



The Provincial Centre of Excellence for Child and Youth Mental Health at CHEO  
Le Centre d'excellence provincial au CHEO en santé mentale des enfants et des ados

## **Access & Wait Times in Child and Youth Mental Health: *A Background Paper***

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The Canadian Association of Paediatric Health Centres  
The National Infant, Child, and Youth Mental Health Consortium Advisory  
The Provincial Centre of Excellence for Child and Youth Mental Health at CHEO

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## EXECUTIVE SUMMARY

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Analysis of available data on prevalence of mental disorders in children and youth reveal a body of work that is somewhat dated, highly variable, and not necessarily reflective of the diverse Canadian population, especially indigenous and immigrant peoples. Despite this considerable knowledge gap, it is possible to infer from epidemiological information that a significant number of young Canadians struggle with mental health problems. The effects of these problems on children and youth are extensive. Mental disorders permeate every aspect of a child's functioning in the home, at school, and in the community, affecting their overall development at considerable social and fiscal costs (National Institute of Mental Health, 2001). These challenges then follow young Canadians into adulthood; the lifetime prevalence of mental disorders is approximately 46 percent, and nearly 75 percent of all cases start by age 24 years (Kessler et al., 2005). Access to effective prevention and intervention during childhood and adolescence is essential to stemming the tide of chronic mental health disability into adulthood.

An overview of access and wait time literature reveals considerable gaps in Canadian data. While evidence suggests that child and youth mental health needs are largely unmet, and the system-, community-, and individual-level barriers to access are well documented, it is entirely unclear *who* is waiting for *what*, from *who*, and for *how long*? In order to begin to address access to child and youth mental health services, comprehensive Canadian data cataloguing the state of wait lists and the need for these services must be gathered and disseminated.

Just as mental health services for children and youth in Canada are considered fragmented, provincial and territorial efforts to address paediatric mental illness and access to health care through clear policy guidelines are similarly scattered. Some boast policy frameworks of varying levels of comprehensiveness, others reference unique paediatric care needs in general mental health plans, and still others operate patchwork programs to address specific mental health needs. Within the four provinces that have developed child- and youth-specific mental health plans, there is considerable variability in the degree to which access is addressed and operationalized. International mental health access initiatives offer insight in both policy and practice. These are highlighted with an emphasis on processes that may be relevant in a Canadian context.

In practice, several broad and evidence-based themes emerge in approaches to improving access and wait times across the continuum of care. Tele-mental health care and e-mental health programs have multiplied in the last decade, backed by a solid body of research. Similarly, school-based initiatives, primary service providers, and family-centred care have also

been adopted as means to enhance access. Strategies for waitlist management, such as interim services, are also reviewed. Ongoing applied research is required to properly evaluate these approaches, to generalize their use to new populations, and to help guide innovations in both access and alternatives to care.

The importance of collaboration, innovation, and family-centred care are identified as key principles to guide efforts to improve access to child and youth mental health care. Gaps in research, policy, and practice are synthesized and suggestions for future work are presented. All of the above will require strategic leadership and strong partnerships as efforts are made to move the yardsticks in the provision of accessible, effective, and acceptable child and youth mental health care across Canada.

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## **ACCESS & WAIT TIMES IN CHILD AND YOUTH MENTAL HEALTH: A BACKGROUND PAPER**

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### **1.0 INTRODUCTION**

While 14 percent of Canadian children and youth are affected by mental disorders that require professional intervention (Waddell, Offord, Shepherd, Hua & McEwan, 2002), as few as one in six will access speciality mental health care (Offord, Boyle, Fleming, Munroe Blum, & Rae Grant, 1989) – treatments which are not necessarily evidence-based or effective. In addition to having a tremendous impact on well-being, development, and educational achievement in childhood (National Institute of Mental Health, 2001), these mental health problems then follow young Canadians into adulthood (Kessler et al., 2005), with considerable social, psychological, and fiscal costs (Institute of Medicine, 2009).

Despite growing concerns about lengthy wait times for child and youth mental health services in Canada (Western Canada Waiting List Project, 2001; OPESU, 2005), there is a paucity of data on the scope and complexity of the problem. As will be seen, reportedly lengthy waitlists are among many factors which impede timely access to mental health services. Simply identifying a need for service can be problematic. For example, research on the duration of untreated psychosis suggests that young people with psychotic symptoms may go unidentified for months or years (McGlashan, 1999; Normal & Malla, 2000). When young people with mental health problems are identified by primary care providers, they may not even be placed on waitlists due to the perceived futility of referral, as specialist services are often considered inaccessible.

This background paper draws on pertinent information from research, policy, and practice in order to identify gaps and inform further work to address access and wait times in child and youth mental health care. Although the survey of relevant data is comprehensive in nature, it is by no means exhaustive.

Prevalence data are presented, along with current contextual factors and definitional issues. Research concerning access, wait times, and barriers to care are summarized. A discussion of Canadian and international policy initiatives to enhance access to child and youth mental health care is articulated and practice examples drawn from across the continuum of care are highlighted. By way of conclusion, gaps in research, policy, and practice are synthesized and suggestions are made for future work.

## 1.1 Methodology

Electronic search strategies were developed by an experienced information specialist in consultation with the research consultant. The following databases were searched: PubMed, PsycINFO on OVID; and the Cochrane Library on Wiley (including Cochrane Database of Systematic Reviews, DARE, HTA, CENTRAL, Methods, and NHS EED). Searches were performed on August 7, 2010.

Strategies utilized a combination of controlled vocabulary (Mental Health Services, Health Services Accessibility, Waiting Lists, etc.) and keywords (mental health, access, wait times, etc.). Results were limited to the publication years 2000 and following. PsycINFO results were limited to journal articles and the English language.

Over 3000 unique records were retrieved. An initial set of 300 articles was pre-screened by the information specialist with the research consultant checking for agreement. All subsequent pre-screening was completed by the information specialist. The resulting set of potentially relevant citations was reviewed and specific references were selected and grouped thematically by the research consultant.

Grey (unpublished) literature was identified through searching the Web sites of relevant psychology and mental health organizations, government departments or ministries of health (with a focus on Canadian, United States, United Kingdom, Australia, New Zealand, and Scandinavia countries), centres of excellence, key social science sites, and so on. Advisory group members also identified key documents for review from both the published and unpublished literature.

## 1.2 In Brief: Prevalence of Mental Disorders in Canadian Children and Youth

In the past 30 years, many research efforts have been directed at estimating the prevalence of mental disorders among children and youth in Canada. The *Ontario Child Health Study* (OCHS), a landmark community survey conducted in Ontario in 1983, found that 18.1 percent of four to 16 year olds experience at least one psychiatric disorder (Offord, Boyle, Fleming, Munroe Blum, & Rae Grant, 1989). The one-in-five rate drawn from the OCHS findings is widely cited and continues to be accepted as one of the definitive estimates of prevalence today.

More recent work reveals a range of prevalence rates and considerable heterogeneity among epidemiological studies. In 2002, Waddell and her colleagues reviewed six studies of



prevalence of child psychiatric disorders, including the OCHS, the Quebec Child Mental Health Survey, and four non-Canadian works (Waddell, Offord, Shepherd, Hua & McEwan, 2002). The review uncovered prevalence rates ranging from 9.5 to 20.3 percent and data combination methods were used to suggest an overall prevalence of 14 percent – the equivalent of 1.1 million children in Canada. Another recent meta-analysis by the Institute of Medicine in the US found a prevalence rate of 17 percent for any mental, emotional, or behavioural disorder among youth up to 25 years (O’Connell, Boat & Warner, 2009).

Casting a wider net and enforcing more stringent exclusion criteria, the Provincial Centre of Excellence for Child and Youth Mental Health at CHEO undertook a systematic review of current scientific evidence of prevalence (2010). While no recent Canadian study reported an overall prevalence rate for mental health problems, the review of non-Canadian research revealed rates ranging wildly from 0.6 percent to 60.7 percent. Given the great variation in populations, methods, definitions of disorder or ‘caseness’, and findings, the review concludes that meaningful comparisons are impossible and presents recommendations for a rigorous primary study of mental health suffering among Canadian children and youth.

Reviews of available data on prevalence of mental disorders in children and youth reveal a body of work that is somewhat dated, highly variable, and not necessarily reflective of the diverse Canadian population, especially indigenous and immigrant peoples. Despite this considerable knowledge gap, it is possible to infer from epidemiological information that a significant number of young Canadians struggle with mental health problems. Anxiety, behavioural, and depressive disorders are the most common mental disorders among children (Costello et al., 2003). The effects of these and other mental health problems on children and youth are extensive. Mental disorders permeate every aspect of a child’s functioning in the home, at school, and in the community, affecting their overall development and the social and fiscal costs are estimated to be enormous (National Institute of Mental Health, 2001). These challenges then follow young Canadians into adulthood; the lifetime prevalence of mental disorders is approximately 46 percent, and nearly 75 percent of all cases start by age 24 years (Kessler et al., 2005).

### **1.3 Setting The Stage: The Current Canadian Context**

While the prevalence data may suggest a dire future for the mental health of young Canadians, many contextual factors hint at a strengthening platform for change. Throughout the past decade, several projects, publications, and initiatives have set the stage for action to address timely access to services for children and youth. While some directly address mental health

care, most provide potentially applicable insights from other sectors of care. A brief summary provides insight into the present climate surrounding access in child and youth health care:

- ◆ In 2001, the **Western Canada Waiting List Project** issued a final report: *From Chaos to Order: Making Sense of Waiting Lists in Canada*. The Project made significant advances in defining the key issues and developing landmark priority criteria tools for five specialty areas, including children's mental health. Additionally, the report highlights the present Canadian context, stating, "Reports of lengthy queues and waits for care have been interpreted as evidence that the health care system is failing and that reasonable access to care is being seriously compromised," (p.1).
- ◆ Many **provincial initiatives** have been undertaken to reduce wait times, such as the British Columbia Surgical Wait List Registry and Ontario's Wait Time Strategy.
- ◆ Since 2004, the federal **Wait Times Reduction Fund** has invested over \$4 billion to augment existing provincial investments and assist jurisdictions in their various initiatives (Health Canada, 2007).
- ◆ Statistics Canada has released several **Access to Health Care in Canada** reports, which provide information on access to family physicians, 24/7 access to first contact services, self-reported unmet health needs, non-urgent access to specialized services, and waiting for care.
- ◆ The Canadian Child and Youth Health Coalition (CCYHC) developed a **Paediatric Surgical Wait Times Strategy** to establish access targets for ten subspecialties, determine current wait time burden, and develop strategies to manage wait times.
- ◆ In 2006, the Standing Senate Committee on Social Affairs, Science and Technology released the report ***Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada***. A culmination of more than two years worth of hearings, briefs, literature reviews, and other explorations, the Committee's report contains several recommendations pertaining to children and youth.
- ◆ Most recently, in June 2010, the Canadian Institutes of Health Research (CIHR)'s Institute of Human Development, Child and Youth Health (IHDCYH) facilitated a **Consensus Workshop on Access to Mental Health Services for Children and Youth**. Nearly 60 representatives of academic institutions, non-government organizations, government departments, professional associations involved in children and youth's

health, as well as parents and youth with lived experience, came together to define research opportunities focused on improving access to mental health care for children and youth.

With the exception of the recent IHDCYH workshop, this review of wait time initiatives highlights the lack of efforts to increase access to paediatric mental health services. While most of these ventures do not explicitly concern child and youth mental health care, their lessons can undoubtedly be applied to future action to improve access and wait times. The sum of the last decade's worth of projects, publications, and initiatives is an environment that is ripe for positive change in access to mental health care for Canada's children and youth.

#### 1.4 Creating Shared Language: Key Definitions

In scholarly research, policy, and practice, no shared language exists to address issues of access and wait times in child and youth mental health. Not only are common definitions absent in the mental health community, they are also absent across all sectors affected by mental health issues. Following are several suggested definitions drawn from relevant literature, which lay the foundation for this background paper.

**Mental Health:** a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community (World Health Organization, 2001).

**Mental Illness or Disorder:** a condition that meets DSM-IV diagnostic criteria for mental or substance abuse disorders, which includes the presence of both significant levels of symptomatology and impairment in functioning (Institute of Medicine, 2009).

**Mental Health Problems:** difficulties that may be early signs or symptoms of mental (or behavioural or emotional) disorders but are not frequent or severe enough to meet the criteria for a diagnosis (Institute of Medicine, 2009).

**Access:** the empowerment of an individual to use health care and benefit from services, given their circumstances and experiences in relation to the health care system. Access may be considered to have three dimensions: (1) Availability – includes physical and time-dependent access, as well as elements of quality and quantity available; (2) Affordability – relates to the individual's ability to pay the full costs of care, including travel and lost earnings; (3)

Acceptability – defined as the fit between provider and patient attitudes towards, and expectations of, each other (Boyle, Appleby & Harrison, 2010).

**Evidence-Based Care:** the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients (Haynes and Haines, 1996).

**Wait List:** a queue of patients who are deemed to need a health service that is in short supply relative to demand. Generally two lists are operating: wait one to see the specialist who controls access to the services and wait two to receive the service once need has been verified (Haddorn, 2000).

**Wait Time:** the number of days, weeks, or months elapsed from the times patients are placed on a list to the time they receive service. Waiting times are affected by a number of factors, including system capacity, the number of patients, and the number of emergency or urgent cases (Haddorn, 2000).

**Wait Time Benchmarks (or Targets):** health system performance goals that reflect a broad consensus on medically reasonable wait times for health services delivered to patients (Wait Time Alliance, 2005).

While these suggested definitions provide a skeletal starting point, it is evident more work needs to be done in developing shared, cross-sector language for child and youth mental health, particularly for issues of access to care. It should be noted that definitions of wait lists, wait times, and benchmarks do not speak to the quality or effectiveness of the care eventually received. In order to improve access, it will be necessary to address these issues, along with carefully defining and distinguishing between *unmet need* and *met un-need* – definitions which the relevant literature has yet to establish.

## 2.0 RESEARCH ON ACCESS AND BARRIERS

While there may be a paucity of evidence concerning prevalence of mental disorders and mental health problems among Canadian children and youth, there is no shortage of literature chronicling the barriers to accessing mental health care. Following a brief review of research on access and service use, a summary of system-, community-, and individual-level barriers will be presented in table format.

### 2.1 Access, Service Use, and Wait Times

As reports indicate that less than half of youth (Kessler, Avenevoli, & Merikangas, 2001) and only one in six children with mental disorders (Offord, Boyle, Fleming, Munroe Blum, & Rae Grant, 1989) receive needed mental health services, while up to 80 percent of children 6 to 17 years fail to access mental health care (Katoaka, Zhang, & Wells, 2002), it is evident that access is a major problem facing young Canadians.

#### ***Unmet Needs: Adolescents with Depression***

Data collected in both Canada and the United States suggests that young people suffering from depression and suicidal ideation are not having their mental health service needs met. Among American youth who had recently attempted suicide, Wu and colleagues (2010) found that less than half of respondents received mental health support services of any kind preceding or subsequent to their attempt(s). Canadian data reflects the same trend; Cheung and Dewa (2007) found that approximately 40 percent of 15 to 18 year olds suffering from major depression had not used mental health services. Given that suicide remains the second leading cause of death in Canadian youth (Heath Canada, 1994) and more than half of those who attempt suicide have a diagnosable mood disorder (Shaffer et al., 1996), the prevalence of untreated youth with unmet mental health needs is cause for deep concern.

#### ***Accessing Who?***

A patchwork of published research only begins to define precisely what mental health services are being accessed and to what extent. In the same study of Canadian adolescents with major depressive disorder, Cheung and Dewa (2007) examined the types of service providers accessed by boys and girls:

- ◆ Psychiatrists: 45 percent of boys, 21 percent of girls;
- ◆ General practitioners or family physicians: 24 percent of boys, 30 percent of girls;
- ◆ Psychologists: 25 percent of boys, 16 percent of girls;

- ◆ Social workers or counsellors: 10 percent of boys, 39 percent of girls;
- ◆ Other providers: 23 percent of boys, 16 percent of girls.

In addition to highlighting significant gender differences in access patterns, these findings also suggest that youth are more likely to seek primary care to meet their mental health needs. Similarly, the *Ontario Child Health Study* (Offord et al., 1989) established that 59 percent of children and youth with mental disorders received primary care, while only 24 percent received specialist services. The OCHS data also indicate greater use of special education services for children with psychiatric disorders, at a rate of almost twice that reported for children without disorders.

Highlighting the youth perspective, Davidson and Manion (1996) present data from the Canadian Youth Mental Health & Illness Survey. Canadian youth reported similar trends in accessing mental health services, identifying the same preference for primary and school-based care. Forty-eight percent of youth surveyed indicated they would turn to their family doctor for information on mental illness, while 42 percent said they would turn to their schools. In a recent survey of adolescent attitudes about depression treatment, Bradley and colleagues (2010) found that youth preferred talk therapy delivered by family doctors, psychiatrists, or psychologists to antidepressants. Given the existing evidence that respecting young persons' preference for treatment increases compliance (see, for example, Lin et al., 2005), a clear understanding of these preferences is essential to encouraging access.

### ***Appropriate, Evidence-Based, and Effective Care***

The most glaring gap in the literature appears to be the lack of information concerning access to appropriate, evidence-based, and effective mental health treatment. While there has been some research on access to mental health care in general, and considerable work has examined effective treatment for myriad mental health problems, there has been no effort to investigate access to *good* mental health care. Are young Canadians accessing services and professionals that are appropriately matched to their presentation and level of need? Are the interventions they receive demonstrated to be evidence-based, effective, and associated with positive long-term outcomes? What evidence exists that general health care providers have the competencies needed to appropriately diagnose and treat young people with mental disorders? Simply having accessed mental health services does not imply that the care being given is adequate.

### ***Access Point: The Emergency Department***

A considerable body of Australian work has examined the emergency department as a key access point for children and youth. Starling, Bridgland, and Rose (2006) reviewed paediatric

emergency department records for patients presenting with mental health problems, including self-harm, suicide attempts, behavioural disorders, and medical disorders associated with psychological problems. The vast majority of cases were first presentations. Stewart, Spicer, and Babl's work furthered the understanding of emergency department use (2006). They found that 18 percent of mental health cases in the emergency department were repeat visits and that more than one quarter of all paediatric mental health visits involved a security incident. Given these results, and the additional finding that 47 percent of cases reviewed resulted in admissions, the authors conclude that mental health presentations to the paediatric emergency department require significant resources and merit further study.

Recent Canadian data further confirms the emergency department as an access point for children and youth with mental health problems. In a four-year review of paediatric emergency visits in Alberta, Newton and colleagues (2009) found a 15 percent increase in mental health presentations during the study period and more than one third of all presentations were repeat visits. Four factors were associated with multiple visits (Newton et al., 2010); females, older children, those with parents in receipt of social assistance, and patients who originally presented for mood or psychotic-related disorders are more likely to return to the emergency department.

### ***Service Use Across Canadian Provinces***

No Canadian data concerning child and youth mental health service use across provinces has been published. However, several studies have examined general mental health service use across provinces.

Drawing on adult data from the *Canadian Community Health Survey*, Afifi, Cox, and Sareen (2005) found that **perceived need** for seeking help was lowest in Prince Edward Island and Saskatchewan and highest in the territories. Rates of both professional **help-seeking** and **use of self-help** were lowest in Newfoundland and Labrador and highest in the territories. Reasons for not seeking help were also examined, revealing still more provincial variations. 'Inability to find time to seek services' was the most often cited reason in Prince Edward Island, Nova Scotia, and British Columbia. 'Unavailability of services' ranked highest in Newfoundland and Labrador, New Brunswick, Manitoba, and the territories. Finally, 'doubts, fears, and changed mind' was the most common reason for not seeking help in Ontario, Alberta, and Saskatchewan. In Quebec, 'inability to find time' and 'unavailability of services' were tied. The authors infer that variations are likely caused by rural isolation and differences in socioeconomic status across regions.

Further analysing data from the *Canadian Community Health Survey (CCHS)*, other researchers have found similar provincial variations. Vasiliadis and colleagues (2005) identified highest rates of service use in Nova Scotia and British Columbia and lowest rates of use in Prince Edward Island and Newfoundland. Their review also revealed that the general medical system was most accessed, while the voluntary sector was least accessed for mental health support. Also examining data from the CCHS, Starkes, Poulin, and Kisely (2005) focused on adults with major depression in Atlantic Canada. Their work uncovered that only 40 percent of respondents accessed services of any kind, and less than one quarter reported receiving care consistent with practice guidelines, as defined by the study's methodology.

Overall, research on the significant variations in service use patterns across Canada indicates that efforts to improve access and the delivery of care should consider the potentially unique needs of the nation's diverse regions.

### ***Wait Times in Canada***

Anecdotal evidence suggests that for those young Canadians who do seek mental health care, many will face considerable wait times. However, there is a complete paucity of Canadian data on wait times for child and youth mental health services. In a recent presentation at the Canadian Academy of Child & Adolescent Psychiatry's annual conference, researchers Kowalewski and McLennan posited, "The lack of data on wait times for child and adolescent mental health services in Canada impedes our understanding of the current state of the system and leaves us uncertain as to the success of initiatives aimed at reducing wait times," (September 2010). Their survey of agencies providing child and adolescent mental health services in Canada (Kowalewski et al., 2008) found that current practice does not meet the Canadian Psychiatric Association's benchmark wait times (2006), particularly for routine care.

Additional work by these Canadian researchers focused on the characteristics of waitlists and the strategies agencies employ to manage them. Member organizations of Children's Mental Health Ontario were surveyed concerning their waitlist experiences and service management strategies (Kowalewski, McLennan, Waddell, Perry & Lavis, in press). While only half of member agencies responded, almost all participants confirmed that there were waitlists for their services. In general, estimated wait time until assessment was shorter for cases with greater priority levels. The researchers found that offering services at non-traditional times, such as evenings and weekend, was the most commonly cited strategy to reduce wait times. While the implications of these preliminary findings merit further investigation, it is evident that employing an evidence-based, systematic method of prioritizing cases is imperative. The results also raise the issue of waiting for assessments versus waiting for appropriate interventions.



Although families benefit from diagnostic clarity, they are also in need of active interventional help for their children and youth.

Given the lack of wait time data, it is clear that future research efforts, applying a standardized approach, must be directed at comprehensively capturing wait times for child and youth mental health care in Canada. Such work should also differentiate between waiting for assessment and waiting for active treatment. In order to develop evidence-based strategies to enhance access, undertaking comparative studies to explore the nature and extent of the problem is a natural first step.

### ***Parents: Navigating the System***

No review of literature concerning child and youth access to mental health services would be complete without mention of the parents who must become expert system navigators and informed consumers of mental health care. A largely under-researched area, one Ontario-based study sought to interview parents concerning their experience of seeking help for their child (Shanley, Reid & Evans, 2008). Parents recruited from a child mental health centre reported, on average, seeking help for two different child problems, contacting five different agencies or professionals for help, and receiving two different treatments. In the year preceding the study, almost all parents were simultaneously in contact with more than once agency. These findings suggest highly fragmented service delivery and pathways to care that can be very difficult to navigate.

In a highly collaborative initiative by a community organization, an academic institution, and a parenting magazine, over 4,500 parents were surveyed on their perspectives on child and youth mental health (Anderson, Kutcher & Connell, 2010). While more than half of parents identified their child's mental health as something they think about occasionally or often, one quarter of respondents were not aware of any treatment programs in their region and one half were not aware of parent support groups. Paired with the Ontario data concerning parental help-seeking experiences presented above, these results highlight the importance of supporting parents in becoming informed consumers of paediatric mental health care.

This succinct overview of access and wait time literature reveals considerable gaps in Canadian data. While evidence suggests that child and youth mental health needs are unmet, and as will be seen, the barriers to access are well documented, it is entirely unclear *who* is waiting for *what*, from *who*, and for *how long*? In order to begin to address access to child and youth mental health services, comprehensive Canadian data cataloguing the state of wait lists and the need for these services must be gathered and disseminated.

## 2.2 System-Level Barriers

Barriers to care operating at the system, or macro, level include fragmentation of services, workforce concerns, wait times, and inadequate funding. Descriptions of these barriers are presented in Table 1.

<i>Barrier</i>	<i>Description</i>	<i>Key References</i>
Fragmentation of Services	Much of the published literature points to fragmentation of services as a significant barrier to accessing mental health care. Silo-style programs are disconnected from other mental health and general health care. Disciplinary differences and weak clinical linkages between specialist services, primary care, and community programs result in a lack of collaboration. Similarly, the cross-sector nature of mental health care (e.g. spanning Health, Education, Criminal Justice, Social Services, etc.) and confidentiality policies inhibit communication and coordination.	Reid & Brown, 2008; Sterling, Weisner, Hinman & Parthasarathy, 2010.
Workforce Concerns	Research on barriers to access highlights growing concerns about a workforce crisis in the child mental health professions, particularly in rural settings. Challenges in this area encompass the recruitment and retention of staff, in addition to the delivery of accessible and effective training in both initial and continuing education settings.	Breton, Plante & St-Georges, 2005; Hoge, Morris, Stuart, Huey, Bergeson, Flaherty, et al., 2009; Reid & Brown, 2008; Sarma & Peddigrew, 2008; Thomas & Holzer, 2006.
Wait Times	While virtually no information exists concerning average wait time to receive children's mental health services, it has been determined that lengthy wait times present a significant barrier to access. For example, the time elapsed between initial contact and intake appointment is a significant predictor of appointment attendance. In other words, the longer a person or family waits, the less likely they are to seek treatment.	Reid & Brown, 2008; Sherman, Barnum, Buhman-Wiggs & Nyberg, 2009.
Funding	Information gathered from stakeholders, such as Reid and Brown's survey of managers of children's mental health centres in Ontario, suggests inadequate system funding as a barrier to access. Unfortunately, there is no available empirical evidence on the adequacy of funding in this sector. In order to advocate for greater funding and more efficient resource allocation, this knowledge gap must be addressed.	Reid & Brown, 2008; Stelk & Slaton, 2010.

Table 1 System-Level Barriers to Access

### 2.3 Community-Level Barriers

Barriers to care operating at the community level include geographic location and social location, such as gender and socioeconomic status amongst others. Descriptions of these barriers are presented in Table 2.

<i>Barrier</i>	<i>Description</i>	<i>Key References</i>
Geographic Location	<p>Geographic location is perhaps the most commonly reported barrier in the published literature. Boydell and colleagues state, “The route to mental health care for children in rural communities is complex, dynamic, and nonlinear, with multiple roadblocks,” (p.182). Factors impacting access to care for young Canadians in rural communities include:</p> <ul style="list-style-type: none"> <li>◆ Physician and other mental health <b>professional shortages</b>;</li> <li>◆ Lack of reliable <b>transport</b> to and from mental health services and associated transportation costs;</li> <li>◆ <b>Long waiting lists</b> and lack of an after-hours services;</li> <li>◆ Rural gossip networks, social visibility, and <b>lack of anonymity</b> within rural communities greatly compounds the experience of stigma and social exclusion for children and youth.</li> </ul>	<p>Afifi, Cox &amp; Sareen, 2005; Aisbett, Boyd, Francis, Newnham, &amp; Newnham, 2007; Blais, Breton, Fournier, St-Georges &amp; Berthiaume, 2003; Boydell, Pong, Volpe, Tilleczek, Wilson &amp; Lemieux, 2006; Diaz-Granados, Georgiades, &amp; Boyle, 2010; Happell, Moxham, Reid-Searl, Dwyer, Kahl, Morris, et al., 2009; Paul, Gray, Elhai, Massad &amp; Stamm, 2006; Smalley, Yancey, Warren, Naufel, Ryan &amp; Pugh, 2010; Starkes, Pulin &amp; Kisely, 2005; Vasiliadis, Lesage, Adair &amp; Boyer, 2005.</p>
Social Location	<p>Research on barriers has revealed that patients’ and/or families’ social location may have a significant impact on their ability to access mental health services. Social identities that influence access include:</p> <ul style="list-style-type: none"> <li>◆ <b>Gender</b>: Numerous studies have examined the impact of gender on accessing services. In general, girls have more mental health knowledge and boys experience more stigma. Some work suggests that boys are more often referred for services, particularly concerning ADHD and other disruptive behaviour disorders;</li> <li>◆ <b>Socioeconomic</b> status: Even under universal health care in Canada, low-income families are far less likely to receive specialist mental health services;</li> <li>◆ <b>Sexual orientation</b>: LGBTQ youth are at greater risk of mental health problems and experience complex challenges in accessing care. They place as much</li> </ul>	<p>Corliss, Belzer, Forbes &amp; Wilson, 2007; Cross, Bartgis, Fox, 2009; Ochoa &amp; Nash, 2009; Hoffman, Freeman, &amp; Swann, 2009; Kutcher &amp; McDougall, 2009; Lee, Juon, Martinez, Hsu, Robinson, Bawa et al., 2009; Nadeau &amp; Measham, 2006; Raghavan, Inkelas, Franke &amp; Halfon, 2007; Rue &amp; Xie, 2009; Steele, Glazier &amp; Lin, 2006; Wells, Hillemeier, Bai, &amp; Belue, 2009.</p>

<p>Social Location (continued)</p>	<p>importance on provider qualities and interpersonal skills as provider knowledge and experience, and place little importance on a provider's gender and sexual orientation;</p> <ul style="list-style-type: none"> <li>◆ <b>First Nations</b> identity: In addition to highlighting increases in prevalence and greater barriers to access, some literature also points to Western biases inherent in system of mental health care, which alienate Canada's Aboriginal, Inuit, and Métis people;</li> <li>◆ <b>Guardianship</b>: Prevalence is considerably elevated among children in the child welfare system, and yet a body of U.S. work clearly indicates that these children face significant barriers to access.</li> <li>◆ <b>Citizenship</b> status: A small number of publications consider the pronounced barriers immigrant and refugee children face in accessing care.</li> <li>◆ <b>Incarcerated</b> youth: Studies suggest that up to 70 percent of incarcerated youth have mental disorders and that lack of access to mental health services leads to inappropriate contact with the justice system.</li> </ul>	
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Table 2 Community-Level Barriers to Access

### 2.4 Individual-Level Barriers

Barriers to care operating at the individual, or micro, level include stigma, health status, attitudes, parental risk factors, and previous experience of seeking mental health care. Descriptions of these barriers are presented in Table 3.

<i>Barrier</i>	<i>Description</i>	<i>Key References</i>
Stigma	<p>The experience of stigma permeates the mental health literature, including work on access to children’s mental health services. Many studies have identified stigma as a significant barrier to access.</p> <p>Stigma can be understood as negative stereotypes about mental illness, devaluation of and discrimination towards people affected by mental health problems. The stigma of seeking mental health services can be experienced by both the patient and their family.</p> <p>While families of children and youth affected by mental health problems may experience stigma, they may also further stigmatize the sufferer. Parental disapproval and perceived stigma have been found to act as barriers to willingness to use mental health services. Concern about family member response has been reported by teens as the most significant barrier to help seeking.</p>	<p>Chandra &amp; Minkovitz, 2006; Gerson, Davidson, Booty, McGlashan, Malespina, Pincus, et al., 2009; Mukolo, Heflinger, &amp; Wallston, 2010;</p>
Mental Health Status and Comorbidity	<p>Research has established that current and historical mental health status influences access to care. For example, increased levels of suicidal ideation and general psychological distress have been linked to lower intentions to seek help. Comorbidity of mental disorders with substance abuse or other health problems also complicates access to adequate care. Mental health status affects perception of barriers. Teens with depression report significantly more barriers to care when compared with non-depressed teens. Findings such as these suggest that those who are in greater need of care are more like to avoid obtaining it.</p> <p>Similarly, family members’ health status impacts access to care. Studies have found that maternal psychosocial factors may greatly enable or impede access. Children whose caregivers experience symptoms of depression are significantly more likely to encounter difficulties in accessing mental health care services.</p>	<p>Gaskin &amp; Mitchell, 2005; Meredith, Stein, Paddock, Jaycox, Quinn, Chandra, et al., 2009; Moran &amp; O’Hara, 2006; Wilson, Deane, Marshall &amp; Dalley, 2010;</p>

<p>Attitudes and Help-Seeking Behaviours</p>	<p>Investigations of individual-level barriers to service use often uncover attitudinal factors, such as the belief that a mental health problem will improve on its own or a preference for managing symptoms alone. Understandably, young Canadians who believe their problems can be solved without assistance are unlikely to seek services independently.</p> <p>Other work has found that youth prefer and seek out informal resources for help managing mental health problems, such as friends, partners, and parents or other significant adults. These findings suggest that models of care should emphasize the importance of seeking help and promote less specialized, more informal services.</p>	<p>Abram, Paskar, Washburn &amp; Teplin, 2008;                  Marcell &amp; Halpern-Felsher, 2007;                  Power, Eiraldi, Clarke, Mazzuca &amp; Krain, 2005;                  Sareen, Jagdeo, Cox, Clara, Ten, Belike, et al., 2007;                  Urbanoski, Cairney, Bassani &amp; Rush, 2008;</p>
<p>Family Risk Factors and Parental Engagement</p>	<p>Research on service use data suggests that children and youth with a family history of mental illness or substance abuse had more services recommended and used more services than young Canadians without these family risk factors.</p> <p>Parental engagement and perception have also been identified as highly significant barriers and/or enablers to access. Studies have shown that the more engaged a parent is in various aspects of a child’s life, the more likely that child is to access mental health services. Similarly, parental perceptions of problem behaviours and preference for available treatments greatly impact service use.</p>	<p>Bannon &amp; McKay, 2005;                  Mendez, Carpenter, LaForett &amp; Cohen, 2009;                  Sayal, Taylor, Beecham &amp; Byrne, 2002;                  Schneiderman &amp; Villagrana, 2010;                  Whitson, Connell, Bernard &amp; Kaufman, 2010;</p>
<p>Previous Experience</p>	<p>Previous experience with mental health care may also create barriers to access when further treatment is necessitated. Research has found that assessments of prior treatment outcome and aspects of relationships with former providers are linked to doubt about the utility of treatment and perceived barriers to obtaining treatment.</p>	<p>Kerkorian, McKay &amp; Bannon, 2006;</p>

Table 3 Individual-Level Barriers to Access

**Spotlight: STIGMA**

Stigma is a powerful barrier to accessing mental health care for children and youth. As described above, young Canadians struggling with mental health problems and their families face stereotypes and discrimination known as stigma. Additional statistics shed more light on the potency of stigma. Data from the Canadian Youth Mental Health & Illness Survey (Davidson & Manion, 1996) indicate that 63 percent of youth point to embarrassment, fear, peer pressure, and(or) stigma as most likely to keep a person their age from getting help. Moreover, 38 percent of Canadians would be embarrassed to admit their children suffer from anxiety or depression (Kinark Child and Family Services, 2007). Given this self-stigma and resounding fear of embarrassment, it is little wonder that stigma presents such a significant barrier.

### 3.0 POLICY: GUIDELINES TO IMPROVE ACCESS

Mental health policies describe the values, objectives and strategies of the government to reduce the mental health burden and to improve mental health. They define a vision for the future that helps to establish a blueprint for the prevention and treatment of mental illnesses, the rehabilitation of people with mental disorders, and the promotion of mental health in the community. Policies specify the standards that need to be applied across all programmes and services, linking them all with a common vision, objectives and purpose. Without this overall coordination, programmes and services are likely to be inefficient and fragmented (WHO Mental Health Policy Project, 2001).

If service delivery systems across Canada are fragmented and failing to meet the mental health needs of young Canadians, clear standards and guidelines are undoubtedly necessary to improve timely access to appropriate care in the form of assessment and intervention. In order to comprehensively sketch the landscape of access to paediatric mental health services in Canada, relevant mental health policies will be surveyed and a provincial case study will be presented. International mental health policy will also be reviewed, as a means to evaluate and further explore Canadian directions.

#### 3.1 Canadian Policy

Unlike fellow G8 nations, Canada does not have a unifying policy framework for child and youth mental health. A review of provincial and territorial policy reveals varying levels of progress in addressing the mental health care needs of children and youth and increasing access through policy-making.

##### ***Provincial Policy Frameworks***

In a recent evaluation of child and adolescent mental health policies, Kutcher, Hampton, and Wilson (2010) found that only four of ten provinces and none of the territories have policies or plans that explicitly address paediatric mental health. Table 4 names the relevant policy documents in each province and territory.

<i>Province</i>	<i>Child and Youth Mental Health Policy Document</i>
BC	<i>Child and Youth Mental Health Plan for British Columbia</i>
AB	<i>Positive Futures: Optimizing Mental Health for Alberta's Children &amp; Youth</i>
SK	<i>A Better Future for Youth: Saskatchewan's Plan for Child &amp; Youth Mental Health Services</i>
MB	<b>None</b> – A mental health and addictions plan is under development.
ON	<i>A Shared Responsibility: Ontario's Policy Framework for Child and Youth Mental Health</i>
QC	<b>None</b> – Québec has a Suicide Prevention Strategy and, released more recently, the <i>Plan d'Action Santé Mentale</i> does include a section on children and youth.

<i>Province</i>	<i>Child and Youth Mental Health Policy Document</i>
NB	<b>None</b> – New Brunswick’s Community Mental Health Centres are mandated to provide services tailored to children and youth.
NS	<b>None</b> – Nova Scotia has identified Strategic Directions for their mental health system, including established standards of care, but child and youth mental health needs are not explicitly addressed.
PE	<b>None</b> – Both the <i>Substance Abuse and Addictions Strategy</i> and the <i>Mental Health Service Delivery Plan</i> reference child- and youth-specific priorities.
NL	<b>None</b> – Newfoundland’s <i>Mental Health and Addictions Framework</i> identifies children and youth as a special population.
YT	<b>None</b> – The territory does not have a mental health plan, nor any related plans or programs.
NT	<b>None</b> – The territory’s <i>Mental Health and Addictions Action Plan</i> references the need to promote child and youth mental health.
NU	<b>None</b> – While Nunavut does not have policy explicitly addressing child and youth mental health, the territory has released a suicide prevention strategy and a mental health and addictions strategy.

Table 4 Provincial and Territorial Child and Youth Mental Health Policies

British Columbia, Alberta, Saskatchewan, and Ontario have all developed some form of plan or framework to guide child and youth mental health service delivery in their respective provinces. Kutcher and colleagues suggest that while each document has strengths, “there is variability in the extent to which they address essential components and translate policy to action,” (p.104). Furthermore, the scope, specificity, and available funding differ dramatically between the four frameworks. Among provinces and territories that do not possess a child and youth mental health policy, many have general frameworks that include a paediatric component, such as Québec’s *Plan d’Action Santé Mentale*. Beyond policy, several provinces have implemented programs that tackle various elements of adolescent mental illness, including suicide and addiction.

While each of the four provincial child and youth mental health policies address access and wait times, there is still more variability in the specificity and degree to which these elements are operationalized. During pre-plan consultations, British Columbia identified several gaps in service related to access, such as lengthy waitlists and the need for accessible locations and timely services. However, none of the BC Plan’s four key elements explicitly name access as a priority. Conversely, Alberta, Saskatchewan, and Ontario all identify improved access and(or) decreased wait times as strategic goals or priorities. Among these three provinces, many of the guiding principles and activities are known to be linked to improved access (e.g. family-centred care, community-driven care); however, the plans fail to concretely define how access will be enhanced.



Just as mental health services for children and youth are highly fragmented, provincial and territorial efforts to address paediatric mental illness and access to health care are similarly scattered. Some boast policy frameworks of varying levels of comprehensiveness, others reference unique paediatric care needs in general mental health plans, and still others operate patchwork programs to address specific mental health needs. Furthermore, almost no practice evidence verifies that existing provincials and territorial plans for child and youth mental health have been fully implemented. Kutcher, Hampton, and Wilson write, “Nationally, there is neither a cohesive vision nor a common approach regarding how youth and adolescent mental health should be addressed,” (2010, p.105). The authors conclude their review by recommending that the federal government or a national ‘arm’s-length’ body initiate the development of a national child and youth mental health policy framework for Canada.

Recommendations such as Kutcher et al.’s have not fallen on deaf ears. In addition to developing the Mental Health Strategy for Canada, the Mental Health Commission of Canada, under the guidance of their Child and Youth Advisory Committee, is presently advancing a framework specific to the mental health needs of children and youth ([www.evergreen.ca](http://www.evergreen.ca)). Entitled *Evergreen* and complementary to the Mental Health Strategy in progress, the framework will be developed collaboratively with an aim to improve policy and programming for young Canadians. Nonetheless, as health care remains within provincial jurisdiction, ongoing efforts to support provinces and territories in developing policies and plans to improve access to paediatric mental health services must be made.

### ***Wait Time Benchmarks***

On the heels of the Canadian Medical Association’s publication *It’s About Time!: Achieving Benchmarks and Best Practices in Wait Time Management* (2005), the Canadian Psychiatric Association (CPA) released a policy paper detailing wait time benchmarks for psychiatric practice (2006). Their recommendations are prefaced with, “If clinicians do not establish appropriate targets themselves, then no service can be evaluated against good clinical criteria,” (p.1). Three levels of urgency for access are identified and described, and associated wait times are established.

The most pressing level of need – **emergent** – implies danger to life or limb in an immediate timeframe of hours or days. Examples of psychiatric symptoms in this category include suicidal ideation and acute mania. The CPA recommends that patients with emergent need have access to specialist care within 24 hours. Next, **urgent** need includes clinical conditions, such as hypomania, that are unstable, “with the potential to deteriorate quickly and result in emergency admission,” (p.2). According to the CPA, consultation within one to two weeks is indicated for patients presenting with an urgent need for care. Finally, **scheduled** need for care

involves stable symptoms, such as chronic depression without suicidal ideation, that cause a 'tolerable' level of disability or dysfunction for patients in the community. The CPA suggests that patients in this category should be able to access care within four weeks.

The CPA's *Wait Time Benchmarks for Patients with Serious Psychiatric Illnesses* (2006) provides an excellent starting point for further development of access to care targets. As the guidelines are for the general population, they need to be customized to the unique needs and presentations of paediatric patients.

***Spotlight: British Columbia and the Ministry of Child and Family Development***

Approved by the government in early 2003, British Columbia's *Child and Youth Mental Health Plan* was the first of its kind in Canada. Housed under the Ministry of Child and Family Development (MCFD), the Plan was backed by an investment of \$44 million and centred on four key strategies: risk reduction, capacity building, treatment and support, and performance improvement. Comprehensive and ambitious, the Plan has been widely lauded for its emphasis on 'upstream' approaches (i.e. prevention and early intervention) and evidence-based practice, as well as its innovative regional resource allocation strategy.

Another great strength of the Plan is the degree to which the four key strategies are operationalized. The objectives of each strategy are clearly articulated, and are associated with measurement techniques and desired outcomes. Despite the fact that access to care is not explicitly named as a central priority, many of the Plan's principles and activities are closely linked to improving access, such as the strong emphasis on collaboration and community-based care.

While the Plan has evidently had a significant impact throughout the province, one program exemplifies the progressive work being done in BC. FRIENDS for Life is a school-based early intervention and prevention program proven to build resilience and reduce risk among elementary school children ([www.mcf.gov.bc.ca/mental\\_health/friends.htm](http://www.mcf.gov.bc.ca/mental_health/friends.htm)). The MCFD-funded initiative teaches children skills and tools to cope with worry and manage challenging situations. Endorsed by the Ministry of Education, the program fits into the province's health curriculum. As will be seen in the Practice and Recommendations sections of this paper, FRIENDS for Life models many of the factors that will be necessary to improve access across Canada.

As the end of the initial five-year term of the Plan was drawing near in 2008, the Ministry commissioned an external review to evaluate progress and make further recommendations (Berland, 2008). With engagement from over 600 stakeholders, the resounding message communicated to reviewers was one of support for the Plan, its coherence and follow-through. Recommendations included more and better data collection, increased collaboration between professionals and sectors, and efforts to address wait times.

A brief spotlight on the innovative and ground-breaking work happening in child and youth mental health care in British Columbia suggests that Canadians need not look much farther than our own (westerly) backyard for leadership on policy and program development. As provinces and territories from coast to coast begin and continue to improve mental health care

delivery for young Canadians, effective collaboration, active coordination, and a unifying strategy are of the utmost importance.

### 3.2 International Policy Development Publications

The World Health Organization (WHO) is presently the only international agency advancing the child and youth mental health policy agenda through the creation and dissemination of many policy tools. Brief exploration of relevant WHO documents is warranted, as a means to evaluate and further explore Canadian directions

#### ***WHO Child and Adolescent Mental Health Policy and Plans***

A module of the *Policy and Service Guidance Package* (described below), the *Child and Adolescent Mental Health Policy and Plans* framework details the steps needed to develop and implement child and youth mental health policies and plans. Targeted at a broad audience of stakeholders, policy-makers and public health professionals included, the document aims to inform those responsible for building and executing policy for the unique paediatric population, share workable solutions, and identify resources. Prefaced with an overview of the context of child and adolescent mental health, the module should be considered an integral element of efforts to develop child and youth mental health policy, with a focus on timely and accessible care.

#### ***Additional WHO Policy Development Documents***

In 2001, the annual WHO World Health Report was *Mental Health: New Understanding, New Hope*. A landmark publication, the Report aims to raise widespread awareness of the burden of mental illness and “intends to help dismantle many of those barriers – particularly of stigma, discrimination and inadequate services – which prevent many millions of people worldwide from receiving the treatment they need and deserve,” (p.xi). Following detailed chapters on mental health problems, solutions, and policies, the Report concludes with ten overall recommendations, many of which resonate strongly in the Canadian context.

Born of the 2001 World Health Report, the Mental Health Policy Project’s *Policy and Service Guidance Package* (2001) provides extensive guidance on how to implement the policy statements and recommendations of the Report. The package was assembled by experts in the field of mental health policy and service development, in consultation with a wide variety of stakeholders around the world. Comprehensive in scope, the package contains user-friendly modules in the following areas: mental health context, policies and plans, financing, legislation, advocacy, service organization, budgeting, quality improvement, information systems, and evaluation. As was seen in greater detail above, the package also includes a module on child

and adolescent mental health. The WHO *Guidance Package* is certainly an essential tool for policy-makers, public health professionals, and researchers alike, as Canada continues to develop a vision and comprehensive strategy for improving access to child and youth mental health care.

*Caring for Children and Adolescents with Mental Disorders: Setting WHO Directions* is yet another publication of the WHO Mental Health Programme (2003). Complementary to the *Child and Adolescent Mental Health Policies and Plans* module, this report provides further information on the burden of disease, barriers to care and interventions to address them, and current trends in caring for children and adolescents with mental disorders. In order to improve access, this WHO document recommends improving family communication, increasing awareness of psychosocial development, and encouraging the development of national child and adolescent mental health policy. This concise publication of WHO directions for caring for children and youth with mental disorders should be an instrumental background piece for all Canadian professionals involved in this work.

The *Assessment Instrument for Mental Health Systems* (AIMS) is a WHO tool for collecting data and assessing the key components of a mental health system (2005). Based on the WHO strategy to provide evidence-based mental health assistance to member nations, AIMS is intended to identify major weaknesses in mental health systems in order to strengthen them through public action. Evolved through several intensive revision processes, WHO considers AIMS to be an essential technical tool, complementary to other WHO documents in this area.

As Canadian governments focus on developing child and youth mental health policy, the availability of these WHO tools and support documents should not be overlooked. Research concerning the applicability of these tools in the Canadian context could greatly inform efforts to increase access to mental health care.

## 4.0 PRACTICE: IMPROVING ACCESS ACROSS THE CONTINUUM OF CARE

As researchers and practitioners in Canada and around the world seek to improve child and youth mental health care, several broad and evidence-based themes emerge in approaches to improving access and wait times across the continuum of care.

### 4.1 Approaches to Enhancing Access and Service Delivery

#### *Tele-Mental Health Care*

For more than a decade, mental health service delivery systems have been developing tele-mental health programs to improve access to care (see, for example, Starling 2006 for a ten-year review of telepsychiatry services in Australia). Tele-mental health initiatives are especially important in Canada, as children and families living in vast rural regions report significant barriers to accessing care. Nelson writes, "Because of the overwhelming maldistribution of mental health specialists in metropolitan areas and the many underserved families living in rural settings, rural areas are natural homes for the use of telemedicine or videoconferencing technology for clinical services," (2010, p. 490).

The increase in tele-mental health services has prompted a growing body of research concerned with utilization trends, patient and family satisfaction with tech-based care, and service provider perceptions of telemedicine programs. In a Seattle-based study, Myers and colleagues (2010) established that telepsychiatry services for young people were well used and significantly improved access. Moreover, the authors identified four core components necessary to a successful telepsychiatry program: (1) service providers who are interested in innovative methods to reach underserved patients, (2) clearly identified stakeholders to collaborate and make use of the services, (3) a children's mental health 'champion' to advocate for the service in their community, and (4) stable administration that perceives telepsychiatry as useful.

Children, adolescents, and parents alike have resoundingly supported the use of tele-mental health programs and have repeatedly reported their satisfaction with these services (e.g. Simpson, Doze, Urness, Hailey & Jacobs, 2001; Grealish, Hunter, Glaze & Potter, 2005; Grubaugh, Cain, Elhai, Patrick & Frueh, 2008; Myers, Valentine & Melzer, 2008; Pignatiello, Boydell, Teshima & Volpe, 2008; Boydell, Volpe & Pignatiello, 2010). An Alberta-based study concluded, "From the patient's perspective, telepsychiatry was an acceptable technique in the management of mental health difficulties that both increased access to services and produced

cost savings,” (Simpson et al.). Similarly, Elford and colleagues (2001) found that Newfoundland patients and parents were highly satisfied with their telepsychiatry experience and preferred it to travelling for an assessment. While rural patients may have more to gain from telemedicine, Grubaugh and colleagues established that both rural and urban patients were receptive to receiving services via telehealth (2008). In addition to addressing geographic barriers, Lingley-Pottie & McGrath found that a tele-mental health program may also address barriers related to inconvenience and stigma (2008). Paediatric participants reported feeling comfortable in their own home and pleased with the convenience of the service. Additionally, participants did not report feeling stigmatized or apprehensive about self-disclosure.

Service provider perceptions of tele-mental health care have been found to be somewhat more mixed than the overwhelming reports of patient and family satisfaction with these services. Two comprehensive surveys of physicians practicing in rural communities in Ontario highlight service provider perspectives (Greenberg, Boydell & Volpe, 2006; Cloutier, Cappelli, Glennie & Keresztes, 2008; Pignatiello, Boydell, Teshima & Volpe, 2008). Lack of awareness of available services may be a central barrier to referral; Cloutier and colleagues found that only 27 percent of respondents knew of the videoconferencing services available to their communities. However, as many as 92 percent of physicians report that they would refer patients to telepsychiatry resources. While participants clearly identified improved access and reduced travel time as the benefits, they raised concerns about unclear referral patterns and technology compromises. Furthermore, Greenberg et al.’s focus groups with physicians revealed emphasis on additional local services to support treatment recommendations.

***Spotlight: The Strongest Families Program***

A tele-mental health program based in Atlantic Canada, Strongest Families is designed to support families in learning about and dealing with childhood problems in the privacy of their home. Anxiety and behavioural issues are addressed, along with other problems, with a focus on early intervention and prevention. Employing a variety of media including audiotapes, videotapes, and written material, trained coaches provide education and treatment over the phone at conveniently scheduled times.

In addition to reducing the financial costs of seeking mental health care (i.e. time off from work, transportation costs), Strongest Families also addresses barriers to access by decreasing stigma, both by providing private services in the home and by increasing mental health literacy among participating families (Lingley-Pottie & McGrath, 2008).

***e-Mental Health Support***

In addition to tele-mental health services, new technologies are also being adopted to enhance access in the form of web-based education and support. Increasingly, mental health awareness and education materials are available online in kid-friendly formats and a growing body of research finds that these supports are being well received. A recent Australian study found that

71 percent of teenage respondents rated websites as likely to be helpful as face-to-face mental health services (Oh, Jorm & Wright, 2009). Another Australian study of a web-based education program about bipolar disorder found that the program attracted a steady stream of users with good completion rates (Proudfoot et al., 2007).

Studies have also been conducted to discover the type of health information independently sought by children and adolescents online. A group in the United Kingdom found that the most common enquiries were concerning psychosocial issues, hospital and health services, and normal growth and development (Franck, Noble & McEvoy, 2008). Researchers have also investigated the utility of information websites prescriptions as a form of health care intervention. Ritterband and colleagues established that two thirds of families logged on to the prescribed website within one week of the clinic visit and the probability that families would access the site was increased by 45 percent with an e-mail reminder (2005).

While it is clear the educational websites may play an increasingly important role in mental health literacy among young Canadians, Szumilas and Kutcher (2009) caution that not all websites are evidenced-based. Their analysis of the top 20 most commonly accessed youth suicide information sites found that only 44 percent of statements were supported by evidence. Of the top ranked sites, fully one-half had negative evidence-based ratings; nonprofit organization websites were more likely than government websites to have positive evidence-based ratings. Given their results and the increasing importance of high-quality web-based mental health information, Szumilas and Kutcher advocate for evidence-based information on youth suicide websites, especially those operated by the federal government and national organizations.

***Spotlight: eMentalHealth.ca***

Perhaps equally as important as providing high-quality mental health information, websites may also connect users with relevant local resources. An initiative of the Provincial Centre of Excellence for Child and Youth Mental Health in Ontario, [eMentalHealth.ca](http://eMentalHealth.ca) is a national hub for communities to share information about local resources and events. At low- or no-cost, community organizations may create their own portal through the easily accessible website to disseminate information about local mental health resources for children, youth, and families.

Beyond educational websites, innovative web-based interventions to improve access are also being developed. Online support groups offered for teens concerning eating disorders (Heinicke, Paxton, McLean & Wertheim, 2007; Bruning, Winzelberg, Abascal & Taylor, 2004) and suicide prevention (Hoffmann, 2006) have been found to be popular and effective. Evidently, as the modern age of technology advances, tele- and e-mental health programs will be among the most innovative strategies to improve access to care for children and youth.

### ***School-Based Care***

In an exploratory piece on the evolving partnership between schools and mental health care, Baggish and Hardcastle state, “Schools, by their very nature, are ideal settings for primary care. They are structured to allow for professional observation of students' behaviors, over time, within a caring learning environment,” (2005, p.535). A well developed body of literature provides strong evidence that school-based mental health care considerably improves access for children and youth. Studies have shown that convenient school-based programs and services, staffed by youth-friendly professionals, simultaneously address stigma, greatly improve access, and allow for more holistic integration among other key care providers in a child’s community (e.g. Clayton, Chin, Blackburn & Echeverria, 2010; Soleimanpour, Geierstanger, Kaller, McCarter & Brindis, 2010; Guo, Wade & Keller, 2008; Wade et al., 2008; Petersen, 2008).

Despite the supportive evidence for school-based mental health care, a recent survey of Nova Scotia youth found that while one in two reported a need for mental health support, only one in six visited the school-based health centre nurse (Szumilas, Kutcher, LeBlanc & Langille, 2010). Female sex, lower socioeconomic status, sexual risk-taking behaviours, and suicidal behaviours were all significantly associated with the use of school-based health centres. The authors suggest that stigma and lack of awareness of the range of services offered may explain the underuse of school health centres, and they go on to suggest steps to improve utilization. If school-based health centres are to be part of a multi-dimensional strategy to enhance access to mental health care for children and youth, Szumilas and colleagues’ suggestions for improvement should be further explored.

Mental health care in schools may come in the form of screening initiatives (Husky et al., 2010), special topic program such as suicide prevention (Kataoka, Stein, Nadeem & Wong, 2007), or school-based health centres (Clayton et al., 2010), which are particularly important in rural settings. Research has proven the effectiveness of these services with the following populations:

- ◆ Children with ADHD (Sayal et al., 2010)
- ◆ Adolescents at risk of suicide (Gould et al., 2009)
- ◆ Refugee children (Rousseau & Guzder, 2008)
- ◆ Adolescents causing self-injury (Shapiro, 2008)
- ◆ Children with Disruptive Behaviour Disorder from high poverty areas (Atkins et al., 2006)
- ◆ Adolescents with Social Anxiety Disorder (Masia-Warner et al., 2005)



Faced with a paucity of research on school-based interventions in Canada, McLennan, Reckford, and Clarke (2008) presented a study on the COPE program in Alberta. The Community Outreach in Paediatrics/Psychiatry and Education (COPE) seeks to link children, families, schools and mental health professionals. Participating schools refer students with developmental, behavioural, or emotional difficulties and, following a multidisciplinary screening, physicians conduct assessments within the school setting. An action plan is then developed with the team and the family, in order to link children with needed services. McLennan and colleagues conclude that the COPE program is a viable approach to improving access by linking students with mental health services.

Similarly, the Mental Health Integration and Navigation model is presently being piloted in Nova Scotia (Wei, Kutcher & Szumilas, in press). An integrated pathway to care, the model includes curriculum to improve mental health literacy, training of school personnel to identify young people who may have a mental disorder, a seamless referral process between schools and health providers, and training of primary care health professionals in diagnosis and treatment. Integrated models such as this, and COPE operating in Alberta, seek to address stigma and the fragmentation of services identified as barriers to accessing mental health services. As such, integrated pathways to care are certainly an integral element of an overarching strategy to improve mental health care access for Canadian children and youth.

### ***Primary Care***

Between somewhat poor help-seeking behaviours among young people and the relative inaccessibility of specialist mental health services, the importance of primary care practice in improving access to child and youth mental health services is evident. A significant body of research highlights the effectiveness of primary care interventions. Researchers have found primary care settings to be effective for addressing emotional disorders (Sanci, Lewis & Patton, 2010), treating behavioural difficulties (Kolko, Campo, Kelleher & Cheng, 2010), and screening for suicidality (Gardner et al., 2010), amongst other mental health concerns.

Researchers Mauerhofer, Berchtold, Michaud, and Suris write, “The large majority of young people reporting psychological problems do not seek help, although they regularly consult their GP,” (2009, pg. 308). Mauerhofer and colleagues’ work with general practitioners suggests that systematic psychosocial screening for mental health problems is a youth-friendly approach to enhancing access to needed mental health care and support. Other research has found that educating family physicians about child and youth mental health concerns and creating opportunities to collaborate with mental health professionals significantly improves the quality of primary mental health care and access to specialist mental health services (Power et al.,

2007; Kisely, Duerden, Shaddick & Jayabarathan, 2006; Spenser, Gillies & Maysenhoelder, 2009; Lester, Birchwood, Freemantle, Michail & Tait, 2009; Stiffman et al., 2010).

In order to address shortages of child and adolescent psychiatrists, many have focused on the nursing role in providing mental health care (e.g. Kolko et al., 2010; Kaye et al., 2009; Sharrock, Grigg, Happell, Keeble-Devlin & Jennings, 2006). Of particular relevance to barriers to access in rural areas is Hanrahan and Hartley's (2008) work on advanced-practice psychiatric nurses. The researchers found that psychiatric nurses are more likely to live in rural areas than psychiatrists, and therefore have great potential to increase access to quality mental health care for those living in rural regions. In a similar vein, the primary mental health worker interface role was introduced in England more than a decade ago. Hickey, Kramer, and Garralda's (2010) research into this primary care strategy indicates that primary mental health workers have been effective at helping to close the service gap between primary care staff and specialist services.

While this body of research indicates that primary care providers should be central in efforts to improve access to mental health care, it is necessary to ensure that physicians, nurses, and other frontline professionals are equipped with the evidence base necessary to provide effective diagnosis, treatment, and referral services.

### ***Collaborative Care***

In a retrospective discussion of collaborative mental health care in Canada, Kates, Gagné, and Whyte write,

Over the last 10 years, shared or collaborative mental health care has moved from being a "fringe" area of practice for a handful of providers across the country to one that is increasingly seen by provinces and health authorities as an integral part of their mental health care delivery systems. (2008, p.1).

This excerpt is indicative of the push to develop integrative and collaborative approaches to improving access and quality in mental health care. Bridges must be forged, as child and youth mental health needs cross many sectors and disciplines. Research has established that coordination between child welfare agencies, mental health service providers, and substance abuse treatment programs will significantly improve access and outcomes for children and adolescents (e.g. Bai, Wells & Hillemeier, 2009; Drabble, 2007; Libby & Riggs 2005). Moreover, Wagner and colleagues study of collaboration in paediatric hospitals (2005) indicates that participation of allied health and nursing staff extends opportunities for the identification of mental health problems and enhance timely management of referrals.

A constant frontrunner in research and practice of child and youth mental health, Australian work has established the necessity of integration and collaboration. Webster and Harrison highlight the effectiveness of multi-disciplinary mental health liaison teams in the paediatric emergency department (2004), while Scott and colleagues found that multi-disciplinary and collaborative specialized services for youth provide greater access to a range of clinicians (2009).

### ***Family-Centred Care***

If families' lack of awareness and experience of stigma create barriers, it follows that engaging families in the mental health care of children and youth will positively affected access. Several studies have examined the effectiveness of different parent engagement models. Olin and colleagues (2010) developed a Parent Empowerment Program (PEP) designed to prepare family advocates to bridge the gaps in service access among children with behavioural and emotional difficulties. PEP is based on the concept of empowerment as a process and the need to engage parents in becoming active agents of change in their child's care. While no evidence of the positive outcomes of PEP has been published, the authors suggest that the PEP framework is highly useful in creating innovative family-centred initiatives.

Other research has adopted a psychoeducation approach to engaging families in child and youth mental health care. Mendenhall, Fristad, and Early (2009) found that participation in a multi-family psychoeducation group significantly improved the severity of their child's mood symptoms and assisted parents in becoming better consumers of the mental health care system. Still more practice research suggests that employing an ecosystemic approach in treating children and families with mental health problems will lead to positive clinical outcomes (Coffey, 2004). Australian research with Indigenous groups recommended that involvement of parents should be culturally-sensitive, stating, "Parenting programs need to be sensitive to the political and cultural context in which parenting takes place [and] flexibly incorporate cultural practices and expectations," (Turner & Sanders, 2007, p.39).

While the literature concerning parent involvement in child and youth mental health care may be varied in terms of theoretical approach, the resounding message is that parents play an integral role in accessing services and efforts must be made to engage and inform them. Cunningham et al.'s (2008) investigation of the information preferences of parents of children with mental health problems supports this contention; the researchers found that maximizing the use and realizing the benefits of mental health information materials requires education strategies that are tailored to parents' preferences.

***Spotlight: headspace, Australia***

While many Scandinavian and United Kingdom nations are making excellent progress in addressing access to mental health care for children and youth (e.g. Johannessen et al., 2001; Lester, Birchwood, Tait, Shah, England, & Smith, 2008; Halsteinli, 2010), Australia continues to model innovative access strategies for nations around the globe. *headspace* is one such Australian initiative that demonstrates a clear commitment to youth mental health and comprehensive, collaborative strategies to enhance access (McGorry et al., 2007).

Created in 2006, *headspace* aims to promote and support early intervention for youth with mental and substance abuse disorders. Designed to complement and integrate primary care and specialist services, the Australian Government has supported the initiative with an investment of more than \$54 million. Thirty *headspace* youth service platforms, or 'communities of youth service' (CYSs) are being established in metropolitan, regional, rural, and remote locations across Australia to build local capacity and improve visibility. Developed and guided by a consortium of researchers and practice experts, *headspace* aims to build local and national awareness, create youth- and family-friendly services environments, promote evidenced-based interventions, and improve access through co-location, outreach, and collaboration. (Click on <http://www.headspace.org.au/> for more information).

As Canadians continue to create and improve strategies to enhance access, Australia's myriad groundbreaking research, programs, and services, *headspace* included, can serve as an evidence-base for our own innovations.

## 4.2 Strategies for Waitlist Management

While research into child and youth mental health agencies' response to wait time challenges is presently being conducted in Canada (i.e. McGrath & Cunningham, in press), a brief review of the published literature suggests several types of strategies are being practiced.

### ***Priority Tools***

In order to effectively screen and triage patients, many Canadian mental health service providers employ a variety of tools. For example, Ayliffe, Lagace, and Muldoon (2005) chronicle the development and implementation of the Mental Health Triage Assessment Tool at the Children's Hospital of Eastern Ontario (CHEO). Designed to assist triage nurses in assessing and prioritizing psychiatric patients in the emergency department at CHEO, the Tool also helps direct patients to the most appropriate care provider, either a physician or a crisis intervention worker.

On a larger scale, Barwick, Boydell, Cunningham, and Ferguson (2004), present Ontario's screening and outcome measurement initiative in children's mental health agencies. Children six to 17 years are systematically screened at selected hospital- and community-based organizations using the Brief Child and Family Phone Interview (BCFPI; Cunningham, Pettingill & Boyle, 2000). This standardized computer-based interview can be used to a variety of different ends, including identifying a client's need for services and connecting families with interim support.

The federally-funded Western Canada Waiting List (WCWL) Project has also developed a priority criteria tool for waitlist management of children's mental health services (2001). Researchers engaged with the project have established that the priority score generated by the tool is able to capture clinicians' judgments of the relative urgency of patients' needs (Smith & Haddorn, 2002). Similarly, external reviews of the priority criteria tool have concluded that it is a "useful, efficient measure of clinical urgency adequate for use in priority-setting for children waiting for mental health services," (Cawthorpe et al., 2007. p.25).

### ***Interim and Alternative Services***

Providing interim services for children and families while they wait is another approach to managing waitlists. An excellent example drawn from the field of autism services, Wong and Kwan (2010) developed a two-week early intervention for children with a new diagnosis and their families. Their research concluded that offering short-term training to parents enhanced communication and social interaction with their children and, perhaps more applicable to child

and youth mental health services, significantly reduced parents' stress-level during the long waiting time for services.

In the area of child and youth mental health services, McGarry and colleagues (2008) developed a brief consultation and advice approach to dealing with routine referrals. A time-limited, client-centered, and solution-focused strategy for dealing with common presentations, the interim service was found to lead to better clinical outcomes for children and increased satisfaction with wait times for parents.

### ***Direct Management***

A variety of direct waitlist management initiatives to shorten wait times have been tested. In the United Kingdom, Clemente and colleagues (2006) evaluated Initial Assessment (IA), a new system for managing referrals. In addition to reducing wait times, the system is also meant to reduce 'no-shows', and improve multidisciplinary collaboration. Overall, the researchers established that the IA system was associated with significantly shorter average wait times and a lower 'no-show' rate at the intervention centre where it was piloted.

Additional UK research has examined the effectiveness of an opt-in appointment system for wait list management (Woodhouse, 2006). In this system, referrals with presentations where psychological interventions are known to be helpful were prioritized over cases with characteristics of poor outcomes. Woodhouse found that attendance at first appointments was increased and wait times were significantly reduced.

While this brief review of strategies for waitlist management provides some hint of shorter wait times, there is little doubt that completion and dissemination of a pending CIHR-funded study conducted by McGrath and Cunningham will greatly advance understanding of these strategies and their usefulness in the unique Canadian context.

## 5.0 MOVING FORWARD: GUIDING PRINCIPLES, GAPS, AND OPPORTUNITIES

People of all ages have timely access to appropriate and effective mental health programs, treatments, services and supports in their community, or as close as possible to where they live or work, regardless of their ability to pay. The mental health system is centred on fostering people's mental health and meeting the full range of people's needs – however complex – in the least restrictive way possible. It is seamlessly integrated within and across the public, private, and voluntary sectors, across jurisdictions and across the lifespan. (Goal Five from *Toward Recovery & Well-Being: A Framework for a Mental Health Strategy for Canada*, 2009).

In order to achieve the Mental Health Commission's vision for timely, effective, and seamless access to care, it is imperative that gaps in research, policy, and practice in child and youth mental health care be addressed.

### ***Guiding Principles***

Moving forward, it is essential that efforts to enhance access to child and youth mental health care are guided by several key principles highlighted in this background paper.

- ◆ The fragmentation of existing services and cross-jurisdictional nature of child and youth mental health problems indicate that an actively **collaborative approach** must be adopted in all work in this area.
- ◆ As families are deeply implicated in mental health struggles and play a significant role in accessing services, either as barrier or enabler, an emphasis on **family-centred care** must permeate actions to improve service delivery.
- ◆ While there is tremendous groundbreaking work yet to be done, many frontrunners have provided leadership and begun to establish strong foundations. British Columbia, Australia, and the World Health Organization have been spotlighted, and still more innovative leaders are making change in the field. It is essential that efforts are not wasted on re-inventing the wheel, but are directed at adapting and further developing lessons already learned.
- ◆ Just as it is essential to build on lessons learned, applying **innovative and transformational solutions** to addressing access and wait times in child and youth mental health care is of the utmost importance. Innovative solutions must be carefully evaluated to establish effectiveness and appropriateness.

## 5.1 Synthesis of Gaps

***In Prevalence Data*** Despite significant epidemiological efforts at determining the prevalence of mental disorders in children and youth in the last thirty years, this paper has highlighted the highly variable and dated nature of this work. Presently, there is no current and definitive information concerning the prevalence of mental disorders and mental health problems among young Canadians. Such data is critical for mental health human resource planning.

***In Wait Time Evidence*** While the gap in the evidence of prevalence may create challenges in addressing access to child and youth mental health services, so too does the paucity of data concerning wait times in the sector. In Canada, it is entirely unclear just how long young people are waiting, which services they are waiting for, and if the services they eventually receive are appropriate, evidence-based, and effective.

***NOT in Barriers to Access*** This background paper has highlighted the strength and breadth of our understanding of the barriers to accessing mental health services for children and youth. Barriers to care have been well documented and further research in this area is not indicated; however, investigation of strategies to overcome barriers is certainly merited.

***In Access Policy*** As yet, no national policy concerning child and youth mental health exists. Although four provinces have developed policy frameworks, the degree to which each one identifies, prioritizes and operationalizes access to care is variable and little practice evidence verifies that these plans have been fully implemented. Similarly, provinces and territories without child and youth mental health policy are at varying stages of addressing the gap.

***In Wait List Management*** While the practice literature does document several strategies for addressing access and managing lengthy wait lists, there is no clear evidence on best practices in this area.

## 5.2 Suggestions for Future Work

1. Gather comprehensive data on the prevalence of mental disorders and mental health problems among Canadian children and youth using standardized protocols.
2. Measure current wait times for myriad mental health services and determine if these services meet families' needs and are appropriate, evidence-based, and effective.



3. Clarify definitional issues by developing shared language: access, wait time, wait list, and so on.
4. Build on the Canadian Psychiatric Association's *Wait Time Benchmarks* by establishing evidence-based paediatric targets for explicit levels of need and care.
5. Disseminate work presently being done on access and wait list management in a manner that empowers agencies to implement the strategies in their unique settings and mobilizes the mental health community to action.
6. Establish clear evidence of the (in)adequacy of paediatric mental health funding. If indicated, advocate for increased funding and innovative allocation of existing funding.
7. Conduct research that explores the process of building and sustaining collaborative initiatives and integrated pathways to care meant to improve access.

The challenges associated with finding systemic solutions to the complex problem of access and wait times in child and youth mental health care are daunting. Progress will require innovation, active collaboration and strategic leadership. Quality research and clear evidence will undoubtedly build the necessary foundation for positive change and lasting impact in this area. Future work and the efforts of others can be informed and guided by careful documentation and mindful exchange of current and growing knowledge. In many respects, the timing to address access in child and youth mental health is ideal. Strong partnerships are emerging with a commitment to engaging in this challenging and complex work. The National Infant Child and Youth Mental Health Consortium is one such collective of committed experts and, in partnership with CIHR, is eager to move this agenda forward.

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