EXPLORING MENTAL HEALTH SERVICES AND SUPPORTS FOR CHILDREN, YOUTH AND FAMILIES IN CALGARY

A REPORT TO THE UNITED WAY CALGARY & AREA

DRAFT MARCH 31

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Table of Contents

Acknowledgments ........................................................................................................... 5

List of acronyms ................................................................................................................ 6

Executive summary ........................................................................................................... 7

Key findings ....................................................................................................................... 7

The superordinate finding ................................................................................................. 8

Possible pathways for moving forward ............................................................................ 9

Build a new foundation: Develop a continuum or framework for mental health services and supports that is grounded in a philosophical shift ................................................................................. 9

Disruptions to address key issues .................................................................................. 10

Some less disruptive but potentially impactful short-term actions .................................. 11

A multitude of strengths and passion for change: A powerful base for moving forward .......... 12

Introduction and overview ............................................................................................. 13

Purpose of the project ...................................................................................................... 13

Overview of the report .................................................................................................... 13

Definitions ....................................................................................................................... 14

Methods .......................................................................................................................... 15

Advisory group ................................................................................................................. 15

Qualitative methods ....................................................................................................... 15

Limitations and strengths ............................................................................................... 17

Findings ............................................................................................................................ 18

Insufficient attention to the “front end” – supports foundational to child, youth and family mental wellbeing .................................................................................................................. 19

Early childhood development ......................................................................................... 20

Credible and accessible information for youth and families about mental health problems and illnesses ................................................................................................................................. 23

Gaps and challenges in accessing and receiving mental health services and supports .......... 25

Getting in: Accessing mental health services and supports .......................................... 25

Assessment challenges .................................................................................................... 41

Supports for the whole family ....................................................................................... 44

Supports while waiting for, and beyond ‘treatment’ ......................................................... 47

Transitions ....................................................................................................................... 51

System issues .................................................................................................................. 57

Why so much fragmentation? ....................................................................................... 58

Resourcing ....................................................................................................................... 62

Capacity – quality of supports and professional development ...................................... 65

Service provider suggestions regarding potential roles for the United Way ..................... 67

Strengths ......................................................................................................................... 67

Advisory Group discussion March 14, 2018: The need for system disruption ..................... 68

Gap and Challenges: Where to focus .............................................................................. 69

How to get there: Priority actions .................................................................................. 71

Discussion ....................................................................................................................... 75

The need for a philosophical shift ................................................................................. 76
Person and family-centred care, mental health promotion and recovery: Inspiration for a re-designed system? .....................................................................................................................................................................................77
  Person and family-centred care and services ..........................................................................................................................77
  Mental health promotion .........................................................................................................................................................77
  Recovery ..................................................................................................................................................................................78
About aligning with provincial directions: Valuing Mental Health Next Steps .................................................................79
Thoughts about moving forward ...............................................................................................................................................80
Pathways for moving forward: Some possibilities .................................................................................................................80
Disruptive actions ...........................................................................................................................................................................81
  Build a new foundation: Develop an integrated continuum or framework for mental health services and supports that is grounded in a philosophical shift ........................................................................81
  Disruptions to address key issues: Access, transitions, and better supports for children, youth, and families ...............................................................................................................................82
Some less disruptive but potentially impactful short-term interventions ................................................................................84
Concluding remarks ........................................................................................................................................................................85
Appendix A: Compilation of summary tables ..........................................................................................................................86
Appendix B: Interview guides ......................................................................................................................................................94
  Interview guide for service providers ........................................................................................................................................94
  Interview guide for youth and family .........................................................................................................................................97
Appendix C: Challenges Identified in this Review and Relevant Valuing Mental Health Next Steps ..................................................................................................................................................99
“There can be no keener revelation of a society’s soul than the way in which it treats its children.”

- Nelson Mandela
Acknowledgments

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### List of acronyms

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<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACES</td>
<td>Adverse Childhood Experiences</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
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<tr>
<td>AHS</td>
<td>Alberta Health Services</td>
</tr>
<tr>
<td>AMH</td>
<td>Addiction and mental health</td>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>CAAMHPP</td>
<td>Child and Adolescent Addiction, Mental Health and Psychiatry Program (AHS)</td>
</tr>
<tr>
<td>CCAMH</td>
<td>Calgary Council on Addiction and Mental Health</td>
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<tr>
<td>CIHR</td>
<td>Canadian Institutes of Health Research</td>
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<tr>
<td>CMHA</td>
<td>Canadian Mental Health Association</td>
</tr>
<tr>
<td>CDVC</td>
<td>Calgary Domestic Violence Collective</td>
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<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency department</td>
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<tr>
<td>ECMap</td>
<td>Early Childhood Development Mapping Project</td>
</tr>
<tr>
<td>ER</td>
<td>Emergency room</td>
</tr>
<tr>
<td>FASD</td>
<td>Fetal Alcohol Spectrum Disorder</td>
</tr>
<tr>
<td>MH</td>
<td>Mental health</td>
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<tr>
<td>MHCC</td>
<td>Mental Health Commission of Canada</td>
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<tr>
<td>NFP</td>
<td>Not-for-profit</td>
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<tr>
<td>NGO</td>
<td>Non-governmental organization</td>
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<tr>
<td>PaCER</td>
<td>Patient and Community Engagement Research</td>
</tr>
<tr>
<td>RCSD</td>
<td>Regional Collaborative Service Delivery</td>
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<tr>
<td>SCN</td>
<td>Strategic Clinical Network (AHS)</td>
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<td>VMH</td>
<td>Valuing Mental Health</td>
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Executive summary

In the fall of 2017, the United Way of Calgary and Area embarked on a project to explore the existing continuum of mental health services for children, youth, families and their natural supports in Calgary. An independent consulting team was contracted to conduct this inquiry.

The specific purposes of this work were to:

- Conduct a review of community-based mental health services and supports for children, youth, families and their natural supports in Calgary in order to identify system gaps and barriers or challenges to access; and,
- Make recommendations for addressing identified gaps and challenges so as to improve the continuum of mental health care for children and youth in the city.

Key findings

Based primarily on the conduct of 35 interviews with 47 individuals, including service providers, funders, researchers, youth and families; review of findings from other research regarding youth and family experiences with mental health services; and informed by an expert Advisory Group, the key findings of the inquiry include the following gaps and challenges.

- **Insufficient attention to the “front end” – mental health promotion, mental illness prevention, early childhood development and early identification of and interventions** for developmental, learning, psychosocial and other concerns. More preventative work is required to bolster child, youth and family so they don’t require formal mental health services in the first place.

- **Gaps and challenges associated with accessing and receiving mental health services and supports.** These include:
  
  - “Getting in” - Accessing mental health services and supports. Children, youth and families experience many challenges in “getting in” to mental health services and supports for a variety of reasons including: lack of awareness of what is needed and what is available; restrictive program inclusion or exclusion criteria; lengthy wait lists; and, the costs, hours and locations of services. Difficulties in accessing services generate additional stress when families are already struggling to support their child or youth. Service providers similarly struggle to keep track of what services are available.

  These access challenges and gaps place children and youth at risk for “falling through the cracks” and missing out on supports. The most widely cited group of children at risk for this are those who are experiencing significant mental health or other related challenges but who are not ill enough for admission to Alberta Health Services’’ (AHS’s) Child and Adolescent Addiction, Mental Health and Psychiatry Program (CAAMHPP).
Assessments. Ideally, the goal of assessment is to identify the right resources and the right intensity of service for a child or youth at the right time. There is a need for a rapid and appropriate assessment so that children, youth and families can receive the supports they need in a timely manner. A number of challenges make achieving this difficult.

Supports for the whole family. A strong theme emerging from youth and family experiences is the extreme and often long term distress that families endure when their child is experiencing a mental health problem or illness. They are not always treated with kindness or compassion. There needs to be support for the whole family, not just the child or youth. An intergenerational approach that also supports parental mental health is important.

Supports while waiting for and beyond “treatment”. There can often be a lengthy wait list for clinical services and treatment, leaving families to cope with mental health concerns or behaviours that can be extremely stressful and challenging to manage and that can significantly impact the entire family. Supports are needed during this “in limbo” period. They are also needed throughout the course of mental health problems and illnesses to help children, youth and families live well.

Transitions. Transitions from one age group to another, or from one service to another are times when services may be lacking or poorly coordinated, creating the potential for getting “dropped out” of the system. The most widely cited problematic transitions are: transitions from one agency or service to another; transitions between community based NGO services into AHS acute care, and back to the community; and transitioning from adolescent mental health services into adult services.

System issues – there is no planned system of services and supports for child, youth and family mental health. The result is a fragmented, piecemeal array of services that results in poor child, youth and family experiences and poor continuity of care. Many factors contribute to this fragmentation, particularly the lack of a common language or framework for collaboration and divergent understandings of “mental health”.

The superordinate finding
The superordinate finding is that these issues have plagued the system, not only in Calgary, but provincially, nationally and internationally, for decades and that it is time for a new approach - something disruptive that will open the door for collaborative innovation and change that better supports children, youth and families in Calgary. A philosophical shift is needed – a rethink about existing ways of thinking and working, moving toward a system that truly focuses on what children, youth and families need to achieve and sustain mental wellbeing and to live fulfilling and enjoyable lives whether or not they have a mental health problem or illness.
Some principles underlying this philosophical shift, identified by key informants and Advisory Group members for the project include:

- **The focus should be on the fundamental “technology” of health care: human beings supporting and serving other human beings in a kind and compassionate manner.**

- **The focus should be on the whole family and their natural supports;** not just the individual child or youth.

- **The focus should be on what children, youth, families and their natural supports need to function well on their journey to wellbeing.** There will always be a need for diagnosis and treatment for a certain proportion of the population, but to better serve families, the system needs to embrace a more holistic approach that considers the whole person/family in context and focuses on what they need to be well and to manage well at the present time.

- **The focus should also be on providing supports to children and youth and families before they need to use the formal system** – information, peer support, sports, recreational activities and so on, and mental health promotion and mental illness prevention efforts can be powerful tools here.

- **The focus should be on strengths and building capacity** – helping children, youth and families to help themselves, but not necessarily *only* by themselves; rather, with the support of many easily accessible people and supports to help them along the way. For people to feel empowered, they must be able to access the supports they need when they need them. There needs to be an appropriate balance between professional care and self-help/empowerment.

**Possible pathways for moving forward**

Based on the findings of the inquiry and a deliberative dialogue with Advisory Group members, a number of possible pathways for moving forward have been identified. Some of these pathways will disrupt current ways of working; others may address pressing issues in the more immediate term.

**Build a new foundation: Develop a continuum or framework for mental health services and supports that is grounded in a philosophical shift**

The most disruptive approach is making the philosophical shift and re-designing to create an integrated system focused on meeting the mental health needs of children, youth and families. An important “disruption within the disruption” is the integral involvement of children, youth, and families in this process; that is, “nothing for us without us”. This is the starting point for a system grounded in what they need.
There are many ways to approach this and careful consideration will be required to find the most promising way(s) forward. Different perspectives and ideas have been shared about this, including the following:

- “Start small” with simple one day integrated, cross-agency planning meetings
- Create a coordination table that brings agencies together to find ways to improve coordination
- Bring case managers from community-based NGOs and AHS (and other relevant government organizations) together to discuss their approaches to case management (it was thought that this process would help people from both “sides” understand the approaches they take, and the challenges they experience)
- Bring people from NGOs and AHS together, along with youth and families (i.e., people with lived experience) to talk about how things currently work, perhaps using some examples
- Convene a small, cross-organizational group to pilot something new, evaluate and fine-tune it, then scale it up
- Achieve agreement on what “mental health” means, and identify shared principles for serving Calgary’s families; or, to start with a full out comprehensive visioning and design
- Engage in a full-out process to develop an “ideal” continuum or framework of mental health services and supports for children, youth and families in Calgary

Whether starting on big or small actions, highly skilled facilitation will be required to bring stakeholders together - ideally, children, youth, families, NGOs, government organizations (health and other sectors as well), and the private sector (e.g., private psychologists) in a constructive space. The United Way is developing a co-design lab, which may be an excellent vehicle for this work.

Disruptions to address key issues
A number of innovative actions outlined by participants in this review could address several identified challenges simultaneously. These include: integrated service hubs, peer support, and e-mental health. Each is briefly described below.

1. **Experiment with integrated service hubs or similar approaches that enable rapid access to multiple services and supports.** The review revealed a great deal of energy, enthusiasm and action around the concept of integrated youth service hubs, based on the original headspace model developed in Australia and now being adopted in different forms in many other countries, including in Alberta. Integrated hubs are understood as, “the integration of health and social services under one roof in a youth-friendly environment”. These hubs would address access and integration issues, in particular.

2. **Expand youth and family peer support in Calgary.** Given that peers can help address a number of issues including providing supports when people first begin to experience issues; serving as a first

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contact in agencies; working in emergencies and in-patient units to support people through the process; and, so on. Peers can interact with youth and families in many ways including in person, through texts, e-mails and telephone and thus can be highly accessible for people. Thus, they have great potential to help youth and families cope with issues before they need to access formal services; they can be a support while people are waiting for appointments and treatment; and, they can support people through the journey and make the experience for children, youth and families a more humane and comforting one. Peer support is an integral component of integrated service hubs, so there is an opportunity to expand the peer support through integrated service hubs as well.

Peer support is also a key recommendation of the Mental Health Commission of Canada (MHCC):

“Peer support works because people who have experience with mental health issues can offer encouragement and hope to each other – often reducing hospitalization, providing social support and improving quality of life. It can also connect families experiencing similar situations, helping them better understand the mental health system and improving their ability to take care of their loved one’s needs.”

3. Implement e-mental health solutions to support youth and families. Many interviewees referenced various e-mental health solutions to some of the gaps and challenges identified herein, yet Alberta was noted to be “way behind the eight-ball” in this arena. This may be about to change given that AHS’s Addiction and Mental Health Strategic Clinical Network (SCN) and partners recently received a Canadian Institutes of Health Research (CIHR) research grant to test e-mental health for adolescents and young adults experiencing the three most commonly occurring mental illnesses in youth and young adults under 25: anxiety, mood, and substance disorders. The project will involve e-mental health innovations including peer-to-peer and family support; internet-based cognitive behavioural therapy; and, internet-based screening for alcohol consumption.

Beyond this CIHR grant, there are many other potential applications for e-mental health. One example is a phone app to improve access and navigation. A starting point for this work may be to consult with those who have conducted research about the use and effectiveness of various e-mental health technologies, and seek to identify those approaches that may effectively address various challenges addressed herein. An important reminder would be to ensure that youth in particular are involved in these processes since they would likely be the primary users of these technologies.

Some less disruptive but potentially impactful short-term actions
There are many other possible and less disruptive actions and pathways; many have been outlined in the summary tables in the “Findings” section of this report. Three that seem to have good promise are briefly described below.

1. **Access – increase awareness about what services are available and how to access them.** Some possibilities include targeted social marketing campaigns (customized approaches for different groups, such as youth, families, service providers, primary care physicians, clinics/networks, schools). A caution is that increased awareness would ideally result in increased demand for services. Other strategies to increase services need to be considered in tandem with this action.

2. **Access – increase the number of single-session and walk in mental health services** for youth and families, and test new ways of reducing wait lists. A number of agencies in Calgary have found ways to increase access through, for example, the use of detailed data to anticipate resource needs and eliminate wait lists; walk in clinics; single-session clinics; the use of an intake and engagement team where the first contact with a client is viewed as an intervention in itself; an approach of “screening people in rather than out; and barrier-free counseling. Lessons can be learned from these organizations. It may be helpful to convene a dialogue amongst agencies to share practices that could help reduce wait lists and provide rapid access to supports.

3. **Transitions - begin to move toward an “every door is the right door” approach, and more warm entries and hand-offs** across the web of mental health services and supports in Calgary.

One approach might be to convene meetings with stakeholders to talk about how this might work, and perhaps develop a pilot project. This might be something that a small group of actors comes together to work on, pilot, refine and scale up.

**A multitude of strengths and passion for change: A powerful base for moving forward**

This inquiry revealed a number of significant challenges, perhaps resulting in a rather one-sided picture. In reality, there is a rich array of mental health services and supports for Calgary’s children, youth and families. And, there is a great deal of innovation underway. A number of interviewees, for example, spoke of AHS’s CAAMHP Program in glowing terms, describing the program as innovative and progressive. It was similarly noted that there are many excellent community-based NGO programs and services. There is also a strong and shared desire to do better for children, youth and families in Calgary, and to work together to do so. Some key points about this include:

- Amongst all participants in this review, there is a strong and shared passion for child, youth and family mental wellbeing
- There is also a shared passion for a better system of supports/services for children, youth and families
- There is ample good will and desire to work together more collaboratively
- People are excited about this project and eager to participate - many simply said, “How can we help?”
- Many ideas were offered for moving forward

All of this equates to a powerful base for change.
Introduction and overview

“Successful kids are the future of our city.”

“Healthy emotional and social development in early years lays the foundation for mental health and resilience throughout life. An estimated 1.2 million children and youth in Canada are affected by mental illness – yet, less than 20 percent will receive appropriate treatment... Youth who are engaged in child and mental health services, and who require continued services, are also often not well supported as they prepare to enter the adult mental health system... Increased access to appropriate services and supports across the continuum of care is needed.”

The mental health (MH) and wellbeing of children and youth is a key resource for a vibrant and resilient society, yet the existing array of MH services and supports for young people across the country is insufficient to meet current and future needs.

Similar issues face Calgary children, youth and their families. In the fall of 2017, the United Way of Calgary and Area embarked on a project to explore the existing continuum of mental health services for children, youth, and families in Calgary. An independent consulting team was contracted to conduct this inquiry and document the findings.

Purpose of the project
In this report, findings of the inquiry are presented. The specific purposes of this work were to:

• Conduct a review of community-based mental health services and supports for children, youth, families and their natural supports in Calgary in order to identify system gaps and barriers or challenges to access; and,
• Make recommendations for addressing identified gaps and challenges so as to improve the continuum of mental health care for children and youth in the city.

The United Way of Calgary and Area will use the findings of this inquiry for ongoing planning and efforts to promote a strengthened network of community-based child, youth and family mental health services and supports in Calgary.

Overview of the report
This report is organized in the following manner. First, a brief description of methods used for the inquiry is presented. This is followed by a presentation of findings. For those who wish to move quickly through this document, a summary table is presented at the end of each section of findings. Each table lists the key points for the finding as well as existing strengths and efforts underway, and interviewee

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5 Recognizing that acute care services are not in the purview of the United Way
suggestions for action. It should be noted that these latter two lists are based only on information provided by key informants; they are not the result of any comprehensive search or analysis, and hence are inevitably limited and incomplete. A compilation of all summaries is presented in Appendix A. The presentation of findings is followed by description of a significant turn in the inquiry that occurred at the March 14, 2018 meeting of the Advisory Group developed to support this project. At this meeting it was agreed that the challenges identified in this inquiry are not new and that disruptive change is needed in order to make real progress and change. A discussion section follows this description, and the report is concluded with a presentation of some possible pathways for moving the work of this inquiry forward.

**Definitions**

The term “mental health” is problematic, given that different people use it to mean different things – and how people define the term influences what kinds of services and supports are deemed to be relevant. Indeed, this is a challenge identified by key informants in this project (see “System issues” in the Findings section below). For purposes of this report, the term “mental health” is used in a positive sense, as in the presence of mental *wellbeing* - these terms are used interchangeably. The term “mental illness” has traditionally been defined as a “medically diagnosable illness” that significantly impairs how people think, feel, behave and/or interact with others, causing significant distress. The terms “mental health problem” and “mental health issue” refer to more common mental health complaints, often experienced temporarily as a reaction to life stressors, that are less severe and of shorter duration than mental illnesses.

A gray area, and a manifestation of a system narrowly focused on disease rather than child, youth and family needs and functioning, is those children and youth who may not have a “medically diagnosable illness” but who nevertheless are experiencing issues that impact how they think, feel, behave and interact. These issues might include, for example, childhood trauma, neurodevelopmental issues, severe behavioural issues or learning disabilities. Some of these children and youth may require extensive and ongoing support, just like those with “medically diagnosable” illnesses, while others may require less.

To deal with this matter, and for lack of better terms, when we use the term “mental illness” in this report, we include those with “medically diagnosable” illnesses and those with other issues that require more intensive care and support. When we use the terms “mental health problems” or “mental health issues”, we also include children and youth with these other kinds of issues who require less intensive support.

Also, we use the term “family” in its broadest sense, including mothers, fathers, other relatives, and natural supports (e.g., friends, teachers, mentors, neighbours).

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**Methods**
The approach adopted for this project was twofold. First, the project was significantly informed and shaped through the formation of an advisory group that provided insight and advice over the course of the project. Second, a number of qualitative methods were used to collect a large amount of rich information regarding mental health services and supports for children, youth, and families in Calgary.

**Advisory group**
A very important part of the project was formation of an advisory group, composed of experienced and knowledgeable service providers from a number of community-based not-for-profit organizations and Alberta Health Services (AHS) that provide mental health services and supports for Calgary’s children, youth and families. The United Way recommended a number of people for this group; the consulting team also identified a number of members through key informant interviews.

The purpose of the group was to advise on the process of the inquiry, to review and discuss findings, and to discuss and advise on possible ways forward for the United Way. The group met twice over the course of the project – once on November 30, 2017 to review preliminary findings, and again on March 14, 2018 to review a synthesis of findings and discuss possible actions or strategies that could improve the continuum of mental health services and supports for Calgary’s children, youth and families.

**Qualitative methods**
Qualitative methods were used for this inquiry; that is, the focus was on understanding the experiences of service providers, researchers, and users of child and adolescent mental health services in Calgary. This form of inquiry was well suited to the project because it allowed in-depth conversations with knowledgeable people about various aspects of the “system” - particularly, gaps, challenges and strengths - to inform the project.

Approaches taken to collect information included the following:

- **Key informant interviews with service providers and other system stakeholders (e.g., funders, researchers)** (hereafter referred to collectively as “service providers”) – people with substantial knowledge of child/youth/family mental health services and supports in Calgary. Initial informants were identified by United Way Calgary and Area. A snowball sampling method was adopted, meaning that original key informants were asked to identify other people with rich knowledge, and these people were subsequently interviewed.

  In total, 26 interviews were conducted with 36 service providers. The interviews lasted from 30 to 90 minutes; they were audio-recorded with the participants’ permission, and detailed notes were taken. A list of participating organizations is provided in Table 1. The interview guides for key informant interviews can be found in Appendix A.

- **Key informant interviews with peer supporters and researchers who are studying the experiences of children/youth and families with mental health services and supports in Calgary and Alberta.**
To understand the “system” from the perspective of children/youth and families, nine interviews were conducted with eleven people, as follows:

- Five peer support workers from CMHA Calgary; each of whom spoke of their own experiences in the system, as well as their observations about the experiences of people they have worked with in their peer support roles.
- Three PaCER (Patient and Community Engagement Research) patient researchers from the University of Calgary who conducted a qualitative study exploring families’ experiences going to the Emergency Department (ED) with children/youth experiencing a mental health crisis. These families also have lived experience accessing other kinds of mental health services and supports. This research was part of a joint project of Addictions and Mental Health and Emergency Department Strategic Clinical Networks looking at youth and family ED experiences.
- One researcher from the University of Calgary who is a part of a team studying transitions of youth/young adults into adult systems of care.
- One parent who volunteered to be interviewed about their family’s experiences with Calgary services and supports.

In total, 35 interviews were conducted with 47 people. In addition to these formal interviews, a number of informal conversations with other service providers, family members, researchers and funders were also conducted.

- **Review of AHS reports summarizing the findings from two surveys conducted in Alberta Emergency Departments**, another component of the Strategic Clinical Networks project described earlier regarding the experiences of children/youth/families who have accessed Alberta emergency rooms for mental health issues. There was a good response to both the youth age 15-24 (n=982), and the family of children and youth age 7-24 (n= 553), surveys.

- **Observation of the Brain Trust 2 meeting** held by Alberta Health Services (AHS) on February 28, 2018. This was a full day meeting of approximately 80 people to hear about and discuss findings both of the ED surveys, and the PaCER qualitative research, regarding the experiences of children/youth/families who have gone to an emergency room in Alberta for mental health concerns.

- **Reviews of websites** of relevant Calgary-based organizations, and other provincial, national or international organizations mentioned by key informants.

- **Reviews of documents**, including a small number of academic articles pertaining to the experiences of children/youth and families in using mental health services and supports, and a number of reports such as the Government of Alberta’s *Valuing Mental Health* reports and publications by the Mental Health Commission of Canada.
Two meetings with the Advisory Group for the project. Detailed notes were taken during these meetings, and participants were asked to provide written comments on particular topics.

Table 1. Key informants: Participating organizations

<table>
<thead>
<tr>
<th>Access Mental Health (AHS)</th>
<th>CUPS</th>
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</thead>
<tbody>
<tr>
<td>Addiction and Mental Health Strategic Clinical Network and Maternal Newborn, Child and Youth Strategic Clinical Network (AHS)</td>
<td>Hull Services</td>
</tr>
<tr>
<td>Burns Memorial Foundation</td>
<td>Independent parenting education and healthy child development consultant</td>
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<tr>
<td>Calgary Counselling Centre</td>
<td>Mental Health Promotion &amp; Mental Illness Prevention (AHS)</td>
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<tr>
<td>Calgary Regional Collaborative Service Delivery (RCSD)</td>
<td>O’Brien institute for Public Health, University of Calgary – PaCER research team</td>
</tr>
<tr>
<td>Canadian Mental Health Association (CMHA) Calgary</td>
<td>Palix Foundation</td>
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<tr>
<td>Canadian Mental Health Association (CMHA) Calgary – Peer Supporters</td>
<td>PolicyWise for Children &amp; Families</td>
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<tr>
<td>Carya</td>
<td>Sheldon Kennedy Child Advocacy Centre</td>
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<td>Catholic Family Services</td>
<td>United Way Calgary</td>
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<tr>
<td>Child and Adolescent Addictions, Mental Health &amp; Psychiatry Program (CAAMHPP) (AHS)</td>
<td>University of Calgary Faculty of Social Work</td>
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<tr>
<td>Child and Youth Mental Health, Provincial (AHS)</td>
<td>Valuing Mental Health (Government of Alberta)</td>
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<tr>
<td>Children’s Link</td>
<td>Wood’s Homes</td>
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Limitations and strengths
There are some limitations of this inquiry that should be considered when reviewing this report. First, there are many dozens of not-for-profit organizations in Calgary, each offering numerous services relevant to child, youth and family mental health. It was not within the scope of the project to conduct a comprehensive review of the entire array of existing services in Calgary. Some perspectives may therefore be missing.

Second, there is no established or agreed upon framework, continuum or pathway of mental health services and supports for children, youth and families in Calgary. And, there are multiple pathways into, through, and out of services given that children, youth, and families may have different levels of need and at different ages; that they may move in and out of crisis – at times requiring more intense support; and that mental illnesses can be complex and multi-faceted. For example, the pathway for a child or youth having troubles with bullying at school maybe quite different from the pathway of a youth who is experiencing a first psychotic episode. This makes it difficult to identify all of the possible gaps and challenges that may exist. However, the high level of agreement across the 47 people interviewed for this project, congruence with findings of larger inquiries such as the Government of Alberta’s Valuing
Mental Health (VMH)\textsuperscript{8} review, reviews in other provinces, and of the Mental Health Commission of Canada, lends a good level of confidence that key issues and challenges have been identified.

Third, it would have been ideal to have greater representation of child/youth/family/natural support voices in this inquiry. Given the time and effort that would have been required to obtain ethical approval and find participants, this was not feasible. Nevertheless, the findings are enriched significantly through the inclusion of at least nine people with lived experience of mental health problems and illnesses, and through the opportunity to review the findings of the SCN PaCER research. The high level of congruence between service provider concerns and youth/family concerns again lends credence to the findings reported herein.

An important strength of the inquiry is the rich information gathered through the large number of in-depth interviews conducted with knowledgeable individuals, enabling a deeper understanding of the current state of affairs in Calgary. The opportunity to hear directly from youth and families about their experiences, as well as to speak with patient researchers about their qualitative research findings, added an important dimension to this work. Another strength is the use of the Advisory Group, which was able to validate (or not), and further elaborate on the findings. The discussions at the Advisory Group meetings were rich and led to the development of new insights and Calgary-specific ideas for moving forward.

In the next section, findings of the inquiry are presented.

**Findings**
In this section, the findings from the inquiry are presented in three broad categories, as follows:

- Insufficient attention to the “front end” – supports foundational to child, youth, and family mental wellbeing
- Gaps/challenges related to accessing and receiving mental health services and supports
  - Access – “Getting in” to mental health services and supports
  - Assessment
  - Supports for the whole family
  - Supports while waiting for treatment or clinical care, and in between treatments
  - Transitions
- System issues

In the sections below, each gap or challenge is described. Efforts already underway to address gaps, and/or suggestions of key informants to augment or leverage that work or try something new, are also outlined in table format. As noted previously, the content in these tables is based on information from 2015.

provided by key informants; it is not a result of comprehensive review of existing services and as such, is inevitably incomplete, and a compilation of all summary tables is presented in Appendix A.

Note also that we describe the system issues last, but this is not because they are the least important. Indeed, the dominant finding from this review is that there is no planned system of services and supports for child, youth and family mental health. Many described this as there being no continuum of services and supports, and/or a patchwork of services that is incredibly challenging to navigate. One family member said: “It’s all cracks” (SCN PaCER research). Factors contributing to this fragmentation are described in the “System issues” section of the findings.

**Insufficient attention to the “front end” – supports foundational to child, youth and family mental wellbeing**

At least half of key informants, including youth and families, noted the importance of “working on the front end” of mental health services; that is, promoting mental health and resilience, and preventing mental health problems before kids wind up in crisis. These practices are wide ranging in nature and can occur at many levels (e.g., individual, family, community) including, for example, action on the social determinants of health (e.g., food security; safe, stable and affordable housing; adequate and sustained income and so on), strengthening protective factors and reducing risk factors. Many interviewees included early childhood development, parenting, the early identification of issues and early intervention in this “up front” work as well. They also noted that paying greater attention to mental health promotion and mental illness prevention would resolve a number of the challenges inherent in the current “system”.

“*We need more of that early on piece – being aware of and supporting the social determinants of health – we all know that’s the biggest bang for the buck early on – prevent, identify early, provide early intervention. That’s a huge piece that will stop people from needing to go up the pyramid.*” (Service provider)

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9 Protective factors enhance and protect mental wellbeing – they include, for example, parental resilience, good coping and social skills, good social connections, social and emotional competence, supportive and caring parents, concrete supports in times of need, safe and secure living and economic security. Risk factors increase the likelihood that mental health problems and illnesses may develop – they include, for example, low self-esteem, poor coping skills, insecure attachments, abuse and violence, poverty, and homelessness.

10 ‘The pyramid’ is reference to a pyramidal model of service delivery, which begins with mental health promotion and illness prevention for all children/youth/families at the base, and increasingly more intense levels of care/service moving up the pyramid, culminating in specialized care for individuals with severe mental illness at the top of the pyramid.
“We keep paying more to go down the path of paying more for illness care, but I think we need to go down the path of paying more for prevention...mental health just has to be standard learning for everybody. We know a lot about how to identify early signs of mental illness, but we don’t know as a society what mental health is, and then we need to know how to create environments that promote positive mental health.” (Service provider)

“What are you providing at the universal level that touches all kids... and then what are you providing at the targeted level for those who have some need but aren’t yet in the clinical realm? And to me, that’s an area where there’s real potential for traction. If we could get better at those programs to bolster mental health earlier on.” (Service provider)

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“If you look at research about ACES [adverse childhood experiences] – childhood trauma – most of our adult issues – mental or physical health related and other social ills can be contributed to childhood... if you’re really in the business of early intervention and prevention, it seems to me you really want to put more of your money ... into children’s health and mental health as a whole. Our model doesn’t reflect that at all. We still very much maintain a disease model or a treatment model in our healthcare system.” (Service provider)

A small number of people recognized that mental health promotion is also important for those who are experiencing mental illness – that is, that it is possible to live well while having ongoing mental health problems or illnesses. This approach is referred to as “recovery” and is described more fully later in this report.

**Early childhood development**
At least half a dozen interviewees spoke to the importance of early childhood development, referencing well-established research indicating the first six years of life set the stage for lifelong mental and physical wellbeing. One interviewee noted the single best prevention program is universal home visiting where every mother with a new baby gets a home visit. In particular, interviewees noted that parenting education, and also, early assessment, identification and interventions for developmental or other issues are particularly important.

**Supports for parents**
Parenting, specifically education about parenting and the critical importance of nurturing relationships, was raised by a number of interviewees. Some noted that parenting education for all parents is needed, rather than only for “at risk” families.
“There’s lots of parenting support that’s out there [but] it tends to be targeted. So it tends to be “those” families that really need it. And really, all families really need it... I remember a fellow in a parenting class who said ‘Between me and my wife, we have five degrees. I don’t know anything about child development’. It’s a common thing for new parents that they have no idea where to even start. So they fall back on the way they were raised, what they’ve heard, what they read on Google...we have to be looking at strategies that we’ve been using for many years that don’t help... So, to have a system that is thoughtful about how we provide parent support would be a really great thing.” (Service provider)

“It’s not enough to have parent education when you’ve identified that there’s a risk – you need to have skill building earlier on for parents... even for [myself]... I needed to have concrete supports and I needed to understand about my child and youth development and I needed peers and social ties around me.” (Service provider)

It was also noted that existing parenting programs should be reviewed in terms of whether they are grounded in recent developments in brain science, and the importance of nurturing relationships between parent/caregiver and child. One interviewee noted that a number of programs currently used in Alberta have not yet integrated this research, but there are new programs that have done so.

**Psychosocial and psychoeducational assessment wait lists**

Another challenge noted by several interviewees was the difficulty of getting psychosocial, psychoeducational and other similar kinds of assessments done for children in their early years. Interviewees reported lengthy waiting lists for such assessments in the public sector, ranging up to six or seven years. While such assessments are offered in the private sector, they can be prohibitively expensive and therefore not accessible to everyone who may need this service. One interviewee noted it is “criminal” to not be finding these children until they reach kindergarten given the long-ranging impacts of not intervening early, including erosion of self esteem, development of challenging behaviours, and lack of supports for learning. It was also noted it becomes more difficult for children to access appropriate services as they grow older.

Two interviewees specifically referenced findings of a large study conducted by Alberta Education regarding the development of kindergarten children. The ECMap (Early Childhood Development Mapping Project)\(^\text{11}\) study revealed that less than 50 percent of kindergarten-aged children in Alberta, including Calgary, are developing appropriately; and, nearly a third are falling below the Canadian norm – they are not getting the support they need in the crucial early years.

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Some points made by interviewees include:

“We don’t recognize children going off the rails soon enough... need to have some kind of system for catching that because it’s criminal that we’re not finding these kids till they get to kindergarten – that’s ridiculous.” (Service provider)

“There are high wait lists of six years for kids to get a [psychosocial or psycho-educational assessment] – so we’re not getting an intervention for kids at an earlier stage, which again is a mental health concern if you have kids with learning disabilities and ADHD and they’re not getting the assessment for six or seven years. If you are looking and seeing a kid at around 8 or 9 when those start to come out... and if you have to wait another seven years... if you don’t get an assessment and intervention early, then the behaviours continue and the self esteem drops and all these mental health issues, it becomes harder and harder to access services. And you also have a lack of understanding of how to access services and a fear of services.” (Service provider)

“There’s huge waiting lists in the school system for any standardized psychoeducational or emotional behavioural educational testing and families end up coming to private practitioners or others and are paying thousands of dollars to have these assessments completed because if they don’t they could be on a waiting list for years. To me, that’s unacceptable if we have kids with developmental or learning or emotional behavioural challenges. Every year that we delay those, that’s one more year that they’re behind in terms of getting services and supports.” (Service provider)

Others mentioned the importance of daycares and preschools having knowledge of early child development, early identification of problems and early intervention:

“There are probably more problems with day care and preschools where there are identified problems right away... and there’s an awful lot of undereducated people who are bright but they just don’t know what to look for and they don’t know who to call. I don’t know if those daycares have partnerships with children’s mental health centres where if something came up they could just call and say could we have somebody come over and check this kid out or talk to a parent. I’ve never heard of such a thing.” (Service provider)
Credible and accessible information for youth and families about mental health problems and illnesses

A striking finding from the PaCER research and also identified by youth in this review was the thirst of young people for knowledge about mental health issues and illnesses. A youth speaker at the Brain Trust 2 forum spoke of struggling to find information that would help her understand and make sense of what she was experiencing. While she encountered many service providers in her journey, none offered her any information about her illness. Another youth we spoke with similarly described being relieved to get a diagnosis so she could Google it and learn all she could. A service provider similarly noted the need for education and information provision. Others also spoke about the value of education/information to help parents talk with their kids about mental health problems.

“We can’t overlook the need to provide education and supports that will prevent kids and families from needing more invasive and intrusive services... That needs to be there for sure...So that education piece is key and having that provided in a public way through the schools, through community events, through primary health care professionals.” (Service provider)

In the table below, a summary of key points for this set of gaps/challenges is presented. Information provided by key informants about existing strengths and efforts, and suggestions for addressing challenges is also included.

| Table 2. Summary. Gaps/challenges, strengths, and possible responses related to: Services and supports foundational to child, youth and family mental wellbeing |
| Key gaps/challenges |
| • Insufficient attention to the promotion of mental wellbeing, resilience, the prevention of mental health problems, and early identification/early intervention for emerging mental health or developmental issues |
| • Early childhood development is crucial and a core opportunity to promote mental wellbeing, prevent mental health problems, identify issues and intervene early; ECMap study: many children in Calgary are not getting the support they need during their crucial early years |
| • There are extremely long wait lists in the public sector for psychosocial, psychoeducational and other kinds of assessments which means children may not get access to the supports they need in a timely manner |
| • More preventative work is required to bolster child/youth/family mental wellbeing so they don’t require formal services/supports in the first place; or, where there is a need not yet requiring clinical care – there is great potential for traction in this area |

| Existing strengths/efforts underway as identified by key informants |
| • First 2000 Days Network – enabling collective action to improve early childhood development outcomes |
| • AHS’s “Early Years” book – all new parents receive this book; has recently been updated to integrate |
new knowledge re: brain science

- AHS and Alberta Education – comprehensive school health initiatives throughout Alberta
- AHS – Mental Health Capacity Building in schools – working with more than 180 schools re: positive mental health
- Burns Memorial Fund – work that is congruent with mental health promotion – Children’s Fund goals related to child development (healthy, safe, access to optimal health care; ready for school, experiences success and graduates; opportunity to participate in recreational activities to help them discover their talents); moving toward greater focus on social-emotional learning; Families Moving Forward Program; work re: natural supports
- Carya – numerous positive mental health promotion and mental illness prevention programs that address risk and protective factors for children/youth/families (e.g., self esteem, coping skills, self confidence, relationships, creativity); parent resilience, youth and community engagement
- Council of Champions for Children and Youth – looking at building resilience
- The Alex – numerous initiatives aimed at preventing crisis – mental illness prevention; the Alex Community Bus
- CUPS – Services based on a resiliency; supports for low income Calgarians
- Change in Mind initiative (Palix Foundation and the Alliance for Strong Families and Communities in the US, CUPS, Big Brothers, Big Sisters Calgary are participating – an initiative to integrate brain science concepts into action)
- United Way, Calgary and Area – All in for Youth, Enough for Everyone Poverty Reduction Strategy
- Alberta Children’s Hospital resource library re: child/youth mental health
- AHS – doing work regarding mental health literacy – education about mental health issues and illnesses; community education services
- School-based mental health services/supports (significant investment here)
  - Comprehensive School Health - AHS
  - MH Capacity Building (MHCB) initiative – AHS
  - PolicyWise and the AHS Maternal Newborn Child and Youth SCN - based on a recommendation from Valuing Mental Health, currently examining mental health supports for children and youth in schools
  - Safe and Caring Schools - Alberta Education – promotion of positive mental health; socio-emotional learning; healthy, respectful relationships;
  - MH Literacy Project – AHS
  - Smiles – based on Dr. Stan Kutcher’s MH literacy program – for Grade 9-10 students (AHS)
  - Secondary education work re: MH
    - University of Calgary - Campus Mental Health Strategy
    - Alberta Government work re: post-secondary mental health

**Possible responses as identified by key informants**

- Focus on building resilience and strengthening protective factors for children, youth, families, natural supports, communities
- Parent education based on new brain science would be beneficial for all parents
• Revisit parenting and other ECD programming in Alberta – are they based on brain science?
• AHS CAAMHPP program is doing some work with daycare operators, community providers around increasing mental health capacity – talking about the impacts of trauma and mental health
• Work with daycares to increase/apply knowledge of brain science; help them to identify issues early and refer appropriately (link to work by Muttart Foundation’s “Well Ahead” initiative – working with daycares)
• Explore childcare consultation services (re: child development, screening, early intervention) for child care/day care settings (e.g., Ontario model)
• Screening and early intervention - Explore issues re: timely assessment for developmental delay, learning disabilities, socio-emotional/behavioural issues; implement strategies to reduce wait lists for these assessments and expedite access to appropriate supports

Gaps and challenges in accessing and receiving mental health services and supports
One of the strongest themes emerging from the key informant interviews was related to the challenges people experience in accessing and receiving treatment, supports and services for mental health problems and illnesses. Almost every interviewee – service providers and youth/families alike - mentioned these challenges. Gaps and challenges include the following: “getting in” – finding and accessing mental health services; issues related to assessments for mental health problems and illnesses; the need for supports for the whole family when a child or youth is experiencing mental health problems or illnesses; the need for supports for children, youth and families while they are waiting for treatment/clinical support; and, issues related to transitions from one service to another. Each of these is described in detail below.

Getting in: Accessing mental health services and supports
Service provider interviewees consistently noted that there are very few formally defined pathways to access mental health services or supports in Calgary. Nevertheless, if one is to think in terms of pathways into, through, and out of mental health services, the initial point might be seeking help. Figure 1 below depicts what seems to be, for many, this earliest part of the journey into the service world; that is, it is very difficult to find appropriate supports and services and to access them in a timely fashion. As such, even as the “journey” of having a mental health problem or illness begins, it is hard to even find and get on the path. In this depiction of the “journey”, people often spend months or years struggling to find help before they reach a crisis that leads some to seek help in an emergency department (ED).
Several potential points of entry into the “system” were mentioned, but it was also noted that there are problems with some of these access points, making them less effective than they might be. Some of these include:

- **Primary care** – but there are a number of capacity issues here. For example, family physicians and nurse practitioners may lack expertise in mental health issues (this is described in further detail in a section called “Lack of capacity in primary care” below)

- **Private services** (e.g., psychologists) – can be expensive, and there may be wait lists

- **Telephone or online resources** (e.g., Access Mental Health; and 811 (AHS); 211; Wood’s Homes) – people may not be aware of these resources, they may not know what they need, or what to ask for when they call

- **Schools and post-secondary institutions** – may or may not have the capacity to support children/youth with their mental health concerns

- **Emergency departments (ED)s** – the experience of going to the ED can be traumatic and children/youth/families may not get the supports they feel they need
**Community based agencies with storefront/walk-in services** – people may simply not know that these services exist

A common story was that young people or families beginning to experience issues might spend a lot of time trying to find information and appropriate supports, but often wind up being frustrated. Eventually, without support, they may wind up in crisis and in the emergency. But once there, they may not get the help they expected. It was commonly stated that unless one is at serious risk of harming oneself or others, they are more likely to be sent home with a referral to services - sometimes with wait lists of several weeks to several months.

“I ended up in a hospital stay at Unit X after a very bad time in the, in the psych ward...I was picked up by an ambulance...you’re not able to get those services until you’re at the end of your rope...it seems to be the only way to get in there right?” (Youth)

Through the AHS surveys, we learned that 80 percent of children and youth visiting the ED with addiction or mental health (AMH) issues had one ED visit over a two-year period. This is contrary to previous perceptions held by many in the healthcare system that these young people are going back and forth to the ED frequently. Most of them only present once, as after the first experience in the ED, going back is often seen as a last resort. Finally, parents spoke about not wanting to take their child back to the ED, but that they are often directed to do so by healthcare professionals such as their family physician.

A strong theme throughout the AHS SCN survey and PaCER research was that going to the ED ends up being a harmful experience. EDs are not currently designed to help children, youth and families in any consistent way. ED staff often don’t know how to properly support children, youth and families experiencing a mental health crisis. The protocols followed often feel like punishment:

“My daughter had her personal items taken and put into a small cell-like room with a guard. She asked me why she was being punished. I had no answers. I had no ideas what it would be like to go to the ER for this, no idea.” (SCN PaCER research)

In the sections below, some of the issues associated with this gap are described.

**Lack of awareness of what's needed, what is available, and how to “get in”**

A number of related issues contribute to people not being able to find their way “in” to services. This includes that families may not know what they need or how to access supports, the myriad array of services available in Calgary, and inclusion or exclusion criteria that restrict access to programs. These are described in more detail below.

**Families may not know what they need, what to ask for, what to say, or how to access supports**

First, service providers stressed that families may not know what supports they need or what to ask for when they call; and they don’t know how to access supports. It was also noted that youth and families
might be unsure of what to say or disclose over the phone. And, when they do connect with a service such as 211 or Access Mental Health, they may still be frustrated particularly when they’re told to go to a program but then find they aren’t able to access it. This challenge amplifies the distress experienced as parents/caregivers struggle to help their child or youth, creating a vicious cycle: being in distress makes it more difficult to find supports, and trying to access supports further adds to the distress.

“I would say our current system relies heavily on the families and youth to know what their needs are, so you first have to be able to identify what it is that you need before you go looking for what that might be. So I think that navigation of the system is a barrier in and of itself when we’re relying on families who are in distress, struggling with their young people to figure out what it is specifically that would be helpful, and there’s no real place to help them sort that out.” (Service Provider)

“If you’re in a situation where your child is suffering with mental health issues – it’s very stressful and confusing and you’re trying to manage behaviours and you want the best and you don’t know – you’re in a new arena. It’s impossible to try and figure out how to navigate that.” (Service provider)

“Families have a hard time knowing what to ask for when they call Access Mental Health – they’re being interviewed over the phone and the interviewer is trained and has questions to ask, covering lots of areas, but parents sometimes are unsure about what to share and sometimes we need to have a clinical or professional supporting them through that – being aware of what they’re looking for and what their needs are. If, for instance, a child is needing medication review or to see a psychiatrist, you can’t call Access Mental Health for that, and lots of people don’t know that.” (Service provider)

Youth and families also described finding and then getting into services as the biggest struggle in the current system. As is described in more depth below, there are: a confusing array of services to navigate; inclusion and exclusion criteria that restrict access; and often a lack of help from service providers who also often don’t know the supports and services that are available.

“As far as accessibility goes, the main issue I believe is the, you know the hoop jumping and the bureaucracy and the waitlists.” (Youth)

“That’s a big problem, people don’t know what’s out there, they don’t even know where to start...finding resources.” (Youth)

A confusing array of services to navigate

A large number of interviewees – service providers and youth/family members alike – spoke about a confusing array of mental health services and supports in Calgary, and described the challenge of navigating through them. Some spoke of the wealth of mental health resources in Calgary but almost all interviewees spoke about how difficult it is to find them. Many mentioned existing directories of
services such as Access Mental Health and 811 (Health Link), and 211, but said people either may not know they exist, or may not find them helpful. In addition, many programs have specific inclusion or exclusion criteria which bar entry to many. The challenge is made more difficult when families require more than one kind of service and must navigate their way through multiple agencies.

“It’s very hard for families to figure out where they should go. There are listings and directories of services. Woods publishes a list of all the things that they offer. Access Mental Health has their directory – but those are challenging for parents to find and make sense of.” (Service provider)

“These are all such separate services that are not really operating in an organized, integrated, coordinated way and it becomes very confusing for the youth and their parents trying to navigate all of this. They already have a very complex child and now they’re trying to make sense of all of these services and each service may have a particular thing that they can address.” (Service provider)

“We have many families who tell us, and youth who tell us, and are in a position to speak independently, that the whole system of how do you get referred to something, do you meet a criteria, can you go independent of parental permission – it’s a quagmire out there.” (Service provider)

“I know that when people call the mental health number... I know they say it’s quite simple, but that’s not what I’m hearing from families. What I’m hearing is they’re frustrated. They’ve been told, ‘Go to this program; go to that program; go to this program’ but they can’t get into any of the programs for a whole bunch of reasons. Either there’s such a long wait list ... or people aren’t calling them back once again because there’s such a great big list. And health services are pretty swamped in a variety of areas and they only have so much capacity... But families can be getting desperate.” (Service provider)

Youth peer supporters also described the challenges young people experienced trying to navigate as follows:

“It’s a stressful thing for someone who is mentally unwell let alone someone who is struggling with any kind of developmental disability or mental illness, like, it’s an incredibly difficult system to navigate.” (Youth)
“I think that, in my own experience and through what I see with the people I talk to at work every day, it’s the accessibility… and, and what I hear a lot of is that we went to this place, they said they couldn’t [help] but if you go to this place then maybe they can help…they go on a waiting list, and then what do you do in the meantime and it’s the biggest struggle.” (Youth)

Inclusion and/or exclusion criteria that restrict access to programs and services

Youth and families described the narrow inclusion and exclusion that restrict access to mental health programs and services as one of the most challenging and frustrating aspects of the current state. Some youth peer support workers said that if they could change one thing about the current state it would be getting rid of restrictive criteria, so that children, youth and their families did not have to turn to multiple services trying to find help. Nobody should be denied help.

“[Interviewer: What would be the ‘ideal’?] Oh, I would say nobody is denied services and no matter what crisis level they are at…so I would say nobody is denied help.” (Youth)

Service provider interviewees described the same challenge:

“So, there’s inclusion and exclusion criteria that is certainly elusive to parents and sometimes confusing to other professionals. I find that these criteria are especially narrowing in the AHS mental health sector.” (Service provider)

People might call an information service such as Access Mental Health or 211 and be referred to a number of programs; however, when they call those programs they learn they are not eligible. For example, some programs are restricted to children/youth/families who are patients in AHS’s Child and Adolescent Addiction, Mental Health and Psychiatry Program. A commonly cited example was that children/youth with neurodevelopmental disorders such as autism may not be eligible for mental health programs because autism is not a “treatable diagnosis”:

“Autism and mental health can be connected. So, there’s two different kinds of supports and they are addressed differently. So the gap that’s hard is if you have an autism diagnosis, mental health may say, ‘Oh, well, we can’t support you because you have autism and we don’t know how to support people who have autism’. And then people who support the autism diagnosis, they go, ‘Oh, well, we don’t know how to help with mental health’.” (Service provider)

Families in distress, trying to find appropriate services and supports for their child/youth can find this process very difficult. If they reach out to a service and find they can’t access it, it may take a lot of effort for them to reach out somewhere else.

Perhaps the biggest, and most frequently described exclusion criteria are those for admission to hospital or to AHS’s CAAMHP program. This is described in a separate section below.

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12 [See the “Transitions” section below for more detail re: children/youth with neurodevelopmental issues]
Service providers are challenged to keep track of what is available

Service providers consistently said that they, too, struggle with finding services and supports for young people and their families, given the large number of programs and services and their inclusion or exclusion criteria. One interviewee commented that even 211 can’t keep up with the services and supports that are available in Calgary. Some noted they often get invitations from 211 and other similar systems to update their list of programs. This updating of programs is challenging, especially for not-for-profits (NFPs), since funding envelopes and priorities often change, and the NFPs must change their programming accordingly. Thus, there is an ongoing shifting of programs and supports making it difficult for everyone to keep track of what is currently available, and what the criteria are for admission.

“Funding envelopes and priorities can shift and change... and the criteria for entering them shifts and changes, so it’s not easy to keep up with that... we send Access Mental Health about a 30 or 40 page summary every year of what we’re offering. That’s is difficult not only from a professional level, but more so from people seeking services.” (Service provider)

Another concern noted by some service providers was about referring people to other services for fear that they will be not be accepted and/or concern about how they will be treated:

“Of course, there’s provincial initiatives like 211 and other things that we all the time are getting invitations...to update our list of programs. So, they’re out there, but...they’re a bit of a nightmare even for a highly skilled intake worker to remember what’s changed and what’s the entrance criteria and... you don’t always have the confidence about how the clients are received when they get there – whether they’ll meet at a closed door or some limit of practice, or they’ll just get dropped.” (Service provider)
**Inaccessibility due to hours, costs and location of services**

Other interviewees noted that not all, but many community-based services provided by AHS and NFPs, operate on a Monday to Friday, 8 to 4 basis, making services inaccessible for youth and families who are often working or in school during these hours. This makes access particularly difficult for families living in poverty, especially the working poor who may have more than one job. Furthermore, transportation and parking costs, as well as costs of services may prevent access.

“Families love their children but are being asked to come Monday to Friday between eight and four and we don’t recognize that people often cannot do that repeatedly without risk of losing their jobs.” (Service provider)

“It is harder for [families living in poverty] to navigate and get from place to place and they are working two jobs and AHS services end at a certain time of the day… the working poor need accessible hours.” (Service provider)

While private psychologists are a solution for improving access, even they have wait lists, particularly child and family psychologists, the costs of private care can be prohibitive, and the hours of service may not be any better than in the public or not for profit (NFP) sectors.

“Most of my struggles have been finding an affordable place for mental health care and it’s only been since starting to work here and kind of doing my own research that I’ve been able to find places that offer sliding scale counseling you know free, free groups and now of course peer outreach so that’s a super amazing and important thing just like people don’t, that’s a big problem, people don’t know what’s out there, they don’t even know where to start.” (Youth)

Many youth and families described finding and getting affordable psychological counseling as particularly difficult.

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“It would have been super awesome for example if when I was growing up my family had been put in touch with [name of service] who offer sliding scale and free support groups and children’s counseling and that sort of thing versus a psychologist that we had to seek out independently that charged us 180 dollars an hour for a consult… You know like, families just don’t necessarily know what’s out there and they want to do their best for their kids.” (Youth)
In terms of location of services, a handful of service providers spoke of needing to bring services to where the people are, such as malls and leisure centres. One interviewee said, “One of our dreams is to is that youth could have our therapists housed in non-traditional settings – like Franklin Mall... we need services where kids and families are.”

**Long wait lists**
The next challenge for people is that once they find an appropriate service or support, they may encounter significant wait lists. Interviewees spoke of wait times ranging from a few weeks to two years or more, depending on the service. This, people noted, is extremely problematic especially when people are in crisis, and also, given the rapid growth and development of children and youth, the importance of intervening early in order to prevent development of more serious problems. Having to wait weeks or months for support adds further distress for children, youth and families.

“I left the ER in shock with a list of names and numbers, frightened I would lose my child to this illness but uncertain what I could do as a parent to support my child.” (SCN PaCER research)

A key finding from the SCN PaCER research was that after visiting the ED in crisis, children and youth often find themselves on a wait list for a mental health service or program. Many families said they wished there was some kind of support, and at a minimum someone to call for help if their child/youth’s condition deteriorates while they are waiting.

“I left the ER in shock with a list of names and numbers, frightened I would lose my child to this illness but uncertain what I could do as a parent to support my child.” (SCN PaCER research)

Service providers also spoke of long wait lists, many noting that they are unacceptably long when people are sick or hurting:

“Our waitlist for [program] is at eight months now...eight months is too long. If you’re hurting, you’re going to be broken in eight months or have given up.” (Service provider)

“Our average wait times are from one month to fourteen months.” (Service provider)

“There are amazing programs but it’s difficult to ask someone to wait four months to get a community counselor... if kids had somewhere to go in a timely manner, would it help with wait time.” (Service provider)
“So someone in a mental health episode is having to wait on a waiting list to get in to see our psych nurses or our psychiatrist... We used to be able to guarantee people could get in in two weeks, now they wait up to six weeks and that’s a long time when you’re sick.” (Service provider)

Lack of capacity in primary care
As previously noted, family doctors and others working in primary care clinics might seem to be a natural place to seek help for child/youth mental health issues. However, a number of interviewees noted this is not necessarily the case, for a number of capacity-related reasons. Family physicians and nurse practitioners may lack training and expertise in mental health issues and illnesses. They often don’t know where else to send a child or youth for help when things are getting worse. This may be the case especially when the child or youth is on a waiting list for mental health supports. It was also noted that many people think physicians cannot assist with mental health issues beyond writing a prescription. Further, physician office hours are inconvenient, and those who work on a fee for service basis don’t have time for the relational work that is needed to address mental health concerns. Also, a number of interviewees noted that youth tend to want help in the immediate sense, rather than waiting for a doctor’s appointment and then getting a referral to other supports. That is, when youth are in crisis, they want support immediately; a referral system does not support their needs well.

“I saw a talk on a research project that showed that family docs are the last to know and the last to be consulted about a mental health issue.... When they asked kids about it, kids think docs are only there for physical health and there was no point in telling them whether you had any mental health problems. And families felt the same way – they felt the doctor would just give them medicine instead of counseling. There again, some research to indicate that lots of physicians don’t get mental health training – they don’t identify a mental health issues and so they don’t respond to it, and there aren’t the partnerships around referrals. But, they are definitely a point of intervention or entry into the system that is not effective.” (Service provider)

“Yeah, so I have gone to my family doctor before. In my opinion... family doctors do not have enough knowledge about mental health resources and accessible counseling and whatnot. I’ve always been referred to a private psychologist through my family doctor...which obviously cost money if you don’t have coverage...I was never told about Calgary Counselling or Access Mental Health or anything like that through my family doctor and obviously that’s my family doctor and I might have just had bad luck and other people may be different.” (Youth)

Youth and families described mixed experiences with seeking help through their family physician. Some young people got prescribed medications that worked for them. Most said that their family physician didn’t have a good idea about potentially helpful mental health services (e.g., affordable counseling, Access Mental Health, other community services) other than private counselors, which are unaffordable for many people.
“Yeah, so I have gone to my family doctor before. In my opinion… family doctors do not have enough knowledge about mental health resources and accessible counseling and whatnot. I’ve always been referred to a private psychologist through my family doctor…which obviously cost money if you don’t have coverage… I was never told about Calgary Counseling or Access Mental Health or anything like that through my family doctor and obviously that’s my family doctor and I might have just had bad luck and other people may be different.” (Youth)

Underserved groups and those “falling through the cracks”
A number of groups of children and youth were noted by interviewees to be underserved or falling through the cracks. Most frequently mentioned were children with neurodevelopmental issues; other groups, all of whom are also at greater risk for development of mental health problems and illnesses, include: justice-involved youth; LGBTQ2S and particularly transgender youth; refugees and immigrants; those who are homeless and/or living in poverty; and, Indigenous children and youth.

Children with neurodevelopmental and behavioural issues
When asked about gaps and/or challenges or places where some children/youth might be “falling through the cracks”, many interviewees mentioned children/youth who have some kind of neurodevelopmental issue such as autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD), or other similar issues, and those with severe behavioural issues. Part of the issue is that in many cases, there is more than one issue, and also that these issues don’t fit neatly into the box of “treatable mental illnesses”.

“The ASD population is one group that my heart breaks for. We don’t seem to be managing well. There are a number of areas where we do a really good job of assessing, but no one is able to provide the treatment and support required. Community services are doing the best they can if you are looking at co-occurring ASD and mental health. We really struggle in Calgary to provide services for this group of kids, as well as other kids with severe behavioural issues.” (Service provider)

A number of youth interview participants described living with a complex array of issues that could include a combination of ASD, ADHD, learning disabilities, and a mental illness (e.g., anxiety and/or depression; bipolar). Some also fit into other groups that we heard by service
providers to be underserved (e.g., LGBTQ2S youth, youth struggling with poverty). Rarely did their conditions and issues fit into a neat little box. They told stories of how their parents struggled to get them help, and how they continued to look for services on their own when they got older.

“I’ve struggled with mental illness and the mental health system for most of my life. I’ve been in counseling since a very early age, since I was about four or five years old. Yeah (chuckle) kind of thrown around the system that way. It’s definitely a very, very broken system I’ve experienced and really amazing people within it and some really not so amazing parts of the system. Yeah I struggled with a number of learning disorders growing up and was pretty much constantly in touch with the school counselor and doctors and psychologists and so on and so forth.” (Youth)

Other underserved groups and those “falling through the cracks”
A number of other underserved groups were identified as at risk both of developing mental health problems and also of “falling through the cracks”. These include:

• **Justice-involved youth** – one interviewee spoke at length about the challenges faced by justice-involved youth in accessing mental health services as they move through the justice system. This is an issue that is in part due to processes within the justice system, as well as lack of mental health services. Youth are referred to a Forensic Adolescent program run by AHS after they have entered a plea. At that point, they are placed on a waiting list:

  “And it’s a lengthy wait list. They may be waiting a very long time for services. These youth are definitely falling through the cracks. Many of these youth have maltreatment or trauma issues that have not been adequately addressed, or other mental health challenges. Eventually they will be seen by the Forensic Adolescent Program, which has very few staff and long wait times. They’re getting their treatment a year or two years after their offence. Not just because of the wait list but the court process needs to unfold first.” (Service provider)

If these youth continue to commit offences, they wind up in the Calgary Young Offenders Centre – the most costly and invasive alternative. What’s needed instead is quick and effective intervention.

• **LGBTQ2S, and particularly transgender youth** – This population was noted to have a higher risk of developing mental health problems, but there are insufficient supports. In regard to transgender youth, there is a clinic at AHS that provides multi-disciplinary services once a month; however, there is a three-year wait-list for entry into the clinic.

• **Refugees, immigrants and those for whom English is a second language** – a number of service providers noted they are seeing a huge influx of people from countries around the world who are experiencing trauma. Those from acute care settings said that psychiatrists lack expertise in this area and training is needed. There is also a perception that this population is “weighing heavily” on community resources where expertise for supporting these people lies. Refugees and immigrants have unique needs and require culturally safe supports that may be incongruent with Euro-centric
approaches. It was pointed out, however, that not all people require therapy; some may do well with supports such as helping their children get settled in school, or using other natural supports to help them manage.

- **Youth with addiction issues** – one interviewee observed that Alberta in general is underserved in regard to youth addiction, and particularly treatment that isn’t 12-step based.

- **Youth/families who are homeless or living in poverty** – a number of interviewees also said that youth and families who are homeless or living in poverty are underserved. It was noted that many youth are not necessarily living on the street, but may be couch surfing.

- **Indigenous youth and families** – Indigenous youth and families were described as being underserved. Barriers for this population often coincide with those of poverty (e.g., costs of travel, parking, services only provided on weekdays and so on). Indigenous communities are heterogeneous and more knowledge is needed about how they experience various treatments/supports and how these might need to be adapted. One interviewee also spoke about difficulties in recruiting staff with expertise in understanding and treating Indigenous families or who are themselves Indigenous.

**Not ill enough for admission to hospital or AHS programming**

As referenced previously and linked to inclusion/exclusion criteria, another strong theme coming out of the key informant interviews is the issue of children/youth not being ill enough for admission to AHS programming – that is, the Child and Adolescent Addiction, Mental Health and Psychiatry Program (CAAMHPP), or for admission to hospital. A number of interviewees noted that if a child or youth is severely ill and is admitted into AHS services or hospital, they generally get good, integrated care within the AHS system’s wide range of services and supports. One interviewee noted, for example, that, “if you get into AHS programming, you get tapped into a wide range of services with greater integration”.

“After 12 hours of waiting, my daughter was sent home, and as a parent I failed to get her the help I told her we would get if she agreed to go.” (SCN PaCER research)

However, a common scenario is that children and youth don’t meet the threshold for admission into AHS programs or hospital, even though they are experiencing significant issues that can be difficult for them and their families to manage at home. As described previously, families are sometimes referred to programs or clinicians, but they may encounter long wait times of several weeks to several months. A number of families had the experience taking their child/youth to the ED, expecting they would be admitted because they felt they were severely ill. Many times, however, the child was not admitted.

“After 12 hours of waiting, my daughter was sent home, and as a parent I failed to get her the help I told her we would get if she agreed to go.” (SCN PaCER research)
Young people also described difficulty getting into mental healthcare services, as they weren’t ill enough. When asked about the ‘ideal’ system, many of them noted that this is something they would change.

“I would completely abolish the, like I said before, the, you’re, you’re not trying to hurt yourself or others so we will not help you.” (Youth)

Service providers spoke at length about this gap/challenge. Some of their comments are presented below.

“If kids have a high level of complexity and acuity and they need to be an inpatient, the system does that really well. But there’s a cluster in the middle that aren’t quite sick enough for admission but are really too much or struggling within community resources. They wind up presenting to the emergency department.” (Service provider)

“It’s the group that’s in the moderate [level of need]… if you’re in the extreme end of things you’re going to get service. If you’re in the moderate range and you’re a child or youth who is struggling and it might not be useful for you to be having a diagnosis, but it’s harder to get service because you might not be meeting the mandate for mental health services, for example, that would be provided in community mental health clinics provided by AHS. The narrowing of the mandate for those kinds of services is potentially problematic. At the same time if you were able to beef up some of the work going on in universal and targeted areas1 you could offset that... But we’re not good enough at doing that yet.” (Service provider)

“One of the frustrations – we have kids routinely going to hospitals who are in acute states of needing significant supports that are far beyond what we can manage... and we have kids being turned away...basically stamped as “fine” and sent back into the community...And I have heard similar stories of parents and families who have been turned basically back to the community and

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1 This is a reference to broader mental health promotion and mental illness prevention efforts
it’s like – you’ve got a suicidal 17 year old who doesn’t meet hospitalization criteria and now you’re expected to be on watch at home with them. Some of the scenarios that parents and caregivers are put in…. for some of the more extreme population, it’s pretty fascinating with some of the decisions that are being made. I’m surprised there actually hasn’t been more parents and families crying foul.” (Service provider)

This challenge links directly to another challenge that is described below; that is, the need for supports for children, youth and families while they are waiting for treatment.

In the table below, a summary of key points for this set of gaps/challenges is presented. Information provided by key informants about existing strengths and efforts, and suggestions for addressing challenges is also included.

**Table 3. Summary. Gaps/challenges, strengths, and possible responses related to: Getting in – Accessing MH services and supports**

**Key gaps/challenges**
- Lack of awareness of what’s needed and what’s available
  - Families/youth may not know what supports they need, what to ask for, or may be unsure about what they should share
  - Families and youth don’t know where to find supports → they wind up in the ED as a last resort
  - Service providers are also challenged to keep track of all the available services and their inclusion/exclusion criteria; primary care physicians may simply opt to send to the ED
- Exclusion criteria or narrow inclusion criteria limit access
- Lengthy wait lists for clinical supports; and, costs, hours and location of services = barriers to access
- A current lack of capacity in primary health care re: child/youth/family mental health issues/illnesses
- Children/youth not ill enough for admission to hospital or AHS’s CAAMHP program – where do they go for help?
- A number of underserved groups/populations who are at higher risk for problems and also of falling through the cracks:
  - Children/youth with ASD, FASD, other developmental and behavioural issues
  - LGBTQ2S, and particularly transgender youth
  - Youth involved with the justice system
  - Families and youth living in poverty and/or who are homeless
  - Youth with addictions
  - Newcomers (refugee, immigrant families); families for whom English is a second language
  - Indigenous families
Existing strengths/efforts underway as identified by key informants

- Calgary is “rich” in mental health services and supports; many that offer e-therapy, telephone, text, chat, and walk-in services; others offer single-session visits to help people cope and make a plan for moving forward while waiting for more intensive support
- Calgary Counseling Centre has eliminated wait lists by using data to customize supports for clients and predict resource requirements; and by supervising students or post-graduate students to work with clients
- Crisis counseling is available at least in the following agencies
  o Wood’s Homes – 24/7 crisis counseling via telephone, text, live chat & mobile response
  o Wood’s Homes - Eastside Family Centre – no charge walk in counseling for families
  o Kids Help Phone (piloting a text messaging approach in Manitoba)
  o Distress Centre ConneTeen
  o After hours crisis support to UofC students (Wood’s Homes, Calgary Counseling Centre, Distress Centre)
- Some organizations are working with primary care to build capacity. AHS, for example, has CANReach – a fellowship with pediatricians and family physicians which includes online modules and offers continuing medical education credits

Possible responses as identified by key informants

- More preventative work to support children/youth and bolster their mental wellbeing so they don’t get into crisis in the first place
- More mental health literacy training for the general public and youth; education for parents/youth
- Increase public/family/youth awareness about where/how to access services – marketing campaign, branding strategy
- Find ways to reduce wait times – rethink traditional approaches
- E-mental health (e.g., apps or social media for finding services)
- Build MH capacity in primary care
- Increase the number of single session and walk in clinics; Ontario requires all funded mental health service providers to offer walk-in clinics
- Expand peer support services (phone, online, in-person)
- Locate services where children/youth/families gather – e.g. shopping malls, leisure centres
- Implement community-based integrated service hubs/one-stop-shops; explore organizations that are currently operating in this kind of manner (e.g., The Alex)
Assessment challenges

Once children, youth and families do gain entry into mental health services and supports, they may face a number of other challenges related to assessment and diagnosis that can impact their journey through the system. At the November 30, 2017 Advisory Group, members discussed a number of these issues. The bottom line, they concluded is that the goal is to identify the right resources/solutions, and the right intensity of supports at the right time: what kind of assessment is needed, and when?

Some of the challenges raised include the following:

- **There is a need for a rapid and appropriate assessment**, triaging to more intensive assessment as required, but in some cases, **it can take years to get an initial assessment.**

- **Different providers use different assessment tools**, and thus make different decisions about what supports are needed. Depending on who is doing the assessing, it could be possible to wind up with five different recommendations for treatment. Is it possible to develop or agree upon a common assessment tool to be used across organizations?

  "So, there is a matching component that needs to be better understood. The process of assessment, which doesn’t need to be hours upon hours, but there needs to be a consistent way to assess needs of young people and then provide the most appropriate services and supports."

  (Service provider)

- **Trauma as a concept is not addressed in the DSM** (which classifies illnesses/diagnoses) yet trauma in relation to the intensity of supports required is a huge driving factor. That is, the current diagnostic system used by clinicians is missing a large piece regarding the intensity of service that is provided, and this can affect quality of care.

- **A lot of resources are often expended on comprehensive, multi-disciplinary assessments** that may not be necessary and that divert resources away from actual treatment and supports.

  "One of the biggest concerns I have about services in mental health in the formal [Health] system is the requirement for a formal assessment that’s usually team based, that is really expensive and also serves as a gatekeeper. So what happens is if you have to have a social worker, psychologist, psychiatrist, nurse, maybe an [occupational therapist] at this assessment meeting. Look at all the resources you’re putting into that case. With hundreds of families sometimes waiting. When you don’t even know at that stage that you need that kind of resource... there are cases that need [that kind of] assessment – my bet is 20 percent or less of clients do or less, and we put up all those resources up front and then there are fewer resources in the back end."

  (Service provider)
• A viable alternative, it was suggested, was to first **simply have an initial conversation** about what brought the child/youth/family in, what they need and expect to happen, and what supports they’ve accessed to date. This is more of a person-centred initial triaging step before any formal assessment is done.

In terms of the point above, youth and families also strongly supported the concept of a more person-centred process, starting with a conversation, trying to sort through what might be helpful now, and then providing immediate support before jumping into more complex assessments and diagnoses. One youth referred to this as a “gentler approach.”

“I think just kind of, just kind of talking...and listening to the other person ‘cause I find with assessments a lot of the time it’s just someone sitting opposite you asking a lot of questions, you’re usually not making eye contact, ticking off boxes, rather than hearing the person and getting to know what’s actually going on and then I feel like sometimes when it becomes more diagnosis focused rather than whether the right support for this individual focused.” (Youth)

“Just because of how isolated I was feeling so I was talking to my doctor and then he referred me to the hospital which wasn’t a great first thing to happen when you kind of open up to your doctor, that the first place you get sent is the hospital (chuckle)... Yeah. There was no connections [to other programs or services] through it. It was just for the assessment piece.” (Youth)

**Diagnosis: Pros and Cons**

There were mixed perspectives on the importance of “getting a diagnosis”, and where in the child and family journey getting a diagnosis best fits, if it ever does. Some key informants and Advisory Group members felt that looking at young people through these diagnostic lenses could rule out access to some kinds of programming. For example, children with autism will have a difficult time accessing mental health programming. Once labeled with a diagnosis, children and youth get directed to a narrow set of programs. On the other hand, having a specific diagnosis can result in access to the appropriate kinds of supports.

Some key informants suggested it might make more sense to look at the whole child in the context of their environment and looking across their lifespan. Rather than spending considerable resources and effort trying to arrive at a diagnosis, starting with a conversation, and then working with the child and family and other natural supports to figure out where they are at, and what would be most
helpful at the current time, seems to make a lot of sense. A diagnosis may be helpful at some point, however.

Youth and families also described having mixed perspectives about the importance of a diagnosis, and where it might be helpful. They felt it might be different for everybody. For some, as two youth noted, it might be “empowering and a sigh of relief”:

“I feel like it’s different for everybody. For me it was very empowering and like a, like a sigh of relief ‘cause I had been struggling with these things for my entire life and haven’t really known why or you know how to, how to research and how to get help and find people you know relate to me and that sort of thing. (Youth)

“So, getting the diagnoses that I have was super relieving to me because I was able to Google the terms and learn more about it and connect with other people who you know shared similar experiences with me... I know that some people don’t like diagnoses. They feel like it’s very limiting but I, I found it empowering personally.” (Youth)

In the table below, a summary of key points for this set of gaps/challenges is presented. Information provided by key informants about existing strengths and efforts, and suggestions for addressing challenges is also included.

**Table 4. Summary. Gaps/challenges, strengths, and possible responses related to: Assessment**

<table>
<thead>
<tr>
<th>Key gaps/challenges</th>
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<tbody>
<tr>
<td>• What kinds of assessments are needed and when? How many children/youth actually need a full, multidisciplinary assessment – these are expensive and there are wait lists. When would a less intense, rapid approach be more appropriate, and what would that look like?</td>
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<tr>
<td>• It can take years to get an initial assessment</td>
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<tr>
<td>• No agreement on a particular type of screening/assessment to identify the underlying trauma and how the issue gets framed; different approaches = different recommendations for care /treatment</td>
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<tr>
<td>• Trauma is not addressed in the DSM yet it is a huge driving factor in relation to clinical severity – diagnosis system is missing a big part of the intensity of need</td>
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<tr>
<td>• Need to do a better job of matching the service need with what the child/youth/family needs</td>
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<tr>
<td>• There are advantages and disadvantages of having a formal diagnosis</td>
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<table>
<thead>
<tr>
<th>Existing strengths/efforts underway as identified by key informants</th>
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<tbody>
<tr>
<td>• The ACES screening tool being is used by AHS CAAMHPP</td>
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<tr>
<td>• Some community-based NGOs have a softer approach to assessment, beginning with listening and having a gentle conversation</td>
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<table>
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<tr>
<th>Possible responses as identified by key informants</th>
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<tbody>
<tr>
<td>• Work collaboratively to review assessment processes - co-create a rapid and appropriate assessment tool or a one-stop triage service</td>
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Supports for the whole family
A strong theme emerging from the experiences of youth and families with mental health services is the extreme and often long-term stress and distress that families endure when their child is experiencing a mental health problem or illness. While service provider informants noted how stressful it can be to support a child who is ill and also navigate the “system”, the voices of youth and families amplified this message exponentially. The bottom line is that there needs to be services/supports for the whole family throughout the journey.

Many youth and families described experiences where they felt they were not treated with respect and they were not listened to. Youth talked about being “experts in their own experience”, and families said they had useful information about their child, but nobody asked them about this.

“No one asked me how I was, what I might know, what I needed, or anything about any of our family.” (SCN PaCER research)

“But I want to know the medical information and what’s happening, should I call my husband, but the social worker knew nothing about what was going on...calming me was for staff, not to help me.” (SCN PaCER research)

Another family was told, when they asked if they could stay with their child in an ED setting, that their “parental rights had been revoked for 25 hours, as their child had tried to commit suicide”. (SCN PaCER research).

A young person spoke about how when she started having learning and behavioural problems early on in elementary school, her family was investigated for abuse, which was totally unfounded and made her afraid to seek help.

“My family is brilliant. They were not abusive to me in any way but [service providers] didn’t believe me or my family...so then I became scared to, you know, to express anything ‘cause you know it caused a big, a big stress on my, my parents of course and that sort of thing.” (Youth)

“[There is a] critical role of family and support for families – how do you wrap around an entire family when someone you love has a mental illness or addiction disorder?” (Service provider)
“We share that view of the importance of the family and the family system and I always get concerned that the parental resilience piece doesn’t become enough of our focus in continuums or frameworks because there can be mental health issues going on with the parents but there can also be issues in relationship to custody, access or even just relationship stability things that have a huge impact on child and youth mental health. So I think how we define what we’re trying to do with child and youth mental health is really important to consider those pieces.” (Service provider)

Need for more family therapy and an intergenerational focus

Service providers, youth and families also described the need for more family therapy services, although one youth found that family therapy only focused on the loved one who was ill, and not really the other family members:

“If one believes that a child or the youth’s mental health is best managed within a secure family or relationship, there is a very huge shortage of anyone who does family work in this community. I would say that even in the private system if you have money, it’s very hard to find someone who will do family therapy.” (Service provider)

One young person, who had grown up with a parent living with severe mental illness described some of the limitations of the family therapy she had experienced.

“The family therapy session is always guided towards the loved one and, and, and spoken about the loved one and, and, and it’s never, you’re never taken into consideration when you’re dealing with these kinds of processes.” (Youth)

Some interviewees also commented on the importance of taking an intergenerational focus. The Palix Foundation, for example, asserts that in relation to adverse childhood experiences (ACES), access to quality mental health supports for adults is primary prevention for children.

Along this line, a small number of service providers noted a lack of services for parental mental health – that is, in situations where parental mental health issues impact how they experience and interact with their child/youth who is also experiencing mental health problems. This could be, for example, significant parenting stress, or challenges relating to their own childhood such as a history of unresolved child abuse. The care that is needed in these situations reaches beyond sending parents for treatment for their own issues; it also requires finding supports to help the parent meet their child’s needs. For example, treating a parent’s depression may not be enough to support him/her as a parent to support their child. Youth who grew up in families where a parent struggled with a mental illness described the impact this had on them and their families.

In other words, children and youth can’t be treated in isolation to their environments and when a parent is struggling with their own mental health issues, it is more difficult for them to support their child.
What’s needed, interviewees said, is a position that is specific to parental mental health. AHS’s CAAMHPP does have such a service - a consultation clinic for parents that includes a psychiatrist with expertise in adult mental health, a social worker, and a family therapist. However, only families being served by the CAAMHPP can access this clinic. This is another example of inclusion/exclusion criteria that limit access to services.

In the table below, a summary of key points for this set of gaps and challenges is presented. Information provided by key informants about existing strengths and efforts, and suggestions for addressing challenges is also included.

<table>
<thead>
<tr>
<th>Table 5. Summary</th>
<th>Gaps/challenges, strengths, and possible responses related to: Supports for the whole family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key gaps/challenges</strong></td>
<td></td>
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<tr>
<td>- “Parents are in a lot of pain”</td>
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<tr>
<td>- Children/youth/families want to be have a voice/be listened to, and be understood as experts regarding their own health, experiences and needs; they need and expect services/supports to be provided in an empathetic, caring, respectful and safe environment, yet this does not always occur</td>
<td></td>
</tr>
<tr>
<td>- Parental/caregiver mental health is crucial; an intergenerational approach is important, and supporting parents with their own mental health needs – a holistic, family centered approach</td>
<td></td>
</tr>
<tr>
<td><strong>Existing strengths/efforts underway as identified by key informants</strong></td>
<td></td>
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<tr>
<td>- Catholic Family Services – intake process as an intervention – the value of talking with people in a compassionate manner for as long as they want (with highly positive feedback from clients)</td>
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<tr>
<td>- CMHA – trains and employs youth and family peer supporters</td>
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<tr>
<td><strong>Possible responses as identified by key informants</strong></td>
<td></td>
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<tr>
<td>- Family and youth peer support; inclusion of natural supports</td>
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<tr>
<td>- Engage children/youth/families in defining issues and designing services/supports</td>
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<tr>
<td>- Mental health supports for parents and families as a whole</td>
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<td>- Single session and walk in clinics</td>
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<tr>
<td>- Psychosocial and other non-clinical supports – e.g., sports, recreation, arts</td>
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</table>
Supports while waiting for, and beyond ‘treatment’

Another powerful message emerging from the child, youth and family perspective and also, from service providers, is the lack of support while waiting for clinical treatment or therapy. A common example is being referred to a program or specialist but having to wait several weeks to several months for that appointment. (See Figure 2 below.) What, then, are families to do in the meantime to support their child or youth who may be quite ill? In some cases, parents wind up having to take time off from work to stay with their child, creating additional stress related to job security and finances.

Figure 2: Gaps related to waiting for “treatment”

The key message here is that clinical care or therapy in and of itself, is insufficient. A focus on “fixing” and “treating” stems from a narrow, biomedical point of view that focuses primarily on the individual and the illness. This provides little in the way of helping people manage for the several weeks or months before they can receive this treatment. Essentially, they are left in limbo while they wait.

“You can go to a clinician and have a once a month meeting with them, but what do you do for supports the rest of the time? People really are left to their own devices. We support them to build their own community.” (Service provider) CMHA

Another service provider spoke at length about this:

“From my experience in the field... sometime the best intervention was a youth worker and a rec worker and a lot of other wrap around services that didn’t directly do clinical work because the kid might not be there. But a support network... a bunch of different support networks including the parent... they can build out those support systems for self-esteem to try to build up involvement in activities that will lead to better mental health.... Without it being really obvious and you’re not sitting in a clinician’s office asking how you feel.... Don’t get me wrong - there’s total value in
community counseling...[but] a lot of the different teams out there are starting to look at mental health in not such a clinical, formalized setting.” (Service provider)

She continued:

“When we think of coordinating mental health services I don’t think we work in a holistic ...type of thinking and I think that’s too bad because we can’t just have a kid leave a hospital and say, ‘Okay, in three weeks you’ll go to counseling at one of the community agencies and a nurse will pop in on you in a couple of days’. ... While you wait for those things, what else can you do and ... I’ve seen it where kids with self-regulation issues – and youth workers have taken them to hit golf balls and talk about things as they’re doing it, in a relaxed and informal way.”

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Many youth and families felt that there was a significant role for peer support in this “waiting period”. Peer support workers who are currently working with youth and families find that they are providing a support role while people wait for a particular program and service, and also work with people to help connect them with other services while they are waiting.

“I would love to see peer support like, absolutely everywhere and it is getting more widespread.” (Youth)
Living with mental health problems and mental illness, the recovery model

The encounters that children, youth and families have with formal services and supports, even if they are living with the severe and/or complex mental and emotional health issues, form only a small part of their life. That is, the amount of time people spend visiting psychiatrists, psychologists, social workers, and other counselors and services, is minuscule compared to the amount of time they spend living their lives in the context of families, other natural supports and communities. Ultimately, both the recovery model (see definition in box below) and a family-centred approach to care/services recognize this reality. The focus shifts from “treating” mental illness to helping people with mental illness thrive and optimize their wellbeing.

The young people interviewed who had participated in the CMHA Calgary’s Recovery College described the value of this model, noting that peer support is an essential component of this model.

“We’re very much person focused as opposed to diagnosis focused...I feel like peer work specifically and what CMHA is doing is different than a lot of other organizations because there’s like a client counselor relationship in other organizations whereas like with a peer you’re sitting across from someone who...we’re not assessing you, we’re not writing notes, we’re just listening and helping you come to your own conclusions and supporting you on your own recovery journey ... we’re not focused on like fixing things for people, just kind of supporting them fixing things for themselves.” (Youth, Peer supporter)

What is Recovery?
The concept of recovery in mental health refers to living a satisfying, hopeful, and contributing life, even when a person may be experiencing ongoing symptoms of a mental health problem or illness. Recovery journeys build on individual, family, cultural, and community strengths and can be supported by many types of services, supports, and treatments.

Recovery principles, including hope, dignity, self-determination, and responsibility, can be adapted to the realities of different life stages, and to the full range of mental health problems and illnesses. Recovery is not only possible; it should be expected.

Championed by people with lived experience of mental health problems and illnesses for decades, recovery is being widely embraced by practitioners, service providers, and policy makers in Canada and around the world. It is recognized as key to achieving better mental health outcomes and improving mental health systems.
In recovery-oriented practice, service providers engage in shared decision-making with people with lived experience of mental health problems and illnesses, offering a range of services and supports to fully meet a person’s goals and needs.

Recovery approaches stand on two pillars:

- Recognizing that each person is unique, with the right to determine their path toward mental health and wellbeing; and,
- Understanding that we live in complex societies where many intersecting factors (biological, psychological, social, economic, cultural, and spiritual) have an impact on mental health and wellbeing.

Retrieved March 28, 2018 from: https://www.mentalhealthcommission.ca/English/recovery

A number of interviewees noted there are many other kinds of psychosocial supports that people can use to cope with or manage their mental health problems, such as sports, recreation/leisure, arts, skill development, building supportive social networks.

“We do really well on the community based side of things and that’s where we’re growing our resources and where we’re really seeing there being a need in the community is that, you can go to your clinician and you can have a once-a-month meeting where they check in or they give you your prescription for your next round of medication that you need to take, but what happens in the 80-90 percent of the time that you’re not accessing those supports? You’re left to your friends and your family to take care of you. You may find some other non-profit that offers some kind of programming and support, but really, you’re left to your own devices and so we’re looking at how can we capture those people? How can we find a space in the community for them to live in where they’re building their own community.” (Service provider)

Others spoke about finding ways to live a fulfilling life despite having a mental illness – and the value of being connected to a “touch point” in order to do well:

“Sometimes a person might be experiencing a fairly severe mental illness... and just having that monthly touch point into a resource allows them to stay stable and/or flourish, whereas not having it creates huge issues in terms of their life and in terms of the cost to them, to the system.” (Service provider)

“[There’s] compliance with treatment, but what else are you going to do to support yourself with lifestyle management things, and especially kids.... That also includes things like communication skills and relationship skills and emotional management and self-regulation and understanding those pieces -- building competence, resilience, supportive environments, empowerment -- all strong words but they all relate to things that can be modeled, taught and should be part of the child’s environment.” (Service provider)
In the table below, a summary of key points for this set of gaps/challenges is presented. Information provided by key informants about existing strengths and efforts, and suggestions for addressing challenges is also included.

**Table 6. Summary. Gaps/challenges, strengths, and possible responses related to: Supports while waiting for, and beyond ‘treatment’**

**Key gaps/challenges**
- Long wait lists for clinical care, or failure to qualify for AHS’s CAAMHP program, or not ill enough for hospital admission means that families are often left on their own to cope with child/youth MH concerns that can be extremely stressful and challenging to manage (e.g., suicidal; self-harming; violent/aggressive) and can significantly impact the whole family.

**Existing strengths/efforts underway as identified by key informants**
- CMHA’s Peer Support School, peer supporters, Recovery College
- Distress Centre’s ConnecTeen
- A number of organizations have walk-in clinics and single session clinics that people might access to talk about coping strategies and next steps

**Possible responses as identified by key informants**
- Expansion of existing family and youth peer support services; inclusion of natural supports
- Mental health supports for parents and families as a whole
- E-mental health supports
- More single session and walk in clinics
- Integrated family/youth services hubs
- Psychosocial and other non-clinical supports – e.g., sports, recreation, arts
- Engage children/youth/families in defining issues and designing services/supports

**Transitions**
In terms of gaps and challenges in accessing and receiving mental health services and supports, a final theme is transitions; that is, children, youth and families transitioning from one service or age group to another. These are times when services may be lacking or not coordinated, and when people could inadvertently get “dropped out” of the system. One interviewee noted that any time of transition is potentially a weak link. Some particularly problematic transitions described by key informants are outlined below.

**Transitions from one agency or service to another**
Transitions from one agency or service to another can be problematic. For example, if a child/youth/family is seen by one agency, but then is referred to another agency, there are few mechanisms in place to make sure that transition actually occurs and that necessary information is
shared appropriately. The family essentially winds up retelling their story over and over again. Some interviewees noted that in very complex cases, they might do more of a “warm” handoff – that is, introducing the child/youth/family to the receiving agency and sharing relevant information. However, this was noted to be the exception, rather than the norm.

Transitions between acute care and community-based services
The second, and widely cited problematic transition is when children/youth/families receiving care from community-based NGOs wind up being admitted to AHS mental health and addiction programs, or to hospital, and then when they are transferred out of the AHS system back to community-based care provided by NGOs. This is depicted in Figure 3 below.

Figure 3: Transitions between acute care and community-based services

Youth and families also described the challenges they experienced at these transition points. Much of this was described earlier in the context of transitions into and out of the ED.

Service providers certainly recognized the challenges that children, youth and their families experienced at these transition points:
“We have ongoing struggles with discharging patients who are in existing programs within AHS for fear that if we discharge them, we don’t think they’re going to get what they need in the community. So, we’ll keep them longer in an acute care site… Again, if that natural sort of hand off was there, they would feel more like they could discharge that patient – knowing there’s supports out there and those supports are well supported.” (Service provider)

“If you know how to access services, once you know how to do that, there’s a real disconnect between government services like Alberta Children’s Hospital and community based resources…there’s a disconnect between grass roots organizations who want to work with mental health versus professionals in a government setting. ... There’s a lot of misconception about the community from the government end of it – if they refer out, they only want to refer to clinically trained people. There’s a devaluing of community partners as far as using them for support.” (Service provider)

“One of the problems with institutions is the information doesn’t go back to the people who deal with the family and child everyday - such as schools. Not that you should share all information, but you should share certainly plans for helping the kid.” (Service provider)

One interviewee described a lack of trust between community-based NGOs and “Health” and the associated lack of communication and sharing of information. She observed that this isn’t an intentional thing, but more of an oversight. Another similarly spoke of trust issues in terms of whether or not other agencies would treat their clients appropriately.

“The other factor is we don’t trust - Health doesn’t trust those of us that are in the community... My staff could have been involved in a case for one to three to four months. We decide we need an assessment or some respite care or there’s medical intervention that’s required and the child gets admitted to Children’s. We are never, ever consulted by Health for a consultation or meeting. It’s as if our work doesn’t exist.” (Service provider)
in the community and worries that if they don’t do what the team in the hospital says, they’re going to lose access to services there. So they say goodbye to us. So that’s a problem because what about continuity of care?” (Service provider)

“We’re just all trying to fly by the seat of our pants and make the best decisions to guide our clients... It’s about, ‘Oh, my God, this 14-year old truly does need hospitalization. How do I make that happen without him getting bounced out of emergency and sent home to a family that is really struggling with how to care for the child who’s in an acute mental health crisis?’” (Service provider)

“We will have our preferred [agencies] that we will absolutely work with because we know them. We know their reputation. We know that if we have to hand off one of our clients to someone, they’re going to get appropriate service, but I’m telling you – it’s a dig deep; it’s a deep dig to find that connection and to actually be successful with it...We’re just all trying to fly by the seat of our pants and make the best decisions to guide our clients... It’s about, ‘Oh, my God, this 14-year old truly does need hospitalization. How do I make that happen without him getting bounced out of emergency and sent home to a family that is really struggling with how to care for the child who’s in an acute mental health crisis?’” (Service provider)

**Transitioning from adolescent mental health services to adult services**

Another widely cited transition issue was that of moving from adolescent mental health services into adult services. A number of challenges are associated with this transition, including different philosophies of care between youth and adult services; fewer resources and supports in the adult system; and, changes in the role of the parent, issues of consent and sharing of information. This is particularly difficult for youth and young adults who have complex issues and involvement in multiple systems. They may be involved in the child welfare system, or the justice system; they may be permanent wards of the province or they may have significant health issues that have excluded them from more traditional ways of accessing services. While there are some programs in place to support young adults in this transition, they tend to have long wait lists. AHS interviewees, for example, noted for example, a one-year waiting list for emerging adult treatment services; Hull’s Bridging the Gap program has approximately 100 people on the waiting list.

“In the best case scenario, young adults are very well supported with lots of wraparounds and family engagement. And then they turn 18 and they’re technically adults, but they don’t necessarily fit into the adult world in terms of their functioning or the resources that they need. So we have a number of emerging adult treatment services within [AHS] but they’re very, very stretched in terms of the demand into that service. They have a year-ish wait list. A very long time and folks that are really struggling.” (Service provider)
“Even if [young adults] met the criteria for service in the child and youth system, they no longer meet the criteria in the adult system. So that can be a gap... Again, as you get into the adult system, the criteria for service narrows. You need to be experiencing more extreme problems in order to access services.” (Service provider)

“When you transition from being in child mental health supports into adult mental health supports. It’s almost night and day. You get dropped instantly, almost and it’s, ‘Figure it out’”. (Service provider)

“Our young people who are 16 to 24 ... maybe coming out of their childhood years with some behavioural mental health, addictions and depending on the family system or other resources and supports – these are often times marginalized groups that very much need to be attended to or they fall into our health care system or our justice system or our homeless population. Just because of inadequate access to resources and supports.” (Service provider)

Other potentially difficult transition
Interviewees pointed out three other transition points where children/youth might fall through the cracks.

• Transitioning into adolescence - A general lack of services for the middle years – ages 7 to 13. One interviewee noted a lack of services for this age group, which is the time when many mental health problems and illnesses begin to emerge, other than through child intervention services or school interventions. However, this person said there are few youth workers in elementary or junior high schools. This is a missed opportunity to catch emerging issues early, and prevent more serious ones down the road. Another interviewee noted there is a spike of presentations in kids aged 11 to 13, which is not surprising given children this age are entering junior high, “hormones are kicking in”, and they have greater access to the broader community and “things they can get themselves into trouble with”. This interviewee concluded, “That’s definitely a group I think we need to put a lot of energy and effort into”.

• Transitions from school based mental health supports to clinical care – “I don’t think there’s a great pathway between school based mental health into more clinical services or treatment.. there’s still a gap. People have to wait. You have to go on a waiting list. It’s not a smooth transition.” (Service provider)

• Transitions between community-based residential care and other community supports – a small number of interviewees mentioned that this transition can also be difficult.
In the table below, a summary of key points for this set of gaps/challenges is presented. Information provided by key informants about existing strengths and efforts, and suggestions for addressing challenges is also included.

**Table 7. Summary. Gaps/challenges, strengths, and possible responses related to: Transitions**

<table>
<thead>
<tr>
<th>Key gaps/challenges</th>
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<tbody>
<tr>
<td>• Major gap – disconnects when clients transition from community-based NGO-provided services into AHS, and then back to community-based services – lack of trust, communication and information sharing between organizations</td>
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<tr>
<td>• Major gap – transition between adolescent MH services and adult MH services (significant differences between adolescent and adult services make the transition very difficult)</td>
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<tr>
<td>• Another gap in services may be for children aged 7 to 13</td>
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<tr>
<td>• Gap – transition from school based MH programs to clinical MH programs</td>
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<tr>
<td>• Gap – transitions between community-based residential care and other community supports</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Existing strengths/efforts underway as identified by key informants</th>
</tr>
</thead>
<tbody>
<tr>
<td>• RCSD is currently funding CONEX and a mental health transitions position (working with Psych ER, inpatients, school divisions, children’s services and FSCD – however this is only a pilot; it is not annualized funding)</td>
</tr>
<tr>
<td>• Research is underway in the Faculty of Social Work at the University of Calgary re: use of navigators in transitions from adolescent to adult health services (Susan Samuels and Gina Dimitropoulos)</td>
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<table>
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<tr>
<th>Possible responses as identified by key informants</th>
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<tbody>
<tr>
<td>• Bring AHS and community-based orgs together to find ways to improve transitions and ensure “warm” entries and hand-offs between services</td>
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System issues
Perhaps one of the strongest themes emerging from the key informant interviews is that currently, there really isn’t a “system” of mental health services and supports in Calgary; rather, people described the current state as, “fragmented”, “piecemeal”, and “siloed”. A common concern in particular was the lack of integration across government, non-government and private organizations not only in Calgary, but provincially. One interviewee described it this way:

“A ‘continuum’ suggests that there is intent in terms of, and transition from programs or from acuity or from expertise and a web always has the connecting point as well from which things radiate. I would not say that in Calgary specifically and perhaps even in the province, that there is any structure in place that allows the non-profit, the private, and the public sectors around mental health for children and youth to actually interact in a very intentional manner for families.” (Service provider)

symptoms and child abuse, but these are all separate services that are not operating in an organized, integrated or coordinated way. This becomes very confusing for youth and their parents:

“This becomes very confusing for the youth and their parents trying to navigate all of this. They already have a very complex child and now they’re trying to make sense of all of these services. Each service may have a particular thing that they can address. There isn’t one program or body that could take charge and oversee this. Some services are trying to do this – for example the CONEX program offered by Calgary Area Regional Collaborative Service Delivery (RCSD), which brings agencies together for case conferencing, but this program has some very specific inclusion criteria which then presents barriers for those not meeting the criteria.” (Service provider)

Another interviewee spoke of the need to structure children’s services as a joint arrangement in which multiple departments are involved and co-located - which should ideally avoid the siloing and the, “that’s your child issue, not my child issue”. This person noted how difficult it is for professionals to manage this complexity, let alone families:
“In some instances, you realize kids may hit on five or six different systems at once and you realize very quickly – what happens there when you have different funding streams or different ways in which needs are managed – the service provider or the clinician ends up being the case manager of all these systems. That’s a trained professional. Imagine a parent or guardian trying to get everybody on the same page…. A significant amount of onus seems to be put on the families to do this in many instances and I think given what many are experiencing and in some instances in terms of the day-to-day challenges of some of their children – putting that additional burden on them to figure out where to call and who to speak with and waiting lists and all those kinds of things… I think it’s … we’re all busy in this world. For some of them it almost becomes their full time job of trying to manage these systems.” (Service provider)

The issue of navigation to help families find their way through all of this surfaced a number of times. There are different understandings of what “navigation” might look like and for whom. It was consistently noted that there are resourcing requirements that accompany navigation, and also that navigators would similarly struggle with all the fragmentation in the system:

“The concept of [a navigator] makes sense – it’s how much resources are people prepared to provide to these kinds of individuals... Again, you need to have awareness of the programs and services, but you also need to understand all these different programs and services act and react to one another...that’s also the knowledge and expertise you need to have as well.” (Service provider)

“Children’s mental health is complicated... It could be easier with service navigation, except that those people would have to deal with the kinds of things we’ve been dealing with forever, which is different mandates, turf protection, people saying they can’t do this and they can’t do that...often people just begin to get frustrated because it’s basically the larger systems that are not communicating. The Ministry of Children’s Services does not talk with the part of Health where they’re talking about children’s mental health, wherever that is.” (Service provider)

Interviewees also spoke at length about the reasons for fragmentation. These are described below.

**Why so much fragmentation?**

Interviewees offered many insights about why the “system” is so fragmented. This includes its historical development, lack of mechanisms or a body for overall oversight and planning, lack of shared language and principles for supporting people, divergent understandings of “mental health”, and the way that services are resourced.
Historical development of the NGO sector in Calgary

Some interviewees attributed fragmentation to the history of not for profits in Calgary, specifically that there was never any vehicle for collaborative planning or integration, there is competition amongst not-for-profits, and programs and services were developed in response to needs as they arose in the community, or on mandates imposed by funders. Over several decades, this has resulted in the current patchwork of services and supports that exists today.

“We’re still trying to undo the harm caused by this fragmented funded model...that’s what is behind it all is that people have a particular legal mandate to look after a particular population or issue, whether it be health and mental health, or rehab or immigration and settlement and so on – then we’re all facing a career trying to integrate this mess that started back in the beginning when there wasn’t an integrated view about what we’re trying to accomplish. And so the money drives and populations and the mandates and terms and it creates that competitive environment between the agencies as well. So we’re really not getting at the underlying problem that started at that level.” (Service provider)

“We started this ‘never turn anyone away’ philosophy [decades] ago...so we started saying ‘yes’ all the time regardless of whether or not a program had a particular mandate. As a result, we created programs to fill gaps that people seemed to need. That’s why we have this. Sometimes donors ask why it has to be so complicated... I tell them we actually created programs because people said, ‘Help me’ and we didn’t have that program so we created something to fill that gap and that’s why it’s complicated. That’s because people are complicated.” (Service provider)

No overall system oversight or planning

Several interviewees pointed out that there is no body that oversees the bigger picture of mental health services and supports in the city, and there are few, if any opportunities for people to come together to discuss things and plan together, especially in relation to child/youth/family mental health needs. They also noted there is a lack of clarity regarding the scope of NGOs in the community and of AHS that can create unnecessary duplication. Some expressed hope that the current project would be an opportunity to bring people together for these kinds of discussions.

“There is no party that has taken responsibility for overall system planning for social and human services – it’s not clear where responsibility for that fits – maybe that’s the root cause for a piecemeal system?” (Service provider)

“There’s a lack of clarity in the community as to what peoples’ scope is and where does each individual player play and how far do they stretch out and where do others maybe overlap or where are the gaps. Because with that, especially in youth mental health, there’s small grant funding that pops up and gives people the ability to do bits and pieces and so all these little things are going on .... Where is AHS’s line in the sand and then when does it go into community and where is each community player’s line and so we’re not duplicating services; so that we’re playing a true part in the continuum and that there can be a smooth handover. This is where our work
ends, and then let’s hand you over to these experts. But there’s not a lot of clarity in the community around that.” (Service provider)

It was also noted that every organization has some piece of the child/youth/family mental health puzzle, but not the entire puzzle, so it is important to work collectively toward better outcomes for children/youth/families, understanding how each organization can make a contribution. As one interviewee noted:

“Our focus is to change the trajectory of the individual outcomes – so trying to knit all of this together from an evidence-based perspective yet we only have scope and control of small bits of it. Again, like, who is our neighbour and how can we, together, boost more supports and services.” (Service provider)

Lack of common language, principles and/or a framework for collaboration and integration

Another common explanation for the current fragmentation was the lack of shared language, principles and/or a framework that could serve as a foundation for an integrated web of supports. This would enable people across agencies and organizations to work from the same page, although it was recognized that this may be challenging given the diversity of cultures and perspectives:

“Even if there were some commonly shared principles ... like a family or systemic orientation customer service model – that would make a difference ... but there’s even different cultures... and some people are coming in from a hierarchical way of ‘knowing better’ than some people...I want all people working from the same page.” (Service provider)

Others spoke of the need for a shared vision, which requires organizations to think in a collaborative fashion, rather than only self-promotion. One example cited as an effective collaborative in Calgary is the Calgary Domestic Violence Collective (CDVC):

“For the CDVC, it’s about building a new narrative around domestic violence and engaging the community at large in the prevention of [DV] – so it is about shared vision, not just self interest of particular organizations.” (Service provider)

Suggested principles for supporting children/youth, families and natural supports

Interviewees suggested some principles that might undergird a framework for child, youth and family mental health services and supports. Many of these are the same values that underpin family-centred and recovery models of care and services.

• A broad and positive definition of mental health and a holistic approach that includes not only clinical aspects but also supports for living and developing well despite having a mental health problem or illness

• A kind, compassionate human being-to-human being focus.
“For us, it’s about a human being to human being focus and understanding that any of us – you know, life hits us all – right? You don’t get out of it scot free.”

- Keeping the family core to supporting kids and young people and using natural supports that kids have identified wherever possible
  
  o “If we’re talking about children’s mental health, we’re really talking about family mental health or family health – it’s really how do we create environments and places where families can have greater access to these types of services and supports that on behalf of their child.”
  
  o Ensure we use the word family – or even better, mothers and fathers - “because when you think ‘parents’, people think ‘mothers’

- Needs to include the “front end” – mental health promotion, mental illness prevention, early childhood development, early identification and intervention for problems, and the social determinants of health

- Should align with provincial directions (i.e., Valuing Mental Health Next Steps)

Divergent understandings of “mental health”
A key aspect regarding the lack of a common language and principles is divergent views and understandings of “mental health”. Some interviewees referenced “mental health” purely in clinical terms, as in diagnosable mental illnesses. Others referenced “mental health” in much broader terms and in a positive sense as in mental wellbeing, resilience and flourishing. The challenge is that how “mental health” is defined shapes what is considered to be within the legitimate purview of “mental health” services and supports. Those with an illness, clinical orientation will tend to focus more on diagnosis and treatment, while those adopting a broader and positive view of “mental health” will tend to embrace a larger array of services and supports that include multiple dimensions of “health” - spiritual, social, emotional, financial and so on. The two positions are not mutually exclusive; rather, both are essential if the desire is a comprehensive system of supports.

“Mental health – overall, I’ve kind of come from the school of, in some ways, modern thought, really that it’s all about mental wellness and that primary care and many other things, social and environmental and community, all feed into that... but for youth in particular, or a child to be mentally well, a lot of things have to come into play.” (Service provider)

“You’ve got a medical model looking at the child but not the context and then a community model that’s looking at the context with the child. Totally different frames of thought...It’s like an alien talking to a giraffe – different languages.” (Service provider)
“When we think mental illness or mental health – in a clinical setting like a hospital, their perception of the community and what the community is doing, isn’t holistic in that way. And the value of what you can put in place from different agency workers to do that work and to do some socio-emotional learning, which also builds mental health, I don’t think that there’s an acceptance or acknowledgment that that’s important as well. That’s a barrier.” (Service provider)

Resourcing

Resourcing of mental health services and supports also surfaced as an important factor underlying the current state of affairs. Two themes emerged from the data here: the first is that mental health services are underfunded; the second relates to the way that NGOs are funded.

A lack of resources

A handful of service provider interviewees note that mental health is underfunded. This lack of resourcing also places strain on organizations, including staff who are overworked. While government and NGO organizations alike work to the best of their ability to operate efficiently and effectively, a lot more could be done with additional dollars:

“You’ve got a medical model looking at the child but not the context and then a community model that’s looking at the context with the child. Totally different frames of thought...It’s like an alien talking to a giraffe – different languages.” (Service provider)

“Mental health is underfunded – the big challenge is actually a resource challenge. [Mental health] is underfunded and so I’m always reluctant to provide suggestions around navigating programs and services when – that’s great in principle, but if you don’t have the programs and services or you have huge waiting lists or you don’t have supports in places that families could adequately access, then those are all things that are significant impediments right from the word ‘go’.” (Service provider)

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“Lack of resources is definitely something I hear, not only internally from all of our staff but we work in a lot of community-based resources…it’s the number one issue that people say is a barrier to mental health for any population and so we know internally that lack of resources requires my staff to carry way heavier caseloads than is probably good for them or their patients and it creates long waiting lists.” (Service provider)

Others similarly noted that demand for their services, despite efforts to streamline and improve flow, is outstripping resources and adding to wait times. This is an important matter to attend to, said one interviewee, given that there is a large cohort of children going through the system now who will soon become adolescents, further increasing the demand on both AHS and community-based services.

“Despite all of our best efforts, we still have wait lists. Most of our services have gone through [process improvement] programs to make them more efficient…but the demand is outstripping our resources.” (Service provider)

The way that non-governmental organizations are funded

There is a limited pool of resources to support the NGOs that are providing mental health services and supports in the community, and in tough economic times this pool shrinks. NGOs are dependent on ongoing funding to support their programs. The current system requires that these organizations rely on the same pool of resources, which can result in competition rather than collaboration. How can funders encourage partnerships between these community organizations?

“[We] need more conversation about funding structures for community organizations, in order to enable less competition and more collaboration. How do we do this? If all your energy goes into survival and competition, then there is nothing left for collaborative innovation”. (Service provider)

Additional issues described by service providers included the following:

- **NGOs are subject to the changing priorities of funders.** One person described this as, “the list of what I must do based on what funders want”. Whatever funders decide to fund makes organizations shift what they are doing. This can influence inclusion and exclusion criteria for programming. One service provider gave the example of shifting programming to a different age group. Also, given funder priorities, NGOs may also not have the latitude to take on additional supports that would be advantageous to the people they serve because they are restricted to the mandates of their funding envelopes.

  “So, Funder X has a new idea about something – it all has to appear in our documentation.” (Service provider)

  “The way our funding is provided, oftentimes a lot of programs and services don’t have the latitude to look at other resource options. Just because their mandate is to provide parent education, that’s what they’re going to do, even recognizing there’s some children and families
that may benefit from something else - but, that’s not what their mandate is.” (Service provider)

• **NGOs have many masters** – they rely upon numerous funders, each of which has a different mandate. One organization reported having over 90 contracts with different funders:

  “We are funded in a whole variety of different ways by a bunch of different funders... and of course all of these people have different mandates related to their funding.”

• **Short funding cycles inhibit innovation and learning**, especially in terms of mental health promotion, mental illness prevention and early intervention. These kinds of interventions require time to “wrestle” with and determine what works best for children and youth. A lot of creativity and energy goes into projects but then the funding ends prematurely. The result is that there is a dearth of longitudinal outcome research because there aren’t the resources to bear this out.

  “To truly understand the impact of these programs requires years of funding and the ability to see and we really don’t seem to have many funding or governmental entities that want to look beyond three or four years and frequently, people are given grants or given funding to develop programs and services and a lot of energy goes in and a lot of creativity a lot of outside of the box thinking and then you get to year three and its like ‘Oh, well, thank you. Your pilot is now done and we’re on to other things’.

  And I think funders need to recognize and appreciate that some of the things that we’re trying to do here are going to take time and they need to have a funding structure that supports that...funders need to think and fund long term...Many programs long to demonstrate or prove beyond a three year cycle that they can have an impact or a measured impact on addressing many of these issues.” (Service provider)

An associated issue is around outcomes required by funders, particularly in relation to mental health promotion.

  “We do a fair amount of work in mental health promotion and education...but finding outcomes that funders will want to fund is difficult.” (Service provider)

• **Ideally, funders would collaborate and coordinate with each other in order to reduce duplication of effort for NGOs.** It was said that there are three major funders in Calgary, and that NGOs often find themselves completing numerous applications that ask the same things. It was suggested that a common intake process would help NGOs by eliminating duplication of effort in completing funding applications.
“Wouldn’t it be great if there was a centralized funding intake system for the United Way, Calgary Foundation and the City of Calgary...we’re doing these three different applications that really kind of ask the same thing.... Could they all work together and have one pot that they could code? There’s all sorts of opportunities around that.” (Service provider)

Capacity – quality of supports and professional development

One last theme related to system issues is concern not only about access to services, but also about the quality of services and the importance of ongoing professional development for those working with children, youth and families. In the face of scarce resources, this is not something that can be forgotten. As one organizational leader noted: “Those working with families need education and professional development to be effective.”

A small number of interviewees specifically referenced professional development regarding new knowledge about brain science – how adverse childhood events shape the brain, and the importance of nurturing relationships and trauma informed care. One suggestion was to fund professional development workshops around this research.

Others said that as demand grows for clinical services, more children and youth with acute mental health issues are being treated in the community, and this will grow, possibly resulting in the need for those in community organizations to build capacity for addressing this higher level of acuity.

In the table below, a summary of key points for this set of gaps/challenges is presented. Information provided by key informants about existing strengths and efforts, and suggestions for addressing challenges is also included.

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<tr>
<th>Table 8. Summary. Gaps/challenges, strengths, and possible responses related to: System issues</th>
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<tbody>
<tr>
<td><strong>Key gaps/challenges</strong></td>
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<tr>
<td>• No planned, integrated continuum of services and supports; a fragmented, patchwork of programs and services that aren’t well connected to one another = poor continuity of care and added stress for families</td>
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<tr>
<td>o For those requiring multiple supports – no single place where these are offered; separate services that don’t operate in an integrated or coordinated way → confusing and difficult for families to navigate</td>
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<tr>
<td>• Insufficient mechanisms for integration and coordination of services</td>
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<td>o No shared, long-term vision</td>
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<td>o Lack of common language – divergent understandings of the term “mental health” and appropriate actions to address it; disconnect between biomedical, clinical models that focus on clinical diagnosis and treatment (where “mental health” really means “mental illness”), and broader holistic, socio-ecological models that consider the child/youth in context and are based in a broader view of “health” and “wellbeing”</td>
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Multiple sectors involved, but they rarely speak to each other; jurisdictional issues about “who owns what”

Some degree of mistrust across orgs

No defined forum for people (i.e., public sector and NGOs) to come together to discuss issues, plan together, etc.

- Resourcing – scarcity of resources; current funding mechanisms for NGOs promote competition rather than collaboration
- Concerns about quality of service/care
  - Are people using evidence informed practice/leading practices?
  - Is practice informed by brain science, trauma informed care?

Existing strengths/efforts underway as identified by key informants

- The Calgary Council for Addiction and Mental Health (CCAMH), for which CMHA is a backbone organization, includes both NGO and government sector members

Possible responses as identified by key informants

- Strong agreement re: need to develop a common framework for child/youth/family MH services and supports, or at least a common understanding of what “mental health” is and principles for MH services and supports – interviewees identified a number of principles
- Develop a continuum/matrix – what is the ideal pathway toward wellbeing? How would people ideally move through this pathway?
- Strengthen relationships and enhance collaboration across orgs that support the MH needs of children/youth/families; AHS and community orgs need to work collectively to get an understanding of each other and the roles they play – maybe work together to pilot something
- Could Calgary organizations work collaboratively to support government in moving the Valuing Mental Health plan forward in Calgary? Develop a local Valuing Mental Health plan and seek government funding?
- Is the Calgary Council for Addiction and Mental Health (CCAMH) a possible forum for bringing orgs together to work on issues?
- Fund professional development re: brain science, trauma informed care, patient/family centred care, use of ACES tool, etc.
Service provider suggestions regarding potential roles for the United Way

Finally, service provider key informants were asked to suggest potential roles for the United Way Calgary and Area to move forward with addressing some of the gaps and challenges identified in this review. Almost all said a key role could be as a convener – an organization that would bring players together to talk about, support system planning and take action to improve the web of community-based mental health services and supports for children, youth and families in Calgary. While the United Way may not take the lead in directing the work, it could have an “eye on the big picture” and help people to think about together how the system could be better integrated, functional and family centred.

“Convening but with a clear purpose - not on the treatment end but rather, the United Way is good at the broad community initiatives – should be focusing on child and youth mental health and the community involvement in that – could bring funders together around child and youth mental health to see what they could fund together.” (Service provider)

“The United Way has the advantage of being able to view across sectors, so is a good convener.” (Service provider)

“There’s a convener role for an organization like United Way, to get a pulse on the community... but there is also [a role related to] advocacy and leverage with the Government of Alberta because that is where the money lies in terms of being able to more fully address the mental health needs of our children, youth and adults in our communities.” (Service provider)

Some cautions for the United Way were also offered, including the importance of “working with” agencies and exercising caution before jumping in to address gaps so as to support a stronger continuum of care rather than starting something new. It was also suggested that whatever work is done should align with the direction the province will be taking:

“If the United Way takes something on in relation to child mental health... need to exercise caution before just jumping in to address gaps – so the United Way needs to apply a fair amount of diligence to “working with” in order to support a stronger continuum of care rather than starting something new.” (Service provider)

“It’s fabulous that the United Way [is doing this work], but I really want them to be aligned with the direction that our province might develop.” (Service provider)

Strengths

The focus to this point has been the “bad news” – the gaps, challenges that exist in the “system” today, resulting in a rather one-sided picture. In reality, interviewees spoke to the rich array of mental health services and supports for Calgary’s children, youth and families. And, there is a great deal of innovation underway. A number of interviewees, for example, spoke of AHS’s CAAMHP program in glowing terms, describing the program as innovative and progressive. It was similarly noted that there are many
excellent community-based NGO programs and services. Throughout the Findings section above, existing strengths and actions underway to address gaps and challenges have been briefly listed in the tables at the end of each section. These lists are only a microcosm of what likely actually exists – given it was not within the scope of this project to conduct a comprehensive review of existing strengths and programs.

This capacity also includes a strong and shared desire to do better for children, youth and families in Calgary, and to work together to do so. Some key points include:

- Amongst all participants in this review, there is a strong and shared passion for child, youth and family mental wellbeing.
- There is also a shared passion for a better system of supports/services for children, youth and families
- There is ample good will and desire to work together more collaboratively
- People are excited about this project and eager to participate - many simply said, “How can we help?”
- Many ideas were offered for moving forward

All of this equates to a powerful base for change.

In the section below, an interesting Advisory Group discussion, demonstrative of these points, is described.

**Advisory Group discussion March 14, 2018: The need for system disruption**

“The invention of the light bulb did not come from the quality improvement of candles.”

(Oren Harari)

The Advisory Group for this project was brought together for a second time on March 14, 2018 to: 1) review and validate (or not) the findings of the inquiry, and 2) talk about possible actions that might address some of the identified gaps and challenges. The following strategic question was posed to guide this discussion:

“What gap(s) (if addressed) and potential actions (if implemented) would have the greatest impact on improving the mental wellbeing of children/youth/families in Calgary?”

The discussion was conducted in two phases. In both phases, the Advisory Group was given time to reflect and write their thoughts on a work sheet before launching into a group discussion. These worksheets were collected at the end of the workshop. Themes that emerged from the worksheets and the discussion are briefly described here.
Gap and Challenges: Where to focus

In the first phase, the group was asked to identify which of the gaps and challenges should be focused on (i.e., which most impacts the strategic question?). Rather than choosing specific gaps or challenges, an interesting discussion ensued. It was noted by many that these problems have been in existence for decades and that, rather than “tinkering around the edges”, it is time to “blow things up” or, “start a movement”, or at least introduce some degree of disruption in the system in order to make real change and progress.

“We need to blow things up. All of our training, models, perspectives, teachings are not truths – they are ways to organize our thinking that often create barriers to the best care… they are constraining our thinking…every time we add rules, we serve clients less well. How are we going to meet the need of people without the jargon and academic philosophies? We need to be responsive and flexible, not bound by constrained ways of thinking.”

“If I was in United Way’s, shoes, I’d be asking, ‘How do we show up in a positively disruptive way as a funder?’ Rather than tinker with navigators and so on, why don’t we support people to navigate their own way versus making the formal system more explicit?...How [do we] create a movement and have youth and families take the lead?’ United Way’s mandate is not about funding clinical services, so how do they play in this space that complements this? So, what’s the new space?”

It was suggested also that thinking at this point needs to be more strategic than tactical – that is, it is important to step back and re-envision how things ought to work, to peel away jargon and models and focus on what children/youth/families and their natural supports really need. As the previous quotes illustrate, this kind of re-envisioning needs to be done collaboratively with youth and families, as it’s not possible to determine what they need without having their experience and insights at the table.

Some of the fundamental principles and ways of working that would guide this strategic shift emerging through this discussion and included the following. These are closely aligned with the literature on family centred care/services and a recovery approach.

- **The focus should be on human beings supporting other human beings in a humane and compassionate manner.** An exploration of what accessible and compassionate services might look like is needed. “It’s about humanity here – it’s about talking to human beings.”
• **The child, youth and family needs to be at the centre of care, and services should be organized with them not for them.** “It’s families’ experience of what they need that is so important.”

• **The focus should be on wellbeing, not illness.** Children, youth and families may have clinical needs that require treatment, but the supports and services that promote child, youth and family wellbeing encompass more than this, and involve natural and peer supports. Not all of this can or should come from funded agencies. The focus should be on supporting people on their journey to wellbeing, drawing upon and building their own strengths and natural supports as much as possible, but also, working with peer supports and agencies to help meet their needs. This is congruent with a family-centred approach.
  
  o “It’s meeting people where they are at, listening and then working with them and supporting them to start somewhere.”

  o “We need to move away from jargon, “must do’s” and figure out what we need to do. How can we organize/construct services to meet the varying needs of the people we see?”

• **Different children and youth will have different needs and different levels of complexity, and thus the pathway they take will be different.** For example, the pathway for a youth experiencing their first psychotic episode will be different from a youth who is anxious about relationships at school.

• **The focus should be on “every door being the right door” and the system players being able to find ways to work together.** It is necessary to develop strong transitional processes across organizations – for example, expectation of warm entries and handoffs in transitions.

• **We should build on the recovery framing and support individual and family strengths and capacity development;** build on the DIY (do it yourself) concept where information and supports help keep families out of the formal system; take an approach that is not reliant upon physicians but builds peer and natural supports.
  
  o Some cautions were expressed about the “do it yourself” language. Some people felt more comfortable with language such as “family centred”, which incorporates many of the principles described above and includes the concepts of building on strengths, and agency. Ultimately it is about working with youth and families, supporting them on their journey, not abandoning them.

• **System collaboration, culture change across the system that is person/family centred is much bigger than it sounds.** Integrated planning is required, that involves both the government funded
and not-profit organizations. It was also noted that the private sector (e.g., private psychologists) should also be involved.

- “Based on today’s conversation, it seems that we need to rethink the system, particularly so that government and non profit orgs are much more integrated, playing to their strengths, offering seamless, “warm” experiences to youth and families. Can an integrated planning process be started with the ultimate outcome that youth and families get individualized support based on their needs, that involves their natural support network?”

How to get there: Priority actions
In this second phase of discussion, Advisory Group members were asked to consider what had emerged through the phase one discussion and reflect on what some priority actions might be: “What would help us to move forward with addressing some of the challenges raised and discussed in phase 1?” The need for a large shift, rather than continuing to tinker at the edges was front of mind.

The group was asked to consider these criteria, as they considered priority actions.

<table>
<thead>
<tr>
<th>Some guiding criteria</th>
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<tr>
<td>➢ Is it do-able?</td>
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<tr>
<td>➢ Is it community-based?</td>
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<tr>
<td>➢ Does it address more than one identified gap or challenge?</td>
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<tr>
<td>➢ Does it have synergy with work underway?</td>
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<tr>
<td>➢ Is there some excitement around this possible action?</td>
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<tr>
<td>➢ Is there evidence to support this action?</td>
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<tr>
<td>➢ Is there an opportunity for collaboration, and in particular between AHS and community-based non-profit agencies?</td>
</tr>
<tr>
<td>➢ Of the possible actions to address this gap/challenge – which ones would have the “biggest bang for the buck”?</td>
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Priority actions that participants wrote on their worksheets, and then discussed, fell into four overarching and interconnected themes. These are briefly described below.

1. **System redesign and integration.** Building on the earlier discussion, group members described it being important to take actions that would shake things up, that there was a need for some systemic change and a philosophical shift. This would require in part: flexing of boundaries; reducing gatekeeping; and the bridging of clinical, NGO and peer options. The development of some archetypal addiction and mental health stories could drive this change. If we can shift from identifying children and youth as patients, perhaps the challenges with information sharing will be reduced.
Some felt that one way of addressing of these required changes, would be to build on the concept of an “integrated youth services hubs located in the broader community that bring health, mental health, social services and community services together in an inclusive communities frame”. This has the potential to develop common expectations for all systems to have a role; normalizes help seeking and broader community connections and participation; and is co-created with youth. Working on the development of an integrated services hub, would be one way of addressing a concern expressed by some about focusing solely strategically; where there is a danger of “a lot of talk and no action”, as this quote illustrates.

“Sometimes taking the long view – an integrated system – can mean that people talk a lot but don’t move forward because ultimately the system is too hard to really change. What motivates real, effective change? Maybe a combination of a long-term focus on system disruption and change and short-term winnable strategies.”

2. Access. The strong theme emerging from key informant interviews about how challenging it is for young people and their families to find the services and supports they need and then access them, was again a strong theme in this workshop. This is not distinct from the concept of an integrated system, but rather is a key dimension of such a system. A number of ideas were described and discussed specifically around access, including:

• Pulling together some sort of community-wide communications plan/program to let schools/doctors and others know what is available, and have this marketed in a way that all service providers can connect in
• Creating a “DIY virtual mental health system”
• Integrating tele-psychiatry into a walk-in community service hub, with two-way connection to hospitals
• Creating multiple points of entry that are client/family centred, where there is a shared culture amongst service providers to increase collaboration, information sharing, and the use of technology
• Shifting perspectives about access and how systems work. For example, it was noted that there could be a policy of “no wait lists” (i.e. “someone will see you today”) or next day support, which has been successful in Ontario
• Ensuring there are many paths or doors in that fit the hopes and expectations of children, youth and families; there is a need to decrease the frustration and loss of hope due to poor accessibility
• Optimizing the use of technology to improve access and navigation; one idea shared was to develop an interactive app, like Open Table, where one can book an appointment or conversation in real time with a closing loop: “Would you like us to call you, text you, email you? Is there anyone else you would like to bring?”
• Incorporating more conversations and listening into the way agencies work; this is critically important when people are initially reaching out for help
“People want to know they can call one place and have a compassionate, caring human being on the other end...having the opportunity to talk with a human being for as long as they want. The very act of being “heard” is an intervention in itself.”

Again, a common theme that resurfaced many times in this discussion was that improving access requires a big philosophical shift, which will require creativity and thinking collaboratively with youth and families: “What do they need and when?”

3. **Navigation, and transitions and between services and systems.** Similar to the issue of access, navigation and transitions between services and systems, as part of an integrated, family-centred approach, emerged in the workshop discussion as an important piece to address. The notion of warm entries and handoffs to help people transition to other services and supports, dominated. With respect to a more targeted action, it was suggested that one thing that could be done is to “support something collectively around transition”. There was recognition that doing some work on transitions has the potential to greatly improve the navigation experience for youth and families, and that there is already work underway that could be leveraged (e.g., RCSD work; research being conducted at the University of Calgary). Participants noted that moving forward here requires a will to change, and people working in services must be willing to “go beyond their mandate”.

There were mixed perspectives around how best to enhance navigation. Some felt that developing a navigation service where navigators work with children, youth and families with more complex needs, and that builds youth and family navigation abilities, would be useful. Using technology to support navigators within the systems and navigation was felt to be an important component of this work. For example, the idea of developing a phone app, described under “Access” below, would be critical here.

However, there was some concern expressed that adding navigators could lead to agency staff to feel this was not part of their job. Also, funding of navigators might have a negative impact on community-based services if it results in decreased funding for other needed supports and services. As one participant noted, “We need navigation, but not at the expense of sustainable clinical care for children youth and their natural supports. Both are essential and it must be family centred. Services need to be grown and sustained.”

4. **Collaborative and integrated planning across organizations.** Keeping at top of mind the caution of “all talk and no action”, group members thought that bringing NGO and government organizations together for collaborative and integrated planning is required in order to achieve an integrated continuum of mental health services and supports for children, youth and their families - one that is underpinned by some common principles and ways of working. Again, this work needs to be done collaboratively with youth and families and the private sector as well.
System integration is required to ensure that families don’t have to do, as one person wrote, “ALL “the work” of calling so many entry points”. Some group members referred to this as almost “inhumane”. The use of technology to increase awareness of services and supports, and potentially increase access and improve navigation, was described as an opportunity to “force us to collaborate” and has the potential to transform services long term. Some felt this integrated planning might be a good fit with the work of the Calgary Council on Addictions and Mental Health.

This integrated planning should also include a focus on education and mental health promotion, “supporting mental health promotion activities where expertise already exists”, as well as providing more “opportunities for community to take on contracts for prevention and promotion.” Community development, along with peer support, was noted to be “an important change-maker for children, youth, families.”

It was also noted that it will be necessary to get to a place where services provided by community-based NGOs are valued as highly as more government funded services. As one participant noted, “We need to get rid of the stigma of worth and effectiveness of community services versus government”.

The ideas described under access, navigation and transitions could all be built upon through this collaborative planning effort. Participants framed some additional questions that might be addressed in such a planning process:

- Are we sure we have enough of the right, affordable services available for youth and their families when they need it? Do we need to rethink, add more resources?
- Why are there services that continue to be available and are not being used?
- Can we promote what mental wellbeing could/should look like?
- Can we knit together the patchwork of wonderful/effective services that exist?
- Can we propose a mental health and addictions vision for Calgary?

Finally, the Advisory Group members agreed there is a willingness to act. It was recognized that the status quo is not tenable, not for youth and families, nor for the people providing the services and supports. “Everyone around the table appears to be passionate about the ideas around improvements.” Nevertheless, there is no expectation that the process will be easy. To be truly disruptive, and to make the philosophical shifts required, there will need to be some tolerance for an innovation – failure - learning cycle. There was some concern that egos and fear may get in the way, and recognition that this can only succeed if there is leadership from, and partnership between funders, and a commitment to work across sectors. The change management required will have to be acknowledged and stewarded.
Discussion

Through the course of this project, many challenges and gaps have been identified in Calgary’s current array of mental health services and supports for children, youth, families/natural supports. Some of the findings, particularly the experiences of youth and families, are disturbing.

But, these are not new challenges – some noted the system has been like this for decades. This was echoed at the Brain Trust 2 meeting, hosted by Alberta Health Services in February of this year. After hearing about the traumatic experiences of youth and families accessing emergency departments for mental health concerns, the general consensus of meeting participants (mostly service providers) was, “this isn’t new”. Furthermore, other inquiries, and most recently, the Alberta Government’s *Valuing Mental Health* (VMH) inquiry, have generated strikingly similar findings and recommendations for action.

The Valuing Mental Health review, for example, identified children, youth and families as an underserved and priority population for action. Some of most relevant findings and recommended actions from this work include:

- Albertans need to be able to access the right care when and where they need it;
  - One way is to increase awareness, amongst professionals and individuals about the services that are available; another way is to help people navigate the system
  - The primary health care system must be supported and challenged to increase its capacity to provide these services
- Once in the system, individuals need to be able to move from one service to another with ease; this requires a coordinated, integrated system with better collaboration between hospital and community and primary health care services

Similarly, recommended actions outlined in the Mental Health Commission of Canada’s *Mental Health Strategy for Canada: A Youth Perspective*\(^\text{15}\), based on an extensive nation-wide consultation process, are also highly congruent with this review. Some of the recommended actions that are most congruent with findings in this review include:

- Give people access to the right service, treatments and support when and where they need them
- Give primary care a larger role in mental health
- Make mental health services more readily available in the community

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• Give people living with complex mental health issues better access to the specialized services and treatments they need
• Include peer support as an essential part of mental health services
• Improve mental health services for immigrants, refugees, ethno-cultural and racialized groups
• Meet mental health needs related to gender and sexual orientation
• Work with First Nations, Inuit and Metis peoples to meet their distinct mental health needs while respecting their unique experiences, rights and cultures
• Improve mental health by improving peoples’ living conditions

The need for a philosophical shift
What is interesting, different and exciting about this review of services and supports in Calgary is that the Advisory Group members, all leaders of key mental health-related service agencies and organizations, have called for disruption and a philosophical shift, which is not something discussed in the Valuing Mental Health review. While the idea of disruption may be embedded in that work, it is not explicitly stated that the values and principles upon which mental health services and supports are grounded need to be scrutinized and re-considered.

Through the course of this project, culminating with the Advisory Group meeting on March 14, there has been a consistent call for re-thinking the current system in terms of what it is trying to achieve, and how. Advisory Group members have articulated a very clear need and desire for transformative change, not just “tinkering around the edges”. This is a massive shift and it will be difficult to achieve, but it seems to hold great promise for change and a better way of doing things. If change efforts simply continue to be grounded in old ways of thinking, then the “system” will keep behaving as it has for the past several decades.

Specifically, Advisory Group members and key informants have identified a need for a philosophical shift, essentially from a clinical, biomedical, disease and treatment focused collection of services to a broader and positive understanding of “mental health” and what people need to function and live well, whether or not they have a mental health problem or illness, and taking an approach that is centred on children, youth and families. The following shifts were consistently suggested:

• The focus should be on the fundamental “technology” of health care: human beings supporting and serving other human beings in a kind and compassionate manner.

• The focus should be on the whole family and their natural supports; not just the individual child or youth.

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16 The MHCC’s focus on recovery and wellbeing, however, is more consistent with ideas surfacing in this review
17 Recognizing that many organizations may already be working in these ways
• **The focus should be on what children, youth, families and their natural supports need to function well on their journey to wellbeing.** There will always be a need for diagnosis and treatment for a certain proportion of the population, but to better serve families, the system needs to embrace a more holistic approach that considers the whole person/family in context and focuses on what they need to be well and to manage well at the present time.

• **The focus should also be on providing supports to children and youth and families before they need to use the formal system** – information, peer support, sports, recreational activities and so on, and mental health promotion and mental illness prevention efforts can be powerful tools here.

• **The focus should be on strengths and building capacity** – helping children, youth and families to help themselves, but not necessarily only by themselves; rather, with the support of many easily accessible people and supports to help them along the way. For people to feel empowered, they must be able to access the supports they need when they need them. There needs to be an appropriate balance between professional care and self-help/empowerment.

**Person and family-centred care, mental health promotion and recovery: Inspiration for a re-designed system?**

These ideas are highly congruent with the notions of person and family-centred care, mental health promotion and recovery – could these approaches be the inspiration for a re-designed system?

**Person and family-centred care and services**

Some Advisory Group members specifically referenced family centred care in discussions and some are already working in this manner. And, a principle of the *Valuing Mental Health* review is, that “a person-and family-centered approach is used to address addiction and mental illness". A core concept of this approach is recognizing that children and youth live in, and are supported by families and other natural supports in their communities, and that it is necessary to meet people where they are at and to work in partnership with these families so they can optimally support their children. Beyond providing children, youth and families with useful information and support, family centred care involves truly listening to children, youth and families about what is happening, things they have already tried, and what might be help them in the current moment. Ultimately, family centred care involves developing a collaborative relationship between service providers and youth and families - one that is based on mutual trust and respect characterized by “working with”, rather than “doing for”.

**Mental health promotion**

Mental health promotion (MHP), like its parent - health promotion, is often misunderstood as simply the provision of education about “being healthy”. While this may be part of a health promoting approach, the more important aspects of are its foundational principles. These include a holistic and positive

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conceptualization of “health” (including, for example, mental, emotional, spiritual, intellectual, social/relational and physical dimensions) and perhaps, most importantly, supporting people to take control over their own lives (e.g., self determination and empowerment). MHP starts where people are at and walks beside them to support their needs –again, “working with” rather than “doing for”. Its foundations are equity, social justice, and collaborative and multi-sectoral action on the social determinants of health. Both the person and family centred approach to service delivery and the recovery model are aligned with the concepts embedded in mental health promotion.

Recovery
The notion of recovery was briefly described earlier in this report. We raise it here again because it is highly resonant with the desired philosophical shift and because there is a strong precedent to base a mental health system on the concept. The term, “recovery” does not imply “cure” of a mental illness; rather it implies that people with a mental illness can also enjoy a good level of wellbeing and the ability to be happy and live a fulfilling life, just like someone living with diabetes or some other chronic illness. While people may still require diagnoses and treatments, this is only a part of their lives.

The strong precedent for basing a mental health system or framework/continuum on the concept of recovery comes from the Mental Health Commission of Canada’s Mental Health Strategy for Canada, which is grounded in mental health and recovery terminology. A key focus is on children and youth becoming resilient and attaining the best mental health possible. The second strategic direction is, “Focus the mental health system on recovery and wellbeing for people of all ages and protect the rights of people with mental health issues.”

Unfortunately, these approaches to date have generally gotten lost in the health system. (Some not for profits seem to have a better handle on this, however.) Although family centred care has a strong evidence base and has been considered a “best practice” in child health for decades, it has been slower to take root in child and youth mental health settings. It would seem that a paradigm shift is required where families are viewed as a part of the solution, rather than as part of the problem. Similarly, mental health promotion is extremely underfunded, despite its potential to reduce the incidence and severity of addictions and mental illnesses. The Valuing Mental Health (VMH) inquiry found that mental health promotion accounts for only 0.1 percent of health care costs. And finally, in terms of recovery, the concept doesn’t seem to be on the radar in Alberta, with some important exceptions such as CMHA Calgary, which is strongly oriented to this approach. And, the MHCC notes that while recovery should be at the centre of mental health reform, it is not:

“Even today, our mental health system is still not focused enough on the full range of services, treatments and supports that promote recovery and wellbeing.”

**About aligning with provincial directions: Valuing Mental Health Next Steps**

Some participants in this review expressed concern that whatever comes of this work should align with provincial directions, particularly the *Valuing Mental Health Next Steps* work. Indeed, one suggestion was that a unique Calgary version of the *VMH Next Steps* plan could be developed. This might be the process of developing a continuum/framework for child/youth/family mental health services, for example. However, a key challenge is identifying and resourcing *concrete and implementable* actions.

The VMH report outlines a number of principles that are highly resonant with findings from this inquiry, plus some others. An overarching principle is that, “*individuals are seen in a holistic way, where prevention is a priority and early intervention leads to better treatment and recovery*”.

Other stated principles include the following:

- A *person-and family-centred approach is used to address addiction and mental illness*.
- *The social determinants of health play a significant role in prevention, treatment, stabilization and recovery from addiction and mental illness*.
- *The cultural diversity of individuals, caregivers and families is respected and welcomed in addressing mental health issues*.
- *Albertans are heard and play an active role in influencing improvements to services*.
- *Albertans have equitable access to quality services regardless of geography, diversity or economic status*.

A concern expressed by some key informants is that there are few resources attached to the VMH work, and there appears to be challenges with coordination on the ground. Another concern was that VMH may not have a strong enough community-government alliance to be successful and that more advocacy is needed – including a strong NGO voice at the VMH tables to show, for example, the cost savings that could be achieved through integrated actions between NGOs and government organizations. This may be particularly important in the face of a coming election and a potential change of government. As such, there may certainly be advantages for Calgary community-based NGOs to ensure they have a voice at the VMH tables. This could simultaneously support the work of VMH and actions arising out of this United Way inquiry.

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Thoughts about moving forward
A key dynamic to address when moving forward is building mutually respectful and trusting relationships amongst players. This theme emerged strongly from the March 14 workshop with the Advisory Group; and as noted in the “Findings” section, there appears to be a longstanding tension, particularly between community-based NGOs and AHS. Much of this may be due to lack of time, and lack of opportunities to come together and learn more about what each other does, the respective challenges they face, and so on. Given that collaborative action depends on mutually respectful and trusting relationships, this will be foundational to whatever work is undertaken. Some people thought that working on small projects together might be a fruitful way to begin this process.

Another consideration is who will lead the process of moving forward with this work? A key finding of this review was that fragmentation of services is due in part to the absence of a group or body that has oversight of child, youth, and family mental health services and supports in Calgary, and that regularly brings stakeholders together to plan. Interviewees almost unanimously described the United Way as an ideal convener – of bringing people together – but, is there a need for another body to lead the process, to “see the big picture”, to pull things together, and perhaps even to communicate as one, unified voice to government? It was suggested that the Calgary Coalition for Addiction and Mental Health, which includes NGOs and government organizations, could be a potential leader in this work.

Another consideration in terms of leadership has to do with funding agencies in Calgary, and current funding models that tend to foster competition rather than collaboration. To support partnerships, collaborative action, integration and innovation, there may be a need for funders to explore alternate funding models.

In the next and final section of this report, some possible pathways for moving forward are presented.

Pathways for moving forward: Some possibilities
Based on the findings presented herein, there are a number of potential pathways that the United Way could take in moving forward. Some of these pathways will disrupt current ways of working; others may address pressing issues in the more immediate term; and some may do both. The most important factor here will be engaging stakeholders, including children, youth, families and their natural supports, alongside NGOs, government and private sector groups in the process. In this section, some ideas for action, grounded in the findings of this review, are briefly described. Wherever relevant, actions being taken under the VMH Next Steps banner that are in place in Calgary already or that could be augmented/leveraged are identified below. (See Appendix C for a table comparing challenges identified in this review with actions outlined in the Valuing Mental Health Next Steps document.)
Disruptive actions

The term “disruptive” is used here to imply actions that disturb the status quo or way of doing things, and in so doing, result in change. There are many ways to disrupt a system – adopting a new philosophical stance or approach for example; or introducing new ideas, innovations, programs, approaches that change the usual way of “doing business”; changing the way people interact and work together; engaging system users in redesign efforts; and, so on. Many of the suggestions put forward by key informants and Advisory Group members are synonymous with such disruptions. A philosophical shift and system redesign are at the top of the list and represent the greatest disruption. A number of other actions that have energy around them and that would support this shift include innovations to address access and transition issues and to better support children, youth and families. These are described below. Note, however, that the intent is not to prescribe any particular action; rather, it is outline what has been suggested and where there seems to be the most energy for action. What is presented below is merely a starting point for dialogue and deliberation. There are many other possibilities.

Build a new foundation: Develop an integrated continuum or framework for mental health services and supports that is grounded in a philosophical shift

The most disruptive approach is making the philosophical shift and re-designing to create an integrated system that is focused on meeting the mental health needs of children, youth and families. An important “disruption within the disruption” is the integral involvement of children, youth, and families in this process – “nothing for us without us”. This is the starting point for a system grounded in what they need.

There are many ways to approach this and careful consideration will be required to find the most promising way(s) forward. Different perspectives have been shared about this, including the following:

- “Start small” with simple one day integrated, cross-agency planning meetings
- Create a coordination table that brings agencies together to find ways to improve coordination
- Bring case managers from community-based NGOs and AHS (and other relevant government organizations) together to discuss their approaches to case management (it was thought that this process would help people from both “sides” understand the approaches they take, and the challenges they experience)
- Bring people from NGOs and AHS together, along with youth and families (i.e., people with lived experience) to talk about how things currently work, perhaps using some examples
- Convene a small, cross-organizational group to pilot something new, evaluate and fine-tune it, then scale it up
- Achieve agreement on what “mental health” means, and identify shared principles for serving Calgary’s families; or, to start with a full out comprehensive visioning and design
- Engage in a full-out process to develop an “ideal” continuum or framework of mental health services and supports for children, youth and families in Calgary
Whether starting on big or small actions, highly skilled facilitation will be required to bring stakeholders together - ideally, children/youth/families, NGOs, government organizations (not just health, but other sectors as well), and the private sector (e.g., private psychologists) in a constructive space. The United Way is developing a co-design lab, which may be an excellent vehicle for this work.

**Disruptions to address key issues: Access, transitions, and better supports for children, youth, and families**

A number of innovative actions outlined by participants in this review could address several identified challenges simultaneously. These include: integrated service hubs, peer support, and e-mental health. Each is briefly described below.

1. **Experiment with integrated service hubs or similar approaches that enable rapid access to multiple services and supports.** The review revealed a great deal of energy, enthusiasm and action around the concept of integrated youth service hubs, based on the original headspace model developed in Australia and now being adopted in different forms in many other countries, including in Alberta. Integrated hubs are understood as, “the integration of health and social services under one roof in a youth-friendly environment.” These hubs may address access and integration issues, in particular.

   Better integration of services and systems (“Act in partnership: Create an integrated system) is a core strategy outlined in VMH Next Steps document. One of the actions outlined under this strategy is: “Implement a community-based service hub model where services are jointly planned and delivered by multiple sectors through one location, either physically or virtually. Services include housing, physical and mental health services, primary health care, addiction services, justice, social services, school-based services, etc.”

Based on the Valuing Mental Health review, PolicyWise for Children & Families has been contracted to assist in the implementation of two to four Community-Based Mental Health Service Hubs for Youth in Alberta’s rural communities. Other efforts underway in Alberta include:

- Edmonton – two ACCESS Open Minds research projects are underway; these are community spaces that can act as a portal for help-seeking youth
- Camrose – has an integrated services hub
- United Way Calgary Community Hubs (partnership with City of Calgary, Rotary Club of Calgary) – in Bowness, Greater Forest Lawn, North of McKnight, Sunalta, Village Square and Vista Heights (not a specific focus on child/youth mental health per se; may also serve broader needs re: mental health promotion at community level)
- Some existing Calgary organizations that operate like integrated hubs include:
  - The Alex Youth Health Centre and Family Health Centre

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Sheldon Kennedy Child Advocacy Centre - co-located, multi-disciplinary wrap around supports for children experiencing severe child abuse

- CMHA Calgary will be hosting a forum re: integrated service delivery hubs on April 11, 2018. This forum will bring together local agencies with world leaders in integrated service hubs.
- Another suggested possibility was to pilot a single point of entry model;
- The Calgary Domestic Violence Collective is working on coordination along the service spectrum as an area for focus in 2018-2020. The goal is to bring leaders in domestic/sexual violence together to ensure a coordinated approach and to identify and fill gaps in service. There may be an opportunity to learn from this group in terms of doing this coordination work “on the ground”.

2. **Expand youth and family peer support in Calgary.** Given that peers can help address a number of issues including, providing supports when people first begin to experience issues; serving as a first contact in agencies; working in emergency rooms and inpatient units to support people through the process; and so on. Peers can interact with youth and families in many ways including in person, through texts, e-mails and telephone and thus can be highly accessible for people. Thus, they have great potential to help youth and families cope with issues before they need to access formal services; they can be a support while people are waiting for appointments and treatment; they can support people through the journey and make the experience for children, youth and families a more humane and comforting one. Peer support is an integral component of integrated service hubs, so there is an opportunity to expand the peer support through the action outlined above as well.

Peer support is also a key recommendation of the MHCC:

> “Peer support works because people who have experience with mental health issues can offer encouragement and hope to each other – often reducing hospitalization, providing social support and improving quality of life. It can also connect families experiencing similar situations, helping them better understand the mental health system and improving their ability to take care of their loved one’s needs.”

As described previously, the CMHA Calgary is playing a leadership role in advancing peer support through their Peer Support School, so there is an opportunity to expand, augment, leverage – broader employment of peer supporters throughout the city. It is also recognized that several other agencies employ peer supporters; it would be fruitful to bring these groups together to talk about mutually beneficial opportunities for strengthening peer support services for child, youth and family mental health in Calgary.

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3. **Implement e-mental health solutions to support youth and families.** Many interviewees referenced various e-mental health solutions to some of the gaps and challenges identified herein, yet Alberta was noted to be “way behind the eight-ball” in this arena. This may be about to change given that AHS’s Addiction and Mental Health Strategic Clinical Network and partners recently received a Canadian Institutes of Health Research (CIHR) research grant to test e-mental health for adolescents and young adults experiencing the three most commonly occurring mental illnesses in youth and young adults under 25: anxiety, mood, and substance disorders. The project will involve e-mental health innovations including peer-to-peer and family support; internet-based cognitive behavioural therapy; and, internet-based screening for alcohol consumption.

Beyond the CIHR grant, there are many other potential applications for e-mental health. One example is a phone app to improve access and navigation, for example. A starting point for this work may be to consult with those who have conducted research about the use and effectiveness of various e-mental health technologies, and seek to identify those approaches that may effectively address various challenges addressed herein. An important reminder would be to ensure that youth in particular are involved in these processes since they would likely be the primary users of these technologies.

The *Valuing Mental Health Next Steps* document includes an action for e-mental health: “**Develop virtual technology-based solutions to help people access tools, information and treatment to address addiction and mental health issues**”.

**Some less disruptive but potentially impactful short-term interventions**

There are many other possible and less disruptive actions and pathways; many have been outlined in the summary tables in the “Findings” section of this report. Three that seem to have good promise are briefly described below.

1. **Access – increase awareness about what services are available and how to access them.** Some possibilities include targeted social marketing campaigns (customized approaches for different groups, such as youth, families, service providers, primary care physicians, clinics/networks, schools). A caution is that increased awareness would ideally result in increased demand for services. Other strategies to increase services need to be considered in tandem with this intervention.

The *Valuing Mental Health Next Steps* document includes an action related to increasing awareness of existing supports: “**Create and maintain a user-friendly comprehensive listing of**
publicly and privately funded addiction and mental health services available in Alberta.27” Some work is underway in Alberta to expand 211 services.

2. **Access – increase the number of single-session and walk in mental health services** for youth and families, and test new ways of reducing wait lists. A number of agencies in Calgary have found ways to increase access through, for example, the use of detailed data to anticipate resource needs and eliminate wait lists; walk in clinics; single-session clinics; the use of an intake and engagement team where the first contact with a client is viewed as an intervention in itself; an approach of “screening people in rather than out; and barrier-free counseling. Lessons can be learned from these organizations. It may be helpful to convene a dialogue amongst agencies to share practices that could help reduce wait lists and provide rapid access to supports.

3. **Transitions - begin to move toward an “every door is the right door” approach, and more warm entries and hand-offs** across the web of mental health services and supports in Calgary. One approach might be to convene meetings with stakeholders to talk about how this might work, and perhaps develop a pilot project. This might be something that a small group of actors comes together to work on, pilot, refine and scale up.

**Concluding remarks**

Many key informants and Advisory Group members for this inquiry expressed appreciation to the United Way for an opportunity to participate. Some said they are rarely asked for their input and so were very pleased to be included in this work. Advisory Group members said they enjoyed the opportunity to come together and talk about issues and challenges that they share, and begin to think about solutions. The important work now is to nurture and grow the goodwill and enthusiasm generated in this project. There are no easy answers and no simple solutions. A lot more discussion is needed.

One Advisory Group member made the following comments at the March 14 meeting:

“If I was in United Way’s shoes, I’d be asking, “How do we show up in a positively disruptive way as a funder... how do we create a movement and have youth and families take the lead? United Way’s mandate is not about funding clinical services, so how do they play in this space that complements this?” So, what’s the new space?”

These are good questions for the United Way to consider. Perhaps through this inquiry, the process of positive disruption has already begun. The new space might be one that brings everyone together, and especially children, youth and families, to rethink a system that serves their needs.

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### Appendix A: Compilation of summary tables

**Table 2. Summary. Gaps/challenges, strengths, and possible responses related to: Services and supports foundational to child, youth and family mental wellbeing**

<table>
<thead>
<tr>
<th><strong>Key gaps/challenges</strong></th>
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<tr>
<td>• Insufficient attention to the promotion of mental wellbeing, resilience, the prevention of mental health problems, and early identification/early intervention for emerging mental health or developmental issues</td>
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<tr>
<td>• Early childhood development is crucial and a core opportunity to promote mental wellbeing, prevent mental health problems, identify issues and intervene early; ECMap study: many children in Calgary are not getting the support they need during their crucial early years</td>
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<tr>
<td>• There are extremely long wait lists in the public sector for psychosocial, psychoeducational and other kinds of assessments which means children may not get access to the supports they need in a timely manner</td>
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<td>• More preventative work is required to bolster child/youth/family mental wellbeing so they don’t require formal services/supports in the first place; or, where there is a need not yet requiring clinical care – there is great potential for traction in this area</td>
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<tr>
<th><strong>Existing strengths/efforts underway as identified by key informants</strong></th>
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<tbody>
<tr>
<td>• First 2000 Days Network – enabling collective action to improve early childhood development outcomes</td>
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<tr>
<td>• AHS’s “Early Years” book – all new parents receive this book; has recently been updated to integrate new knowledge re: brain science</td>
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<tr>
<td>• AHS and Alberta Education— comprehensive school health initiatives throughout Alberta</td>
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<td>• AHS – Mental Health Capacity Building in schools – working with more than 180 schools re: positive mental health</td>
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<tr>
<td>• Burns Memorial Fund – work that is congruent with mental health promotion – Children’s Fund goals related to child development (healthy, safe, access to optimal health care; ready for school, experiences success and graduates; opportunity to participate in recreational activities to help them discover their talents); moving toward greater focus on social-emotional learning; Families Moving Forward Program; work re: natural supports</td>
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<tr>
<td>• Carya – numerous positive mental health promotion and mental illness prevention programs that address risk and protective factors for children/youth/families (e.g., self esteem, coping skills, self confidence, relationships, creativity); parent resilience, youth and community engagement)</td>
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<tr>
<td>• Council of Champions for Children and Youth – looking at building resilience</td>
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<tr>
<td>• The Alex – numerous initiatives aimed at preventing crisis – mental illness prevention; the Alex Community Bus</td>
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<tr>
<td>• CUPS – Services focused on resilience; supports for low income Calgarians</td>
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<tr>
<td>• Change in Mind initiative (Palix Foundation and the Alliance for Strong Families and Communities</td>
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(US) CUPS and Big Brothers, Big Sisters Calgary are participating – initiative to integrate brain science concepts into action

- United Way, Calgary and Area – All in for Youth, Enough for Everyone Poverty Reduction Strategy
- Alberta Children’s Hospital resource library re: child/youth mental health
- AHS – doing work regarding mental health literacy – education about mental health issues and illnesses; community education services
- School-based mental health services/supports (significant investment here)
  - Comprehensive School Health - AHS
  - Mental Health Capacity Building initiative – AHS
  - PolicyWise and the AHS Maternal Newborn Child and Youth SCN - based on a recommendation from Valuing Mental Health, currently examining mental health supports for children and youth in schools
  - Safe and Caring Schools - Alberta Education – promotion of positive mental health; socio-emotional learning; healthy, respectful relationships;
  - Mental health literacy Project – AHS
  - Smiles – based on Dr. Stan Kutcher’s mental health literacy program – for Grade 9-10 students (AHS)
  - United Way – All in For Youth
  - Secondary education work re: mental health
    - University of Calgary - Campus Mental Health Strategy
    - Alberta Government work re: post-secondary mental health

Possible responses as identified by key informants

- Focus on building resilience and strengthening protective factors for children, youth, families, natural supports, communities
- Parent education based on new brain science would be beneficial for all parents
- Revisit parenting and other ECD programming in Alberta – are they based on brain science?
- AHS CAAMHPP program is doing some work with daycare operators, community providers around increasing mental health capacity – talking about the impacts of trauma and mental health
- Work with daycares to increase/apply knowledge of brain science; help them to identify issues early and refer appropriately (link to work by Muttart Foundation’s “Well Ahead” initiative – working with daycares)
- Explore childcare consultation services (re: child development, screening, early intervention) for child care/day care settings (e.g., Ontario model)
- Screening and early intervention - Explore issues re: timely assessment for developmental delay, learning disabilities, socio-emotional/behavioural issues; implement strategies to reduce wait lists for these assessments and expedite access to appropriate supports
## Table 3. Summary. Gaps/challenges, strengths, and possible responses related to: Getting in – Accessing MH services and supports

### Key gaps/challenges
- Lack of awareness of what’s needed and what’s available
  - Families/youth may not know what supports they need, what to ask for, or may be unsure about what they should share
  - Families and youth don’t know where to find supports → they wind up in the ER as a last resort
  - Service providers are also challenged to keep track of all the available services and their inclusion/exclusion criteria; primary care physicians may simply opt to send to the ER
- Exclusion criteria or narrow inclusion criteria limit access
- Lengthy wait lists for clinical supports; and, costs, hours and location of services = barriers to access
- A current lack of capacity in primary health care re: child/youth/family mental health issues/illnesses
- Children/youth not ill enough for admission to hospital or AHS’s CAAMHP program – where do they go for help?
- A number of underserved groups/populations who are at higher risk for problems and also of falling through the cracks:
  - Children/youth with ASD, FASD, other developmental and behavioural issues
  - LGBTQ2S, and particularly transgender youth
  - Youth involved with the justice system
  - Families and youth living in poverty and/or who are homeless
  - Youth with addictions
  - Newcomers (refugee, immigrant families); families for whom English is a second language
  - Indigenous families

### Existing strengths/efforts underway as identified by key informants
- Calgary is “rich” in mental health services and supports; many that offer e-therapy, telephone, text, chat, and walk-in services; others offer single-session visits to help people cope and make a plan for moving forward while waiting for more intensive support
- Calgary Counseling Centre has eliminated wait lists by using data to customize supports for clients and predict resource requirements; and by supervising students or post-graduate students to work with clients
- Crisis counseling
  - Wood’s Homes – 24/7 crisis counseling via telephone, text, live chat & mobile response
  - Wood’s Homes - Eastside Family Centre – no charge walk in counseling for families
  - Kids Help Phone (piloting a text messaging approach in Manitoba)
  - Distress Centre ConnecTeen
  - After hours crisis support to UofC students (Wood’s Homes, Calgary Counseling Centre, Distress Centre)
Some organizations are working with primary care to build capacity. AHS, for example, has CANReach – a fellowship with pediatricians and family physicians which includes online modules and offers continuing medical education credits.

### Possible responses as identified by key informants

- More preventative work to support children/youth and bolster their mental wellbeing so they don’t get into crisis in the first place
- More mental health literacy training for the general public and youth; education for parents/youth
- Increase public/family/youth awareness about where/how to access services – marketing campaign, branding strategy
- Find ways to reduce wait times – rethink traditional approaches
- E-mental health (e.g., apps or social media for finding services)
- Build MH capacity in primary care
- Increase the number of single session and walk in clinics; Ontario requires all funded mental health service providers to offer walk-in clinics
- Expand peer support services (phone, online, in-person)
- Locate services where children/youth/families gather – e.g. shopping malls, leisure centres
- Implement community-based integrated service hubs/one-stop-shops; explore organizations that are currently operating in this kind of manner (e.g., The Alex)

### Table 4. Summary. Gaps/challenges, strengths, and possible responses related to: Assessment

#### Key gaps/challenges

- What kinds of assessments are needed and when? How many children/youth actually need a full, multidisciplinary assessment – these are expensive and there are wait lists. When would a less intense, rapid approach be more appropriate, and what would that look like?
- It can take years to get an initial assessment
- No agreement on a particular type of screening/assessment to identify the underlying trauma and how the issue gets framed; different approaches = different recommendations for care /treatment
- Trauma is not addressed in the DSM yet it is a huge driving factor in relation to clinical severity – diagnosis system is missing a big part of the intensity of need
- Need to do a better job of matching the service need with what the child/youth/family needs
- There are advantages and disadvantages of having a formal diagnosis

#### Existing strengths/efforts underway as identified by key informants

- The ACES screening tool being is used by AHS CAAMHPP
- Some community-based NGOs have a softer approach to assessment, beginning with “just listening” and having a gentle conversation

#### Possible responses as identified by key informants

- Work collaboratively to review assessment processes - co-create a rapid and appropriate assessment tool or a one-stop triage service
### Table 5. Summary. Gaps/challenges, strengths, and possible responses related to: Supports for the whole family

**Key gaps/challenges**
- “Parents are in a lot of pain”
- Children/youth/families want to be have a voice/be listened to, and be understood as experts regarding their own health, experiences and needs; they need and expect services/supports to be provided in an empathetic, caring, respectful and safe environment, yet this does not always occur
- Parental/caregiver mental health is crucial; an intergenerational approach is important, and supporting parents with their own mental health needs – a holistic, family centered approach

**Existing strengths/efforts underway as identified by key informants**
- Catholic Family Services – intake process as an intervention – the value of talking with people in a compassionate manner for as long as they want (with highly positive feedback from clients)
- CMHA – youth and family peer supporters

**Possible responses as identified by key informants**
- Family and youth peer support; inclusion of natural supports
- Engage children/youth/families in defining issues and designing services/supports
- Mental health supports for parents and families as a whole
- E-mental health supports
- Single session and walk in clinics
- Integrated service hubs
- Psychosocial and other non-clinical supports – e.g., sports, recreation, arts
**Table 6. Summary. Gaps/challenges, strengths, and possible responses related to: Supports while waiting for, and beyond ‘treatment’**

**Key gaps/challenges**
- Long wait lists for clinical care, or failure to qualify for AHS’s CAAMHP program, or not ill enough for hospital admission means that families are often left on their own to cope with child/youth MH concerns that can be extremely stressful and challenging to manage (e.g., suicidal; self-harming; violent/aggressive) and can significantly impact the whole family “

**Existing strengths/efforts underway as identified by key informants**
- CMHA’s Peer Support School, peer supporters, Recovery College
- Distress Centre’s ConnecTeen
- A number of organizations have walk-in clinics and single session clinics that people might access to talk about coping strategies and next steps

**Possible responses as identified by key informants**
- Expansion of existing family and youth peer support services; inclusion of natural supports
- Mental health supports for parents and families as a whole
- E-mental health supports
- More single session and walk in clinics
- Integrated family/youth services hubs
- Psychosocial and other non-clinical supports – e.g., sports, recreation, arts
- Engage children/youth/families in defining issues and designing services/supports
**Table 7. Summary. Gaps/challenges, strengths, and possible responses related to: Transitions**

**Key gaps/challenges**
- Major gap – disconnects when clients transition from community-based NGO-provided services into AHS, and then back to community-based services – lack of communication and information sharing between orgs
- Major gap - transition between adolescent MH services and adult MH services (significant differences between adolescent and adult services make the transition very difficult)
- Another gap in services is for children aged 7 to 13
- Gap - transition from school based MH programs to clinical MH programs

**Existing strengths/efforts underway as identified by key informants**
- RCSD is currently funding CONEX and a mental health transitions position (working with Psych ER, inpatients, school divisions, children’s services and FSCD – however this is only a pilot; it is not annualized funding
- Research is underway in the Faculty of Social Work at the University of Calgary re: use of navigators in transitions from adolescent to adult health services (Susan Samuels and Gina Dimitropoulos)

**Possible responses as identified by key informants**
- Bring AHS and community-based orgs together to find ways to improve transitions and ensure “warm” entries and hand-offs between services

**Table 8. Summary. Gaps/challenges, strengths, and possible responses related to: System issues**

**Key gaps/challenges**
- No planned, integrated continuum of services & supports; a fragmented, patchwork of programs and services that aren’t well connected to one another = poor continuity of care and added stress for families
  - For those requiring multiple supports – no single place where these are offered; separate services that don’t operate in an integrated or coordinated way → confusing and difficult for families to navigate
- Insufficient mechanisms for integration and coordination of services
  - No shared, long-term vision
  - Lack of common language – divergent understandings of the term “mental health” and appropriate actions to address it; disconnect between biomedical, clinical models that focus on clinical diagnosis and treatment (where “mental health” really means “mental illness”), and broader holistic, socio-ecological models that consider the child/youth in context and are based in a broader view of “health” and “wellbeing”
  - Multiple sectors involved, but they rarely speak to each other; jurisdictional issues about “who owns what”
  - Some degree of mistrust across orgs
  - No defined forum for people (i.e., public sector and NGOs) to come together to discuss issues,
plan together, etc.

- Resourcing – scarcity of resources; current funding mechanisms for NGOs promote competition rather than collaboration
- Concerns about quality of service/care
  - Are people using evidence informed practice/leading practices?
  - Is practice informed by brain science, trauma informed care?

**Existing strengths/efforts underway as identified by key informants**

- The Calgary Council for Addiction and Mental Health (CCAMH), for which CMHA is a backbone organization, includes both NGO and government sector members

**Possible responses as identified by key informants**

- Strong agreement re: need to develop a common framework for child/youth/family MH services and supports, or at least a common understanding of what “mental health” is and principles for MH services and supports – interviewees identified a number of principles
- Develop a continuum/matrix – what is the ideal pathway toward wellbeing? How would people ideally move through this pathway?
- Strengthen relationships and enhance collaboration across orgs that support the MH needs of children/youth/families; AHS and community orgs need to work collectively to get an understanding of each other and the roles they play – maybe work together to pilot something
- Could Calgary organizations work collaboratively to support government in moving the Valuing Mental Health plan forward in Calgary? Develop a local *Valuing Mental Health* plan and seek government funding?
- Is the Calgary Council for Addiction and Mental Health (CCAMH) a possible forum for bringing orgs together to work on issues?
- Fund professional development re: brain science, trauma informed care, patient/family centred care, use of ACES tool, etc.
Appendix B: Interview guides

Interview guide for service providers

United Way project: The status of mental health support for children and youth in Calgary

Guide for initial key informant interviews

Introduction
- Brief description of the project
  - This is a review project examining mental health supports for children and youth in Calgary. Areas of focus include:
    ▪ Identification of existing community-based mental health supports
    ▪ Identification of barriers to access
    ▪ Identification of gaps
    ▪ Recommendations and ideas for improvement
  - “The findings and recommendations will be used inform the future work of the United Way of Calgary and potential partnership opportunities with stakeholders to strengthen the community based continuum of care for children and youth.”
- Any questions for us
- Permission to audiotape the interview

Questions

Opening
- Could you tell me a little about your role <with X organization>?
  - Probe re:
    ▪ Explicit link to child and youth mental health support and/or research
    ▪ Why interested/excited about this project; what you hope will be achieved through this project?
- What kinds of child and youth mental health services or programs does your organization provide/support/work with in Calgary?
- Are there particular communities or populations that you serve/support/work with (e.g., children, youth, “at risk” – new immigrants/refugees, poverty, indigenous, homeless, justice-involved, living with chronic illnesses or disabilities, LGBTQ, others?)

Current continuum/web of supports and flow through these
- How would you describe the current continuum or web of community mental health supports for children and youth here in Calgary?
  - Probe around:
    ▪ Pretty complete or full of holes? Smooth or bumpy?
  - Where would you say the services/programs/initiatives that your organization provides fit in this continuum/web?
- Looking through the eyes of child, youth and their natural supports: How would you describe the way that people currently move through this continuum/web?
What kinds of barriers to access do you think they experience?
Where do children and youth fall through the cracks/where are the gaps
  - Probe: around where children & youth may exit the ‘system’ prematurely and/or have problems with transition points?
  - Does this continuum/web and any barriers/gaps look different in different communities/populations?

- What would timely and seamless flow look like?
  - Does this look different in different communities/populations? If yes, how.
  - What seems to be working well or is currently helpful in facilitating timely and seamless flow?

- Who might we talk to in order to better understand what navigating the web of services/supports feels like for children, youth and their families/natural supports?
  - For example: do you have any (or know of any) advisory councils, board members, youth groups, that might be interested in speaking with us?
  - Other ideas re how to map this flow, looking through the eyes of children, youth and their families/natural supports

An ‘ideal’ Calgary continuum/web of supports
- What are your thoughts about what an ideal continuum/web of supports for children and youth in Calgary might look like?
  - Probe around
    - Early intervention and prevention components of this continuum
    - The concept of positive mental health and addressing risk/protective factors
- Does your organization/you use any kind of model or continuum of services for child/youth mental health – that is, something that depicts promotion/prevention/early intervention, treatment, recovery and so on?
  - If yes, could you describe it? Share it with us?
- Are there other good continua/webs in other places, or models, that you are aware of that we should take a look at?

One model out there: A continuum of needs-based services and supports from Ontario’s Policy Framework on Child and Youth Mental Health (attached)
- What are your thoughts about this as a continuum?
- Focusing on the yellow, green and orange columns:
  - Reflecting back on the current continuum/web in Calgary, and looking at the functions listed here, are there functions that you’d say are missing or not currently well developed?
  - Thinking about an ‘ideal continuum’ for Calgary, are there important functions that you’d say are missing from this particular continuum?

Given our discussion about barriers, gaps and the ideal Calgary continuum, where might the United Way of Calgary and their partners best focus their efforts?

OR

Reflecting on this statement about this project: “The findings and recommendations will be used to inform the future work of United Way of Calgary and potential partnership opportunities with stakeholders to strengthen the community based continuum of care for children and youth.”
- Where might the UW and their partners focus their efforts in order to strengthen the Calgary community-based continuum, and ultimately make a positive difference in the lives of children, youth and their families?

**Closing**
- Are you aware of any existing inventories of Calgary-based child and youth community mental health services and programs?
- Are there other projects/initiatives (past or present) that we should be aware of?
- Are there other people you would recommend we speak with?
- Are there any resources out there that you think would be useful in informing this work?
- Is there anything else that you want to say?
Interview guide for youth and family

United Way Project: The status of mental health support for children, youth and families in Calgary

Youth and family experience with mental health supports and services: Interview guide

Introduction

- Thank you for taking time to speak with us. We so appreciate it.
- As you know, we are working on a ‘review’ project for the United Way on mental health supports and services for children, youth and families in the Calgary area.
- They want to have a better understanding of what community-based mental health supports look like now, including any barriers to access, actual gaps in services, and ideas for improvement.
  - “The findings and recommendations will be used to inform the future work of United Way of Calgary and potential partnership opportunities with stakeholders to strengthen the community-based continuum of care for children and youth.”
- We have conducted interviews with many service providers and some researchers here in Calgary. Now we really need to understand how youth and their families/friends experience this ‘continuum’ of services and supports.
- That’s why we need to speak with you, as we understand that not only can you speak to your own experiences but to the experiences of the people you support through your work at CMHA.
- Questions for us?
- Permission to audio-tape our conversation?
- Finally, could you let us know how much time you have? Can you spend half an hour? Longer?
- 3 bins of questions

Questions

Opening

- Could you tell us a little bit about your role here at CMHA? How long you’ve been doing this?

- What led to your interest in doing this work with CMHA?

Child/youth/family experiences with current services and supports in Calgary

Drawing on any of your own experiences navigating the mental health services in Calgary, and the experiences of the people you have supported through your work at CMHA:

- Where do children/youth/families OR young people struggle most with getting the kind of help they need?
  - Barriers to accessing services?
  - Any issues relating to assessments of mental health issues/needs?
  - Gaps in services? Places where children/youth/families might fall through the cracks?
  - Challenges with transitions (e.g., from home to hospital to home; to adult services)?
- Do people turn to their family doctor for help or not? What is this experience like?
- Are there things that work really well in Calgary, or services that tend to work better for children/youth/families OR young people and their families/friends? Is there something we can build on?
- Could you share some real-life examples, so we can truly understand what current services are like?

An ‘ideal’ Calgary continuum/web of supports
- Pretend nothing existed now, and we needed to start from scratch. What might an ideal continuum/web of supports for children, youth and families in Calgary look like? OR an ideal service?
  o Probe around
    ▪ How would people like to be able to access services?
    ▪ What does a good assessment process look and feel like?
    ▪ What would timely and seamless flow across services look and feel like?
    ▪ What about the early intervention and prevention, before people start experiencing more severe problems?
    ▪ What about supports and services for young people living with significant mental illness?
    ▪ Where does peer support fit in all of this?
    ▪ What about supports for recovery?
    ▪ Other???

- Are you aware of other cities, provinces or countries that do a better job of supporting children and youth dealing with mental health issues, and their families/friends? OR of other models of providing services ‘out there’ that you feel are promising?
  o Probe around
    ▪ Where/when/how young people prefer to access services and support
    ▪ Community hub concept, and what is integral to making this concept work for young people
    ▪ E-Mental health (i.e., online supports, apps, etc.)

- If there was one thing that could be changed to better support children/youth and family with mental health needs in Calgary, what would that be? Could you describe what it would look like?

Closing
- Are there other people you would recommend we speak with?
- Are there any resources out there that you think we should take a look at?
- Is there anything else that you want to say?
### Appendix C: Challenges Identified in this Review and Relevant Valuing Mental Health Next Steps

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<tr>
<th>Findings from this review</th>
<th>Relevant actions outlined in Valuing Mental Health – Next Steps</th>
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| **Mental health promotion** | Support learning environments that promote positive mental health and well-being in our schools and post-secondary institutions  
  - Ideas and concepts of positive mental health, including social-emotional learning are found in current and future programs of study  
  - Ensure supports (including tools and resources) that focus on student personal growth and well-being are available to all Alberta schools and post-secondary institutions, including consultation with First Nations |
| **Access – people can’t find services** | Create and maintain a user-friendly comprehensive listing of publicly and privately funded addiction and mental health services available in Alberta.  
  - Consider leveraging Alberta’s existing HealthLink and MyHealth platforms as an interface for this listing and evaluate their effectiveness as an interface  
  - Collaborate with the federal government and Indigenous organizations to compile a shared listing of services and programs available on and off reserve for Indigenous people; initiate use of the listing in three high-needs communities |
| **Access – primary care capacity** | Define the role of primary health care in accessing and providing addiction and mental health services  
  - Include services and supports related to addiction and mental health (based on a community health needs assessment) in the business plans of primary care networks (PCNs)  
  - Provide information to Albertans on the benefits of establishing a long-term relationship with a primary health care team than can provide early services and direct clients to others as needed |
| **Assessment – screening tools** | Proactively support Albertans with adverse childhood experiences  
  - Evaluate whether the Adverse Childhood Experiences (ACES) risk assessment tool should be implemented in Alberta  
  - Implement ACE as a screening tool in identified settings and evaluate its effectiveness |
| **Transitions** | Develop pathways to and from primary health care to support coordination within, and transition between health and community settings (including schools)”  
  - Examine potential models for using volunteer peer mentors as “navigators”  
  - Develop alternative models of care for people with addiction and mental health issues presenting to emergency departments |
| **e-Mental health – Access to information and treatment** | Develop virtual, technology based solutions to help people access tools, information and treatment to address addiction and mental health issues  
  - Focus on vulnerable and rural populations first  
  - Share information on websites, tele-health, mobile applications, and other technologies |