Family Wellbeing: Equitable, Accessible, and Quality Services for Children and Youth with Complex Care Needs

By

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Supervisory Committee

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Preamble

The following Master's Project by Amira Abdel-Malek for the School of Child and Youth in the University of Victoria Care holds two documents. The first document is a reflective conceptual paper for the supervising committee entitled "Family Wellbeing: Equitable, Accessible, and Quality Services for Children and Youth with Complex Care Needs" (p. iii- 26) and provides context and analysis of the Master's Project (the second document). This reflective paper is tasked with the purpose of situating the Master's Project in the Child and Youth Care field and demonstrates how the project informs and draws on Child and Youth Care theory and practice. The second document is the Master's Project itself entitled "Children's Health Foundation of Vancouver Island: Literature Review Study" and is a narrative literature review conducted on behalf of the Children's Health Foundation of Vancouver Island (CHF) who commissioned this writing in November 2019 and received the final draft in March 2020. Please note that this literature review by Amira Abdel-Malek refers only to the first of three literature reviews presented to the CHF which is entitled "Children with Complex Care Needs." The research question for the literature review, which was developed by the CHF and myself is: *What are the ways service quality and accessibility can be improved for families who have children with complex care needs?* This literature review was part of the Children's Health Foundation's 2019-2023 Community Investment Research and presented to their staff, shareholders and teams of health and social care professionals.

Abstract

This reflective paper entitled “Family Wellbeing: Equitable, Accessible, and Quality Services for Children and Youth with Complex Care Needs ” will contextualize the Master’s Project, which is a literature review entitled “Children’s Health Foundation of Vancouver Island: Literature Review Study – Children with Complex Care Needs” conducted on behalf of the charitable organization Children’s Health Foundation of Vancouver Island (CHF). This reflective paper will situate the literature review (referred to in the paper as the “the Complex Care Needs (CCNs) Project”) within the context of the Child and Youth Care field. The CCNs Project explores the ways in which social and healthcare services for children with CCNs can improve their accessibility and quality. CCNs are defined as physical and/or developmental disabilities, medical conditions, or illnesses, however, this reflective paper argues that each CCN, and each person seen as having them, must be contextualized within the continuing and dynamic social and power structures of their societies, circumstances, and cultures. Therefore, the research for both the literature review and in this reflective paper is informed by the Social Determinants of Health perspective, which provides a lens through which to address equity concerns which in this research will discuss the intersections of CCNs, migration and Indigeneity. The CNNs Project utilizes a narrative approach in conducting a literature review that reinterprets, reconfigures, and rediscovers the existing information, thus displaying a new ‘story of the data’ in a fashion accessible and useful to the CHF and their shareholders (a community of professionals, donors, and practitioners in the social and healthcare sector), and this reflective paper will continue that narrative by adding contextualizing factors such as the social location of the author, some post structuralist theory and tenets of Child and Youth Care practice such as strength-based practice and commitments to social justice. The conclusions in the reflective paper reveal insights into the collection of trends and recommendations regarding ways to improve CCNs service quality and accessibility from the CCNs Project. These insights include that a) community inclusion is integral to the wellbeing of persons with CCNs, b) systemic barriers continue to impede the accessibility and quality of programs and services for these children and their families, and such barriers are layered when the family is also Indigenous, racialized, or made up of Newcomers, and c) practices that uphold trusting relationships are key to the inclusion and wellbeing of people with CCNs. This reflective paper also reviews some specific parts of the research findings in the CCNs Project which will provide examples that link this research to practice.

Keywords: Complex Care Needs/Disability; Child and Youth Health and Wellness; Accessibility/Equity; Health/Social Services; Inclusion; Indigenous Health

Contents

Acknowledgments

For the last seven years I have worked, studied, played, cried, lost and gained family members, and have lived my life on the traditional and unceded territories of the Lekwungen, Songhees, Esquimalt and W̱SÁNEĆ peoples. I acknowledge that this land was stolen and that the relationships of Indigenous People with their land is lasting today, beginning from time immemorial. It is with respect and compassion that I make these acknowledgements.

There are two people who have been incredibly supportive across the journey of this degree and toward completion of this Master's project. I would like to offer my deepest gratitude to my supervisor Dr. Mandeep Kaur Mucina for her remarkable scholarship and mentorship, and to Nancy Ami, Manager at the Centre for Academic Communication, for her tremendous support of my work across the years. Thank you both for being such superstars who have guided me to this point.

This Master's Project is dedicated in the memory of my brave and beautiful and cousin Autumn whose resilience continues to inspire me.

Reflective Paper Part A: Project Background

> Let’s invite one another in. Maybe then we can begin to fear less, to make fewer wrong assumptions, to let go of the biases and stereotypes that unnecessarily divide us. Maybe we can better embrace the ways we are the same. It’s not about being perfect. It’s not about where you get yourself in the end. There’s power in allowing yourself to be known and heard, in owning your unique story, in using your authentic voice. And there’s grace in being willing to know and hear others. This, for me, is how we become.
>
> —Michelle Obama, *Becoming*

The CCNs Project is a complex report that reviews the literature on children and youth with Complex Care Needs (CCNs). While there are many ways to define ‘children and youth living with complex needs,’ it has generally been understood to mean either a physical or developmental disability, a medical condition or illness (Brenner et al., 2018). The project is sponsored by UVic Community Partnerships and the client of the CHF, written on behalf of the Children’s Health Foundation of Vancouver Island (CHF), and managed by the Principal Investigator, Dr. Kimberly Speers, from the School of Public Administration at the University of Victoria (UVic).

In this paper I will contextualize my research for the purposes of demonstrating how the research findings may inform the Child and Youth Care field as well as offer propositions for practitioners. This will be accomplished in two parts. Part A will cover the background information about the CCNs Project, including a section about the researcher, and the project description, purpose, approach, and significance. Part B will engage with the specific implications and significance the project has to the CYC field and its practice. The findings and recommendations from this research project were informed by my approach of focusing on Indigenous and Newcomer families with children with CCNs, and this focus resulted in conversations on how this approach to research and traditional Indigenous Knowledge can inform propositions for the CYC field and practice in general.

Social Location: A bit about myself

My career in CYC began in childhood, with caring for my fun-loving sister Layla. Blessed with a great sense of humor, a love for musicals, and the patience needed for puzzles, my sister also happens to have an extremely rare neurological disorder affecting the frontal lobes. She also has epilepsy and experiences some physical mobility issues. If that is not unique enough, my family is also inter-cultural/racial. We are children of a Coptic Egyptian father and a Euro-Canadian mother. My father made his way to Canada as a refugee avoiding the economic limitations and persecution of his fellow Copts and met my mother at SFU, where she was rebelling against her own small colonial town culture through activism and studying sociology.

Both Layla and I are ethnically, culturally, and, depending on official categorizations of “Arab” or “Middle Easterners,” sometimes described as racially mixed. My sister takes after our dad and I look more like mom, but like most mixed children we look very little like either of our parents. I experience privileges that are not afforded my Egyptian relatives. I therefore consider the relationality of identity to be quite relevant in my unique case when I am asked to state my social locations.

As an individual, in a vacuum, I am an able-bodied and white-skinned woman; however, different contexts of space and time, as well as relational factors, have meant that I experienced and experience social consequences through a combination of ableism, racism, and sexism; as a result, I have insight into the mechanisms of these adversarial hegemonic forces. While I do not have the exact same experiences as my many of peers, co-workers, proximate and distant communities, I also do not believe that that is a necessity for empathy, compassion, understanding, and active support (if it was, we would be living in a world where the stars do not shine). Instead, I appreciate how the intricate identities/experiences of all human beings can both bring insight and hide things from us; therefore, I am grateful to the people who share their own stories and knowledge with me. Like Michelle Obama has stated at the end of her memoir *Becoming*, there is a power in owning your unique story and a grace in knowing others; this is an invaluable gift. As someone with multiple relational identities, I hold both a sensitivity to social injustice and have the privilege of navigating spaces closed off to social groups that include some of my family members.

Simultaneously, I refer to the intellectual Judith Butler, who notes the incommensurability of the self in her book *Giving an Account of Oneself* (2005). In the book, Butler concludes that an ethics of care ought to be present whenever a person asks us to give an account of ourselves; this implies the need for a particular sociocultural language and certain concepts to be used such that they allow the other person to become legible to the asking person within the categories made available to them in giving their account. Similarly, I ask that space is made for a hybrid and multi-pronged relational/peripheral identity to be accepted. Thus it is not without both a sense of humour and deep sincerity that I account for myself as a human who is connected to a globalized understanding of Indigeneity by having been raised Coptic, connected to a first-generation “refugee” identity through my father, connected to CCNs through my sister, and connected in a “yes-and” and “both/neither” manner to the experience of racialization, which has recently been termed a ‘racialized adjacent’ identity (Lather, 2006, p. 44).

Project Process Description

This CCNs Project focuses on the scholarly research related to children with CCNs. In this research, CCNs are defined as having either a physical or developmental disability, a medical condition or illness (Brenner et al., 2018). As noted by Brenner et al. (2018), “children’s CCNs refer to multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis” (p.1641). A ‘complex care need’ is therefore simultaneously a medical designation and a highly contextualized socially constructed phenomenon: an individual experience or identity which is continuing and dynamic (p. 1641). In addition, CCNs are present across a range of settings, impacted by many systems, including family and healthcare structures.

The project client is the Children’s Health Foundation of Vancouver Island (CHF), a private charitable organization formally known as Queen Alexandra Hospital. The CHF has invested in the health of Island kids for more than 90 years by collaborating with communities, partner organizations, and donors to fund over 80 organizations and community initiatives. They state in their 2018-2021 Strategic Plan (based on two internal documents shared with me) that their vision is that “all Island kids have access to the health care they need and they fulfill their mission by investing in a variety of programs, initiatives, and resources that focus on three “impact areas,” which are youth mental health, early year development, and children with complex care needs (p. 2). As part of their framework to “Invest in Community; Inspire Giving; Enhance Reach and Reputation; Build Organizational Capacity,” which is intended to both improve quality and accessibility to community health, they intentionally implement mechanisms to engage donors, system leaders, families, and family-serving organizations in collaborative and transformational work (2019-2023 Community Investment Framework, p. 2).

One of these mechanisms included the hiring of three Human and Social Development graduate students to conduct research and write comprehensive literature reviews on the three key focus areas: early childhood development; youth mental health; and complex needs. I applied for the position because I share CHF’s goal to “enhance access to multiple services, therapies and specialists to address the complex needs of children from birth into young adulthood” (2019-2023 Community Investment Framework). The result is a researched report that summarizes and analyses the literature on CCNs in Canada. The CCNs Project provides answers and discussions on the topic of children with CCNs. The broad research question in the literature review is, *what are the ways services for families who have children with complex care needs be improved?* To answer this research question, however, the literature review covers the range of topics including:

- Providing definitions for core concepts on the related topic
- Discovering the general state of the literature (i.e., themes and trends)
- Naming services strategies, types, and stakeholders for CCNs
- Discussing and appraising service quality, processes, communication, and outcomes
- Discussing and appraising services collaboration and partnerships
- Presenting the main findings, promising practices, and lessons learned from the literature
- Presenting research gaps and areas recommendation for further research
- Presenting examples of promising practices and creative ideas for the overall improvement of CCNs services

And lastly the audience is the CHF as well as their donors and stakeholders, who include a wide array of social and healthcare professionals and practitioners.

Research Project Approach & Purpose

One of the purposes of CHF is to highlight current literature on the impact area of CCNs. They noted that children and youth with complex medical needs are “the most at risk in terms of long-term vulnerabilities that, with focus and support, can be reduced or successfully managed” (2019-2023 Community Investment Framework, p. 2). In their “2019-2023 Community Investment Framework” they also stated that “emerging research that speaks to […] industry best practice” is moving in the direction of ‘service provider collaboration’ due to the “positive impact on the outcomes of children and youth” (p. 4). The literature reviews and my CCNs Project form a part of CFH’s commitment to improving the quality and accessibility of healthcare services for Island families. More specifically, referring to the research of Dr. Brenda Poon in the Human Early Learning Partnership (HELP) at UBC, the CHF recognizes the need to “move away from enabling a siloed system through current funding practices” (p. 5).

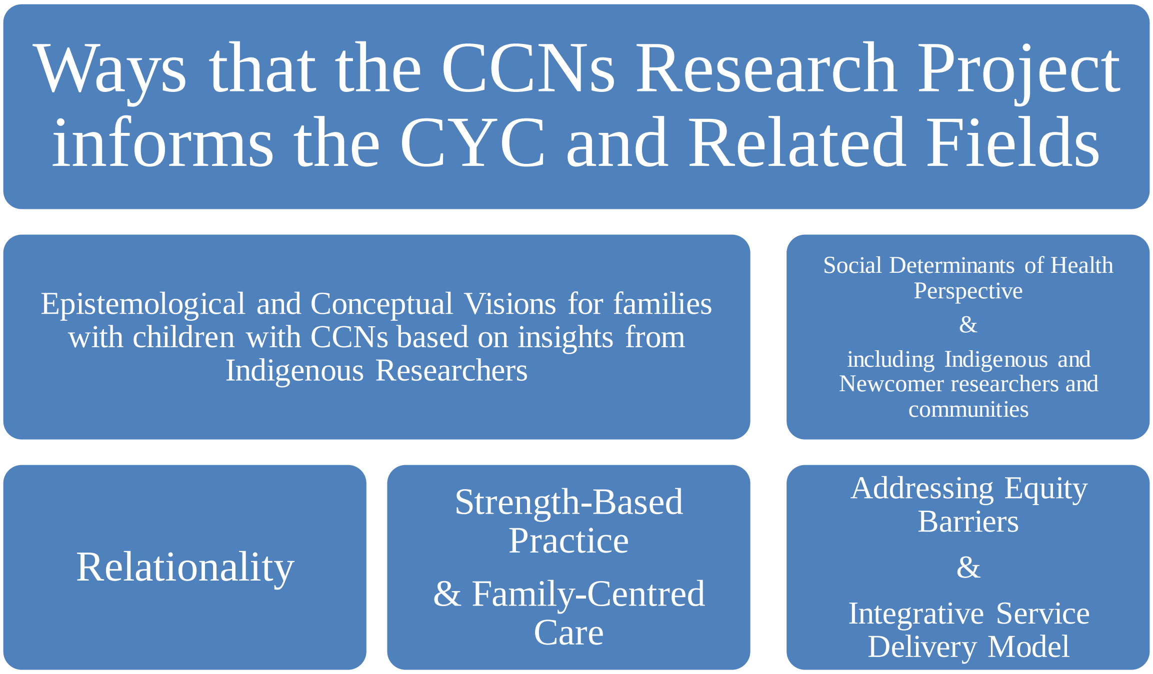
The CCNs Project required a narrative approach to conducting the literature review, as indicated by the project supervisor and project client. Such a narrative approach engages with a “reinterpretation and interconnection” of existing data and literature (Baumeister & Leary, 1997, p. 321). In general, a narrative literature review is designed to gather, synthesize, and present the literature, ensuring that significant and relevant areas of research and studies are highlighted. The diversity of the theories and methods of literature on CCNs makes this narrative approach appropriate.

Project Findings

This CCNs Project offers several findings for the CHF; these findings also have several implications for Child and Youth care practitioners (See Appendix). The CCNs Project reaffirms the following: a) that community inclusion is integral to wellbeing for persons with CCNs, b) that systemic barriers continue to impede the accessibility and quality of programs and services for these children and their families, and c) that practices that uphold trusting relationships are key to inclusion, as well as to the quality of and access to services. I specifically refer to the Strengths-Based Practice and Family-Centred Care models of practice here, which have been overwhelmingly endorsed by experts, advocates, and families alike over the last several decades.

In Part B, I will contextualize these and other findings and recommendations in more detail by explaining how my approach to the research allowed me to focus on Indigenous and Newcomer families with children with CCNs and how this leads to propositions for the CYC field and practice. Fig. 1 visualizes the key concepts utilized in this description of the project findings as well as of my path toward strategies and outcomes.

Figure 1



Reflective Paper Part B: How the Project 'Speaks' to the CYC Field & Practice

Part B will summarize and provide an analysis of the ways the CCNs Project findings and recommendations speak to some relevant tenets of the Child and Youth Care (CYC) field. The following sections will first explain *how* the CCNs Project speaks to these tenets and then provide a full analysis on the ways Indigenous research can inform approaches to improving accessibility and quality of services for people with CCNs. I will end with by providing examples of how these insights may inform CYC practice.

Centering Indigenous and Newcomers

CYC is a broad and swiftly evolving field of interdisciplinary scholarship, community programming, and policy development to enhance children, youth, family, and community well-being (White, 2015). In the CYC field, practitioners work in a variety of settings, inhabit many different roles, and work within multiple and complex contexts. For this research project, my own interpretation of 'CYC practitioners' will refer to anyone in social work, healthcare, public health administration, mental healthcare, childcare, support workers, community workers and even in education. Many practitioners, specialized or not, will work with families where at least one family member will have CCNs, and many of these families may also be Newcomers, Indigenous and/or People of Color (POC). SCYC at the University of Victoria states:

> the School of Child & Youth Care is committed to decolonizing, anti-racist, and anti-oppressive leadership and pedagogies in research and education. Our practices aim at making substantial contributions in advancing social justice and an understanding of diasporic communities, disability studies, critical race theory and studies, gender and

> sexuality, critical queer studies, and Indigenous ways of knowing, doing and being. (SCYC, “Indigenous Initiatives,” 2021)

It is also the case, however, that the CYC field has its roots in a Euro-western, liberal humanist tradition and has been strongly influenced by colonial logic and the ideals of the Enlightenment (de Finney et al., 2012; Saraceno, 2012; Skott- Myhre, 2006 as cited in White, 2015, p. 502). It is important for CYC practitioners to keep the origins of their field in mind when deciphering what approaches and interventions to use and promote because colonial rule continues to assert itself “every day of occupation through violent acts and policies” that result in “disproportionate rates of poverty, policing and incarceration, underhousing, and racialized discrimination” for Indigenous and racialized families (de Finney et al., 2012, p. 32).

As a CYC graduate student and practitioner with a hybrid and multi-pronged peripheral identity—which, as mentioned before, is connected to a globalized understanding of Indigeneity, a first-generation connection to “Newcomers” and “refugees,” as well as shaped by a “yes-and” and “both/neither” connection to the experience of racialization and a significant relational connected to CCNs—I therefore wished to continue to address these inequities, beginning with my ‘behind the scenes’ research questions and my theoretical approach to research, knowing that both would inform the kinds of findings generated. To be specific, while my main research questions were firstly about how to improve service accessibility and quality for families with children with CCNs, my deeper questions within this one were: *What are additional or differing ways to improve CCNs services when the families are Indigenous, Newcomers or families of Color generally? What new insights are produced when we include (centre) communities of Color in the conversation on disability and CCNs?*

Secondly, my theoretical approach to these multileveled research questions made use of the concept of Social Determinants of Health (SDH). And indeed, all these research questions and the SDH approach led me down a path to many creative ideas and promising practice recommendations that speak directly to addressing intersectional inequality in the context of CCNs services. The most developed insights I wish to present here as a way for my MA project to ‘speak back’ to the CYC field are the new insights derived from the research by Indigenous scholars; however, before I present these, I will take the time to provide some contextual discussion points that cover the risks and limitations embedded in this work.

The limits of my MA Project are tied to my ambition to centre People of Color (POC). Due to the classification-based nature of research (and sociocultural trends in the last decade) this meant that I had to discuss categories of people who would be included in this term. In the CCNs Project, I used the terms “Newcomer” and “Indigenous,” and I used phrases like “diverse families.” In this paper I will use terms like racialization, POC, and BIPOC (Black Indigenous and People of Color). I have two points on this matter. First, it is important to note that the CCNs project was ultimately conducted for an audience of “stakeholders” and CHF donors; thus it was born from many discussions with my project supervisors; ultimately, I made the rhetorical move to use apolitical language in the project. Secondly, it should also be noted that the dominant culture has shifted in the years since I wrote the CCNs text. One of the big changes is that it has become more widely acceptable to refer explicitly to racial justice in mainstream institutions. I decided that providing information which spoke to issues of racial justice while using apolitical language was the way forward. If I was to write this report today, I would be more emboldened to explicitly discuss race. There were no issues due to this rhetorical choice, though, and I am mindful of the fact that multiple and conflicting ideas about knowledge, research, language, and practice have no clear answers, no guidebook or ‘right’ path (White, 2015, p. 505).

Now, using terms like BIPOC and Indigenous communities is not without its problems, either. I recognize that, depending on the context, any one of these social groups is diverse within itself; moreover, many people *seen* as POC may not connect with the term, either. Thus, like my scholarly mentors Dr. Sandrina de Finney and Dr. Mandeep Kaur Mucina, my hope is to avoid the tendency to render diverse Indigenous, Brown, Black, migrant, racialized communities as “homogenous or easily comparable” (Moreno & Mucina, 2018, p. 11) or speak for all racialized people; rather, I wish to begin “a conversation that [I] hope continues beyond [my] frames of reference” (2019, p. 88). In the process, I rely on Spivak’s *strategic essentialism*, which recognizes the necessity to essentialize things for knowledge-based or political reasons, while simultaneously not forgetting the limitations and issues of doing so (Spivak, 2001, p. 2194). Therefore, I assert that some of the shared experiences of discrimination based on race, culture, religion, language, and colonialism, as well as the recommended ethical approaches to practice, may bring this wide-reaching community together for the purposes of this conversation (Moreno & Mucina, 2019, p. 88).

In addition, my research offers several insights that speak to racial justice in a CYC context: 1) it reaffirms that people with CCNs who are also part of BIPOC communities continue to face additional and intensified barriers in accessing and benefitting from social services, 2) it notes that Indigenous knowledge is linked to Indigenous wellness, and 3) it verifies that certain approaches to practice (strength-based and family-centred care) provide benefits particular to BIPOC families with children with CCNs. On this basis, 4) it argues that a family with a child (or family member) with CCNs from any background will benefit from Indigenous knowledge, strength-based and family-centred care. However, this last point will require some interrogating.

I wish to keep in mind that under neoliberalism, “an ideology and mode of governance that casts all dimensions of life in terms of a market rationality” (White, 2015, p. 503), the responsibility for care in social services is increasingly downloaded onto Indigenous and racialized communities **(**de Finney, et al, 2018, p. 9). By centring researchers who are Indigenous or POCs, I have taken the risk that my findings will become part of the trend to place unfair pressure and expectations on Indigenous researchers, leaders, and practitioners to educate their peers and policy-makers on “’culturally safe’ trauma-informed care” (p. 9). The recognition by social institutions that Indigenous traditional knowledge contributes to healing and resilience for Indigenous communities (and may also benefit families with children with CCNs from any background) can now be implicated in creating extra burdens for Indigenous communities (p. 9). I also recognize the valid critique that many helping institutions in Canada are taking up Indigenous Knowledge through a process of repackaging it in a “dehistoricized, depoliticized, and disconnected” way that neglects “any conversations about decolonization and Indigenous self-determination” (p. 9).

The fact of the matter is that I speak as an outsider to the Indigenous experience in a Canadian context. Although I acknowledge my hybrid identity and the complex ways in which I navigate an ethical approach to my practice and research, I still work within multiple colonial systems. While acknowledging this is a start, I grappled (and continue to grapple) with the following question: How do I (can I) resist these systems? One attempt to mitigate these risks is to rely on and draw attention to the generous works of the scholars and advocates from my initial research for my Master’s project. Thus, I refer to Margaret Kovach, Cindy Blackstock, Lavonna

Lovern, Elizabeth Cooper, Michelle Driedger, and Anna Green and their co-authors to inform and define ‘Indigenous knowledge, paradigm, research, and practice.’ Therefore, for pragmatic reasons and by using strategic essentializing for knowledge-based and political purposes, the following sections will refer to Indigenous and western knowledge and paradigms in a way that may come across as generalized, even as I acknowledge the many intricacies and complications with these labels. I take this risk to begin this conversation in the hopes that new insights may offer value to improve the lives of children with CCNs, children who are from Indigenous families, and children who are Black or Brown, from migrant families, or otherwise racialized.

Nevertheless, having this conversation at all can unwittingly both risk the appropriation and depoliticization of Indigenous knowledge, as well as run the risk of burdening Indigenous communities to educate non-Indigenous communities. In addition, it may establish a “Indigenous–non-Indigenous binary,” thus leaving out the much needed and nuanced dynamic of non-Indigenous communities of color in the conversation (Mucina & Moreno, 2019, p. 94; de Finney et al., 2018, p.10). My way forward from these risks —in addition to the strategic, pragmatic, and humanistic considerations stated above—is to situate myself under the rubric of the accomplice who “takes up risk” in their support of social justice (Mucina & Moreno, 2019, p. 99). What I risk is the misinterpretation and misappropriation of my work. I must welcome critique by beginning this conversation, because the possibility that these insights could make a positive contribution in a humble way is frankly worth it. In anticipation of this critique, I keep in mind the “Post-Critique” framework of literary theorist Rita Felski (2015), hoping that we as CYC scholars can also follow Felski in going beyond a skeptical deconstruction that may “shed more heat than light” and instead focus on “new perceptual possibilities” to find something that can be “set alight in the reader?” (p. 136; p. 176; p. 179). If, as CYC scholars and practitioners, we are "tasked to embrace a more nuanced, contextualized, heart-centred, and ever-changing praxis that places the needs, desires, holistic growth, and sovereignty of Indigenous, Black, and racialized children, youth, and families at its core" (Mucina & Moreno, 2019, p. 100), then I hope that the Indigenous and racialized communities who I work alongside with will see the start of this conversation as an act of love.

Teachings from Indigenous Knowledge on Children CCNs

The terms 'CCNs' or 'people with disabilities/diversabilities (PWD)' can refer to a wide range of experiences, diagnoses, identities, and contexts, which intersect with race, migration, language, culture, language, and Indigeneity. The goal of this section is to share some of the ways in which Indigenous knowledge, research, and practice overlaps with and enriches the advocacy and support for people with CCNs. This will be accomplished by presenting an expanded version of conversations included in my CCNs Project, most of which are discussions of how Indigenous conceptions of 'difference' and Indigenous epistemologies change the flow of knowledge creation, collection, and dissemination. Both imply suggestions for the CYC field and may inform CYC practice. The last section will describe these propositions by providing examples of recommendations and creative ideas from my CCNs Project.

Indigenous Conceptions of Difference

In her recent article, "Indigenous Perspectives on Difference: A Case for Inclusion," Lovern (2017) has contributed to the initiative of bridging the gap between discourses on Indigenous health and discourses on disability by asserting that "the use of Indigenous paradigms highlights the role of colonization and post-colonization assimilation practices in establishing discrimination dynamics involving disability within Indigenous communities" (p. 303). Her argument is that "the inclusion of Indigenous voices will not only assist Indigenous communities but could also advance disability discussions in Western cultures” (p. 303). Lovern begins by noting how “UN statistics leave no doubt that Indigenous persons with disabilities experience a disproportionate burden” (p. 304) and that “Indigenous knowledge should be a part of global disability documents and research” in order to “[broaden] disability dialogues” (p. 303). To further this point, she discusses how an “emphasis on science assists in establishing a reductionist model of healthcare in Western cultures” and that “reductionist models [and] logical dichotomies” such as “health–illness and abled–disabled” are subjected to a hierarchy “with the positions of good, positive, health, and abled representing a preferable position associated with strength and less desirable positions involving bad, negative, illness, and disabled” then being “associated with weakness” (p. 311).

In contrast, she asserts that traditional Indigenous perspectives have a “diversity equity” position on disability (p. 308). This perspective is based on the assumption that differences in human beings do not hold underlying assumptions that any difference also mean inferior or superior (p. 311). In fact, Lovern notes, “many traditional Indigenous languages have no word for ‘disabled’ or ‘handicapped,’” and that instead all beings exhibit differences with “no preferential position designated as “normal” or “ideal” (p. 313). She points out that most Indigenous knowledge sees “humans and nature [as] interrelated” and that this “interconnectedness involves […] mind, body, and spirit/energy” (p. 313). Hence, these “body and mind differences allow both individuals and communities to gain knowledge that advances human wisdom” (p. 314), therefore, “creating a natural democracy” (p. 311) and “ethical dynamic involving reciprocity” (p. 312).

Just as expressed through the SDH perspective, this interconnection means that the “wellness or unwellness of one impacts the other” (p. 308). Lovern concludes that “a significant component in addressing global issues of disability discrimination requires decolonization involving concepts of body and mind differences" (p. 308). This argument is a cornerstone of the belief in the interconnectedness of community and individual wellness that guided my approach to research on CCNs.

Indigenous Knowledge Creation, Collection, and Dissemination

To be sure, service providers for children with CCNs try to ensure a level of quality; however, familiar processes of "outcome measurements" are often fraught with challenges (BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group, 2015). For my CCNs Project, I was asked to include all approaches and strategies for program quality control; however, when centering Indigenous researchers, I noticed the 'clash' between some of these approaches and what was being said and recommended in Indigenous research projects on CCNs. This led me to include a simplified explanation of how epistemology informs our questions and therefore guides our answers and confirmations. The following is an expanded version of that part.

In recent years, social science research has been leaning towards a more self-reflexive way of doing research. In the context of CCNs, I believe that it is important to take note of Michel Foucault's concept of "power/knowledge," which places power at the centre of the process of knowledge creation (Foucault as cited in Roberts, n.d., p. 33). Some contributions to the research on CCNs agree with this assessment. For example, Jennings et al. (2014), a group of scholars examining newcomer families with children with CCNs, point out that definitions of health and wellness are culturally constructed (p. 1650). This means that families from BIPOC communities may interpret CCNs differently based on their culture and values in ways that trouble the typical establishment in Canadian service provision, which causes barriers and, even worse, harm to the family (p. 1650). In other words, when researchers seek to find “best” or “smart” practices that improve health outcomes, ideally more attention ought to be paid to the ways in which socio-cultural power dynamics and institutional structures greatly influence and constrain their findings.

In her research on suicide prevention for Indigenous youth, White (2009) agrees with this point when she notes that “interrogating the common sense assumptions imbedded in the research-practice” yields more useful insights (p. 2). White promotes a more “complex approach” that empowers the knowledge already existing within the community in which the research is being conducted (p. 2). She believes that adopting a more “critically reflexive orientation” (p. 7) does not mean that one disregard all traditional modes of research, but instead that scholars and practitioners pay attention to what Foucault calls “subjugated knowledge,” and while this concept may refer to many types of knowledge, for the context of this project and local communities I will speak to ‘Indigenous ways of knowing.’

Indigenous scholars in Canada like all assert that Indigenous-led research is appropriate for supporting Indigenous communities (Kovach, 2009; Blackstock et al., 2010). In fact, Cooper & Driedger (2018) acknowledge that “colonial practices, policies, and research studies within Canada have created lasting trauma and harm among indigenous communities” (p. 62), noting that there has been a “long-standing history of deficit-based research conducted on Indigenous people” (p. 62). In turn, they advocate for research that recognizes Indigenous knowledge by “using strength-based approaches” and agree with White that research be “carried out in partnership with community-identified priorities” (p. 64).

Blackstock et al. (2010) point out in the literature review *Commentary: Indigenous Health Special Issue* how “western and Indigenous ontology drive very different research approaches” (p. 136). Ontologies focus on culturally relative conceptions of existence through abstract concepts such as being, knowing, substance, cause, identity, time, and space. In this context, Blackstock et al.’s concern is that “ontology in western research limits the questions it can effectively address” for Indigenous communities (p. 136). Furthermore, Indigenous and western epistemologies, or their theories of knowledge, are also at times disconnected, putting the preferred methods that validate their knowledge at odds with one another. While it is beyond the scope of my research to accurately unpack all the possible ways in which western and Indigenous ontologies and epistemologies can be defined, let alone how they differ from one another, I refer to Blackstock et al. in acknowledging that, with over “300 million Indigenous peoples living in 70 countries around the world,” defining Indigenous knowledge and methodology is a challenge (UNICEF 2003 as cited in Blackstock et al., 2010, p. 135). In a more pragmatic vein, however, any fundamental differences between the two “onto-epistemologies” can be more easily examined with respect to their differing methodological preferences, or modes of knowledge creation and analysis (Blackstock et al., 2010). For instance, Indigenous methodologies arguably have some commonalities, including the notion of “valuing communal rights and relationships” (p. 136), experiential, narrative, arts- and land-based learning (Kovach, 2010), “strength-based approaches” (Cooper & Driedger, 2018), and “interconnectedness” (Lovern, 2017, p. 313).

So, as Kovach (2009) asks in her book, *Indigenous Methodologies: Characteristics, Conversations, and Contexts*, “how are we customizing our Indigenous frameworks to fit within our tribal paradigms while communicating our process to Western academia?” (p. 42). In answering this question, she describes how Indigenous scholars working within the academy face problems utilizing different modes of knowledge creation, stating that “the tension of the insider/outsider dynamic will persist until Indigenous research frameworks have methodological space within academic research dialogue, policy, and practice” (p. 31). And one can hear this issue reflected in practical terms in the BC community research report *Promising Practices in First Nations and Aboriginal Maternal and Child Health Programs: Community Perspectives on what works* (2015): when one participant states that “over the years, we have worked on several evaluation frameworks with relevant indicators and outcomes [and] [p]art of the problem is that we don’t formalize these frameworks and put them into use” (p. 54), another participant adds, “let’s not wait. Let’s select some current programs to evaluate and study, so that we can publish findings and contribute to the ‘evidence’” (p. 54). These sentiments show a clear disconnect and frustration about the different ways communities are obliged to prove that their practices or program structures are valuable and effective.

There are indications, however, that such disconnects are not set in stone. For instance, Kovach (2009) explains that “western research frameworks can be adapted as structural forms that are helpful to the Indigenous researcher” (p. 41) by “allowing the entrance of visual, symbolic, and metaphorical representations of a research design that mitigates the linearity of words alone” as an important piece of “story as Indigenous methodology” (p. 41). For example, in “Navigating the journey of Aboriginal childhood disability: a qualitative study of carers’ interface with services,” Green et al. (2016) use the “journey metaphor” to explore experiences of caregivers with children with CCNs, discovering the “roadblocks” (barriers), “road signs” (the helpful moments), and “navigators” (helpful people) along the way. Green et al. state that “the visual representation of these types of concepts through metaphors aligns with the narrative approach of telling stories that values the spoken word and oral history tradition in Aboriginal culture and is considered a respectful research technique" (p. 4). These methods not only produce findings about the specific ways in which "wrong way signs" and other "roadblocks" are experienced, but also refer to participants' preferred ways to solve them (e.g., the creation of community "navigator positions" for parents with children with CCNs) (p. 6).

The other key piece Kovach (2009) acknowledges in Indigenous research methods is the valuation of community rights and relationships, which involves working collaboratively with communities as research partners, instead of seeing them only as research subjects. For example, in "Creative, strengths-based approaches to knowledge translation within indigenous health research," Cooper & Driedger (2018) ensure that the community has ownership of the data produced by the research (p. 62). By listening with a strength-based lens to qualitative interviews and focus group discussions, they created an all-ages trivia game designed to help convey health-related knowledge to the community and promote heathy practices.

In sum, appreciating the concept of power/knowledge helps to pave the way to better understand the relationship between what we think we know and the authorities in which we are enveloped. Noticing how Indigenous 'onto-epistemologies' arguably emphasize relationality beyond what we typically see in western ones can be a starting point to better understand the existing tensions when making space for Indigenous knowledge in western institutions and thus validating appropriate ways of evaluating and assessing CCNs services.

Conceptual and Practical Ways to Inform CYC Field & Practice

The following section will provide a series of conceptual and practical recommendations from the CCNs Project (see Appendix A) which are also informed by the previous conversations.

These recommendations are for CYC practitioners, researchers, teachers, and especially policy makers. As mentioned in the introduction to Part B, this also includes other related fields such as Public Health, Social Work, and Education. While many of these ideas to inform the policy and practice overlap with each other, for clarity I have placed each offering under sub sections: 1) Relationality, FFC & SBP, and 2) Equity Issues in CCNs Services and the Necessity for more Integrated Services.

Relationality, FCC & SPB

Many CYC practitioners believe that relational practice is at the heart of their work (Mucina & Moreno, 2019, P 93). The more relational ‘onto-epistemology’ allocated in Indigenous knowledge emphasizes the same necessity for trusting relationships rather than seeing them as “added-value” aspects of service delivery. For instance, client family spaces and on-site respite/child care could help reach underserviced communities and also create a sense of welcome for each important family member. For example, spaces in clinical settings where client families can make tea and coffee also serve as sites of organic connection with other families in similar situations and additionally provide them with a moment of refuge while waiting during their child’s appointment. Likewise, many CCNs shareholder organizations offer annual informational conferences and events, but only some ensure that their budgets include on-site respite or childcare, which make all the difference in terms of the accessibility to the families they are serving. In sum, the insights gained through the CCNs Project invite organizations and policymakers to rethink the logistics of on-site respite/childcare, as this not only leads to reaching more families who would benefit from their services but also allows the inclusion of caregiver voices on their advisory boards, thus resulting in further improved services.

The FFC and SBP approaches are two widely recommended approaches to care and relationship-building in a helping context; they are particularly noted by Indigenous and researchers of color as being appropriate for diverse families. FCC, which includes SBP, is compatible with recommendations for Indigenous and Newcomer family clients due to shared philosophies and values. For instance, the shared appreciation of the interconnectedness between families and communities is also at the core of FCC. Practitioners who follow the FFC approaches believe that there is a link between the health and well-being of caregivers (and other family members) and the health and well-being of their children (with or without CCNs); as a result, the families ought to be included in the creation and decision making of the care plans for their loved ones (Couchenour & Chrisman, 2016, p. 3). In addition, because it focuses on strengths rather than deficiencies, the SBP approach has been cited time and time again as a key part of building trusting relationships and as a way of situating problems in systems rather on individual bodies. Through these approaches, families' perspectives and goals for their child are often more respected.

This respect for the interconnectivity of family (and community) alongside a focus on the families' abilities and strengths can inform practitioners in profound ways during their assessments and evaluations, as well as when they administer or recommend any interventions (Andersen, et al 2012; Phoenix & Rosenbaum, 2015; Rosenbaum, 2011; Franck & O/Brian, 2019; Couchenour & Chrisman, 2016). I will illustrate the profound capacity of these frameworks to change outcomes with an example from my own life and observations. Without FCC and SBP as a framing approach, a parent who is late for an appointment can easily be labeled "irresponsible" or even "lazy" and "uncaring" regarding their child's complex needs. Worst of all, some practitioners can come to believe that their client's lateness is a personal sign of disrespect for their professional time. Alternatively, a practitioner who adopts the FCC and SBP framing recognizes that this parent still showed up even though they are facing circumstances that are interfering with their schedule and time management. Based on a clear recognition that lateness is a common challenge for parents with children with CCNs to begin with, they may be working with them to find compassionate and creative solutions rather than taking punitive measures. Furthermore, for policymakers who adopt a FFC and SBP framework, their funding-based and structural recommendations and choices can be influenced profoundly as well. For example, they may invest in more kinship-related CCNs programs and services that include siblings, grandparents, and extended family members, whose participation and needs in their own rights have been well documented (Camden et al., 2013; Meltzer, 2018).

Equity Issues in CCNs Services and the Necessity for more Integrated Services

The other recommendation from the research on CCNs and integrated services is the notion that CCNs services ought be organized in a more integrated and collaborative fashion. This recommendation has some synergy with the Indigenous ways of knowing and holistic approaches to health described above. Taking the relational FCC and SBP practice seriously, CYC practitioners (including researchers and policymakers) may appreciate and take on the following propositions for supporting a more fair and integrative service delivery model.

First, they may create ‘Service Navigator’ positions for communities. This idea is based on the research by Green (2016) to assist families through the bureaucratic mazes they face when trying to receive assistance based on CCNs, which can include other related systems such as Immigration or Legal systems. Imagine a team of professionals whose job is solely to comprehend the twists and turns of service and funding systems and to help families individually as well as by creating resources like maps for communities in general. This idea overlaps with the significance of relational practice as human-to-human help for accessing ‘survive and thrive’-type services that could have dramatic impacts on the health outcomes of a person with CCNs.

Secondly, the may adhere to the T&R recommendations, particularly by honouring Jordan’s Principle (a principle meant to ensure that children receive the public services, often specialized equipment for medical needs, swiftly). Jordan's Principle can be achieved through the coordination and communication of multiple and multileveled organizations; this is a prime example of how to directly remove barriers to health-related supports for Indigenous children with CCNs (First Nations Child and Family Caring Society, n.d.; T&R, 2013). I personally cannot think of any action more poignant in this regard than honouring the legacy of Jordan River Anderson and the community who loved him by endorsing this and other initiatives that address the unjust discrepancies faced by Indigenous families in accessing appropriate healthcare (“Budget” in First Nations Child and Family Caring Society, 2019, p. 1).

Thirdly, practitioners may recognize how settlement services are part of CCNs services and ought to be included as a part of services that benefit children with CCNs (Alsharaydeh et al, 2019; Jennings, 2014; Khanlou et al 2017). Khanlou et al (2017) recognize that “one potentially fruitful endeavor would be to examine how child welfare agencies may assist in creating and implementing family-centered service plans” (p. 240). They consider that since “immigration is increasingly recognized as being an important factor in child welfare” perhaps clinical spaces could better support immigrant mothers in accessing settlement services and settlement services could be more integrated with health and social services addressing CCNs (p. 251).

Fourthly, my research found a less popular, but still consistent issue regarding people with CCNs: the fact that they receive less preventative dental care and more tooth extractions than the rest of the population in Canada (Coultes-Macleod et al., 2008; Ummer-Christian et al., 2018). Some reasons for this have been stated as dentists' "unwillingness" to treat patients with developmental disabilities, sometimes because they receive no additional compensation for the extra time and effort often required (Ummer-Christian et al, 2018). Some solutions include reviewing existing policy gaps, addressing guidelines on provision for additional time and funding of treatment rooms, facilitating academic and continuing professional education for dental practitioners regarding treating patients with CCNs, and developing avenues for dental practitioners to connect to a wider network of disability-related support resources (p. 12).

Based on these recommendations, I have a proposition to write an article which examines the individual approach of a local dentist as a case study. Local Victoria dentist Dr. Sunny Tatra is one of the only dentists that I have encountered who follows a model of "compassionate practice" and, in my mind, also a patient-centred and SBP-based approach (although his website does not label it this way). As a result, he serves many patients with CCNs, anxiety, and other complexities. Furthermore, taking the time to reach out to instructors in the school of Public Administration and dental programs could provide a platform for sharing this piece and its insights. I even consider adapting it into a pamphlet or workshop presentation. Dental healthcare is often ignored because it is usually not a 'life or death' matter as in other areas; arguably, though, dental care has a tremendous amount of significance regarding quality of life and social stigma. People with CCNs deserve the same level of care for their dignity and day-to-day functioning that quality dental care provides.

Conclusion

There are many ways for mainstream disability advocacy to meaningfully include Indigenous communities in respectful ways. I have listed some options above. While listening and learning from Indigenous researchers and family advocates, I acknowledge the valuable insights for CCNs shareholders to learn from their insights to the benefit of both Indigenous children and children with CCNs from any background. I hope that these engagements of learning can be done in a spirit of reciprocity and respect. I reiterate Lovern's invitation to continue to explore the ways in which Indigenous knowledge can assist "western cultures in redesigning their treatment of persons of difference" (p. 316). Indeed, this is a risk, as discussed earlier; however, if "courage is a necessary ethical ingredient in approaching the uncertain future of social work, CYC, and human service work," then this risk is necessary (Moreno & Mucina, 2019, p. 100). This means that non-Indigenous CCNs advocates in positions of power and influence can and ought to incorporate the following in their quest to support families with children with CCNs: 1) support more Indigenous-led research and 2) adhere to the T&R recommendations, particularly by honouring Jordan's principle in their missions and goals. This can be the start, or perhaps even a continuation, of a more "relational ethical praxis" in the helping profession and social/healthcare systems (Mucina & Moreno, 2019, p. 100).

This research is meant to be a contribution to the task of "embrace[ing] a more nuanced, contextualized, heart-centred, and ever-changing praxis that places the needs, desires, holistic growth, and sovereignty of Indigenous, Black, and racialized children, youth, and families at its core" and "consider[s] collaborative, relational, and spirit-engaged" ways of working together (Mucina & Moreno, 2019, p.100). While there is no one-size-fits-all solution, the CCNs Project identifies several practical, creative, and conceptual initiatives and frameworks for addressing quality and accessibility of CCNs services, which may help assist in improving the health and wellness of children with CCNs and their families.

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Appendix

Research Findings from the CCNs Project

Research Findings

- **Complexity-** Children with CCNs spans across many sectors and disciplines, with a large quantity of information and considerations coming from different language and labels, diagnoses, populations, and locations.
- **Barriers to Access** – Barriers in accessing support services occur on multiple levels, which include ideological, institutional, and interpersonal levels.
- **Equity** – One of the greatest barriers is equity of access, particularly for Indigenous and newcomer families with children with CCNs.
- **Relationships and Inclusion** – Both trusting relationships and social inclusion are linked to positive health outcomes for people with CCNs.
- **Integrative and Collaborative Service Delivery** – A reoccurring trend in the literature is that accessing services is found to be extremely complicated with parents stating that there is a lack of available information to assist them. There are extensive recommendations in the literature for a more integrative, holistic, and collaborative service model.
- **Family Centred Care (FCC) –** There are extensive recommendations for the FCC approach when working families with children with CCNs.
- **Knowledge** – Knowledge creation is based on different cultural philosophies which can cause rifts between research and practice, impacting what knowledge is created and what recommendations are made to address the families with children with CCNs.

- **Promising Practices** – Promising practices are recommended by international health authorities and are endorsed in the academic literature. They include 1) the social determinants of health (SDH) perspectives on health and well-being; 2) Family Centred Care (FCC), and 3) Strength-Based Practice (SBP).

Creative Ideas

- Sibling Inclusive Programming
- Settlement Services included as a part of services that benefit children with CCNs
- Practical Recommendations on Improving Dental Services
- Family Centred Care Values, Principles, and Models
- Bridging Indigenous Perspectives on difference and Western concepts of disabilities
- Key Considerations for Community-Based Research
- Making Alternative Therapy Choices Happen (MATCH) Approach
- Strength-Based Practice (SBP)
- Diversity Scholarships
- Creation of ‘Service Navigator’ Positions
- Increases in Childcare/Respite Services

CHILDREN'S HEALTH FOUNDATION OF VANCOUVER ISLAND:

LITERATURE REVIEW STUDY

Three Impact Areas:

Early Childhood Development

Youth Mental Health

Children and Youth Living with Complex Needs

May 2020

Presented to the Children's Health Foundation of Vancouver Island

Presented by Dr. Kimberly Speers, School of Public Administration, University of Victoria

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Executive Summary

Purpose and Background:

This purpose of this report is to highlight the literature related to three impact areas the Children's Health Foundation of Vancouver Island (the Foundation) sees as core to their functions and operations:

- **Early childhood development (0 to 6 years old)** – For this impact area, the Foundation seeks to enhance access to programs and resources for families and their children before birth to age 6, focused on prevention and early intervention.

- **Youth mental health (7 to 24 years old)** – For this impact area, the Foundation seeks to enhance access to programs and resources for youth and their families focused on prevention, early intervention and therapeutic supports addressing mental health and well-being.

- **Children and youth living with complex needs (0 to 24 years old)** – For this impact area, the Foundation seeks to enhance access to multiple services, therapies, and specialists to address the complex needs of children from birth into young adulthood.

Literature reviews are an important method for organizations to learn more about recent research, themes and trends, gaps in the research, and smart practices to provide additional direction and support for evidence-based analysis and to support a learning organization.

Methodology:

There were three literature reviews written for each of the impact areas and while each literature review is presented as a chapter, there is much overlap between the different impact areas given the intersectionality of the issues being addressed.

The type of literature review that was written for each of the reviews is typically referred to as a narrative or traditional type of review. In general, a narrative literature review is designed to gather, synthesize, and present the literature ensuring that significant and relevant areas of research and studies are highlighted. It also identifies areas where there are gaps in the literature whether it be place-based, methodological-based or topic-based.

To complement and support the narrative literature review, a focus on smart practices was applied to various themes within each topic. Smart practice, a term coined by Bardach (2015), refers both to a descriptor of practice, particularly when the use of 'best' is inaccurate, and an evaluative tool to assess the applicability of seemingly effective solutions from one setting to other settings. The use of 'smart practices' instead of 'best practices' is increasingly becoming popular given the understanding that what may work for one organization may not necessarily work for another organization; in other words, there is no such thing as a best practice for all organizations. Alternatives to 'best' were frequent in the literature and ergo, there are other terms such as ‘promising, emerging, and wise’ that are used throughout the literature reviews to denote practices that an organization could further investigate and consider for adoption once other variables are taken into consideration such as culture, size, service focus, clients, legislation, and stakeholders. Such terms in this report are often used to indicate practices that have been acknowledged by their peers or experts to be successful in their source settings and have definable implementing, supportive and optional features (Bardach, 2015, pp. 131-132).

Overall Main Findings:

Some of the key highlights of the literature reviews are:

- **Complexity of needs and solutions** – In each impact area, the literature notes that it is impossible to apply a ‘one-size-fits-all’ or template approach to addressing a problem or issue. While there are demographic features that can help to identify trends and issues, many authors argue that it is important to understand the complexity of needs each child or young person may experience and that solutions span across many sectors and disciplines, with a large quantity of information and considerations coming from different language and labels, diagnoses, populations, and locations.
- **Barriers to access** – In each of the impact areas, the literature identified the following barriers to accessing support services - ideological, institutional, geographical, resource capacity, income, and interpersonal.
- **Family-centred care approach** – The literature in each of the three impact areas focuses on the relationship between the child and a family when addressing mental health, early childhood development, and children and youth living with complex needs. Especially in the children and youth living with complex needs impact area, an emphasis was placed on having a Family-Centred care approach
- **Focus on early childhood development** – The literature found that children’s formative years are of incredible value to the child, family, and society at large. It was found that is a time when both threats and benefits to life-long development are intensified. The literature focused on how children’s early environments are understood and/or augmented and how programs and services can support healthy human development on individual and societal scales.
- **Equity and intersectionality** – Across the three impact areas, one of the significant themes was identifying barriers to and reducing the barriers to accessing services. Some of the barriers to access are especially experienced by Indigenous and newcomer families with children with CCNs. In the early childhood development literature, equitable access to early childhood development services has become an international measure of quality for such services and programs. In the youth mental health impact area, providing better and culturally-sensitive services for Indigenous youth that are Indigenous-led are being called for by researchers.

- **Moving online** – In the youth mental health impact area, a significant trend that was identified in the literature was a move for organizations to provide not only in-person services but online preventative and support service as well.
- **Focus on outcomes and impacts –** In the literature for each of the three impact areas, there was consensus that it was challenging to accurately measure and report on short/medium/long-term outcomes and impacts because of such factors as lack of data to assess, an organization not having measurable goals or objectives, and the overall challenges of attribution.
- **Integrative and collaborative service delivery** - There are many calls for and recommendations in the literature in each of the three impact areas for a more integrative, holistic, and collaborative service model. Collaborating to disseminate knowledge and share data is also an identified trend

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1.0 Introduction

1.1 Purpose

This purpose of this report is to highlight the literature related to three impact areas the Children's Health Foundation of Vancouver Island (the Foundation) sees as core to their functions, services. and operations:

- Early childhood development (0 to 6 years old) – For this impact area, the Foundation seeks to enhance access to programs and resources for families and their children before birth to age 6, focused on prevention and early intervention.
- Youth mental health (7 to 24 years old) – For this impact area, the Foundation seeks to enhance access to programs and resources for youth and their families focused on prevention, early intervention and therapeutic supports addressing mental health and well-being.
- Children and youth living with complex needs (0 to 24 years old) – For this impact area, the Foundation seeks to enhance access to multiple services, therapies, and specialists to address the complex needs of children from birth into young adulthood.

1.2 Value of Literature Reviews

There are many reasons why a literature review may be conducted for an organization. Increasingly so, organizations are developing literature reviews to help improve the learning capacity and retention of knowledge in an organization so that the leadership, employees, and other stakeholders can continue to build their knowledge and expertise in topics related to their area of service. In this sense, we see the Foundation as continuing their learning journey through learning about recent literature in three of their impact areas – youth mental health, children and youth living with complex needs, and early childhood development.

Another reason why literature reviews are valuable to many organizations is that they can be seen as a line of evidence in an organization where measuring and evaluating the short/medium/long term outcomes and impacts can be difficult because of the many variables influencing the goals and objectives of implementing and managing a service or process. In this sense, a literature review can help identify new ways of measuring, how to overcome attribution barriers, and how to develop baselines. Instead of reinventing the wheel, a literature review can help an organization learn what has worked and not worked well in an organization to perhaps learn from smart practices or even worst practices (i.e., what not do to and why). A literature review can help an organization develop a sense of how their own services compare against similar services. For example, is the same lexicon being used within similar services? How does an organization work with their partners? How does an organization improve quality of services given their resource capacity?

Through literature reviews, organizations can also identify research themes and trends, areas of agreement and disagreement, gaps in or open questions left from other research, what programs or services are receiving more attention than others and why, and areas where further research is needed. All of these components of a literature review support not only an evidence-based analysis and decision-making process but one that is critical, strategic, and well-rounded in that it is grounded in the foundations of the scholarly and grey literature for each of the impact areas.

1.3 Organization of Report

Given the current state of literature on each of the topics, the various programs and services offered by the Children's Health Foundation, and CHF's multiple stakeholder relationships across various sectors, numerous topics are addressed in this literature review.

To develop a literature review reflective of a learning organization that supports evidence-based analysis and decision-making, each literature review is structured in a similar manner and addresses topics that are aligned with the Foundation. Most of the following topics are addressed in the three literature reviews:

- Methodology and methods – identifying search strategies and defining the scope
- Definitions and core concepts for each topic
- General state of the literature – themes and trends
- Services – strategies, types, and stakeholders
- Services – quality, processes, communication, and outcomes
- Services – collaboration and partnerships
- Main findings and areas for further research
- Smart practices and examples

References for each of the literature reviews are immediately after each specific literature review and with all of the appendices located at the end of the document in the order they were mentioned in the document.

2.0 Literature Review: Children With Complex Care Needs

Primary author: Amira Abdel-Malek

Secondary author: Kimberly Speers

2.1 Executive Summary

This literature review focuses on children and youth living with complex care needs (CCNs) and uses a narrative literature review design approach to research and write the review.

The sources used in the literature review are academic and grey literature from the past 15 years and mainly situated in and written about from a Canadian context.

The key highlights arising from the literature review are:

- Children with CCNs spans across many sectors and disciplines, with a large quantity of information and considerations coming from different language and labels, diagnoses, populations, and locations.
- Access to services is complicated for families who have young family members with complex care needs – barriers are based on ideological, institutional, and interpersonal factors.
- Barriers include equity of access to CCNs services, particularly for Indigenous and migrant families with children with CCNs in Canada.
- Long term trusting relationships and social inclusion are linked to positive health outcomes for people with CCNs.
- Authors have made numerous recommendations on how to improve current services and have focused on the provision of integrative and collaborative service delivery
- There are extensive recommendations for the FCC approach when working families with children with CCNs.
- Promising practices are recommended by international health authorities and are endorsed in the academic literature. They include 1) the social determinants of health (SDH) perspectives on health and well-being; 2) Family Centred Care (FCC), and 3) Strength Based Practice (SBP).

2.2 Acronyms

The following acronyms are used in this literature review:

- BC - British Columbia
- CHF - Children's Health Foundation of Vancouver Island
- CCNs - Complex Care Needs
- FCC - Family Centred Care
- SBP – Strength Based Practice
- SDH - Social Determinants of Health
- TIP - Trauma informed practice
- UN - United Nations
- UNCRC - United Nations Convention on the Rights of the Child
- UNCRPWD - The United Nations Convention on the Rights of Persons with Disabilities
- UNDRIP - United Nations Declaration on the Rights of Indigenous Peoples
- UVic - University of Victoria
- WHO - World Health Organization

2.3 Introduction

This literature review is part of a collaborative research project, managed by the Principal Investigator, Dr. Kimberly Speers, who works in the School of Public Administration at the University of Victoria (UVic). The project is sponsored by UVic Research Partnerships and the client for the project is the Children's Health Foundation (CHF).

This literature review focuses on the scholarly research related to children and youth living with complex needs (CCNs). While there are many ways to define 'children and youth living with complex needs,' it has generally been understood to mean either a physical or developmental disability, a medical condition or illness (Brenner et al., 2018). Brenner et al., (2018) further note in their systematic concept analysis on CCNs that "children's CCNs refer to multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They [CCNs] are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by family and healthcare structures" (p. 1641).

Related to the content and structure, this literature review focuses on the following key areas:

- General State of the Literature on CCNs: Themes and Trends
- Services for CCNs: Stakeholder Types and Strategies
- Services for CCNs: Quality and Process
- Services for CCNs: Collaboration, Partnership and Engagement

- Promising Practices for Services that address CCNs

2.4 Methodology - Type and Scope

Type of Literature Review and Scope

The following literature review is described as a narrative type of review, which is a "reinterpretation and interconnection" of existing data and literature (Baumeister & Leary, 1997, p. 321). In general, a narrative literature review is designed to gather, synthesize, and present the literature ensuring that significant and relevant areas of research and studies are highlighted. It also identifies areas where there are gaps in the literature. The methodological diversity of literature on the complex subject of CCNs, makes this narrative approach suitable.

To complement and support the narrative literature review, there will be a focus on "smart practices" in the literature review. Smart practices, a term coined by Bardach (2015), refers both to a descriptor of practice, particularly when the use of "best" or "evidence" based is inaccurate, and an evaluative tool to assess the applicability of seemingly effective solutions from one setting to other settings (Bardach, 2015, pp.131-132). Within the CNN literature, the term 'smart practices' is used but another similar term, 'promising practices' is increasingly popular because of the growing recognition that the qualities of any practice may not be applicable to all settings, contexts, and populations. Further, the use of promising practices is when "there is sufficient evidence to claim that the practice is proven effective at achieving a specific aim or outcome, consistent with the goals and objectives of the activity or program" Homeless Hub, 2019). Promising practices also encourages a more reflexive way of defining a highly recommended practice and is thus appropriate for such a complex research area as CCNs.

Search Strategies

To narrow the scope of the literature review, the search and review parameters were:

- Materials from high-income countries (mainly Canada)
- Literature published in English
- Literature published in the last 15 years
- Sources that were primarily peer reviewed and secondly, grey literature when the academic research was non-existent or scarce.
- Sources from various research databases in the University of Victoria library.

Expanding on the above bullet list, this literature review primarily focused on reviewing peer reviewed journal articles and books published in the English language between 2010-2019 with preferences for research conducted in Canada. Sources from Australian and American research were also included when directly relevant and seen to add value to the review. While the focus of the review was on examining the scholarly literature, grey literature from North American authors was included when there was not any academic research on a topic.

The research databases that were used to find resources included Google Scholar, CINAL, PsychInfo, the UVic Library Summons database, as well as Google Search. In addition, reference lists at the end of articles and books were also mined for related works.

The main search terms included:

- Families/children/youth
- Complex (care) needs/disabilities/special needs
- Accessibilities/barriers to services/services/programs
- Canada/BC
- Indigenous/First Nations/Aboriginal
- Migrant/Immigrant

2.5 General Themes and Outline of Literature Review

Given the complexity of developing, implementing, evaluating, and managing services related to children and youth living with complex care needs, which includes a variety of programs and services offered by the Children's Health Foundation and multiple stakeholder relationships across various sectors, numerous topics were addressed in this literature review.

Research Findings

- **Complexity**- Children with CCNs spans across many sectors and disciplines, with a large quantity of information and considerations coming from different language and labels, diagnoses, populations, and locations.
- **Barriers to Access** – Barriers in accessing support services occur on multiple levels, which include ideological, institutional, and interpersonal levels.
- **Equity** - One of the greatest barriers is equity of access, particularly for Indigenous and newcomer families with children with CCNs.
- **Relationships and Inclusion** - Both trusting relationships and social inclusion are linked to positive health outcomes for people with CCNs.
- **Integrative and Collaborative Service Delivery** - A reoccurring trend in the literature is that accessing services is found to be extremely complicated with parents stating that there is a lack of available information to assist them. There are extensive recommendations in the literature for a more integrative, holistic, and collaborative service model.
- **Family Centred Care (FCC) –** There are extensive recommendations for the FCC approach when working families with children with CCNs.

- **Knowledge -** Knowledge creation is based on different cultural philosophies which can cause rifts between research and practice, impacting what knowledge is created and what recommendations are made to address the families with children with CCNs.
- **Promising practices -** Promising practices are recommended by international health authorities and are endorsed in the academic literature. They include 1) the social determinants of health (SDH) perspectives on health and well-being; 2) Family Centred Care (FCC), and 3) Strength-Based Practice (SBP).

In sum, while there is no one-size-fits-all solution, the literature identifies several practical, creative, and conceptual initiatives and frameworks for addressing the barriers to accessing CCNs services that assist in social inclusion and health care.

These promising practices are:

- **Promising Practice 1** - Family Centred Care (FCC) approach encourages more family participation in health care planning
- **Promising Practice 2** - Adopt a social determinants of health (SDH) perspective
- **Promising Practice 3** - Adopt a Strength Based Practice (SBP)
- **Promising Practice 4** - Address equity issues that supports Indigenous research on community health
- **Promising Practice 5** - Increase and improve integrative and collaborative service delivery by facilitating trusting relationships.

2.6 Definitions and Concepts

Children and youth's complex care needs (CCNs) are a vast research topic, which warrants specific concepts and working definitions to be made plain ensuring clarity and comprehension of the analysis. This section identifies the various definitions of the main concepts and terms within the CCNs literature.

Complex Care Needs (CCNs)

The primary concept in this literature review is children and youth with complex care needs and this is a fairly new concept that has been used by both the academic and practitioner communities in the past several decades (Brenner et. al., 2018). Based on the literature, CCNs tends to be used more in the academic environment than a practitioner environment although there is overlap. In general, children and youth with complex care needs is commonly referred to those children and youth who have a wide array of development and physical disabilities, illnesses, and other motor-cognitive conditions. Since the general topic related to children and youth with complex care needs is so complex and has only recently as a concept been systematically analyzed, Brenner et al. (2018) found that CCNs is a growing phenomenon that is often misunderstood or confusing (p. 1641). While there are numerous definitions of children and youth with complex care needs, this literature review relies on the definition developed by Brenner et al., (2018). After analyzing one hundred and forty publications in peer-reviewed journals between January 1990 and December 2017, the authors found that CCNs share the following characteristics: CCNs are "individual and contextualized, continuing and dynamic, and are present themselves across a range of settings, impacted by family and healthcare structures" (p. 1641). In addition, the concept of CCNs is also applicable to children who may not have an official diagnosis for falling under the category. This interpretation is in line with the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD), which subscribes to the notion that "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (UNCRPD, p. 1). In this literature review, CCNs will be used to refer to a vast range of physical and developmental disabilities and medical conditions and illnesses children experience. In short, CCNs refers to "multidimensional health and social care needs" (Brenner et al., 2018, p. 1641).

Social Determinants of Health (SDH)

Another term that has received much attention by the scholarly community and practitioners is the social determinants of health. Social determinants of health can generally be defined as "the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power, and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities – the unfair and avoidable differences in health status seen within and between countries" (WHO, n.d.).

The concept of SDH is important in the discussion of CCNs, because an understanding of the ways in which the bio-medical aspects of CCNs are influenced and shaped by social, economic, and political factors is both a current trend adopted by international health authorities and offers a helpful lens for appreciating the role of social context in the lives of people with CCNs (Furrie, 2018; Rosenbaum & Gorter, 2012; "SDH" in Who, 2017; UN, 2007; 2008). The SDH perspective has been endorsed by the *World Health Organization* (WHO) in an attempt to be more thorough in health analysis (Furrie, 2018, p. 3; "SDH" in Who, 2017).

In general, the SDH literature sees that several of these social forces contribute to the risk factors associated with having a disability; in addition, the SDH perspective also informs the way disabilities are medically conceptualized (Coultes-Macleod et al., 2008, p. 18). In other words, a medical diagnosis is heavily shaped by power structures that include social, cultural, political, and historical contexts. Today, Canada continues to rely on the SDH approach as prescribed by extensive research (BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group, 2015, p. 12; Brenner et al., 2018; First Nations Child and Family Caring Society n.d.; Furrie, 2018; Healthy Child Manitoba, 2013; Jennings et al., 2014; Khanlou, et al., 2017).

This approach pays close attention to the role that social supports and community inclusion play in the overall well-being of families with children with CCNs (Rosenbaum, 2011, p. 69).

On the practical side, the medical dimensions that make up CCNs are often central to interventions and services; however, a SDH perspective shows the challenges associated with caring for a child with CCNs, such as chronic stress, depression, and social isolation. These social determinants of health can also stem from socio-political and historical conditions and their resulting power relations such as a segregated society or a lack of accommodations for CCNs. Ergo, instead of essentializing the 'problem' of CCNs, the SDH perspective locates solutions in the institutional, systemic, and sociological arenas (Brenner, 2018; Franck & O'Brien, 2019 Franck & O'Brien, 2019; Green, et al., 2016; Rosenbaum, 2011; Rosenbaum & Gorter, 2012; Healthy Child Manitoba, 2013; Jennings et al., 2014; Khanlou, et al., 2017; Coultes-Macleod et al., 2008; Inclusion BC, n.d.; First Nations Child and Family Caring Society n.d.).

2.7 General State of the Literature: Themes and Trends

This section discusses the following four primary themes from the literature on children and youth with CCNs: relationships and community inclusion, equity in accessing services, integrated and collaborative services and Family Centred Care.

Relationships and Social Inclusion

This section examines the significance of social inclusion for children with CCNs, as well as the role quality relationships and advocacy for social inclusion play in child well-being. The literature on CCNs reveals that quality relationships and inclusion in one's community are a key part to the well-being of children, especially when they experience multiple barriers. From the Social Determinants of Health (SDH) perspective, the social and bio-medical aspects of human life are interrelated ("SDH" in WHO, 2017; Khanlou, 2017, p. 1647). For example, Khanlou et al. (2017) show that social support is significant for the overall well-being of children and youth with complex care needs and that social integration acts as a protective factor against medicalized issues, such as depression.

The UN defines social inclusion as "the process of improving the terms of participation in society, particularly for people who are disadvantaged, through enhancing opportunities, access to resources, voice and respect for rights" (UN, 2008, p.17). In support of social inclusion, Hiranandani, Kumar & Sonpal (2014) note that "community-based inclusive development and wider participation of persons with disabilities in all spheres of life have been legitimated globally" (p. 151). In addition, Dr. Rosenbaum, co-founder of the award-winning *CanChild Centre for Childhood Disability Research*, also supports the perspective that social inclusion is essential for the health and well-being of children with CCNs (Rosenbaum & Gorter, 2012; Phoenix & Rosenbaum 2015; Rosenbaum, 2011). This notion is reflected in his guidelines presented in a series called “The F-Words in Child Neurodisability —family, function, fun, friends, and fitness,” which he bases on the World Health Organization’s recommendations for the SDH perspective (Rosenbaum & Gorter, 2012). Similarly, Falkson et al. (2017) expand on the point that children living in their family homes show advantages in their physical, psychological, emotional, social, and cognitive development in comparison to those who live in institutions (p. 214). Moreover, the children research participants in their study underline the importance of their friendships, as well as keeping a state of normalcy and independence had in their lives (p. 221).

The presence of caring and respectful social relationships are also protective factors when it comes to health and development (McQuay, 2016, p. 21). McQuay (2016) finds that connections with caring adults at home and at school are powerful predictors of positive adolescent behavior and functioning (p. 28). Moreover, strong connections with caring adults who highlight strengths are often also predictors of personal well-being (p. 33). McQuay raises the concern that, if youth with CCNs living in residential care are without these kinds of foundational, long-term, trusting relationships, they may experience more impaired relational skills, with negative effects on their ability to form positive and meaningful relationships across their lifetime (p. 33).

Presently, many people with developmental disabilities may have less relationships that go beyond their own families or paid caregivers (Coultes-Macleod, 2008, p. 26). As a result, social isolation and experiences of alienation have extensively been reported by families with children with CCNs (Brenner, 2018; James, 2019; Falkson et al., 2017; Coultes-Macleod, 2008). Numerous authors report that these experiences can be traumatizing for all family members. For example, Falkson et al. (2017) describe families’ experiences of negative reactions from the public in response to the sight of their child with a tracheostomy and their respiratory equipment. Alsharaydeh, et al. (2019) also note that families may often experience social ostracization in response to their child’s atypical behavior in public places. Both Falkson et al. (2017) and Alsharaydeh, et al. (2019), as well as James (2019) and Ummer-Christian et al. (2018) report that, in addition to public settings, parents can also feel excluded and isolated by health authorities in healthcare settings, based on their impression that “their children's life has no priority” (Alsharaydeh, 2019; p. 214).

In the literature, it was found that non-profit organizations, who deliver many social inclusion initiatives and advocate-focused services for adults and children with CCNs, depend on both public and private funding for the implementation and sustainability of these initiatives and services. In one of the first academic reviews on the relationship between state spending and the social sector in BC since the 1960s, *How the State Shaped the Nonprofit Sector*, it is pointed out there without a clear philosophy guiding public spending policies, federal and provincial governments budgets are instead “dictated by shifting government priorities” which results in some increases for parts of the social sector and decreases in others areas (p. 318-319). And although the exact scale of public funding for specific organizations is unknown, what is known is that many grants for non-profit organizations are service-delivery-focused, meaning that more long-term projects can become more difficult to establish (p. 315).

Across many advocacy groups for people with CCNs (Council of Canadians with Disabilities, Canadian Association for Community Inclusion, and the Canadian Association of Independent Living Centres), there is agreement that providing more funding is the best way to implement “meaningful inclusion initiatives” (Coultes-Macleod, et al., 2008, p. 40; Brenner, et al., 2018; James, 2019). For instance, Coultes, et al., (2018), finds that “for the government funded social service system, there continues to be difficulty in retaining staff due to wage disparities with other sectors (children’s mental health, education), poor career path options and fragmented training strategies” (p. 43). Furthermore, in the BC report *Promising Practices in First Nations and Aboriginal Maternal and Child Health Programs* (2015), their participants stressed that “competitive, proposal-driven processes place certain communities at a significant disadvantage” (p. 57). Furthermore, they supported funding initiatives that cover the cost of wages and benefits since high staff turnover was identified as a detriment to program security and longevity (p. 57).

In sum, the presence of trusting relationships and social inclusion increases children with CCNs quality of life. The literature shows that the possible absence of fully comprehensive funding policies and short-orientation funding models are barriers for CCNs service delivery, which in turn affects their access to social inclusion opportunities.

Equity in Accessing Services

Another key theme in the CCNs literature is equity in accessing appropriate services. The findings in both academic literature and professional organizations are consistent. While families with children with CCNs from all cultural and ethnic backgrounds experience hardship in their quest to support and include their children (Brenner et al., 2018; Camden, et al., 2010; Coultes-Macleod et al., 2008; Currie & Szabo, 2019; Doucet, et al., 2019; Falkson, et al., 2017; Franck & O’Brien, 2019; Furrie, 2018; Healthy Child Manitoba, 2013; Inclusion BC, n.d.; James, 2019; King, Williams, & Goldberg, 2017; McQuay, 2016; Monney & Lashewicz, 2013; Nihad, et al., 2018; Phoenix & Rosenbaum, 2015; Ritzema et al., 2018; Rosenbaum, 2011; Ummer-Christian, et al., 2018); it is however, Indigenous, migrant and families from non-western cultural backgrounds who can experience additional and intensified barriers (Alsharaydeh, et al., 2019; Coultes-Macleod et al., 2008; de Beco, 2018; Green, et al., 2016; BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group, 2015; Bennett & Blackstock, 2007; Cooper & Driedger, 2018; “Culturally-based Equity for First Nations Children and Youth” in First Nations Child and Family Caring Society, 2013; “Budget” in First Nations Child and

Family Caring Society, 2019; "Research" in First Nations Child and Family Caring Society, 2017; Hiranandani, Kumar & Sonpal, 2014; Hernández-Saca, Kahn & Cannon, 2018; Inclusion BC, n.d.; Healthy Child Manitoba, 2013; James, 2019; Jennings et al., 2014; Kovach, 2009; Khanlou, et al., 2017; Lovern, 2017; UN, 2007; 2008).

As mentioned in section 2, many CCNs practitioners and scholars share the UN *Conventions on the Rights for People with Disabilities* (2007) concern "about the difficult conditions faced by PWD who are subject to multiple or aggravated forms of discrimination on the basis of race, color, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status." To support an accessible and rights-based environment, the Government of Canada has signed the *United Nations Convention on the Rights of the Child* (1989), the *United Nations Convention on the Rights of Persons with Disabilities* (2007), and the *United Nations Declaration on the Rights of Indigenous Peoples* (2008). All three documents uphold the child's unalienable rights to enjoy all human rights fully without discrimination; to receive specialized and/or cultural supports for their health, rehabilitation, social care, education, and recreation.

The following two examples address the equity perspective of families with children with CCNs, thereby showing how different types of social inequities can intensify barriers for community inclusion and service accessibility for families with non-western cultural backgrounds.

According to the literature, Indigenous children with CCNs require more attention and care (de Beco, 2018; Green, et al., 2016; BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group, 2015; Bennett & Blackstock, 2007; Cooper & Driedger, 2018; "Culturally-based Equity for First Nations Children and Youth" in First Nations Child and Family Caring Society, 2013; "Budget" in First Nations Child and Family Caring Society, 2019; "Research" in First Nations Child and Family Caring Society, 2017; Healthy Child Manitoba, 2013; James, 2019; Kovach, 2009; Ordolis, 2008; Truth and Reconciliation Commission, 2015; UN, 2008).

In 2016, the *Canadian Human Rights Tribunal* ruled that the Canadian government can improve its treatment of First Nations children and their families. One significant way to improve is by honoring Jordan's Principle, a principle meant to ensure that children receive the public services (often specialized equipment for medical needs) they need right when they need them ("Budget" in First Nations Child and Family Caring Society, 2019, p. 1). Furthermore, the *Truth and Reconciliation Commission* (T&R), recommend "call[ing] upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties" (T&R, 2015, p. 2). In other words international health authorities and Indigenous scholars assert that these historically-established and current socio-political conditions be included in an assessment or care plan for Indigenous children with CCN (BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group, 2015; Bennet & Blackstock, 2007; Cooper & Driedger, 2018; “Culturally-based Equity for First Nations Children and Youth” in First Nations Child and Family Caring Society, 2013; Ordolis, 2008, p. 37; Lovern, 2017; Kovach, 2009; T&R, 2015; UN, 2008).

Another population that has faced greater challenges for community inclusion and access to service are recent newcomers to Canada. Several studies looking at the experiences of migrant families with children with disabilities in Canada discovered that caregivers (often mothers) face additional barriers and cultural insensitivities while accessing support services and that this serves as an additional impediment to the health and well-being of the entire family (Alsharaydeh, 2019; Khanlou et al., 2017**;** Jennings et al., 2014). For instance, in an integrative review that included 25 studies, Alsharaydeh (2019) mentions that “the main challenges that parents faced were language barriers, financial hardships, service utilization challenges, poor adaptation to new culture, stigma related to mental illness, discrimination, and social isolation” (p. 670). Furthermore, the literature shows that, with the addition of the impacts of trauma, many newcomer families benefit from services that address children and family counselling, social support groups and trauma-informed, culturally-safe health services alongside the legal, language, and career supports offered by settlement agencies (Alsharaydeh, 2019; Khanlou et al., 2017**;** Jennings et al., 2014). In other words, including migration and reasons for migration as factors within the Social Determinants of Health (SDH) perspective, can opens new insights into for addressing equity issues for newcomer families with children with CCNs (de Beco, 2018; Hernández-Saca, Kahn & Cannon, 2018).

In sum, the literature found that the Indigenous and migrant children experience additional and intensified barriers to accessing CCNs services. The SDH perspective reveals more specific barriers, considerations, and recommendations which can better address these equity issues.

Integrated and Collaborative Services

A major trend in the literature on children and youth with CCNs speaks about the experiences of families and the need for additional integrated and collaborative service delivery. This call for more integrative services and more collaboration between CCNs stakeholders, is prevalent across academic scholarship (Brenner, et al., 2018; Coultes-Macleod, et al., 2008; Ritzma et al., 2018; Jennings et al., 2014; James, 2019, King et al., 2017; McQuay 2016; Camden, et al., 2013; Healthy Child Manitoba, 2013; Green et al., 2016). As clearly summed up by James (2019) in the literature review International perspectives *on best practice*, “service co-ordination should be able to deliver support in a coordinated and integrated way” (p. 289). Similarly, Ritzema et al. (2018), in *A model of well-being for children with neurodevelopmental disorders*, also note that “governments should increase and align formal supports for families in order to improve child well-being,” particularly between schools, healthcare centres, and social service (p. 241).

There are compelling reasons for this overwhelming endorsement of integrated and collaborative services. Firstly, Brenner et al. (2018) discuss how families with children with CCNs require multiple health and social care services to ensure a multi-pronged approach to quality care delivery (p. 1648). Currie & Szabo (2019) also agree finding that the fostering of knowledge and understanding to address such complex needs is best accomplished through teams of providers, such as physicians, nurses, social workers, and therapists, in a collaborative effort partnering with parents who share their values, experiences, and perspectives, in order to offer a more holistic approach to the care team (p. 101).

In a scoping review, *Family-oriented services in pediatric rehabilitation,* King et al. (2017) also support a more "holistic approach," inferring that this approach requires a shift from thinking about many social and family services as "added value" and instead viewing them as part of the core services for child and family wellbeing (p. 343). Brenner et al. (2018) further found that the transitions from setting to setting and having many care providers "make them [families] more vulnerable to discontinuity or gaps in care" (p. 1647). Expanding on this, McQuay (2016) states that flexible service delivery and resources are required for making successful transitions into adulthood. Moreover, she asserts that "youth and young adults with complex needs are especially challenging to work with because they use multiple child welfare, criminal justice, mental health, and special education services" (p. 67).

To personalize the experience of struggling to access services, in *Voices of care for adults with disabilities and/or mental health issues in Western Canada,* Monney & Lashewicz (2013) argue that the parental consensus is that it is "unacceptable to have to wait for crisis in order to get assistance" (p. 181). Furthermore, parent participants in Currie & Szabo's (2018) study add that "every time you meet with a clinic or hospital, you are starting at Day 1" (p. 99), with another parent asking, "why do I have to fight and beg for it?" (p. 100). In addition, Green (2016) in her study with the Torres Strait Islander First Nations families with children with CCNs, elaborates that families often experience "roadblocks" due to mixed and missing information and "inflexible bureaucratic policy requirements" (p. 8). Green is in agreement with King et al., (2017) and Coultes-Macleod et al. (2008) in her call to "include a holistic view of the needs of the child and carer" (p. 8), and she proposes solutions such as providing "a one-stop-shop for services" and "operationalizing a centralized team-based approach" as well as creating a new "Service Navigator" position that would help guide families through the service maze (Green, 2016, p. 8).

In addition, Jordan's Principle, which can only be achieved through the coordination and communication of multiple organizations is a prime example of how children with CCNs can be directly impacted by the choices to invest in more integrative and collaborative services (First Nations Child and Family Caring Society, n.d.; T&R, 2013). Alsharaydeh et al. (2017) notes that to honor Jordan's Principle is to directly remove barriers to health-related supports for Indigenous children with CCNs.

In sum, the literature finds that due to the multi-faceted nature of CCNs more integrative and collaborative services is required to improve accessibility and quality of CCNs services.

Family-Centred Care Approaches

Another prominent theme in the literature on children and youth with complex care needs is the support for the use of a Family Centred Care (FCC) approach. For years, scholars in the Disability Studies area and disability activists have endorsed this FCC approach in working with families with children with CCNs (Inclusion Alberta, n.d.; Inclusion BC, n.d.; Franck & O'Brien, 2019; 2015; James, 2019; Rosenbaum, 2011; Rosenbaum & Phoenix, 2015; Rosenbaum & Gorter, 2011; Lietz, 2011; Jennings et al., 2017; Darrah, et al., 2010). Over many decades, multidisciplinary academic research has noted that a FCC approach is the ideal practice for health and social services (Rosenbaum, 2011; Rosenbaum & Phoenix, 2015; Rosenbaum & Gorter, 2011; Franck & O'Brien, 2019, p. 1052; James, 2019, p. 289; Jennings et al., 2017; Darrah, et al., 2010). This section will demonstrate how the FCC approach, informed by the SDH perspective, is both a framework and a practice, with principles and values found to benefit children with CCNs and their families.

The FCC approach is a philosophy, with a set of values, principles, and practices. While there are numerous definitions for practitioners of the FCC approach, *The Council for Exceptional Children*, defines practitioners of FCC as "those that treat families with dignity and respect; are individualized, flexible, and responsive to the unique circumstances of diverse families; provide families with complete and unbiased information to make informed decisions about the supports and services they want for their child and family; and promote family involvement in acting on their choices" (Couchenour & Chrisman, 2016, p. 2). Franck and O'Brien (2019) state that the FCC values are respect, diversity, strength based, choice, flexibility, information sharing, support, collaboration, and empowerment (p. 1046). FCC principles can include: building partnerships with families; providing families with information; responding to family concerns, priorities, and changing circumstances; and building on family strengths; sharing information about their child in the family's preferred language; and helping families know and understand their rights; and encouraging interested families to engage in leadership opportunities (p. 1046).

In the same vein, James (2019) adds the call for professionals who work with families to "work with carers in ways that complement and enhance their roles so that they are able to maximize their capacity to care for their relative" (p. 287). As Rosenbaum (2011) points out, "our concern for children with neurodisabilities (or, in fact, for any child!) must include an interest in their family, and that we have to make the assumption that a child's well-being will be influenced powerfully by the well-being of their parents and families" (p. 69). In turn, Jennings et al. (2014) agree that "the health of children is likewise relationally linked to caregiver health status" (p. 1649).

Numerous authors, such as Rosenbaum & Gorter (2011), Rosenbaum (2011) and Rosenbaum & Phoenix (2015), and Franck & O'Brien (2019), have spent the last years dedicated to researching the FCC approach. Rosenbaum (2011) state that "family-centred services provide a guide to the 'processes' of service by service providers and Rosenbaum (p. 68) and Rosenbaum & Gorter (2011) further assert that "when services are more family-centred, parents report better satisfaction and mental health, and less stress in their dealings with providers" (p. 460). In turn, Franck & O'Brien (2019) endorses the FCC approach by stating "today, general consensus on the importance of family involvement in high quality care for hospitalized children has been reached" (p. 1045). Camden et al. (2013) are in also agreement, identifying principles for guiding "best practices" for children with developmental coordination disorder when they state that "using a family- centred approach to guide all interactions with families," (2013, p. 152).

The FCC approaches, however, go above and beyond simply engaging the family in processes of care; they are ultimately about trusting, therapeutic relationships (Currie & Szabo, 2019; MaQuay, 2016; James, 2019; Rosenbaum, 2011; Camden et al., 2013; Ritzema et al. 2018; Cloultes-Macleod, et al., 2008; Health Child Manitoba, 2013; Phoenix, M., & Rosenbaum, 2015; Rosenbaum & Gorter, 2011; Darrah, et al., 2010; Khanlou at al., 2017; Monney & Lashewicz, 2013). Such relationships include siblings, grandparents and other extended family members of children and youth with CCNs. Ritzema et al. (2018) found that good communication and relationships with clinicians were perceived by families to be a core foundation for continuity of care, resulting in more positive perceptions about their children's functioning (Miller et al., as cited in Ritzema, 2018, p. 245).

In sum, FCC is highly recommended in CCNs literature for helping professionals to use as a guideline and practice with families with children with CCNs. The values of FCC philosophy can address the needs of many diverse families by valuing family's knowledge and building upon their strengths to contribute to care plans for their children.

2.8 Services: Strategies and Types

This section of the literature review examines the literature on the various stakeholders involved in the area of children and youth with complex care needs. Schiller et al., (2013), states that "stakeholders, as originally defined in theory, are groups or individuals who can affect or are affected by an issue. Stakeholders are an important source of information in health research, providing critical perspectives and new insights on the complex determinants of health" (p. 1). The authors identify seven main categories of stakeholders important to the area of children and youth with complex care needs are: the public, policy makers and governments, research community, practitioners and professionals, health and social service providers, civil society organizations, and private business (p. 1). These stakeholders can be the recipients of the service (direct or indirect), involved in the development and delivery of the services, involved in the funding or oversight of the services, or involved in a research capacity.

As found in the research and grey literature, this section provides a small set of examples of services and strategies developed and delivered for those children and youth who have complex care needs.

Strategies and Services – Promising Practices

The following examples of CCNs strategies and services are included in the following section either because they have been identified by the literature as significant for children's and families' health and well-being or because they may outline new directions and research for promising practices.

Example 1 - "Home Away From Home" Accommodations

"Home Away From Home" (HAFH) accommodations are usually large houses that provide families who must travel large distances with a place to live while their child requires hospital treatments. These HAFH accommodations provide families with a comfortable and "home-like" environment to help families with the costs, promote "family cohesion" and other logistical supports (Franck & O'Brien, 2017, p.). Franck & O'Brien (2017), in *The influence of family accommodation on pediatric hospital experience in Canada*, added questions about accommodation to a "standardized inpatient pediatric and neonatal intensive care unit" that would "determine the accommodation types used by [5,105 Parents], compare characteristics across accommodation types and explore accommodation-type influences on overall hospital experience outcomes" across 10 different hospitals in the U.S. (p. 419). Findings revealed that families who stayed at Ronald Macdonald Houses (RMH) "had more positive overall experience scores than families who stayed in other accommodation types" (p. 434). In addition, cultural differences were found "with Hispanic families believing more strongly that their proximity to their child, facilitated by the RMH accommodation, shortened their child's hospital stay" (p. 434). Franck & O'Brien "believe that providing support to families with respect to family accommodation is a quality-distinguishing activity" (p. 344).

Example 2 - Advocacy Services

The UNCRPWD emphasizes "the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development" by recognizing that "the family is the natural and fundamental group unit of society and is entitled to protection by society and the

State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities" (p. 2-4). Advocacy is defined as speaking or acting on behalf of an individual or group to uphold their rights or explain their point of view (APA dictionary of Psychology). Advocacy actions are meant to garner public support and recommendations for a particular cause or policy. For instance, *Inclusion BC* staff hold a diverse team of family advocates and an initiative that provides education about inclusion for potential employers which addresses inclusion by helping to change the hearts and minds of the public (Inclusion BC, n.d.).

Example 3 - Sibling Inclusive Programming

As mentioned in section 3, a key aspect of FCC approaches is for helping professionals to understand the importance of siblings, grandparents, and extended family members in the lives of children, youth, and young adults with CCNs (Camden et al., 2013; Meltzer, 2018). Siblings who have a sibling with CCNs can also benefit from services according to Monney & Lashewicz (2013) who underline the importance of including siblings in future care planning (p. 179). They found that siblings felt unprepared to take over care responsibilities from ageing parents, especially since this transition can happen suddenly when there is an unexpected death in the family (p.181). Including family members who are not the primary caregivers is sometimes limited because of information-sharing policies meant to protect the individual with the CCNs (p. 183), as one brother dismayed "I sometimes feel helpless about what I can do to bring fulfilment to my sister's life" (p. 182). In addition, Monney & Lashewicz (2013) underline the importance of including siblings in future care planning (p. 179). The literature suggests that engaging siblings at an early age can provide foundations for their health and well-being knowing the significant role they may come to play in the health and well-being of their sibling.

Example 4 - Dental Care Services

It has been recorded that people with disabilities received less preventative dental care and more tooth extractions than the rest of the population (Coultes-Macleod et al., 2008; Ummer-Christian et al., 2018). In an international literature review, Ummer-Christian et al. (2018) found that a major barrier was many dentists' "unwillingness" to treat patients with developmental disabilities sometimes because they receive no additional compensation for the extra time and effort often required. In addition, the authors found that barriers to quality dental care occurred due to several factors which included the need for increased education and awareness on people with CCNs and their rights, as well as the need for more specialized equipment (Ummer-Christian et al., 2018; Coultes-Macleod et al., 2008, p. 34).

2.9 Services – Quality and Processes

Research is used to create knowledge, measure service quality and effectiveness, discovers current problems and discover solutions with recommended promising practices. Children with CCNs benefit from these insights gained in research, however the values and methods that guide research projects can influence findings and therefore the recommendations for CCNs services. This section will discuss how different values and methods processes for CCNs research can directly impact CCNs service quality and address equity issues.

Equity in Research Process

Indigenous scholars in Canada like Dr. Kovach (Education) Dr. Blackstock (Social Work), Dr. Lovern (Philosophy & Religion), and Dr. Cooper and Dr. Driedger (Community Health Sciences) assert that Indigenous-led research is appropriate for supporting Indigenous communities. For instance, Cooper & Driedger (2018) acknowledge that "colonial practices, policies, and research studies within Canada have created lasting trauma and harm among indigenous communities" (p. 62) noting that there has been a disregard of Strength-based Practice (SBP) through a "long-standing history of deficit-based research conducted on Indigenous people" (p. 64). Instead Cooper & Driedger (2018) advocate for research that recognizes indigenous knowledge by "using strengths-based approaches" that research be "carried out in partnership with community-identified priorities" (p. 64).

Lovern (2017) shows the value of including Indigenous knowledge into the conversation of how to improve CCNs service quality. In *Indigenous Perspectives on Difference: A Case for Inclusion*, she states that "the use of Indigenous paradigms highlights the role of colonization and post-colonization assimilation practices in establishing discrimination dynamics involving disability within Indigenous communities" (p. 303).

Blackstock (2010) points out the sources of some of the tensions between Indigenous and western based research. In the literature review *Commentary: Indigenous Health Special Issue* how Blackstock states that the "western and Indigenous ontology drive very different research approaches" (p. 136). Ontologies focus on culturally-relative conceptions of existence through abstract concepts such as being, knowing, substance, cause, identity, time, and space. In this context, Blackstock is concerned that "ontology in western research limits the questions it can effectively address" for Indigenous communities (p. 136).

The disconnect between Indigenous and western ontology and how it impacts research method and process is further explored in Kovach's book (2009), book, *Indigenous Methodologies: Characteristics, Conversations, and Contexts.* She develops a comprehensive reconciliation between Indigenous ways of knowing and western ones, beginning with descriptions of how these different modes of knowledge creation cause problems for Indigenous scholars working within the academy. These tensions in research play out for stakeholders who wish to improve quality and accessibility to services for families with children with CCNs. For example, issues of how society is customizing Indigenous frameworks to fit within various tribal paradigms while communicating the process to Western academia (Kovach, 2009, p. 42) are reflected in the BC report *Promising Practices in First Nations and Aboriginal Maternal and Child Health Programs* (2015). For instance, one participant states "over the years, we have worked on several evaluation frameworks with relevant indicators and outcomes. Part of the problem is that we don't formalize these frameworks and put them into use" (p. 54). Another participant drives the point further and notes, "let's not wait. Let's select some current programs to evaluate and study, so that we can publish findings and contribute to the 'evidence'" (p. 54).

Kovach (2009) indicate that such redesigning the research process to better reflect Indigenous knowledge and values need not be seen as belonging to one paradigm or culture only. For instance, Kovach explains that "western research frameworks can be adapted as structural forms that are helpful to the Indigenous researcher" (p. 41), by "allowing the entrance of visual, symbolic, and metaphorical representations of a research design that mitigates the linearity of words alone" as an important piece of "story as Indigenous methodology" (p. 43). For example, in *Navigating the journey of Aboriginal childhood disability,* Green et al., (2016) uses the "journey metaphor" to explore experiences of caregivers with children with CCNs, discovering the "roadblocks" (barriers), "road signs" (the helpful moments), and "navigators" (helpful people) along the way. Green et al., states that "the visual representation of these types of concepts through metaphors aligns with the narrative approach of telling stories that values the spoken word and oral history tradition in Aboriginal culture and is considered a respectful research technique" (p. 4).

The other key piece Kovach (2009) acknowledges in Indigenous research methods is the valuation of community rights and relationships, which involves working collaboratively with communities as research partners instead of seeing them only as research subjects. For example, in *Creative, strengths-based approaches to knowledge translation within indigenous health research,* Cooper & Driedger (2018) ensure that the community has ownership of the data produced by the research (p. 62). By listening with a SBP lens to qualitative interviews and focus group discussions, they created an all-ages trivia game designed to help infer health-related knowledge to the community and promote heathy practices. They uphold specific considerations for future health research, including "creating useful and relevant dissemination products" where stakeholders wish to "continue to engage in research that is meaningful and ethical and strengthens relationships" (p. 61) Key considerations for Community-Based Research from Cooper & Driedger (2018, p. 62) are the following:

1. Can the community easily make copies of the resource?
2. Are there aspects of the product which do not require any written literacy skills?

3. Is there a component of the message which is strengths based and hopeful?
4. Is the product interactive?
5. Has the knowledge from participants and/or communities been acknowledged?
6. Is there an active learning component that spans beyond encounters with the research team?
7. Has the product been returned to the community quickly?

In sum, research is a highly legitimate process that directly impacts people with CCNs as the services to address their needs rely on research findings to assess quality and offer recommended practices. There is scholarly recommendation to increase the presence of Indigenous knowledge and values into the research process on community health and well-being.

Examples Methods for Service Quality and Process

Measure of Process of Care (MPOC)

One common method is the measuring tool Measure of Process of Care (MPOC). Nihad, An & Palisano, (2018) describe the MPOC as a self-reporting survey that is used internationally assess "the extent to which" parents' perceptions of FCC had occurred. In their meta-analysis, Nihad et al., (2018) found that "on average parents rated [the MPOC survey sections] "Providing Specific Information about the Child," "Coordinated and Comprehensive Care," "Respectful and Supportive Care" and "Enabling and Partnership" occur to "a fairly great extent" and "Providing General Information" occurs "to a moderate extent" (p. P 441). More qualitative research on families' experiences of health care, however, reveal other findings.

Monney & Lashewicz (2013) who use a qualitative form of inquiry, uncovered additional information of the experiences of families including parents and adult siblings' desire to work in partnership with paid caregivers but feeling "overlooked, marginalized and powerless" (p. 179). In addition, in an interpretative phenomenological approach to inquiry Currie & Szabo, (2018) use a phenomenological form of qualitative inquiry to explore the ways to improve services provision for parent's caring for a child with a rare disease by gaining the parents' perspective through interviews. The findings in this study are fueled by the voices of the parents with one expressing "if you don't know the right questions to ask, you are just waiting until somebody gives you the information" with another parent states "I learned that right off the bat; people told me I was going to have to fight" (p. 100).

A Logic Model for Planning and Evaluation for Services for children with CCNs

In New Brunswick, Kerrie et al., (2019), The Development of a Logic Model to Guide the Planning and Evaluation of a Navigation Center for Children and Youth with Complex Care Needs, a logic model was developed by the research-based navigation center NaviCare to help facilitate more successful family programming for children with CCNs (p. 1). According to these authors "logic models facilitate the foundational work needed for a successful program, such as planning; establishing program goals and objectives; designing performance and evaluation metrics; identifying evaluation questions; as well as providing a logical illustration of how a program will work" (p. 3).

While the purpose of this logic model is meant to be a tool to "enhance knowledge; identify needs, monitor progress; evaluate systems and outcomes; and improve the quality of the programs and services directed towards children and youth," some limitations discussed are their complexity and time consuming nature and the fact that they require that all team members to understand the logic model 'language' (Doucet, et al., 2019, p. 7 and 11; Kerrie et al., 2019, p. 13).

2.10 Services: Collaboration, Partnership, and Engagement

This section examines the discussion in the literature about the ways in which relationships play a vital role for children with CCNs and their families. There are several different kinds of relationships; however, the two that will be discussed in detail are the relationships between children with CCNs and a caring adult and the relationships between families, practitioners, and their organizations. In addition, this section identifies the barriers to effective engagement and collaboration and provides examples of frameworks that help facilitate collaboration, partnerships, and engagements.

Relationships between Families and Service Providers

As mentioned in Section 3, Family Centred Care (FCC) can be seen as philosophical guide for engaging with families. Nihad, at al., (2018) extends the relational component of FCC to practices such as "active listening, respect, and empathy" with each a part of "maintaining positive and trust-based relationships" (p. 427). The literature reveals the significance of relationships generally and between families and helping professionals, as an important aspect of health and wellness; however, a significant part of the literature reveals that these relationships are under stress. For example, Monney & Lashewicz (2013) uncovered experiences of families including parents and adult siblings' desire to work in partnership with paid caregivers but feeling "overlooked, marginalized and powerless" (p. 179), with only 50% of respondents stating that mental health professionals "always" or "often" involved them in treatment plans (p. 180).

Although there are trusting and therapeutic relationships between paid and family caregivers some studies Currie & Szabo (2018) have similar findings with several parents expressing their experiences of "resistance from physicians" to incorporate family knowledge into the planning and delivery of their children's care (p. 98). Likewise, another study on children who use ventilator supports Falkson et al., (2017) notes that mistrust between nurses and parents can exacerbate family isolation (p. 220). In some cases, the barrier stems from attitudes and assumptions of helping professionals about family makeup and care in general. In *Promising Practices* (2015), family alienation can start from the first encounter they elaborate in a section "Friendliness and Hospitality" (p. 32). The participants discussed how "they are frequently surprised at the unfriendliness of many service providers and the negative effect this has on clients. Alternatively, participants hoped for warm environments, stating "it's always been our way to create a welcoming environment and to offer food and to treat people with kindness and respect" (p. 33).

Examples of Collaboration, Partnership, and Engagement

The following examples identifies a unique method for collaboration, partnership, and engagement. The *Making Alternative Therapy Choices Happen* approach provides pragmatic practices to assist agencies to better offer care to "hard to reach families" while family inclusive programming relies on Family Centred Care practices to trusting relationships between paid and familial caregivers

Making Alternative Therapy Choices Happen (MATCH) Approach

Rosenbaum & Phoenix (2015) in *Development and implementation of a paediatric rehabilitation care path for hard to reach families*, have identified ways for helping professionals to better serve "hard to reach families" who are often in most need of services. It was identified that families miss many appointments every year for a variety of reasons (p. 495). MATCH is a guide that uses "best practices" to inform effective care paths for hard to reach families. It illustrates a practical application of the principles of best-practice for engaging hard-to-reach families, tailored for a specific paediatric rehabilitation setting**.** MATCH was adopted by clinicians within a community-based paediatric rehabilitation centre in Ontario, Canada using a "Knowledge Broker" method to implement learning a guide for practitioners to better serve "hard to reach Families." The Knowledge Broker method is a model, where a volunteer clinician receives information about "the MATCH care path" and how to monitor it and then trains all clinicians at their site of work (p. 494). Rosenbaum & Phoenix, (2015) provide Tables and Figures that identify the barriers and "best practices" for clinicians to serve hard to reach families (See Appendix A).

Family-Inclusive Programming

As mentioned in Section 3.4, Ritzema et al. (2018) found that relationships with practitioners was associated with families' increased perception of quality of care for their child with CCNs (Ritzema, 2018, p. 245). Moreover, the perception of caregivers was itself found to be a key aspect over family wellbeing (Miller as cited in Ritzema et al, 2018). Programs such as the West

Coast Kids 'Cancer Foundation's "Smoothie Sundays" program that offers a twice a month, "fresh, made-to-order smooth[y]" for children, as well as any family members, friends or visitors *and* staff and nurses to the oncology floor at BC Children's Hospital, facilitate relationship building. James (2019), affirms "how developing effective relationships and working in partnership with families makes it possible to identify their specific individual needs so that they are able to support their relative in a way that reduces unnecessary hardship and difficulties" (p. 288). McQuay (2016) offers that "creative initiatives and activities that are focused on bringing youth together with their family members, volunteers, mentors, and friends may be helpful (p. 66). By including all people involved in the context of the child's life at the moment of visitation, West Coast Kids Cancer Foundation are facilitating a shared experience that helps build strong bonds.

2.11 Areas for Further Research

Main Findings

- **Complexity**- Children with CCNs spans across many sectors and disciplines (Nursing, Public and Administrate Health, Child and Youth Care, Indigenous Health, Disability Studies, Social Work, etc.) and different sectors (health clinics, children's hospitals, research institutes, community and social services, etc.) and many specific conditions (Autism Spectrum, Ventilation-users, etc.).
- **Barriers to Access** – Barriers in accessing support services occur on multiple levels, including ideological (continued stigma associated with disability in Canada), institutional (complicated service access, lack of funding), and interpersonal levels (discrimination, disconnected relationships between service providers and families).
- **Relationships and Social Inclusion** - Trusting relationships can improve CCNs services and both trusting relationships and social inclusion are linked to positive health outcomes for people with CCNs. Relationship break down and social exclusion, on the other hand, are found to be detrimental to health and well-being, and decrease perceptions of service quality, treatment outcome and are associated with discontinuity of care.
- **Equity** - One of the greatest barriers is equity of access. Findings show that families with children with CCNs who are either Indigenous, Canadian newcomers, or are from non-western backgrounds experience additional and intensified barriers to CCNs services.
- **Integrative and Collaborative Service Delivery** - There are extensive recommendations in the literature for more integrative, holistic, and collaborative service models. Initiatives to facilitate collaborative service models are the Wrap Around Approach, MATCH and FCC.
- **Accessing Services** – Accessing services is found to be extremely complicated with parents stating that there is a lack of available information to assist them and CCNs service providers reporting a lack of funding to increase delivery and improve services.
- **Family Centred Care (FCC)** – FCC approach is recommended extensively because

an appreciation for the connections between family members' health and well-being to their child with CCNs health and wellbeing has been established; FCC ensures that families' knowledge and goals are included in their children's care plans.

- **Knowledge –** Knowledge creation is based on different cultural philosophies which can cause rifts between research and practice. Indigenous research offers insights into conceptions of disability, as well as promising practices of collaborative research design and strength-based practice (SBP).
- **Promising practices -** Promising practices are recommended by international health authorities and are endorsed in the academic literature. They include 1) the social determinants of health (SDH) perspectives on health and well-being; 2) Family Centred Care (FCC), and 3) Strength-Based Practice (SBP). Each can play a part in improving the quality of and the accessibility to CCNs services by encouraging relationship building between CCNs stakeholders; promoting family inclusion; and addressing equity issues.

Research Gaps and Further Research Recommendations

Several gaps and recommendations have been identified. Firstly, Brenner et al., (2018) recommend a "multidisciplinary focus in research" asserting that this would lead to an "ideal arena for the development of inter- professional education programs" that would provide "healthcare professionals with the skills and knowledge needed to work in a collaborative manner" to better address the "given the complexity of patients' healthcare needs" (p. 1648).

Another recommendation is for research to include family voices. As noted by Falkson et al., (2017), "knowledge from the perspective of siblings of children who are ventilator-dependent at home is marginal" (p. 222). In addition, Currie & Szabo (2019) offer that "additional studies [on families with children with rare diseases] could lead to development of a more integrated approach to health care and social support delivery and thereby improve the quality of life for families with a rare disease" suggesting that "families could also be part of patient-oriented research teams" (p. 102).

With regards to the Family Centred Care (FCC) approach, Rosenbaum (2011) suggests "purpose-designed research to explore specifically the connection between parent well-being and child development in children with disabilities". He pushes for research opportunities that can explore systematically "the cost–benefit of family-centred service" (P. 70). Nihad et al., (2018) states that future research "should be evaluated considering the contextual factors related to child, family, services, and culture" (p. 441).

In agreement, Khanlou et al, (2017) recommends that "future research should focus on comparative research between ethno-cultural groups on the effects of acculturation stressors and resettlement supports on mothers' experiences with school integration, developmental and health services, as well as differences in their adaptation to raising a child with [CCNs]" (p. 252). And Lovern (2017) shares that "more thorough research involving the impact of colonization should be done if the scholarship is to deal effectively with the conditions of persons of difference in Indigenous populations (p. 317).

Lastly, some specific suggestions include more research on the "relationship between accommodation type and families' experiences of hospital treatment" (Franck & O'Brien, 2015, p. 420) and Ummer-Christian et al, (2018) state that there is "a need to conduct research into the extent of understanding of disability legislation and policies among dental service providers" (p. 12). Ummer-Christian et al, (2018) recommends that "a number of policy and practice recommendations appear warranted. These are to (1) review existing policy gaps in public funded programs, particularly guidelines on provision for additional time and funding of treatment rooms; (2) facilitate academic and continuing professional development programs for dental practitioners to expand on issues specific to IDD; and (3) develop avenues for dental practitioners to connect to a wider network of disability-related support resources. Most importantly, there is a need to conduct research into the extent of understanding of disability legislation and policies among dental service providers. The findings of this research will inform appropriate interventions to address the health inequity amongst children with IDD" (p. 12).

2.12 Promising Practices, Examples, Creative Ideas, and Lessons Learned

Bardach (2020) notes that "the basic mechanism in a smart practice is its means of directly accomplishing useful work in a cost-effective manner" (p. 138). The smart practice has a potential for potential for "creating value" and a mechanism for focusing that potential value (p. 138). Bardach supposes that "because smart practices are internally complex, context sensitive, and capable of being used by different parties to pursue slightly different bundles of goals" and believes that "how we talk about them should reflect these qualities" (p. 139).

In *Promising Practices in First Nations and Aboriginal Maternal and Child Health Programs: Community Perspectives on what works* (2015), the term "promising practices" is used in a way that reflects the qualities laid out by Bardach in addition to other considerations (p. 11). Firstly, the authors (the BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group) use the Health Council of Canada's definition promising practices which is "a promising practice is a model, approach, technique, or initiative that is based on Aboriginal experiences, which resonates with users of the practice, and [which] results in positive changes in people's lives" (2015, p. 11). Secondly, the participants in this community research go to "emphasize that promising practices are created at the community level and are context specific—what works beautifully in one community might not work in another community" (p. 12) because promising practices combine knowledge from scientific literature, practical experience, and cultural teachings (p. 12).

This following sections rely on the foundations of Bardach and the considerations put forward by the BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group in order to lay out examples of promising practices.

Promising Practices for CCNs Summary

This literature review has found three key promising practices. They include: Family Centred Care (FFC) (See section 3.4), Social Determinants of Health (SDH) (See section 2) and Strength Based Practice (SBP) (See sections 3 and 5). All three are promising practices because these frameworks for people working with families with children with CCNs can each play a part in improving the quality of and the accessibility to CCNs services by encouraging relationship building between CCNs stakeholders; promoting family inclusion; and addressing equity issues.

The following section includes more specific recommendations and creative ideas for specific service contexts and populations while also being informed by these three promising practices.

Smart Practices, Creative Ideas: Services – Strategies and Types

Sibling Inclusive Programming

Stonebridge (2010) found that siblings are an integral part to the well-being of the family and play a significant role in the lives of their siblings with cancer. Her findings highlight ways in which siblings can build resilient character in spite of incredibly difficult experiences they have undergone. These include: “The need for acknowledgment and attention, honest and open family communication, inclusion in the family during treatment, to know that it is normal to have difficult emotions for instrumental support, to just be a kid and have for humor, laughter, and light-heartedness” (p. iv).

Settlement Services included as a part of services that benefit children with CCNs

Khanlan et al., (2017), identify that “one potentially fruitful endeavor would be to examine how child welfare agencies may assist in creating and implementing family-centered service plans” (p. 240). They consider that since “immigration is increasingly recognized as being an important factor in child welfare” perhaps clinical spaces could better support immigrant mothers in accessing settlement services (p. 251).

Recommendations on Improving Dental Services

As mentioned in Section 4, dental care for people with CCNs is an area of concern. Ummer-Christian et al, (2018) offer three recommendations to improve the dental care system with regards to equity: “(1) review existing policy gaps in public funded programs, particularly guidelines on provision for additional time and funding of treatment rooms; (2) facilitate academic and continuing professional development programs for dental practitioners to expand on issues specific to IDD; and (3) develop avenues for dental practitioners to connect to a wider network of disability-related support resources” (p. 12).

Smart Practices, Examples, Creative Ideas, and Lessons Learned: Services – Quality and Processes

Family Centred Care Values, Principles and Models

Franck and O'Brien (2019) have put together Family Centred Care (FCC) values, guiding principles and models of FCC practice (p. 1046). (See Appendix A).

Bridging Indigenous Perspectives on difference and Western concepts of disabilities

Lovern (2017) has contributed to the initiative of bridging the gap between discourses on Indigenous health and discourses on disability. In *Indigenous Perspectives on Difference: A Case for Inclusion* she asserts that "the use of Indigenous paradigms highlights the role of colonization and post-colonization assimilation practices in establishing discrimination dynamics involving disability within Indigenous communities" (p. 303) and can "not only assist

Indigenous communities, but could also advance disability discussions in Western cultures" (p. 303).

Key Considerations for Community-Based Research

Cooper & Driedger (2018), developed a series of considerations for when "creating useful and relevant dissemination products" where stakeholders wish to "continue to engage in research that is meaningful and ethical and strengthens relationships" (p. 64). By "using creative, strengths-based approaches to not only return results but also to function as tools to address gaps in health knowledge as identified by participants and community members within intergenerational contexts was a central component applied to dissemination and knowledge translation" (p. 63).

Smart Practices, Examples, Creative Ideas, and Lessons Learned: Services –Collaboration, Engagement, and Partnerships

Making Alternative Therapy Choices Happen (MATCH) Approach

As discussed in detail in Section 6. the MATCH approach by Phoenix & Rosenbaum, (2015) helps assist clinicians to better reach "hard to reach families."

Strength-Based Practice (SBP)

Practice that acknowledges the strengths of families and clients, whether explicitly stated as "Strength-Based Practice (SBP)" or simply referring to this concept generally, much of the literature has endorsed this practice (Cooper & Driedger (2018), BC Tripartite First Nations and Aboriginal Maternal and Child Health Working Group, 2015; Lietz, 2011; McQuay, 2016; Lietz, 2011; Phoenix & Rosenbaum, 2015; Rosenbaum & Gorter, 2012; Rosenbaum, 2011; Green et al., 2016).

Diversity Scholarships

The Truth and Reconciliation Recommendations (2013) suggests to “increase the number of Aboriginal professionals working in the health-care field” (p. 3). Offering scholarships to support and bridge the gap for Indigenous, newcomer, or other minority status students in a healthcare or related field is one way to address inequity.

Increases in Childcare/Respite Services

According to their website, Inclusion Alberta (n.d.) offers low cost (sometimes free) childcare and respite services on location for their annual Family Conferences. Offering on-site childcare and respite may allow more family participation in family conferences and also on advisory boards, specialist appointments and other educational workshops and courses.

Creation of Service Navigator Positions

Green et al., (2016) recommends that service “navigator” positions could assist improve families’ accessibility to much needed services and programs (p. 8).

2.13 Lessons to Consider - Moving Forward

Coultes-Macleod, et al., (2008) mention how the “shortage of professionals with skills and expertise to work with people who have developmental disabilities” is a “critical concern” (p. 43). Furthermore, they state that primary care health providers (doctors, dentists) require both the educational/clinical exposure during training and a combination of directives and incentives (for example, practice requirements and fee schedules) to encourage their willingness and capacity to serve this population [people with CCNs]” (p. 43). They offer that in order to “attract people to work and remain in this field, a long-term investment is required that includes changes to post-secondary education curricula, increased research opportunities, and improved training strategies” (p. 43).

For Indigenous scholars, lessons include research approaches, cultural interpretations of disabilities and the lesson from the handling of Jordan River Anderson which led to the creation of Jordan’s Principle. Firstly, Cooper & Driedger (2018) find that “study participants and their families are often not the focal point” but instead the “policy-makers or healthcare professionals” are seen as “the primary users of research knowledge” (p. 62). They assert that “researchers can play a substantial role” in increasing community health by “improving the dissemination of research results through a [Knowledge Translation] process that positions the researcher-participant relationship as central in all phases of the research, programming, and policy decisions” (p. 65). For migrant families with children with CCNs, Jennings et al., (2014) and Khanlou et al., (2017) find similar concerns as “challenges faced by immigrant mothers of children with autism need to be urgently addressed in order to facilitate effective access to needed social support and services” (P 253).

2.14 Summary

In conclusion, the literature on CCNs finds that there are multiple considerations and contexts that contribute to both the conception of CCNs and the promising practice recommendations to improve the health and well-being of families with children with CCNs. While to “ a parent, family or caregiver, a child is first and foremost an individual human being with strengths and abilities… a full citizen with rights, who needs “assistance” to achieve full inclusion and engagement in society” it is clear that inclusion is not a full reality for many children, youth and young adults with CCNs living in Canada (Coultes et al., 2008, p. 8).

Furthermore, this review finds that equity issues contribute to unique and patterned, additional or intensified barriers for Indigenous, newcomer families with children with CCNs. In addition, this literature review has discussed the key role that trusting relationships plays in both the health and well-being of children with CCNs and in encouraging more CCNs stakeholders’ collaboration and integrated CCNs services coordination. Lastly, the promising practices identified in the literature include Family Centred Care, Strength Based Practice, and the Social Determinants of Health perspective. Each promising practice can be used as guide to both practice and policy development towards solutions for the barriers and equity issues in CCNs services.

In sum, providing quality services to families with children with CCNs create more opportunities for their full inclusion into their communities and improve their health and well-being. This is a multi-faceted project that requires an interdisciplinary approach to research and collaboration, addresses inequity and encourages trusting relationships between CCNs stakeholders.

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3.0 Literature Review: Early Childhood Development

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3.1 Executive Summary

The following narrative literature review was completed for the Children's Health Foundation [CHF] of Vancouver Island to assist them in learning more about scholarly and grey literature for the Early Childhood Development [ECD] impact area; in addition a focus on smart practices was applied to identify areas of research and studies to be highlighted.

This review provides syntheses of methodologically diverse ECD literature and data, from high income countries [HIC], which affirms the importance of supportive preventative or intervention measures intended to promote healthy development from before birth to age six. Key themes and trends of ECD are also highlighted and a focus on smart practices was used to identify specific examples of ECD services in consideration of these themes and trends.

This review also identified vulnerabilities and resilience of children below the age of six, race, socioeconomic status [SES] and ethnicity, and the changing landscape of British Columbia's ECD service systems as areas for future research.

Main findings:

- Children's formative years are of incredible value, a time when both threats and benefits to life-long development are intensified; how children's early environments are understood and/or augmented can support healthy human development on individual and societal scales.
- Health and nutrition, early learning and childcare, safety and race, ethnicity and socioeconomic status are key themes in ECD; these themes are interconnected and complex, requiring ECD service responses rooted in nurturing care, utilizing multisector and integrated approaches.
- Equitable access to ECD services, a reduction of barriers within HIC's ECD service systems, has become an international measure of quality ECD.
- Smart ECD practices utilize people and place-based approaches and community driven development with the intended goal of supporting or initiating ECD systems' change**.**

3.2 Acronyms

The following acronyms are used in this literature review:

- British Columbia [BC]
- Community Driven Change [CDC]
- Comox Valley Child Development Association [CVCDA]
- Cree-ative Wonders Daycare (CWD)
- Early Childhood Development [ECD]
- Early Development Instrument [EDI]
- Early Learning and Childcare [ELCC]
- First Nations Partnership Program [FNPP]
- Human Early Learning Partnership [HELP]
- High Income Countries [HIC]
- Lower Middle-Income Countries [LMIC]
- Mainland BC’s Multicultural Early Childhood Development [MECD]
- Ministry of Children and Family Development [MCFD]
- MCFD’s Early Years’ Service Framework [EYSF]
- New Brunswick’s Early Childhood Development Centres [ECDC]
- New Hampshire’s, Family Resource Centre’s Family Support Programs (FSP)
- Ontario’s Better Beginnings Better Futures [BBBF]
- Place/Person-Based Approaches [PPBA]
- Positive Parenting Programs [Triple P]
- Purple Book Health Checks [PBHC]
- Salteau First Nation’s [SFN]
- SDG - Sustainable Development Goals [SDG]
- Socioeconomic status [SES]
- Success by [SB6]
- Sustainable Development Goals [SDG]
- Toddler Development Instrument [TDI]
- The American Academy of Pediatrics [AAP]
- The National Institute for Children’s Health Quality’s [NICHQ]
- University of British Columbia [UBC]
- United Chinese Community Enrichment Services Society [SUCCESS]
- United Nations’ [UN]
- United States [US]
- University of Victoria [UVic]
- Western Australia [WA]
- WA Australian Early Development Census [AEDC]
- WA Child and Adolescents Health Services [WACAHS]
- WA Community Child Health Program [CCHP]

- WA Child Parent Centres [CPC]
- WA Department of Education, [WADE]
- WA Department of Health [WADH]
- World Health Organization [WHO]

3.3 Introduction

This literature review was completed for the CHF to assist them in learning more about scholarly and grey literature for the ECD impact area.

This document is part of a collaborative research project, managed by the Principal Investigator, Dr. Kimberly Speers who works in the School of Public Administration at the University of Victoria [UVic]; the project is sponsored by UVic Community Partnerships and the client for the project is the CHF. The research project consists of three literature reviews which provide respective syntheses and analyses of data for three CHF impact areas: children and youth living with complex needs, ECD and youth mental health.

3.4 Methodology

Type of Literature Review and Scope

The following literature review is often described as a narrative or traditional type of review; according to Baumeister& Leary (1997, p. 321), a narrative approach offers a “reinterpretation and interconnection” of existing data and literature. In general, a narrative literature review is designed to gather, synthesize, and present the literature ensuring significant and relevant areas of research and studies are highlighted. It also identifies areas where there are gaps in the literature whether it be place-based, methodological-based or topic-based. This approach is well suited for a complex subject such as ECD because the methodological diversity of literature and data synthesized renders meta-analysis impractical.

To complement and support the review, a focus on smart practices was applied to identify areas of research and studies to be highlighted. It should be noted within the literature reviewed terms such as promising or emerging practices are frequently used, in lieu of best or smart practices. Smart practice, a term coined by Eugene Bardach, refers to a descriptor of practice, particularly when using “best” or “evidence” would be inaccurate, and an evaluative tool to assess the applicability of seemingly effective solutions from one setting to another (Bardach & Patashnik, 2019). While the terms promising, emerging or smart are not synonymous, where included in this review, they indicate ECD services recognized as successful in their source setting and have definable implementing, supportive and optional features (Bardach & Patashnik, 2019, p. 115; 116).

To narrow the scope of the literature review, the search and review strategies focused on literature and data:

- from high-income countries
- published in English,
- published in the last 20 years, and
- studying development from age(s) 0 – 6.

In addition, given the specialized focus of the other impact areas: children and youth living with complex needs and youth mental health, this review highlighted only those themes, trends and services which could be considered general for all children in HIC from ages 0 to 6.

Search Strategies

The following steps were undertaken to source literature in the ECD impact area. The first step was a search conducted on online databases such as Google Scholar, JSTOR, and Worldcat [OCLC] using the following search terms:

- early childhood development
- access
- Canada, province/provincial
- multi-sector
- collaborative
- intersectoral,
- cross-sector,
- hubs,
- high- income countries [HIC],
- community/based/led,
- governance – decision-making, accountability, reporting, planning, measuring,
- outcomes and resulted-based reporting and measuring.

Combinations of these terms were also used, and some literature reviews were treated as seed articles. Grey literature, specifically from Canadian ECD service providers' websites, was reviewed and referenced where applicable. Reviewed articles varied in methodology, including mixed, qualitative, quantitative, case studies and policy reports.

General Themes and Outline of the Literature Review

Given the current state of ECD literature, the various ECD programs and services enabled by the CHF, and CHF's multiple stakeholder relationships across various sectors, numerous topics will be addressed in this literature review. To address the client's preferences, the areas of focus will be:

- Understanding core concepts of ECD
- Identifying the general state of the literature – themes and trends
- ECD services – types and stakeholders
- ECD services – quality, processes, and outcomes

- ECD services – collaboration, engagement, and partnerships
- Smart practices, examples, ideas and lessons learned

3.5 Definitions and Concepts

Childhood development, the assumption that early human development has normative and/or ideal milestones, to be operationalized, requires layers of context (Woodhead, 2009, p. 48). Because of this implicit need for contextualization, ECD literature and data is typically published for jurisdictionally specific program or policy development that correlates with diverse fields of human development studies. Few articles offer universal definitions of ECD; however, the literature does demonstrate a consensus on core scientific concepts underlying healthy childhood development.

Shonkoff and Richter (2013) list five core concepts from the *National Scientific Council on the Developing Child's* framework as representing the "basic science" of ECD; the first being that human brains' architectural development is an ongoing process whose optimal growth and function is predicated by "bottom up" development" (p. 24;26). The second is that "genes and experiences react", referring to the reciprocal relationship between genetics and experience; meaning children rely on "serve and return" interactions with caregivers, to drive the brain's circuitry development (p.26). The third is that "cognitive, emotional, social capabilities [and] physiological integrity…are inextricably intertwined"; as an example of this, Shonkoff and Richter cite the dependence oral language acquisition has on hearing, cognition, attentiveness, and physiological responsiveness, to be successfully achieved (p. 27). The fourth is that "excessive adversity early in life causes physiological disruptions", meaning a child's exposure to "toxic stress", heightens risk of long term physical and mental health challenges (p.28). Lastly, "neuroplasticity and the ability to change behavior decrease over time", or the brain's ability to adapt to challenges "stabilizes with age"; meaning the expenses to correct poor development in later life both biologically, the metabolic energies needed, and in a societal sense, measures via external intervention, are much higher (p.29).

Complimenting these core scientific concepts in the literature is a life course approach or framework to ECD; a life course approach "aims to identify the underlying biological, behavioural and psychosocial processes" across the life span, with the intent to "identify chains of risk that can be broken and [optimal] times of intervention" to break them (Kuh & Ben-Shlomo, 1997, as cited in World Health Organization [W.H.O.], 2000, p. 4). Indeed, coupling this framework and ECD concepts to research which identifies threats to healthy human development to inform effective intervention, is also definitive of contemporary ECD discourse.

Hertzmen and Boyce's (2010) review, *How Experience Gets Under the Skin to Create Gradients in Developmental Health*, demonstrates how core concepts of ECD have informed the development, implementation, and data analyses of a "comprehensive population-based assessment of ECD", with the early development instrument [EDI]. The EDI is a standardized measurement tool administered by educators to assesses school readiness of children, typically ages 4 – 6 (Janus et al., 2007). Utilizing a checklist, children are marked as “vulnerable or not vulnerable…based on five scale measures of development: physical well- being, social competence, emotional maturity, language and cognitive development, and communication and general knowledge” (Hertzman & Boyce, 2010, p. 333).

Hertzman and Boyce (2010) juxtapose discussion of core ECD concepts or “biological embedding”, how “experience alters biological processes…that influence health over the life course” and its relationship to “socially partitioned experiences, brain and biological development, and outcomes in health, learning, and behavior” with data collected via the EDI by UBC’s Human Early Learning Partnership [HELP] between 2000 and 2004 (p.330).

From this first wave of the BC’s EDI, which revealed “[m]ore than 40% of the variance for vulnerability on one or more scales can be explained by neighborhood socioeconomic characteristics” the authors hypothesized that children:

“who are biologically sensitive to context will be distributed broadly across social partitions, but those from less privileged back grounds will tend to find themselves in risk augmenting contexts, whereas those from more privileged backgrounds will tend to find themselves in protective environments. Over time, the differences in developmental trajectories of those biologically sensitive to context will drive the expression of [social] gradients” (p. 342 & p. 343)

This incorporates a “**bio-ecological approach”** to understanding ECD (HELP, 2019, p.15); “that it is not genes or environment, nor is it genes and environment, but rather it is gene-by-environment interactions that influence developmental trajectories” (Hertzman & Boyce, 2010, p. 341). Meaning the quality of multi-layered “nurturant environments” that surround children, beginning with their immediate caregivers and radiating out to political and economic contexts at national or global scales, buttress healthy development and mediate population-based disparities in well-being (HELP, 2019, p.15; Figure 1).

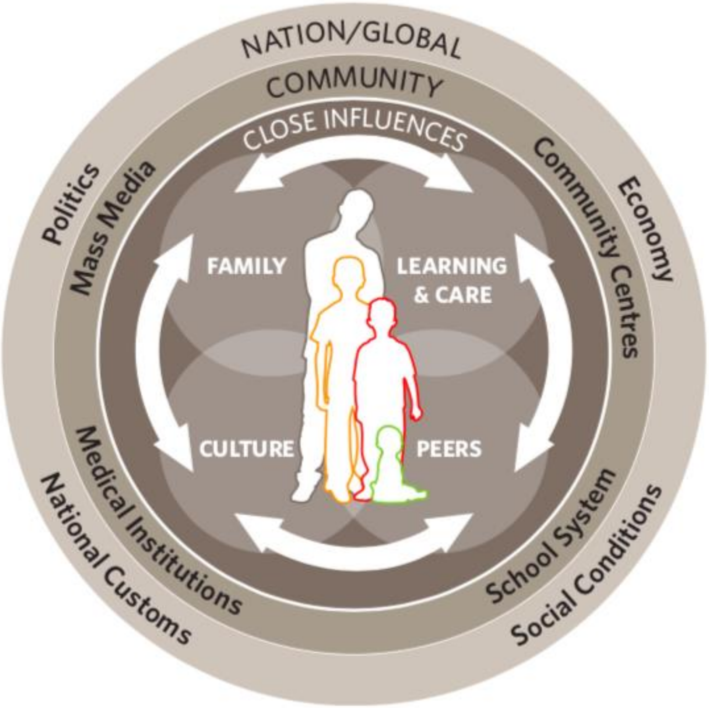

Figure 1. *HELP's Total Environment Assessment Model* [depicting a bio-ecological approach to ECD]. Adapted from HELP, 2013, as seen in HELP, 2019, p.15.

In summary, the reviewed ECD literature, while diverse in methodology and terminology is standard in its scientific assertion that a child's formative years are of incredible value, when both threats and benefits to life-long development are intensified (Black, et al, 2017; Britto, Lye, Proulx, Yousafzai, Matthews, Vaivada & MacMillan, 2017, p. 91; Shonkoff & Richter, 2013). In addition, the literature also states how we understand, and/or augment children's early environments can support healthy human development on individual and societal scales (HELP, 2019; Hertzman & Boyce, 2010 & Shonkoff & Richter, 2013, WHO, 2000). Therefore, to center the review's focus and findings on the incredible importance of a child's earliest years of development, grey literature from CHF, British Columbia's Ministry of Children and Family Development [MCFD], HELP, and their respective websites, were contrasted with peer-reviewed journals to develop the following definition of ECD services as: supportive preventative or intervention measures intended to promote healthy development (primarily) from before birth to age six.

3.6 General State of the Literature: Themes and Trends

Just as the core scientific concepts of ECD depict a progressive, reactive, and intertwined journey of evolution, so too do the key themes and trends of ECD. Four themes identified in the literature and data are: health and nutrition, early learning, and childcare [ELCC], safety and race, ethnicity, and socioeconomic status [SES]. These oft compartmentalized subjects are framed as themes of ECD for two reasons; first, their recurrent frequency throughout methodologically diverse data and literature firmly establishes them as a priori themes (Ryan & Bernard, 2003, p. 89; 88). Secondly, framing these subjects as themes discourages the too frequent assumption that, in the context of ECD service provision, they are somehow extractable from one another or divisible by fixed boundaries. The two trends identified, nurturing care and multi-sectoral and integrated approaches are in effect, a corridor to the successive sections of the review; these trends bridge the gap between ECD themes and their indication in ECD services.

Themes in Early Childhood Development

Health and Nutrition

There are countless subthemes which could comprise "health"; consider the WHO's (1995) broad definition of health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity". However, this sub-section seeks only to provide a general overview of salient physical and mental health topics which could be considered general for all children in HIC from ages 0 to 6, inclusive of nutrition. The subsequent themes of early learning and childcare, safety and race, ethnicity and social economic status more precisely survey the intersection of social well-being and ECD.

The theme of health in ECD literature logically begins with that of the pregnant parent, but, the *Handbook of life course health development*, cites research which draws causal links between both preconception and prenatal health's impact(s) on birth-outcomes, child-health, child obesity and even chronic illness into adulthood (Halfon & Forrest, 2018, p. vi). More specific issues, or "prenatal adversit[ies]" as coded in the *Royal Society of Canada and The Canadian Academy of Health Sciences'* expert panel report on ECD's "adverse childhood experiences", such as poor prenatal and postpartum mental health, smoking, substance misuse, and exposure to intimate partner violence are also well documented risk factors in ECD literature and data (Boivin et al., 2012).

Access to early prevention and intervention services that support healthy pregnancy, delivery, and infant development is a critical determinant of ECD health. A "retrospective population-based cohort study" of births in BC from 2005 – 2010 found, in comparison to women in urban areas, "those in rural areas had higher rates of severe maternal morbidity and severe neonatal morbidity, and a lower rate of NICU admission" (Lisonkova et al., 2016). In addition, access to services which identify and offer supports for "disabling conditions" of infants and children, such as sensory or physical impairments, genetic conditions, or complications in the central nervous system are recognized "as protective factors [which can] remediate and compensate for risk associated with diagnosed disability and identified developmental delay" (WHO, 2018, p. 16 & 18; Slentz, 2017, p. 8).

That being said, assessments of infant mental health, remain controversial as infant behaviors, 0 - 2, are heavily "influenced by factors such as developmental age, cultural and family differences, expectations [,] parental attributions" and are virtually inalienable from the infant-caregiver relationship (Szaniecki & Barnes, 2016, p. 64). While researchers continue to analyze standardized measurements of infant mental health, others such as "the developmental aspects assessed on the social competence and emotional maturity scales" from BC's EDI, provide insight into mental health trends for children entering the school system (Szaniecki & Barnes, 2016; HELP, 2019, p. 27). From data collected via BC's EDI between 2016-2019, three of the four subscales in the emotional maturity scale show an incremental increase in vulnerabilities which correlate "with the behaviors that represent the most common childhood mental health issues – anxiety disorders, attention deficit and hyperactivity disorder (ADHD), and conduct disorders" (HELP, 2019, p.24).

The importance of prenatal nutrition, particularly micronutrients, to ensure healthy gestation is recurrent throughout ECD literature and some impacts of prenatal nutrition that span pre and post birth, also represented (Black, Walker, Fernald, Andersen, DiGirolamo, & Devercelli, 2017; Britto, et. al, 2017; Shapria, 2008). The findings of a Canadian study analyzing data collected from 400 women participating in the *Maternal-Infant Research on Environmental Chemicals-Infant Development* cohort, explored the predictive relationship prenatal diet quality has to automatic nervous system function in infants up to six months of age (Krzeczkowski, et al., 2020). The study concluded that poorer prenatal diet quality, notably a "Western-style diet, low in nutrients, and high in fats and sugars", indicated decreased automatic nervous system function in infants; a core regulatory system, whose healthy function is a protective factor against a host of illnesses, such as "cardiovascular disease or depression" (p.267;268). Another study examining the relationship between household food insecurity and breastfeeding from a sample of 10450 respondents to the *Canadian Community Health Survey*, found that respondents who reported household food insecurity also reported early cessation, meaning termination before 6 months, of exclusive breastfeeding (Orr, et al. 2018).

Indeed, the importance of breastfeeding is highlighted throughout ECD literature. Breastfeeding for the first six months of human life is purported to have numerous health benefits for both the pregnant parent and child (WHO, 2020). In part, breastfeeding's availability and affordability account for its primacy in international literature, which prioritizes health risks for LMIC populations who have limited access to nutrient rich substitutes (WHO, 2020). However, in a meta- analysis of 113 studies from HIC, "longer periods of breastfeeding were associated with a 26% reduction…in the odds of overweight or obesity" for children, both of which are major health concerns in HIC (Victoria, et al., 2016, p. 480). Obesity increases the risk factor of metabolic disease and other chronic health conditions and in 2018, it was estimated that 14% of Canadian children were considered "overweight or obese" (McGee, 2018, p. 39). For children between the ages of 4 and 6, addressing poor habit-forming behaviours towards diet and inactivity can be supported by early learning and child-care settings (Summerbell, et al, 2012).

Early Learning and Child Care

ELCC refers to formalized early learning and childcare (ELCC), which is not universally accessible for children in HIC before entry into formal public-school systems; furthermore, the developmental benefits of ELCC are typically only assessed upon entry into formal school systems at ages 5 or 6, presenting a significant gap in ECD knowledge. Nonetheless, pre-school settings have been found to "improve child outcomes during subsequent schooling" (Black, et al, 2017, p. 12). The BC provincial health officer's report on children's health*, Is "Good" Good Enough?* (2016), supports this finding, indicating that a recent increase in the number of children "entering their formal education prepared from a literacy and numeracy perspective" is the result of provincial investments in ELCC programming (ref). In Wein's (2014) scoping review of ECD programming the author purported that, while reviewed ECD literature documented ELCC's positive effects on global outcomes for childhood development and adult health behaviours, there are no notable effects to "chronic disease outcomes" (p. 26).

Safety

This theme can be refined by the nature of threats children are exposed to in a specific jurisdiction; in HIC, children's safety, in a collective sense, is often protected by national policy and laws. Immunization, while certainly intersecting with the theme of health, is also one of the most essential interventions ensuring safe ECD collectively; where some LMIC are still struggling to develop vaccination policies and programs, HIC have seen "misconceptions" about the risk of vaccinations result in "outbreaks of measles, diphtheria and pertussis" (Gothefors, 2008, p. 55). "Vaccine hesitancy", or parental mistrust of vaccines, has been documented in the United States [US] and Canada and poses tangible risks to the prevention of communicable illnesses for children (Dubé, et. al, 2016)

The prevention of childhood injury is well documented in Canada; the *Canadian Child Safety Report Card* (2020) is an interactive online report of the legislative, public education and policy measures taken by provinces to prevent injuries in children 0 -19. While data could not be disaggregated by age, at the time of this review, BC ranks in first place attributed to the province's effective development and implementation of "distracted driving [,] booster seat [and] bicycle helmet legislation…good graduated driver's licensing program and fair smoke and carbon monoxide detector and pedestrian safety laws" (Canadian Institute of Health and Research, 2020). This report, however, gives little insight into child maltreatment, a possible cause of childhood injury and important subtheme of child safety.

Child maltreatment, as defined by the Canadian government's public health agency, is "the harm, or risk of harm, that a child or youth may experience while in the care of a person they trust or depend on, including a parent, sibling, other relative, teacher, caregiver or guardian" (Government of Canada, 2012). This definition includes five types of child maltreatment, "physical abuse, sexual abuse, neglect, emotional harm and exposure to family violence"; the inclusion of neglect, for example, is important because it asserts that maltreatment is established through substantive evidence of harm, not intent (Government of Canada, 2012). Tran et al's

(2018) *Bibliometric Analysis of the Global Research Trend in Child Maltreatment* affirms child maltreatment is universally considered a serious threat to healthy childhood development; the US, Western Europe, Canada and Australia are identified as leaders in child maltreatment research publications with the most powerful research and organizational collaborations are shared between US, England and Canada (p. 20).

While this bibliometric analysis asserts discourse on child maltreatment from HIC is consistent in terminology, it also notes that data comparison and interpretation is complicated by the impacts legislative or other societal changes have on reported cases. As Halfon (2018) states, the terms neglect and child maltreatment remain highly influenced by "changes in social attitudes towards…definitions of abuse" and "reliability of measurement is not straightforward" (p.269). So, while the BC provincial health officer's report on children's health (2016), indicates a "slight downward trend in the percentage of youth who have experienced sexual abuse", these findings must be accepted with cautious optimism and judiciously interpreted (p. 114).

When considering the maltreatment of children six years or younger, the reviewed literature and data presents varied findings. Infants' physical vulnerability means they incur the highest risk of serious injury or death due to maltreatment; however, while there is no dispute that child maltreatment is deleterious to healthy development, studies exploring whether or not incidents of abuse occurring before the age of six increase the risk of suicidal behaviour, depressive or post-traumatic stress disorder symptoms, in later life, are inconclusive (Montgomery& Trocmé, 2004; Gomez et al., 2017).

Finally, there is a strong intersection between child maltreatment and prenatal adversity, as previously discussed in the theme of health. Taillieau et al's (2019) analysis of the 2008 *Canadian Incidence Study of Reported Child Abuse and Neglect*, focused on reported maltreatment cases, ages 0 – 4, to explore relationships between caregiver vulnerabilities and child maltreatment. Among other correlates, Taillieau et al. (2019) found that "physical abuse perpetration was associated with parental depression" and "neglect was associated with parental obsessive-compulsive disorder and lower socioeconomic status" (p. 3). In addition, Fillipeli et al's (2017) secondary analysis of the 2013 *Ontario Incidence Study of Reported Child Abuse and Neglect*, focusing on children under the age of one, found that a primary caregiver "with few social supports was the most highly significant predictor of the decision to provide ongoing child welfare services" (p 1). Given the unlikelihood that these characteristics manifest exclusively after birth, this study highlights the complex intersectionality of ECD with pregnant parents' and caregivers' well-being across a broad spectrum of characteristics.

Race, ethnicity, and socioeconomic status

Race, ethnicity, and SES are a grouping of characteristics, necessitating both respective definitions and proper context before moving forward. They are presented here as one theme because of this review's limited scope and their implicit association in the literature and data.

The absence of definitive genetic differences between racial groups means “race can more objectively be considered a sociocultural concept wherein groups of people sharing certain physical characteristics are treated differently based on stereotypical thinking, discriminatory institutions and social structures, a shared worldview, and social myth” (Smedley, et al., 2003, as cited in Cheung & Goodman, 2015, p. 227). Ethnicity, in turn, refers to grouping of individuals according to shared cultural norms, practices and ways of life; two individuals may self-identify as belonging to the same racial category and be similarly subjected to systemic discrimination, while also reporting differing ethnic identities (Cheung & Goodman, 227). SES measurement variables may differ according to the social determinants of the assessed population, sometimes overlapping with race and ethnicity; for example, UBC’s HELP includes “multicultural composition” as a component of their SES index (HELP, 2019, p. 32). Universally, SES’s functionality is an assessment of jurisdictional inequities and projected outcomes through measures of employment, educational attainment, income status and other “quality of life attributes” (American Psychological Association, 2020).

Literature and data documenting and analyzing the healthy development of children in HIC uniformly call attention to data which reveals deep fault lines of well-being between categories of race, ethnicity, and SES. For example, many HIC, persistently identify SES as indicative of a child’s potential to achieve healthy development; most notably socioeconomic marginalization in the field of income and/or ethnicity (Hillemeier, Lanza, Landale, & Oropesa, 2013, p. 1859; Adamson, 2010). More precisely, in Canada, despite being the fastest growing segment of Canada’s population, Indigenous children continue to experience aberrant threats to healthy development rooted in the country’s historical and contemporary relationship with colonialism (Public Health Agency of Canada [PHAC], 2019, p. 6).

Revisiting two previous themes, health, and nutrition, through the lens of race, ethnicity, and SES, further illustrates the permeating presence of this fourth theme in ECD literature and data. Beginning with pregnant parent’s health, Dharma et al’s (2019) data analysis from reports of 3,138 mothers who participated in the *“Canadian Healthy Infant Longitudinal Development (CHILD) Study*, a longitudinal multi-center study incorporating 10 distinct waves of psychosocial data collection from pregnancy until the index child was aged 5 y”, found that “ mothers self-identifying as Black or First Nations had consistently higher distress scores than mothers from other ethnicities across all data collection times” (p. 190). Additionally, a 2017 scoping review on maternal health among immigrant and refugee women in Canada found “ [t]throughout the prenatal, intrapartum, and postnatal periods of maternity, barriers to accessing healthcare services were found to disadvantage immigrant and refugee women putting them at risk for challenging maternal health outcomes”; moreover, one of the review’s recommendations, was that future research “[d]isentangle [the] effects of ethnic and immigration contributions to maternal health through comparative research designs including migrant and Canadian- born women with diverse identity and cultural and lifestyle markers”, which emphasizes the importance of measurements which make visible barriers predicated upon race and/or ethnicity, not just migration status (Khanlou, et al., 2017, p. 1 & p. 10).

Halseth and Greenwood's (2019) paper, *Indigenous early childhood development in Canada: current state of knowledge,* illustrates the layered complexity of race, ethnicity, and SES where nutrition is concerned. The authors' review of literature and data reveals "[f]ood insecurity and poor nutrition are contributing to high rates of obesity and overweight among Indigenous preschoolers", as well as especially alarming rates of diabetes among First Nations' children; but they also note "traditional foods continue to be an important source of nutrition" for Indigenous children (p. 6 & p. 18). However, this is not uniformly true, the authors report that "[h]igh concentrations of environmental contaminants have been found in the blood, hair, and breastmilk of pregnant Inuit women and new mothers", due to their unintentional consumption of large amounts of contaminated fish while practicing a traditional diet (p. 18). This provides an apt example of the layered complexity of race, ethnicity and SES when researching ECD; disparities categorized only by race overlook the confounding protective effects of cultural resiliency and how the specificity and environmental context of cultural practice intersect with developmental outcomes.

In a policy paper titled *Race, Ethnicity, and Socioeconomic Status in Research on Child Health* (2015) the American Academy of Pediatrics [AAP] asserts the paralleled increase in "the racial and ethnic diversity of US children", "proportion of children who live in poverty" and "the extensive and persistent racial, ethnic and SES disparities in children's health" establish their high-priority for ECD researchers and stakeholders (p.233). One of the AAP's recommendations is that researchers:

"who study child and adolescent health and development should understand the multiple measures used to assess race, ethnicity, and SES, including their validity and shortcomings. They must apply and, if need be, create research methods that will result in careful definitions of these complex constructs and their influences on child and adolescent health, analysis of interactions between them, and, ultimately, elucidation of the mechanisms of their effects on health throughout the life course". (Cheung & Goodman, 2015, p. 234).

Data collected from UBC's most recent wave of the EDI is evidence of the significance race, ethnicity and SES have in ECD research and, as recommended by AAP, the need for new methods that can accommodate their diversity, intersection, and complexity. As was discussed previously in this literature review, the first EDI, found that between 2000 – 2004 "[m]ore than 40% of the variance for vulnerability on one or more scales" was explained by neighborhood SES (Janus et al., 2007; Hertzman & Boyce, 2010, p. 342). The 7th wave of the EDI, now utilizing an SES Index, revealed that vulnerability has increased, "account[ing] for around 45%, on average, of the overall EDI vulnerability rate at a provincial level" (HELP, 2019, p. 33). Moreover, while the EDI does not disaggregate data based on demographic characteristics, there is a strong indication that in BC, childhood vulnerability attributable to SES often intersects with geographic disparities in well-being (p. 2 & p. 33).

It is important to note that 45% is not the total percentage of children considered vulnerable in BC; HELP considers “10%” to be “a reasonable benchmark for child vulnerability”, with this latest Wave having revealed that “EDI vulnerability on one or more scales in BC has increased to 33.4%” from 32.2% from the prior Wave of data collected between 2013 -2016 (HELP, 2020, p. 14 & p. 5). Instead, this 7th Wave of data indicates that the vulnerability of BC’s children and the percentage of that vulnerability attributable to SES factors continues to grow; and that while the EDI effectively collects population-based measurements of childhood vulnerability, parsing out the differences and interrelationships between measurement variables, including geographic jurisdictions remains a challenge.

3.7 Trends in Early Childhood Development

Bridging the gap between health and nutrition, early learning and childcare, safety and race, ethnicity, and socioeconomic status and ECD services are the trends in ECD: nurturing care and multisectoral and integrated approaches.

Nurturing Care

In 2017, *The Lancet*, published a series of papers on ECD; one of the articles: *Nurturing care: promoting early childhood development*, presents the most comprehensive analysis of ECD interventions to date, which includes recommendations that transcend the challenges of inconsistent terminologies and jurisdiction specific diversity (Britto, et. al 2017). Literature and data, in both LMIC and HIC, across “health, nutrition, education, child protection and social protection”, were systematically reviewed and critically analyzed by researchers and professionals from corresponding fields of study (Britto, et. al 2017, p. 91). While some “evidence-based” interventions were identified to address acute crises in LMIC, the article’s key finding is that “multi-sectoral interventions anchored in nurturing care” are a promising pan-global means to enhance healthy childhood development (Britto, et. al 2017, p. 91).

Nurturing care is grounded in the core concepts of ECD and the life cycle theory, emphasizing the quality of a broad spectrum of “environmental and behavioural factors”, from prenatal nutrition and parent functioning to community and geographic contexts, as key to healthy childhood development (Slentz, 2017, p. 15; Britto et. al, p. 91). Nurturing care is reflected in most, if not all, contemporary ECD policy in HIC (Shonkoff, et, al., 2012, p. 8). Since the adoption of federal-provincial territorial agreements of ECD in 2000, which established federal investment and provincial administration of ECD interventions advancing “healthy pregnancy, birth and infancy; parenting and family supports; early childhood development, learning and care; and community supports”, Canadian ECD policy frameworks have espoused alignment with the concept of nurturing care; particularly those centered on stabilizing global environments of young children with a critical focus on the “home and care” settings (White, 2004, p. 667;

Britto, et. al 2017, p. 91). Nurturing care promotes developmental resilience, the antonym of developmental vulnerability (Slentz, 2017, p. 25).

Multisectoral and Integrated Approaches

These approaches are presented as one theme, due to their pervasive pairing in the literature, although distinction between their functions requires clarification. Black et al. (2017) clarify that "multisector approaches include coordinated services across sectors, ideally with unifying policies… integrated approaches refer to integration across services with shared messages and opportunities for synergy" (p. 10). Some LMIC ECD literature uses "sector" to categorize discipline specific service sectors involved in ECD; Canadian literature typically uses the term to refer to social sectors, such as government, private, or community involved in ECD service provision (CCSDH, 2017). Multisectoral and integrated ECD approaches, also referred to as "initiatives", are often employed in tandem and considered complimentary to a nurturing care approach because they expand and diversify access points to ECD services for children and caregivers, and reduce internal barriers within service systems, helping users navigate access to discipline specific services (CCSDH, 2017; Weins, 2014). Multisectoral and integrated approaches to ECD are typically operated jurisdictionally through "co-located" or "hub" service models, where diverse social sectors offer multiple ECD services from one physical location, with these locations able to assess and refer users' needs to off-site services as well (Weins, 2014).

The following list is a sample of multisectoral and integrated ECD approaches, as presented in the Canadian Council on Social Determinants of Health's [CCSDH] (2017) report *Implementing Multi-Sectoral Healthy Child Development Initiatives: Lessons Learned from Community-Based Interventions*, "classified as[e]ffective or [p]romising, according to the definitions drawn from the Canadian Best Practices Portal" (See Appendix C). Some pan-Canadian examples are: *Aboriginal Head Start in Urban and Northern Communities [AHSUNC] and Aboriginal Head Start On Reserve [AHSOR]*, *Canada Prenatal Nutrition Program [CPNP] and Community Action Program for Children [CAPC]* (p. 9, 10, 12). Some provincial Canada are Ontario's *Better Beginnings Better Futures [BBBF],* Prince Edward Island's *Caring, Helping, And Nurturing, Children Every Step [CHANCES],* New Brunswick's *Early Childhood Development Centres [ECDCs],* and BC's *Success by 6 [SB6]* (p.5, 10, 13 & 14). International examples are: *Positive Parenting Programs [Triple],* operating in multiple countries, or variations of children's "centres" or "community hubs" like the UK's, *Sure Start* (p. 7 & 6).

3.8 Services: Types and Stakeholders

The last twenty years of Canadian ECD policy indicate a familiarity with these concepts and approaches, as well as an understanding of their importance, but persistent challenges remain. In 2018, MCFD published *The Early Years' Service Framework* [EYSF], an outline of policy direction for the creation of a "system of support for young children and families" (BCMCFD, 2018, p. 1). MCFD defines early years services as those received by children between the ages of

0 and 6, noting that between 1.5 and 5 years, after infants receive their final immunization and before school, there are no “universal touch-points” for service delivery (BCMCFD, 2018, p. 6; Figure 2). Moreover, the EYSF, considers a spectrum of potential vulnerabilities families experience such as socio-economic marginalization, mental health crises or familial structure changes, as heightening risks to ECD and requiring a “whole systems approach; [as] no one service area can solve them” (BCMCFD, 2018, p.6).

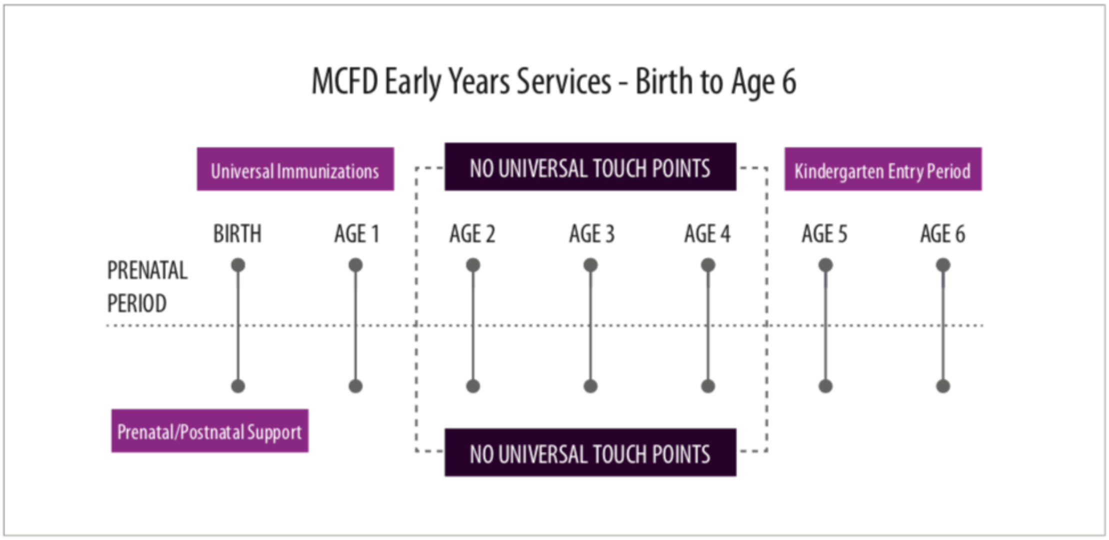

Figure 2. Illustrates the absence of universal touchpoints “for children and families between 18-months and school entry”, from BCMCFD, 2018, p.6.

The EYSF, echoes the Lancet article, even when jurisdiction specific barriers to access ECD services are identified, isolating and investing in discipline specific services will not meet HIC families and children needs to make connections with, and charter pathways through, multiple ECD service systems. For these reasons, the following subsections provide specific examples of ECD services, rooted in the concept of nurturing care which utilize multisectoral and integrated approaches.

Service Types

For the purpose of this review, examples were organized by type as follows: firstly, as previously noted, only ECD services considered smart practices were included. Secondly, ECD services were organized into three separate categories specifying service delivery type: universal, selective or indicated (Gordon, 1983, p.104). Universal services are made available to all, selective services are made available to sub-populations identified as at-risk and indicated services are offered on a case by case basis through screening (Gordon, 1983, p.104) (See Appendix D).

Universal ECD Service Delivery

Purple book health checks [PBHC], is a universally delivered ECD service in Western Australia [WA], part of the WA's "Community Child Health Program" [CCHP] operated from "Child Health Centres" [CHC] or "Child Parent Centres" [CPC] (WA Child and Adolescents Health Services [WACAHS], 2020; WA Department of Health [WADH], 2020). The term "purple book" refers to a physical document similar to BC's *Child Health Passport* (2018) to monitor a child's growth and manage medical appointments, particularly scheduled immunizations (WACAHS, 2018). From birth to age four, community health nurses facilitate five PBHC in the family home or CHC/CPC at 14 days, 6-8 weeks, 4 months, a year, and three years; these appointments titled "child health visits" are staggered with immunization appointments, providing multiple opportunities to connect with other ECD services, if needed (WADH, 2020).

WA uses the Australian Early Development Census [AEDC], a population-based measurement tool modeled after the EDI, to monitor community level childhood vulnerabilities (Department of Education WA, [WADE], 2016). Similar to BC, WA is an ethnically diverse population with children living in urban, rural, and remote communities (WADE, 2016; p. 7). While children in remote WA communities, particularly "Aboriginal" children, have historically been documented as more vulnerable than others, from 2009 the 2016 AEDC recorded a slight reduction in their vulnerability (WADE, 2016, p. 2). It is impossible to attribute this reduction to one service, but PHBC can be considered a smart practice which uses WA's pre-existing immunization program as a platform to increase and extend points of access to ECD services for all children.

Selective ECD Service Delivery

New Hampshire's, Family Resource Centre's family support programs [FSP], are similar to PBHC and include optional home visits, but are selectively delivered, for families in need (FSP, 2017). FSP, part of an expansive county-led ECD initiative, revisited in other sections of this review, integrates modified Triple P program curriculum with localized health service providers to offer: "prenatal and infant care, parenting and co-parenting education, infant growth and child development, childcare, preschool and after school services, ages and stages developmental screenings, growing great kids [curriculum]" and other community resources (FSP, 2017).

A notable aspect of FSP's home visiting program is their adoption of the PHQ2 screening tool for maternal depression. The National Institute for Children's Health Quality's [NICHQ] report: *Designing Systems to Eliminate the Consequences of Maternal Depression: Success Stories from Three States* (2019) documented three case studies, including one in Coös County, New Hampshire; where FSP was part of the county's successful transition from the "Edinburgh Postnatal Depression Scale" administered once in the first year of life, to the PHQ2, a "validated instrument for identifying depression in the primary care setting", administered annually until age 6 (p. 15; Bass & Bauer, 2018). FSP's adoption of the PHQ2 screening tool was part of a successful county-wide project steered by Coös' coalition to identify caregivers and children in need, connect them with services, and guide future service development (NICHQ, 2019, p. 16; See Figure 3). FSP's home visiting program is a smart practice, bringing evidence-based screening and ECD services into homes and providing crucial data for service provision and development.

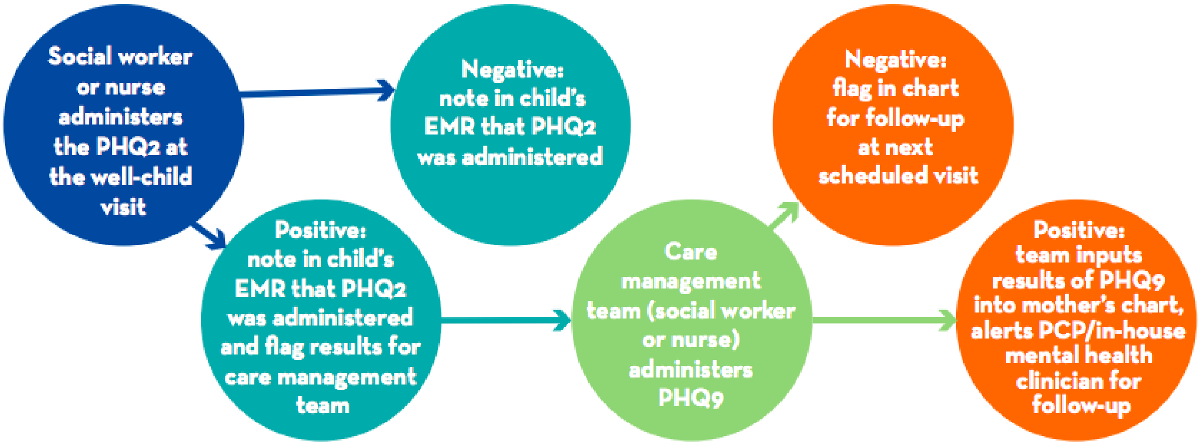

Figure 3. The screening process for maternal depression and access to follow-up care, co-developed by Coös' coalition and local ECD service providers, from NICHQ, 2019, p. 14.

Another selectively delivered ECD service is Salteau First Nation's [SFN] *Cree-ative Wonders Daycare* [CWD]; CWD is an ELCC *Aboriginal Head Start On Reserve* (AHSOR) program in Northern BC (SFN, n.d.). CWD offers two programs: full time childcare for "children aged 1-35 months" and a mixed program for "ages 36 months to grade 1 aged children", with full time spaces, shared spaces, before and after school programs and a "Head Start preschool program" (SFN, n.d.). CWD lists seven components in their approach to ELCC: "culture and language, education, health promotion, nutrition, social support and parental and family involvement" which carefully consider the intersection of ELCC within the culturally specific context of SFN (SFN, n.d.).

Notably, CWD began with support from the *First Nations Partnership Program* [FNPP], (Ball & Pence, 1999, 2006, as cited in Ball, 2009).

"Through the partnership that ensued between the University of Victoria and the Meadow Lake Tribal Council, an innovative model for ensuring the cultural representation of communities evolved, that Dr. Alan Pence called 'The Generative Curriculum Model.' Using this model, the training program has been delivered with eight First Nations organizations to date." (FNPP, n.d).

FNPP graduates went on to create “new programs and new roles within existing programs” and assist their communities in building “community-based infrastructure and intersectoral linkages to support the holistic development of young children and their families” (Ball, 2009, p. 34; Ball, & McIvor,2005, p. 2). CWD is a smart practice providing culturally specific ELCC in a remote community and an ongoing opportunity to develop bicultural ECD services.

Indicated ECD Service Delivery

Mainland BC’s Multicultural Early Childhood Development [MECD] is an indicated ECD service offered through a multi-sectoral partnership with United Chinese Community Enrichment Services Society [SUCCESS], MCFD and Success By 6; families must access MECD services through inter-agency or ministry referrals (SUCCESS, 2020). Through SUCCESS’ service/community centres local families with children from 0 – 6 can benefit from “bridging services” to other ECD services and/or families within the community, and structured parenting programs or drop-in services (SUCCESS, 2020). In addition, MECD also provides cultural competency training for service providers (SUCCESS, 2020). MECD’s objectives are to: “[i]ncrease parents’ awareness of the importance of [ECD], [i]nform families about existing [ECD] resources and services”, and “[a]ssist parents to utilize available services” (SUCCESS, 2020). MECD is a smart practice using pre-existing ethnically specific service/community centres as hubs for families to access culturally competent ECD services, bridge gaps to external ECD services, and offer cultural competency training to other service professionals.

This is by no means an exhaustive list of ECD service types; a comprehensive mapping of ECD services is beyond the scope of this literature review. This list is a companion to the key ECD themes identified, providing practical examples to inspire future ECD stakeholders. Before moving forward, a brief discussion on two common strategies from the ECD services listed, place/person-based approaches [PPBA)] and community driven change [CDC]; as these approaches provide insightful direction for the following sections.

So far, in each section of this review jurisdictional or geographical distinctions have been noted. ECD terminology and themes vary widely, depending on the borders drawn, such as LMIC or HIC; and geographic location, particularly in jurisdictions with ethnically diverse and remote communities, can become fault line markers of disparities in developmental well-being and access to ECD. PPBA targets how those distinctions and differences are addressed though service delivery systems. The term “place” does not indicate simply jurisdictional, geographic or community boundaries, but represents “sense of place” relationships, experiences and interactions; it is families’ “experiential perspective[s]” of their surroundings that inform direct ECD service delivery (Tuan, 1977). Moore & Fry’s (2011) literature review, *Place-based approaches to child and family services,* summarize, as follows:

> A place-based approach is one that seeks to address the collective problems of families and communities at a local level, usually involving a focus on community strengthening. There are a number of advantages to using such an approach, one being that it

> encompasses both a physical and service infrastructure perspective, and social infrastructure perspective. Place-based approaches are usually contrasted with person-based approaches in which the focus is on direct help to the individual person or family with the problem, regardless of their circumstances or where they live. Place-based approaches focus on the whole social and physical environment in a particular area, rather than the individual needs of those who live there. These approaches have usually been developed separately but there are good grounds for using combined people- and place-based approaches (p. 52).

Community-driven change [CDC], is derived from the term "local community driven development", in reference to international development which "gives control of development decisions and resources to community groups and representative local governments" (Binswanger-Mkhize& de Regt, J. P, 2010). CDC accommodates the aforementioned diversity and intersection of complex themes like race, ethnicity, and SES by prioritizing community expertise in ECD processes and governance; this requires all stakeholders to functionally engage with the communities they serve as more than measurements of vulnerability or resilience. CDC changes the conversation from: What is wrong with us? What do we need? to What is happening? What do we want to happen?

Stakeholders

ECD stakeholders are just as diverse as the themes and communities they work with and they need to be! ECD stakeholders can be broadly categorized as representing three social sectors: government, private and public, but some wear more than one hat (Council, 2017, p.17). Understanding why stakeholders are at the table, and what role they will play is important, even if engagement revisits pre-existing partnerships.

BC's Ministry of Health's (2018) *Patient, Family, Caregiver and Public Engagement Planning Guide*, a tool for "individuals in B.C., particularly community partners and health authority and ministry staff, who plan and implement health-care engagement processes and who already have a basic understanding of planning and engagement", includes effective instruments which can be adapted for those who have identified an impact area, such as ECD, and are moving forward with stakeholder engagement (p. 6). These tools can clarify who should be engaged, their role, and set clear objectives for their engagement (Council, 2017, p.15).

3.9 Services: Quality. Processes, and Outcomes

Jurisdiction and discipline specific measures of quality ECD leave only one bench march of quality for all ECD: equitable access. Consider the United Nations' [UN] sustainable development goals [SDG], to:

"3. Ensure healthy lives and promote well-being for all at all ages, [and, to]

4. Ensure inclusive and quality education for all and promote lifelong learning ",

(Desa, U.N., 2016)

underscored by the SDG's core principle that equitable access be promoted both across and within national borders; this challenges the archetype that HIC's role as investors in LMIC ECD, sufficiently promotes equitable access (Raikes, Yoshikawa, Britto & Iruka, 2017, p. 4). That the SDG constitutes HIC address those inequities entrenched within their own borders is an important distinction from previous international commitments to human development. This means reduction of barriers within our own ECD service systems has become an international measure of quality ECD.

Most of the development processes for ECD services listed began with identification of jurisdictional specific barriers to services:

- The scaling up of PBHC, particularly the development of CPC to host child health visits and provide follow-up care if needed, resulted from the state government's cyclical analyses of vulnerabilities reported in AEDC data (AEDC, 2015).
- A three-year $300,000 funding investment in 2007, supported FSP in local partnership with five ECD service stakeholders to "identify opportunities, common goals, and changes necessary to improve services and outcomes for young children and their families" (Payne et al., 2018, p. 3).
- The FNPP and subsequent CWD started with data collected by Indigenous communities on "fragmented [ECD] systems" noting that a lack of locally based service professionals hindered continuity of care and cultural competence in ELCC curriculums (Bal, 2009, p. 32).

These processes used or developed tools to collect data assessing childhood well-being and vulnerabilities so jurisdictional ECD service barriers could be pinpointed, with the intended goal of supporting or initiating ECD systems' change.

System's change or system's initiatives are "organized efforts to improve a system and its impacts"; outcomes are the measurable changes which improve impact (Coffman, 2007, p. 5). Coffman's (2007) *A Framework For Evaluating Systems Initiatives,* or the Build Framework, for example, guides ECD stakeholders through the process of clarifying "what complex systems initiatives are doing and aiming to accomplish, and thereby support both initiative theory of change development and evaluation planning" (Coffman, 2007, p. 2). This framework has been successfully adapted and applied in multiple ECD initiatives, such as the MCFD's 2016 environmental scan data of professional development in the province's ELCC sector (Riel, 2016). Application of the Build Framework helps stakeholders create a "theory of change menu" through five areas of focus: context, components, connections, infrastructure and scale, noting that "systems initiatives do not have to focus on all five areas…some may focus only on one or two…most systems initiatives, however, focus on more than one area, and many focus on four or five." (Coffman, 2007, p. 6; Figure 4).

Among other things, *"By Us and For Us: A Story of Early Childhood Development Systems Change and Results in a Rural Context*" documents the use of the Build Framework as "an analytical construct to examine ECD systems change process" (Payne et al., 2018, p. 29) This case study summarizes the collective impact efforts behind ECD services like New Hampshire's FSP which have "achieved dramatic early childhood systems change in a 10-year period by creating community capacity, a culture of collaboration and improvement, and transforming Coös' early childhood organizations [into] an integrated, high-quality system for early learning and development where none existed before" (Payne et al., 2018, p. 38). FSP's adoption of the PHQ-2, for example, was the outcome of focus on "components: [putting] in place high-quality evidence-based programs, services, or interventions for the system's intended beneficiaries" which contributes to the connections and scale focus areas as well. In this way, systems' initiatives supported autonomous discipline specific ECD services to define and adopt high-quality evidence based "programs, curricula and tools" which contributed to multiple focus area outcomes and systems' change (Payne et al., 2018, p. 31; See Appendix E).

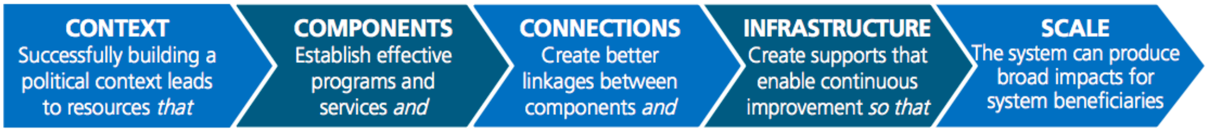

Figure 4. Illustrates "the basic logic of how these areas [of focus] work together to produce systems-level impact", from Coffman, 2007, p. 6.

The Build Framework is only one example of many logic models, or program cycles that can be used to by ECD stakeholders to see the bigger picture and guide them through system's change development and evaluation (See Appendix K).

3.10 Services: Collaboration, Engagement, and Partnerships

Each of the ECD services listed were the result of collaboration and engagement between multiple partners, but in varied contexts and to different degrees. Collaborations are "mutually beneficial and well-defined relationship[s] entered into by two or more organizations to achieve common goals" (Matteessich, et. al, 2001). In the context of collaboration, engagement can be considered the "extent to which collaborative members:(1) prioritize the collaborative's initiative within their own organizations; and (2) commit to a shared path of negotiating common goals and working toward them together with other members" (Latham, 2014, p.3). Partnerships are the varied relationships brokered between members in collaboration.

As previously mentioned, the scaling up of PBHC are facilitated in part from the state government's cyclical analyses of AEDC data, a collaborative effort of Australia's federal governments "State and Territory governments…the Centre for Community Child Health and the Telethon Kids Institute"; the development of the CPC's, "operated by non-government organizations in collaboration with local schools and other child service providers" were supported by WA's pre-existing "Delivering Community Services in Partnership Policy" and continue to foster engagement by serving as hubs for WA's "Departments of Education, Health, Local Government and Communities and Child Protection and Family Support, in collaboration with 14 non-government organizations'" to "develop localized responses to meet the needs of children and their families" (AECD, 2015).

Conversely, with little collaborative support from the government sector, New Hampshire's FSP relied on donor funding to start "relationship-building among initiative partners, including biannual, two-day meetings to build trust and momentum" which "resulted in a population goal and common system strategies" for children ages 0 -5 (Payne et al., 2018, p. 24). The resulting coalition continues to function as an "interagency backbone", sustaining engagement and collaboration between local ECD partners (Payne et al., 2018, p.25).

FNPP and CWD resulted from collaborations with high levels of engagement between an academic institution, UVic, and local indigenous communities and councils, and continues to benefit from partnerships with federal and provincial governments through *Aboriginal Head Start On Reserve* (AHSOR) (FNPP, n.d.; SFN, n.d.). MECD both collaborates with SUCCESS, MCFD and local families, receiving referrals and connecting community members as well as benefiting from a funding and supportive relationship with the United Way through Success By 6 (SUCCESS, 2020).

Weins' (2014) *Integrated Service Delivery Outcomes and Evaluation Processes Literature Review*, prepared for the Provincial Office for the Early Years, which correlated "process evaluation and outcome findings" found that "[e]nablers for multisectoral collaboration have been cited as: a powerful shared vision of the problem to be addressed and what success would look like in solving it; strong relationships and an effective mix of partners; leadership; adequate, sustainable and flexible resources; and efficient structures and processes to do the work of collaboration" (p.12) Moore & Fry's (2011) literature review identified "the engagement of communities in decisions of all kinds (including the 'co-production' of design and delivery of services) the cultivation of community capacity, and the establishment of robust and collaborative governance arrangements" as "key ingredients" to place-based ECD; while citing numerous sources detailing the challenges of collaboration as well (p. iv).

While the collaborative engagement of donors was not directly represented in the reviewed literature, it should be noted that the intensive participatory work PPBA and CCD require is an invaluable ECD investment opportunity. System's change is transformational and takes time, the impact foundations like the Neil and Louise Tillotson Fund and W.K. Kellogg Foundation have had through ECD partnerships in Coös' County is a testament to their collaborative contributions (Payne et al., 2018).

3.11 Smart Practices, Examples and Lessons Learned

All of the ECD service examples listed can be considered smart practices intending to support or initiate systems' change; while the examples report site-specific lessons learned, the following three lessons can be generalized to inform smart practice in HIC target settings:

Place-based, person-based approaches engage communities in discovery of localized ECD service barriers and the infrastructures involved. Service barriers were defined by jurisdiction and engagement with the experiential knowledge of children and families served. As the ECD themes illustrate, the challenges children and families face are complex; PPBA requires ECD stakeholders to adopt roles of advocates and connectors, enabling communities to build on existing ECD sectoral and discipline specific infrastructures to develop "comprehensive multi-level effort[s] to address all the factors that affect child, family and community functioning in that area simultaneously" (Moore & Fry, 2011, p. iv).

Change is community driven. ECD stakeholders, particularly funders, are critically important as catalysts for systems' change but it is equally important that "leadership of ECD remains with the community" (Payne et al., 2018, p. 35).Prioritizing community expertise in ECD processes and governance acknowledges their legitimate role as exponents of their vulnerabilities and resilience; in turn, funders must be "flexible and responsive to community-determined needs" (Payne et al., 2018, p. 35).

Change takes time. The examples provided required collaborative efforts from ECD stakeholders across sectors to sustain, as described in the Coös county case study, "steady, multiyear operating support for ECD grantees and support for infrastructure, convening, strategic planning, communications, advocacy, training, and technical assistance" (Payne, et al., p.35). This requires a clear shared vision of intended long-term goals and the interim outcomes that can be celebrated along the way to sustain momentum; in turn, frameworks, program cycles and evaluative tools can chart and document this journey, making change visible for those involved.

With these lessons in mind, consider the "significant shifts in how the Province of British Columbia addresses the needs of children and families" that have ECD stakeholders hopeful for the future; this includes both federal and provincial investment increases spanning family tax credits, early childcare, housing, health and education (HELP, 2019, p. 7). And while the MCFD shift with the EYSF to investing in "more direct programming in communities", through "systems leaders at local levels" poses some challenges for established ECD services in the Vancouver Island area, it also provides ECD stakeholders an opportunity to create new partnerships, develop, and or advocate proposals for multisectoral, integrated ECD while supporting or buoying those partners who may struggle to adapt (Frog Hollow Neighborhood House, 2019).

Secondly, solid partnerships between ECD stakeholders and service providers across Vancouver Island have already been established. For example, through multi-sourced funding the Greater

Nanaimo Early Years Partnership, provides a co-located hub model to offer and/or connect families and children to multiple discipline specific services (Greater Nanaimo Early Years Partnership, n.d). Collaborative partnerships such as these create an opportunity for ECD stakeholders to develop and scale up data collection tools to better target and coordinate Vancouver Island's ECD services, especially for populations unrepresented in existing data, such as children below the age of 6. Consider HELP's newly piloted Toddler Development Instrument (TDI), a population-based measurement tool based on the EDI, for children between the ages one and two (TDI, now in pilot stages in five BC communities, which uses a voluntary questionnaire to collect data from caregivers; the TDI's purpose:

" is to increase our understanding of the early experiences, needs, and barriers faced by families with young children…findings from the TDI will be shared with communities and stakeholders to inform planning and action at local and regional levels [and] will contribute to building family and community resources" (HELP, n.d.).

Finally, the forthcoming Q̓ʷalayu House, promises to be the "home away from home" for family and children needing medical attention that its predecessor Jeneece Place is, but it is just the beginning. The engagement that has already happened with the We Wai Kai and Wei Wai Kum First Nations in the house's naming bely fertile grounds for further collaborations in PPBA and CDD ECD (Chan, 2019).

3.12 Main Findings and Areas for Future Research

This reviews' synthesis and narrative organization of methodologically diverse ECD data and literature, have resulted in the following main findings:

Children's formative years are of incredible value, a time when both threats and benefits to life-long development are intensified; how children's early environments are understood and/or augmented can support healthy human development on individual and societal scales.

Health and nutrition, early learning and childcare, safety and race, ethnicity and socioeconomic status are current themes in ECD; these themes are interconnected and complex, requiring ECD service responses rooted in nurturing care, utilizing multisector and integrated approaches.

Equitable access to ECD services, a reduction of barriers within HIC's ECD service systems, has become an international measure of quality ECD.

Smart ECD practices utilize people and place-based approaches and community driven development with the intended goal of supporting or initiating ECD systems' change.

In addition, this review has also identified the following areas for future research:

- **Vulnerabilities and resilience of children below the age of 6:** The importance of supporting healthy development from 0 – 6, has been cited exhaustively in this review, however, there remains a paucity of data and literature for this age cohort both generally and jurisdictionally. This indicates the need for data, and development, of research methods which successfully accommodate the complexity of caregiver-child relationships as a primary data source; particularly when caregivers are expected to objectively report on their children's well-being.

- **Race, SES, and ethnicity in ECD:** Echoing the recommendations of the AAP and HELP, as the percentage of vulnerability attributable to race, SES and ethnicity continues to grow parsing out the differences and interrelationships between measurement variables, including geographic jurisdictions, is an area for future research. Again, this not only indicates a need for data but also research methods and analyses cognizant of traditional methods' limitations in these areas. Consider HELP's reliance on the "guidance and support of our Aboriginal Steering Committee…work[ing] directly with First Nations and Metis partners in supporting children and families in their communities to use our data and research" mitigating the limitations of prescriptive data analyses when researching layered complexity [HELP, 2019, p. 2].
- **Changing landscapes of ECD service systems:** As was mentioned in the previous section of this review, BC is in the midst of significant changes in its ECD infrastructure; capturing communities' responses to these shifts is an urgent area for future research. Monitoring and documenting the development of these changes will provide ECD stakeholders timely data about the communities they serve.

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4.0 Literature Review: Children and Youth with Mental Health Issues

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4.1 Executive Summary

This literature review was completed for the Children's Health Foundation to assist them in learning more about the scholarly and grey literature relating to the youth mental health (YMH) impact area. It is a narrative review that synthesizes themes, interconnects ideas, identifies gaps, and points out smart practices in the research and literature. Literature was found using Google, Google Scholar, UVic Summons, and citation mining, and was reviewed thematically for relevance.

There are many definitions for youth mental health (YMH) concepts; however, for the purpose of this review, "youth" is defined as ages 12-24 while "performance measurement framework" is defined as a structured organizational measurement system that has numerous indicators/ performance measures to measure performance and other attributes.

Major themes identified from the literature on service types, strategies, and audiences include: an emphasis on mental health promotion; population-level approaches that match service intensity with need, such as using community-based instead of acute care interventions where appropriate; including youth and families in treatment planning; collaboratively working in networks to better meet youths' needs; offering more community-based services; supporting access to and navigation of the YMH system, and; expanding culturally-appropriate services for Indigenous youth.

To improve the quality of YMH services and the system, improvements in performance measurement are being called for. A performance measurement framework (PMF) that can standardize and share data as well as provide feedback on the system is being called for in particular. To help answer this call, it may be helpful to use tools such as the OPOC-MHA, Inter-RAI, and Mental Health Commission of Canada's PMF. Planning and funding should be strategic, and therefore aligned with strategic policies. Collaboration is also key in improving quality, especially for disseminating information, data, and smart practices. However, collaboration requires having shared understandings and language. Setting up structures for information sharing (e.g. knowledge dissemination centres), communicating online, and making information accessible (e.g. youth versions of documents) are some smart practices.

Youth and their families are increasingly seen as partners in YMH, but their engagement should be meaningful and barriers to participation should be removed where possible. Participative collaboration is key for performance measurement, and participants should be thoughtfully chosen so that a robust set of views are represented in the indicators selected.

Future areas of research include online service provision, which is an emerging frontier; sensory rooms, which may be beneficial in moderating distress; developing Indigenous-operated funding models and using nature-based interventions.

4.2 List of Acronyms

The following acronyms are used in this literature review:

- BC – British Columbia
- CYMHLAC - Child and Youth Mental Health Lead Agency Consortium
- KEC – Knowledge Exchange Centre
- LITS – Live-in Treatment Services
- MHCC – Mental Health Commission of Canada
- SME – Subject Matter Experts
- OAE – Office of Audit and Evaluation
- PHAC – Public Health Agency of Canada
- PMF – Performance Measurement Framework
- YMH – Youth Mental Health

4.3 Introduction

This literature review was completed for the Children’s Health Foundation to assist them in learning more about the scholarly and grey literature relating to the youth mental health (YMH) impact area. The review draws mostly from grey literature as there are many comprehensive grey reports written by academic and expert researchers. Scholarly literature was reviewed to examine consistency between grey and academic research.

This document is part of a collaborative research project, managed by the Principal Investigator, Dr. Kimberly Speers who works in the School of Public Administration at the University of Victoria [UVic]; the project is sponsored by UVic Community Partnerships and the client for the project is the CHF. The research project consists of three literature reviews that provide respective syntheses and analyses of data for three CHF impact areas: children and youth living with complex needs, early childhood development and youth mental health.

4.4 Methodology

Type of Literature Review and Scope

The following literature review is often described as a narrative or traditional type of review; according to Baumeister& Leary (1997, p. 321), a narrative approach offers a “reinterpretation and interconnection” of existing data and literature. In general, a narrative literature review is designed to gather, synthesize, and present the literature ensuring that significant and relevant areas of research and studies are highlighted. It also identifies areas where there are gaps in the literature whether it be place-based, methodological-based or topic-based. This approach is well suited for a complex subject such as YMH because the methodological diversity of literature and data synthesized renders meta-analysis impractical.

Literature specific to youth was used whenever possible, but due to limits in availability of such information literature on mental health for the general population was also used. It should also be noted that within the literature reviewed, services and concepts for youth and children were sometimes grouped together. Information for children programs was not included in this literature because the focus of this review is on youth, who are defined as ages 12 to 24 (Province of British Columbia, 2019).

To complement and support the narrative literature review, a focus on smart practices was applied to identify those areas of research and studies to be highlighted. Smart practice, a term coined by Bardach (2015), refers both to a descriptor of practice, particularly when the use of “best” or “evidence” based is inaccurate, and an evaluative tool to assess the applicability of seemingly effective solutions from one setting to other settings. While the terms promising, emerging or smart are certainly not synonymous, where included in this review, they indicate YMH practices which have been acknowledged as successful in their source settings and have definable implementing, supportive and optional features (Bardach, 2015, p. 131;132).

To narrow the scope of the literature review, the search and review strategies focused on literature and data:

- Published in English
- Published in the last 17 years
- Studying literature relating to youth age(s) 12-24

Search Strategies

Given the availability of high-quality grey literature written by academics and/or subject matter experts (SMEs) and of academic scoping reviews, this literature review primarily drew from these sources. The first step was reading reports provided by the project manager, which were used for content, to identify search terms, and to access other grey literature referenced in these reports. The student researcher then conducted searches on Google, Google Scholar, and the University of Victoria’s Summons database using the following search terms:

- Youth
- Mental health
- Canada
- Data
- Tiered mental health
- Family

- Community
- Best, smart, promising, wise, and emerging practices
- Snoezelen room mental health
- youth mental health framework benefits, youth mental health data framework benefits
- Performance measurement framework youth mental health
- Clear clinical pathways
- Alternatives to residential mental health treatment
- Improving access
- School based
- Substance use
- Quality, quality measures
- Mental health promotion, mental illness prevention
- Definition
- Indigenous collaboration

Combinations of these terms were also used, and several reports and articles were used for citation mining. Search results were scanned for relevancy and 108 articles were reviewed. Subsequent themes were identified.

4.5 General Themes and Outline of the Literature Review

Given the current state of YMH literature, the various programs and services offered by the Children's Health Foundation in YMH, and CHF's multiple stakeholder relationships across various sectors, numerous topics will be addressed in this literature review. To address the client's preferences, the areas of focus will be:

- Understanding the core concepts of YMH
- Identifying the general state of the literature – themes and trends
- Services – types, audiences, and strategies
- Services – quality, processes, and outcomes
- Services – collaboration and partnerships
- Smart practices and examples

4.6 Definitions and Concepts

There are several key definitions and concepts identified in this literature review. Definitions for mental health-related concepts vary widely, and it was widely recommended that partners ensure a shared understanding through discussion, sharing values, and sharing principles (MHCC, 2018; OAE, 2016; Settipani et al., 2019). This will be discussed in more detail in Section 5.2 and 6.0.

The definitions for "youth" varies between countries and organizations because the concept of youth has cultural, political and economic implications in relation to legal responsibilities, access to services and other aspects (CAMH, 2012). In Canadian research it seems common to define youth as ages 12-25, which is the World Health Organization's (WHO) definition of youth (2005); Malla and colleagues define youth as also comprising the adolescent and young adult life stages (2018). In their 2019 mental health strategy document, the Province of BC include the Foundry Centre's definition of youth as individuals ages 12-24 (2019). CAMH recommends recognizing that youth are a diverse category, and may benefit from services that recognize this (2012). This literature review will discuss some of this diversity with you who: are Indigenous; have different levels of need; live in remote areas, and of different sex and genders.

There is also significant variation in the definitions and conceptualizations of mental health and mental illness. To begin, WHO defines mental health as mental and psychological wellbeing, and mental illness as a combination of abnormal thoughts, emotions, behaviours, and relationships with others (*WHO | Mental disorders*, n.d.; *WHO | Mental health*, n.d.). While the MHCC noted that these definitions are very commonly used, they are not preferred universally (2018). The Public Health Agency of Canada (PHAC) defines mental health as the capacity for a person to think, feel, and act in ways that facilitate enjoying life and managing challenges, and mental illness as changes in mood, thinking, or behaviour related to distress and impaired functioning (2002; 2009). With regards to conceptualizations of these terms, the MHCC found that Keyes' two continua model is preferred (2018); this model proposes that mental health and mental illness are separate phenomena that are independent of each other (Keyes, 2007; Westerhof & Keyes, 2010). Mulvale and Bartram added recovery and wellbeing to this model for use in the Canadian context (2015). Indigenous-created definitions and conceptualizations of mental health and illness are also available, such as the First Nations Mental Wellness Continuum Framework (Assembly of First Nations & Health Canada, 2015). As will be discussed, providing more culturally-sensitive services for Indigenous communities is needed.

"Mental health promotion" and "mental illness prevention" are also central terms used in the literature on youth and mental health, and there seems to be more consensus around their definitions. CAMH defines mental health promotion as building capacity and competencies for wellbeing (2012), the American Psychological Association defines it as improving wellbeing (2014), and Joubert defines it as facilitating mental health through developing resilience (2009). CAMH defines mental illness prevention as intervening on risk factors before the onset of illness or to reduce disability after onset (2012), while Arango and colleagues define it as trying to prevent occurrence of mental illness or shift the prognosis to a less severe trajectory (2018).

A major trend in the literature reviewed was on the importance of measuring performance, which has some associated key terms. To begin, performance measures show change in response to a policy, intervention, or service system, and are commonly called indicators (Adair et al., 2003; Adair et al., 2006). Adair and colleagues define a Performance measurement framework (PMF) as a simple conceptual structure with several domains and/or dimensions that serves as a tool to conceptualize, categorize, and assess performance measures, and helps plan the measurement process (2003). Similarly, Urbanoski describes it as using a conceptual model to select a suite of indicators that measure performance and cover all desired performance areas (2017). In the MHCC’s guide on building mental health and addictions PMFs, they define a PMF as being collaborative and system-level (2018). This will be discussed in Section 5.1.

4.7 General State of the Literature: Themes and Trends

This section provides a high-level overview of some of the main themes and trends identified in this literature review for YMH and mental health in general, as well as for methodology and methods, trends and services, and changes being called for in the academic and grey literature.

Literature on Youth Mental Health

There is consensus in the grey and academic literature that addressing the needs of youth should be a priority (CYMHLAC, 2018; Malla et al., 2018; Province of British Columbia, 2019). There have been many reports and literature reviews written on this topic in Canada, such as a scoping review by Settipani and colleagues (2019) on service hubs for YMH and the work by Aarons and colleagues on YMH measurement (2003). Despite an abundance of literature, there remains a lack of performance-related YMH data (MHCC, 2018; OAE, 2016) and fragmented and difficult-to-navigate service systems in jurisdictions across Canada (CYMHLAC, 2018; MHCC, 2018; Settipani et al., 2019). Given this situation, there is a growing recognition that a crucial step in addressing youth mental health is having better quality of performance-related data to understand and improve the current state of YMH services (Adair et al., 2003; CIHR, 2011; Mental Health Commission of Canada, 2018; Nguyen et al., 2019; OAE, 2016).

Literature: Methodology and Methods

Both the grey and academic literature recommend developing and implementing a YMH PMF to better understand the state of YMH and to create a feedback loop where gaps in the system can be identified and addressed (Adair et al., 2003; Bickman, 2008; Mental Health Commission of Canada, 2018; OAE, 2016). A smart practice seems for performance measurement seems to be participatively selecting indicators and collaboratively sharing data and information (Adair et al., 2006; Mental Health Commission of Canada, 2018; Waddell et al., 2013). This will be discussed in Section 5.1.

Literature: Trends and Service

There are many types of YMH programs and services, and some trends in the field. One of the more prominent trends in the academic and grey literature reviewed is promoting mental health and shifting towards preventative and early intervention programs and away from crisis care (OAE, 2016; Province of British Columbia, 2019). Effective youth mental health promotion programs blend promotion and prevention and use strengths-based approaches to emphasize assets and build individual, relational, and contextual capacities (CAMH, 2012; CYCC Network, n.d.; Joubert, 2009; Liebenberg & Joubert, 2019).

There is also a trend towards using broader, population-health service models that match service levels with need (MHCC, 2018; WHO, n.d.). Tiered Models in particular seem to be favoured within and outside of Canada for YMH and youth substance use because they use a needs-based population health model to categorize levels of need and services (Rush, 2010; Tremblay et al., 2019). Another emerging trend is using service models that take a conceptual *and* structural approach and extend beyond the boundaries of formal health systems, which may help with building YMH frameworks (MHCC, 2018).

There is a growing awareness of the value of including families and communities in YMH activities (e.g. treatment) and the benefits of minimizing separation of youth from their families and communities – especially for Indigenous youth (Abba-Aji et al., 2019; Brownlie et al., 2017; CYMHLAC, 2018; Gray et al., 2016). Another prominent trend is around meaningfully including youth; Narendorf and colleagues concluded that youth consultation is needed to make a more responsive YMH system, and Jenkins and colleagues found that engaging rural BC youth with youth-driven mental health promotion increased stakeholder relevance and fostered mental health promotion outcomes (2018; 2012). Another major trend is around helping youth and families navigate the system, such as by improving clinical care pathways so youth can receive the right services no matter where they first seek help (Office of the Auditor General of Ontario, 2016; Settipani et al., 2019), and providing services to help youth and families navigate transition points (CAMH, 2012; Carver et al., 2015; Province of British Columbia, 2019).

The literature emphasizes the importance of collaborating and working in networks to best meet youths' needs (see Section 6.0), such as using service hubs to ease system navigation and facilitate information sharing (CYMHLAC, 2018; Henderson, Chaim, et al., 2017; Hetrick et al., 2017; MHCC, 2018; OAE, 2016, 2016; Settipani et al., 2019). The MHCC concluded that service delivery partnerships with schools are a policy trend (2018), and in their meta-analysis Taylor, Oberle, Durlak, and Weissberg found these programs can be effective in promoting well-being across race, socioeconomic backgrounds, and school locations (2017). In a 2012 survey of youth by CAMH, youth identified intervening on mental health attitudes, optimizing format of service delivery, and providing services for homeless, at-risk, and minority youth as perceived areas of unmet need in school-based mental health programming.

Literature: Calls for Change

The calls for change can be summarized as aiming for a more collaborative, systems-based, and participative approach to YMH. Transforming systems and developing PMFs are being called for to help more effectively meet YMH needs (Bickman, 2008; CYMHLAC, 2018; MHCC, 2018). Furthermore, academics and government organizations agree that PMFs can facilitate system transformation by identifying gaps in the system (Adair et al., 2003; CIHR, 2011; Mental Health Commission of Canada, 2018; OAE, 2016; Settipani et al., 2019). PMFs require collaboration (e.g. data sharing), which is also required to build networks and communities of care that can better meet youths' needs (Adair et al., 2006; CYMHLAC, 2018; Hetrick et al., 2017; OAE, 2016). The literature calls for integrating existing but fragmented services, which may require systems-thinking and collaboration to achieve (CYMHLAC, 2018; Settipani et al., 2019). The final identified prominent call for change was to use community-based services to keep youth with their families and communities (Abba-Aji et al., 2019; CYMHLAC, 2018; Gray et al., 2016).

4.8 Services: Strategies, Types and Stakeholders

This section will review common service types offered by Canadian YMH organizations and the literature for Live-In-Treatment-Services (LITS) and emerging services. It will describe the stakeholders identified in this review and focus on service needs of youth and Indigenous youth.

Types of Strategies and Services

Common YMH services types offered by organizations or as a network across Canada include:

- School-based programs, which target students who may be struggling with mental health and require additional support (CASA, n.d.; CMHA, n.d.)
- Community-based programs such as support groups and therapy (CMHA, n.d.; *Home | CASA Child, Adolescent and Family Mental Health | Edmonton*, n.d.)
- Day programs, which target youth who benefit from intensive services during the day but are able to sleep at home (CMHA, n.d.; *Home | CASA Child, Adolescent and Family Mental Health | Edmonton*, n.d.)
- Services and programs for anxiety and depression (CMHA, n.d.)
- Suicide prevention (CMHA, n.d.; OAE, 2016)
- Substance use (CMHA, n.d.; MHCC, 2018)
- Residential treatment, which targets youth with intensive needs that cannot be met through community-based treatment (*Home | CASA Child, Adolescent and Family Mental Health | Edmonton*, n.d.)

With regards to live-in residential treatment (LITS) – also known as residential treatment - Ontario and BC seem to prioritize improving this service category (CYMHLAC, 2018; Province of British Columbia, 2019). Ontario's Ministry of Children and Youth Services identifies three main aspects of LITS quality: providing (physically) safe and healthy places; feeling at home and cared for by staff; meeting youths' needs, such as ensuring timely access to services that are close to home and; involving youth in decision-making (2017). The Child and Youth Mental Health Lead Agency Consortium found that Ontario youth are too often inappropriately referred to LITS, which results in administering a costly, intensive, and disruptive treatment that does not meet the youths' needs (CYMHLAC, 2018). They recommended improving the assessment process to ensure only youth who require and benefit from LITS receive it (CYMHLAC, 2018). "Step-up/Step-down" tiered care services can help achieve this goal by ensuring youth are getting the appropriate level of care, and also help youth transition back into the community after leaving LITS (CYMHLAC, 2018; Ministry of Children, Community, and Social Services, 2018; Province of British Columbia, 2019).

It is BC's position that alternatives to LITS should be used whenever therapeutically appropriate to minimize separation from families and communities (Province of British Columbia, 2019). A review of alternatives to LITS for children and adolescents by Kwok, Yuan & Ougrin found that the outcomes for intensive community services (ICS) and LITS were mostly non-significant (2016); however, where differences were significant, ICS were associated with more positive clinical outcomes such as shorter hospitalizations and patient satisfaction (Kwok et al., 2016). Kwok and colleagues concluded that ICS seem to be viable alternatives to LITS, but that research needs to be replicated (2016). Multidimensional Family Therapy in particular has been found to be as effective as LITS in the first two months of treatment for youth with substance use and co-occurring disorders, but more effective than LITS after 2-18 months (Liddle et al., 2018).

Along with the common types of service are emerging ones. To begin, services for substance use disorders are increasingly being included in mental health services and policies. The DSM-5 and WHO have included substance use in their conceptualizations of mental health for quite some time (Hasin et al., 2013). Recent academic research reveals that substance use and mental health are often researched together because of their high comorbidity (Dunne et al., 2017; Henderson et al., 2019; Henderson, Hawke, et al., 2017). The MHCC found that 12 of 13 provincial and territorial mental health policy documents included considerations for substance use disorders (2018). Yukon has incorporated substance use and mental health into its Youth Mental Health Framework, and the Province of BC has integrated mental health and substance use into its 2019 mental health and addictions plan (Mulvale et al., 2014; Province of British Columbia, 2019)

Another emerging frontier is delivering services online and/or through technology (e.g. apps). CAMH (2012) found that youth want more resources and services to be available online, although Michel, Slovak, and Fitzpatrick found that ensuring app design and functions align with youth preferences is crucial for uptake (2019). They also concluded that providing services through apps can help youth avoid stigma, while CYMHLAC and the Province of BC think delivering services online shows promise for improving access for youth in remote and rural communities (2018; Michel et al., 2019; 2019).

Services: Stakeholders

Stakeholders are defined by the Treasury Board Secretariat of Canada as “an entity that may be internal or external to the federal government, such as a citizen, business, service provider, service consumer, partner or employee, and has an interest in [a]…service, project or organization or their related activities, resources or deliverables” (Treasury Board Secretariat of Canada, n.d.).

The academic literature identifies many YMH stakeholders, including children, youth, families, governments, health organizations, children and youth ministries, service workers, experts (Mulvale et al., 2016), child and youth mental health agencies, knowledge brokers (Danseco et al., 2017), researchers, policymakers (Abba-Aji et al., 2019), and individuals with lived experience (Brownlie et al., 2017). Youth, service providers, health agencies, and families were referenced in multiple articles, indicating they might be more central stakeholders.

According to the Youth Prevention-Intervention Continuum, there are three main YMH groups:

- **General Population**: low-intensity needs and can benefit from universal prevention strategies that reach the greatest number of people (e.g. school-based programs).

- **At-risk sub-populations**: benefit from selective prevention strategies that aim to increase protective factors and decrease risk factors (e.g. intensive family programs).
- **At-risk subpopulations**: have undiagnosed signs and/or symptoms that may indicate mental illness, and who benefit from more intensive preventative support strategies (e.g. counselling) (CAMH, 2012)

The literature is increasingly identifying Indigenous peoples and youth as stakeholders in mental health and YMH (Cameron et al., 2014; Jacobs & McDaid, 2009; Sénat, 2006). The academic and grey literature is in agreement that services for Indigenous youth need to be improved, particularly in effectiveness and cultural appropriateness (MHCC, 2018; Ministry of Children and Youth Services, 2017; Vukic et al., n.d.). Government agencies and academics are in consensus that to achieve these goals data needs to be improved, services for Indigenous youth should be designed and led by Indigenous individuals and communities wherever possible, and services should be offered closer to youths' homes to prevent separation from their communities (MHCC, 2018; Ministry of Children and Youth Services, 2017; Office of the Auditor General of Ontario, 2016; Province of British Columbia, 2019; Smylie & Firestone, 2015).

4.9 Services: Quality, Processes, and Outcomes

This section discusses the literature relating to quality, processes, and outcomes for YMH. The Quality section focuses on improving data, service, and system quality through using PMFs. The Processes section discusses funding and strategic alignment, and the Outcomes section focuses on sharing information and results.

Quality

As mentioned previously, YMH services can be fragmented and academics including Settipani and colleagues and Malla and colleagues are calling for services to be better integrated (Malla et al., 2018; 2019). The CYMHLAC of Ontario proposes using a provincial system to address this need and address the current practice of service providers designing non-standardized services based on their own resources, capacities, and priorities (CYMHLAC, 2018)

The academic and grey literature both identify a need for better YMH performance data, and that improved measurement of the YMH system and services is needed to improve service quality (Bickman, 2008; Hickie et al., 2019; MHCC, 2018; Settipani et al., 2019). A lack of standardization in mental health program measurement and indicators has resulted in a poor ability to evaluate performance because of:

- Lack of available data because it is not collected
- No baseline data because data is not collected
- Lack of standardization, which means data often can't be compared cross-organization (CYMHLAC, 2018; OAE, 2016)

There seems to be consensus in the grey and academic literature that using PMFs (see Section 2.0) is the preferred approach for improving data, system, and service quality. Settipani and colleagues and the MHCC argue that a PMF will facilitate performance measurement, robust evaluation, replication, knowledge exchange and dissemination, and evidence-based and meaningful service change (2018; 2019). According to the MHCC, a PMF achieves these outcomes through building capacity to collect and report on measures and creating a forum for sharing information and innovations (2018). Bickman and the MHCC state that PMFs can improve system and service quality by acting as a feedback system, which facilitates improvement by identifying system gaps and areas for improvement (2008; 2018). Hickie and colleagues suggest that PMFs may also improve the quality of service provision by helping connect youth to the right services sooner and thus prevent the development of more severe conditions (2019); Malla and colleagues criticize the Canadian YMH system for delays and missed opportunities in treating youth (2018). PMFs may also meet the need identified by the Office of the Provincial Health Officer for mechanisms to address indicators with missing or scarce data in order to improve data quality (Office of the Provincial Health Officer, 2016). Finally, a PMF may help sustain evidence-based practice, which is identified as crucial by Aarons, Hurlburt, and McCue Horwitz (2011).

Nonprofits and government agencies have come up with recommendations for PMFs for mental health, although the MHCC seems to have explored this issue very comprehensively in their expert-written guide on this topic. The MHCC argues that PMFs should be designed to constantly adapt to the data it receives to optimize its feedback and improvement benefits (2018). For YMH specifically, the MHCC suggests that PMFs should be broad, use diverse data sources and types, and have a developmental and life-course-thinking lens (2018). They also recommend that indicators for children and youth cross sectors such as education, health services, and public health (MHCC, 2018). To select indicators, understanding quality outcomes and measurement priorities is helpful.

Kilbourne and colleagues emphasize the need to measure quality outcomes regularly and systematically (Kilbourne et al., 2018), which a PMF could potentially support. The Province of BC, federal Office of Audit and Evaluation (OAE), CYMHLAC, and the MHCC identify the following quality domains as priorities for measurement: equity, effectiveness of programs and services, mental health promotion, and access to services (2018; 2018; 2016; Province of British Columbia, 2019). Kwan, Rickwood, and Telford identified general well-being, daily functioning, relationships with friends and with family, and general coping as key quality measures for YMH specifically (Kwan et al., 2018). Other quality measures according to Hackett and colleagues include transfer to and/or from hospital, intake into hospital, services provided, assessment and treatment, treatment environment, caregiver involvement, and once again access to care (Hackett et al., 2018). For Indigenous YMH, priority quality outcomes include access to care, addressing inequities, and providing culturally safe services (Cameron et al., 2014; Jacobs & McDaid, 2009; Vukic et al., n.d.). Clearly, access to services seems to be a common priority quality outcome.

Improving access to services is considered a priority in BC (Province of British Columbia, 2019) and Ontario (CYMHLAC, 2018), as well as by Hackett and colleagues (Hackett et al., 2018). According to the CYMHLAC of Ontario, access is comprised of availability, affordability, and acceptability of services (e.g. culturally appropriate) (CYMHLAC, 2018). According to these sources, preliminary research indicates that having sensitive and responsive access mechanisms and points, monitoring key performance indicators to identify and address issues, and having standardized and benchmarked core services are key to improving access (2018). As has been discussed in Section 4.1 and will be discussed in Section 8.1, providing services online or by phone could improve access, although this is an emerging frontier of service provision and so evidence is limited (CYMHLAC, 2018). Data analysis and stakeholder consultation can help identify and address underlying causes of unequal access, such as sex/gender and geography (Office of the Provincial Health Officer, 2016).

Processes

Some key processes that will be discussed include financial accountability and funding, strategic planning, legislation, and building a shared understanding.

The OAE identify annual financial reports as a tool for facilitating financial accountability, and also discuss how providing some flexibility to grant recipients may allow for innovation in mental health services (2016). For example, the federal branch of the MHCC utilized resources to develop crucial programs that were not explicitly identified as priorities in the grant agreement (OAE, 2016). These include the Mental Health First Aid program - which is spreading internationally and seen as a smart practice - suicide prevention activities, and developing a National Standard for Psychological Health and Safety in the Workplace (OAE, 2016). For funding in general, the OAE (OAE) recommends that financial reporting is linked directly to priority areas to determine the proportion of funds that are directed towards key deliverables and management (2016). This strategic alignment of funding falls under the broader umbrella of strategic planning.

With regards to strategic planning, some recommended practices are: to align programs with strategic goals, to clearly write out priorities and objectives, and to delineate roles and responsibilities of all partners involved (OAE, 2016). These approaches can lead to better coordination, less duplication, and better sharing of best practices, and may help achieve engagement from partners and outcomes (OAE, 2016). Using these approaches may be particularly beneficial in YMH due to its complex programs and partnerships (OAE, 2016). Other tools for achieving outcomes in such a complex field included legislation and mandated action (OAE, 2016).

Legislation and/or mandated action can be tools to produce change and facilitate accountability through ensuring compliance, particularly when it comes to partnerships and complex issues (OAE, 2016). For example, Australia and New Zealand have more accountability measures (e.g. regular reporting) in place for their mental health strategies than Canada (OAE, 2016). These mechanisms have enabled them to have a clearer understanding of mental health in their countries than does Canada (Mental Health Commission of Canada, 2015; OAE, 2016). The Province of BC has identified a need for improving the understanding of mental health in BC (2019), and the BC Office of the Provincial Health Officer sees value in establishing a provincial inter-ministerial leadership committee to help make progress on YMH (2016). Key to making progress is ensuring that there is a consistency of understanding among partners and stakeholders.

With regards to having a shared understanding, there is benefit in using consistent languages and definitions; the benefits of this are many, but include facilitating consensus, establishing buy-in and facilitating communication (OAE, 2016). Developing a vision and/or mission statement can help achieve this by facilitating shared understandings and communication within and between agencies and with the public (MHCC, 2018; OAE, 2016). Adhering to a framework and/or strategy can be helpful because it acts as a reference point and guides an organization's activities (OAE, 2016). The Evergreen Framework is recommended by the MHCC, because it is designed for use in YMH and has four strategic directions: promotion, prevention, intervention and ongoing care, and research and evaluation (MHCC, 2018).

Communication

The literature seems to agree that communicating online is a priority for reporting information on YMH. The 2019 BC mental health strategy recognizes the values of web portals in supporting youth mental health (Province of British Columbia, 2019). Organizations such as CMHA Ontario act as an online database for services and offer an easy-to-navigate website with links to services and tools for finding services (CMHA, n.d.).

Organizations seem to view knowledge creation, collection, and dissemination as a key outcome of their efforts. For example, the Knowledge Exchange Centre (KEC) at the MHCC creates, collects, and shares evidence-based information, and is often viewed as the MHCC's most significant contribution (OAE, 2016). Its SPARK (Supporting the Promotion of Activated Research and Knowledge) training program uses mentorships to translate knowledge into practice (OAE, 2016)

4.10 Services: Collaboration and Partnerships

This section focuses on the literature on collaboration, partnerships, and engagement for key identified stakeholders in YMH. It covers some functions and benefits of collaboration, and then moves into the literature surrounding meaningful and participative engagement for youth and families. It finishes by discussing collaborating with Indigenous partners and substance use organizations.

To begin, collaboration in YMH is valuable and important; this may be reflected in the apparent favorability of collaborative care models for YMH (e.g. partnerships with schools) and the calls for cross-system approaches to implementing evidence-based practice (Aarons et al., 2009;

MHCC, 2018; Province of British Columbia, 2019). The OAE found the benefits of collaborating can include creating efficiencies, increasing the ability to leverage resources, and can improve the quality and sharing of knowledge (see Sections 5.3 and 8.3) (2016). Hetrick and Colleagues, the Province of BC, and Settipani and colleagues promote the use of service hubs for YMH to integrate services, create single points of entry, and provide comprehensive care (2017; 2019; 2019). Settipani and colleagues identify the following factors of success for YMH service hubs: rapid access to care and early intervention; settings that are friendly for youth; evidence-based approaches, collaboration and partnerships, and; youth and family engagement (2019). When collaborating, one must consider the partners who are collaborated with.

In general, the MHCC recommends picking partners thoughtfully because their views will shape the partnership and be reflected in the end product(s) of your collaboration (2018). The MHCC recommends consulting a diversity of sources (e.g. literature, stakeholders, public health leaders, youth, etc.) to gain a more robust view of an issue because different partners provide different lenses for a given issue (2018). With diverse partnerships, however, comes the issue of obtaining consensus and/or endorsement of any final product(s); the MHCC recommends taking a thoughtful approach to achieve these outcomes (2018). Examples of such an approach in the context of designing a PMF are discussed in Section 8.3.

This raises the question of specific partners that are recommended for inclusion in YMH activities. Youth and their families seem to be increasingly viewed as partners in YMH treatment - especially for Indigenous youth (CYMHLAC, 2018; MHCC, 2018). Academics, non-profits and government agencies – including the Province of BC – promote partnering with people with lived experience in mental health service design and delivery (Brownlie et al., 2017; MHCC, 2018; OAE, 2016; Province of British Columbia, 2019). Partnering with such populations requires being able to engage them, which will now be discussed.

According to subject matter experts (SMEs) consulted by the MHCC – all of whom had PhDs and/or Master’s degrees - engagement ought to be meaningful; this means using a co-designed, reflective, participatory process that acknowledges sociohistorical contexts, biases, power dynamics, and those who benefit (MHCC, 2018). Raanaas, Bjøntegaard, and Shaw found that participatory action research involving youth is underutilized but crucial for fully involving youth voices in YMH (2018). The MHCC recommends using culturally-safe engagement principles (2018). The OAE emphasizes the importance of clearly defining the roles and responsibilities of all partners, having a shared language and understanding to facilitate a shared approach, and having an overarching vision to support engagement efforts (2016). Recommendations for engaging youth and their families specifically will be addressed below.

Engaging Youth

Youth should be engaged meaningfully in YMH; Roger Hart’s “Ladder of Youth participation” is a continuum for youth participation (1992), which Nunes promotes as a useful tool for differentiating true participation from "not true participation" (2012). See Appendix L for a graphic. A scoping review by Nunes found several principles for engaging youth:

- Be inclusive
- Take an approach that promotes positive youth development
- Develop accountability for youth engagement (e.g. report back)
- Design operational practices that sustain youth engagement (e.g. youth-led initiatives)
- Be flexible and innovative
- Be transparent
- Ensure engagement activities are financially sustainable
- Coordinate, where possible, across sectors
- Collaborate
- Create a safe and supportive space for youth
- Use a strengths-based approach (Nunes, 2012)

With regards to the last two principles, Zinck et al. explored engaging youth in challenging contexts (e.g. Indigenous youth, youth with health-related challenges) and found that considering culture, context, and potential harms from your practices are some key themes (2013). These may relate to creating a safe space for these youth. Zinck et al. also recommend evaluating innovative or promising practices, and using a strengths-based approach (2013).

The principles identified by Nunes and Zinck go beyond conceptualizing engagement as "attendance," which was the most common operationalization in 50 studies reviewed by Becker and colleagues (2017). Becker and colleagues found that assessment, education, increasing accessibility, removing barriers to treatment, and goal setting are common practices that are effective at engaging youth and their families (2017). They note that it may be beneficial to use other practices as needed to target particular aspects of engagement, and that engagement can be improved through targeted interventions (Becker et al., 2017). Brownlie and colleagues and Raanaas and colleagues concluded that including youth participatively in YMH research is a key engagement practice, with additional implications for YMH service and system improvement (2017; 2018).

Hawke and colleagues found that engaging youth is also key to making YMH services youth-friendly; other factors that make services youth-friendly include; a comfortable environment with information resources; welcoming, genuine, and skilled workers, accessible location, individualized and innovative approaches, minimal wait times, and; policy and organizations that are integrated, confidential, inclusive, and safe (Hawke et al., 2019).

Families as Partners

Families are important partners in delivering services to youth, as their involvement and input is critical for youth to achieve mental health (Chovil, 2009). The family model of care sees the family as a client, resource for change, and expert on their child (Chovil, 2009). It empowers the family, involves them in the decision-making process, and can improve their satisfaction with services (Chovil, 2009). This model can also improve the YMH system of care by gaining feedback on how the system is experienced by families (Chovil, 2009). Chovil found that this model is associated with successful treatment outcomes, and may be more important than the type of intervention used (2009). To achieve these outcomes, families must be well-informed and supported, and barriers to their participation need to be addressed; key barriers include work schedule, staff attitudes, and making families feel safe, unjudged, and comfortable (Chovil, 2009). Because families play an important role at all levels of the mental health system, Chovil argues that it's beneficial to involve them at all levels of YMH (2009). See Appendix M for a more information on family engagement elements and examples of family engagement at multiple system levels.

Indigenous Peoples as Partners

The OAE recommends more collaboration and partnerships with Indigenous organizations (2016); however, there seems to be a lack of academic literature exploring this topic. As previously discussed, such partnerships should strive to produce products that are Indigenous-designed and/or -led whenever possible (MHCC, 2018; Province of British Columbia, 2019). Programs should be culturally relevant and guided by community priorities (OAE, 2016).

Substance use organizations as Partners

As discussed in Section 4.0, there are calls to integrate substance use and mental health due to high comorbidity (OAE, 2016). The Yukon has integrated these domains of care their Youth Mental Health Framework (Mulvale et al., 2014), as has the Province of BC in their 2019 mental health strategy (Province of British Columbia, 2019).

Knowledge Quality and Dissemination

As discussed in Section 5.0, there seems to be a growing focus in the grey literature on sharing information (e.g. research, data, smart practices) as a key activity for YMH organizations (CMHA, n.d.; OAE, 2016). Sharing information facilitates collaboration (CMHA, n.d.; OAE, 2016), but collaboration also facilitates sharing information; for example, the OAE found that utilizing partners to disseminate info can help it reach more people (2016).

Having a Common Assessment Tool (see details on the Inter-RAI in Section 8.2) is a key building block for several collaborative efforts to improve YMH system services:

- *Facilitates clinical and care pathways during transitions, especially in the adult mental health system*. It does so by improving integration with the adult mental health sector, enabling better triage, and removing the need to for youth to re-do assessments as they transition across services and agencies (CYMHLAC, 2018).
- *Allows data to be compared and shared*. This is key for identifying system gaps, strengths, and areas for improvement (CYMHLAC, 2018). In fact, surveilling

  (defined as collecting and reporting data) has been found to foster collaboration, and could improve data strategies provincially (OAE, 2016; *Realizing the Potential*, 2018)
  - *Prevents duplication of efforts*. This can make staff more efficient (CYMHLAC, 2018).

4.11 Main Findings and Areas for Further Research

Main Findings

There are many types of services being offered to youth, however services that promote mental health and prevent mental illness seem to be favorable (CAMH, 2012; CYCC Network, n.d.; MHCC, 2018; G. Mulvale et al., 2014; Nunes, 2012). Service intensity should be matched with youths' needs, particularly with intensive treatments such as LITS (CYMHLAC, 2018; Province of British Columbia, 2019). Providing better and culturally-sensitive services for Indigenous youth that are Indigenous-led are being called for by government and non-profit agencies (Mental Health Commission of Canada, 2015; Ministry of Children and Youth Services, 2017; Office of the Auditor General of Ontario, 2016; Province of British Columbia, 2019) . Including substance use and online services are emerging trends for YMH (CAMH, 2012; CYMHLAC, 2018; MHCC, 2018; Province of British Columbia, 2019).

There is a focus on measuring performance to improve YMH service quality, particularly by using PMFs (CYMHLAC, 2018; MHCC, 2018; OAE, 2016; Settipani et al., 2019). PMFs can facilitate service and outcome improvement, identify gaps, improve knowledge and data sharing and facilitate evidence-based practice (Aarons et al., 2011; CYMHLAC, 2018; MHCC, 2018; Office of Audit and Evaluation, 2016).

The OAE recommends linking activities and goals to strategic priorities, and is considering the potential benefits of allowing flexibility in grants to facilitate innovation (2016). Having a common language and understanding is crucial, and may be facilitated by sharing a vision (MHCC, 2018; OAE, 2016).

Collaboration is crucial for meeting youths' mental health needs, and key groups such as youth, families, people with lived experience, Indigenous people, and substance-use organizations are recommended partners in this process (MHCC, 2018; OAE, 2016; Settipani et al., 2019). Collaborating to disseminate knowledge and share data is a trend (OAE, 2016); smart practices are discussed in Section 8.3.

Areas for Further Research

Online and app-based service provision is a new frontier of service delivery that holds potential for addressing access issues, and has been requested by youth themselves (CAMH, 2012; CYMHLAC, 2018; Michel et al., 2019; Province of British Columbia, 2019). Mindfulness programs may also be an area deserving of further research (CYCC Network, n.d.)

Alberta's CASA organization for child, youth, and family mental health is implementing a sensory room for use with their clients (*Snoezelen Room | CASA*, n.d.). Most existing research on sensory rooms appears to have examined applications for dementia, however Scanlan and Novak concluded in their review that sensory approaches show promise in regulating distress and physiological and emotional arousal (2015). These are preliminary findings however, as Scanlan and Novak found that research on the mental health applications of sensory rooms is scarce and of mixed results (2015). They concluded that while sensory approaches appear safe and effective, more research should be done (Scanlan & Novak, 2015).

Another emerging frontier are nature-based mental health programs. Preu and colleagues found that adults had worse mental health if they had low childhood nature exposure, and Thompson Coon and colleagues found that exercising in natural environments compared to indoors has a more positive effect on physical and mental wellbeing (2019; 2011). However, both concluded that research is lacking, and Coghill and colleagues' review found that the methodology and diverse operationalizations in this area of research limited their ability to make conclusions (2018; Preuß et al., 2019; Thompson Coon et al., 2011)

4.12 Smart Practices and Examples

This review has discussed the trends in the grey and academic literature, however understanding the smart practices can be helpful in guiding and inspiring actions for YMH. This section will review the smart practices identified in this review for the three main themes: strategies, types, and stakeholders; quality, processes, and outcomes, and collaboration, engagement, and partnerships.

Smart Practices and Examples– Strategies, Types and Stakeholders

In its 2019 mental health strategy, BC implement several smart practices that aligned with recommendations from the literature. First, it shifted further towards collaborative care by expanding school-based programming and committing to opening more Foundry Centres, which act as YMH service hubs are very successful (Province of British Columbia, 2019). Hetrick and colleagues and Settipani and colleagues emphasize the importance of service hubs in addressing YMH needs (2017; 2019). BC also committed to implementing "Step-up/step-down" services to improve LITS and created "Peer Coordinators/Navigators" staff to help individuals navigate transition points, although this initiative is not specific to YMH (Province of British Columbia, 2019).

In addition to providing navigation and transition support for families, the literature has also called for including families in YMH services (Chovil, 2009). The Phoenix Centre for Children and Families in Pembroke, Canada offers some seemingly innovative services that involve families. CYCC Network highlighted two of the Phoenix Centre's services as being particularly promising for youth who have experienced violence or challenging contexts (n.d.): integrating CBT with creative activities (e.g. scrapbooking) which helps youth express themselves and reduces self-harm, substance use, and traumatic distress, and; equine-assisted therapy, which is used for clients that aren't benefitting from conventional therapies (CYCC Network, n.d.). Other promising services highlighted by CYCC Network but provided by other service providers include: the Youth Advocate Program in Halifax, Canada, which decreases peer problems and improves family relationships for youth at risk of gang involvement by using family counselling and a relational strengths-based approach; Family Therapy (MST) and Ecologically-based Family Therapy (EBFT), which integrate treatment with a range of services to meet the needs of youth and families, and the Minnesota Runaway Intervention Program involves families and focuses on relationships to reduce girls' responses to trauma and improve relationships and overall wellbeing (n.d.).

In discussing innovative services, online services must be discussed. To begin, youth have identified the following online service features as desirable: they want social media campaigns that feature youth-created content and/or people with lived experience, and; interactive, online, web-based programs with regularly updated content (CAMH, 2012). BounceBack is an interactive, online, free skill-building program available in BC and Ontario for youth and care providers (*Bounceback*, n.d.; *BounceBack Ontario – Canadian Mental Health Association, Ontario*, n.d.). It is highly accessible because it does not required a referral for its web-based videos and modules, but also offers more intensive services by referral for youth with higher needs (*Bounceback*, n.d.; *BounceBack Ontario – Canadian Mental Health Association, Ontario*, n.d.). Another example of an online service is the online counselling service for post-secondary students that the Province of BC is planning to launch in 2020 (2019). MyHealthPassport is another online tool that enables youth to access their personal health information from anywhere, and aims to help them navigate care transitions by preparing them to discuss their health with new providers (*Transitioning from Youth to Adult Mental Health Services*, n.d.). Online services are also showing promise for and being used in helping connect youth and providers with resources. Carver et al. (2015) found that youth struggle to know what services are available to them, and so services such as CMHA Ontario's easy-to-navigate online database for services can help meet this need (CMHA, n.d.). The websites for the MHCC and PHAC also act as online resource hubs by publishing mental health strategy and resource guides for providers (OAE, 2016).

While seemingly not as requested by youth as online services, delivering services by phone may meet some of the same needs. For example, Good2Talk is a confidential phone helpline available 24/7 and free of charge to all postsecondary students in Ontario (*Youth engagement*, 2019). Callers can get anonymous professional counselling over the phone, and can access information and referrals for addictions and mental health services (*Youth engagement*, 2019). According to the OAE, having a national suicide hotline that can be accessed anywhere in Canada to connect someone with the closest distress centre is one of the most common suggestions for preventing suicide (2016).

Services for Indigenous youth was identified as needing particular attention (MHCC, 2018). The *Aboriginal Head Start on Reserve Program* and *Aboriginal Head Start in Urban and Northern Communities* are examples of community-based and Indigenous-led and -designed programming that promote the development of various protective factors, including those that promote mental health (Government of Canada, 2019; PHAC, 2010; OAE, 2016). While these programs target children and not youth (Government of Canada, 2019; PHAC, 2010), they could potentially inspire such programs for youth. According to Ontario's CMHA branch, Aboriginal Child and Family Services, Aboriginal Health Access Centres, and Indigenous Friendship Centre are resource and service hubs for providing culturally-sensitive services (*Mental Health and Wellness Services for Indigenous Children and Youth*, n.d.).

Finally, stigma still seems to be an issue for YMH. Youth expressed to CAMH that to continue making progress, school-based programming should focus on attitudes towards mental health instead of awareness (CAMH, 2012). A smart example of an anti-stigma program is Opening Minds, which addresses stigma in service providers and the media, is recognized as an international best practice, and won the 2015 Innovator Award from the World Psychiatric Association. (OAE, 2016). It has a youth version available called HEADSTRONG, which involves student champions attending a national summit and bringing back messaging to their schools (OAE, 2016)

Smart Practices and Examples: Services – Quality, Processes, and Outcomes

Quality

Relating to the concepts discussed in the above section, Yukon has built an overarching service provision framework to improve service quality; Yukon's *A Child and Youth Mental Health and Addictions Framework for the Yukon* aligns with several major themes identified in this literature review. To begin, it is evidence-based, uses a needs-based approach, and is concerned with facilitating access (Mulvale et al., 2014). It includes promotion and prevention, and promotes collaboration across levels of the system (Mulvale et al., 2014). It integrates substance use and mental health, and its two foundational components are sharing understanding and values to facilitate a shared approach (Mulvale et al., 2014). While such frameworks may improve quality, another framework is perhaps more crucial: PMFs.

As was discussed in Section 5.1, designing and implementing a PMF shows particular promise for improving YMH. The MHCC has published some comprehensive guidance on designing PMFs, including some steps for developing a framework (2018). These steps can be seen in Appendix N, but some other smart practices include: using participatory and social-justice-oriented collaboration and engagement to build a framework and select indicators; incorporating mechanisms for regularly reporting on indicators, and; developing aspirational indicators to improve mental health and addictions system (MHCC, 2018)

In addition to the MHCC's thorough report, there are several examples of PMFs that could be used to provide further smart practices. Bickman describes America's Peabody College's measurement feedback system that is designed to continuously improve system quality for youth mental health services (2008). SMEs consulted by the MHCC recommended examining the PMF used by the Canadian Partnership Against Cancer (CPAC), which is collaborative and has mechanisms for reporting and managing the non-standardized data from the many jurisdictions across Canada (MHCC, 2018) which are major themes identified in this literature review. The SMEs are quite confident that CPAC's PMF could be adapted for use in mental health and addictions (MHCC, 2018). The MHCC also share that Australia and New Zealand also have initiatives for national and system-level performance measurement for mental health and addictions (MHCC, 2018). It should be noted, however, that these same SMEs recommend against looking too much at past PMFs when building a new one, as they feel this could create a backward-looking lens that impedes building a progressive PMF (MHCC, 2018).

To help build a PMF, it may be helpful to examine some components of them: indicators, measures, and models. To begin, in Appendix O is a list of potential indicators from various reports and organizations reviewed for this literature review. When exploring this list, it should be noted that PHAC's efforts with regards to positive mental health indicators are seen as an international best practice (OAE, 2016). There are also measures that have been recommended for helping to build PMFs.

Ontario CYMHLAC recommend two measures for improving child and youth mental health care (2018). They recommend using the Ontario Perception of Care Tool For Mental Health and Addictions (OPOC-MHA) to improve quality of care, and using the Inter-RAI Child and Youth Mental Health (Inter-RAI ChYMH) to standardize assessment (CYMHLAC, 2018).

The OPOC-MHA is an evidence-based measure of quality of care that gives a voice to youth and can improve access to services, quality of care, client-centredness, and safety (CYMHLAC, 2018). It is valid for individuals over age 12 and for use in addictions, mental health, and concurrent disorders (CYMHLAC, 2018). It standardizes perception of care for YMH agencies and has a centralized database that all organizations' data can go into and from which reports can be generated; this feature can help answer the call for better sharing of YMH data (CYMHLAC, 2018).

While the OPOC-MHA does standardize some data, the Inter-RAI ChYMH is specifically used to standardize data and is intended to act as a "Common Assessment Tool" for screening, assessment, outcome measurement, and follow-up (CYMHLAC, 2018). It is already commonly used in Ontario, but to optimize standardization it is recommended that use of this tool - or any tool intended to be a common assessment tool - be mandated (CYMHLAC, 2018). The benefits of this tool are listed below, and relate to some of the themes and needs identified in this literature review:

- Enables comparison of data across systems
- Facilitates care pathways, particularly through transitions
- Ensures consistency of language across the province
- Increases evidence-based practice
- Helps identify future priorities and resource allocation within the organization and/or service area (CYMHLAC, 2018)

In addition to using quality indicators and recommended measurement tools, using the appropriate model can help with building a PMF (MHCC, 2018). The MHCC discusses several appropriate models in their comprehensive guide. They describe the Matrix Model as a model that can be easily adapted for use in performance measurement and facilitates addressing key elements and organizing tools; however, it is a relatively simple model (2018). The MHCC shares the more comprehensive models used in Alberta and the Northwest Territories that depict the whole mental health system and its complexity; these diagrams can be seen in Appendix P (2018).

Process

With regards to funding, the OAE recommends providing additional funding when requesting certain actions and/or changing expectations to help organizations meet these new priorities so organizations don't have to internally re-allocate resources to meet them (OAE, 2016).

SickKids seems to have many strong accountability processes. To demonstrate financial accountability, SickKids Foundation uses a Financial Accountability and Transparency plan to enhance public trust in their organization (*Financial Practice and Transparency | SickKids Foundation*, n.d.). This plan involves openly publishing their Executives' Contracts and Expenses, Travel and Expense Reimbursement Policy, Supply Chain Code of Ethics, and Broader Public Sector Accountability Act Attestation Forms (Children, n.d.). They are also committed to continuing to receive the Imagine Canada Standards Accreditation, which focuses on multiple areas of accountability and is designed to increase confidence in charitable and non-profit organizations (*Our Accountability | Donate | SickKids Foundation*, n.d.). According to SickKids, to receive this accreditation an organization must demonstrate excellence in board governance, financial accountability and transparency, fundraising, staff management, and volunteer involvement (*Our Accountability | Donate | SickKids Foundation*, n.d.).

Reporting

Websites seem to be a key mechanism for reporting information, and seem to be commonly used to publish research, strategy documents, and reports. They can also generate data, such as tracking the number of views of documents to determine which documents are the most accessed on a website (OAE, 2016). With regards to reports, making them available to researchers can also improve reporting by increasing the likelihood of being cited in journals; the MHCC did this with their Mental Health Strategy and it was subsequently cited in over 20 international scientific journals as of 2016 (OAE, 2016).

Infographics are favoured as a useful method to convey information, however it may be a smart practice to: solicit feedback on the effectiveness of the infographic in conveying information (e.g. surveys), and; advertise such data releases to raise awareness an increase the likelihood they will get accessed (OAE, 2016). According to a lesson learned by MHCC and PHAC, it is a smart practice to collaborate and communicate around shared data releases to avoid creating confusion for the public (OAE, 2016).

Reporting recommendations that are specific to youth include tailoring documents to this audience. Examples include creating youth versions of reports, using social media, and developing summary/ "at-a-glance" documents can make information more accessible to youth (CAMH, 2012; OAE, 2016).

Smart Practices and Examples: Services – Collaboration, Engagement, and Partnerships

As was discussed in Section 6,0, there are some recommended approaches for collaboration and engagement. Deliberative dialogue is seen as a favorable general model for systematic engagement and consultation, and was used in the Mental Health Strategy for Canada (Mulvale et al., 2014).

Collaboration and Engagement for PMFs

In their PMF design guide, the MHCC described several examples of initiatives that used smart collaboration and engagement practices in the context of designing a suite of indicators. Specifically, these examples demonstrate the smart practices of careful selection of stakeholders to ensure representation, and achieving meaningful engagement through using a participative approach (MHCC, 2018). The more common approach to collaboration and engagement used in these examples – and by Yukon to build their child and youth mental health framework - was to build an initial suite of indicators by consulting experts and/or the literature, then use stakeholders and key informants to inform the modified Delphi analyses to refine the final suite (MHCC, 2018). This participative approach facilitated consensus on the indicators and the representation of key groups that key groups (MHCC, 2018). The other approach used was to begin with stakeholders selecting priority domains, then having experts select potential indicators for said domains (MHCC, 2018). A group of experts and stakeholders then participated in several rounds of modified Delphi analyses to build the final indicator set (MHCC, 2018).

Youth as Partners

The Office of the Provincial Health Officer has suggested establishing an ongoing provincial forum that connects youth to community stakeholders as a means of engaging youth (2016). This initiative would also aim to advance services and improve youth mental health and wellbeing (Office of the Provincial Health Officer, 2016).

The Ontario Centre of Excellence for Child and Youth Mental Health seems to be a prolific producer of smart practices on YMH. For example, they have a draft youth engagement standard, youth engagement resources (*Youth engagement*, 2019), and a resource database for a variety of issues (CYMH, n.d.).

Families as Partners

Idaho has involved families as full partners in the design, implementation, and evaluation of the system of care (Chovil, 2009). Treatments plans and services are seen as a collaborative effort between service providers and families, and families are supported and empowered in participating as much as possible in planning the care for their child (Chovil, 2009). They have also removed barriers to involvement, which is another key recommendation in the literature (Chovil, 2009). Specifically, they ensure families are well-informed, and compensate them for participating in meetings to plan the implementation of a system of care for youth (Chovil, 2009).

Knowledge quality and dissemination

There are several examples of partnerships that have been created specifically to facilitate the sharing of information. To begin, the MHCC's KEC seems to be a smart practice for knowledge dissemination (OAE, 2016). Furthermore, the OAE conceptualizes certain organizations as "convenors," which means those organizations build networks and facilitate collaboration among service providers (2016). The federal branch of the MHCC currently plays such a role, and has been able to leverage resources and partnerships to create efficiencies and better disseminate information (OAE, 2016). Ontario uses "Service Area Lead Agencies" to support other agencies in their service area by sharing best practices for improving access to services, and collaborate with Ontario Health Teams to (CYMHLAC, 2018). Using mechanisms like the ones described above could help meet the identified need to better share information, resources, and smart practices among YMH providers (Office of the Provincial Health Officer, 2016; OAE, 2016). Finally, the MHCC found that another benefit in PMFs is in translating knowledge to action, which is crucial to changing processes and outcomes (2018).

In addition to partnerships, measures such as common assessment tools (e.g. the Inter-RAI) can be seen as a collaborative approach to improving data quality and dissemination of knowledge by removing data silos and improving the data available for dissemination (CYMHLAC, 2018; Office of Audit and Evaluation, 2016). Having a mechanism for coordinated and ongoing data collection and reporting has been called for in the literature (Office of the Provincial Health Officer, 2016). Section 8.2 can provide examples of smart practices for reporting.

4.13 Summary

In summary, there is much grey and academic literature on the topic of YMH, and many smart practices that can be derived from this work. New and promising services are emerging, which complement the wide variety of services already in place. To further improve, the literature is calling for the use of PMFs to improve the quality of data available, which will in turn improve services. Collaboration is key to meeting youths' needs, and engaging youths and their families in their care is key. Collaboratively sharing and disseminating knowledge is also an emerging trend, and there are many smart practices for doing so. Other examples of smart practices and specific measures were discussed to help guide service providers and organizations.

4.14 References

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Appendix A - Making Alternative Therapy Choices Happen (MATCH)

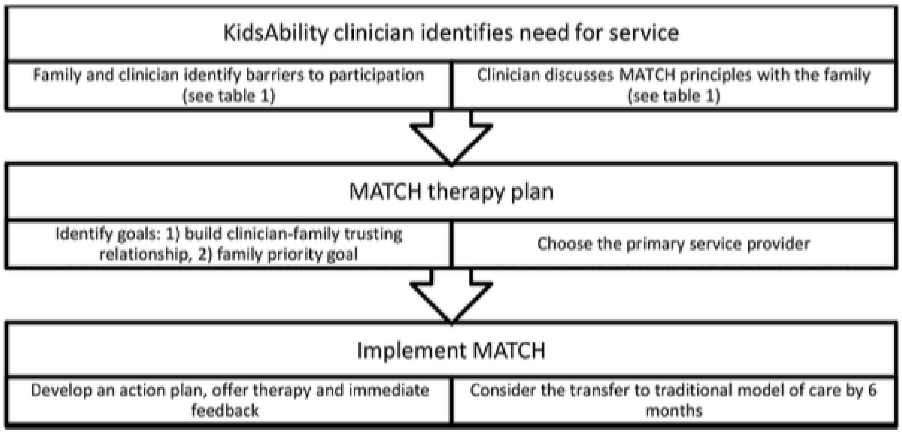
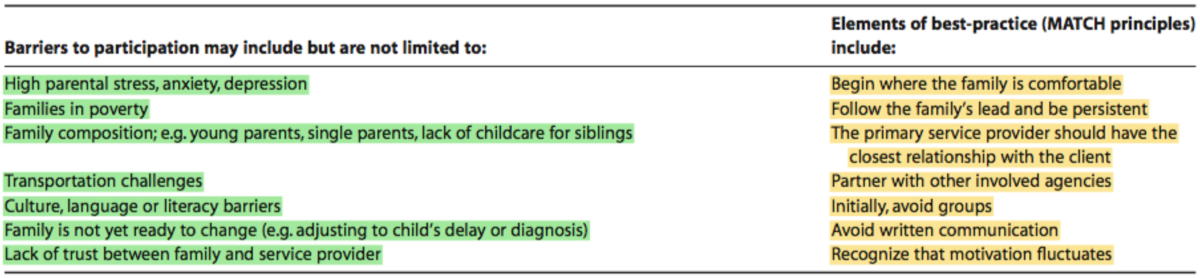


Figure 1. MATCH care path.

Table 1. Barriers to participation and key elements of best-practice to engaging hard to reach families



Barriers to participation may include but are not limited to:	**Elements of best-practice (MATCH principles) include:**
High parental stress, anxiety, depression	Begin where the family is comfortable
Families in poverty	Follow the family's lead and be persistent
Family composition; e.g. young parents, single parents, lack of childcare for siblings	The primary service provider should have the closest relationship with the client
Transportation challenges	Partner with other involved agencies
Culture, language or literacy barriers	Initially, avoid groups
Family is not yet ready to change (e.g. adjusting to child's delay or diagnosis)	Avoid written communication
Lack of trust between family and service provider	Recognize that motivation fluctuates

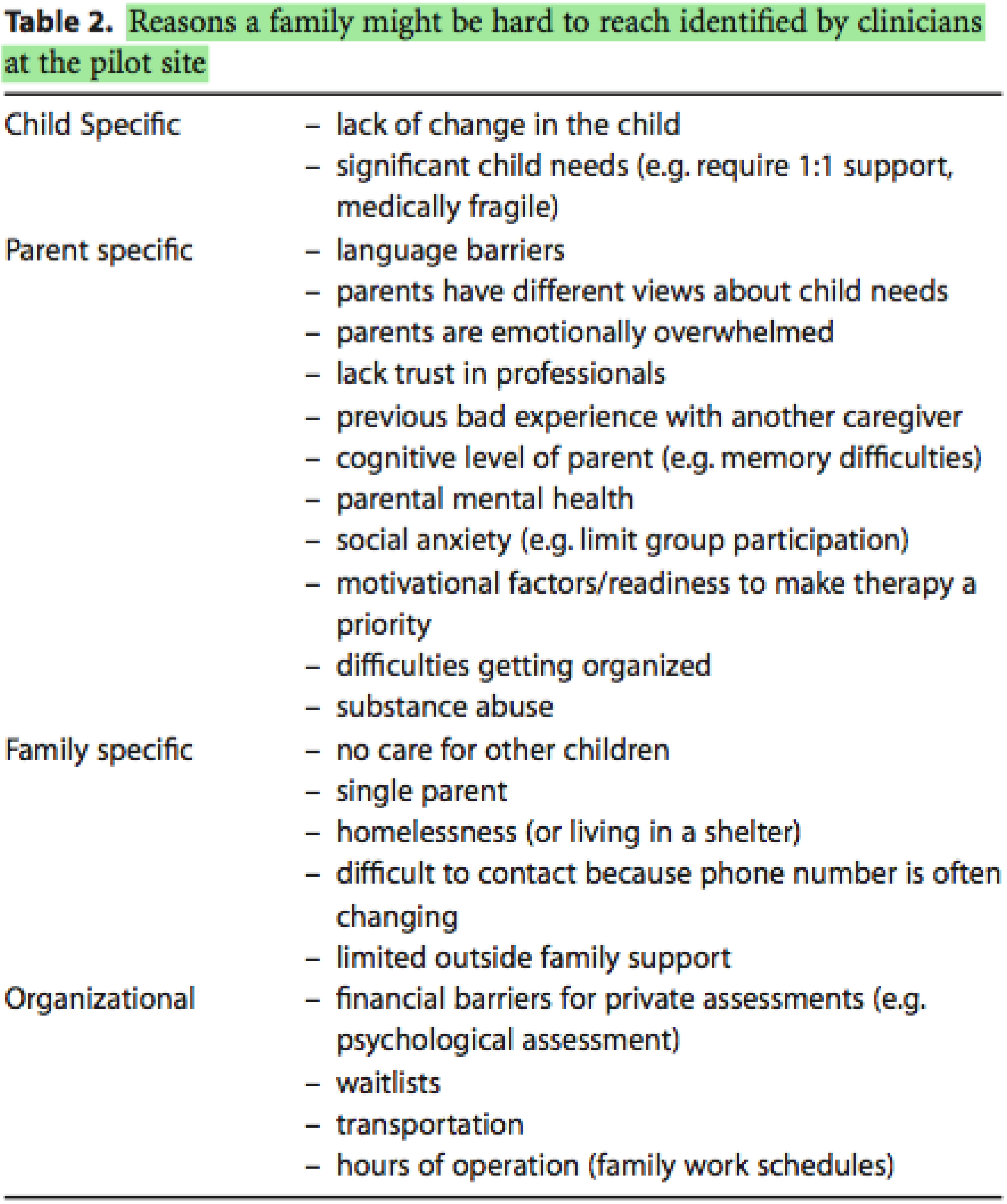


Table 2. Reasons a family might be hard to reach identified by clinicians at the pilot site

Child Specific	– lack of change in the child
	– significant child needs (e.g. require 1:1 support, medically fragile)
Parent specific	– language barriers
	– parents have different views about child needs
	– parents are emotionally overwhelmed
	– lack trust in professionals
	– previous bad experience with another caregiver
	– cognitive level of parent (e.g. memory difficulties)
	– parental mental health
	– social anxiety (e.g. limit group participation)
	– motivational factors/readiness to make therapy a priority
	– difficulties getting organized
	– substance abuse
Family specific	– no care for other children
	– single parent
	– homelessness (or living in a shelter)
	– difficult to contact because phone number is often changing
	– limited outside family support
Organizational	– financial barriers for private assessments (e.g. psychological assessment)
	– waitlists
	– transportation
	– hours of operation (family work schedules)

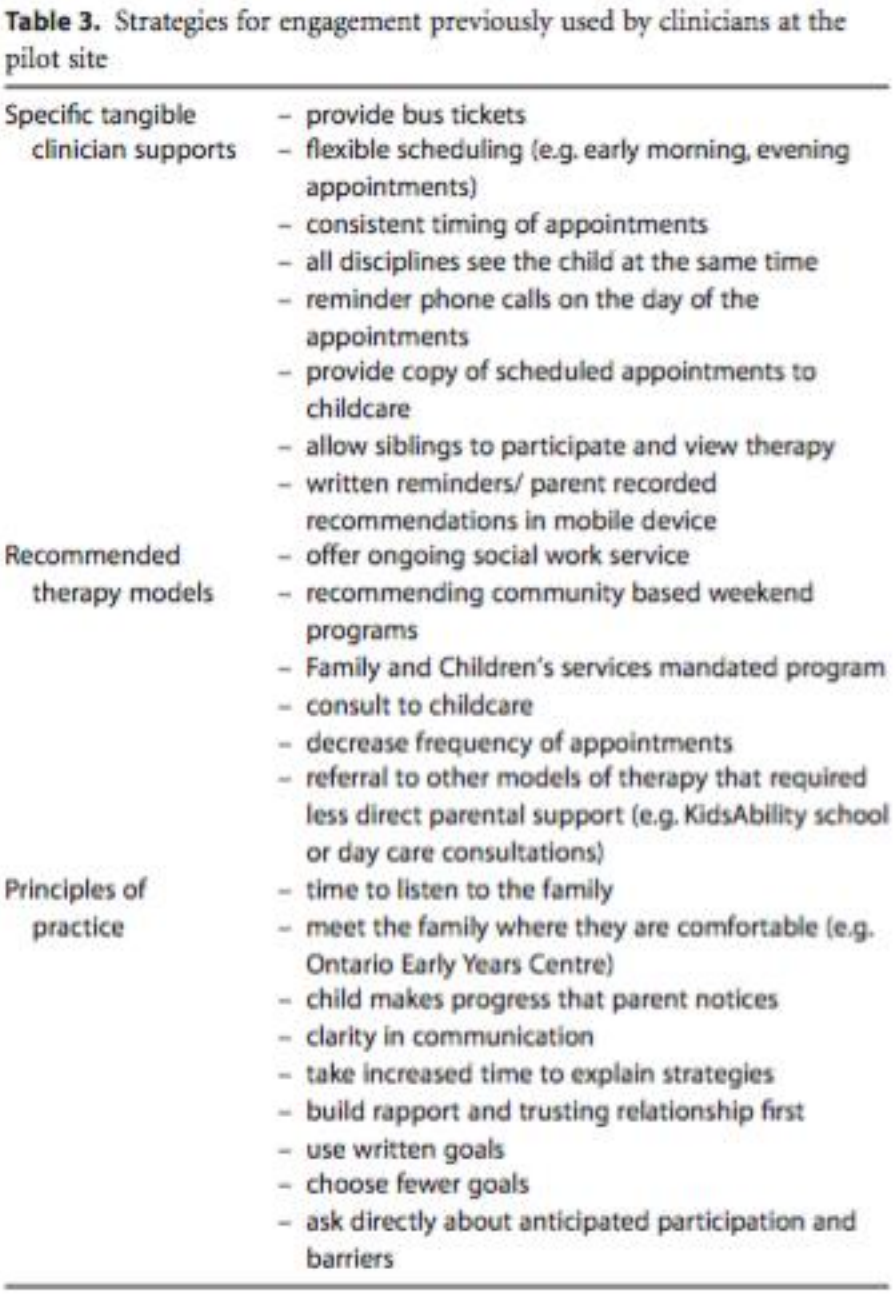


Table 3. Strategies for engagement previously used by clinicians at the pilot site

Specific tangible clinician supports	– provide bus tickets
	– flexible scheduling (e.g. early morning, evening appointments)
	– consistent timing of appointments
	– all disciplines see the child at the same time
	– reminder phone calls on the day of the appointments
	– provide copy of scheduled appointments to childcare
	– allow siblings to participate and view therapy
	– written reminders/ parent recorded recommendations in mobile device
Recommended therapy models	– offer ongoing social work service
	– recommending community based weekend programs
	– Family and Children's services mandated program
	– consult to childcare
	– decrease frequency of appointments
	– referral to other models of therapy that required less direct parental support (e.g. KidsAbility school or day care consultations)
Principles of practice	– time to listen to the family
	– meet the family where they are comfortable (e.g. Ontario Early Years Centre)
	– child makes progress that parent notices
	– clarity in communication
	– take increased time to explain strategies
	– build rapport and trusting relationship first
	– use written goals
	– choose fewer goals
	– ask directly about anticipated participation and barriers

Appendix B - Family Centred Care Values, Principles and Models

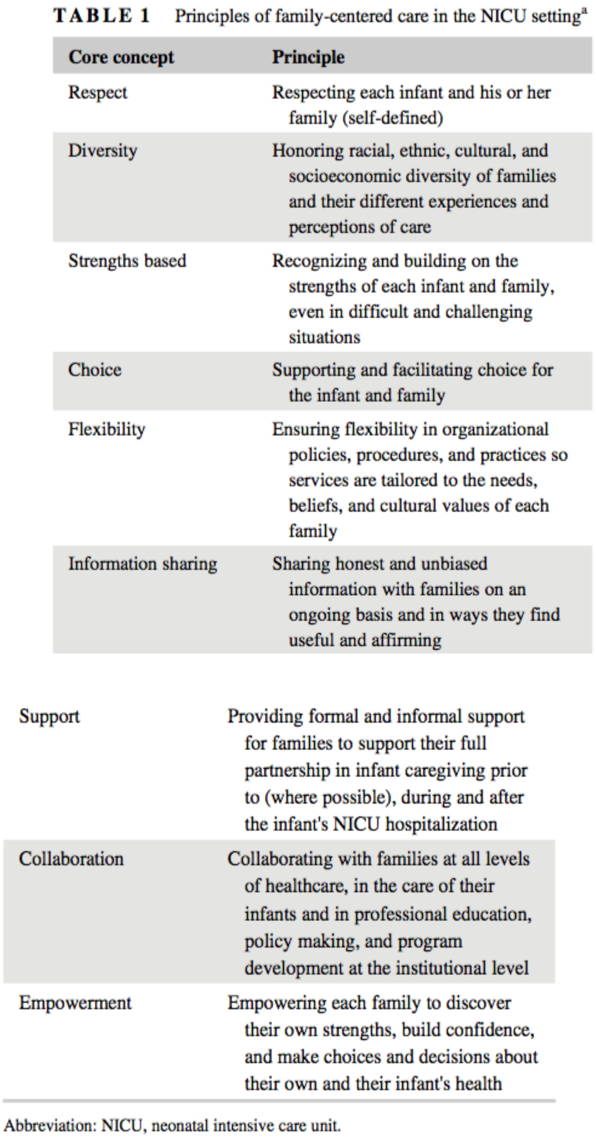


TABLE 1 Principles of family-centered care in the NICU setting[a]

Core concept	Principle
Respect	Respecting each infant and his or her family (self-defined)
Diversity	Honoring racial, ethnic, cultural, and socioeconomic diversity of families and their different experiences and perceptions of care
Strengths based	Recognizing and building on the strengths of each infant and family, even in difficult and challenging situations
Choice	Supporting and facilitating choice for the infant and family
Flexibility	Ensuring flexibility in organizational policies, procedures, and practices so services are tailored to the needs, beliefs, and cultural values of each family
Information sharing	Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
Support	Providing formal and informal support for families to support their full partnership in infant caregiving prior to (where possible), during and after the infant's NICU hospitalization
Collaboration	Collaborating with families at all levels of healthcare, in the care of their infants and in professional education, policy making, and program development at the institutional level
Empowerment	Empowering each family to discover their own strengths, build confidence, and make choices and decisions about their own and their infant's health

Abbreviation: NICU, neonatal intensive care unit.

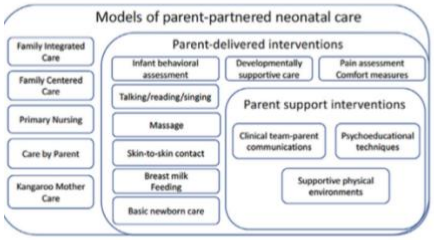


FIGURE 1 Taxonomy of parent-focused NICU interventions and parent-partnered care models

Appendix C – Sample of Multi-Sectoral and Integrated ECD Approaches

Name	**Jurisdiction**	**Description**
Aboriginal Head Start in Urban and Northern Communities [AHSUNC] and Aboriginal Head Start On Reserve [AHSOR]	Pan-Canadian	"AHSUNC and AHSOR programs are national community-based programs, locally managed, that address the unique needs of each community. The programs focus on providing culturally appropriate early childhood development programs populations and work to benefit the health, well-being, and social development of Indigenous children through a population health approach that embraces culture as a core determinant of health." (CCSDH, 2017, p. 9)
Better Beginnings Better Futures [BBBF]	Ontario	"BBBF began as a large-scale, multi-year, longitudinal research- demonstration project, and has become a program model designed to reduce emotional and behavioural problems experienced by children, promote healthy child development, and enhance family and community. Service integration is a key principle of BBBF: the aim is that children and their families receive seamless support from the BBBF projects, schools, and other services. The initiative has a proven economic outcome, with cost savings to Ontario government funders of more than $2 for each $1 originally invested." (CCSDH, 2017, p. 5)
Canada Prenatal Nutrition Program [CPNP]	Pan-Canadian	"CPNP aims to improve maternal-infant health, increase the rates of healthy birth weights, and promote and support breastfeeding. It also promotes the creation of partnerships within communities and strengthens community capacity to increase support for vulnerable pregnant women and new mothers. This initiative includes a separate funding stream for First Nation Communities with activities related to nutrition screening, education, and counselling; maternal nourishment; and breastfeeding promotion, education, and support." (CCSDH, 2017, p. 10)

Caring, Helping, And Nurturing, Children Every Step [CHANCES]	Prince Edward Island	“CHANCES is a community- based, non-profit initiative that provides a range of child development and parent support services, particularly to more vulnerable families. The initiative carries out its mission through seven program streams: prenatal and postnatal programs (Canada Prenatal Nutrition Program); Best Start Program; Strong Start; Early Years Centres / Smart Start; parenting and child development programs; Smart Play; CHANCES Family Health Clinic.” (CCSDH, 2017, p. 10)
Community Action Program for Children [CAPC]	Pan-Canadian	“CAPC provides funding to community-based groups and coalitions to develop and deliver comprehensive, locally and culturally appropriate prevention and early intervention initiatives. Programs aim to promote the health and social development of young children and families facing challenging life conditions (e.g., low- income families, teenage parents, children with developmental delays), Indigenous children, recent immigrants and refugees, single-parent families, and families in remote/ isolated communities. Program-wide, many CAPC sites have developed partnerships with a broad variety of organizations from different sectors of activity (e.g., health organizations, educational institutions, community associations, early childhood or family resource centres). Programming may be offered through family resource centres, parenting classes, drop-in groups, parent- child groups, home visiting, or specialized programs.” (CCSDH, 2017, p. 12)
Early Childhood Development Centres (ECDCs)	New Brunswick	“Located in schools and integrated into existing pre-school, childcare and parenting programs, the ECDC sites serve as neighbourhood hubs where early childhood services can be accessed in an integrated way, under the direction of a local community network and a non-profit board of directors. They also provide research and evaluation to inform provincial strategies” (CCSDH, 2017, p. 13)

Positive Parenting Programs (Triple P)	International; in 25 countries	"Triple P is a parenting and family support system, a suite of interventions of increasing intensity for parents, designed to prevent—as well as treat—behavioural and emotional problems in children and teenagers. It aims to prevent problems in the family, school, and community before they arise, and to create family environments that encourage children to reach their potential" (CCSDH, 2017, p. 7).
Success by 6 [SB6]	British Columbia	The SB6 Provincial Initiative and Partnership strengthens communities by funding programs and engaging citizens in building child- and family-friendly communities. A central pillar of the initiative is a focus on meaningful engagement of Indigenous peoples, guided by a province- wide strategy and framework based on recognition of self-determination, as well as the Truth and Reconciliation Commission's Report and Calls to Action. Its Aboriginal Engagement Strategy, developed in 2006 and backed by a dedicated funding stream, is designed to support Indigenous-identified priorities through the development of partnerships and relationships intended to promote collaboration across sectors and across cultures, as communities strive to support young Indigenous children and their families. To date, SB6 has supported the development and ongoing strategic planning of over 120 community-based Early Years and Aboriginal Early Years Planning Tables/ Councils. These tables bring together local stakeholders from multiple sectors to plan and improve service integration and program delivery for young children and their families. (CCSDH, 2017, p.14).
Sure Start Children's Centre	United Kingdom	Children's centres offer services to all families with young children living in disadvantaged neighbourhoods without stigmatizing users. They assess local needs by studying the characteristics of local communities and undertaking outreach to attract and serve the most vulnerable families. Some services are therefore targeted to particular groups of high-risk families (e.g., teenage parents, jobless households (CCSDH, 2017, p. 6).

Appendix D – ECD Service Delivery Types

Universal ECD Service Delivery

Service	Description	Implementing Features	Secondary Features	Optional Features	MS	INT
Western Australia's Purple Book Health Checks	"The Purple Book is a free, parent-held child health record, provided by WA Health to every child at birth…[it]helps parents keep a record of their child's health and development from birth to school entry, in partnership with child health nurses and other health professionals." (WACAHS, 2020).	• Birth registry • Universal immunization program • ECD professionals to facilitate health checks • ECD service network	• Population based ECD data • Guiding partnership policies	• Localized ECD physical infrastructures (public schools/libraries, private daycares) as a hub sites for service access and community engagement	**X**	**X**

Selective ECD Service Delivery

Service	Description	Implementing Features	Secondary Features	Optional Features	MS	INT
New Hampshire's, Family Resource Centre's family support programs (FSP)	FSP offer: "prenatal and infant care, parenting and co-parenting education, infant growth and child development, childcare, preschool and after school services, ages and stages developmental screenings, growing great kids [curriculum], [Triple P] program curriculum" and other community resources (FSP, 2017).	• High-quality evidence-based programs, curricula, and tools • ECD professionals to facilitate screenings, assessments, and programming • Physical infrastructure to host activities	• Collaborative ECD system infrastructure: namely, Coös' coalition and Coös Director Network	• Population specific services, such as the *Supportive Services for Veteran Families* program	**X**	**X**

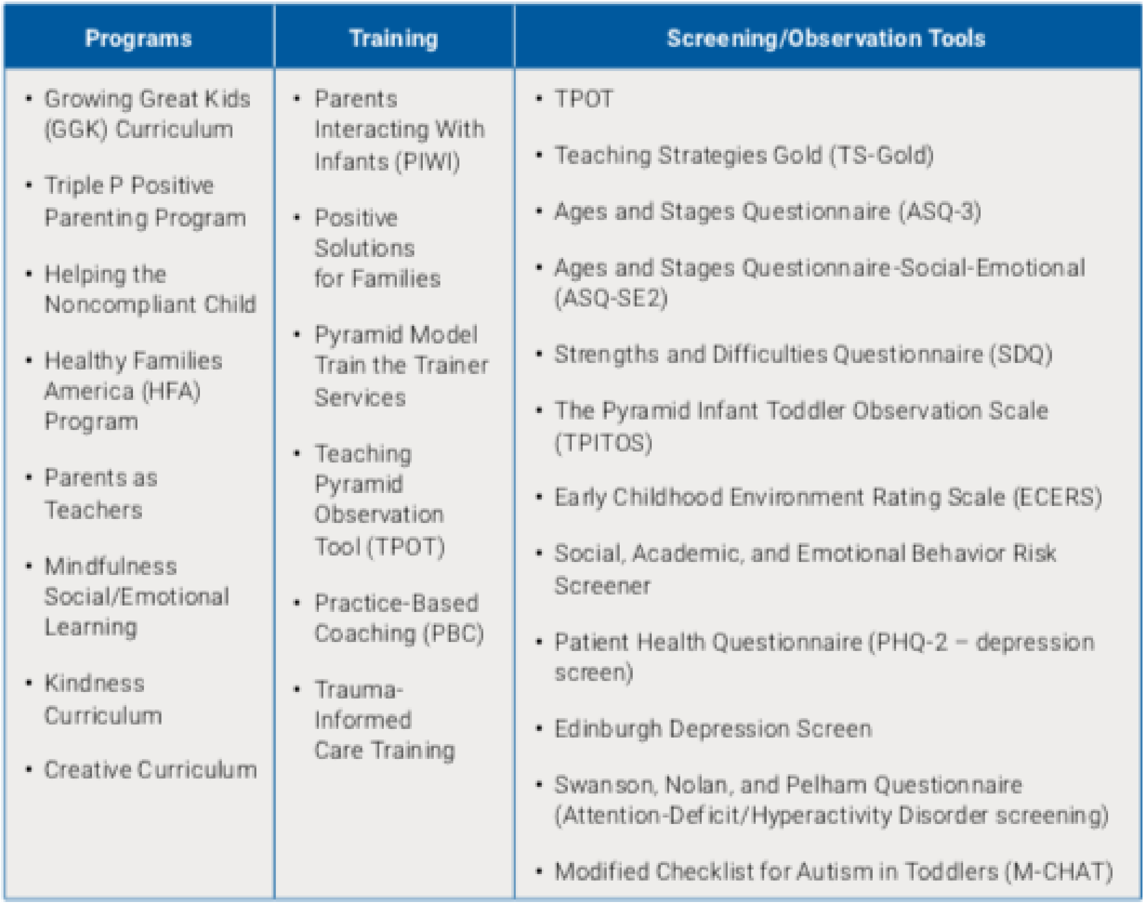
Salteau First Nation's [SFN] Cree-ative Wonders Daycare (CWD)	CWD is an ELCC Aboriginal Head Start On Reserve (AHSOR) program in Northern BC offering two mixed programs and listing seven components which anchor the culturally specific context of SFN as key to their ELCC: "culture and language, education, health promotion, nutrition, social support and parental and family involvement" (SFN, n.d).	• Community based culturally specific curricula • Local ELCC professionals • Physical infrastructure to host activities	• Collaborative partnerships with academic institutions and MS federal ECD programs • Generative Curriculum Model		**X**	**X**

Indicated ECD Service Delivery

Service	Description	Implementing Features	Secondary Features	Optional Features	MS	INT
Mainland BC's Multicultural Early Childhood Development (MECD)	"This project provides [a variety] of services for families with children ages 0-6 who reside in [Anmore, Belcarra, Coquitlam, Port Coquitlam and Port Moody], and are primarily from three different ethnic communities (Korean, Farsi and Chinese)" (SUCCESS, 2020).	• Physical infrastructure (established community-based cultural centre) • ECD service network • ECD professionals to facilitate programming, referrals	• Reciprocal service referral relationships with external ECD services	• Provision of culturally competent ECD training to broader community	**X**	**X**

Appendix E – ECD Evidence-Based Programs, Curricula and Tools

TABLE 1 ECD Evidence-Based Programs, Curricula, and Tools



Programs	Training	Screening/Observation Tools
• Growing Great Kids (GGK) Curriculum • Triple P Positive Parenting Program • Helping the Noncompliant Child • Healthy Families America (HFA) Program • Parents as Teachers • Mindfulness Social/Emotional Learning • Kindness Curriculum • Creative Curriculum	• Parents Interacting With Infants (PIWI) • Positive Solutions for Families • Pyramid Model Train the Trainer Services • Teaching Pyramid Observation Tool (TPOT) • Practice-Based Coaching (PBC) • Trauma-Informed Care Training	• TPOT • Teaching Strategies Gold (TS-Gold) • Ages and Stages Questionnaire (ASQ-3) • Ages and Stages Questionnaire-Social-Emotional (ASQ-SE2) • Strengths and Difficulties Questionnaire (SDQ) • The Pyramid Infant Toddler Observation Scale (TPITOS) • Early Childhood Environment Rating Scale (ECERS) • Social, Academic, and Emotional Behavior Risk Screener • Patient Health Questionnaire (PHQ-2 – depression screen) • Edinburgh Depression Screen • Swanson, Nolan, and Pelham Questionnaire (Attention-Deficit/Hyperactivity Disorder screening) • Modified Checklist for Autism in Toddlers (M-CHAT)

(Payne, 2018, p.27)

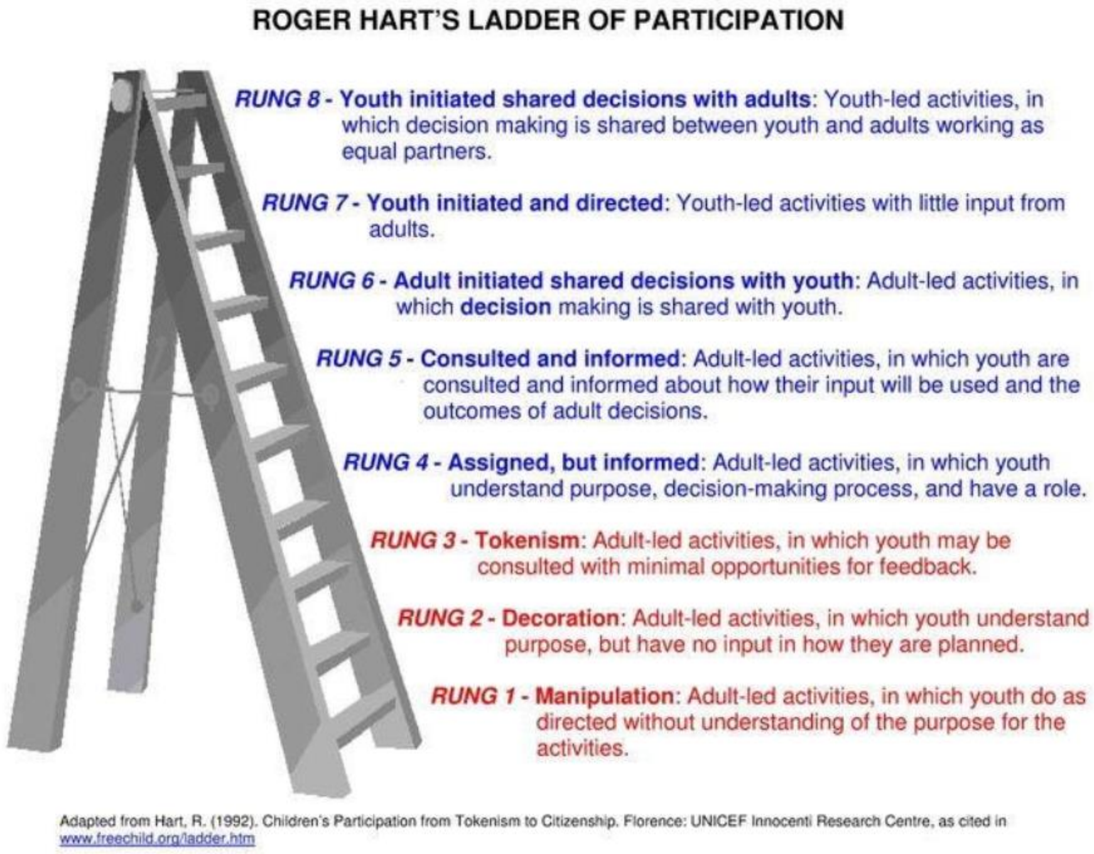
Appendix F – Examples of Logic Models and Program Cycles

Framework / Model	Reference	Abstract
Logic Models and Outcomes for Early Childhood Programs	Bronte-Tinkew, J., & Calkins, J. (2001). Logic models and outcomes for early childhood programs. *Prepared for the DC Children and Youth Investment Trust Corporation). Washington, DC: Child trends*.	The primary purpose of this report is to provide revised logic models and measurable outcomes for the early childhood programs of the DC Children and Youth Investment Trust Corporation (DCCYIT). The logic model was revised from the initial draft of the Board of Directors of DCCYIT using the framework and terminology developed by the United Way Foundation of America.[1] The report combines both an academic and applied research perspective on child development, and is intended to complement, not duplicate in any way, the work that has already been completed by the DCCYIT in this program area. The report focuses on Early Childhood Development and contains a brief overview of the research literature that informs our conceptualization of the logic model and proposed outcomes.
Development of a Child Evaluation Framework for early childhood services using deliberative democratic evaluation and the mosaic approach	Kingston, K. (2016). Development of a Child Evaluation Framework for early childhood services using deliberative democratic evaluation and the mosaic approach. *Evaluation Journal of Australasia*, *16*(3), 25-34.	The purpose of this article is to present an evaluation design for the development of a Child Evaluation Framework (Framework). If implemented, this Framework would give four to six year old children attending early childhood services in an Australian context the capacity to impact upon the design and delivery of their early childhood service. As highlighted, the current lack of ability for children to have a voice and participate in the evaluation of their early childhood service infringes upon their rights under Article 12 of the 1989 United Nations Convention on the Rights of the Child (UNCRC) which calls for the child's right to freedom of expression and information, and for participation. It is hoped that the successful development and implementation of this design would advance child participation rights and child empowerment. The design utilises the principles of deliberative democratic evaluation, and methodologies advocated within the mosaic approach to researching with young children.

Better Beginnings, Better Futures: Theory, research, and knowledge transfer of a community-based initiative for children and families	Worton, S. K., Caplan, R., Nelson, G., Pancer, S. M., Loomis, C., Peters, R. D., & Hayward, K. (2014). Better beginnings, better futures: Theory, research, and knowledge transfer of a community-based initiative for children and families. *Psychosocial Intervention*, *23*(2), 135-143.	This paper provides an overview of the Better Beginnings, Better Futures initiative from its outset in 1990 to the present, with a view towards examining the ways in which knowledge generated from such initiatives can be transferred to other communities. [Logic model on pg. 138].
EarlyON Action Plan (2018-2020)	City of Toronto. EarlyON Action Plan. Retrieved from: https://www.toronto.ca/wp-content/uploads/2018/12/94fd-cs-early-on-action-plan-2019.pdf	What follows is a blueprint that will be universally applied to all service providers across the city. It outlines how Toronto's vision for the early years and care system will be achieved through an ambitious series of Action Items. These Action Items consist of processes and tools that will help us create greater consistency across the EarlyON sector. They also include approaches that will ensure EarlyON Centres reach and support traditionally marginalized communities, including Indigenous and Francophone families. Through EarlyON, our intention is to create a community-led, |7| City of Toronto | Children's Services city-managed resource that provides all families with the local supports that they need. This Action Plan will help us do that. [Logic model on page 6-7].
Scaling early child development: what are the barriers and enablers?	Cavallera, V., Tomlinson, M., Radner, J., Coetzee, B., Daelmans, B., Hughes, R., ... & Dua, T. (2019). Scaling early child development: what are the barriers and enablers?. *Archives of disease in childhood*, *104*(Suppl 1), S43-S50.	Abstract The Sustainable Development Goals, Global Strategy for Women's, Children's, and Adolescents' Health (2016–2030) and Nurturing Care Framework all include targets to ensure children thrive. However, many projects to support early childhood development (ECD) do not 'scale well' and leave large numbers of children unreached. This paper is the fifth in a series examining effective scaling of ECD programmes. This qualitative study explored experiences of scaling-up among purposively recruited implementers of ECD projects in low- and middle-income countries. Participants were sampled, by means of snowball sampling, from existing networks notably through Saving Brains®, Grand Challenges Canada®. Findings of a recent literature review on scaling-up frameworks, by the WHO, informed the development of a semi structured interview schedule. All interviews were conducted in English, via Skype, audio

		recorded and transcribed verbatim. Interviews were analysed using framework analysis. Framework analysis identified six major themes based on a standard programme cycle: planning and strategic choices, project design, human resources, financing, and resource mobilisation, monitoring and evaluation, and leadership and partnerships. Key informants also identified an overarching theme regarding what scaling-up means. Stakeholders have not found existing literature and available frameworks helpful in guiding them to successful scale-up. Our research suggests that rather than proposing yet more theoretical guidelines or frameworks, it would be better to support stakeholders in developing organisational leadership capacity and partnership strategies to enable them to effectively apply a practical programme cycle or systematic process in their own contexts. [Program cycle on page 44].
A Practical Guide to Evaluating Systems Change in a Human Services System Context	Latham, N. (2014). A Practical Guide to Evaluating Systems Change in a Human Services System Context. *Center for Evaluation Innovation*.	Ultimately, the Guide proposes that we can tackle complexity by staying grounded in straightforward and familiar concepts – while at the same time respecting the complex nature of systems change. To help evaluators walk this fine line, the Guide offers: • A concrete way to operationalize the concept of systems (with a focus on human service delivery systems), • A correspondingly concrete way to visualize what it means to say that the system is changing, • A way to think about the factors contributing to the effectiveness of the collaboratives that undertake systems change initiatives, • A list of the steps involved in systems change evaluation (likening this evaluation to standard change-over-time program evaluation), • A set of tools for you to tailor and use in your own evaluation, and • Guidance for how to bring together this approach with some key aspects of a developmental evaluation.

Appendix G - Roger Hart's Ladder of Participation



ROGER HART'S LADDER OF PARTICIPATION

RUNG 8 - **Youth initiated shared decisions with adults**: Youth-led activities, in which decision making is shared between youth and adults working as equal partners.

RUNG 7 - **Youth initiated and directed**: Youth-led activities with little input from adults.

RUNG 6 - **Adult initiated shared decisions with youth**: Adult-led activities, in which **decision** making is shared with youth.

RUNG 5 - **Consulted and informed**: Adult-led activities, in which youth are consulted and informed about how their input will be used and the outcomes of adult decisions.

RUNG 4 - **Assigned, but informed**: Adult-led activities, in which youth understand purpose, decision-making process, and have a role.

RUNG 3 - **Tokenism**: Adult-led activities, in which youth may be consulted with minimal opportunities for feedback.

RUNG 2 - **Decoration**: Adult-led activities, in which youth understand purpose, but have no input in how they are planned.

RUNG 1 - **Manipulation**: Adult-led activities, in which youth do as directed without understanding of the purpose for the activities.

Adapted from Hart, R. (1992). Children's Participation from Tokenism to Citizenship. Florence: UNICEF Innocenti Research Centre, as cited in www.freechild.org/ladder.htm

Figure 1. Roger Hart's Ladder of Participation. Image copied from youthpower.org/youth-drg-toolkit-3-models-roger-hart-ladder (n.d.).

Appendix H – Elements of Family Engagement

Elements of Family Engagement

The diagram below illustrates the multiple elements that make up family engagement.

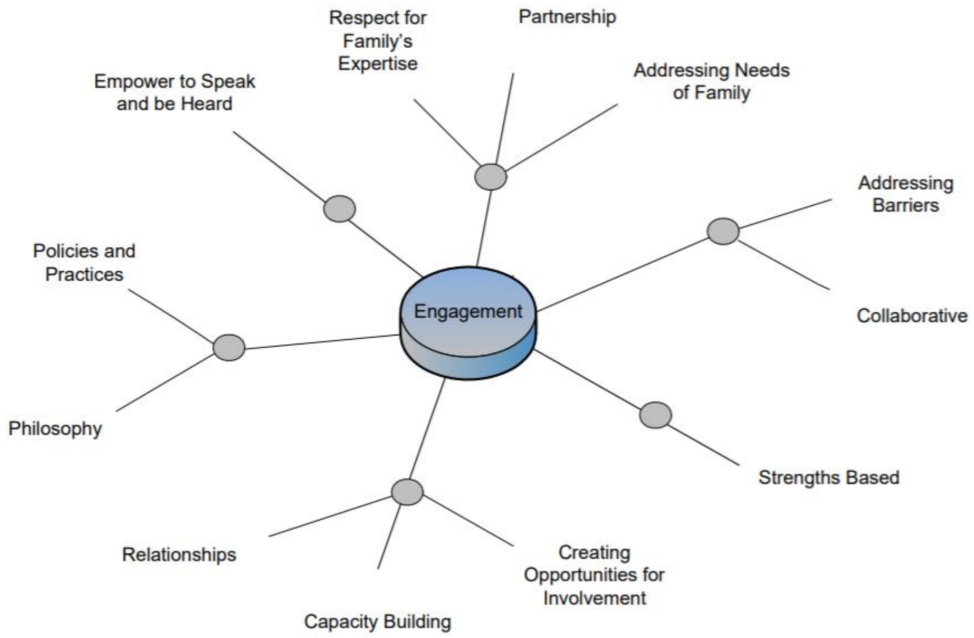
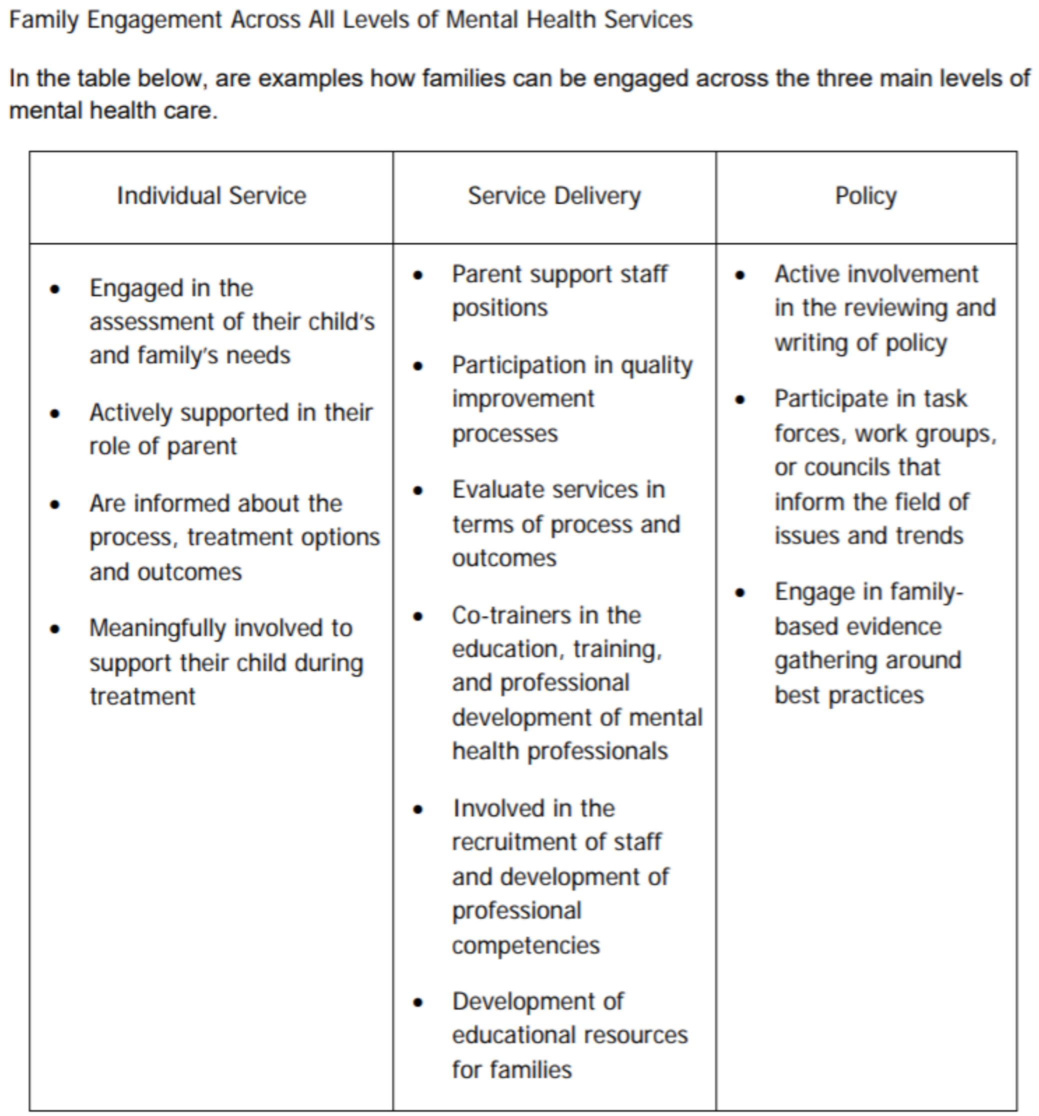


Figure B1. Elements of Family Engagement. Image copied from Nunes (2012).



Family Engagement Across All Levels of Mental Health Services

In the table below, are examples how families can be engaged across the three main levels of mental health care.

Individual Service	Service Delivery	Policy
- Engaged in the assessment of their child's and family's needs - Actively supported in their role of parent - Are informed about the process, treatment options and outcomes - Meaningfully involved to support their child during treatment	- Parent support staff positions - Participation in quality improvement processes - Evaluate services in terms of process and outcomes - Co-trainers in the education, training, and professional development of mental health professionals - Involved in the recruitment of staff and development of professional competencies - Development of educational resources for families	- Active involvement in the reviewing and writing of policy - Participate in task forces, work groups, or councils that inform the field of issues and trends - Engage in family-based evidence gathering around best practices

Figure B2. Family Engagement Elements. Image copied from Nunes (2012).

Appendix I – MHCC Steps for Mental Health Frameworks

Table C1. The MHCC's steps for developing mental health frameworks (2018).

Step	Description	Recommendations and important considerations
1.Recognize and acknowledge key issues regarding performance measurement	Identify and address key issues and/or concerns regarding performance measurement early in progress.	Determine what is the ultimate purpose of performance measurement, whose performance will be measured, whether comparisons will take local conditions into account, and if there is the available capacity to produce quality measures and take action.
2.Cultivate a shared language and understanding of key concepts	This helps create consensus on the framework's key features. It can also be an opportunity to establish shared principles and values.	Have a research team develop an initial set of concepts and then letting stakeholders suggest additional "concepts, frameworks, and worldviews." This is especially important to do with views that are under-represented in research, such as youth and Indigenous groups.
3.Define overall scope of performance measurement	This could include defining the breadth of services and interventions, levels of service, and service recipient populations that will be covered by the framework.	Align the framework as much as possible with the parameters of the mental health and addictions service system model. Be explicit about the decisions made with regards to scope and costs/benefits. Include substance use issues in mental health frameworks.
4.Define framework's key dimensions and domains	According to the literature, these absolutely need to be aligned with strategic priorities and goals. The top 5 policy priorities across the provinces and territories are: access, promotion and prevention, children and youth, person-centred care, and indigenous peoples.	Seek stakeholders' input on this step, particularly from equity-seeking groups. In particular, stakeholders should lead the aspects that relate to their communities. Do not look to past frameworks; look ahead and be aspirational in order to be progressive.
5.Select Indicators	Are four general approaches:	Delphi methods are the most common approach for indicators selection, and the

	- Simple selection by a project team - Selection by an expert panel - Systematic ranking approaches (e.g. Delphi methods) by experts or stakeholders - Approaches like care mapping/concept mapping	MHCC implies that systematic ranking approaches are the preferred method, as the five examples of frameworks they provide all use this method, especially the modified Delphi method. MHCC recommends selecting aspirational indicators to facilitate progressive and faster momentum for change. MHCC recommends selecting indicators that are based on input from equity-seeking groups and those with diverse lived mental health, and that this engagement is meaningful, participatory, and sensitive to history, biases, and who benefits. Indicators should be a balance of structure, process, and outcome indicators. Indicators should clearly relate to a desired goal. Indicators could be grouped according to level/strategic location in the system, which is what New Brunswick did in their mental health performance measurement framework. There should be national-level indicators as well as regional indicators to understand differences in needs and capacities, and to allow provinces and territories to set their own priorities.

Appendix J - List of Indicators From Various Reports and Organizations

Note: Adair and colleagues and Langton and colleagues strongly recommend using a conceptual model or theoretical framework to guide indicator selection because so many indicators are now available (2003; 2016). The list provided here is not intended to be an endorsement of these indicators; it is meant to be a sampling of those found during the review.

Mental Health Commission of Canada: Measuring Progress (MHCC, 2018)

Responsiveness – how health systems anticipate and adapt to changing healthcare needs

Patient-centredness of services

- Patient experience measures: focus on processes of care
- Patient report outcome measures: how the person does in their life as a result of care

Feasibility – availability of data

Meaningfulness/connection to strategy

Alignment with needs and values

Actionability

Unintended effects

Stakeholder/subject matter expert involvement on key domains of interest

Meaningful participation of people with lived experience and their families

Equity

Mental Health Commission of Canada: Informing the Future report (MHCC, 2015)

Children and Youth

- Anxiety/mood disorders
- College and university students who set a drink limit when partying or socializing
- Intentional self-harm among college and university students
- Receipt of stress reduction resources in colleges and universities
- Receipt of suicide prevention information in colleges and universities
- School-based mental health promotion
- Self-rated mental health
- Serious consideration of suicide
- Suicide rates

Access and treatment

- Individuals hospitalized for more than 30 days in a year
- Mental illness hospital readmission within 30 days
- One-year rate of repeat hospitalization for persons with a mental illness
- Unmet need for mental health care among people with mental disorders

Diversity

- Measures specific to:
  - Immigrants
  - Lesbian, gay, and bisexual
  - Northern communities

Recovery

- Employment

Canadian Association of Mental Health (CAMH, 2012)

Note: CAMH’s “Mental Health Promotion for Youth” report has an extensive list of program outcome indicators; the following indicators are ones that are discussed within their report.

- Improving experiences and understandings
- Increasing positive feelings
- Reducing negative feelings
- Decreasing negative behaviours
- Clarifying feelings and attitudes
- Developing skills and awareness
- BC’s Office of the Provincial Health Officer
- Sex/gender (to address disparities), Ottawa Public Health (Procter, n.d.)

Positive mental health outcomes (these indicators all have associated measures):

- Self-rated mental health
- Happiness
- Life satisfaction
- Psychological well-being
- Social well-being
  - Assessed through social connections found in daily routines and positive attachments/relationships

Mental Health Care Utilization, Mental Health Challenges and Illness, Substance Use and Addiction (these indicators have associated measures)

- Mental health care contact
- Self-injury
- Suicidal behaviour
- Suicide
- Alcohol use
- Drug use

ICES: Quality Dimensions of System Performance in Ontario (ICES, 2018)

Equity

- Geography, income by neighborhood, immigration status, age, and sex

Client-centred

Safe

- Indicator: use of restraints

Effective

- Indicator: year of potential life lost due to schizophrenia
- Indicator: rate of death from suicide

Timely

- Emergency department as first point of contact for Mental Health and Addictions system

Efficient

- Indicator: repeat unscheduled emergency department visit within 30 days OR rate of inpatient readmission within 30 days of discharge
- Indicator: doctor visit within 7 days of leaving hospital after treatment for mental health and/or addictions

Middlesex Health Unit, Hamilton Public Health Services, and Thunder Bay District Health Unit (Murphy et al., 2015)

Indicators/themes revealed through a literature review:

- Social connectedness
- Parenting
- Resilience
- Stigma reduction
- Physical health
- Mental health literacy

Indicators/themes revealed through stakeholder interviews

- Upstream approaches
- System integration
- Definition of mental health promotion
- Mental health promotion across the lifespan

Indicators/themes revealed through focus groups with public health leaders

- Understanding mental health promotion
- Role of public health
- Life course approach to public
- Social determinants of health

Child and Youth Mental Health Lead Agencies Consortium: Access Indicators (CYMHLAC, 2018)

- Service utilization
- Service duration
- Average service latency (how long they have to wait)
- Average time on waitlist
- Length of waitlist and/or how many people are on it
- Proportion of children//youth requiring transitions
- Proportion of population served
- Individuals waiting for assessments
- Individuals waiting for service initiation

CMHA – Systems-Level Indicators (CMHA, 2016)

Strategic leadership for data and performance measurement

- Centralize data governance and oversight
- Implement common provincial performance measurement scorecard

Measure client journey

- Implement common business intelligence solution to provide access to timely data analysis across province
- Implement use of unique client identifier
- Expand the collection of socio-demographic information

Establish a cohesive and standard approach

- Implement a standardized process for data collection and reporting
- Reduce redundancies in data collection and reporting

Build information infrastructure and capacity

- Implement a provincial IT fund
- Support clinicians with data collection
- Support agencies with data-driven decision-making

Appendix K – Matrix Models

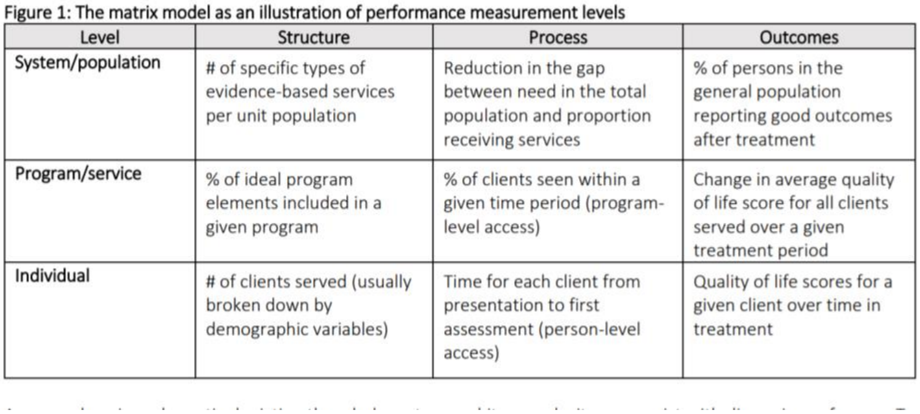


Figure 1: The matrix model as an illustration of performance measurement levels

Level	Structure	Process	Outcomes
System/population	# of specific types of evidence-based services per unit population	Reduction in the gap between need in the total population and proportion receiving services	% of persons in the general population reporting good outcomes after treatment
Program/service	% of ideal program elements included in a given program	% of clients seen within a given time period (program-level access)	Change in average quality of life score for all clients served over a given treatment period
Individual	# of clients served (usually broken down by demographic variables)	Time for each client from presentation to first assessment (person-level access)	Quality of life scores for a given client over time in treatment

Figure E1. Matrix Model. Copied from Mental Health Commission of Canada (2018).

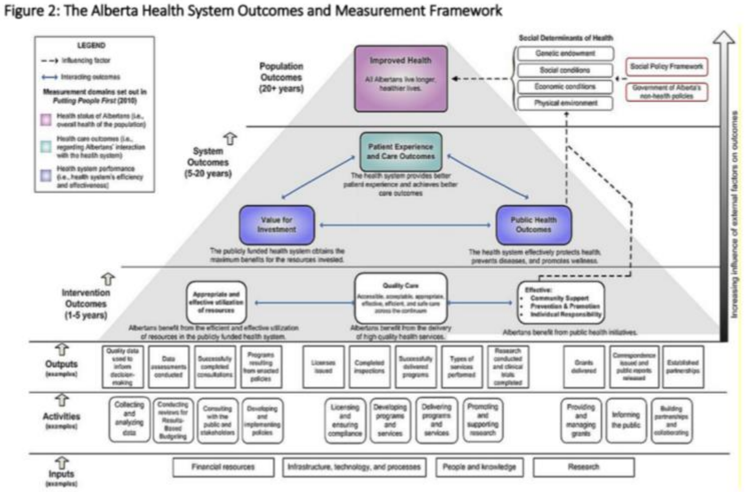
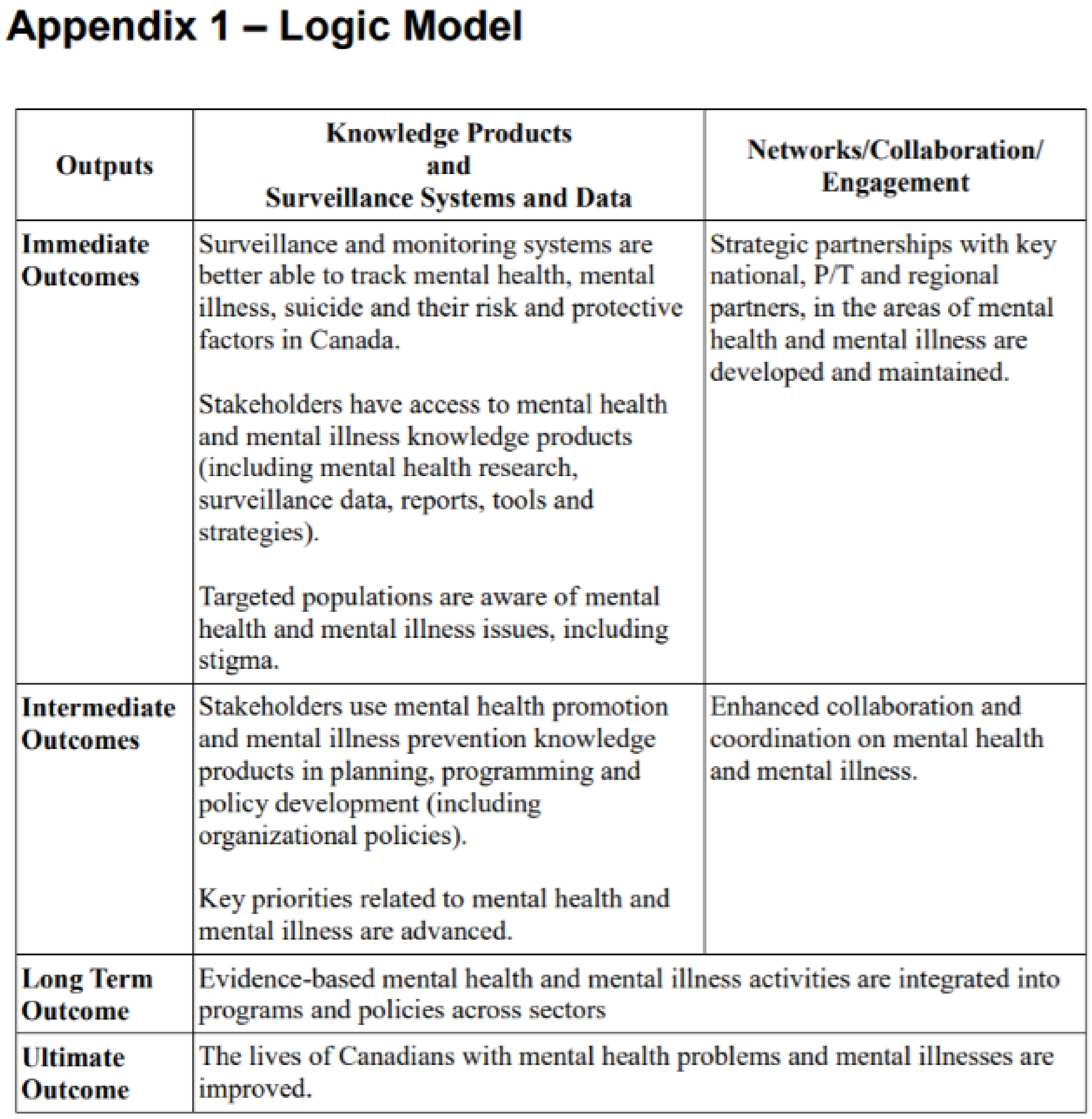


Figure 2: The Alberta Health System Outcomes and Measurement Framework

Figure E2. Model of the Alberta Health System. Copied from Mental Health Commission of Canada (2018).

Appendix L - MHCC Logic Model



Appendix 1 – Logic Model

Outputs	**Knowledge Products and Surveillance Systems and Data**	**Networks/Collaboration/ Engagement**
Immediate Outcomes	Surveillance and monitoring systems are better able to track mental health, mental illness, suicide and their risk and protective factors in Canada. Stakeholders have access to mental health and mental illness knowledge products (including mental health research, surveillance data, reports, tools and strategies). Targeted populations are aware of mental health and mental illness issues, including stigma.	Strategic partnerships with key national, P/T and regional partners, in the areas of mental health and mental illness are developed and maintained.
Intermediate Outcomes	Stakeholders use mental health promotion and mental illness prevention knowledge products in planning, programming and policy development (including organizational policies). Key priorities related to mental health and mental illness are advanced.	Enhanced collaboration and coordination on mental health and mental illness.
Long Term Outcome	Evidence-based mental health and mental illness activities are integrated into programs and policies across sectors	
Ultimate Outcome	The lives of Canadians with mental health problems and mental illnesses are improved.	