[35]

Finally, similar to the literature on the first group of children and youth with complex needs, a distinct **lack of data** for needs-based population level planning and performance measurement was noted across much of the literature for this group as well.[e.g. 40,44]

Service Models

A remarkable number of collaborative care service models were described in the literature for this group of children and youth with complex needs. As with the first set of literature, the degree of specificity of information available for the models was highly variable. In some cases, there was little more than a mention of an approach; in others entire articles and book chapters were dedicated to their description.

Table 6 – Service Models Noted by Authors for Children and Youth with Complex Social Service Needs

Name	Service or Structural Components/Features	Principles*	Sectors/Levels/General Comments
Systems of Care Approach (SOC) Partnership for Family Success (Intensive Case Management)[46] **Minnesota, USA**	Shared population focus in which multiple systems come together to create and offer services based on the needs and strengths of the target population Cooperative work across systems to create an integrated process for meeting the needs of families Case manager Some services co-located Individual education and care plans Inter-agency agreements Home visits and virtual visits Parent supports including childcare	Community-based services Strengths-based practices Cultural competence Child, youth, and family full participation	Note: for all children with child welfare involvement not just those with complex needs but in families involved in at least two sectors (child welfare/protection, disability, substance use, or justice) Stated to be considered a best practice in the US
Care Coordination Service[54] **Nebraska USA**	Family engagement Assessment and service planning Coordination/navigation Advocacy Teaching Fostering independence	Individualized Needs-based Family-centred Empowerment	Described as ecological-behavioural model – strong focus on therapeutic alliance. Scaled up for eight sites Logic model with specific activities for each component; and short, medium, and long-term outcomes specified
Wraparound [30,32,40,55] **MANY LOCATIONS WORLDWIDE**	Defined structure and process for team-based care-coordination strategy Single point of contact Individualized consensus care plan Information sharing Structured communications	Child, youth, and family directed Strengths-based Culturally informed	Has been around for about 30 years and is stated to be aligned with the SOC philosophy; versions for children/youth and for families Defined as "*a team based process for many systems to come together with the [child, or youth and caregivers] in creating an integrated highly*

	Co-location of program staff and cross-sectoral funding in some applications Family relationships (therapeutic alliance) Parent supports via family support providers/peers Coordinators span system and service boundaries Navigation Quick engagement intervention Includes fidelity measurement and performance measurement Fiscal policies and sustainability Human resource development and accountability	Access to needed supports Individualized Peer support Best interests of the child Voices and choices of the child/youth and family Close to home Natural supports Unconditional Outcome based	*individualized plan that includes the coordination of existing services and the development of new/non-traditional supports to address complex emotional and behavioral challenges…Wraparound is an ongoing process that may last for many months or even years. Uses a strong and specific set of principles and practices, requiring high fidelity implementation and related to better outcomes in behavioral, functioning, least restrictive living placements and improvement in caregivers' satisfaction with progress".* Olibris 2017 is a review of an application of this model in Ontario Has been used for many different aims – e.g. to reduce out-of-home placements or to achieve greater inclusiveness of students with challenging behaviours in schools etc. In Manitoba connections to wraparound are explicitly included in special needs entitlements – through wraparound plans (also called circle of care plans)[40] Coldiron (2017) describes a tool developed by Walker et al. that helps systems assess their level of development for the model which may have applicability to broader collaborative models [30,55, 56,57]
Complex Needs Assessment Panel and Integrated Support (CNAPIS)[27] **Gold Coast, AUSTRALIA**	Multi-disciplinary approach to support existing service delivery and the primary agency Communication processes; monitoring and evaluation Consensus support plans Brokerage fund for extraordinary needs Referral process; regular case meetings; case coordinator		An interagency form to coordinate service delivery

Evolve Behaviour Support Services[28] **Queensland, AUSTRALIA**	Multilateral MOU among all Ministries Mandated shared responsibility for outcomes Regular meetings / communication mechanisms Cross-learning Systematic follow-up Coordination of assessment, planning and intervention Support for carers	Ecological approach Broad stakeholder inclusion Child-focused Needs-based	For a special subgroup of children and young people with disabilities in out-of-home care
Cross Sector Collaborative Care[33] **BELGIUM**	Joint intake Team meetings Shared goals and decision-making Independent living skills Accountability strategy Outcome evaluation Joint decision-making	Person-centred Shared vision	Collaboration across child welfare and mental health sectors for adolescent girls with multiple and complex needs in residential care Described as a ’step-up’ from conventional collaboration
Practice Model for Youth involved with Child Welfare and Justice[31] **Nebraska, USA**	Systematic identification of youth in need Coordinated decisions Evidence-based pathways		Two sector model for crossover youth (child welfare and juvenile justice). Appears to lack connection with education and health sectors
Collaborative Juvenile Justice Re-Entry[58] **California USA**	Multidisciplinary assessments Specialty courts Individualized education plans Structured mechanisms for communication Community navigators Welcome teams and student support teams in schools Family supports	Ecological developmental perspective Comprehensive	Interagency collaboration including juvenile justice, probation, health, education, and violence prevention systems; local level
Care Models for Children and Youth with Severe and Persistent Complex Mental Illness[34] **WORLDWIDE**	Multi-disciplinary team Child and family involvement Care plan Multiagency collaboration Focus on independent living skills Specialist interventions if needed (e.g. substance use) Transition planning including discharge planning		A review article describing 15 different clinical community-based interventions (with a range of degree of cross-sector aspects) alongside including residential and acute components of a continuum of services. Components listed here are common *across* the models reviewed
Healthcare Home/Primary Care Model[59] **AUSTRALIA**	Local service networks Single access point Family-centred way of working Case coordination	Patient and family centred	For families with complex needs (poor mental or physical health, drug/alcohol problems, victims of

	Co-designed intervention plan Brokering of specific therapeutic services Navigators	Supports cultural and social needs Patients as partners Accessible Affordable Equitable Appropriate	abuse financial hardship, and with a child with a disability)
Program for Youth with Multiple and Complex Needs[60] Victoria State AUSTRALIA	Better coordination of supports and services Holistic care Central and area level coordinators Special brokerage funding		Specialist service for young adults with mental illness, substance use, intellectual impairment, acquired brain injury and forensic involvement posing a risk to themselves and the community, shared service across justice, health and human services
Saskatchewan Intersectoral Partnership[43] Saskatchewan, CANADA	Model of collaborative risk driven intervention (called the Situation Table) to address lack of service coordination, disjointed case management, fragmented information sharing and lack of collaboration A multi-sector team with specific roles, functions and processes		Noted to also be in use in Ontario
Centre for Juvenile Justice Reform[21] Washington DC, USA	Identification Equitable treatment “family teaming” Information sharing Coordinated case assessment, planning and management Evidence-based services Trauma-informed care Judicial administration Permanency	Family-centred Pro-social bonds Youth engagement	Across two sectors – juvenile justice and child welfare in the US ‘family teaming’ means everyone involved with the child/youth and family works together

*these items may have been expressed explicitly as principles or just implied

A few authors in this set of literature discussed enablers and barriers to implementation of models. Enablers were listed as champions, trusting relationships among all participants, organizational and system level structures for collaboration (not just individual-level), shared vision and goals, effective governance structures; clear protocols/procedures and data systems; cross-systems training; cross agency information sharing; organizational coaching, and resources for family supports.[32,33,58,61]

Barriers were noted to be strongly held professional values, differences in philosophy/culture/mandate/ perspective between service or sectors, lack of engagement of some providers or important sectors;

difficulty working across geographic distances, failure to follow the care plan, staff turnover, child/youth placement changes and carer changes, lack of infrastructure for communication and information sharing; insufficient resources for the necessary supports; lack of immediate pay off; fee-for-service physician payment structures; and lack of effective governance structures.[23,28,31,32,33]

This list of models displays a range of approaches from single site and only two sectors, through to jurisdiction-wide and multi-level approaches. They also would ideally connect to general child and youth health, mental health or social policy for a full population context. One example of a recent Canadian child and youth mental health policy that addresses some of the issues is *Child and Youth Mental Health in British Columbia: Concrete Actions for Systemic Change* from the Legislative Assembly Province of B.C., 2016[62] and subsequent steps of implementation. The policy emphasizes the importance of integrated and coordinated service delivery and a 'one child one file' approach. It supports the implementation of innovative models of child and youth mental healthcare along the full continuum of promotion, prevention, early intervention with care pathways to higher levels and intensity of treatment for children and youth with complex needs. One important innovation is province wide implementation of integrated youth services (IYS), described as (all accessible, youth friendly 'one-stop shops')[63] which are also being implemented in many countries and other provinces in Canada. These mostly serve youth with less complex needs, but they play an important early intervention role. Innovations like these along with a range of other evidence-based interventions now available for parenting pre-school and elementary school-aged children hold promise for reducing the number and severity of children and youth with complex needs in the future.

Effectiveness

Evidence for effectiveness of the models was nearly impossible to summarize and ranged from approaches that are already listed as best practices to recent innovations with very little evaluation. Mitchell (2011) and colleagues write that the evidence to inform the design and implementation of approaches (including the necessary infrastructure) is still lacking.[23] Van den Steene et al. (2018) used a life cycle model to study the development and implementation stages of a collaboration approach in Belgium.[33] They found that initial investments were large and rapid organizational change was disorienting for some.

The wraparound model has the most evidence accumulated to date and findings are mostly positive (including the youth's living situation, behaviour, functioning, community adjustment and cost-effectiveness).[30] Wraparound is included in inventories of best practice.[30] It is an inter-organizational approach which allows for individual level evidence-based clinical approaches to be embedded. Knowledge has also accumulated on implementation issues such as the necessary system conditions, fidelity, and measurement.

Other authors also discussed the evidence for outcomes for systems of care models including wraparound and noted that they can ensure coordination of services, increase in needed service use and engagement and decrease overall costs.[46,64] Other outcomes noted were fewer hospital, emergency room and unnecessary general practitioner visits, better working relationships among providers; and family capacity improvement.[27,55,64]

Ziviani and colleagues (2014) identified an unintended benefit of their model, which was the carry over of learning about collaboration to other program when staff moved on to new positions.[28] Other authors noted that evidence overall is still mixed and that effectiveness depends on what you measure. For example, in their program Karatekin 2014 et al. found that child maltreatment outcomes improved but because the education sector was not involved in the intervention, educational outcomes did not.[46] In summary, evidence for these more coordinated approaches is accumulating, but it is often challenging to identify the specific 'ingredients' that are necessary for success.

Summary

The challenges of achieving effective care and positive outcomes for these very high needs children and youth was abundantly clear in this set of literature. At the same time, there was quite an extensive set of recommendations on what can and should be done to improve care and achieve those outcomes, and a range of models at mostly local and regional levels with some common components. Many of the articles discussed approaches for subsets of these children and youth, such as those in care or those at risk due to family context or those with serious mental health and behavioural conditions. Yet the messages were relatively consistent on the need for systematic needs-based cross-sector approaches, ideally at multiple levels.

3.4 Children and Youth with Complex Learning Needs

ONE CHILD'S STORY - SAMMY

Sammy is now 10-years old. He has autism and intellectual disability. He has been striking his head with his hands since he was one year old and banging his head on objects since he was three years old. Sammy is non-verbal, has limited communication via augmentative communication, is not toilet-trained and has not attained any school readiness skills. Challenging behaviours continue including aggression (squeezes, pinches, and grabs peers, teachers, and his parents), property destruction, eloping, and skin-gouging. He has chronic eczema with multiple open wounds, anaphylactic peanut allergy and irregular sleep patterns. Multiple medications have been tried with uncertain benefit.

Sammy has received three years of intensive behavioural intervention and is supported by outpatient health services, school and autism services. He has government supports for children with disabilities available, but his parents have been unable to find consistent and capable caregivers. He has partial attendance in a segregated classroom with two-to-one support. He requires constant prompts for a negligible amount of on-task behaviour which is not possible at home or in the community.

Sammy's brother also has an intellectual disability, his parents have physical injuries from his aggressive behaviour, and one parent has been unable to work because of the constant care required by the two children. The family is in crisis and there is risk of family breakdown.

The total yield of articles was relatively smaller for this third group of children and youth with complex learning needs. It is not clear if that was due to the search process or whether there is a small literature overall. However, the articles found did address the content of interest for all the subtopics so was reasonably parallel to the other categories.

Terms and Definitions

In this set of documents, it was more difficult to distinguish broader and narrower groups. The term 'complex needs' was used in combination with specific diagnoses (e.g. Autism, Attention Deficit Hyperactivity Disorder, Fetal Alcohol Disorder) more often than the other two complex needs groups, and sometimes without acknowledgement. Spectrums of functioning and needs ranged from low to high. If even a brief mention of comorbidities (e.g. with behavioural issues) or additional service needs that crossed sectors was made, the content of the article was included where relevant in the subtopics in this section.

A review of 27 OECD countries (not including Canada) published in 2012 found enormous diversity in all of definitions and proportions of special needs children/youth in various educational settings; from segregated special schools, to special classes in mainstream schools, to regular classes (despite widespread inclusion policies dating back to the 1970s).[65] Many countries' definitions include physical and sensory needs but not behavioural or social needs. Only one of 24 countries providing definitions used the term 'complex needs'. The report called for standardization of terms and reporting processes before it would be possible to produce credible prevalence estimates. A similar report from the European Commission (2013) noted the same issues but also included the concept of normative versus non-normative disabilities.[66] The former are disabilities that are relatively easy to measure (e.g. degree of vision or hearing impairment) but which are relatively rare, and the latter require more extensive assessment and professional judgement. In 2016 an EU report included the concept of 'pluridisability' to refer to multiple disabilities which recognized a higher needs group within a high need group.[67]

US data from the National Center for Education Statistics show that among students aged 3 to 21 years, who received special education services for 10 disability types, the proportion with multiple disabilities was 2%.[68] Another notable diagnostic related development is a recent shift toward use of the term 'neurodiversity' rather than more deficit and stigmatizing terms.[69]

Table 7 – Broader Group Terms, Definitions and Prevalence

Term/Acronym	Implied Definition	Prevalence Estimates
Children with Special Educational Needs (CSEN)[70,71]	All children with special educational needs, also referred to as disabilities and including physical, cognitive, and/or psychosocial/behavioural needs	2% of NZ student population[70,71]
Children with Developmental Disabilities[72]	Includes intellectual disabilities, autism spectrum disorders, cerebral palsy. Definition from the Developmental Disabilities Act (2000) which includes that they start before adulthood and have lifelong impairments.	2 – 3% of the US child population[72]
Children with Neurodevelopmental Disabilities[73]	Autism spectrum disorders, global delay, or intellectual disabilities.	
Children and Youth with Special Needs 2019[74]	Autism spectrum disorders, complex health needs, fetal alcohol spectrum disorders, hearing/vision loss, intellectual disabilities	
Children and Youth with Neuro-Diverse Special Needs[69]	Neurodevelopmental disorders such as autism spectrum disorders, fetal alcohol spectrum disorders and developmental delay	

Table 8 – Narrower Group Terms, Definitions and Prevalence

Term/Acronym	Informal or Preliminary Definitions Descriptions/Examples/Diagnoses	Prevalence Estimates
Dual Diagnosis[72]	A developmental disability with a mental health and/or behaviour disorder. Require specialized treatment.	30 – 35% of the developmental disability population above so about 1% overall[72]
People with Learning Disabilities whose Behaviour Challenges[75]	Children and youth with learning/intellectual disabilities and behaviours like aggression, self-injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour, and can also include violence, arson or sexual abuse and involvement with the justice system	5 – 15% of those with a learning disability (higher in youth and hospital settings)[75]
Children and Youth with Fetal Alcohol Spectrum Disorders[76]	Considered a 'hidden disability'/condition requiring a lifetime of multi-sectoral services including health (primary, acute and specialty care) plus education, justice, and social services and one for which integration is critical.	1% of primary care patients and up to 6.3% for full spectrum – also increasing[76]
Children with Dual Diagnosis[77]	Children/youth with neurodevelopmental disorders and psychiatric disorders. Neurodevelopmental disorders include intellectual disability, autism spectrum disorders, fetal alcohol spectrum disorders, genetic conditions (e.g. Down syndrome).	
Children with Complex Care Needs[78]	Examples provided were children with autism spectrum disorders and attention deficit hyperactivity disorder requiring access to multiple health and social supports	
Pluridisibility[67] **EU report 2016**	Multiple disabilities	6% of all those with disabilities[67]
Children and Youth with Complex Needs[79]	Eligible in the US for means-tested disability funding "*a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. Must have an extreme limitation or at least 2 limitations that are marked in the areas of acquiring and using information, attending and completing tasks, interacting and relating with others, moving about and manipulating objects, caring for oneself, and health and physical well-being".* Neurodevelopmental disorders such as autism spectrum disorder and intellectual disability are majority of these children and youth.	1.6% (conservative estimate)[79]

Prevalence and Impact

All of the authors that discussed prevalence of these conditions reported increasing prevalence, more often as a general observation but also frequently with specific statistics. US data show increased numbers from 2000 to the present in most years[68]. The proportion of children or youth with disabilities generally in regular classes increased from 2000 to 2017 by about 10% to over 60% but among those with multiple disabilities, only 14% spent most of the school day in general classes in 2017.

An Ontario survey of families of youth and adults with autism spectrum disorders documents the complex needs of just one diagnostic group of interest[80]. Diversity and comorbidity were very high. The dramatic increases in diagnosis in the past two decades was attributed to both better identification and higher incidence and the current prevalence in Canada was estimated at 1.06%. The report documented an increase in complaints to the Ombudsman including instances of support being refused to some of these children/youth due to high needs and challenging behaviours. This was consistent with another report from Ontario[81] noting increased referrals for children and youth with complex needs for placement because of inability of parents and schools to cope with challenging behaviours, and a very recent report in BC noting growth in demand for services[74].

In a Canada-wide survey of parents of children and youth with severe developmental disabilities aged 3 to 21 years published in 2014, 60% reported that their child/youth required support for most or almost all of the activities of their daily lives.[82] Over 50% of the children/youth were reported to have aggressive behaviour, self-injurious behaviour, or anxiety/depression. Many other details of the impact of complex needs-related conditions on the children and youth themselves and their families were also extensively described in this set of literature.

Care Concerns and Recommendations

Articles over the period of the scoping review from the US, Canada, Australia, the UK and Belgium all outline similar concerns with services for this group of children and youth with complex learning needs as were previously noted. They include lack of availability of specialized services including in more remote locations; administratively and fiscally siloed services and supports; inequities in eligibility for services; service fragmentation; bureaucratic processes, lack of collaboration/communication among providers, lack of culturally appropriate approaches, lack of respite care and options when out-of-home care is needed, limited specialized training, inconsistency across jurisdictions in disability eligibility and inclusion practices, financial and practical burden of care and care coordination left to families and so on.[69,70,72,74,76-78,80,84] McAllister et al. (2018) note that services are still not effectively integrated for the broader group with general disabilities[73], and Masotti et al. (2015) provide a detailed picture of the current care picture for children and youth with fetal alcohol spectrum disorders, as just one example, noting that up to 26 different providers may needed and/or involved in the care of one child.[76]

Recommendations for service delivery improvement from this set of articles included the following:

- Integration of care/interagency/cross-sector collaboration
- Designated case manager/key worker/case coordinator
- Mandated interorganizational networks (informal collaborations are not sufficient)
- Formalized agreements among providers
- Dedicated resources to support collaborative processes
- A single care plan/record
- Common language and protocols for care across systems

- Facilitation of assessments and referrals
- Coordination/communication and improved information sharing across systems
- Parent empowerment and peer support
- Family/client advocates to help with navigation
- Multi-disciplinary practice model (possibly primary care based)
- Wrap around services
- Full continuum of services, co-located if possible
- Individualized, flexible, and least restrictive care
- Early identification (universal screening) and intervention as well as organized transitions to adult services
- Greater parent choice in disability benefits including payment of family members for provision of services
- Public awareness
- Better supports for families including respite and out-of-home options
- Fund based on need rather than diagnosis and recognize the need for funding for a higher level of complexity
- Culturally safe and trauma-informed services
- Break down siloes between professional groups, government departments and sectors
- Evaluation

Key Issues

The first key issue that emerged in this set of materials was the noted **problematic practices around eligibility for services based on diagnosis** which, combined with a general lack of availability of assessment or diagnostic services, can result in children and youth without any intervention for unacceptably lengthy periods of time, often at developmentally sensitive timepoints. Related to this are the impacts on prevalence estimates created when funding for services is based on specific diagnoses.

A second key issue in this set was about **commensurate funding**. An example was found (from the UK) where service obligations of the Education system were expanded (to youth up to age 25, plus early identification, family involvement and cross-sector integration), at the same time that prevalence was otherwise increasing without a corresponding increase in funding. This resulted in a variety of unintended consequences, instigated a major financial audit as well as court action by parents, and is a cautionary tale about ensuring that funding is commensurate with service delivery and reform expectations. There is a strong message across all children and youth with complex needs groups that funding is not keeping up with need, but it was quite marked in this set.

As with the other categories, a third issue is the availability and quality of **out-of-home care**, not just for respite but also for extreme situations where home management is untenable. Part of this is connected to the deinstitutionalization movement of the 1980s and 1990s and part also seems to be related to the increased prevalence of intense support needs.[77] A related issue is the pressure to avoid **alternative**

education settings at the same time that classroom management challenges are reported to be worsening.

Once again, an issue of the importance, but relative lack of **early identification** and intervention strategies to reduce the severity and longer-term impact of these conditions is noted, as a fourth key issue. And a fifth key issue, common to both other groups, was the paucity of standard definitions and population level **data** for planning and monitoring.

Service Models

The service models that were described in this set of documents are positioned in a larger trend toward tiered models of education that serve students with special learning needs in a continuum framework of more general to specialized needs. These are typically three-tiered models wherein schools are expected to identify at-risk students and provide prevention and early intervention programs and services; [e.g. 26, 87] and reflect less of a categorical approach to special needs.[70,71]

One Canadian example of this type of overall system redesign occurred in Nova Scotia, after mounting concerns about increasing difficulties with accessing testing and long wait times for supports, along with noted increases in concurrent disorders, disruptive behaviour in younger and younger children, episodes of violence/aggression and school evacuations/lockdowns. New funding was announced in 2018 for the hiring of more professional disciplines, along with educational assistants and parent navigators for students with complex needs (also called severe needs or severe complex needs – severe and persistent challenges with learning, behaviour, development, mental health or communication) which were estimated at approximately 500 children/youth in the province. The model is a multi-tiered system of supports based on needs, with the third tier called ‘intensive’. The website is very detailed on what is provided and what joint agreements among Departments govern services (including alternative schooling and residential services/day treatment, and things like medical procedures for children/youth with complex medical needs). The authors acknowledged the siloes that existed prior to this reform. The aim was to address these issues and to ensure access and equity. Notably, *time for collaboration* was built into the system as well.[88,89]

More specific collaborative or integrated service models seem to have a shorter history for this group than those for the children and youth with social needs. Colvin et al. (2013) reported finding no such programs in the literature prior to 2006.[72]

Table 9 – Service Models Noted by Authors for Children and Youth with Complex Learning Needs

Name	Service or Structural Components/Features	Principles*	Sectors/Levels/General Comments
Intervention and Supports for Adolescents and Families (ISAF)[72] NY, USA	Multi-disciplinary treatment crossing multiple service systems Parent choice on service composition Youth specialists for one-on-one care Special education teacher and behaviour specialist on the team One shared individualized intervention plan 6-bed residential alternative with 24-hour staffing for planned respite and emergency admissions All services under one funding contract	Family-centred Home and community-based care Voluntary services Services based on risk/need, not diagnosis	Sectors are mental health, disabilities, social services (child welfare) and education
Children's Hospital Westmead Collaboration[90] Sydney, AUSTRALIA	A collaboration between a developmental psychiatry team, specialized behaviour intervention services and schools; school-based interventions		Health, disability, and education sectors
Shared Plan of Care Approach[73] Indiana, USA	Health home and health neighborhood approach Referrals from pediatrics Includes pre-visit assessments, planned visits, co-designed/shared care plan using a step-by-step process, care coordinator, family involvement	Family-centred	Note: for broader group with developmental disorders
Interorganizational and multidisciplinary collaboration[83] Flanders, BELGIUM	Interorganizational network for both general and specialized care Fully accessible regional system of care		Note: For broader group with autism spectrum disorders Mentions movement toward mandated interorganizational networks
Treatment, Research and Education for Autism and Developmental	A special school setting/day program for children/youth not able to be served in community schools		For children/youth with autism spectrum disorders, intellectual disabilities and severe behaviour disorders 'severe complex

Disorders Program (TRE-ADD)[91] **Toronto, CANADA**	Treatment plus respite and in-home behavioural assessment and supports Team includes teachers, social workers, psychiatrists and family Parent training Continuous evaluation External panel review		challenging needs and complex needs' Coordination and collaboration with many community agencies Now developing step-up and step-down care components
NaviCare/SoinsNavi New Brunswick[92,93] **St. John, CANADA**	A navigator program including training and resources for children/youth 0 – 25 with complex needs Shared care plan Clear scope of practice Roles and responsibilities defined System connections and advocacy Single point of contact	Personalized Family-centred	Expanding to include peer support and e-health innovations
Hamilton Children with Complex Needs Program (CCNP)[94] **Hamilton, CANADA**	For children/youth with dual diagnosis (developmental disorder and mental health concerns) Intensive behavioural support At home, at school or in the community Case management includes navigation support and assisting with transitions between services		No information on cross-agency or cross-sector aspects

*these items may have been expressed explicitly as principles or just implied

Effectiveness

While there were fewer models identified and reported for this group, the models that were listed did include information about their outcomes. For the ISAF model, a preliminary case study documented reduced risk of both maladaptive behavioural and out-of-home placement.[72] The services were reported to be positively received by families. Effective communication and support for families were considered important components by stakeholders. Dossetor et al. reported positive outcomes for the first 150 cases for their hospital-based service model.[90] Outcomes for the Shared Plan of Care Approach were listed by McAllister et al. as improved access to care, reduced needs, achieved goals, family empowerment and reduced family worry.[73] The TRE-ADD program received a very positive external panel review by international experts.[91]

Also, notably in this section there were two recent reviews of the overall evidence relevant to 'ideal' models. The first was a published guideline by the National Institute for Care Excellence *"Challenging*

Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities whose Behaviour Challenges".[75] The guideline includes recommendations for assessment and clinical interventions but also recommendations for the effective organization of care, including a designated leadership team that crosses sectors, involves family and carers, is accessible, acceptable, responsive, integrated and focused on outcomes. It prescribes clear policies, care pathways, training and support, audits, and performance reviews. It also includes a wholistic perspective including physical healthcare for coexisting health problems (e.g. sleep), supports for families, early identification, a single intervention plan, and least restrictive environments.

Another review published by Anaby et al. in 2018 assesses service models for the broader group of special needs students (i.e. with behavioural issues or cognitive/learning disabilities) in regular classrooms.[87] Of the 33 approaches listed, eight were relevant to this group of children and youth with complex learning needs, and of those the average number of 10 recommended components was only three. The recommended components were grouped as macro-level (collaborative intervention, coordination of services, multilevel services, universal design) and micro-level (support for teachers, ecological interventions, family involvement, direct group services, pull-out therapy, direct individual services). Seven implementation strategies were also suggested: ***training***, designating a coordination role, meetings, internal support, preparation, external support, and continuous evaluation.

Summary

This set of literature was smaller and more recent than the previous set, but it is clear that there are increasing concerns about children and youth with complex learning needs and in particular those with mental health and/behavioural concerns in addition to their learning needs. As with the other sub-groups, the importance of cross-sectoral/collaborative/integrated approaches was universally expressed.

3.5 Serving All Children with Complex Needs

ONE CHILD'S STORY - DAVID

David is an 11-year-old boy with a history of traumatic brain injury. He has a severe overall communication delay, extremely low level of adaptive functioning and sensory processing difficulties. He has frequent seizures that have not responded well to medications and he requires constant monitoring for a major medical emergency. He cannot participate in most physical activities and some sensory activities without risk of seizure so he must be held back from many peer interactions that put him at risk.

David has one to one support for his time at school. He attends half days with a willingness to engage in schoolwork for no more than a few minutes of each day. He expresses his frustration with periods of throwing objects, biting, and screaming, usually following a negative response to his request for a desirable activity. Assessments says he is operating at the level of a toddler. He has had 17 school placements so far due to family instability and his challenges with learning. He is unable to engage with his classmates and has not developed friendships in school. He has tried to interact with others but has been unsuccessful so far as he lacks social skills and developmentally appropriate interests.

David's mother is a single parent and is overwhelmed with financial stressors and David's extensive needs. He has no siblings and the family has no natural supports in this province. Mom has mental health issues that limit her ability to follow through with medical appointments and administration of medication. Transportation is also a barrier for the family. Child Protection has been intermittently involved over the past several years due to concerns about the family's circumstances, but the file is currently closed.

Key Cross-cutting Messages

In this section of the report, five key themes/messages that cut across the three mostly separate subsets of literature on children and youth with complex needs and related cross-sectoral approaches will be presented. Although the literature that integrated information across the types of children and youth was relatively rare, a subsequent section lists four leading documents to inform and guide future practices. Following this is a discussion of the effectiveness of cross-sector/collaborative approaches synthesized across the literatures reviewed.

1. **The issues associated with complex needs and complex service delivery are very similar across these groups of children and youth. Each child or youth is unique in presentation and needs but the similarities, including population prevalence and impacts of their conditions and life circumstances on them and their families, are striking.**

Figure 1, drawn by a parent and published in a National Academies of Science report published in 2018[79] illustrates this first key message across all the complex need subgroups considered in this review. It underscores that the experience of complexity for these children and youth, regardless of the combination of conditions or circumstances.

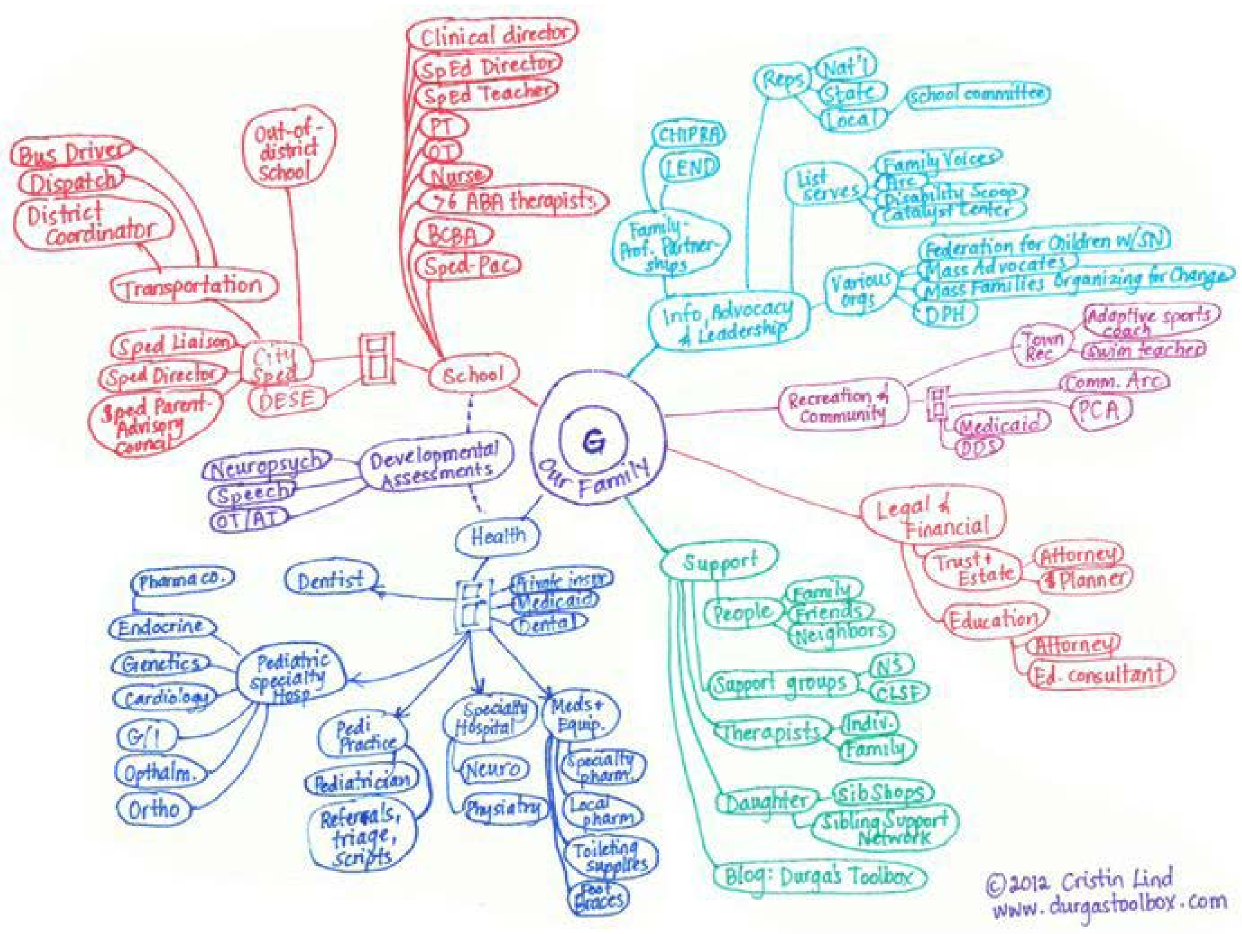


Figure 1 – "One Child": A boy's view of his interactions as drawn by his mother.
Used with permission from C. Lind

In addition to the very broad initial working definition for the review, which was developed for RCSDs in Alberta, other examples found of initiatives using broad and inclusive definitions were Ontario's complex needs approach, which is described in detail in the next section, though the authors of other reports still express concerns about multiple terms for these children/youth still being used.[96] The Education system in Ontario, according to CFHI, has also used a broad definition as far back as 2001 that includes: more than two comorbid diagnoses; a mental health diagnosis or concern; significant concerns regarding the safety of self and others; requires significant medical needs; inability to cope with typical school setting or frequent attendance in a variety of settings; out of school or limited attendance; receiving or requiring support from outside community agencies; history or risk of encountering difficulties with law enforcement; typical school interventions identified as ineffective; and/or treatment (medical or behavioural) as a necessary component of the student's success plan (CFHI)[10].

2. **Authors of articles and reports for all groups across all countries expressed concern about the ability to plan for effective and comprehensive system- and local-level service responses to children and youth with complex needs when definitions are diverse, and data are unavailable or piecemeal.**

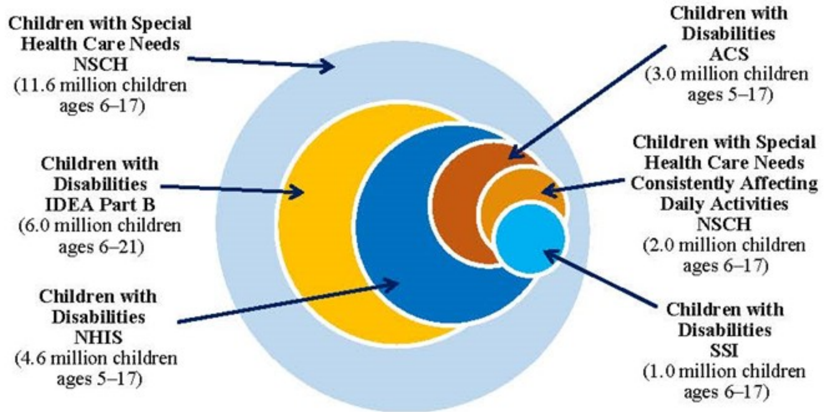


FIGURE 2-1 Prevalence of childhood disability based on selected definitions.
NOTE: ACS = American Community Survey; IDEA = Individuals with Disabilities Education Act; NHIS = National Health Interview Survey; NSCH = National Survey of Children's Health; SSI = Supplemental Security Income.

Used with permission from: National Academies of Sciences, Engineering, and Medicine. 2018. *Opportunities for improving programs and services for children with disabilities*. Washington, DC: The National Academies Press.

Figure 2 – Estimates of prevalence of childhood disability in the United States by definition and source

Of the jurisdictions included in the review, the US appears to be a leader in terms of data improvement, with an annual national survey of parents of children with special healthcare needs as well as data from several other surveys and administrative sources. However, as shown in Figure 2 above, even with better data sources there are still challenges in piecing together a complete picture of even basic prevalence estimates of the broader group of children with disabilities. The clearer picture of severity of conditions needed to characterize the smaller group with complex needs, as well as measure service use and outcomes, would appear to be very far from attainable.

Other jurisdictions, including Canada, have even fewer and less comprehensive data sources, making population health and/or whole of government planning approaches much more difficult. For example, the UK Council for Disabled Children (2017) describe a situation where an increasing prevalence of children and youth with complex needs of all types has been long recognized informally, but that separate data systems and non-standard terms in the education, disability services, and health sectors have been a big hindrance to planning.[95] As just one problem, they note that typically categorical terms are used that provide no information about severity. They characterize their circumstances in this regard as "a big messy jigsaw". Overall, the prevalence of the group "*whose disabilities have a significant and enduring impact on their life and who are likely to need specialist support for education, health and/or social care at times or throughout their childhood and adolescence"* [95 p. 9] is believed to be around 2% of all children in the UK. The report notes that most of these children/youth are known to local service providers and will often have some form of intervention such as learning plans, but overall impressions are that they (and their families) have high levels of unmet need. The authors make a strong case for an integrated data picture.

A recent National Academies of Science report on improvement of programs and services for children with disabilities also identifies the lack of a consensus definition of childhood disability as a serious barrier to improved planning.[79] The authors note that it has been recognized on the theoretical level for a long time that the *"nature and severity of disability are not determined solely by underlying medical conditions but are a function of interaction with the physical world, opportunities, policies, available supports, and social role expectations for children."*[79 p.ix] They lament that:

> *"differing definitions of disability on a programmatic level may be appropriate for service allocation and delivery, …[however] the lack of a consistent conceptual framework guiding a harmonized approach to disability solidifies divisions among services and introduces hurdles for families who must navigate between agencies and programs that provide health, education, employment, social, emotional, and financial supports. Various barriers in these arenas often impede the trajectory of a child with disabilities toward independence, autonomy, success, and happiness in adulthood. Programs and services for children with disabilities are not organized for ease of use, and families affirm the challenges of navigating the various systems involved. Notably, there is no one "system" of care for children with disabilities, no organized, unified assemblage of programs and services. The lack of a cohesive network or system means that opportunities to intervene and improve health and functioning are often missed".*[79 p. x]

3. Service model concepts and related terms are mostly used without definition, sometimes interchangeably and other times with enormous diversity of implied meaning.

Conceptual and definitional problems also hinder a coherent examination of knowledge about service approaches and models, even when our aim in the review was to focus on cross-sector approaches. Multiple search terms were required to capture a very ethereal conceptual space. A lack of shared language and understanding for abstract concepts such as collaboration, coordination, integration, cross sectoral etc., at least in this literature on children and youth with complex needs, challenges the assessment of best practice and other types of comparisons across models. As just one example, a systematic review of health systems integration published more than a decade ago identified more than 170 unique definitions of 'integration'.[97] Table 10 provides a list of definitions for terms used for cross-sector-related approaches that emerged from the review, and Figure 3 illustrates the confusion with a simple cloud map of the diversity of concepts covered by these definitions. This lack of consistent, and interchangeable use of, terminology is a serious barrier to clarity of thinking and planning for collaborative work.

Table 10. Definitions for Concepts Related to Cross Sector Approaches for Children and Youth with Complex Needs

Terms	Definition
Meta-system[26]	Includes families, cultural norms and values, and sectors such as schools, general health services, specialty health services, juvenile justice, child protection etc. Many cross-sector approaches now recognize the importance of the family but this concept is innovative in acknowledging cultural norms and values.
Cross-sector care[8]	The ideal includes four minimum components: • Integration of services across health, social and education sectors • Cross-organizational communication strategies and systems of information exchange • Key workers • Strong leadership, equitable partnership, and a shared vision
Integrated service delivery[8]	Management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system. Involves defined operational policies and procedures, pooling of human and financial resources and governance / management structures (WHO 2008 in [8]).
Integrated systems[98]	Highly integrated systems are characterized by: Shared goals, coherent treatment philosophies, individualized care pathways unrestricted by organizational priorities, funding structures and referral practices
Integrated System of Care[79]	A streamlined and coordinated concept that aligns the delivery and management of systems and services related to an individual's care plan. The goal is to provide a seamless experience so the individual may receive quality care that is efficient, effective, and comprehensive.
Collaboration[61]	A process which includes the steps of negotiation, compromise, and decision-making; it is relational, involving interdependency and (informal) partnerships. A continuum with 5 levels: • communication (individuals from different disciplines talk together) • cooperation (some joint work on a case by case basis) • coordination (more formalized joint working occurs but no sanctions for noncompliance) • coalition (joint structures exist, and participants begin to sacrifice some autonomy) • integration – (organizations merge to create a new joint identity)
Coordinated Care[99]	Coordination is a process that links children and youth with special health care needs and their families with appropriate services and resources in an effort to achieve good health.
Coordinated Care[79] **(adapted)**	Not truly integrated but involve consultations among providers located in different organizations or settings through various means of communication, such as by telephone or online.

Interagency Collaboration[100]	Interagency collaboration is described briefly as *"coordination of assessment and planning around the individual child, involving all relevant services, facilitated by information sharing and a lead professional or key worker."*
Co-located care models[79] **(adapted)**	One or more providers from one setting or organization is present in another organization which enables more cooperation and collaboration and information sharing, but they may not have a common care plan. Allows referrals and scheduling in house.
Collaborative Care [79] **(adapted)**	A fully integrated approach which implements a collaborative team-based approach among all providers in partnership with the child and family with a common treatment plan focused on the whole person.
Cross-sectoral Collaboration[101]	Alliances of individuals and organizations from the non-profit, government, philanthropic, and business sectors that use their diverse perspectives and resources to jointly solve a societal problem and achieve a shared goal.
Inter-sectoral[102]	Actions affecting health outcomes taken by sectors outside the health sector, possibly, but not necessarily in collaboration with the health sector
Multi-sectoral[103]	Deliberate collaboration among various stakeholder groups (e.g., government, civil society, and private sector) and sectors (e.g., health, environment, and economy) to jointly achieve a policy outcome.
Service-level integration[46]	Several models: Overall philosophy/approach with same team (who may be cross-trained) delivering all services within the same framework; or Coordination and/or co-location of separate services either parallel or sequentially
Systems-level Intersectoral linkages (SLIS)[104]	The development of more comprehensive approaches to care provision that depend on formal relationships or structural arrangements to organize and deliver that care. Includes levels – direct service delivery level wherein the needs of the individual are met without altering the systems within which the services are provided; and system level – any attempt to improve the service system for a defined population (may involve linkages between agencies and programs or reconfiguring or consolidating agencies – often a continuum of strategies from information-sharing through to arrangements involving coalescing of service provision and/or funding under a single authority)
Inter-agency collaboration[105]	The process in which service providers from different agencies work together to try and positively impact care OR a continuum with communication and cooperation' at the low end and collaboration referring to more intense interactions involving interdependent problem-solving and decision-making which bridges professional knowledge boundaries. The terms integration or partnership describe relationships where agencies merge into a single structure.
Team-based multi-coordinated care[21]	Many disciplines working together in the same setting at the same time though they may have different goals.
Team-based inter-coordinated care[21]	Communication about goals allows team members to work together toward common goals.
Team-based trans-coordinated care[21]	Disciplinary boundaries are blurred to better achieve shared goals and produce synergies.
System-based Care Coordination[21]	"Involves having someone who knows about what a child's needs are, knows what a family's lived experience is, knows what challenges they face, and helps access aspects of care in the health care system and outside of it". May take a variety of forms (e.g. co-management) depending on context but stays true to some overall principles.

Metagovernance[106]	The governance of governance – in context is the reflexive choice of governance mechanism or deploying different managerial tools that may contribute to improving the performance and impact of particular governance arrangements; one arrangement might be a collaborative governance regime for a network of organizations and stakeholders

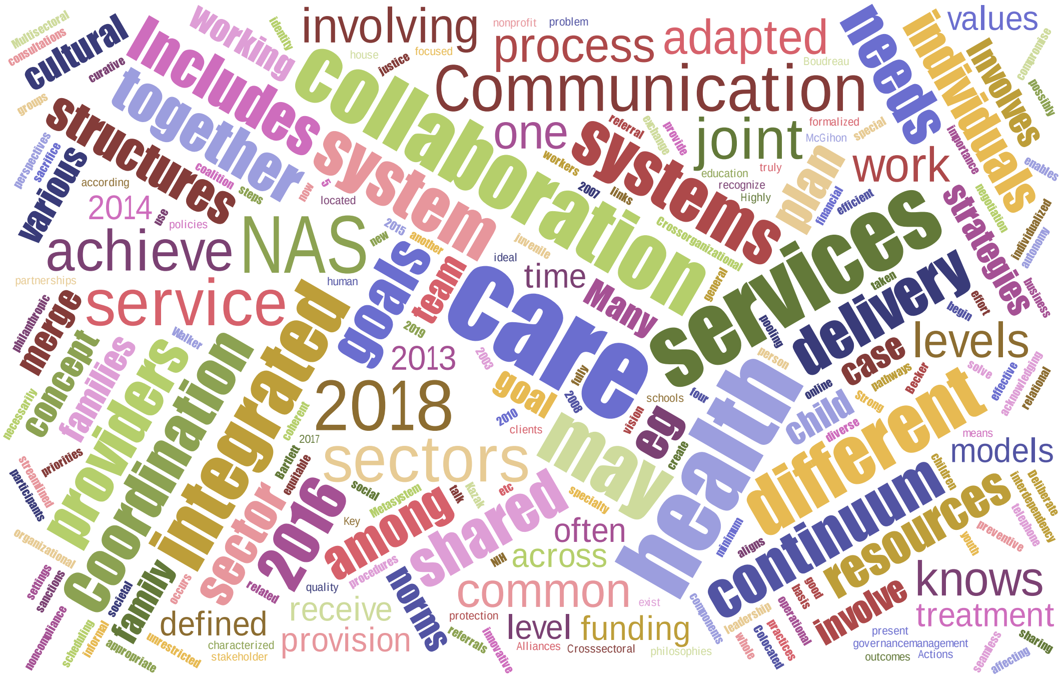


Figure 3 Cloud Map of Concepts Related to Cross-Sector Approaches in the List of Definitions

A few documents in the broader literature reviewed attempted to provide some conceptual clarity to the field, but none mentioned any widely accepted conceptual approach to guide research and practice. One example is the schematic below from an article by Murphy and colleagues published in 2019[5].

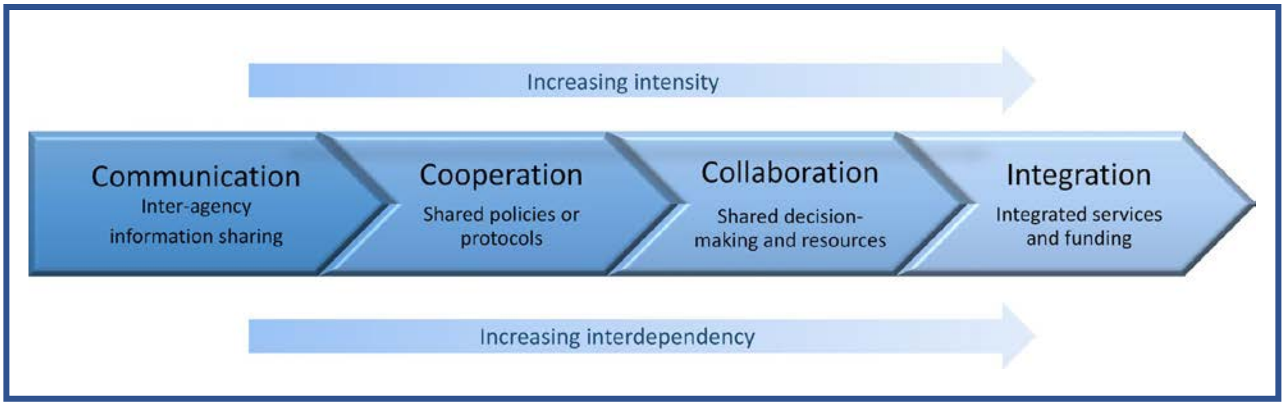


Figure 4 Continuum of Inter-Agency Approaches

Used with permission of the authors

Bartlett et al. (2017) provide five levels of collaboration (details in Table 10) in an article about collaboration for children or youth with mental illnesses[61]. In 2013, Alberta Education published “Working Together: Collaborative Practices and Partnership Toolkit” which provides a very similar four-level continuum of collaboration ranging from networking, through cooperating, collaborating and integrating, with helpful descriptions of the characteristics of each level[107].

4. Collaboration/coordination/integration approaches are considered to be essential and a ‘normative good’ for children and youth with complex needs.

The lack of standard definitions aside, better collaboration/coordination/integration is increasingly seen as important for a range of health, social and educational services for children and youth (and other specific groups including those with multiple conditions).[46] An example is Integrated Youth Services (IYS) which is a service model now being widely implemented around the world including in Canada[63]. In Canada, British Columbia and Ontario are currently working on strategies for special needs children and youth more broadly; it will be important to watch for aspects of those strategies that address the subgroup with more complex needs.

For children and youth with complex needs, ***integrative/collaborative approaches services are considered to be critical***. ***There was complete unanimity in this view across the three subsets of literature examined.*** The question is no longer *whether* this should be done, it is now more about how to do it and how to improve it. The following are some examples of broad jurisdiction-wide cross-sectoral approaches for these children. These are not necessarily the best examples, and certainly are not the only examples, but are some that emerged from the literature reviewed that may have interesting features to inform ways forward.

Cantan at al. (2017) describe related developments in Ireland, in reaction to concerns about a history of piecemeal responses having been developed for specific diagnoses, resulting in gaps for children who don’t fit. Services are now being reconfigured into interdisciplinary Children’s Disability Network Teams – for all children with complex needs in each geographic area and all of primary care, disability services, health and mental health services, education and child and family services.[12] Local forums are tasked with designing an optimal pathway for each child or youth. This policy at the national level is aimed at consistent equitable access for the whole population. Access to the service is based on need (referencing the WHO International Classification approach), not diagnosis. Complexity is determined by the impacts of impairments on functioning and community participation.

In Finland in the past couple of years there has been an initiative to integrate health and social care systems at all levels – called the Better Everyday Life Project.[108] It covers all ages but is aimed at high needs, high cost individuals. It is theoretically aligned with the chronic care model, now widespread in adult health. Clients and professionals in primary care, secondary care, social care, and education work together in teams to develop concrete tools for integrated care – using breakthrough and lean methods, concrete collaboration models, and shared intervention plans. Most of the activity is at the local level, but everything is guided by national and system level reform. Additional information would be needed to understand how such a model would change care for children and youth with complex needs, and particularly the role of the education sector, but the 'bones' of a more integrated approach for these children appears to be in the works.

New Zealand has had an intersectoral strategy at both national and regional levels since the early 2000s that was mentioned in a few documents in the review and which is still in operation.[109] This is an initiative very specifically for children and youth with complex needs whose requirements are considered to be so great that regular services are not enough. The definition of 'high and complex needs' includes social and learning subcategories, elevated risk to themselves and others, and both mental health-related issues and disabilities. The service acknowledges the difficulty in providing a comprehensive definition given the uniqueness of each child. The service crosses the ministries of health, education, child/youth and family services, Maori development, and social development. It arose out of an identified need to 'think and act differently' and to foster collaboration aimed at solutions. It includes a 'last resort', extraordinary circumstances pool of funding. The approach is local case collaboration and collective response which is guided by a set of principles and coordinated at the national level. It includes very specific cultural components and processes, transitions to adult care and defined outcomes. It is structured as a national support unit with regional implementation teams.

The current province-wide approach for children and youth with complex needs in Ontario was described online[110] and by key informants from Ontario. It is a Ministry of Children and Youth Coordinated Service Planning approach. Once again, the target population, referred to as children and youth with 'multiple and/or complex special needs', is broad and crosses the usual subgroups identified in the review. A diagnosis is not required to access the service. Funding is available for children/youth who: *a) are in need of long term and/or continuous specialized supports; b) have "two or more different special needs" and require integration of services across different sectors (e.g., mental health, disability services, education); and c) have needs based on a variety of comorbid conditions which can include: intellectual and developmental disabilities, physical disabilities, and chronic, terminal and severe physical health. These children typically have needs so complex that they require services that are specialized, intensive, costly, and require a high degree of collaboration.*

The program is delivered via transfers to 28 coordinating agencies in 34 service delivery areas. Cross-sectoral oversight of services is provided by the lead agencies in each area and in turn lead agencies have agreements with specific service providers. Components of the approach include a single service plan, responsiveness to goals, strengths and needs, and a clear point of contact and accountability. This is noted to ensure that service providers and educators working together avoid duplication of services and intake processes, and it includes a clear process for connecting to other service partners. Services are provided from birth through age 21 years. The target population includes considerations of the child, family, and environment. A special envelope of funding (with a fixed annual allocation) is available for situations where there is immediate risk to health and safety and the complexity of service needs are beyond the capacity of existing services. Services that may be covered by this special fund (provided directly to agencies) are residential services, in and out-of-home respite services and behavioural supports, and clinical assessments and nursing. Principles of the approach are child/youth and family centred, seamless service and information sharing, and meeting diverse needs. All of governance, roles and responsibilities and performance measurement are spelled out.

A relevant, albeit broader, regional planning approach in Ontario also came up in the review which was driven by the health sector. It is described in a document called *Thrive:* The Future of Integrated Health Service Planning for Children and Youth in the Champlain Region, Champlain Local Health Integration (LHIN) Network, 2017.[111] The authors describe increasing incidence and complexity of mental health and developmental conditions in children and youth, with most needed services falling under four ministries, and that coordination with the school system, in particular, was lacking. They also note the lack of consistent, integrated planning approaches, and burden on families. Their work is guided by six principles; the most relevant is that *"child and youth healthcare must be integrated and coordinated across the continuum from community-based and primary care services to hospital-based and sub-specialist services, putting the outcome and experience of patients and their families at the center"*. Of 10 themes, the first is integration, consistency, and coordination and the seventh is school system collaboration. The document contains long lists of recommendations for integrated services planning and delivery including transitions, mental health and addictions supports, and connections to the education system. It is not clear if this regional planning work has been fully operationalized given the change in the LHIN structure in Ontario, but it exemplifies a strong vision for integration efforts at least across health and education at the regional level.

5. There is a broader knowledge base beginning to emerge that considers the full range of children and youth with complex needs and relevant policy and practice approaches to serve them more effectively and ultimately to improve outcomes.

Only a handful of documents discussed a knowledge base, including models, practices and effectiveness for children and youth with complex needs *across* the three categories discussed above. Even these had some limitations in being completely applicable to the questions of the review, but their comprehensiveness, recency and quality of content warranted listing them as the best sources of knowledge emerging from the review materials overall. The level of detail is so rich that although some aspects were extracted for particular points elsewhere in the report it was also considered to be important to highlight them in full as high-quality resources for future work.

Four Relevant Comprehensive Reports

- **Olson S. Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs: Proceedings of a Workshop. The National Academies Press 2016.**[21]

  This document summarizes the findings of a major stakeholder that included panel presentations from parents, youth, and young adults. A very broad perspective was taken on the types of children and youth under consideration and their circumstances. Common themes across specific chapters on different types of children and youth with complex needs were formulated. While there are clear differences in the way services are delivered in the US, the expression of enormous unmet need and gaps in care was consistent with the peer-reviewed literature and the grey literature from other jurisdictions. The research on prevalence was thoroughly reviewed – noting a quadrupling of the number of children with one ore more activity limitations due to a chronic health condition (without counting children in institutions). Increases in the proportion of conditions involving mental health and behavioural disorders are also noted, even after controlling for socioeconomic status, and lack in equity of access to assessment and services is documented. A distinct shift, including in (US) legislation, toward functional and 'consequence-based' definitions (i.e. needs for services of various types) is noted.

Initiatives at national and state levels to try to improve systems are described, and huge concerns expressed about *"funding supports for individual disorders and not thinking carefully about the overall needs of entire populations*". [21 p. 60] The document also identifies the need for a much stronger role for the education system, arguing that children and youth with complex needs require a level playing field in the educational environment and that other agencies need to help create a "safety net' in the education context to support children to be successful.

Some of the key messages about systems of care from the document are so resonant with the other materials of the review that relevant portions are paraphrased or quoted here:

- **Moving Forward When the Evidence Base is Lacking**: Research needs to be integrated with practice; many evidence-based practices are targeted toward specific groups, thresholds or diagnoses; they need to be broader and earlier. Screening and earlier intervention are needed. Public/parent participation is needed including to inform policy makers.
- **Community Engagement and Partnerships:** Communities are diverse; approaches need to be reactive and flexible.
- **Overcoming Barriers to Collaboration:** *"The care of any complex, chronic condition is going to require multidisciplinary approaches, and yet we have substantial barriers, both in practice and policy, that interfere with that kind of collaboration". "A particularly difficult collaboration is with the education system, yet this collaboration is essential once children reach school age. Schools need to come to appreciate how important it is to collaborate with all the rest of the systems that are serving children and families".*[21 p. 73]
- **Coordinating Systems of Care:** Too many siloes still exist; a need to join forces was identified. Levering the health equity agenda was considered to be important because of the close links between disability and disparity. Questions about whether public schools are currently equipped from an infrastructure perspective, or from a staffing perspective, to meet the needs of children with complex medical and health and mental health problems were raised.

- **Opportunities for Improving Programs and Services for Children with Disabilities: A Consensus Study Report. Washington DC. National Academies Press, 2018.**[80]

  Another very comprehensive report with in-depth background research and coverage of the issues from multiple stakeholders' perspectives. This document addresses the *broader* group of children with disabilities from a total population and system perspective. Some (of many) highlights include a summary of current gaps and limitations in systems for these children:

    - Disparities
    - Regional differences in implementation

- Insufficient workforce
- Service and information fragmentation
- Persistent issues with data sharing
- Difficult access
- Issues with transitions
- Wide variation in how disability and related outcomes are defined and measured
- Limited longitudinal data on health and functional outcomes
- A lack of rigorous evaluation of programs and services; limited reporting

and eight characteristics of models that contribute to their effectiveness:

- Child/youth/family-centred care in support networks
- Individualized services
- Evidence-based care
- Outreach to needed services on behalf of families
- Coordination including navigation
- Goal-oriented including preparation for youth transitions to adulthood
- Help negotiating new processes during transition
- Continuous improvement and evaluation

All of these attributes are consistent with the issues and remedies identified for children and youth with complex needs as well.

- **National Institute for Health and Care Excellence (NICE). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. (2015)** [76]

This is a systematic review of the evidence on children/youth with learning disabilities/intellectual disabilities and behaviours such as aggression, self-injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour including in some instances violence, arson or sexual abuse, and which may result in justice system involvement. These types of problems are reported to be present in about 5 to 15% of those with a learning disability with even higher proportions found in residential and hospital settings. The recommendations range from the more clinical aspects of care (such as risk and functional assessment, and treatment in the domains of medication and behavioural intervention) to the organization and principles of effective care. On this topic, the authors of the report recommend a designated leadership team (that crosses sectors) – which involves families and carers; is accessible, acceptable and responsive; and is integrated and focused on outcomes. Clear policies and protocols for care pathways as well as audits and performance reviews are given. All of physical healthcare, supports for families, early identification, behaviour support plans, reactive strategies (least restrictive environment as a first consideration), and interventions for coexisting health problems such as sleep problems are addressed. Recommendations are also made for research on prevention through to residential care.

- **National Institute for Health and Care Excellence (NICE). Disabled Youth and Young People up to 25 with Severe Complex Needs: Integrated service delivery and organization across health, social care and education (forthcoming 2021).** [112]

In addition to the report above, this UK-based institute is also in the process of developing a new Guideline (to be released in 2021), which is directly and comprehensively on the subject matter of this review. Its rationale, currently online, confirms that *"more [children with] disabilities and severe complex needs are surviving and that an integrated, inter-agency approach for both health and social care is needed".* It lists current practices of concern including exclusion from schools; lack of nearby care; discrimination for transport/housing/social activities; lack of voice; prolonged hospitalizations; service delays due to funding responsibility issues between health and social care; and parent burden of coordination. The Guideline will also address equality issues. The initial scoping document indicates a comprehensive perspective with respect to type of complex needs, but a definition is not provided at this stage of the work. It also notes that, "*Whereas 'integration of services' can relate to unifying service infrastructure at a national, regional or local level, the aim of this guideline is to deliver seamless provision of services from the perspective of the child or young person and their families and carers."*

Relevant Comprehensive Reviews of Effectiveness

On the topic of effectiveness of service models for children and youth with complex needs, it was not possible to systematically compile all models and all of the evidence for them for each of the three need groups, either at the individual model level or the specific intervention level. In addition, there were almost no effectiveness reviews for complex needs children and youth specifically across all three groups. However, there were a few very comprehensive and recent articles (including reviews) that stood out as good summaries of evidence (process or outcomes) for broad scope or high level collaborative models. Serendipitously, these papers also provide recent perspectives from the US, Australia, the UK and Canada.

Kazak et al. published a comprehensive article in the prestigious journal American Psychologist in 2010 that provides an in-depth discussion of the theory and implementation approaches based on multi-state work, including implementation trials in the US[26]. The aim of the body of work described is on implementation of evidence-based practice using a meta-systems framework to address the needs of children and youth with emotional and behavioural needs. While this is not about the subset of children and youth with complex needs, it is very important contextual work. The authors listed the key components of the meta-systems approach as schools, pediatric health centres, specialty mental health systems, juvenile justice systems, child protection services and substance use treatment systems. Their approach is based on broader public health models and aimed at improving outcomes for the whole population. As one example of work described, they discuss a trial that trained providers in family engagement practices and navigation and emphasized therapeutic alliance and family-centred approaches. The trial also included a cross-sector committee *"to ensure that multiple systems interact in ways that facilitate rather than undermine the implementation of evidence-based practice"*.[26 p. 90] The availability of sound assessments and evidence-based interventions were considered to be critical. Several attitudinal aspects were also included such as constant observation and inquiry. The article goes on to discuss reforming and 'upending' traditional mental health service models and ensuring inclusion of promotion, prevention and early intervention, strengths and developmental approaches, family engagement, clinical decision supports, measurement feedback and structural linkages among providers. What is required is *“oversight of constellations of idiosyncratic, complex microsystems”*.[26 p. 93] The article also discusses ‘both-and’ approaches (i.e. blending top down and bottom-up approaches) to system-level interventions. While the effectiveness for the multi-level approaches described is not fully summarized in the article, it can be considered a gateway to a rich set of implementation and outcomes evidence.

Whiteford et al. (2014) provide a thorough review of the outcomes of systems-level intersectoral linkages (SLIS) for adults and youth with severe and persistent mental illness.[104] The review summarized 40 high-quality studies (14 of which focused on complex needs youth populations) of a range of mechanisms for intersectoral linkages including coordinating committees, joint planning, a single care plan, cross-training, service co-location and funding initiatives. Effectiveness, summarized across all age groups, was positive for both clinical and non-clinical outcomes and included: improvements in interagency communication, greater mutual understanding of and empathy for each other’s services, reduced bureaucracy and improved service efficiency, improved cost efficiency across sectors, and improved capacity for non-clinical staff to manage the mental health needs of clients. Client-level outcomes included clinical improvement, improved vocational and employment-related outcomes, housing stability, reduced foster placements, and reduced recidivism/involvement in juvenile justice. Notably, outcomes in sectors broader than health were shown to be attainable, but outcomes that matter to children, youth and parents were not mentioned (e.g. quality of life). Some studies had nil findings, but the majority had positive effects. A few ineffective processes were also identified; in one example, funds were pooled but for too few agencies to constitute a whole systems approach. For youth populations, some learnings include the importance of a shared vision and a focus on organizational climates along with a caution that centralization of authority can lead to diffusion of responsibility. Facilitators of intersectoral linkages across all the studies reviewed were listed as communication, strong leadership, shared perspective, colocation and clarity around responsibility/accountability, strategic planning, a coordinating body, and ongoing monitoring of effectiveness. Barriers to intersectoral linkages were resource constraints in all of funding, time, workloads, and technology; turf issues, privacy issues, and worry about increases in inappropriate referrals. Fewer studies reported on mechanisms to establish intersectoral linkages, but those that did mentioned grants to garner interest from multiple agencies; broad stakeholder consultation, and seeking consensus amongst stakeholders on values, goals, language, and definitions. The authors summarized the approaches associated with positive outcomes, including ensuring mutual respect and understanding of roles, streamlined communication among all agencies, formal interagency memoranda of understanding, joint service planning and provision, single cross-agency care plans, cross training of staff, shared case records, integrated funding, service colocation, and designation of a lead agency for coordination. The article describes a nation-wide funding initiative in Australia to advance this type of work, given the promising evidence.

There was very little evidence reported on cost-effectiveness of approaches relevant to cross-sector work in the literature reviewed. One exception was an analysis conducted in Ontario by the Provincial Advocate for Children and Youth published in 2015 on approaches for the broader group of special needs children and youth.[113] The report states the prevalence of this group as 11%. It notes that in Ontario all Ministries have a role in serving these children and youth but five are more central. It also mentions the limitations on current data and the problem of underfunding (including an estimated $5 billion in unmet costs). The authors report on a return-on-investment analysis for just one mechanism for cross-sectoral work with these children, namely the individualized educational plan (IEP), and identify a very good return for spending on that one intervention. The report concludes with recommendations for a government-wide strategy for these children and youth, the need to continue and expand supports, and the need for an outcome tracking system.

Cooper et al. (2016) provide a review of 33 studies of interagency collaboration published between 1997 and 2015 for mental health services for children and youth – again this article is about a broader group of children.[100] The article offers description of the history of UK policy back to 2003 up to a task force report published in 2015 that noted that fragmentation, lack of cohesion among services, and services gaps were still present. The authors identify that interagency collaboration is a key tenet of health services policy in many countries. They also underscore the importance of multi-agency work *especially for children and youth with complex needs* and report that policies in the UK and US promote a system-of-care (SOC) approach. The review indicates that many attempts at the approach have been made, and that the majority of studies in the review reported at least one positive finding between the level of collaboration and client-level and system-level outcomes across different types of collaboration: mental health and wellness status, more positive behaviour, greater academic achievement, improved school attendance, reduced school exclusions, receipt of needed services, better service focus on higher needs, lower level of disparities in service receipt, increased mental health literacy, earlier problem detection, more appropriate referrals, reduced time from referral to intervention, increased ratings of adequacy and availability of services, increased ratings of professional partnerships, and positive perceptions of a range of stakeholders on impact. Once again there was no mention of measurement of outcomes valued by the children, youth, and families. A few unintended negative effects that have been found include increased workload/role overload, professional identity confusion, fear of inappropriate referrals, problems in information sharing, and management difficulties. One study found that increased service co-ordination was associated with poorer service quality, underscoring the need for careful monitoring of service quality. The article also summarizes the evidence for facilitators and barriers of interagency collaboration. These are summarized in Table 11.

Table 11 – Summary of Facilitators and Barriers (Inhibiting Factors) in 33 studies[100].

Facilitating Factors	Barriers/Inhibiting Factors
Good communication across services	Inadequate resourcing
Joint training	Poor communication across professionals
Good understanding across services	Lack of valuing, respect and trust
Mutual valuing, trust and respect	Differing perspectives/cultures
Senior management support/leadership	Poor understanding across professionals/services
Protocols	Confidentiality issues
Named link person	Lack of senior management support
Joint meetings	No-one taking responsibility
Positive individual relationships	Referral difficulties
Co-location	Unrealistic expectations of other's services
Joint case conferences	Interagency collaboration not prioritized
Adequate resourcing	Lack of protocols on interagency collaboration
Child-youth and family centred	Bureaucracy

Consultative or supervisory role Joint assessments Training in interagency collaboration	

Studies are increasingly using innovative analyses to describe the progress and features of cross-sectoral integration as well. In a recent study set in Canada, McGihon et al. (2018) focused on youth with concurrent disorders (similar to the complex needs population of interest in this review) and the state of development of service integration.[98] The study was predicated on prior evidence for a strong association between inter-organizational relationships and increased mental health service access and use, as well as improvement in mental health and psychosocial functioning. Networks for the study from across the country were identified through the National Youth Screening Project. The authors concluded that:

> *the moderate level of cross-sectoral integration in Canadian youth-serving agencies justifies the need to address residual fragmentation. A systems-level approach emphasizes connections between organizations operating in different service sectors and is often endorsed as a "gold standard" integrative strategy to supplement those at the level of individual clients and services. A number of recommendations guiding the development of integration strategies have emerged from the general health systems literature: the need for standardized referral procedures, indicator-based performance management, effective information systems, and shared organizational culture and leadership."* [98 p. 5]

Several authors note the difficulty in measuring outcomes in these complex interventions with diverse children where change may be multi-faceted, subtle and/or and nuanced. There is increasing value in 'practice-based evidence' in addition to 'evidence-based practice'. Two authors in the review exemplify more systematic approaches to tapping this practice-based evidence and illustrate the value of capturing the wisdom of practitioners. Thomas et al. (2015) collected the views of service providers in a partnership-based pediatric outreach service for urban Indigenous children with complex needs. Main components of the collaboration were regular communication mechanisms (i.e.in writing and via email), regular face to face meetings and an identified case manager.[115] Four key enablers were identified through in-depth qualitative analyses: cultivating effective relationships, using informal and formal ways of working (flexibility), cultural sensitivity, and strong leadership. Barriers to the work were listed as separate funding streams, management structures, and reporting requirements. "*Leadership emerged as an essential component of effective partnerships, cultivating the ethos of the workplace, creating an environment where collaboration is supported and staff are encouraged to develop effective relationships that improve access to a wide range of child health services for those children most in need"*.[114 p. 841]

The second article, by Morgan et al. (2019), examined front-line staff perspectives in an interagency collaborative care approach for youth with complex needs.[105] Staff had very positive views of the value of collaborative care to meeting the needs of these youth and were positive about working together, including both aspects of service delivery itself and communication among agencies. Challenges were listed as 'different world views/cultures' of different agencies. The role of a lead agency that was valued and trusted was considered essential. Without it, participants indicated that collaboration was less frequent and rarely went beyond information exchange.

In summary, the evidence-base for cross-sector approaches to serving the needs of children and youth with complex needs is diverse but is mostly positive and accumulating. Practice-based evidence is increasingly available, but outcomes from the perspective of children and youth and their families (e.g. quality of life) seem to be rarely measured or even acknowledged. Mechanisms that promote or hinder the work are well described, as are the few unintended negative effects to guard against. These approaches are increasingly enshrined in the health and social policy statements of many jurisdictions, although usually for broader populations. **As such, cross-sector collaboration can be considered a 'normative good'.** ***It is no longer reasonable to question whether it should be done, the focus is more on how to do it to maximize impact.***

4. The Alberta Context

4.1 Twenty Years of Policy Approaches to Serving Children and Youth with Complex Needs

Alberta has a long history of encouraging collaboration for better care for our children and youth. What follows is but a sample of some of the policy initiatives that have shaped service delivery to children and youth in Alberta over the last 20 years.

In 1998/1999 the Alberta Government launched the **Alberta Children and Youth Initiative (ACYI)** with the aim of removing some of the traditional mandate boundaries and encouraging cross-ministry collaboration to improve the lives of children, youth, and families in Alberta.[136] In a 2006 ACYI update, seventeen cross-ministry initiatives were reported under the ACYI umbrella,[136] several of which were relevant to children and youth with complex needs. For example, in 1999/2000 the **Student Health Partnership (SHP)** was created to support collaboration and service delivery for children with disabilities. While Alberta Education, Health, and Human Services were considered equal decision-making partners, the new dollars were assigned to Education with school boards taking on the role of Banker Board for the local Student Health Partnerships, which at the time included school authorities, local health regions and child and family services. A second and highly relevant example, the **Children and Youth with Complex Needs (CYCN)** initiative was subsequently announced in 2003, also as part of the broader ACYI. As with SHP, the CYCN initiative was a partnership among child-serving ministries and their corresponding regional boards/authorities and communities. Implemented in 2004/2005, CYCN aimed to support local regions with the integrated care of children and youth who were involved with two or more sectors and whose extraordinary needs were beyond the baseline services of the involved systems. The structure of CYCN included a provincial coordinator, regional support coordinators, and integrated case management review teams. While funds for CYCN again flowed through Education to a school Banker Board, in Calgary and surrounding area, the Southern Alberta Child and Youth Health Network facilitated the work of CYCN and the corresponding system case review process, with referrals accepted from education, health and child and family services. The initial work on these and other ACYI initiatives was very well received.

In 2008, Alberta Education undertook a review of all the Severe Disabilities Coded student files and determined that the process of basing funding on this model resulted in significant disparities across regions. It began a series of community consultations called **Setting the Direction** to look at a new paradigm for service delivery to these children and youth. Twelve strategic directions were proposed including developing regional centres to provide specialized expertise and resources using a case manager model to facilitate the collaboration and coordination of partners. In June 2010, Setting the Direction was renamed **Action on Inclusion** to signal the start of implementation. A significant outcome of this work was that it formed the basis for the 2013 implementation of the **Regional Collaborative Service Delivery (RCSD)** structure. Adding to this, at about the same time a study of processes for rehabilitation of children with disabilities was published, which provides a rich description of challenges and accomplishments in this realm.[115]

A Fact Sheet on children and youth with complex needs dated 2012 describes the operation of the **Children and Youth with Complex Needs (CYCN)** approach by that year.[116] It included a single access point for services delivered from several ministries. It states that the initiative "fosters collaborative planning and service coordination for children and youth with complex needs who require significant *extraordinary* services and supports due to the unique nature and severity of their impairment(s)". Supports are provided through local cross-sector teams (referred to as Regional Review Teams) which enabled *"additional support and implement extraordinary elements of an integrated services plan".* The Fact Sheet also indicates that referrals were possible from health, education and/or child and family service authorities and that parents could access the process indirectly. Responsibility for the CYCN approach and population was shifted to Regional Collaborative Service Delivery (RCSD) entities in 2013.

Several initiatives at the provincial policy level that are closely related to/or cover some of the children and youth of interest were also identified in the grey literature searches.

A Nova Scotia education planning document mentions that Alberta Education was studying a model of tiered supports with a connection to wraparound services around 2010.[117] The process recommended memoranda of understanding among government departments as well as agreements between schools and partner organizations to foster collaboration. Alberta Education went on to develop an approach to Collaborative Practices which are based on wraparound principles.[118] They are collaboration, shared leadership, team-based, school-community linked, persistent, family voice and choice, natural supports, cultural responsiveness, individualized, strength based; and data informed. In a broader but related development, Alberta Education, along with the Alberta School Boards Association, the Alberta School Council's Association, The Alberta Teacher's Association, and the College of Alberta School Superintendents published principles and practice for collaboration in 2013.[107] The resource, not specific to children and youth with complex needs, was aimed at education leaders and partners and covers the processes of effective collaborative practice and provides some templates for as well as a very helpful framework and definitions for concepts related to collaboration.

Also, in 2013, Human Services and Alberta Education published the report **PUF/FSCD Specialized Services Common Approach Framework: Working Together for the Delivery of Programming and Services to Preschool Children with Disabilities.**[119] It describes a two-way Ministerial vision to integrate planning and supports between PUF (program unit funding) from Alberta Education to school authorities for individualized early childhood programming for children with severe disabilities or delays, with the Specialized Services being provided for some children with severe disabilities through the Family Supports for Children with Disabilities program. The Framework provides guidance for collaborative planning and service delivery, with the ultimate goal of a child and family being served by one health professional team and one plan across both education and home settings. The vision is for a network of supports and services for preschool-aged children with disabilities and their families that is strong, integrated and coordinated. Seven guiding principles are: child and family centred, collaborative and coordinated, culturally responsive, strengths based and capacity building, responsive and flexible, outcomes-based and focused on continuous improvement, efficient and sustainable. Features include a common entry approach, family and child priority planning, successful resource planning, individualized service and program planning (key contact/program coordinator and a single consensus plan for both systems), team reviews, enhanced information sharing, and successful transition planning. The document outlines the roles of all partners at all levels. The Common approach was adopted throughout the province as a pilot in 2012/13. It has not been recently evaluated for provincial acceptance and adherence.

A summary report describing the proceedings of a symposium to address complex needs and mental health system access was published in 2014 called **The Case for Change: Children and Youth with Complex Needs & Access to the Mental Health System.**[120] The rationale for the stakeholder (including youth) symposium was presented as concern for children and youth in care being in greater need of mental health services, yet not having their needs met. The Symposium referenced the 2011 Addictions and Mental Health Strategy that was in place at the time. Recommendations and suggested actions were many. Those most relevant to cross-sector collaboration for complex needs children and youth are:

- Build a system that helps navigate – including navigators which can be one point of contact
- Provide services that put children and youth first – (integrated, coordinated, wrap around, flexible, single point of entry, among others).
- Include communication that builds bridges, commensurate funding allocation, measuring outcomes, building leadership.
- Suggested actions included ‘accelerating integration across key ministries’; developing a single point of entry common to all ministries, coordinating case management that is inclusive of children, youth and families, formalizing information sharing policies and practice, fostering cross-ministerial culture, establishing a common language etc.

In 2017, Alberta Education led work that crossed school authorities, community, and cross-ministry partners from Alberta Children’s Services, Alberta Health, Alberta Health Services and Alberta Justice and Solicitor General and resulted in a document entitled **Working Together to Support Mental Health in Alberta Schools.**[121] The initiative used the School Mental Health Assist (Ontario) planning tool which addresses school mental health as a broader, tiered model. It described the third tier as *“supports and interventions for those two to seven per cent of students who require more intensive and individualized supports that focus on their particular mental health needs.”* [121 p. 24] The document outlines that the role of school staff is to support students as they move to, through and from community services. Clear communication and the sharing of appropriate information, providing a supportive classroom and reinforcing mental-health related skill development at all levels are key components. Also included are specified roles for partners at the ministerial level and in the community. The document cites a collective impact model and calls for collaborative practices that strengthen relationships, reduce service overlaps and gaps, and focus on the strengths of children/youth and their families; and that in the end promote optimism, enhance motivation, and increase school capacity.

Echoing some of the concerns identified for children in care in the broader literature, a review of issues published in the Journal of Contemporary Issues in Education in 2018 concluded, based on data from Alberta Education, that there remains a very high achievement gap for children in care in Alberta (regardless of care setting), including low attendance and completion rates.[122]

The child protection system has also recently undergone extensive review, the results of which are reported in **A Stronger, Safer Tomorrow. A Public Action Plan for the Ministerial Panel on Child Intervention's Final Recommendations. Government of Alberta, 2018.**[123] The review panel was led by Children's Services. It reported that about 10,000 children/youth receive child intervention services every day, and like some other provinces, the majority (60%) are Indigenous. The report made 26 recommendations. One specific to complex needs was to increase available placement options and access for children and youth with complex needs by obtaining therapeutic out-of-home care services and reorganizing services across the province. It also recommends improved service delivery and names these services as mental health, juvenile justice, disability, education etc. Specific to mental health and addictions services, it calls for increased treatment beds and trauma-informed care. The document does not, however, provide definitions for complex needs or disability.

Following on from the Ministerial Panel, a framework for children in care, with an important focus on meaningful Indigenous participation in the system, was introduced by the government in 2019. **The Well-Being and Resiliency: A Framework for Supporting Safe and Healthy Children and Families** report provided a plan for reform of the operations of the Children's Services Ministry.[124] It reported that 1.7% of all Alberta children are in care. It included the following principles: Indigenous experience, family preservation, strengths-based, connection, collaboration, continuous improvement, organizational capacity, and knowledgeable and effective workforce. Promising practices are outlined in the report using three levels of evidence (client-based, practice-based, and research-driven). Complex needs are mentioned only briefly with a recommendation that "Intensive programs, delivered by qualified staff that have the education, skills and competencies required to work with individuals and families experiencing complex circumstances, are better options for this population".

Other policies from Alberta Education that provide important context to the topic of children and youth with complex needs include:

- **Welcoming, caring, respectful and safe schools.**[125] This policy outlines the expectations for provision of an environment of acceptance for all students, including those with disabilities. It situates supporting practices (such as trauma-informed practices and peer support) in context of a whole-school approach for the development of social-emotional competencies and the promotion of positive mental health.

- **Mental Health in Schools.**[126] This content outlines how understanding and promoting positive mental health in schools is a shared responsibility of parents, educators and community partners and speaks to promotion of positive mental health in schools as a mechanism to increase resilience and provide a counterbalance to negative life experiences of children and youth.

- **Establishing inclusive learning environments.**[127] Here, the province's approach to inclusion underscores the importance of each learner receiving a high-quality education regardless of their ability, disability, language, cultural background, sexual orientation, gender identity, gender expression, or other characteristic. It notes that it is not just about learners with special needs. Two of six key principles most relevant to children and youth with complex needs are to "understand learners' strengths and needs" and to "set high expectations for all learners".

- **Services and Supports Grants.**[128] This document outlines the mechanisms to support specialized learning needs of students, including for multi-disciplinary team practice, to address needs that may vary between school jurisdictions and to support capacity in school authorities to offer programs to support the educational outcomes of all students. Included is funding for students in kindergarten with severe disabilities and delays.

In 2020, a multi-sector review was undertaken on an incident involving a youth who assaulted a member of the public[129]. Ministries involved were Children's Services, Community and Social Services, Justice and Solicitor General, Health and Alberta Health Services. The report included many findings and recommendations. Those most relevant to the complex needs of the youth were that assessments (including neuropsychology, caregiver, mental health and risk assessments) were not timely despite clear signs and high risk conditions; that support for families who are involved with multiple systems and services (including secure settings) is essential; and that despite coordinated services, families and services providers still have challenges in escalating concerns. The report found that ministries were working in isolation and that agencies did not share information. While collaboration was noted to have improved over time (with a case management lead and regular connections with health, education and community providers) and some flexible service options in existence for the family's needs (e.g. cultural supports, community treatment orders, 24/7 in-home supports), challenges continued with misalignment of risk assessment and conflicting advice and treatment planning. The report indicated that despite the services offered, the family's capacity to carry out the treatment plan was limited, and no one had "an official process for escalating collective concerns". The report goes on to describe positive developments in this realm: *"Information-sharing and collaborative practice have changed substantially since the youth and family's interaction with government services. For example, protocols have been developed to outline how sectors interact, and changes to legislation have given ministries greater flexibility to share information to enhance planning. In cases where complex family challenges require the involvement of multiple sectors, cross-ministry collaboration needs to take a broader approach to problem-solving but need to be more proactive."* [129 p.8]

The first recommendation of the report was for a cross-ministry response team to help children, youth and families with complex service needs (with an escalation process for risk issues) and *"an evaluation of barriers to enhanced, timely, cross-ministry collaboration. This could include evaluating: the authority structure of current cross-ministry teams; the financial structures that may limit the ability of ministries to meet the immediate needs of children, youth and families; access to data and information on the challenges facing children, youth and families; how multi-sector case conference teams interact and build* *trust with families; and barriers affecting policies and programs".*[129 p. 8] The second recommendation was for *"a review of Alberta's secure settings to determine if they are meeting the needs of youth with complex service needs"*.[130 p.10] In the report's conclusion, it was noted that a *"cross-ministry leadership committee has been formed to focus on improving services for youth and families with complex service needs".*[129 p.10]

A brief look at current codes/definitions being used by Alberta ministries was also taken to help understand where children and youth with complex needs fit. The Government of Alberta/Alberta Education currently lists coding criteria (2020/2021) for early childhood services through to Grade 12 according to categories (mild/moderate, gifted and talented, and severe). The severe category includes further categories for severe intellectual disability, severe emotional/behavioural disability (a range of diagnoses listed), severe multiple disability (two or more disabilities that result in severe to profound level functioning), and severe physical or medical disability (a list of diagnoses), as well as deafness, blindness, and severe delay involving language. It also provides details of regulations around professional assessment and diagnosis. There are provisions for qualified professionals to make statements rather than diagnoses as long as there is extensive documentation of need.[130]

The Family Supports for Children with Disabilities program (FSCD) administered by Community and Social Services is another program that *partially* interfaces with approaches for complex needs children and youth in Alberta.[131] Overall, FSCD has an early intervention focus. It offers supports called for children more generally who meet criteria, including a medical diagnosis, under the FSCD Act as having a disability. Supports can include counselling, clothing, some defined travel/transportation, sibling care and respite. Enhanced supports are also available for those children and youth who are additionally determined to have a severe disability via formal assessment and according to the following criteria:

- a severe disability that significantly limits the child's ability to function in normal daily living activities
- the child requires continual and ongoing assistance and supervision to make sure they are safe and able to participate in daily living activities
- the child has critical service needs in two or more areas including behaviour, communication and social skills, physical abilities, cognitive abilities, or self-help skills and adaptive functioning, and
- there are no other programs or services to meet your child's needs.

These children/youth/family may receive respite, homemaker services, extraordinary childcare, day care aide, personal care aide, community aide, behavioural or developmental support services, health-related supports, special diet or prescription formula, or out of home care. FSCD does not define these recipients as having complex needs and instead uses the term 'specialized services' for providing supports to disabled children and youth with a higher level of need. Children and youth falling under regional complex needs System Case Reviews may be receiving services and supports from FSCD including even out-of-home services; however, they are often not the same children and youth as those receiving specialized services according to the definition above.

As one example we also looked at the definition of complex needs used by the Calgary Board of Education as just one of 379 current school authorities in Alberta.[132] The definition is *"cognitive developmental disabilities, autism fetal alcohol spectrum disorders, physical disabilities and special health needs. At two* *special school locations the terms multiple and complex learning needs and moderate to severe cognitive disabilities and/or complex learning, medical and emotional needs".* The latter are further listed as:

- Autism Spectrum, Cognitive/Developmental Disabilities, Fetal Alcohol Spectrum
- Blind and Visually Impaired
- Deaf and Hard of Hearing
- Giftedness
- Gifted and Talented Education
- Learning Disabilities
- Mental Health and Wellness (social/emotional/behavioural challenges)
- Physical and Medical Disabilities.

In summary, the grey literature on children and youth with complex needs in Alberta included many policies, definitions, reviews and initiatives by various ministries and other organizations that reveal the importance of making a difference for children and youth of various subgroups. Terms and definitions are diverse. It is not completely clear, based on written materials found in the public domain, how this policy landscape fits together to best serve the small group of children and youth with complex needs of interest to this review.

4.2 RCSD Approaches to Children and Youth with Complex Needs

As described above, supports for children and youth with complex needs were being provided as part of the Children and Youth with Complex Needs (CYCN) provincial initiative between 2004 and 2013. In the Region 3 (Calgary and area) Annual CYCN Report for 2011/2012 the approach was reported to have very positive outcomes, but also continuing challenges with a) the cross-sector funding component being structured as a short-term support when longer term was needed; b) increased referrals; c) lack of access to mental health services; d) insufficient alternative placement options with educational supports; e) difficulties with youth transitions from FSCD to PDD funding; and, f) limited access to training for rural area staff. The report also acknowledged the extra time necessary for collaboration.[133]

In September 2013, the 17 RCSDs were established in Alberta and the responsibility for cross-sector collaboration for children and youth with complex needs was assumed under that regional structure. Funds for RCSD geographic areas flowed through the education system in each region. Since inception, RCSDs have assessed the needs in their communities for these children and youth and have taken diverse approaches to improving cross-sector collaboration. Extractions from annual reports for the past year show that some RCSDs have used the funding allocated to this area to hire professionals such as psychologists, nurses, physiotherapists, occupational therapists and/or speech-language pathologists for consulting services, direct service provision, or for planning service pathways. In some cases, the work has included a broader group of children and youth with more moderate needs and others have included work focused on special groups (e.g. autism spectrum disorders, medically fragile children and youth). Urban regions have teamed up with more rural regions to share resources and processes, although that has not always worked as intended and one such approach was recently discontinued. Some have hired staff (e.g. navigators) with a specific role to connect across services or have used funds to pilot approaches such as case management. Others have used funds to enhance mental health supports to children/youth or families (e.g. family school liaison workers). Some RCSDs in more rural areas have used distributed committees in each community to review and collaborate around meeting the needs of these children. Funding has also been used to develop multi-agency protocols for handling violent behaviour in schools. Most have used funding to develop processes for case identification and integrated service, although some were just in the planning stages for this sort of collaborative process and a few had not yet developed any formal processes.

4.3 A Brief Look at the Tri-Region RCSD Complex Needs Model

As described above, the CYCN provincial approach was maintained by Calgary and Area RCSD when RCSDs were established in 2013. The decision rested with RCSDs on whether or not to maintain a separate budget or process for complex needs. The geographic boundaries for RCSDs were in alignment with the former Student Health Partnership boundaries, which were not aligned with the provincial CYCN boundaries. This meant that a single CYCN region now entailed three RCSD regions. Given the likelihood that children and youth with complex needs would continue to require access to highly specialized often urban based services, and a desire to maintain a similar approach to the population, Calgary and Area, Bow River and Central East RCSDs agreed to explore collaborating on a cross-sector regional service model. The Tri-Region model developed was very similar to the previous CYCN approach and focused on planning and supporting children and youth with complex needs aged 0 to 20 years, in alignment with the overall purpose of RCSD which was to: enable the collaboration between Health (including Alberta Health Services), Children's Services, Community and Social Services, Education, interested First Nations and community organizations to address identified needs, coordinate and leverage systems, build system capacity, and plan for sustainability in meeting the needs of children, youth, and their families.

The partners of the three RCSDs worked together, pooled their resources, and used a collaborative, team-based approach to serve children with complex needs (according to the definition provided to the RCSDs by government in the Introduction section of this report). The approach was refined and formally adopted in 2014 and continued to evolve in 2015. It included mandate, principles, process maps and identified outcomes. Oversight was provided by a Tri-Region Complex Needs Committee. The approach integrated and/or coordinated supports and services irrespective of setting or location, in order to ensure children and youth with complex needs reached their full potential.

In terms of structure, each system/sector in each RCSD identified a senior manager as their 'Point Person'. This person vetted referrals coming from their system and ensured that all internal options had been exhausted before forwarding the case. In each instance, for cases thought to be of concern, local team meetings/case conferences for cross-system collaboration/problem-solving were held before elevating the case to the Tri-Region RCSD level. If the case was deemed eligible to go forward, the RCSD Complex Needs System Coordinator initiated the next steps of the review. One important step was ensuring that families were oriented to, invited to, and supported in the process (called the System Case Review). The Coordinator assembled a team of senior managers from all the partner systems, as well as other senior school representatives with an interest in and the experience to help with problem solving along with the other team members. A primary outcome of most System Case Review team meetings was the development of an integrated plan with consensus goals, and identification of an individual (from any sector) to act as the ongoing Case Manager who was expected to ensure accountability for the implementation of the plan. Creative options, innovative responses, and agreement to overcome barriers were all aims of the review meeting.

The Tri-Region RCSD approach also included pooled funding for extraordinary needs exceeding the service capacity of all systems combined. Funding to support the resources to meet the extraordinary needs was allocated yearly and was intended to provide a short-term opportunity to increase the success experienced by the child/youth and systems supporting them. It was expected that this funding would be applied to supports for the individual child/youth, provide time to evaluate the benefit of the additional support, and allow for system partners to build the support, if needed, into their future budgets. However, given the ongoing nature of the needs of children and youth with complex needs, the immediate concerns were often not ameliorated, and the systems became dependent on the funding. Challenges in discontinuing funding were frequent, and not resolved despite attempts to institute guidelines. This funding dilemma challenged the sustainability of the model as both the number and complexity of children increased. The most recent fiscal year annual expenditures of the approach were just over $1.14 million.

In 2017, an additional specialized function for children/youth with co-morbid mental health issues, safety issues, at least two systems involved, and needs exceeding existing resources was initiated. This service, called CONeX (Collaboration, Outreach, Navigation and Exchange of Information) was added as a two-year pilot of a specialized function for children and youth aged 6 to 20 years and was evaluated in 2019. It included consultation, some direct service delivery including intensive case coordination, navigation, facilitation of information exchange and an integrated service plan. The vision for CONeX was also to build system capacity to better manage children and youth with complex needs, including assistance with managing transitions between acute care and community settings and strengthening the collaboration among providers already involved with the family.

Before summarizing key statistics from the Tri-Region RCSD approach and the evaluation of the CONeX component, it is important to note some closely related initiatives in the regional context.

In 2017, Alberta Health Services (Alberta Children's Hospital), Children's Services (Calgary Region Child and Family Services), and Community and Social Services (Calgary Region Disability Services) launched the **Children with Medical Complexity (CMC) Collaborative Initiative**. This cross-sector initiative was established due to an increasing prevalence of children with medical complexity; the ongoing fragility and needs of these children for specialized medical care preventing them from attending school; and the often unavoidable, costly out of home placements necessary due to lack of alternatives for families. All systems were challenged to meet the needs of these children and recognized the need for collaboration and an overall strategy to support this population. The focus of the CMC initiative was to develop an integrated approach that included families as partners, was grounded in the best available practices, and aligned supports and services across systems with the ultimate outcome of improving the quality of care for children with medical complexities. Additional community partners including Calgary and Area RCSD, public school authorities, and Office of the Public Guardian were invited to participate.

Coinciding with the CMC initiative, a 2018 report on Integrated Service Delivery Approaches for Children with Complex Medical Needs[134] identified eight programs in the literature that used family-centred care in the community to support these children and youth to live and receive education at home. It indicated that the evidence was as yet not strong for these relatively new programs but some key themes such as family centred care, communication, access to care, skills and training, caregiver and family impact, hospitalizations etc. emerged from the literature to guide planning. The children and youth to be served by the approach were defined as having the four aspects noted by Cohen et al. (2011)[4]: high need, high service use, chronic conditions (medical fragility), and severe functional limitations.

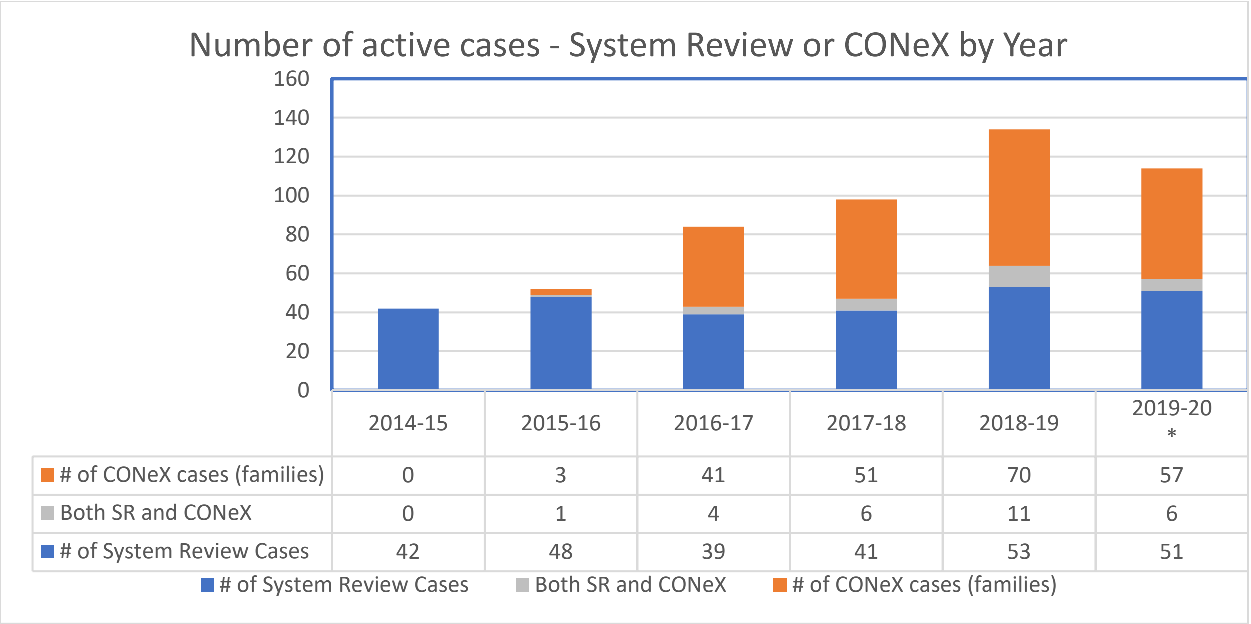
The CMC initiative recommended the use of integrated care system plans in alignment with the RCSD Complex Needs approach, but also recommended new connections to services including the Community Paramedic program, development of two new specialized respite/transition homes, and a Navigator resource.

The second Calgary-based initiative is the **Complex Needs Network** that was formed as a joint initiative between Alberta Health Services Calgary Zone and Disability Services to enable more coordinated services for older youth transitioning to adult disability supports (Persons with Developmental Disability [PDD]). The population of interest were those youth with developmental disabilities and who "*pose a significant risk and/or are destructive to themselves, others or property*". They are described as having had a mental disorder, termination from services due to challenging behaviours, specialized treatment for psychiatric and/or behaviour issues, multi-system involvement, incarceration or criminal justice involvement and/or chronic substance abuse/dependency problems. This network was available as a key youth to adulthood transition planning connection and presented a possible discharge pathway for older youth served through the Tri-Region RCSD complex needs approach.

Statistics from the Tri-Region RCSD Complex Needs Approach

Descriptive statistics on children and youth served by the Tri-Region RCSD approach have been tracked since initiation. Figure 5 below, drawn from the 2019-2020 Tri-Region Annual Complex Needs Case Review Report[137], shows the number of active System Review and CONeX cases per year. The number of System Review cases has been relatively stable, but dropped somewhat in 2016-2017, as expected, with the first full year of implementation of CONeX. Both were on a rising trajectory through early 2020, but then impacted by two unforeseen events which meant that new referrals could no longer be accepted.

Children and youth from the full target age range have been served but most have been in the 13 to 17 year age range, especially for CONeX, which reflects both the increasing numbers and increase in complexity noted in the literature more broadly, although over this short a time period, much of that increase is likely due to awareness and availability of the service. The diagnoses of the children/youth served include the comprehensive range reflected in the RCSD definition, with an average of 3.3 diagnoses per child/youth. Attention Deficit Hyperactivity Disorder and Autism Spectrum Disorder are the most common diagnoses but there are many concurrent disorders including mental disorders. Outcomes are tracked using Goal Attainment Scaling.



	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20 *
🟧 # of CONeX cases (families)	0	3	41	51	70	57
⬜ Both SR and CONeX	0	1	4	6	11	6
🟦 # of System Review Cases	42	48	39	41	53	51

*On February 27th, 2020, Alberta's provincial budget was released which eliminated RCSD as of August, 2020. On March 11th, 2020, the World Health Organization declared Covid-19 a pandemic and locally, measures were put in place to minimize contact and reduce the spread of the virus.

Figure 5 Number of Active Cases - System Review or CONeX by Year

CONeX Evaluation Findings

A two-year review of the CONeX program noted the impact of the program on sharing information, coordination and connections to supports.[135] System outcomes were measured over two time points using stakeholder (including parent) surveys. A range of positive findings from level of comfort with collaboration, understanding of the service, unique elements such as better coordination, communication and mental health supports, system enhancement and better supports for children and youth were reported by type of respondent. Ratings on the value of CONeX were very high. The program was also found to be unique in providing better support services, a neutral perspective and the power to hold systems accountable.

4.4 Alignment with Leading Practice

Table 12 shows the components or features of leading practice that emerged from the models found in the literature across all three subgroups of children and youth with complex needs. As reported previously, not every individual component has been evaluated as an effective component on its own, but there is reasonable consistency of these components with models that have been shown, as a package, to have positive outcomes for children and youth with complex needs of any type. The column on the right indicates which components are present in the Tri-Region Complex Needs approach as assessed by the author and confirmed by four members of the Tr-Region Complex Needs Committee independently.

Table 12 – Components of Cross-Sector Models and Tri-Region RCSD Approach

Component of Cross-Sector Model	Details	Tri-Region RCSD Approach
Mandated shared responsibility – policy level	The mechanisms for this were cross-Ministry/Dept. memoranda of agreement, designated leadership and accountability	√
Mandated shared responsibility – local or regional level	The mechanisms for this when described were inter-organizational agreements, leadership structure and designated accountability This was sometimes described as 'a single locus of responsibility' where one organization had the lead role or was the 'primary agency' but sometimes it was just implied for the collaboration overall; if the geographic catchment area was large sometimes the structure was distributed but still connected	√
Shared resources	Mechanisms included pooling or sharing funding, human and other resources, and having all services under one funding envelope. Some models had a designated pool of funds and shared processes for accessing it for extraordinary needs or circumstances	√
Funding to support the collaborative process	Funding to support the processes/infrastructure necessary to ensure effective collaboration	√
Funding responsive to need	Funding increases (or decreases) for changes in caseload numbers or need levels	
Principles-based approach	Work is based on a set of shared principles (some models use related terms goals, mission, vision etc.)	√
Single shared service plan	These are also called treatment/service/education plan, some are described as individualized (to the person's needs) and some are noted to be developed in collaboration with or 'co-designed' with family; some also mention a standard template for these plans	√
Multi-disciplinary team(s)	Some models also mentioned mechanisms for adding specialists (e.g. behaviour specialists) to the team and/or for accessing additional specialists as needed;	√
Case management	Also called key worker or case coordinator and described as the point of contact for all involved including professionals and family and with an ability to span organizational boundaries; in one case there were case manager dyads across the systems; in some models this person also provides navigation assistance; in other	√

	models individuals with a specific navigation function are also on the team; brokering specific services and central management of all appointments were also mentioned as a functions	
Human resource development	Some models had explicit mechanisms for training, including cross-training and training in effective collaborative processes	√
Identification and assessment	Shared processes for identifying children and youth with complex needs in a catchment area using population perspective and a shared or coordinated assessment process; some also emphasized processes for early identification such as standard times and tools for screening	
Clear and explicit referral processes and evidence-based care pathways	Usually described as referrals possible from any participating organization, but in some cases also from family (directly or indirectly)	√
Structured regular communication/	This was usually described as regular face-to-face meetings of all involved, but there were also descriptions of specific structured mechanism for phone or digital communication – communication was explicitly indicated to be shared decision-making in several instances	√
Information sharing	Mechanisms noted were legislation and/or inter-organizational agreements and protocols; often noted that training was necessary to break down barriers to sharing; a few mentioned IT infrastructure for sharing records	√
Quick engagement and intervention	An emphasis on shortening the typical lag times for processes across organizations including assessment, intervention and follow-up	
Roles and responsibilities	Documentation of agreed upon and expected roles and responsibilities, scopes of practice, and/or duties but flexibility in practice	√
Role of family	Most models referenced a child-, youth- and/or family centred approach and emphasized therapeutic alliances or related relationship-based processes plus additional family support services such as respite, psychoeducation/training, childcare/peer support groups	√
Monitoring/evaluation/ performance measurement	Shared, defined and regularly measured and reported goals, processes and outcomes, as well as research/evaluation processes; some mentioned fidelity	√

	measurement specifically and one mentioned external panel review	
Flexible service settings	Models described the delivery of services to be home, health setting, school and/or community	√
Co-location of some services	Most descriptions indicated that complete co-location was not possible but that it helped to co-locate some of the more frequently used services	
Peer support	In the school context examples were welcome teams and student support teams	
Specific transitions planning	This included transitions between services or settings (e.g. hospital discharge planning) but also transitions from child/youth to adult services/supports	
Connection to higher care levels 'stepped care'	Access to residential 'beds' for severe needs, emergency circumstances and/or parent respite or in the case of education access to alternative educational (special class or special school placements)	

As shown in the table, the Tri-Region RCSD approach had most components of relevant leading practices in models found in the review (16/23). Because it was a 'connector' function across existing services and programs and not a direct delivery program, some of the items were less applicable (e.g. peer support); however the presence of the cross-sector approach may have indirectly enabled partner services to be more effective in those aspects if they were available at the lower level.

The components listed above are important structures and processes to enable more coordinated care for children and youth with complex needs. However, they do not capture some of the qualitative aspects of a model. In a slightly different lens on the approach, consideration was also made of facilitating factors from Table 11 and the broader literature on aspects of cross-sector work. Two critically important aspects that came up in the literature repeatedly are the degree and quality of relationships in this type of work, including individual relationships and organizational relationships. Facilitators that depend on the quality of individual relationships include good communication, good understanding, and mutual valuing, trust and respect. Both observations and documentation suggested significant strength in these aspects of the work for the Tri-Region RCSD cross-sector approach to complex needs.

Leadership includes management processes and structures, but also the ability of sector leaders to come together with a common vision and relay and instill that vision into the 'ecosystem' of the cross-sector activities that occur routinely. In the Tri-Region RCSD approach, this had to happen for the sector leaders within each RCSD as well as across the three RCSDs. The longevity, growth and positive evaluation of the Tri-Region RCSD approach is evident, and these qualities in turn, reflect the quality of leadership provided.

4.5 Common Recommendations for Service Systems Across All Children and Youth with Complex Needs

A content analysis of the recommendations listed across the three types of complex needs children and youth revealed the following four core themes.

Attributes of a System (mostly at the policy level)

- Systems-level reform for a shared vision for inter-agency, multidisciplinary approaches
- Articulation of roles and responsibilities
- Whole systems and whole of government approaches (particularly important for equity)
- Cross-department and cross-Ministry governance and accountability
- Collaborative, multi-faceted, multi-system, and well-structured
- Better data/information overall
- Human resources issues addressed including training, recruitment, retention
- Better licensing and oversight of the quality of residential care
- Mandated interorganizational networks (informal collaborations are not sufficient)
- Formalized agreements among providers
- Common language and protocols for care across systems
- Public awareness
- Siloes between professional groups, government departments and sectors are broken down

Attributes of a System (mostly at the regional/local level)

- Articulation of roles and responsibilities
- Case management for care coordination and navigation across sectors
- Flexible provider roles and care in place (including home care and tele-home care)
- Sustained linkages through regular team communication including case conferencing
- Integration of all of health, mental health, education, recreation, childcare, early intervention, prevention, and developmental services based on need
- Single point of entry
- Information sharing, joint records
- Trauma-informed, relational, and family preserving approaches
- Early, systematic, and consistent screening and assessment and proactive care
- Wide range of higher quality placement options
- Better understanding of services by all stakeholders
- Measurement and evaluation
- Integration of care/interagency/cross-sector collaboration
- A single care plan/record
- Facilitation of assessments and referrals
- Family/client advocates to help with navigation
- Multi-disciplinary practice model (possibly primary care based)
- Wrap around services
- Full continuum of services, co-located if possible

- Individualized, flexible, and least restrictive care
- Prevention and early identification through universal screening as well as organized transitions to adult services using a life course approach
- Culturally safe and trauma-informed services

Families

- Better financial and social supports for parents
- A whole family perspective
- Family centred; strengths and capability-based
- Culturally responsive and supportive of empowerment particularly for Indigenous children /youth/families
- Inclusion of the voices of those with lived experience
- An ombudsman role and/or appeal mechanism
- Parent/youth empowerment and peer support for both
- Parent choice in disability benefits including payment of family members for provision of services
- Better supports for families including respite and out-of-home care options

Funding

- Funding based on need rather than diagnosis
- Recognition of the need for increasing funding for a increasing numbers *and* complexity of cases
- Alternative payment/funding models that incent care coordination (in both US and Canada)
- Options for funding to follow the person
- Simplification of processes and eligibility for benefits
- Funding to support alternatives to in-person service delivery (e.g. e-health)
- Fund infrastructure to build model systems of care with the full range of health, education and social services and family partnerships
- Dedicated resources to support collaborative processes

5. Summary and Considerations for Future Work

Despite the lack of standard search terms, diverse literatures across disciplines and sources, and diversity across the literature searches and the environmental scan, there was a surprising level of unanimity in best ways forward for these children, who could easily be characterized as the "most vulnerable of the vulnerable" and whose numbers and needs are increasing in all jurisdictions studied. The following are some considerations, focused at both the policy level and the service level, for building on the strong legacy of serving complex children and youth in Alberta and are firmly supported by the literature reviewed:

Develop a 'whole of government' approach starting with a cross-ministry plan for special needs that includes a range and continuum of complex needs levels, including those that are so severe as to be considered catastrophic. In the plan include:

- ***a set of shared terms and definitions that maps, if not harmonizes, existing definitions and coding systems across ministries;***
- ***a plan for measurement and monitoring at the population level including prevalence, intervention and outcomes;***
- ***a multi-level (provincial and regional) model for collaborative/integrative care for complex needs across the full continuum including residential services (a strong provincial approach to ensure equity of services; a strong regional approach to ensure responsiveness to local need and geography);***
- ***a plan for training and professional development;***
- ***screening, which is universal, early and repeated;***
- ***overall multi-disciplinary assessments based on function and need across all domains rather than a single discipline diagnostic assessment (while allowing for more specialized assessments);***
- ***'one child-one plan' integrated supports based on an inclusive lifespan approach for wholistic needs including educational (in whatever setting and format needed), medical, social, and healthcare (including mental health) with special attention to transitions of all types;***
- ***a plan for cultural relevance and responsiveness in all aspects;***
- ***supports for catastrophic needs that include supports for families (in whatever form family takes including foster and natural supports) in all of social and mental health support, peer support, respite, lost income (and/or direct payment of families for care), transportation and housing; and,***
- ***a single appeal/escalation approach.***

Alberta has been advancing approaches for children and youth with complex needs of all types for more than two decades, first through a provincial initiative focused exclusively on children and youth with complex needs, and later through the broader mandate and structure of RCSD. The Tri-Region RCSD Approach to serving children/youth with complex needs has been consistent with leading practices since 2013 but also evolved in response to need, with the addition of CONeX. The most important predictors of successful collaborations – leadership and cultivation of relationships – have been strong in the approach. Some challenges have been ongoing, particularly with funding levels that were short-term and not commensurate with increasing case numbers and severity of needs. There is a sound foundation and track record in these regions to inform future policy and practice.

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