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# Transitioning from Children's Mental Health to Adult Care: Stakeholder Perspectives and Tracking Service Use into Adulthood

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# Abstract

Transitioning youth from Children's Mental Health (CMH) services to adult care poses a major challenge for our mental health and health care systems. This dissertation used a mixed-methods approach to explore the challenges of caring for youth with ongoing mental health problems into young adulthood. A grounded theory *qualitative* study consisted of interviews with youth (i.e., ages 12 to 15) treated in CMH, their parents, CMH providers, and family physicians. Using administrative health record and CMH data in the province of Ontario, a complementary *quantitative* study examined the likelihood of receiving mental health services within the medical sector after the age of transfer (18 years old).

In Chapter 2, perceptions from youth and their parents revealed that common CMH disorders were viewed as long-lasting, but not necessarily persistent problems over time. Parents feared their children would disengage from needed mental health services after CMH treatment. Chapters 3 and 4 shed light on provider perspectives, specifically those of CMH providers and family physicians. The consensus view of participating youth, parents, CMH providers, and family physicians themselves was that family physicians were *"out of the loop"* or not involved with a youth's mental health care.

Chapter 5 presents the first longitudinal, case-control study in Canada to focus on the problem of transition to mental health adult care. Two key findings were: (1) youth treated in CMH were more likely than the general population to have a mental health visit in the medical system during and after CMH treatment; (2) most factors that significantly predicted having a mental health related visit in the medical system after age 18 were related to prior service utilization in either CMH or the medical system. Overall, youth treated in CMH continued to receive mental health services in the medical sector as young adults.

The combined findings presented across this dissertation revealed two common themes. First, the ongoing mental health needs of some children and youth are unlikely to be met within the CMH system. Second, there is uncertainty about the role of family physicians in caring for youth who are treated in CMH. Implications for policy and practice are discussed.

Keywords: children's mental health, transition to adult care, primary health care, Ontario

# Co-Authorship Statement

This dissertation is composed of four manuscripts, which were prepared by Kyleigh Schraeder as part of her dissertation. Ms. Schraeder conducted all participant interviews, statistical analyses, and wrote the manuscripts. Feedback from Ms. Schraeder's supervisory committee was provided during the preparation of these manuscripts. The manuscripts are mainly the work of Ms. Schraeder, thereby ensuring that the integrity of the academic dissertation and Ms. Schraeder as an independent researcher are maintained.

The manuscripts submitted for publication are not the same as the versions presented in this dissertation and may involve editing and revisions based on journal reviewers' feedback. The first three manuscripts submitted for publication are co-authored by Dr. Graham Reid, Ms. Schraeder's thesis supervisor, and Dr. Judith Brown, who was a co-investigator on both studies and provided input on the qualitative design and analyses. The final manuscript is co-authored by Drs. Graham Reid and John Cairney, a member of the advisory committee, who provided input on statistical analyses. Dr. John Cairney is a Scientist at the Institute of Clinical Evaluative Sciences (ICES) and served as Ms. Schraeder's ICES supervisor. Co-authorship was determined based on the guidelines for authorship developed by the International Committee for Medical Journal Editors. At the time this dissertation was submitted in August 2017, two manuscripts (Chapters 2 and 5) were accepted for publication by peer-reviewed journals. Journals were informed that manuscripts would be submitted in the electronic thesis repository at The University of Western Ontario.

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# List of Acronyms

ADHD = Attention Deficit Hyperactivity Disorder

AMHS = Adult Mental Health Services

BCFPI = Brief Child and Family Phone Interview

CMH = Children’s Mental Health

CGT = Constructivist Grounded Theory

FP = Family Physician

ICES = Institute for Clinical Evaluative Sciences

MHLTC = Ontario’s Ministry of Health and Long-term Care

NICE = National Institute for Health and Care Excellence

OHIP = Ontario Health Insurance Plan

OHIP-MH = Mental health visit in medical system (OHIP)

OHIP-Health = General health visit in medical system (OHIP)

ON-MARG = Ontario Marginalization Index

PHC = Primary Health Care

TRACK = Tracking Adolescents into Adulthood Study (Singh, 2008)

UK = United Kingdom

US = United States

# Chapter 1

## 1 General Introduction

The global prevalence of mental illness among children and adolescents is 10-20%, and incidence rates are expected to increase by 50% over the next 10 years (Canadia Pediatric Society, 2006; World Health Organization, 2015). In Canada, 15-18% of children and adolescents (1.1 million individuals) have a diagnosable mental health disorder (Offord, Boyle, Fleming, Blum, & Grant, 1989; Waddell, Offord, Shepherd, Hua, & McEwan, 2002). For many youth, these disorders will last into young adulthood (Canadian Community Health Survey, 2002; Kessler et al., 2005). The life-long costs of children's mental health (CMH) problems include: poor academic and occupational success; substantial personal, interpersonal and family difficulties; increased risk for physical illness (e.g., heart disease, Type II diabetes); shorter life expectancy and increased risk for suicide; criminal behavior and substance abuse (Davidson, Cappelli, & Vloet, 2011; Kutcher, 2011; Mental Health Commission of Canada, 2010; Richards & Vostanis, 2004). Though CMH problems should be treated early and effectively, some youth will require additional treatment as young adults. The overarching goal of this dissertation was to explore key issues related to transitioning youth from CMH to adult care. A mixed-methods approach was used. Perspectives were obtained from youth treated for CMH problems, their parents, CMH providers, and family physicians about the *possibility* of requiring adult care. Mental health service utilization during childhood, adolescence, and young adulthood amongst individuals who have received CMH services in Ontario was also examined.

Evidence from three areas of research support the need for this work. First, the scope of the problem, in terms of caring for youth with ongoing and recurring mental health problems, is defined by reviewing the natural history of child psychopathology and relevant evidence from longitudinal treatment studies. Second, existing research that has examined the issue of transition from CMH to adult care is reviewed. This will highlight gaps in our understanding of how care should be provided to youth during the transition period. Third, the role of Primary Health Care (PHC) providers, particularly family physicians, in caring for youth who require transition to adult care is explored. PHC is highly relevant to CMH because family physicians are the only professionals who follow patients across the lifespan. Lastly, the general objectives for each manuscript in this dissertation and a rationale for the mixed methods approach are provided.

## 1.1 Scope of the Problem: Children's Mental Health Problems Can Be Long-Lasting

### 1.1.1 The Natural History of Child Psychopathology and Longitudinal Treatment Studies

Approximately three quarters of adults with a mental illness recall the onset of their mental health problems occurred before 24 years of age (Kessler et al., 2005). Broad-band forms of childhood psychopathology, including anxiety and mood problems [e.g., (Albano, Chorpita, & Barlow, 2003; Hammen, Brennan, Keenan-Miller, & Herr, 2008; Rohde, Lewinsohn, Klein, Seeley, & Gau, 2012)], and attention and behavior problems [e.g., (Broidy et al., 2003; Bussing, Mason, Bell, Porter, & Garvan, 2010)], exhibit considerable continuity and persistence. For example, research shows depressed and anxious youth confer a two- to three-fold risk for these disorders in early adulthood (Pine, Cohen, Gurley, Brook, & Ma, 1998). Although some youth (10-18%) exhibit a persistent or un-remitting course of these problems into adulthood [e.g., (Dunn & Goodyer, 2006)], most tend to experience an *episodic* course marked by brief "symptom-free" periods of remission (i.e., at least 2 months asymptomatic or having minimal symptoms independent of treatment) (Emslie et al., 1997; Frank et al., 1991). Indeed, remission rates for depression and anxiety disorders are reported to range from 64% to over 90% within 1.5 to 2 years after onset (e.g., Birmaher et al., 1996; Birmaher et al., 2004; Essau et al., 2002). Community-based samples show, however, that problems will recur for many (40-70%) depressed and anxious youth (e.g., Beesdo-Baum et al., 2012; Birmaher et al., 2004; Dunn & Goodyer, 2006; Rao, Hammen, & Poland, 2010). For youth (aged 6-19 years) treated for a disruptive behavioural disorder, such as Attention Deficit-Hyperactivity Disorder (ADHD) or oppositional defiant disorder, about 14% do not fully recover 15 years after onset (Biederman, Petty, Evans, Small, & Faraone, 2010; Bussing et al., 2010; Keller et al., 1992).

Even for youth who receive an evidence-based treatment for their CMH problems, recurrence is common. Notably, recurrence amongst children and youth treated for depression is reported to be as high as 47% within five years after having received cognitive-behavioural therapy or a pharmacological treatment (Curry, Silva, Rohde, Ginsburg, & Kratochvil, 2011; Kennard et al., 2009). Anxiety disorders also tend to recur following treatment; up to half of youth treated for anxiety have been shown to return for additional treatment years later (Manassis, Avery, Butalia, & Mendlowitz, 2004; Nevo & Manassis, 2009). In general, our understanding of the course of CMH problems following treatment is very limited. Very few longitudinal treatment studies have actually reported on long-term outcomes, such as disorder recurrence or persistence (Curry, 2014). Further, methodological variability in sample characteristics (e.g., age of participants), definitions of outcomes (e.g., recurrence) and predictive risk factors (e.g., severity, comorbidity), assessment instruments, and the frequency and timing of follow-up assessments complicate interpretation of study findings. What we do know from existing treatment studies [e.g., (Curry et al., 2011; Vitiello et al., 2011)] is that even the best available evidence-based treatments do not necessarily provide long-term, disorder-free periods for children and youth following a single course of treatment. Research is needed to better our understanding of who is most likely to experience ongoing and recurring mental health problems following CMH treatment.

### 1.1.2 Research on CMH Service Utilization

Longitudinal research on service utilization among youth and families involved with the CMH system is an area of research that also highlights the ongoing and recurring nature of CMH problems (Chavira, Garland, Yeh, McCabe, & Hough, 2009; Yeh et al., 2002). Of particular relevance to this dissertation, a large-scale administrative study examining service utilization (i.e., mental health visits) over time across five CMH agencies in the province of Ontario revealed five patterns of service use (Figure 1.1). Almost one quarter of all youth (ages 4 to 11; N = 5, 206) exhibited ongoing care lasting more than one year (Reid, Stewart, et al., 2011a). The total number of “episodes of care” [i.e., 3 visits with 180 days between episodes (Reid et al., 2014)], was considered for each youth over a 4-year period. A total of 14% of youth had two or more episodes of care over a four-year period, with an average length of time *between* episodes longer than one year (*M* = 17 months between first and second episode; *M*=

13 months between the second and third episode). Again, these findings suggest a sizeable percentage of youth require *ongoing*, albeit not *continuous*, care. Assuming 15% of children or youth receiving CMH have ongoing or recurring mental health problems, an estimated 22, 500 children a year in Ontario require ongoing care (Children's Mental Health Ontario, 2012).

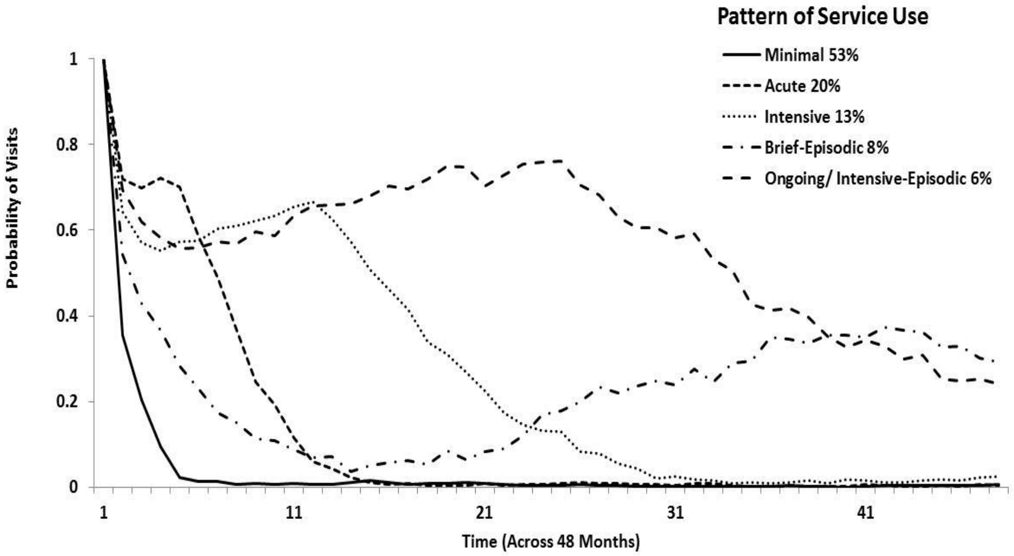

**Figure 1.1: Latent class cluster analysis of visits to five Children's Mental Health (CMH) agencies in Ontario, across four years (N = 5,632)**

From: From: Reid, G. J., Stewart, S. L., Barwick, M., Carter, J. R., Evans, B., Leschied, A. W., Neufeld, R. W. J. Predicting and understanding patterns of service utilization within children's mental health agencies. In Problems, Preferences, Service Use and Outcomes: Children's Mental Health Services in Canada. G. Reid (Chair) Symposium presented at the American Psychological Association meeting, Toronto, ON.

Visit data were re-categorized to reflect whether a child had face-to-face (as opposed to telephone) contact during a given month, beginning at the month of the child's first visit. Multi-level latent class cluster analyses of face-to-face visits (outpatient, day-treatment or residential) were conducted. A 5-cluster solution was viewed as the best solution based on both statistical criteria and conceptually-meaningful distinctions between clusters. Labels show the proportion of children in each cluster. The Y-axis indicates the probability of a visit in a given month.

### 1.1.3 Relevance to Transitions to Adult Care

Why focus on children and youth who have ongoing and recurring mental health problems? Youth with these problems will likely require transfer to adult care. Seamless mental health care from childhood and adolescence into young adulthood should be considered a priority for youth, given that this period is marked by major physiological, emotional, and social changes in a young person's life. Yet, transitioning youth from CMH to adult care is often poorly managed (Cappelli et al., 2014; Davidson et al., 2011; Embrett, Randall, Longo, Nguyen, & Mulvale, 2015; Mulvale et al., 2016; Paul, Street, Wheeler, & Singh, 2014; Singh & Tuomainen, 2015). Before reviewing the literature on transitions to adult care in mental health, key terms relevant to this area are defined below.

*Transition* has been defined in the health care literature as "the purposeful, planned movement of adolescents with chronic physical and mental conditions from child-centered to adult-oriented health care systems" that is intended "to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive" (p. 570, Blum et al., 1993). The process of transition can be distinguished from *transfer*, or the moment when responsibility for patient care is "handed off" to a provider in the adult system. Paul et al. (2013), for example, describes transfer between CMH to specialized Adult Mental Health Services (AMHS) as "an event or transaction between [child and adult] services".

The *age of transfer* will hereafter refer to age 18 years in this dissertation. This age can vary by jurisdiction and even by mental health center. In the province of Ontario, funding for mental health services shifts from primarily the Ministry of Children and Youth Services (MCYS) to the Ministry of Health and Long-Term Care (MHLTC) when a youth turns 18 (Kutcher, Hampton, & Wilson, 2010). In the United States (US), most states end CMH at age 18, while a few serve youth up to the age of 21 (Davis & Sondheimer, 2005). In the United Kingdom (UK), CMH teams generally do not accept patients aged 16 to 18 years, most only see youth up to the age of 16 or 'school-leaving' age, yet the lower age limit for the majority of AMHS in the UK is 18 years (Belling et al., 2014; Singh, Paul, Ford, Kramer, & Weaver, 2008). In Australia, mental health reform is currently underway to implement an enhanced primary care model that promotes and supports youth aged 12 to 25 years with mental illness (McGorry, Bates, & Birchwood, 2013).

There are no clear, evidence-based guidelines about who should transfer to adult care. The *episodic* or *recurring* course of common CMH problems likely contributes to this problem. For example, there may be uncertainty about the need for adult care for those who are asymptomatic at the age of transfer. Youth might be discharged from CMH services when problems remit and subsequently “fall-through-the-cracks” when problems recur months or years later. Transitions to adult care need to be further examined for youth at-risk of ongoing and recurring problems.

## 1.2 Research on Transitions from CMH to Adult Care

Prior work on the issue of transition from CMH to adult care has primarily focused on older youth (i.e., ages 16 to 24 years) who have transferred to specialized Adult Mental Health Services (AMHS), which tends to focus on treating severe and enduring mental illnesses (e.g., schizophrenia, psychosis). This important work has shed light on the numerous barriers that youth encounter in attempting to re-access services as older adolescents or young adults. Existing studies are reviewed below and outline the gaps in our current knowledge on transitions from CMH to adult care.

### 1.2.1 Quantitative Studies

To date, two studies have attempted to follow adolescents treated for mental health problems beyond the age of transfer (Cappelli et al., 2014; Singh et al., 2010). The TRACK study, based in the UK, was the first to identify a cohort of 16 to 21 year olds (N = 154) who had received CMH within the UK’s National Health Services and assessed their access to AMHS. Of the total sample, 85% (n = 131) were considered “suitable” for adult services by CMH providers. However, only 49% of youth actually transferred to AMHS. Being accepted by AMHS was predicted by having a severe or enduring mental illness (i.e., schizophrenia, psychotic disorders, bipolar affective disorder, or depression with psychosis) at the age of transfer. Over a third (n = 52, 40%) of youth were not referred by CMH providers to AMHS, and few youth (6%) simply did not meet AMHS eligibility criteria (Paul et al., 2013). CMH providers' decisions not to refer youth to AMHS were based on a common belief that AMHS would not accept the referral or have the appropriate services. In a recent secondary data analysis of the TRACK study (Islam et al., 2016), over half of youth (56%; N = 52) who were not referred to AMHS were discharged to their family physician; one quarter continued to receive CMH services beyond the age of transfer. Few referred youth (n=7) were rejected by AMHS; they were discharged to their family physician and/or continued with CMH care.

A recent Canadian study (Cappelli et al., 2014) examined outcomes for a cohort of youth (N=215) aged 16 to 20 years (*M*=17.63; *SD*=0.78). These youth received services from CMH agencies located in Ottawa, Ontario, and who were referred to a transitional program (i.e., the Youth Transition Project), using a shared management model approach (Kieckhefer & Trahms, 2000). Unlike the TRACK study, *all* youth in this study were considered suitable for AMHS based on the fact they met eligibility criteria for a referral to the transitional program. However, eligibility criteria were not reported. In this study, AMHS consisted of general hospitals, mental health centers, community youth services agencies, substance abuse treatment centers, community health centers, anxiety groups, and private psychologists. (NB: referrals to family physicians or other providers within the medical sector were not examined). The majority of youth had a comorbid disorder (64%) and a family history of mental illness (56%) (Cappelli et al., 2014). Youth were assessed at specific time points during the transition process: (1) time of referral to the program, (2) during the initial assessment with the coordinator, and (3) following transition to AMHS (if successful). Of the total sample, 59% (n = 127) completed their transition and were seen by an AMHS provider. This group was reported to be more psychologically distressed and presented with more significant internalizing disorders (e.g., depression). The remaining youth were either wait-listed for AMHS (19%) or cancelled services (22%; i.e., declined further services, moved away). Wait-listed youth were more likely to have behavioral disorders.

Findings from these two studies highlight three important issues: (1) there are no clear guidelines within CMH to identify who should transfer to AMHS; (2) only youth with the most severe problems, and those without behavioural disorders, are most likely to transfer; and (3) many older adolescents may continue to be seen in CMH. Without consistent criteria about who should transfer to adult care, programming and planning of transition services are impaired, and

CMH providers likely will encounter challenges in caring for youth with ongoing and recurring problems beyond the age of transfer. This has yet to be examined. Specifically, do CMH providers anticipate youth clients and families to need ongoing care? If so, how do they provide this care within CMH?

### 1.2.2 Qualitative Studies

A total of 14 studies, including the TRACK study (Singh et al., 2010), have examined the issue of transition qualitatively (Appendix 3). The perspectives of *youth* were obtained in six studies (Jivanjee & Kruzich, 2011; Jivanjee, Kruzich, & Gordon, 2009; Singh et al., 2010; Thomas, Pilgrim, Street, & Larsen, 2012; Williamson, Koro-Ljungberg, & Bussing, 2009), *parents* were involved in five studies (Gilmer, Ojeda, Leich, et al., 2012; Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Singh et al., 2010; Swift et al., 2013), and *service providers* (e.g., CMH or AMHS clinicians) were involved in five studies (Belling et al., 2014; Davis et al., 2005; McLaren et al., 2013; McNamara et al., 2013; Singh et al., 2010; Thomas et al., 2012). One study interviewed policy administrators and mental health directors in the US (Davis & Sondheimer, 2005). Two studies (Dimitropoulos, Tran, Agarwal, Sheffield, & Woodside, 2012; Swift et al., 2013) focused on issues related to transitions for a specific mental health disorder (i.e., ADHD, eating disorder) and all studies focused on youth who had transferred to AMHS.

Semi-structured qualitative interviews were conducted in the TRACK study with a subsample of patients (n = 11) who had transferred to AMHS; parents and AMHS providers were also interviewed about the process of transfer (Hovish, Weaver, Islam, Paul, & Singh, 2012; Singh et al., 2010). Emergent themes included barriers related to transition and the issue of parental involvement. Although parents play an essential role in the mental health care of their children, whether to involve parents in the mental health care of older adolescents and young adults is less clear. Thus, while parents may be reluctant to concede responsibility for mental health care to the adolescent, providers may be reluctant to involve parents in mental health care even when adolescents continue to reside with them.

Across studies, emergent themes included the need for stronger patient-provider relationships (Gilmer, Ojeda, Leich, et al., 2012) and continuity of relationships between youth and families with key providers during the transition period (Hovish et al., 2012; Singh et al., 2010). A lack of adequate time for transition preparation, or feeling that transition planning started too late (Jivanjee et al., 2009), as well as lengthy wait times for adult services (Gilmer, Ojeda, Leich, et al., 2012; Hovish et al., 2012; Singh et al., 2008) were frequently reported as barriers to transition. One study revealed that youth (ages 17-19 years) with ADHD viewed potential transfer as inconvenient and “unnecessary” (Swift et al., 2013). This raises concerns about how youth are prepared for transition, and whether youth and their parents anticipate the possible need for adult care.

To date, qualitative research on the issue of transition in mental health has focused on older youth, ranging in age from 16 to 24 years, who have transferred to AMHS. If transfer to adult care is needed, preparing for that transition well before the actual event would be helpful. However, does the parent of a 10-year old, who is currently struggling with generalized anxiety and was treated as a preschooler for separation anxiety, even consider that their child might require mental health care services as an older adolescent, let alone the possibility of needing to transfer to adult care? No previous literature exists to answer this question and no previous studies have asked younger adolescents (ages 12 to 15) or their parents for their views about the possibility of requiring mental health services as young adults.

Another issue is *when*, and *by whom*, discussions about transition should occur. Premature or delayed discussions of the need for transfer can increase the possibility of distress for youth and their families. For chronic physical health problems (e.g., diabetes, cystic fibrosis), it is recommended that discussion of transition should begin at age 14 years (American Academy of Pediatrics, 2002) and age 12 years for some conditions (Sable et al., 2011); others have recommended the transition process should start in childhood or at the time of diagnosis by “envisioning a future” (Reiss & Gibson, 2002). Chronic physical health problems are relatively stable over time and sub-populations requiring transfer can be defined by delineating other disease-relevant parameters (e.g., severity). For example, although Reid et al. (2004) used established definitions for severity amongst patients with congenital heart disease to document the proportion of individuals who “successfully transferred” to appropriate adult care at specialized adult congenital heart disease centers, defining mental health populations in need of transfer is not as straightforward.

A number of factors need to be considered from the perspective of youths, their families, and their CMH providers. If transfer to AMHS has not been considered, then discussion of this possibility might in fact be harmful, especially given the possible stigma associated with labeling a young person as having “chronic” mental health issues. As such, extrapolating findings from the literature on pediatric chronic illness to children and youth with mental health problems is likely inappropriate. Perspectives from PHC providers, such as family physicians, are also needed. The role of family physicians in the transition process for youth with CMH problems has been a neglected area of research. This will be reviewed in the following section.

## 1.3 Providing Mental Health Care to Children and Youth in Primary Health Care (PHC)

PHC has been envisioned as “the first point of care for people with mental health problems and the place where ongoing care could be monitored and coordinated” (pp.4) (Kates et al., 2011). Family physicians are in a unique position to monitor youth as they are essentially the only health professionals who routinely follow individuals across the lifespan. Following specialized CMH treatment, youth at-risk of recurring mental health problems might benefit from follow-up care. Providing this type of care within PHC for youth has been recommended (Schraeder & Reid, 2017; Singh, Anderson, Liabo, & Ganeshamoorthy, 2016), but not yet examined.

The positive impacts of integrating mental health care into PHC have long been recognized (Kelleher, Campo, & Gardner, 2006; Unutzer, Schoenbaum, Druss, & Katon, 2006; van Orden, Hoffman, Haffmans, Spinhoven, & Hoencamp, 2009; Woltmann et al., 2012). Mental health care within PHC has been viewed as more accessible, less stigmatizing, and more comprehensive since it manages both physical and mental health problems (Campo, Bridge, & Fontanella, 2015; Kutcher, Davidson, & Manion, 2009; Rothman & Wagner, 2003). In only the last decade, however, have systematic approaches to effectively address mental health in PHC been undertaken at a national level in countries such as Canada [e.g., (Kates et al., 2011; Kutcher, 2011; Leitch, 2010; Pawlenko, 2005)], the US [e.g., (Campo et al., 2005; Kelleher et al., 2006)], and the UK [e.g., (Appleton, 2000; National Institute for Clinical Excellence (NICE), 2005)] and at a global level (World Health Organization, 2010). In Canada, a significant improvement in the integration of PHC and mental health service delivery has been reported (Fleury, Imboua, Aube, & Farand, 2012; Kates et al., 2011; Kutcher, 2011). PHC and mental health policy frameworks have been developed to support collaborative care in each province and territory (e.g., PHC Transition Fund, the Collaborative Mental Health Network), progress has been made on reducing legislative, service delivery, and funding barriers to collaborative care, and the availability and use of technology supports are increasing (Pawlenko, 2005; Romanow, 2002).

Very few studies have examined the issue of integrating mental health care within PHC specifically for children and youth (Kutcher, 2011; Kutcher et al., 2009; Tobon, Reid, & Brown, 2015) and none have focused on transition to adult care. Collaborative care between CMH and PHC has primarily centered on the *assessment* (e.g., screening or recognition) [e.g., (Gardner, 2014; Gardner et al., 2010; Gardner, Kelleher, Pajer, & Campo, 2003; Kelleher, McInerny, Gardner, Childs, & Wasserman, 2000) or *short-term treatment* of mental health problems [e.g., (Asarnow et al., 2009; Campo et al., 2005; Kelleher et al., 2006; Richardson, McCauley, & Katon, 2009). For youth with recurring and ongoing mental health problems, maintaining collaborative relationships between CMH and PHC care *after* a youth has received specialized care within the CMH system could be beneficial.

Recent NICE guidelines emphasize the need to engage PHC providers in transition planning for youth (Singh et al., 2016). Yet, research suggests PHC providers experience difficulty managing youth who have ongoing and complex needs, and involvement with multiple sectors of care (Tobon et al., 2015). Similar barriers have been encountered in managing chronic health problems, where “care is delivered by a shifting roster of individuals who are often not well coordinated or connected; they are distributed across several institutions and settings in which values, routines, tools, and resources may differ” (Lingard & Mcdougall, 2013, p. 903). The challenges of incorporating routine monitoring into the care of older youth and young adults at risk for recurring mental health problems, and the unique issues within PHC, need to be identified and solutions tested. Perspectives from PHC providers are therefore needed to understand the potential barriers and implications for integrating PHC with CMH.

## 1.4 Summary

Caring for youth with recurring CMH problems is an ongoing challenge in our mental health care system. Without appropriate follow-up into young adulthood, youth with recurring CMH problems might disengage from mental health services during a time when they need them most. The existing literature on transition to adult care draws predominately on interviews with young adults (ages 16-25) and their parents on their experiences transferring to AMHS [e.g., (Hovish et al., 2012; McNamara et al., 2013; Paul et al., 2013)]. Perspectives from younger youth (12 to 15 years old), their parents, and CMH providers is needed to improve our understanding about how and when discussions related to transition to adult care should occur.

The integration of PHC with CMH and adult services needs to be understood and supported. Youth treated in CMH may be discharged to their family physician or another medical health professional following treatment. Yet, the proportion of youth seen by one of these providers after the age of transfer is virtually unknown. The lack of a shared electronic record database between CMH and medical systems contributes to this problem. No studies to date have examined perspectives from family physicians on their involvement in the mental health care of youth treated in the CMH system. Other than the TRACK study (Singh et al., 2010), no longitudinal research exists on the involvement of family physicians and/or other health professionals (e.g., pediatricians, psychiatrists) in caring for youth following CMH treatment, and as young adults. A better understanding of what happens with youth treated for CMH problems as young adults is needed to inform the development of new models of mental health care that can strengthen our system. Exploring mental health service use amongst young adults within the medical sector is especially needed. The present dissertation aimed to explore these issues.

## 1.5 Overview of Dissertation

The specific objectives for this dissertation were to:

1. Examine perspectives of younger youth (ages 12-15 years) and their parents about the course or expected duration of their mental health problems, and the possibility of requiring mental health services in adulthood. (Chapter 2)

2. Examine the challenges of caring for youth with ongoing and recurring mental health problems within the CMH system from the perspective of CMH providers. (Chapter 3)

3. Examine the role of family physicians in a youth’s mental health care from the perspective of youth involved with CMH, their parents, CMH providers, and family physicians themselves, and the possibility of incorporating routine monitoring within PHC. (Chapter 4)

4. Examine predictors of mental health service use within the medical sector after the age of transfer by youth who have received CMH services in the province of Ontario. (Chapter 5)

A mixed-methods approach was used to address these objectives. This methodology is particularly useful in health care research, as only a broader range of perspectives can do justice to the complexity of the phenomena studied (Östlund, Kidd, Wengström, & Rowa-Dewar, 2011). This type of approach was therefore well suited to examining the issue of transition to adult care. The integration of both qualitative and quantitative data allowed for a more comprehensive and complete picture than what could have been achieved using a single approach (Creswell, Plano, Guttman, & Hanson, 2003; Östlund et al., 2011).

Mixed-methods studies can vary in their design. This is based on three essential components: (a) the *priority* given to quantitative or qualitative data in a given study, (b) the *implementation* sequence (concurrent or sequential), and (c) the phase of research in which the *integration* or relationship between quantitative and qualitative data occurs (Creswell, Fetters, & Ivankova, 2004; Creswell et al., 2003; Tashakkori & Teddlie, 1998). In this dissertation, equal weight was given to both qualitative and quantitative study findings as they played an equally important role in addressing the research problem. A *parallel design* involved both qualitative and quantitative data being collected and analyzed concurrently, due in part to reasons of practicability that considered the time required to complete both studies. The integration of qualitative and quantitative data occurred at the interpretation and conclusion phase (Figure 1.2), in line with a triangulation design model (Creswell et al., 2004).

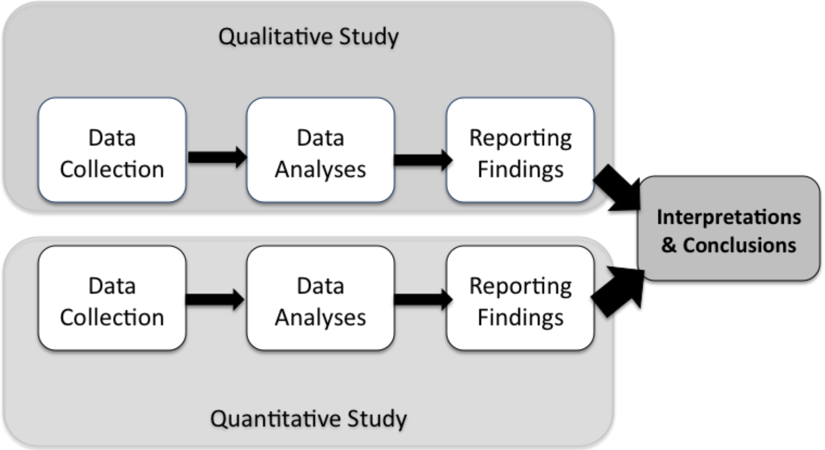

**Figure 1.2: Parallel mixed methods design.**

The first three objectives of this dissertation were addressed by a qualitative study using a multi-perspective approach. Interviews with youth (12 to 15 years old), their parents, CMH providers, and family physicians were conducted. Findings are presented in Chapter 2 (Objective 1), Chapter 3 (Objective 2), and Chapter 4 (Objective 3). The final objective of this dissertation was addressed by a quantitative study which involved a data linkage between administrative CMH visit data across the province of Ontario and corresponding health record information held at the Institute for Clinical Evaluative Sciences (ICES). This linkage allowed for prediction analyses of mental health service utilization (i.e., by a family physician, pediatrician, or psychiatrist) after the age of transfer amongst youth who had received CMH services. Together, these studies aimed to provide information necessary to gain a better understanding of transition to adult care and to develop stronger links between CMH and PHC.

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# Chapter 2

# 2 “I think he will have it throughout his whole life”: Parent and Youth Perspectives about Children’s Mental Health Problems

## 2.1 Abstract

Children’s mental health (CMH) problems can be long-lasting. Even amongst children and youth who receive specialized CMH treatment, recurrence of problems is common. It is unknown whether youth and their parents view CMH problems as chronic. This has important implications for how CMH services should be delivered. This Grounded Theory study gained perspectives from youth (aged 12 to 15) who have received CMH treatment (n = 10) and their parents (n = 10) about the expected course of CMH problems. Three disorder trajectories emerged: (1) *not chronic*, (2) *chronic and persistent*, and (3) *chronic and remitting;* with the majority of youth falling in the third trajectory. A gap in available services between CMH and adult care was perceived by parents, leaving them either *“help hopeful”* or *“help hungry”* about their child’s future care. Improving care for youth with ongoing mental health problems is needed to minimize costs to families and the system.

## 2.2 Introduction

Some mental health disorders (e.g., schizophrenia, bipolar disorder) that are viewed as *chronic* conditions share three characteristics: (1) prolonged in their duration, (2) do not resolve spontaneously, and (3) rarely cured completely (Stanton, Revenson, & Tennen, 2007). For children and youth, chronic disorders are defined as “any physical, emotional, or mental condition that prevents him/her from attending school regularly, doing school work, or doing usual childhood activities, and that require frequent attention or treatment from a health professional” (Van Cleave, Gortmaker, & Perrin, 2010, p. 624). Only a small percentage (10%) of children and youth will experience a mental health disorder that is *unremitting* (Dunn & Goodyer, 2006). In contrast, many mental health problems tend to follow an *episodic* course.

In community-based and clinical samples, over 70% of depressed youth experience a recurrence within 5 years (Lewinsohn, Clarke, Seeley, & Rohde, 1994; Rao et al., 1995). Anxiety disorders also recur and last into young adulthood (Essau et al., 2002; Pine, Cohen, Gurley, Brook, & Ma, 2013). Youth diagnosed with a disruptive behavioural disorder experience high rates of recurrence (50-71%) (Keller et al., 1992). Even amongst youth who receive specialized children’s mental health (CMH) treatment, problems are likely to recur; rates of relapse are as high as 47% following treatment for depression (Curry et al., 2011).

We might consider recurring mental health problems to be chronic, given their long-lasting impact on youth. It is unknown, however, whether youth and parents[1] share this view. Does the mother of a 13-year old, who is struggling with generalized anxiety and who was treated for attention problems years earlier, consider that her child might require mental health services as an older adolescent? Examining youth and parent perceptions about the course of CMH problems is needed to better understand how youth and families use services over time.

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[1] This includes cases in which the youth may be cared for by someone other than a parent (e.g., grandparent).

### 2.2.1 Conceptualizing the Course of Childhood Mental Health Disorders

When individuals are diagnosed with an illness such as diabetes or cancer, they strive to make sense of it (e.g., where it came from, how long it will last). Based on theoretical models for conceptualizing illnesses [e.g., Self-Regulation Model (Hagger & Orbell, 2003; Leventhal, Leventhal, & Contrada, 1998)], the perceived *timeline* of an illness (i.e., chronic, acute) guides individuals' coping and help-seeking behaviours (Hagger & Orbell, 2003). For children and youth, parents also develop perceptions about their child's illness. Very little research has examined perspectives from youth and parents about the course or timeline of CMH problems.

#### 2.2.1.1 Parent Perspectives

Only two studies to date have assessed parental perceptions of CMH problems (Shanley, Brown, Reid, & Paquette-Warren, 2015; Shanley & Reid, 2015). In one study (Shanley & Reid, 2015), parents completed measures of child psychopathology and a modified version of the Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002) for CMH problems: Parents' Illness Perception–Children's Mental Health. Higher problem severity was correlated with parents' views that problems were longer and more cyclical/recurring. As noted by the authors, this finding might be explained by the relationship between problem severity and parental burden [e.g., (Brannan, Athay, & De Andrade, 2012). Thus, highly burdened parents might experience additional difficulties in caring for their child which might prolong problems. Parents were also found to be more likely to accept certain treatments (i.e., family therapy, medication) when they perceived their child's problems as long-lasting. Parents might be open to trying medication, for example, if they believe their child's problems are not short-term. That said, prior experiences with receiving CMH treatment for their child might also influence parents' perceptions about the course of their child's problems; this has not been examined.

Parent perceptions of CMH problems have been examined qualitatively. Interviews with parents about the potential *causes* of their child's problems reveal substantial diversity in the complexity of their views (Shanley et al., 2015). Parents' own experiences with receiving mental health treatment might result in more complex views. Variation in parents' understanding of the *onset* of their child's problems likely also exists for how parents conceptualize the *course* of CMH problems. Qualitative methodology is well-suited to capture such complex perceptions.

#### 2.2.1.2 Youth Perspectives

Amongst youth receiving CMH treatment, two clinic-based studies (Imran, Azeem, Chaudhry, & Butt, 2015; Munson, Floersch, & Townsend, 2009) examined illness perceptions using the IPQ-R (Moss-Morris et al., 2002). In both studies, over half of youth viewed their mental health problems as chronic or recurring and to have major consequences on their lives. This work was limited by a narrow focus on a culturally-specific [e.g., Pakistani youth (Imran et al., 2015)] and disorder-specific sample [e.g., conversion disorder (Imran et al., 2015); depression and bipolar disorder (Munson et al., 2009)]; a broader scope of research is therefore needed to examine this issue.

If youth and parents perceive CMH problems to be chronic, this has important implications for how mental health services should be delivered. Youth at-risk of recurring problems might require additional care as young adults. No studies have asked youth or their parents about the possibility of needing mental health services in adulthood. The issue of transition from CMH to adult care is relevant in this case.

### 2.2.2 Transitioning from CMH to Adult Care

In many countries, including Canada, the age of transfer (when youth become ineligible for CMH services) is 18 years old. Transitioning youth from CMH to adult care is poorly managed (Mulvale et al., 2016). For youth with recurring problems, managing this transition is difficult as existing transition services tend to focus on youth with severe and enduring mental illnesses (e.g., schizophrenia). Youth who receive CMH treatment encounter numerous barriers when attempting to re-access services as young adults (e.g., Davis, 2003; Singh, 2009). Amongst those who transfer, lengthy wait-times for Adult Mental Health Services (AMHS) reinforce a common view that transition planning starts too late (Jivanjee et al., 2009).

For chronic physical health conditions (e.g., diabetes, cystic fibrosis), discussions about transition should begin at age 14 years (American Academy of Pediatrics, 2002), at age 12 years for some conditions (Sable et al., 2011), and at the time of diagnosis by 'envisioning a future' (Reiss & Gibson, 2002). Chronic physical disorders are relatively stable over time and the need for long-term supports is recognized at the age of diagnosis. Determining future service needs for youth with CMH problems, where the disorder course is often episodic and marked by “symptom-free” periods, is much less clear. The stigma associated with labeling a child as having a “chronic” mental health issue needs to be considered.

No studies to date have examined the *possibility* of requiring adult care amongst youth still engaged with CMH. The literature on transitions in mental health draws predominately on interviews with young adults (ages 16-25) transferring to AMHS [e.g., (Hovish et al., 2012; McNamara et al., 2013; Paul et al., 2013)]. A focus on younger youth (ages 12-15) in this study addresses a major gap in the literature caused by a focus on young adults with mental health problems.

## 2.3 The Current Study

The objectives of the current qualitative study were: (1) to gain perspectives from youth and parents about the course or expected duration of CMH problems, and (2) to examine views about the possibility of needing mental health care in young adulthood.

## 2.4 Methods

Constructivist Grounded Theory (CGT) was selected as the optimal qualitative methodology as it tends to be more abstract and has the potential for improving understanding or offering explanation, compared to descriptive methods (Charmaz, 2006, 2014). The purpose of CGT is to build an explanatory theory by examining how participants construct meanings and actions for specific circumstances. The constructivist approach assumes the resulting theory is an interpretation of the data, which depends on the researchers’ views and their relevant expertise.

### 2.4.1 Recruitment Procedures

Youth and their parents were recruited from two CMH agencies located in London, Ontario, Canada. Youth were eligible if they: (a) were 12 to 15 years old; (b) currently resided with a parent/guardian; (c) had been receiving care for 1 year or longer at the agency, or for at least 9 months with a previous episode of care (i.e., 3 face-to-face visits) within the previous 5 years (Reid et al., 2014); and (d) could be interviewed in English. Youth with extensive involvement with CMH were purposefully recruited to allow for questions about ongoing care needs. Parents were eligible if they were the legal guardian of eligible youth. Consent to participate in the study included the agreement to be audio-recorded.

A list of potentially eligible youth was generated by a supervisor at each agency, who also initiated recruitment by contacting CMH providers of eligible youth and informing them about the study. Providers supplied families with a contact information form inviting them to participate in the study and allowing a Research Assistant (RA) to contact them. Interested families were contacted by telephone by the RA who confirmed interest and conducted a brief screening to ensure eligibility. Youth and their parents provided verbal consent prior to scheduling the interviews; consent involved allowing the RA to contact the youth’s CMH and family physicians, as part of the larger study (see Chapter 4). Prior to starting the interview, youth and parents reviewed the letter of information and signed consent. Parents and youth received a $40 or $25 gift card, respectively. The study was approved by the Research Ethics Board at both CMH agencies and at The University of Western Ontario.

### 2.4.2 Data Collection

Data were collected through in-depth interviews by one investigator. Parents completed a demographics questionnaire (e.g., educational attainment, income). Interviews with youth and parents were conducted separately and in-person at the CMH agency or on the university campus; interviews ranged from 40 minutes to 2 hours.

Semi-structured interview guides were developed for youth and parents (Appendix 4). These included open-ended questions about the youth’s problems (e.g., diagnoses), service utilization, and perceived current and future needs. A timeline was drawn during the interview to facilitate a chronological history of mental health service utilization over time. Participants were probed about their service use across sectors of care (e.g., education, child welfare). Views about the expected duration of CMH problems (e.g., how long will youth's problems last?) and about re-accessing help in young adulthood (e.g., where will you turn to for help if problems return?) were elicited. Since youth or parents may not have thought of adult services as relevant to them, the interviewer posed broad questions about expectations, hopes, and fears for the future. Across all interviews, questions focused on participants' suggestions for change, consistent with critical research approaches supporting empowerment and social change (Carroll, 2004).

Interviews were open and flexible and, where appropriate, deviated from the interview guide to enhance the richness of data collected. All interviews were audiotaped and subsequently transcribed verbatim and checked for accuracy by the interviewer. Field notes were recorded to capture specific details such as interviewer perceptions and nuances of communication. Transcripts were de-identified and assigned numeric codes to preserve confidentiality.

## 2.5 Data Analyses

Data collection and analysis occurred simultaneously and iteratively. Data were analyzed using the constant comparison methods of CGT, building the emergent theory and returning to particular instances to analyze discrepancies and refine understanding of relationships between categories (Charmaz, 2014). CGT requires three sequential phases of coding: open coding, focused coding, and theoretical coding (Appendix 6). The *first phase* of the analysis focused on developing initial codes that emerged from the data. A line-by-line analysis of transcripts involved constructing coding templates for youth and parents, separately. Coding was entered into NVivo10 (NVivo, 2012), a qualitative research software program for organizing the data.

The *second phase* of analysis involved 'focused' coding or making decisions about which initial codes best represented the data (Charmaz, 2006; Miles & Huberman, 1994). This process attended to the "most useful" codes to synthesize and analyze larger amounts of data.

This iterative process allowed new questions about emerging themes to be added to the interview guide and facilitated theoretical sampling. For example, an additional female youth was recruited to explore possible gender differences. Advanced focused coding involved saturating categories and generating explanations from the descriptions within the data. Data collection ceased upon "theoretical saturation" or when gathering new data did not provide new theoretical insights.

The *third phase* involved theoretical coding, which conceptualized relationships between categories to move the 'analytic story' in a theoretical direction. To facilitate this process, a data matrix was created to represent a visual summary of common emerging themes among participants with exemplar quotes. Matrices were created to analyze categories and make comparisons between participants, as well within youth-parent dyads (Lingard & Mcdougall, 2013). At each analytic phase, memo-writing and diagramming bridged the gap between coding and conceptual development, providing a logic for organizing the analysis.

Credibility and trustworthiness of the data were enhanced through the use of verbatim transcripts and independent and team analysis (O'Brien, Harris, Beckman, Reed, & Cook, 2014). Researchers were from multiple disciplines (i.e., psychology, social work, family medicine) and provided theory triangulation (Guion, 2002). Reflexivity processes, which account for the researchers' influence on the research process (e.g., analysis, writing) given their own background knowledge and perspectives, included reflective memo-writing and referring back to the literature to explore how the analysis provided new conceptual insights (Charmaz, 2006; Malterud, 2001).

### 2.5.1 Final Sample

A total of 20 eligible families were approached about the study by their CMH provider. Eight families were not interested and did not provide their contact information. Of 12 families who completed a telephone screening, two families did not consent to participate. A total of 10 families (10 youth, 10 parents) participated; 20 interviews were conducted between April and December 2015. Tables 2.1 and 2.2 present demographic characteristics for youth and parents, respectively. Notably, all parents were the youth's biological mother except for one grandmother and half of the families reported a household income of less than $40,000, compared to a median family income of $75, 985 in London, Ontario (Statistics Canada, 2015). The majority of youth (70%) had externalizing problems (e.g., oppositional behaviour, aggression), but problems were highly comorbid with other disorders (e.g., anxiety, post-traumatic stress disorder). The average length of a youth's involvement at their CMH agency was 2.4 years (1–5 years) and with the CMH system was 4.4 years (1–8 years). For many youth, care was not continuous and rather episodic. All youth had received care from a specialist physician (e.g., child psychiatrist) and most had involvement with multiple sectors of care. Exemplar quotes are referenced in the findings section by type of participant within the same dyad (e.g., Y1=youth, P1=parent). See Appendix 7 for additional participant exemplar quotes.

**Table 2.1: Youth demographic characteristics**

| Demographic Characteristics | Proportion of youth sample (n = 10) % or *M*, Range |
|---|---|
| Sex | |
| Female | 20% |
| Age | |
| 12 years old | 50% |
| 13 years old | 20% |
| 15 years old | 30% |
| Presenting problem(s)[a] | |
| Attention-Deficit Hyperactivity Disorder (ADHD) | 60% |
| Anxiety | 50% |
| Behavioural problems | 70% |
| Depression | 30% |
| Sleep Problems | 20% |
| Trauma-related problems | 50% |
| Other providers involved in youth's mental health care | |
| Child welfare provider | 30% |
| Family physician | 80% |
| Pediatrician | 40% |
| Psychiatrist | 90% |
| School provider (e.g., social worker) | 20% |
| Duration of service involvement with CMH agency | *M* = 2.4 years (1 – 5 years) |
| Duration of service involvement with CMH system | *M* = 4.4 years (1 – 8 years) |

*Note.* [a] Most youth (70%) had multiple problems that were the focus of treatment; thus, percentage of cases for type of problem sum to >100%.

**Table 2.2: Parent demographic characteristics**

| Demographic Characteristics | Proportion of sample (n = 10) % or *M*, Range |
|---|---|
| Sex | |
| Female | 100% |
| Age | |
| 30 to 39 years | 30% |
| 40 to 49 years | 60% |
| 50 to 59 years | 10% |
| Marital Status | |
| Married/Common-law | 80% |
| Single parent/Never legally married | 20% |
| Household income | |
| <$40,000 | 50% |
| $40,000 - $59,999 | 20% |
| >$59,999 | 30% |
| Education attainment | |
| Less than high school | 10% |
| High school graduate | 20% |
| College or trades certificate or diploma | 60% |
| University graduate | 10% |
| Spouse education attainment | |
| Less than high school | 10% |
| High school graduate | 40% |
| College or trades certificate or diploma | 40% |
| Not applicable (i.e., single parent) | 10% |

## 2.6 Findings

The majority of youth and their parents believed their mental health problems were chronic and did not anticipate problems would "*go away*", even with CMH treatment. "*I don't believe serious depression goes away. I think you have highs and lows. I think that complex post-traumatic stress disorder does not go away. Anxiety, same thing…it doesn't go away"* (P10). Most parents expected their child's problems to continue into adulthood: "*I think he's going to have anxiety throughout his whole life"* (P6). For a few youth participants, problems were described as unremitting. However, most parents anticipated an episodic disorder course:

> *It's going to go in stages. That's what the anxiety disorder does... Through phases of your life, it will kinda almost go away and you won't see it for a long time and then something will change, and it will come back a little bit… or a lot.* – P6

Though the majority of youth had not considered their future needs, many felt they would always have mental health problems: *"I think that I'm always going to have, like, a little piece of it"* (Y2). *Family psychopathology* emerged as an overarching theme which influenced participants' perceptions. For example, youth were generally aware of their family's mental health history:

> *[Mom] said she was taking me to [CMH agency] to see if I had a mental illness, which I did understand because a lot of people in my family have mental illness. My sister does. My mom… My whole family pretty much does.* – Y2

Some parents had received treatment for their own mental health issues. Having a family mental health history reinforced parents' beliefs about a *"predisposition"* or *"hereditary"* component to their child's problems, and a need for long-term care:

> *I'm pretty sure he's going to need mental health care, probably for the rest of his life. I think that given my mental health, and his father's mental health, and both of our family histories, I needed to get him help now before he was 20.* – P10

The findings below describe key themes and sub-themes from the analysis in two sections. The first section describes perceptions amongst youth and their parents about the course of CMH problems. Three disorder trajectories emerged: (1) *not chronic*, (2) *chronic and persistent,* and (3) *chronic and remitting.* Trajectories were defined by distinguishing features (e.g., problem severity, service history) and influenced how youth and parents interacted with the CMH system. The second section describes participants' views about seeking help in the future.

## 2.6.1 Perceived Mental Health Disorder Trajectories

### 2.6.1.1 Not Chronic Trajectory

Only one parent believed her child's problems were not chronic. If a professional suggested this to her: "*I'd probably think they're whacked"* (P4). She hoped her child, diagnosed with ADHD, would "*grow out of it*". Her child shared a similar view about his problems. Some parents believed their child's problems were chronic, though their children felt differently. For example, a 12-year old participant who had just completed treatment believed the chances of his anxiety coming back were *"one in a million"* because he had *"conquered it"*. In contrast, his parent believed the anxiety had not completely resolved. Another youth with complex mental health issues also believed his problems would go away *"because they [bullies] will probably forget me; I look a lot different without my glasses on"* (Y3).

#### 2.6.1.1.1 Prior Treatment History and Service Utilization

For the one parent who perceived her child's problems as "not chronic", this was her child's first contact with the CMH system. Interestingly, though she believed her child's problems would remit, she did not feel her child was not yet ready to be discharged: *"Things aren't resolved and we wanted to go a bit further into the transition to Grade 7. We're kind of extending it…"* (P4).

### 2.6.1.2 Chronic and Remitting Trajectory

The majority of youth were described by their parents to have problems that were chronic and remitting. For some youth, treatment was perceived as helpful: *"I started coming here on a regular basis to meet with [CMH provider]. And for a long time, it stopped. And things got better. The depression, everything, it all kind of went away*" (Y10). However, despite symptom improvement, participants did not perceive problems as completely resolved: "*It didn't really completely go away. I was always really upset. I have always been really emotional when it comes to family problems. So, it never really fully went away, but [treatment] made it easier"* (Y10). For youth who fell on this trajectory, some experienced a recurrence of problems, while others had not.

Experiencing a recurrence reinforced a view amongst youth and their parents that problems were chronic: *"It goes away and it comes back. I feel like if it's not going to go away now, it's not going to go away ever"* (Y10). Parents were "*no dummy"* about their child's problems and often anticipated problems to recur after treatment: *"I'm glad he completed the program. But I'm no dummy… Since he's been home, there's been quite a large number of 'blips'"* (P8). Recurring problems were common amongst older youth, particularly those with ongoing stressors (e.g., family conflict). "*I think depression, in my case, I don't think it'll go away. I'm just preparing for if it doesn't*" (Y8).

Some youth had not experienced a recurrence. Yet, some still perceived CMH problems as potentially chronic. This stemmed from a few key factors. First, some parents' views of their children's problems were based on their own experience with mental illness: "*It's going to come back. 100%. At some point in his life, it's going to come back. Who knows how many times"* (P6). Second, participants identified risk factors for recurrence. For example, a 12-year old participant with ADHD recognized the risk of treatment non-compliance: *"I can focus when I'm on the medication"* but *"some days, I test myself and don't take my medication. Those days, especially if those days are at school, they don't turn out as well as I hoped"* (Y2). Participants perceived potential risk factors at school (e.g., peer influences) that might lead to recurrence. Parents worried about the transition to high school: *"He's got good control of it now. I'm not sure how it's going to go when the work starts getting harder"* (P6). Finally, youth perceived problems as chronic based on information they had received. One youth saw a commercial on television about adulthood ADHD and thought "*yeah, I could tell that it could probably affect me"* (Y6). Another youth learned about ADHD during a presentation by college students:

> *They all had ADHD as well. We got to talk to them and they told us all about how they are doing now. We talked to one who is doing really well without medication. The other one still needs his medication. He has problems every now and then.* – Y2

Finally, youth's perceptions of their problems may have been influenced by information received by their parents. One parent described explaining the diagnosis of a behavioural disorder when her daughter was 7 years old: *"If she's old enough to get the diagnosis, then she's old enough to at least have a basic understanding of what she has, right? Like, you have* *this and it is something that's going to follow you your whole life"* (P2). No participants reported receiving information about the course of problems from a provider.

##### 2.6.1.2.1 Prior Treatment History and Service Utilization

Youth with remitting problems experienced some treatment success. Youth often described receiving help within CMH as *"stop and go"* as problems recurred: *"I would go and I would stop, and I would go… And then I wouldn't come for a few weeks. And then I'd come. Then I wouldn't go for a few weeks. It wasn't completely non-stop"* (Y10). Some youth perceived having fewer recurrences as a result of treatment: *"I feel like I've been able to handle my anger a lot better. Like together, the 'blips' are more spread apart, and I'm working to get them even more spread apart*" (Y8). However, when youth started to "*feel good*" they did not always view a need for ongoing CMH treatment to manage potential recurrences. One 15-year old youth explained problems "*spiraling down"* when he stopped checking-in with his CMH provider: *"Things started really clearing up. So, I guess in a way, I just didn't feel a need to come any more, which wasn't a smart idea because I did need the help"* (Y10).

Overall, a chronic and remitting disorder trajectory was often defined by a treatment history of requiring help in CMH at various points over time. Some parents explained months passing by before their child had a recurrence, or a "*slip*" or *"blip",* which brought them back for services: *"I usually call [CMH provider] or [youth] will sort of be like, "I think maybe it's time that I go talk to [provider]". It's usually me that says that I think it's time that we go see [provider] again"* (P10). Ultimately, recurring problems led parents to re-engage with services: *"It got really bad… then he had a major blip. He ran away. He said he was going to commit suicide. Then I called [CMH agency] for an emergency counselling session"* (P8).

#### 2.6.1.3 Chronic and Persistent Trajectory

Youth on a chronic and persistent trajectory described very complex and severe problems compared to youth on other trajectories: "*We've had 3 different times with fires set in the house by him. He cannot be left alone. He cannot be unsupervised"* (P3). A history of childhood trauma and abuse was common amongst these youth, which reinforced a perception that problems would be *"ongoing throughout life"* because *"so much damage was done"* (P9).

Parents anticipated problems to last into adulthood: "*I can see him acting out really badly especially like when he's 25 years old. So, that would be a chronic mental health issue"* (P9). Parents seemed resigned to this lifelong course:

> *Honestly, this is who [youth] is. This is what his life is - what he's been dealt. We'd like to see him as a member of society. We'd like to see him go to school… go to college. We'd like to see him move out; have friends. Will that happen? We don't know.* – P3

A significant impairment in functioning was a distinguishing feature of youth with chronic and persistent problems. As described by one parent: "*We [parents] have faced the fact that we will have [youth] living at home with us. We don't know whether he's going to be able to function in society; be able to look after himself. But he's not totally disabled"* (P3). Another parent described how her child had not attended school in over a year. At the time of the interview, she was completing disability forms for her child. She expressed difficulty with envisioning a future for her child. *"When he was little, I couldn't even see his future. For a while, we thought that if we could get him through [program] that he would be able to function in some scope. Now, I don't know"* (P7).

In contrast, youth perceived by their parents to have chronic and persistent problems remained somewhat hopeful. As one 15-year old participant stated: *"I hope the depression will be gone. The anxiety, I know, is going to be forever, but I hope it like tones down a lot"* (Y7).

###### 2.6.1.3.1 Prior Treatment History and Service Utilization

Parents of youth with chronic and persistent problems perceived little success with CMH treatments: *"It wasn't working. He still needed more. [CMH agency] refused to keep him"* (P7). When youth were perceived to 'fail' at treatments, parents questioned whether it was the 'right' help to begin with: "*I think he can get better if he has the right help. But I don't know what the right help is*" (P9).

Parents described a high level of mental health service utilization within CMH: *"I'm not sure when we stopped seeing [CMH provider]. Then I requested some more. I said I want more"* (P9). This was the case especially when problems worsened: *"[Youth] stopped going 3* *times per week… [psychiatrist] was going to drop him to one but the anxiety and depression really geared up. [Psychiatrist] bumped him back up to two [sessions per week]*" (P7). Youth with chronic and persistent problems had received intensive treatments given their impairments. A parent applied for government funding for continuous in-home support for her child: *"We got to the end of the first [round of] "complex funding", then we had to ask for more. That was pretty much unheard of, getting two rounds of emergency funding"* (P7).

Compared to youth with remitting problems, youth with chronic and persistent problems were involved with care continuously or 'non-stop': *"We had told them from very early on that it wasn't working. The minute he left [CMH agency], he left for [another CMH agency]"* (P7). Parents wished they had known when CMH services would end: "*I would have like to have known that this wasn't something that he could hang on to. We had no clue. [CMH provider] said we would have to fight to keep him [at agency] this year"* (P7). Parents of youth with persistent CMH problems commonly described continuously *"fighting for services"*.

### 2.6.2 Re-Accessing Mental Health Services as Young Adults

Almost all youth and parents anticipated needing some services in young adulthood: *"I never thought it wouldn't be long-term. I don't think [youth] will ever not need therapy"* (P7). Yet, when asked about whom, or where, they would turn to for help in the future, youth and parents were uncertain: *"I don't know what's available to him when he's done here. I have no clue"* (P7). Planning for *"slips" or "blips",* or a treatment failure, was not discussed within CMH: "*Nobody is ever willing to talk about what if it [treatment] doesn't work… sometimes, it doesn't work at all. When that's happening, as a parent, you feel like you're drowning"* (P7). This parent questioned the utility of labeling a CMH disorder as "chronic":

> *I think people like to label and then walk away. So you tell me it's chronic, that's nice. Now what do I do? This isn't going away. So what are the steps for that? Nobody ever discusses it.* - P7

An overarching theme of "*not having a plan*" for young adulthood emerged. Parents described trying to get as much help as possible within CMH before their child reached the age of transfer. A gap in available services between CMH and adult care was perceived:

> *I wish that something like [CMH agency] could exist for youth, 18 to 24, because that's a really important coming-of-age part of your life. But that's when all the "kid's stuff" stops being there for you. If things aren't okay, those things stopping seems so much harder.* – P10

Parents of older youth (ages 14-15), in particular, feared the consequences of not having a plan:

> *Now he's at that nice awkward age of almost 16. And he's not a kid and he's not an adult. So what's going to happen? He can't go to [CMH agency] and he can't go anywhere else… And then he'll be alone dealing with adults and perhaps set up in a home where there's going to be some 40-year old man who's going to rape him.* – P8

Parents expressed different views about their child's ability to re-access help in young adulthood. One group of parents was comprised of those that were "*help hungry*" and included parents of youth on a *chronic and persistent* trajectory. A second group of parents was "*help hopeful",* which included parents of youth who had not experienced a recurrence or who had problems perceived as *not chronic*. Parents of youth with *recurring problems* fell into both groups. Most youth expressed having *"no idea"* where they would turn to for help as a young adult for their problems, other than to a parent.

### 2.6.3 "Help Hungry" Parents

These parents felt "*out of options*" after CMH care, and focused their efforts on *"trying to get right now under control"*. Parents of youth with a chronic and persistent trajectory desired a different kind of help than those of youth with recurring problems.

#### 2.6.3.1 Chronic and Persistent Problems

Parents of youth with chronic and persistent problems had considered more intensive long-term supports (e.g., foster care) to meet their child's needs. One parent expressed her concern about her son being *"a drain on the system": "I don't want him to have no value and be on welfare. But that's going to happen because after [CMH agency], as far as I know, there's nothing"* (P7). Parents were *"fearful"* about their child's future and wanted to prepare for the transition from CMH to adult care: *"It would be good to know how long this service is* *going to last. And when the service is done, if it hasn't worked, then what's the next step?"* (P7). Parents of youth with persistent problems were doubtful their child would re-access mental health treatment on their own, especially if this meant establishing a relationship with a new (adult) provider: "*I think if [psychiatrist] for some reason stopped, I don't know whether I could get [youth] to go to somebody else. If that ended, I don't think, as an adult, he would reach out for anything"* (P7). Parents of youth with persistent problems wondered how they were going to "*bridge that gap between now and then [after age 18]",* which led them to *"fight to get things for [youth] now"* (P3). When CMH treatment ended, parents felt like they were *"drowning"*: "*We walked out of [CMH agency] and we had no safety nets. Their response was, "Well, if he won't go to school, call the police". What the hell are the police going to do?"* (P7). Parents who were "*help hungry*" were desperate for help: *"We're pretty worried that if in the next say six months, things don't change, we've lost him*" (P7).

### 2.6.3.2 Chronic and Remitting Problems

Some parents of youth with remitting problems were also *"help hungry".* These parents desired less-intensive help. One parent believed receiving an "*outline*" for managing her child's problems would have been helpful: *"So when [youth] has an outburst, this is how you should deal with it. Try this and this and this. If that doesn't work, try this. If that doesn't work, then you need to go here. There's nothing like that"* (P8). When parents were not given a plan, and problems recurred, some felt treatment had ended prematurely: "*I'll be honest with you. I think a lot more needed to be done between [youth] and myself"* (P1). Some parents were told by providers to call the police, a crisis line, or to take their children to the emergency department if problems recurred. For "help hungry" parents, this was not viewed as a "*good plan*".

> *During one of his 'blips', I called the crisis line. It gave me three other numbers. There was a recording. It gave me three other numbers to call. Like this is a crisis line. I am so glad I didn't have a gun to my head...* – P8

Overall, *"help hungry"* parents anticipated having to *"jump through major hoops"* to re-access mental health services in the future. Parents perceived significant barriers (e.g., availability of professionals, lengthy wait-times) for adult care. A theme of helplessness emerged amongst *"help hungry"* parents: "*I honestly wouldn't know what to do. With his 'blips', he'll end up arrested or in the hospital. I guess that's where we're going"* (P8).

### 2.6.4 "Help Hopeful" Parents

These parents were hopeful that *"somebody will get [youth] into the right place*" if problems recurred. As one parent described: *"I think there's lots of advertising and lots of people out there that would help him and guide him in that direction*" (P5). One parent anticipated contacting her child's CMH provider in adulthood:

> *I would like to think, to be honest with you, [youth] would still be able to see [CMH provider]. I can't see [CMH provider] saying, "Well, no, you're 18." I can't foresee [youth] turning 18 and then just shut the door.* – P10

When reminded of the age cut-offs in CMH, this parent remained confident in her child's CMH provider to connect her child with the 'right' help: *"I think they would connect us with the right services. I'm sure [CMH provider] would have somebody he could recommend"* (P10).

Compared with "*help hungry*" parents, *"help hopeful"* parents expressed confidence in their children's ability to manage their problems. For example, one parent stated: *"I'm not too worried for when [youth] becomes an adult. I think she'll totally be able to manage it on her own, without medication, as she gets older"* (P2). Another hopeful parent explained: *"Hopefully these years of treatment will educate him enough that I don't have to worry about him knowing to take care of himself"* so, *"hopefully, this will all be under control by then. I'm hoping"* (P10). Finally, *"help hopeful"* parents were confident in their own role as *"advocator"* and *"safety net"* for their children: *"[Youth]'s probably going to flop. But I don't know that she'll actually flop because she'll have me beside her and I won't let her. She'll be fine"* (P2). Though parents identified friends and supports, they considered themselves the main person their children would rely on: "*I'm sure he will get to the right place. If the doctor doesn't do it, I will"* (P6).

Although some parents were "*help hopeful*", they also expressed uncertainty about service availability in adulthood. Yet, they were hopeful this would not seriously affect their children. Parents’ hopes were sometimes linked to their own positive experiences with managing mental health issues:

> *I know my support system and I know when a bad day is coming. You don’t always catch them, even now as an adult, but I know what to do when they come. I think she’ll probably be the exact same way. I hope.* – P2

## 2.7 Discussion

The current study uncovered beliefs amongst youth (ages 12-15 years), who have received CMH treatment, and their parents about the course or expected duration of their mental health problems. Views about the possibility of requiring mental health services as young adults were also elicited. Emergent themes are discussed below and compared with the current literature at the level of: (1) parents, (2) youth, and (3) the CMH system. Implications for caring for youth with ongoing and recurring mental health problems are addressed.

### 2.7.1 Parents: Feeling “Out of Options”

None of the participating parents considered their children completely “recovered” from their mental health problem(s). Most youth had behavioural problems that were comorbid with other disorders (e.g., depression). This is consistent with research on youth that require ongoing mental health care (Cappelli et al., 2014; Islam et al., 2016). Three perceived disorder trajectories emerged in this study: (1) not chronic, (2) chronic and persistent, (3) chronic and remitting; with the majority of parents perceiving their children to fall in the third trajectory. These trajectories map well onto the existing evidence base for CMH disorders. For instance, while a minority of youth do not respond to CMH treatment (10-15%) (Dunn & Goodyer, 2006) and experience a persistent course, the majority improve and achieve remission. Almost half of youth experience a recurrence following CMH treatment (Curry, Silva, Rohde, Ginsburg, & Kratochvil, 2011; Kennard et al., 2009). In the current study, parents perceived their children to be “at-risk” for recurring problems given factors consistent with the literature, including family conflict (Birmaher, Brent, Kolko, & Baugher, 2000; Knappe et al., 2009) and peer relationships (Steinhausen, Haslimeier, & Winkler Metzke, 2006).

How did parents' perceptions about their children's problems influence service utilization? Youth perceived to have persistent or recurring CMH problems were linked to more intense levels of help-seeking in CMH. The majority of participating youth were involved with multiple sectors of care (e.g., education, child welfare) and mental health professionals, and had been seeking services within CMH for extended periods of time (up to 8 years). High rates of CMH service use and intense levels of help-seeking are consistent with research on how families access and use CMH services (Reid, Cunningham, et al., 2011). Parents' own experiences with mental illness, either their own or of family members, were influential and helped them to anticipate their children's future needs. In other work, parents' mental health treatment histories are associated with higher CMH service use (Farmer, Stangl, Burns, Costello, & Angold, 1999; Schraeder & Reid, 2015).

Although youth participants with chronic and recurring problems had received extensive care within CMH, parents expressed uncertainty about available mental health services in adulthood. A common view amongst participants in the current study was "*not having a plan*". Some parents were optimistic (*"help hopeful"*) about their children's future and some indicated they would rely on their children's CMH provider if problems recurred. More often, however, parents perceived CMH professionals as not willing to discuss follow-up plans following treatment. A perceived gap in services at the age of transfer contributed to parents' "*feeling out of options*". Though this finding is consistent with research on parent and youth perspectives on transitions between CMH and adult care (Hovish et al., 2012; Jivanjee et al., 2009), it is notable that parents of younger participants in this study already anticipated this gap in services.

Only one parent perceived her child to not have a "chronic" mental health problem. Compared to other participants, not having an extensive family history of mental health problems and shorter CMH involvement might have contributed to this view. This finding, sometimes referred to as a 'negative case' in qualitative methodology, is important as it represented a critical variant or property of our emergent theory related to CMH disorder trajectories (Charmaz, 2014). There is potential stigma associated with labeling a child as having a "chronic" mental health problem. Research suggests stigmatizing responses are still significantly associated with labeling mental health problems amongst youth (Pescosolido, 2013) and with receiving CMH treatment (Pescosolido, Perry, Martin, McLeod, & Jensen, 2007). Public stigma and social rejection are higher for youth with common CMH problems (e.g., ADHD, depression) compared to youth with other chronic physical health problems (e.g., asthma) (Pescosolido, 2013). Though it was unnecessary to have a larger sample of parents to substantiate this perceived not-chronic trajectory (Charmaz, 2014), future research should explore other factors that might contribute to perceiving CMH problems as not chronic.

### 2.7.2 Youth: Not Ready to Talk Transition

In contrast to their parents, some youth viewed their problems as not chronic. This might be related to cognitive development. As illustrated in the current study, younger youth are more likely to see their problems as contingent on concrete factors (e.g., a bad teacher) compared to older youth who recognized multiple factors (e.g., genetics, family environment). This shift from “concrete” to “formal stage” thinking is a normal part of development during adolescence (Piaget, 1972), and likely impacts how youth conceptualize their CMH disorder.

In general, participating youth had not considered their future mental health needs or where they would turn to for help. Not surprisingly, most youth indicated they would rely on a parent if problems recurred. Caution should therefore be exercised before extrapolating the literature on pediatric illnesses (i.e., age to discuss transition) to youth with mental health problems. In addition to the stigma associated with labeling a mental health problem as “chronic”, some families might perceive a discussion about transition planning to be premature at younger ages. In some cases, such discussions might even be harmful. This does not mean that discussing the course of a mental health disorder is unnecessary. Participating youth described learning about the course of their mental health disorder from information they had received (e.g., at school, from television programs, parents), but no youth indicated receiving this information from a mental health professional. Youth might feel even more anxious about the course of their CMH problems without accurate information (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). Recommendations for having this discussion with youth are outlined below.

### 2.7.3 The Children’s Mental Health System

This study is the first to our knowledge to interview youth who have received CMH treatment and their parents about the *possibility* of requiring mental health services as young adults. Participating parents often feared their children would disengage from needed services after the age of transfer; a steep decline in service utilization among transition-age youth (16-24 years) supports this (Paul et al., 2014; Pottick, Warner, Vander Stoep, & Knight, 2014). Some parents felt their children might end up in the justice system; a regrettably common outcome amongst some treated youth (Davis, Banks, Fisher, & Grudzinskas, 2004). In the absence of a crisis management plan, parents were told to rely on emergency services to manage their children’s recurring problems. This expectation, along with increasing trends in Ontario for mental health related emergency department visits and hospitalizations amongst children and youth (Gandhi et al., 2016), reinforces the need to consider new models of mental health service delivery for youth with ongoing and recurring CMH problems.

Improving care for chronic mental health problems amongst youth and families is needed. If transfer to adult care is needed, preparation before the age of transfer would be helpful. First, psychoeducation about the typical course of mental health problems should be discussed with youth and their parents early in treatment by their CMH provider to clarify reasonable expectations about the duration and efficacy of treatment. Addressing family mental health might be beneficial, since awareness about a genetic predisposition can mitigate negative perceptions of mental health problems for youth (Corrigan et al., 2005). Second, discussions with youth about their experience with treatment would be helpful; in particular, attention should be given to the therapeutic alliance, whether treatment is perceived as beneficial, and supports that will be available to youth at the end of treatment. This could improve treatment engagement in the short-term and might also improve engagement in follow-up or booster sessions (Gearing, Schwalbe, Lee, & Hoagwood, 2013; Horwitz et al., 2012). Research suggests that discussing follow-up plans (e.g., booster sessions) early in treatment might have an “anticipatory effect” on youth outcomes (Gearing et al., 2013). Knowing that continued support is planned and available can provide a sense of safety and security for both youth and parents.

Finally, at the end of treatment, steps for re-engaging with mental health services in the event of a recurrence or relapse should be reviewed with families. This would be important to clarify any misconceptions about re-engaging with CMH after the age of transfer. Guidelines within CMH to facilitate transition planning are still in their infant stages. Criteria for identifying youth at-risk of recurrence and persistence, when symptoms resolve prior to age 18, has recently been presented for depressed and anxious youth (Schraeder & Reid, 2017). Though some youth who exhibit a chronic and persistent trajectory will meet criteria for AMHS, most youth will not meet criteria. Following treatment, youth could be monitored in Primary Health Care (PHC) by their family physician (Kutcher, 2011; Schraeder & Reid, 2017; Singh et al., 2016; Taylor, Fauset, & Harpin, 2010). Barriers for integrating CMH and PHC need to be overcome, as PHC offers valuable opportunities to monitor youth with recurring problems and improve long-term outcomes.

### 2.7.4 Limitations

The current study has some limitations. First, member checking was not completed as part of the qualitative methodology. Given the emotional nature of interviews, the authors refrained from having parents review transcripts. Member checking is also questioned in the literature, as it relies on the assumption that a fixed truth exists, that can be accounted for by researchers and confirmed by participants (Cohen & Crabtree, 2008). Secondly, all parents were female. By recruiting the parent who was seeking help, this sample captured parents most likely to be engaged with the treatment process. Future work could explore differences in perceptions within parental dyads. Third, the proportion of married parents (80%) in the current sample was higher than reported across CMH agencies in Ontario (59%) (Reid, Cunningham, et al., 2011). This limits our understanding of how single-parent families navigate the CMH system. Fourth, more male youth were interviewed than females. This likely reflects an over-representation of boys with externalizing disorders in treatment (Reid, Cunningham, et al., 2011).

Finally, this study relied on interviews with participants at a single time-point, providing a ‘snapshot’ of a parent and a child’s help-seeking journey. Some parents expressed hope about their ability to help their children re-access services if needed. It is not possible, however, to attribute parents’ intent for accessing services in the future with outcome. It is also unclear whether *"not having a plan*" actually leads to poorer long-term outcomes amongst youth. What proportion of treated youth with ongoing and recurring CMH problems will receive services in adulthood? The answer to that question requires longitudinal research. In qualitative work, serial interviews (i.e., interviewing participants at multiple time points) are rarely conducted (Pinnock et al., 2011) and pose substantial recruitment barriers. Future research should therefore explore service utilization in adulthood among youth involved with CMH. This might substantiate the costs to the mental health and health care systems by "*help hungry*" parents.

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# 3 Stretching the Boundaries: Perspectives from Children's Mental Health Providers on Caring for Youth with Ongoing Problems

## 3.1 Abstract

Many youth who receive specialized Children's Mental Health (CMH) treatment might require additional treatment as young adults. Little is known about how to prepare youth for transition to adult care. This qualitative study gained perspectives from CMH providers (*n* = 10) about the challenges of caring for youth (aged 12-15 years) with ongoing and recurring CMH problems. Providers were asked about their clients' future mental health needs. Using Constructivist Grounded Theory methodology, a theme of "stretching the boundaries" or continuing to care for youth beyond the standard number of treatment sessions emerged. All providers perceived their clients to be at-risk of ongoing problems yet, were reluctant to discuss the possibility of transfer to adult care. Findings indicate a lack of treatment capacity within CMH to monitor all youth following treatment. Guidelines on who should be monitored are needed. For younger adolescents, the topic of transition should be carefully considered by providers.

## 3.2 Introduction

Recurring problems are common for a subset of youth who receive specialized Children's Mental Health (CMH) treatment. Rates of recurrence are as high as 47% for youth following treatment for depression (Curry, Silva, Rohde, Ginsburg, & Kratochvil, 2011; Kennard et al., 2009). Anxiety disorders also tend to recur and last into young adulthood (Essau et al., 2002; Pine et al., 2013). As well, about 14% of youth (aged 6-19 years) diagnosed with a disruptive behavioural disorder, such as Attention Deficit-Hyperactivity Disorder (ADHD) or oppositional defiant disorder, do not fully recover 15 years after onset (Biederman et al., 2010; Bussing et al., 2010; Keller et al., 1992). Some youth will therefore require additional treatment, possibly as young adults. The absence of a model of care for youth with ongoing and recurring problems in Canada, or elsewhere in the world, speaks to an urgent need to enhance the evidence base for CMH service delivery.

CMH providers can offer unique insights on how youth with ongoing and recurring problems navigate the system. In an era of guidelines and recommendations, it is critical to gain provider perspectives to understand how CMH care is being delivered in relation to ongoing care and transitions, where evidence-based protocols do not exist. The following sections review two relevant areas of research. First, existing longitudinal treatment studies and research on CMH service utilization are presented to highlight a research-practice gap between what we know about the long-term course of mental health problems, and how treatment is actually delivered. Second, research on the transition from CMH to specialized Adult Mental Health Services (AMHS) is reviewed. Youth with recurring problems will likely require adult care; however, it is unclear how CMH providers manage the possibility of transition with youth and families. Do CMH providers anticipate the need for adult care for their clients? How is the topic of transition discussed? The current study addresses these questions.

### 3.2.1 Are Children's Mental Health Problems Chronic?

Almost two decades ago, Kazdin (1987) suggested that children's behavioral problems might be viewed as chronic problems that require ongoing care, similar to diabetes. Unfortunately, little has changed in how CMH treatments are delivered (Kazdin & Rabbitt, 2013). For youth with chronic physical health problems (e.g., diabetes, cystic fibrosis), a need for long-term care is known at the point of diagnosis. In contrast, long-term services needed by youth with mental health issues are less clear. CMH problems can wax and wane over time, and many youth experience “symptom-free” periods. This creates some uncertainty about who should receive ongoing care. For youth with recurring problems, regular monitoring and scheduled follow-up might be beneficial post-treatment. This element of care is consistent with a “chronic care model” (Wagner, Austin, & Von Korff, 1996), which has not been tested in CMH.

It is unclear how many youth with mental health problems would require follow-up post-treatment. Very few longitudinal treatment studies have followed youth with mental health problems after receiving an evidence-based treatment (Curry, 2014). For those treated for anxiety during childhood, up to half of youth return for additional treatment years later (Manassis et al., 2004; Nevo & Manassis, 2009). Longitudinal research on CMH service utilization also suggests a sizeable percentage of families require ongoing care, either episodically or continuously, over time. For example, in a large-scale administrative study examining service use (i.e., CMH visits) across five CMH agencies in the province of Ontario, Canada, almost a quarter of youth (ages 4 to 11; N=5, 206) received care lasting more than one year (Reid, Stewart, et al., 2011a). A total of 14% of youth had two or more episodes of care [i.e., 3 visits with 180 days between episodes (Reid et al., 2014)] over a four-year period, with an average duration between episodes longer than one year ($M$ = 17 months between first and second episode). Thus, some youth who receive CMH treatment will return for more services. Substantial costs are incurred by families and the CMH system when youth receive care over many years. Understanding the ongoing needs of these youth and families is critical for planning their care.

If we know some youth will have recurring problems, what is the best way to care for them? One suggestion is to provide follow-up care or further intervention. Research on “booster sessions” provides some evidence that these can be effective for maintaining or improving treatment outcomes (Bry & Krinsley, 1992; Clarke, Rohde, Lewinsohn, Hops, & Seeley, 1999; Eyberg, Edwards, Boggs, & Foote, 1998; Gearing et al., 2013; Kolko & Lindhiem, 2014). A meta-analysis found cognitive-behavioural therapy (CBT) interventions with booster sessions were more efficacious for managing mood and anxiety disorders amongst youth ($M$ = 11.9 years old, SD = 2.7) than CBT interventions without booster sessions (Gearing et al., 2013). It is worth noting, however, the vast majority (85%) of CBT protocols reviewed in this meta-analysis did *not* include booster sessions.

In “real-world” CMH settings, booster sessions tend not to be part of standard practice protocols. Substantial variation in how booster sessions are operationalized across studies limits our understanding about the optimal number or timing of sessions to maintain or improve long-term outcomes (Eyberg et al., 1998). Further, the efficacy of booster sessions for other childhood problems, such as disruptive behavioural disorders (e.g., oppositional defiant disorder), has not been supported (Eyberg, Boggs, & Jaccard, 2014; Eyberg et al., 1998; Kolko, Lindhiem, Hart, & Bukstein, 2014). For youth with these disorders, booster sessions show no significant improvements in their clinical functioning, and appear no better than “enhanced usual care” (i.e., a follow-up assessment) (Kolko, Lindhiem, et al., 2014). The effectiveness of booster sessions on long-term outcomes (over a year) is virtually unknown. For youth with ongoing and recurring problems, it is unlikely that one or two booster sessions would be sufficient to prevent relapse or recurrence into young adulthood (Clarke et al., 1999).

Clinical practice guidelines suggest some youth will need more than just a few booster sessions. Guidelines for managing depression in CMH (American Academy of Child and Adolescent Psychiatry, 2007) recommend youth should be monitored monthly for 6-12 months after depressive symptoms resolve, regardless of the length of treatment; and for 2 years, if the depressive episode is a recurrence. Successful uptake and implementation of clinical guidelines in CMH, however, is very complex. Engagement from CMH providers is critical (Leathers, Spielfogel, Blakey, Christian, & Atkins, 2015; Powell, Proctor, & Glass, 2014). To date, no studies have asked CMH providers about their views on caring for youth with ongoing and recurring mental health problems. The perceived benefit of providing some form of ongoing monitoring for treated youth has also not been examined. Perspectives from CMH providers would add substantially to our understanding of these complex issues.

### 3.2.2 Transitioning to Adult Care

Youth with ongoing and recurring problems may require adult care. An age-based criterion for transfer to adult care (typically 18 years of age) creates an artificial divide between CMH and AMHS. Cross-sectional studies demonstrate a steep decline in mental health service utilization (including outpatient, inpatient, and residential care) for transition-age cohorts (i.e., 16 to 24), compared to other age cohorts (Manteuffel, Stephens, Sondheimer, & Fisher, 2008; Pottick, Bilder, Vander Stoep, Warner, & Alvarez, 2008). Further, transitions between CMH and AMHS are often poorly managed (Davidson et al., 2011; Hovish et al., 2012; Kutcher et al., 2009). Many youth encounter numerous barriers when attempting to re-access treatment during a time that they need them most (Clark, Koroloff, Geller, & Sondheimer, 2008; Davidson, Cappelli, & Vloet, 2011; Singh, 2009).

The TRACK study is the only study to date that has attempted to follow adolescents treated for mental health problems beyond the age of transfer (Paul et al., 2013; Singh et al., 2010). It identified a cohort of 16 to 21 year olds (N=154) who had received CMH within the United Kingdom's (UK) National Health Services and assessed their access to AMHS. Of the total sample, 85% (n=131) were considered "suitable" for adult services by CMH providers. However, only 49% of these youth actually transferred to AMHS; 6% did not meet AMHS eligibility criteria and over a third (n=52, 40%) were not referred by CMH providers to AMHS (Paul et al., 2013). CMH providers' decision not to refer youth to AMHS stemmed from a common belief that AMHS would not accept the referral or have the appropriate services or expertise, as AMHS tends to focus on treating severe and enduring mental illnesses (e.g., schizophrenia, psychosis). In a recent secondary data analyses of the TRACK study (Islam et al., 2016), almost half of youth who failed to transfer (i.e., who were rejected by AMHS or not referred by CMH) continued to receive care within CMH. It is unclear whether participating CMH providers had discussed the possibility of adult care with youth clients who were not referred to AMHS.

As highlighted by the TRACK study, a lack of appropriate services in young adulthood means that some youth, who might otherwise "fall-between-the-cracks" , will continue to receive care within CMH (Belling et al., 2014; Hovish et al., 2012). In another study (McNamara et al., 2013), CMH providers (i.e., child psychiatrists) reported seeing youth beyond the age of transfer for several reasons, including: (i) supporting their client until high-school education was complete; (ii) perceiving their clients' diagnosis to not meet AMHS criteria; (iii) completing a piece of therapeutic work; (iv) supporting their client through other transitions (e.g., starting university); (v) having a strong therapeutic relationship; and (vi) waiting for an AMHS appointment. However, simply continuing to provide care to youth within CMH is unlikely to be the solution in all cases. For some youth, extending care within CMH for a short period of time might be beneficial, if that is all that they require (Schraeder & Reid, 2017); for others, extending CMH care might simply delay a needed transfer to adult care.

At what point should CMH providers consider transition for their youth clients? Does the CMH provider of a 12-year old client, who recently completed treatment for anxiety, consider the possibility of them requiring adult care? Prior research has focused on youth immediately at or before the age of transfer. No studies to date have examined the possibility of transition amongst younger adolescents (ages 12-15). If transfer to AMHS is needed, based on guidelines for pediatric physical health problems (American Academy of Pediatrics, 2002; Reiss & Gibson, 2002; Sable et al., 2011), discussion and preparation well before age 18 would likely be required. The current study therefore sought the perspective of CMH providers in relation to 12-15 year olds receiving CMH treatment.

### 3.2.3 The Current Study

The current qualitative study explored the challenges of caring for youth with ongoing and recurring mental health problems from the perspective of CMH providers. Two questions were asked: 1) Do providers perceive their clients' problems as chronic and, if so, how does this influence services they anticipate them to need? and 2) How do providers deliver services to youth who require longer-term CMH care?

## 3.3 Methods

Constructivist Grounded Theory (CGT) was selected as the optimal qualitative methodology because it tends to be more abstract and has the potential for improving understanding or offering explanation when compared with descriptive methods (Charmaz, 2006). The purpose of CGT is to build an explanatory theory by examining how participants construct meanings and actions for specific circumstances. The constructivist approach assumes the resulting theory is an interpretation of the data which depends on the researchers' views and their relevant experience (Charmaz, 2014).

### 3.3.1 Recruitment Procedures

The current study was part of a larger project which examined the perspectives of youth receiving CMH treatment, and their caregivers, on their future mental health needs and the possibility of transition (Schraeder & Reid, *In press*). CMH providers were recruited from two CMH agencies located in London, Ontario, Canada. These agencies offer a full range of services (e.g., assessment, individual/group/family counselling) to children who have serious emotional or behavioural problems and their families. As part of the larger study, youth were eligible if they: (a) were 12-15 years old; (b) currently resided with a parent/guardian; (c) had been receiving care for 1 year or longer at the agency, or for at least 9 months with a prior episode of care (i.e., 3 face-to-face visits) within the previous 5 years (Reid et al., 2015); and (d) could be interviewed in English. Youth with extensive involvement with CMH were purposefully recruited to allow for questions about ongoing care needs. Participating families allowed a member of the research team to invite their CMH provider to participate in the study.

CMH providers were eligible if they: a) had provided care to the youth for at least 3 face-to-face visits (Reid et al., 2014); (b) had authority to make decisions about the youth's treatment planning; and (c) could be interviewed in English. Consent to participate included the agreement to be audio-recorded. CMH providers were contacted about study participation and scheduling an interview by telephone and/or email. Prior to starting the interview, providers reviewed the letter of information and signed consent. CMH providers participated in the study during staff time and were given a $10 store gift card in appreciation for completing the interview (N.B., the dollar value of compensation received by CMH providers was suggested and agreed upon in collaboration with managers at the agencies). The study was approved by the Research Ethics Board at both CMH agencies and at The University of Western Ontario.

### 3.3.2 Data Collection

Data were collected through in-depth interviews by one investigator (KS). Interviews with CMH providers were in-person at the CMH agency, and were on average about one hour in length. Providers provided demographic and training information (e.g., educational attainment, discipline). A semi-structured interview guide (Appendix 5) included open-ended questions about involvement with the youth's treatment and their views on this youth's current and future service needs. CMH providers were asked about whether they had discussed the possibility of transfer to adult care with their client. Providers were also asked about caring for youth with ongoing and recurring problems more generally. Across all interviews, questions focused on participants' suggestions for change, consistent with critical research approaches supporting empowerment and social change (Carroll, 2004).

Interviews were open, flexible and, where appropriate, deviated from the interview guide to enhance the richness of data collected. All interviews were audiotaped, transcribed verbatim, and checked for accuracy by the interviewer. Field notes were recorded to capture specific details, such as interviewer perceptions and nuances of communication. Transcripts were de-identified and assigned numeric codes to preserve anonymity.

## 3.4 Data Analyses

Data collection and analysis occurred simultaneously and iteratively. Data were analyzed using the constant comparison methods of CGT, building the emergent theory and returning to particular instances to analyze discrepancies and refine understanding of relationships between categories (Charmaz, 2014). CGT requires three sequential phases of coding: open coding, focused coding, and theoretical coding (Appendix 6). The *first phase* of the analysis focused on developing initial codes that emerged from the data. A line-by-line analysis of transcripts involved constructing an initial coding template. Coding was entered into NVivo10 (NVivo, 2012), a qualitative research software program used to organize data.

The *second phase* of analysis involved 'focused' coding or making decisions about which initial codes best represented the data (Charmaz, 2006; Miles & Huberman, 1994). This process attended to the "most useful" codes to synthesize and analyze larger amounts of data.

This iterative process allowed new questions about emerging themes to be added to the interview guide and facilitated theoretical sampling. Focused coding involved saturating categories and generating explanations from the descriptions within the data. Data collection ceased upon “theoretical saturation” or when gathering new data did not provide new theoretical insights.

The *third phase* involved theoretical coding, which conceptualized relationships between categories to move the ‘analytic story’ in a theoretical direction. To facilitate this process, a data matrix was created to represent a visual summary of common emerging themes among participants with exemplar quotes. Matrices were created to analyze categories and make comparisons between participants (Lingard & Mcdougall, 2013). At each analytic phase, memo-writing and diagramming bridged the gap between coding and conceptual development, providing a logic for organizing the analysis.

Credibility and trustworthiness of the data were enhanced through the use of verbatim transcripts and independent and team analysis (Charmaz, 2006; O’Brien et al., 2014). Researchers were from multiple disciplines (psychology, social work, and family medicine), providing theory triangulation (Guion, 2002). Reflexivity processes, which account for the researchers’ influence on the research process (e.g., analysis, writing) given their own background knowledge and perspectives, included reflective memo-writing and referring back to the literature to explore whether the analysis provided new conceptual insights (Charmaz, 2006; Malterud, 2001).

### 3.4.1 Final Sample

A total of 10 CMH providers across two CMH agencies in London, Ontario participated. No CMH providers declined participation. Interviews were conducted between April and December 2015. Table 3.1 summarizes demographic characteristics for CMH providers; see Table 3.2 for characteristics of their youth clients. CMH providers had been in their current positions for an average of 15 years (0.67 - 30 years) and in their profession for an average of 11.8 years (0.67 - 36 years). Educational backgrounds included: Master’s program (n = 2), college program (n = 7), and a bachelor’s degree (n = 1). CMH providers had been working with their youth client for an average of 1.2 years (0.25 - 2.5 years). Most youth clients were male and the majority (70%) had externalizing problems (e.g., oppositional behaviour, aggression); problems were highly comorbid with other disorders (e.g., anxiety). The average length of a youth's involvement at the CMH agency was 2.4 years (1–5 years) and within the CMH system was 4.4 years (1–8 years). For many youth, care was episodic rather than continuous. All youth had received care from a specialist physician (e.g., child psychiatrist), and most had involvement with multiple sectors of care (e.g., child welfare, education).

**Table 3.1: Characteristics of Children's Mental Health (CMH) providers**

| Demographic Characteristics | Proportion of sample (n = 10) |
|---|---|
| Sex | |
| Female | 60% |
| Age | |
| < 30 years old | 10% |
| 30 – 50 years old | 60% |
| > 50 years old | 30% |
| Training Qualifications | |
| University – Master's degree | 50% |
| University – Bachelor's degree | 10% |
| College (e.g., Child and Youth Counsellor) | 40% |
| Length of time working in current position (*M*, Range) | 15 years (0.67- 30 years) |
| Length of time working in profession (*M*, Range) | 11.8 years (0.67 – 30 years) |
| Length of time working with patient (*M*, Range) | 1.2 years (0.25-2.5 years) |

**Table 3.2: Youth demographic characteristics**

| Demographic Characteristics | Proportion of youth sample (n = 10) % or *M*, Range |
|---|---|
| Sex | |
| Female | 20% |
| Age | |
| 12 years old | 50% |
| 13 years old | 20% |
| 15 years old | 30% |
| Presenting problem(s)[a] | |
| Attention-Deficit Hyperactivity Disorder (ADHD) | 60% |
| Anxiety | 50% |
| Behavioural problems | 70% |
| Depression | 30% |
| Sleep Problems | 20% |
| Trauma-related problems | 50% |
| Other providers involved in youth's mental health care | |
| Child welfare provider | 30% |
| Family physician | 80% |
| Pediatrician | 40% |
| Psychiatrist | 90% |
| School provider (e.g., social worker) | 20% |
| Duration of service involvement with CMH agency | *M* = 2.4 years (1 – 5 years) |
| Duration of service involvement with CMH system | *M* = 4.4 years (1 – 8 years) |

*Note.* [a] Most youth (70%) had multiple problems that were the focus of treatment; thus, percentage of cases for type of problem sum to >100%.

## 3.5 Findings

### 3.5.1 Viewing Youth's Problems as "Chronic"

CMH providers generally felt their youth clients' problems were chronic. Providers did not anticipate their clients' problems would resolve completely, even after receiving treatment: *"I think he's always going to be an anxious kid. I don't think there will be a day when [youth] is not an anxious kid"* (CMH5). Certain factors contributed to this perception. First, providers' understanding of psychopathology reinforced their perception that both internalizing (e.g., anxiety) and externalizing problems (e.g., aggression) can be chronic problems: *"The impact of the PTSD really colours everything. It affects all kinds of relationships. It will affect [youth]'s daily life continuously"* (CMH10). Second, CMH providers were more likely to view their clients' problems as chronic when they were severe and comorbid with other disorders: "*She's only got the ADHD, but if [youth] had a further assessment, chances are we'd probably find out more about her. Do I think she'll need mental health services in the future? Yes"* (CMH2). Finally, providers viewed the impact of environmental stressors and family psychopathology on the course of CMH problems: *"This would be your classic multi-problem family: mom's mental health, history of abuse, ongoing dubious relationship with [step-father]"* (CMH10).

While problems were perceived to be chronic, most CMH providers described their youth clients' disorder trajectory as *recurring* over time. When youth had not experienced a recurrence, providers perceived them to be "*at-risk*" of problems coming back in the future. One provider believed her client was at-risk given her knowledge of ongoing family stressors (e.g., father might leave family) and parental psychopathology (e.g., mother was recently hospitalized for a mental health-related issue): "*Right now, at the end of [treatment], he is not complex. But he has the potential to be very complex"* (CMH5). Another CMH provider had also considered the likelihood problems might recur in spite of his client's *"success story"* with treatment: *"I still think he's got that fragility"* (CMH6). This provider considered the transition to high school as pivotal in terms of his ongoing needs: "*A lot depends on how the next couple of years go. I know sometimes high school is very tough on kids and that's where his anxiety could really start to overwhelm him"* (CMH6). Only one CMH provider viewed her clients' problems as *persistently* chronic, and based that on a lack of response to several different types of CMH treatments at the agency, comorbidity of problems, and extensive service involvement.

The following sections illustrate how CMH providers' perceptions about problems, as either persistent or recurring, influenced their beliefs about needed future services. First, the ways in which CMH providers cared for youth with chronic problems within the CMH system are described. Second, perspectives on the issue of transition to adult care are examined.

### 3.5.2 Caring for Youth with Ongoing Mental Health Problems in CMH

Providing care to youth with ongoing mental health problems was articulated as a major challenge within CMH. Providers anticipated youth with chronic problems would require services again: "*[Youth, age 13] will need further services. There's no question in my mind"* (CMH1). Many providers reported their clients had already returned for additional CMH treatment. One provider described providing care to his client intermittently, as needed, over time: "*I felt the family was ready to take a break… I think we kind of consider ourselves a brief-intermittent model. The family would come, get some services, and go off for a period of time. We knew she was coming back"* (CMH1). Comparatively, providers did not describe "breaks" in treatment for youth with persistent problems. As stated by one provider, more complex problems required longer-term services:

> *If you look at 75% of the kids that come through our doors, they have 3-5 different diagnoses. They're not simple diagnoses… they're psychosis or extreme anxiety or depression. Those don't just go away after somebody gets services. We know that. The fact that kids are lasting longer in our program is a good indicator they need the services.* – CMH7

CMH providers expressed frustration with short-term treatment models: *"With the amount of diagnoses that some of the kids come in with, it's really hard to take them from one step, to the next step in a short period of time"* (CMH7). CMH providers foresaw an increase in service demands for ongoing mental health care for youth. A provider felt very few of her cases have "*fit the bill*" for brief CMH treatment:

> *I think in the 11 years we have run this program I have had maybe a handful of appropriate cases that would fit that bill. Those cases that you open, you build rapport, you get them set, and they're done, you close, and life is all good for everybody. But more often than not, we get 'these' cases. When someone like this comes through, it's a bit of a muddy situation and there isn't clear direction from the top [CMH agency managers]. That's why we bend the rules a little bit.* – CMH2

When youth did not "*fit the bill*" for short-term CMH treatment, most providers described "*bending the rules*". For some, this meant "*informally*" checking-in or monitoring youth post-treatment or in-between sessions. In general, a theme of 'stretching the boundaries' emerged.

The practice of 'stretching the boundaries' captured multiple instances when CMH providers altered their usual practice to respond to their client's ongoing mental health needs. To illustrate, one CMH provider explicitly contrasted his usual care to what he actually provided the client: *“We’re usually 12 to 14 sessions. And I have on file… 23 sessions. That would not include ongoing or booster-type of sessions”* (CMH1). Extending a youth’s CMH involvement was particularly common for youth with ongoing stressors (e.g., high family conflict, self-medication through substance abuse). Providers described efforts to ‘stretch the boundaries’ of the standard number of sessions when youth were not *“ready to leave”* CMH. As an example: “*I’m going to push to keep [youth] here… it’ll be 2 years. That’ll be a first [within the program]. But he is not the only one that I would push past this semester* [i.e., typically the program provided services by academic semesters]*”* (CMH7).

CMH providers often described following up with youth well past their agency’s standard *“6-month window”*. Some providers anticipated their clients would check-in post-discharge: “*[Youth] is somebody I could see coming to meet with me or talking to me on the phone over the years to come”* (CMH10); this was also the case for parents of youth: *“I think [parent] will use me as a resource or even just to check-in and update [me] on youth”* (CMH4). Many CMH providers described “*leaving it open”* for youth and their families to re-engage: *“I sort of left it open for [parent]. Like even though we’re closed, it doesn’t mean you can no longer call me or exchange emails”* (CMH4). A strong therapeutic relationship reinforced the CMH providers’ expectations about seeing their clients again post-treatment: “*If you build a good relationship with the family and they trust you, and you’ve helped the family, they will contact you again. I’m quite certain [family] will be in touch with me again* (CMH1).

CMH providers perceived costs to the CMH system associated with ‘stretching the boundaries’: *“Sometimes it just means working a longer day or bumping clients, current clients too*” (CMH1). For some providers, follow-up care felt like *“a whole caseload on its own”* (CMH4). One provider described treatment programs operating more like *“a revolving door service”* for families. Providers also perceived a *“limited amount of time”* to follow youth post-discharge due to a lack of treatment capacity: *“I can’t keep seeing people from outside discharge because I haven’t got the hours to provide that kind of follow-up with the caseload here”* (CMH8). This was exacerbated by a lack of resources and CMH professionals: *“It can get crazy. We really need another social worker”* (CMH8).

CMH providers viewed ongoing monitoring as not being the ‘norm’ or expectation within their agency: *“The way it works now, when the case is closed, you’re done”* (CMH9). CMH providers identified a need for providing more “formalized” monitoring: *“[Youth] made good progress but I think, without support, it’s easy for [youth] to fall back into old patterns”* (CMH8). Monitoring was also viewed as an important part of assessing for a client’s risk of harm: *“I think the older [youth] gets, the bigger he gets, and more out of mom’s control. And violence is always just over the horizon with this family”* (CMH10).

CMH providers viewed several benefits to monitoring, including cost-savings by off-setting crises (e.g., ER visits): *“I think it would save emergency room visits where the kid is really at their wit’s end, or it might bypass some very costly crisis”* (CMH5). One CMH provider viewed monitoring as important for improving continuity of care: “*Youth won’t feel like they have to start over telling their story all the time. The therapist is up to speed as to where they actually are. I think it would truly make a seamless transition”* (CMH8). However, providers were unsure about how monitoring would be implemented. Some providers felt this care would be less *“intense”* or frequent: *“It doesn’t need to be continuous. The timing may need to be thoughtfully considered”* (CMH9). Overall, providers were unclear about how youth would be monitored beyond the age of transfer. The following section explores this issue more in depth by covering CMH providers’ views on transition to adult care.

### 3.5.3 Transition to Adult Care

CMH providers anticipated youth who had received CMH services over a long period of time to likely require transfer: *“I’ve been in this business for 36 years. You get a client that starts at a young age - if they’re still continuing into teenage-hood, you can guarantee they’re going to be needing services in adulthood*” (CMH7). Yet, the topic of transition was not discussed by providers: *“What would it look like? [laugh] I don’t know because I don’t often do it”* (CMH1). CMH providers repeatedly expressed they *“don’t look that far into the future”* and tended to focus on the short-term: *“I don’t look at 10 years from now. I look at maybe six months from now, maybe a year from now”* (CMH3). Three main questions emerged amongst CMH providers: (1) will this youth require transfer? (2) when would I have this discussion? (3) what adult services would be available?

### 3.5.3.1 Will This Youth Require Transfer?

Conversations with youth about adult care were described to be *"hit or miss"* and *"very situational"*. This seemed to stem from providers' uncertainty about whether youth would require adult services: *"I'm rather hesitant to go predicting or recommending services for the future"* (CMH8). Another CMH provider indicated he would discuss transition "*if it seemed relevant… if it looked like the family needed extensive long-term services"* (CMH2). The majority of CMH providers believed their clients would benefit from "*periodic counselling*". However, providers could not identify clear criteria for which youth would require transfer to adult care. Providers hoped their clients would continue to use the coping strategies they learned and, in spite of "*not having a crystal ball*", this could offset the need for additional treatment.

### 3.5.3.2 When Would I Have This Discussion?

Providers were unsure when a discussion about transition would be appropriate in CMH. Some CMH providers felt their client was too young for this discussion: *"Most of the kids that I deal with are, like, seven to eleven. He's what, 12? We didn't go there"* (CMH3). Providers did not know if it was appropriate for them to have this discussion with youth, especially with other more present issues: "*I guess I didn't know if that was really appropriate for me to bring up. Because this is a family that's on the day-by-day. Looking down the road 4 years is probably not overly realistic"* (CMH5). Providers also frequently described being in "*the thick of it*" or still trying to make treatment progress with their clients: *"I guess I haven't shifted to closure in my mind yet. I'm still sort of trying to make [treatment] make a difference"* (CMH9).

Providers perceived parents to struggle with navigating the CMH system alone, which seemed to delay any conversation about the adult system. Related to this, another reason for not discussing transition was inadequate time to plan in CMH: *"We don't often get a lot of notice when somebody's going to be discharged. If I had my way, we'd have time to make the referral a couple of months ahead so that when they walk out the door, they've got an appointment"* (CMH8). Some providers worked less with older youth clients, and assumed this discussion would occur at the age of transfer. As noted by one provider: "*most of the families stop working* *with us long before the youth turns 18"*, so *"if [youth] ages out, then that would provide the opportunity to look at transition into adult service"* (CMH8).

#### 3.5.3.3 What Adult Services Would Be Available?

A perceived gap in available services between CMH and adult care also contributed to providers' reluctance to discuss transition: *"Services that bridge between 16 and 20 is terrible. There's nothing there. The gap is ridiculous"* (CMH7). Many providers acknowledged their lack of awareness about available AMHS: *"[Youth] needs trauma work. Who's going to do that? Who's going to pay for it? I don't know where to refer them for that"* (CMH9). Frequent changes in AMHS made this challenging: *"The toughest part is things change so much. Agencies change. Phone numbers change. Mandates change. Giving [families] information now - in 4 years when they go to access it, it may not be what it was"* (CMH6). According to CMH providers, discussing transition to adult care was not part of their routine practice: "*I've never really looked at the long-term or the big picture. But it wouldn't surprise me if I were to continue to hear from [client]"* (CMH8). As stated by one provider, *"we're not used to thinking beyond… into the gap that your study is looking at"* (CMH6).

## 3.6 Discussion

Very little is known about caring for youth with ongoing and recurring mental health problems within CMH. This study explored perspectives from CMH providers about delivering services to these youth (ages 12-15) and their families. Providers were specifically asked about their views on the long-term course of their clients' problems and about the possibility of needing future services or transfer to adult care. The current qualitative approach allowed for in-depth discussions and uncovered beliefs amongst providers about the course of common CMH problems among youth.

For this study, youth and their parents were recruited if they had received at least three CMH visits over the prior year. The aim was to recruit families who *might* be in need of ongoing CMH care and who *might* require transfer to adult care. It should be emphasized that *all* participating CMH providers believed their clients were at-risk of re-experiencing mental health problems at some point in the future. This perception stemmed from providers' knowledge about their clients' individual (e.g., family history of mental illness) and situational (e.g., parental conflict) factors. Providers also believed standard treatment protocols in CMH did not match their clients' ongoing and recurring needs. Youth were generally perceived to "not fit the bill" for short-term treatment and this influenced how providers delivered services. Even though CMH providers anticipated their clients would need services as young adults, they were reluctant to discuss the possibility of transition to adult care with them. The reasons for this are discussed below, and emergent themes are compared with the current literature.

### 3.6.1 What Are the Costs Of 'Stretching the Boundaries'?

A theme of 'stretching the boundaries' was pervasive across CMH providers. This involved working beyond the standard number of sessions in treatment protocols, checking-in with clients between sessions, and "*leaving it open*" for families to re-engage post-discharge. This theme is consistent with prior work which shows CMH providers frequently continue to work with older youth clients (e.g., 17-19 years) beyond the age of transfer, especially when a strong therapeutic relationship has been established (Belling et al., 2014; McNamara et al., 2013). The current study suggests CMH providers also "stretch the boundaries" for younger adolescents (12-15 years) who have ongoing problems, and who are not yet 18 years old.

CMH providers 'stretched the boundaries' in spite of not having the resources or infrastructure to provide long-term care. Some providers described working longer hours or "*bumping*" other clients to provide additional treatment to youth with ongoing and recurring mental health problems. There are three potential issues with this. First, increasing caseloads and demands on front-line staff can lead to burn-out and high staff turnover in CMH (Hovish et al., 2012; Reid & Brown, 2008). Second, if post-treatment monitoring is provided for some clients, this might reduce time and resources for new referrals. As a result, wait-listed youth might experience longer delays for treatment. Participating CMH providers acknowledged lengthy wait-times as a barrier to "*bending the rules*" for their clients. Finally, retaining cases in CMH also risks young adults disengaging from services that are not developmentally appropriate (Islam et al., 2016).

### 3.6.2 Barriers to Discussing Transition to Adult Care with Families

CMH providers acknowledged a need for longer-term services for their clients. However, they were reluctant to discuss the possibility of adult care with their clients. This stemmed from a lack of knowledge about: (1) *who* should transfer; (2) *when* this discussion would be appropriate; and (3) what adult services would be available.

#### 3.6.2.1 Who Should Transfer

In some cases, transfer is not a controversial issue. Youth who have a disorder with onset in late adolescence and an established severe and chronic course (e.g., schizophrenia, psychotic disorders) will almost invariably require adult care. For older youth clients close to the age of transfer who are still receiving treatment (e.g., therapies, medication), CMH providers might be more likely to consider transfer (McNamara et al., 2013). For younger adolescents with recurring problems, determining transfer is much less clear. This was exemplified in the current study as all participating CMH providers expressed some uncertainty about their clients' long-term care needs.

Criteria for identifying youth at-risk of disorder recurrence or persistence was recently proposed for depressed and anxious youth (Schraeder & Reid, 2017). Researchers have also begun to explore the utility of applying clinical staging models to determine a youth's future mental health needs by establishing markers of illness progression (Hickie et al., 2013; R. Purcell et al., 2015). Very large sample longitudinal studies would be required, however, before long-term predictive value of such staging classifications are determined. Ultimately, research is needed to support the development of criteria for screening youth with a wide range of CMH problems for transfer to adult care.

#### 3.6.2.2 When to Discuss Transition

Having adequate time to prepare youth and families for transition to adult care and not "leaving it too late" has been emphasized in other studies (McNamara et al., 2013). From the perspective of youth who have transferred, many wished transition planning had started earlier (Hovish et al., 2012). There is very little research to inform when the topic of transition should be discussed. In a comprehensive review of transition protocols in the UK, none specified *when* the transition process should start or exactly *how* youth should be prepared (Singh et al., 2008). The current findings suggest that, for younger adolescent clients (ages 12-15) involved with CMH, determining *when* to discuss transition should consider additional factors. For instance, youth and their parents may not have considered the possibility of adult care. Discussing transition with youth, who are only at increased risk for recurrence, might even be harmful. The potential stigma associated with labeling a CMH problem as "chronic" needs to be considered. Thus, the guiding principle of "do no harm" might understandably deter CMH providers from discussing transfer with younger adolescent clients and their families.

#### 3.6.2.3 Where to Find Appropriate Services

Many individuals with recurring problems (e.g., anxiety, depression) do not meet criteria for specialized AMHS. A lack of appropriate services in adult care has been emphasized (Singh et al., 2010); specific concerns have also been raised by CMH providers for youth with ADHD and learning disorders (Belling et al., 2014; Gilmer, Ojeda, Fawley-King, Larson, & Garcia, 2012). The current study indicated that many CMH providers 'stretch the boundaries' to fill a gap in service provision during the transition period for youth. In these cases, any instances of stretching the boundaries should be systematically documented so that CMH agencies can advocate and allocate resources for their clients.

### 3.6.3 New Models of Mental Health Care Are Needed

Current treatment approaches in publicly-funded CMH systems appear to be based on an acute-illness model (Weisz & Kazdin, 2003). CMH services are provided only in times of extreme need and evidence-based treatments are brief (about 6-months or less) (Barrett, Dadds, & Rapee, 1991; Kendall & Hedtke, 2006; Lochman & Wells, 2003). The current findings highlight how such a model of care is not appropriate for youth with ongoing and recurring CMH problems. New models of care that incorporate routine monitoring need to be considered.

Monitoring youth at-risk of recurring problems might offset the need for more intensive and costly services (e.g., hospitalization) in the future; for example, a youth who experiences a significant decrease in functioning could be managed by their CMH provider during a scheduled follow-up appointment, rather waiting for a relapse or crisis to occur. Without follow-up, families likely rely on acute care services (e.g., emergency department, crisis lines) to manage their children's recurring problems. In Ontario, there has been an increase in mental-health related emergency department visits and hospitalizations amongst children and youth from 2006 to 2011 (Gandhi et al., 2016). This may reflect general problems with access to CMH service. However, it might also suggest the need to consider new models of mental health service delivery for youth with recurring problems.

The current findings suggest monitoring *all* youth post-discharge is not feasible within CMH. A serious lack of treatment capacity and funding within CMH contributes to this problem (Mental Health Commission of Canada, 2010; Schraeder & Reid, 2015; Waddell et al., 2002). Cost-effective and feasible solutions to monitoring should continue to be explored (Forchuk et al., 2013; Kazdin & Rabbitt, 2013). It has been recommended that, following treatment, youth should be monitored in Primary Health Care (PHC) by their family physician (Kutcher, 2011; Schraeder & Reid, 2017; Singh et al., 2016). Family physicians are in a unique position to monitor youth, as they are the only health professionals who routinely follow individuals across the lifespan. For youth who are not appropriate for AMHS, over half (56%) are discharged to their family physician (Islam et al., 2016). In the current study, the majority (80%) of youth reported having a family physician. Ultimately, barriers for integrating CMH and PHC need to be overcome, as PHC offers valuable opportunities to monitor youth and improve long-term outcomes (Collins, Hewson, Munger, & Wade, 2010; Durbin, Durbin, Hensel, & Deber, 2013; Kates et al., 2011).

### 3.6.4 Strengths and Limitations

The current study has several strengths. It is the first to examine issues related to transition for younger adolescents (12 to 15 years) from the perspective of CMH providers. Providers varied in terms of sex, training background, and years of work experience, and also represented different programs (e.g., day treatment, residential care, intensive family therapy). Other studies have reported recruitment barriers for CMH providers (e.g., high staff turnover, lack of consent from youth/families to contact providers) (Hovish et al., 2012). A limitation is that this sample reflects providers from only two CMH agencies in the province of Ontario.

Perspectives from CMH providers might differ from providers in other sectors of care (e.g., education, child welfare) (Pryjmachuk, Graham, Haddad, & Tylee, 2012). This work would benefit from these additional perspectives of professionals in other sectors of care.

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# Chapter 4

# 4 Perspectives on Monitoring Youth with Ongoing Mental Health Problems in Primary Health Care: Family Physicians are “Out of the Loop”

## 4.1 Abstract

Children’s Mental Health (CMH) problems often recur. Following specialized mental health treatment, youth may require monitoring and follow-up. For these youth, Primary Health Care (PHC) is highly relevant, as family physicians are the only professionals who follow patients across the lifespan. The current study gained multiple perspectives about: (1) the role of family physicians in caring for youth with ongoing and recurring CMH problems; (2) incorporating routine mental health monitoring into PHC. A total of 33 interviews were conducted, including: 10 *youth* (aged 12-15) receiving CMH care, 10 *parents*, 10 *CMH providers*, and 3 *family physicians*. Using Grounded Theory methodology, a theme of family physicians being “out of the loop” or not involved in their patient’s CMH care emerged. Families perceived a focus on the medical model by their family physicians and believed family physicians lacked mental health expertise. Findings indicate a need for improved collaboration between CMH providers and family physicians in caring for youth with ongoing CMH problems

## 4.2 Introduction

Common childhood mental health problems, such as depression and anxiety, are long-lasting and tend to follow an episodic course (Beesdo-Baum et al., 2012; Birmaher et al., 2004; Dunn & Goodyer, 2006; Rao et al., 2010). Disruptive behavioural disorders, such as Attention Deficit-Hyperactivity Disorder (ADHD) or oppositional defiant disorder, also tend to recur and persist into young adulthood (Biederman et al., 2010; Bussing et al., 2010; Keller et al., 1992). Some youth receive specialized Children's Mental Health (CMH) treatment. Following treatment, many youth will require monitoring or follow-up into young adulthood. Integrating mental health within Primary Health Care (PHC) is relevant for these youth as family physicians are the only health professionals who routinely follow individuals across the lifespan. There is an urgent need to consider new evidence-based approaches to mental health service delivery because, without follow-up, youth may disengage from mental health services during a time when they need them most (Davis & Koroloff, 2010; Pottick et al., 2008).

### 4.2.1 Caring for Children and Youth with Ongoing Mental Health Problems

Clinical practice guidelines suggest youth with ongoing and recurring mental health problems require long-term monitoring and follow-up. For example, guidelines for managing depression in CMH (American Academy of Child and Adolescent Psychiatry, 2007) and in PHC (Cheung et al., 2007) recommend patients be monitored monthly for 6 to 12 months after the resolution of depressive symptoms, and for 2 years, if the depressive episode is a recurrence. There are barriers to monitoring youth in "real-world" settings. One barrier is existing CMH care models are based on an acute-illness model (Weisz & Kazdin, 2003) which means specialized CMH treatments are brief, lasting 6 months or less (Clarke, DeBar, & Lewinsohn, 2003; Kendall & Hedtke, 2006), and only provided in times of extreme need. This is not adequate for youth with recurring mental health needs who require long-term care.

Another barrier to monitoring youth is the age limit in CMH (typically 18 years old) which creates an artificial divide between CMH and Adult Mental Health Services (AMHS) (Davidson et al., 2011; Kutcher et al., 2009). As a result of this disconnect, re-accessing mental health services is difficult for young adults (Davidson et al., 2011; Mulvale et al., 2016). Further, youth might not be accepted into specialized AMHS, which tends to focus on treating severe and enduring mental illnesses (Cappelli et al., 2014; Singh et al., 2010). One solution is to incorporate family physicians into routine monitoring and transition planning (Schraeder & Reid, 2017; Singh et al., 2016; Taylor et al., 2010). As reviewed in the following section, very few studies have examined the issue of integrating mental health care within PHC specifically for children and youth (Kutcher, 2011; Kutcher et al., 2009; Leitch, 2010; Tobon et al., 2015); none have focused on transition to adult care.

### 4.2.2 Integrating Mental Health Care within PHC for Youth

PHC is a key point of contact for children and youth with mental health problems (Burns et al., 1995; Gilbert, Maheux, Frappier, & Haley, 2006; Kates et al., 2011; Kelleher & Starfield, 1990; Olfson, Blanco, Wang, Laje, & Correll, 2014). Existing collaborative care models between PHC and CMH providers have focused on the *assessment* [e.g., (Gardner, 2014; Gardner et al., 2010, 2003; Kelleher et al., 2000)] or *short-term treatment* of mental health problems amongst children and youth [e.g., (Asarnow et al., 2009; Campo et al., 2005; Kelleher et al., 2006; Richardson et al., 2009)]. The approach to collaborative care *after* a youth has received specialized treatment within CMH would be expected to be different but has not yet been examined.

Maintaining collaborative relationships might be needed for a number of reasons. Family physicians could provide ongoing monitoring and encourage re-engagement with the CMH provider when necessary (e.g., significant deterioration in functioning) to maintain treatment gains. Family physicians also have the advantage of building longitudinal and family-based perspectives on youth patients that no other provider has. Finally, collaboration between CMH and PHC has important implications for improving transitions to adult care. The need for monitoring within PHC into adulthood has been emphasized for common childhood mental health disorders, such as ADHD (Taylor et al., 2010) and depression and anxiety disorders (Schraeder & Reid, 2017). It has been recommended that family physicians be informed when a youth receives CMH treatment and that they monitor youth at-risk for recurring problems

(Schraeder & Reid, 2017). The challenges of incorporating this type of follow-up care within PHC still need to be identified.

Despite the compelling rationale for integrating CMH and PHC, uncertainty remains about the role of family physicians (Reid, Brown, & Hahn, 2013). Two recent studies (Greene, Ford, Ward-Zimmerman, & Foster, 2015; Tobon et al., 2015) reveal that, when care is shared between PHC and CMH, coordination of care and communication between providers is problematic. As part of a project on continuity of care related to CMH in Ontario, Canada (Tobon et al., 2015), parents expressed disappointment with their family physician and felt they were not knowledgeable about CMH issues; youth (ages 15-18) experiences were similarly negative. In a United States-based study (Greene et al., 2015) parents felt they acted as “communication bridges” between their children’s providers in PHC (i.e., pediatricians) and CMH. Collaboration between CMH and PHC providers *after* a youth has received treatment has not been addressed in the literature. The question of whether monitoring youth with mental health problems is achievable within PHC remains unanswered.

### 4.2.3 The Current Study

This qualitative study explored the role of family physicians in a youth’s mental health care by gaining perspectives from youth (ages 12-15), their parents, CMH providers, and family physicians themselves. Two main questions were addressed: (1) How are family physicians involved in the mental health care of youth with *ongoing* and *recurring* mental health needs? (2) What do participants think about family physicians monitoring these individuals into adulthood, and what are the potential barriers of incorporating this within PHC?

## 4.3 Methods

Constructivist Grounded Theory (CGT) was selected as the optimal qualitative methodology as it tends to be more abstract and has the potential for improving understanding or offering explanation when compared with descriptive methods (Charmaz, 2006). The purpose of CGT is to build an explanatory theory by examining how participants construct meanings and actions for specific circumstances. The constructivist approach assumes the resulting theory is an interpretation of the data, which depends on the researchers' views and their relevant expertise (Charmaz, 2014).

### 4.3.1 Recruitment Procedures

A multi-perspective sampling strategy was used (Lingard & Mcdougall, 2013). Youth and their parents were recruited from two CMH agencies in London, Ontario. Youth were eligible if they: (a) were 12 to 15 years old; (b) were currently residing with a parent/guardian; (c) had been receiving care for 1 year or longer at the agency, or for at least 9 months with a prior episode of care [i.e., 3 face-to-face visits; (Reid et al., 2014)] within the previous 5 years; and (d) could be interviewed in English. Parents were eligible if they were the legal guardian of eligible youth.

A list of potentially eligible youth was generated by a supervisor at each CMH agency, who also initiated recruitment by contacting CMH providers of eligible youth and informing them about the study. CMH providers supplied families with a contact information form inviting them to participate in the study and allowing a Research Assistant (RA) to contact them. Interested families were contacted by telephone by the RA who confirmed interest and conducted a brief screening to ensure eligibility. Youth and their parents provided verbal consent prior to scheduling the interviews; consent to participate in the study included an agreement to be audio-recorded. Consent also allowed the RA to contact the youth's CMH and PHC providers. Prior to starting the interview, youth and parents reviewed the letter of information and signed consent. Parents and youth received a $40 or $25 gift card, respectively.

CMH providers were eligible if they: a) had provided care to the youth and/or family for an episode of care; (b) had authority to make decisions about the youth's treatment; and (c) could be interviewed in English. The same eligibility criteria applied to PHC providers, except only one face-to-face visit (in the past year) with the youth patient was required. When families identified a pediatrician as their children's PHC provider, these providers were invited to participate; however, pediatricians were excluded from the current analyses as they typically do not see youth past age 18 and questions focused on long-term monitoring [NB: pediatricians are recognized as a specialist physician in Canada, and not typically considered a PHC provider]. The RA contacted providers about participation by email or telephone, and provided them with copies of their patients' consent forms (Thorpe et al., 2009). Verbal and/or written consent was obtained prior to interviews. CMH providers participated during staff time and were provided with a $10 gift card. PHC providers received a $50 gift card. The study was approved by the Research Ethics Board at both CMH agencies and at The University of Western Ontario.

### 4.3.2 Data Collection

Data were collected through in-depth interviews by one investigator (KS). Parents completed a demographics questionnaire (e.g., educational attainment, income). Interviews with youth, parents, and CMH providers were conducted separately and in-person at the CMH agency or on the university campus; interviews ranged from 37-116 minutes. Interviews with PHC providers were conducted by telephone ($M$ = 44 minutes).

Semi-structured interview guides were developed for parents, youth, and providers (see Appendices 4 and 5). These included open-ended questions about the youth's problems (e.g., diagnoses), service utilization, and perceived mental health needs. The current analyses specifically focused on the involvement of family physicians. Parents were specifically asked to describe how they had sought and/or received help from their family physician for their children's mental health issues. CMH providers were asked about their collaboration with family physicians, and vice versa. Across all interviews, questions focused on participants' suggestions for change, consistent with critical research approaches supporting empowerment and social change (Carroll, 2004).

Interviews were open and flexible and, where appropriate, deviated from the interview guide to enhance the richness of data collected. All interviews were audiotaped and transcribed verbatim and checked for accuracy by the interviewer. Field notes were recorded to capture specific details such as interviewer perceptions and nuances of communication. Transcripts were de-identified and assigned numeric codes to preserve anonymity.

## 4.4 Data Analyses

Data collection and analysis occurred simultaneously and iteratively. Data were analyzed using the constant comparison methods of CGT, building the emergent theory and returning to particular instances to analyze discrepancies and refine understanding of relationships between categories (Charmaz, 2014). CGT requires three sequential phases of coding: open coding, focused coding, and theoretical coding (see Appendix 6). The *first phase* of the analysis focused on developing initial codes that emerged from the data. A line-by-line analysis of transcripts involved constructing initial coding templates for each group of participants (e.g., youth, parents). Coding was entered into NVivo10 (NVivo, 2012), a qualitative research software program used to organize and manage data.

The *second phase* of analysis involved ‘focused’ coding or making decisions about which initial codes best represented the data (Charmaz, 2006; Miles & Huberman, 1994). This process attended to the “most useful” codes to synthesize and analyze larger amounts of data. This iterative process allowed new questions about emerging themes to be added to the interview guide and facilitated theoretical sampling. For example, an additional female youth was recruited to explore possible gender differences. Advanced focused coding involved saturating categories and generating explanations from the descriptions within the data. Data collection ceased upon “theoretical saturation” or when gathering new data did not provide new theoretical insights.

The *third phase* involved theoretical coding, which conceptualized relationships between categories to move the ‘analytic story’ in a theoretical direction. To facilitate this process, a data matrix was created to represent a visual summary of common emerging themes among participants with exemplar quotes. Matrices were created to analyze categories and make comparisons between members within each participant group. At each analytic phase, memo-writing and diagramming bridged the gap between coding and conceptual development, providing a logic for organizing the analysis.

Credibility and trustworthiness of the data were enhanced through the use of verbatim transcripts and independent and team analysis (Charmaz, 2006; O’Brien et al., 2014). Researchers were from multiple disciplines (i.e., psychology, social work, family medicine), providing theory triangulation (Guion, 2002). Reflexivity processes, such as attending to preconceptions brought into the project, accounted for the researchers’ influence on each stage of the analytic process (Charmaz, 2006; Malterud, 2001).

### 4.4.1 Final Sample

A total of 20 eligible families were approached about the study by their CMH provider. Eight families were not interested and did not provide their contact information. Of 12 families who completed a telephone screening, two families did not consent to participate. A total of 10 families (10 youth and 10 parents), 10 CMH providers, and 3 family physicians participated in the study. In total, 33 individual interviews were conducted between April and December 2015.

Tables 4.1 and 4.2 present demographic characteristics for youth and parents, respectively. Notably, all parents were the youth's biological mother except for one grandmother and half of the families reported a household income of less than $40,000, compared to a median family income of $75, 985 in London (Statistics Canada, 2015). The majority of youth (70%) had externalizing problems (e.g., oppositional behaviour, ADHD) and a comorbid disorder. The average length of a youth's involvement at their CMH agency was 2.4 years (1–5 years) and with the CMH system was 4.4 years (1–8 years). For many youth, care was not continuous and rather episodic. All youth had received care from a specialist physician (e.g., psychiatrist), and most had involvement with multiple sectors of care (e.g., child welfare). Table 4.3 below describes the characteristics (e.g., age, training background) for providers. Two families did not identify a PHC provider; one family used a walk-in clinic and the other youth had not been in contact with his family physician in over three years. Eligible PHC providers included two pediatricians and 6 family physicians. The current analyses focused on perspectives from three participating family physicians; three other family physicians did not consent for various reasons (i.e., refused to be audio-taped, not interested, lack of time).

**Table 4.1: Youth demographic characteristics**

| Demographic Characteristics | Proportion of youth sample (n = 10) % or *M*, Range |
|---|---|
| Sex | |
| Female | 20% |
| Age | |
| 12 years old | 50% |
| 13 years old | 20% |
| 15 years old | 30% |
| Presenting problem(s)[a] | |

| | |
|---|---|
| Attention-Deficit Hyperactivity Disorder (ADHD) | 60% |
| Anxiety | 50% |
| Behavioural problems | 70% |
| Depression | 30% |
| Sleep Problems | 20% |
| Trauma-related problems | 50% |
| Other providers involved in youth's mental health care | |
| Child welfare provider | 30% |
| Family physician | 80% |
| Pediatrician | 40% |
| Psychiatrist | 90% |
| School provider (e.g., social worker) | 20% |
| Duration of service involvement with CMH agency | *M* = 2.4 years (1 – 5 years) |
| Duration of service involvement with CMH system | *M* = 4.4 years (1 – 8 years) |

*Note.* [a] Most youth (70%) had multiple problems that were the focus of treatment; thus, percentage of cases for type of problem sum to >100%.

## 4.5 Findings

A pervasive theme expressed by youth and their parents was that family physicians were "out of the loop" or not directly involved in a youth's mental health care. Youth and their parents identified a few key reasons for this: (1) having inadequate time to discuss mental health problems in PHC, (2) perceiving a focus on the medical model, and (3) believing their family physician lacked knowledge and expertise for providing mental health care. CMH providers and family physicians unanimously described a lack of collaboration that arose from system and agency-level factors. All participants expressed mixed views on family physician involvement in monitoring youth's mental health problems.

**Table 4.2: Parent demographic characteristics**

| Demographic Characteristics | Proportion of sample (n = 10) % or *M*, Range |
|---|---|
| Sex | |
| Female | 100% |
| Age | |
| 30 to 39 years | 30% |
| 40 to 49 years | 60% |
| 50 to 59 years | 10% |
| Marital Status | |
| Married/Common-law | 80% |

| | |
|---|---|
| Single parent/Never legally married | 20% |
| Household income | |
| <$40,000 | 50% |
| $40,000 - $59,999 | 20% |
| >$59,999 | 30% |
| Education attainment | |
| Less than high school | 10% |
| High school graduate | 20% |
| College or trades certificate or diploma | 60% |
| University graduate | 10% |
| Spouse education attainment | |
| Less than high school | 10% |
| High school graduate | 40% |
| College or trades certificate or diploma | 40% |
| Not applicable (i.e., single parent) | 10% |

**Table 4.3: Characteristics of Children's Mental Health providers and family physicians**

| Characteristics | CMH providers (n = 10) % or *M*, Range | Family physicians (n = 3) % or *M*, Range |
|---|---|---|
| Sex | | |
| Female | 60% | 66% |
| Age | | |
| < 30 years old | 10% | 0% |
| 30 – 50 years old | 60% | 66% |
| > 51 years old | 30% | 33% |
| Training qualifications | | |
| Bachelor degree or college only | 50% | 0% |
| Post-graduate degree only | 50% | 0% |
| Medical degree | 0% | 100% |
| Length of time working in profession | 15 years (0.67- 30 years) | 18.3 years (12 – 30 years) |
| Time spent working with patient | 1.2 years (0.25-2.5 years) | 5.3 years (1 - 12 years) |

Findings are organized to cover the perspectives of each group of participants: (1) youth and parents, (2) CMH providers, and (3) family physicians. For each group, key themes and sub-themes from the analysis are described with supporting exemplar quotes. Quotes are referenced by type of participant and an identification number linking participants involved in a youth's care (e.g., Y1=youth, FP1= family physician). See Appendix 8 for additional exemplar quotes.

### 4.5.1 Youth and Parents

#### 4.5.1.1 Having Inadequate Time to Discuss Mental Health in PHC

Parents regarded a lack of time within PHC for discussing their children's mental health problems: "*By the time they go through all your medical history, there's 5 minutes left… unless they want to run into the next [appointment]"* (P6). A parent described trying to maximize time during PHC appointments, and commented on her family physician's efforts to make time to talk:

> *With a family doctor, you only have so much time, and you're always rushed… you only have 10 minutes and you panic. But a lot of times, she just knew right away, [youth] is coming in for a check-up. So, she would just leave me an extra 5 or 10 minutes*. – P2

Problems related to accessing PHC were also described: *"Sometimes you can't get an appointment; we've been meaning to go and change my medication…we were supposed to go back but she didn't have any time and she still hasn't"* (Y2).

#### 4.5.1.2 Perceiving a Focus on the Medical Model in PHC

Youth and parents perceived visits within PHC to focus on the "medical model", where visits not only felt time-limited but focused on physical issues and medication: *"What's your problem? Okay. Great, there's your prescription. Get out"* (P6). Youth and parents described negative experiences with receiving "medical" help and felt that family physicians were *"quick to put a pen to paper"*: *"Our family doctor just wrote her a prescription for insomnia… my daughter is this age and you're writing her a prescription [for] sleep? Do you have any idea what that's going to do to her body?"* (P1). A parent perceived medications to be a "*Band-Aid*" approach for treating her child's mental health problems within PHC. When parents were not satisfied with the medical help offered or provided to them, they often 'pushed' their family physician 'out of the loop' and looked for the 'right' help elsewhere: *"I had pushed our family doctor for quite a while that things weren't quote-unquote, normal. He tried medicating him but that wasn't a solution. So, I finally put my foot down… I said we needed something more"* (P7).

### 4.5.1.3 Perceiving a Lack of Mental Health Experience in PHC

Youth and parents expressed uncertainty about whether family physicians were qualified or “*equipped*” to provide mental health care: “*I don’t think doctors know as much about [mental health]. Because they have no experience. Like, they give you needles”* (Y5). Parents questioned whether their family physician could provide certain types of medical help, such as prescribing ADHD medication: *“[Pediatrician] was the one that diagnosed him, he prescribes the meds to him. I don’t even know if family doctors can prescribe them”* (P4). Being referred to a specialist physician reinforced the perception among youth and their parents that mental health was outside the scope of their family physicians’ expertise: “*That’s not his expertise… he would rather have him be seen by somebody else. He’s more of a general practitioner”* (P3). Parents commonly expressed relying on family physicians solely for their children’s *physical* care needs:

> *I mostly rely on [FP] for your normal doctor stuff, like your weight and your height. When it comes to their mental health and medication, I always like to go to someone. It’s not like I’m downplaying my doctor at all. She knows a little bit of everything. When it comes to mental health, you don’t want someone who knows a little bit of everything… you want someone that knows a lot about what you’re going through.* – P2

When mental health was perceived to be outside the scope of family physicians’ expertise, some families admittedly did not share this relevant information and relied on emergency services instead: *“I never told [FP]. I never went to him with the worries or anything, I just took [youth] to Emerg and called the crisis line”* (P5). Overall, family physicians were “out of the loop” when youth and parents perceived them to be separate from mental health care.

### 4.5.1.4 Views on Family Physicians Monitoring Problems

Youth and parents believed monitoring after CMH treatment was “*needed*” and “*would be helpful”: “If you were okay a month ago, that doesn’t mean you’re going to be okay at this month… you’re just going so crazy inside”* (Y10). Several benefits to monitoring were expressed, including not letting problems “*build up”* and not waiting for a crisis to access care. Yet, some youth and parents expressed ambivalence about the possible role of family physicians in monitoring CMH problems: *"I honestly don't know... I wouldn't necessarily have a problem [with it]. I don't think [FP] would be able to do much. I mean he can't do therapy"* (P7). Most youth were confused about how this would work in PHC: *"Like a normal doctor is trained to do surgery and not like dissect someone's mind. I just couldn't see a family doctor being able to sit down with someone and make them feel like themselves again"* (Y10). In contrast, some parents felt family physicians were in the *"best position"* to monitor youth: *"That's really the only professional they're going to see, even if it's infrequently - like that physical once a year"* (P6).

The possibility of monitoring by family physicians was seen as being contingent on some key factors. First, youth expressed a need to build a relationship with their family physician: "*I don't see my family doctor often, but if I had one that I saw often, I would be comfortable talking to them"* (Y8). Secondly, all youth and parents reported a need for family physicians to have the *"skills"* to provide monitoring: *"[FP] is a very good doctor. If he's got the skills to help monitor, I don't have a problem with it, but somebody needs to have the skills"* (P7). Similarly, a need for additional training was perceived: "*they would probably have to go through a lot more schooling"* (Y8). Finally, parents recognized a need for family physicians to shift away from a medical model, and provide more time for discussing mental health in PHC:

> *I think it's important for doctors to start saying, you know, "Is everything going on okay at home?" And taking a little bit more time than, "Your blood pressure is good. Your heart rate is great." Maybe giving [the patient] that couple of minutes to say, "I've been feeling really down lately," or "Things aren't going well at work".* – P6

### 4.5.2 Children's Mental Health (CMH) Providers

The perception that family physicians were "out of the loop" of youth's mental health care was shared by CMH providers, and captured in two distinct subthemes: "health care system culture" and "agency culture".

#### 4.5.2.1 Healthcare System Culture

Family physicians were perceived as not part of the client's mental health care. This stemmed from three perceived features of the "health care system culture": (1) a lack of time for discussing mental health problems within PHC, (2) a focus on the medical model within PHC, and (3) a lack of mental health training amongst family physicians.

CMH providers felt there was inadequate time for family physicians to *"actually talk"* or *"get to know"* their patients, especially those with complex needs: *"Some family physicians have it posted, "one question-one visit". So, if you're a family with complex needs, what do you ask first? That's a little tricky"* (CMH2). They perceived family physicians did not have time to build a *"relationship"* with youth: *"They don't have time to get to know the kids. A relationship with your family doctor… what is that? So, a doctor that you see for two seconds… there isn't enough time"* (CMH7).

A perceived medical model within PHC was linked to a belief amongst CMH providers that family physicians would not follow-up about mental health problems that had resolved:

> *People who've been treated for mental health issues in the past - if they go in for a sore throat or a sore shoulder - the doctor doesn't always check in with them about their depression. It's like, well, treated that, done and dusted. But we know that mental health issues don't go away like the sore knee.* – CMH5

Finally, some CMH providers felt family physicians were not an appropriate professional to be involved with their client's care: "*I don't think [FPs] specialize in mental health. I don't think they totally understand the needs of the client. I'm not sure how much experience family doctors have, and how much training they have in mental health. I think it's limited. Very limited"* (CMH1). If family physicians were *"educated"* about mental health and "*knew the right questions to ask*", CMH providers would feel more confident about involving them in their clients' care. A CMH provider felt that family physicians need *"the right beside manner - there are some that are good and some that absolutely suck at it"* (CMH8).

### 4.5.2.2 CMH Agency Culture

Collaborating with family physicians was described as "*not typical*" within CMH agencies: *"I virtually never have contact with family doctors. They rarely seem to be involved"* (CMH8). Another provider noted, "*I've been here a year. I've not talked to one physician. Not one MD have I talked to"* (CMH9).

Most of the time, CMH providers described encouraging parents to *"share the report"* with their family physician assuming parents would keep their family physician "in the loop". CMH providers also explained contacting family physicians *"because medication isn't working"* or to help initiate a specialist referral for their client. However, CMH providers did not expect to have subsequent communication with the family physician: "*We send a letter to the family doctor saying [psychiatrist] is willing to have a look at this patient of yours. But then, [FP] sends information directly to [psychiatrist]. I don't talk to the doctor. It would be very unusual for me to ever talk with a family doctor"* (CMH10).

Strong collaborative relationships between CMH providers and specialist physicians emerged as an important feature of "agency culture". [NB: One participating CMH agency employed a part-time pediatrician to provide consultation]. In contrast, CMH providers perceived family physicians to operate in a "*silo*" or *"off on another spoke of the wheel*".

### 4.5.3 Family Physicians

*"As a family physician, I seem 'out of the loop'"* (FP2). Being unaware of patients' mental health involvement was commonly expressed by participating family physicians: *"Sometimes a whole world of treatment is happening to my patients and I don't even know they're having an issue"* (FP6). Two key factors emerged as barriers to providing mental health care to youth in PHC: (1) a lack of communication between mental health professionals and PHC, and (2) an uncoordinated CMH system.

#### 4.5.3.1 Lack of Communication Between CMH and PHC

*"I don't know that a lot of true collaboration goes on"* (FP6). Participating family physicians often did not receive information (e.g., intake assessments, progress reports) about their patients' CMH involvement. They viewed this as a major gap in service delivery:

> *I think it's really important that [CMH] always communicate with the family physician, that there's always notes sent back to them that this person has accessed their services and this is what we're planning for them and this is the follow-up. This instance, it's the perfect example, things seemed to be going fine, she was doing okay… I renew her medication and then 2 ½ years later I find that things aren't [fine].* – FP2

When family physicians did not receive information from CMH agencies, they frequently relied on whatever parents told them. "*It's really just what the parents are telling me, which is not always entirely accurate"* (FP7).

Feeling "out of the loop" also stemmed from a lack of communication and collaboration between family physicians and other physicians involved in their patient's care: *"[I'm] more of a receiver of information and not much more. I just kind of get the updates from their notes, but they don't contact me directly, or talk to me on the phone about [youth]'s care, or make suggestions"* (FP7) and *"[psychiatrists] do their own thing. They'll kind of give their opinion. But getting together and having a family meeting? That doesn't happen"* (FP6). Overall, family physicians acknowledged a lack of communication and collaboration between PHC and other mental health professionals/agencies, and this reinforced feeling "out of the loop".

#### 4.5.3.2 An Uncoordinated Mental Health "System"

Participating family physicians described patients accessing mental health services from several different pathways, without requiring a physician referral:

> *It's not really clear to me the route kids go through. Sometimes kids will come through me. Other times they come to me and it's already been started through the school and some other means I don't even know about. Should there just be one access point?* – FP7

When youth were involved with multiple providers or services, family physicians felt it was unclear *who* should be coordinating care: *"I find it very frustrating because sometimes you don't know who's taking the lead. What is the expectation of me as a family doc?"* (FP7). Overall, family physicians felt they should be part of their patient's mental health care: "*I definitely think the family doc needs to be 'in the loop' of what's happening, even if they aren't the referring source, they definitely need to know"* (FP6).

### 4.5.3.3 Providing Mental Health Care to Youth in PHC

All family physicians described providing some mental health care. Though this type of care was not consistent: *"It's an ebb and flow, right? Because some people get better, some get worse again. I wouldn't say it's a large percentage but there's certainly several times a year where I'm like: who needs what, and where should I send them?* (FP6). As expressed by one physician, knowing their youth's treatment plan or plan for re-engaging with services was sometimes unclear: "*Sometimes kids get sort of lost in the system and then they'll resurface and I'm the one that ends up having to figure where they should best go and what their needs are... pretty frustrating"* (FP2). Accessing appropriate mental health services for their youth patients was perceived as difficult due to lengthy wait-times, program/service eligibility cut-offs, and *"changing services all the time".*

Participating family physicians also reported managing mental health problems amongst children and youth within PHC: *"I just don't refer them out, we try different medications, talk therapy - it's only when I reach my limits of my expertise, that's when I look for the extra help"* (FP6). Family physicians viewed their role as being a "*listening ear*" for youth and families. All family physicians felt comfortable managing common mental health medications for children and youth and indicated providing supportive counselling. However, they commonly described reaching a *threshold* or limit in their expertise when youth had complex mental health needs: "*It's a bit overwhelming… it's hard to change a lot of things that are going on [for youth] in the family doctor's setting, it's a challenge"* (FP7). Similarly, a family physician described reaching a threshold with treating certain mental health problems that require more than just medication: *"With the ADHD, I wouldn't have the true education background to be able to give them advice; other than medication… I don't think I have that experience to be able to provide* *that part"* (FP6). This threshold also appeared to stem from a perceived lack of training: "*I can't say I feel competent doing the real therapeutic counselling, other than just supportive listening"* (FP7). In these cases, family physicians preferred to consult with specialists (e.g., psychiatrists).

#### 4.5.3.4 Implications and Barriers for Monitoring in PHC

Monitoring mental health problems amongst youth was viewed as critical *"so that [youth] don't get lost in the loop"*. As one family physician put it: "*Well it should be done; obviously, I think somebody should be, whether it's the primary case worker at [CMH agency] or myself; somebody should be monitoring similar to the chronic health issues"* (FP2). Monitoring was viewed as particularly important during a youth's transition to adult care. A patient's relationship with their family physician was described as unique from CMH providers, and other specialists, and ideally suited for this role: "*Suddenly [youth] hit 18, and they have to go to somebody else. That's really tough if they've had a relationship and a bond with someone. Whereas I'm different; I see them from the time they're born until old age"* (FP2).

Yet, monitoring youth who have received CMH treatment was not perceived as the "*norm*" in PHC: *"I'm sure [youth] feels that [with] seeing the specialist - "I don't need to see my family doctor for this". But just see your family doctor every couple of months to keep him in the loop. That would probably not be a bad idea"* (FP7). The most commonly stated barrier was a perceived lack of incentive for youth to attend follow-up appointments in PHC: *"It's very hard to get someone that's feeling good to keep coming back for follow-ups when they're not on medication, because they feel like there's no point of the visit"* (FP6). Further, a family physician felt that youth would require a certain level of insight into their care needs: "*They have to have some cognitive ability or understanding of what they're dealing with. I mean, at 10 [years old], they come in because mom brings them in and they have to take a pill so they do well in school"* (FP2). All participating family physicians considered resource issues; one questioned the value of monitoring *all* youth: *"How many kids that are feeling good would I follow up with to actually find the one that started to slip down the slope, but wasn't at crisis yet?* (FP6). Overall, family physicians believed monitoring was important and necessary for youth with ongoing mental health problems, but noted several barriers associated with implementing this into practice.

## 4.6 Discussion

Perspectives from youth, their parents, CMH providers, and family physicians were explored. Most youth had behavioural problems that were comorbid with other disorders (e.g., depression). This is consistent with research on youth that require ongoing mental health care (Cappelli et al., 2014; Islam et al., 2016). The consensus view of participants was that family physicians were "*out of the loop*" or not involved with their youth patient's mental health care. Moreover, youth and their parents were ambivalent about receiving help for their mental health needs in PHC in the future.

While the finding that mental health issues were generally not discussed in PHC is somewhat surprising since youth had accessed CMH treatment, it is consistent with previous research (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013; Garrison et al., 1992; A. Rhodes et al., 2012; Sharp, Pantell, Murphy, & Lewis, 1992). As noted by participating family physicians, youth can access CMH without a PHC referral. Physician's failure to ask about CMH problems (A. Rhodes et al., 2012), and parents' reluctance to disclose this information in PHC (Lynch, Wildman, & Smucker, 1997), exacerbates the problem. Time-limited patient appointments in PHC are also commonly perceived as a barrier for discussing complex health and mental health concerns (Chen, Farwell, & Jha, 2011; Ostbye et al., 2005; Steele, Lochrie, & Roberts, 2010; Tai-Seale, McGuire, Colenda, Rosen, & Cook, 2007). Without an awareness that a youth patient is having significant mental health problems, it is not unusual that family physicians would not routinely ask about such issues.

Even when mental health problems *were* discussed within PHC, participants perceived a focus on the "medical model" or any acute-care approach. There has been increased attention on applying an adapted version of the chronic care model [e.g., CCM; (Coleman, Austin, Brach, & Wagner, 2009; Wagner, Austin, & Von Korff, 1996)] to CMH problems within PHC (Campo et al., 2005; Foy, Kelleher, & Laraque, 2010; Kelleher et al., 2006; Kolko, Campo, et al., 2014; Richardson et al., 2009; Wissow et al., 2008), wherein youth patients are taught self-management strategies and attend planned 'check-up' visits. Only one study to date has assessed the efficacy of a CCM approach for CMH problems (Kolko et al., 2014), and has revealed positive outcomes (e.g., higher rates of treatment completion, improved symptom severity). For adult mental health problems in PHC, research has generally revealed a lack of uptake of CCM strategies (Bishop, Ramsay, Casalino, Bao, & Pincus, 2016). For children and youth specifically, protocols for long-term management of ongoing and recurring mental health problems do not exist.

### 4.6.1 Monitoring Complex Mental Health Problems in PHC

Participating family physicians felt comfortable managing mild childhood mental health problems within PHC. It was only when treating complex problems went beyond their expertise that family physicians referred out or consulted with specialists. A perceived "threshold" of expertise amongst our family physicians is consistent with a *stepped-care approach* (Bower & Gilbody, 2005; Campo et al., 2005; Katon, 1999; Kelleher et al., 2006). In this approach, family physicians have key roles in detection and assessment of CMH in general, with management of mild CMH problems in a PHC setting, and referring to specialized or "stepped up" care for patients with more complex issues.

So why did youth, parents, and CMH providers think family physicians lack mental health "*skills*" while participating family physicians thought otherwise? One reason for these differing views might stem from a pervasive and long-standing public belief that mental health operates independently from physical health care, namely in separate "silos" (Kutcher, 2011). Other studies also suggest youth and parents view mental health problems as "not relevant" in PHC (A. Rhodes et al., 2012) and see PHC as strictly for physical health care (Boydell et al., 2013; Larson et al., 2015). If parents and youth do not see their family physician as having a role in mental health care, it becomes understandable why physicians are not included in youth's care. If this is the case, youth and parents should be educated about the role of their family physician, possibly by their CMH provider.

Another reason for these differing views could be that youth and parent participants were thinking about monitoring as a specific skill-set. Although recent work has shown increased efforts towards enhancing mental health training for family physicians, much of this has focused on refining assessment and referral skills (Chisolm, Klima, Gardner, & Kelleher, 2009; Gardner et al., 2010, 2003). Using a stepped care approach, youth who have been referred to specialized CMH and who have received treatment should be transitioned back ("stepped down") to PHC when their problems subside or remit. Skills for mental health monitoring and for managing youth *after* they have received specialized CMH treatment are reasonably different than skills required to detect and treat these complex problems. This type of care requires an ongoing patient-physician relationship. Prior research suggests PHC providers feel more confident making appropriate referrals than treating mental health problems and believe their role is to identify and refer rather than to treat and/or monitor (Heneghan et al., 2008; Olfson et al., 2014; Steele et al., 2012; Steele, Lochrie, et al., 2010). This appears consistent with parents' views. In a recent study (Larson et al., 2015), parents were divided about the role of their PHC provider *after* a mental health referral was made; some viewed their PHC provider has having "*done their part*" while others expected them to remain involved in their children's care. In the current study, youth and parents also expressed ambivalence about the role of their family physician after treatment. This is not surprising as aftercare following CMH treatment is routinely neglected by all providers involved in mental health care and is rarely studied (Gardner, Kelleher, Pajer, & Campo, 2004). The current findings highlight an opportunity to educate youth and their parents about the potential PHC role in monitoring mental health problems after treatment.

Improving youth's long-term mental health outcomes, *after* they have received CMH treatment, requires formalized guidelines within PHC. A paucity of research on how to provide ongoing or episodic care for children and youth with mental health problems limits the ability to develop these guidelines. A lack of training and knowledge in monitoring complex and recurring mental health problems likely contributed to participating family physicians feeling "*out of the loop*".

### 4.6.2 Unique Issues within CMH for Bringing Family Physicians "Into the Loop"

A lack of collaboration between CMH providers and family physicians was highlighted in the current study. The current legislation in Ontario contributes to this perceived disconnect. For example, CMH providers require patient consent for collaborating and sharing confidential patient information with providers outside their agency, including the youth's family physician. CMH issues routinely involve providers from multiple sectors of care (e.g., education, child welfare), which fall outside a patient's health-related "circle of care". Complex physical health conditions may also involve multiple providers, but virtually all other specialty providers (e.g., pediatricians, cardiologists) are in the medical sector and fall within a patient's 'circle of care'.

An uncoordinated CMH system is another issue. As noted by our family physicians and in other studies, relying solely on parents to coordinate care between CMH and PHC is problematic (Greene et al., 2015; Tobon et al., 2015). When families access CMH from multiple entry points and receive services simultaneously across sectors, it is difficult for PHC and CMH providers to know "*who is taking the lead"*. System reform is currently underway in Ontario to designate one CMH agency as the "lead agency" or main access point into the system (Ontario Ministry of Children and Youth Services, 2012). Yet, coordinating care for youth at-risk of a recurrence, and who will likely need services in adulthood, has not been addressed in policy frameworks and remains a major gap in service provision. Recommendations for improving collaborative care between CMH and PHC for this subset of youth are outlined below.

### 4.6.3 Implications for Behavioural Health

New models of collaborative care for youth with ongoing and recurring mental health problems need to be considered. Without monitoring, youth may re-surface in hospitals, psychiatry units, or emergency departments if problems recur after treatment. The widespread perception that family physicians are "*out of the loop*" needs to be challenged, since PHC offers valuable opportunities for improving mental health care for youth. As the role of family physicians in mental health care continues to evolve, it is critical that they are seen as more than 'gateway providers'. Family physicians can play an essential part for youth with recurring problems. Monitoring CMH problems and facilitating re-engagement with specialized mental health services, should problems recur or escalate, are two ways in which family physicians could be particularly helpful. This study highlights two areas for improving mental health care provision within PHC.

First, PHC should adopt a longitudinal perspective when managing CMH problems. Formalized protocols and guidelines for managing these problems should be developed and earlier work suggests family physicians would be receptive to this (Steele, Shapiro, et al., 2010). Since monitoring (e.g., relapse prevention) would apply across CMH disorders, protocols for managing these problems within PHC do not need to be “disease-based” (Wissow et al., 2008). Guidelines should focus on identifying which youth require monitoring as not all will be at-risk for recurrence. The complex needs of treated youth are best understood by their treating CMH providers. Thus, it is recommended that CMH providers share treatment plans with family physicians and develop procedures for re-engaging with mental health services. Standards of care within PHC should not be solely defined by the specialty of CMH (Collins et al., 2010); however, increased transparency and collaboration between these sectors would be an initial starting point.

Secondly, family physicians may reasonably anticipate barriers to monitoring within PHC (e.g., resources, training). Research suggests that addressing mental health concerns does not add to the burden of care within PHC (Gadomski, Wissow, Slade, & Jenkins, 2010; Kolko, Campo, et al., 2014). Once protocols have been established, it will be important for future research to explore barriers to monitoring older youth (16-18 years), especially those who do not already have routine visit (e.g., medication) or who move away from home for post-secondary education. Not all family physicians will have the time, interest, or interpersonal style that would lead them to pursue additional training in providing mental health care for children and youth. However, all family physicians should feel confident asking about mental health issues, helping families connect with appropriate services, and clarifying their roles in terms of caring for youth with CMH problems. Family physicians trained in patient-centered care (the prominent training model across North America) already have the basic skills needed to do this (Stewart, Brown, McWhinney, Mcwilliam, & Freeman, 2014); guidance on how to apply their existing knowledge and skills when working with youth patients with CMH problems may be needed. Then, it would be helpful to promote a “culture” within the healthcare system that this is within family physicians’ purview.

Finally, educating youth and parents about the role of their family physician is needed. At the community-level, programs aimed at improving “literacy” about mental health could include the role of family physicians. CMH providers should be mindful of referring practices within an agency, where ‘in-house’ specialists (e.g., pediatricians) who offer time-limited services may further divide CMH from PHC. Rather, CMH providers could promote the role of family physicians as an opportunity for an enduring patient-physician relationship across the lifespan (Stewart et al., 2014). For this reason, family physicians could be identified as the main provider to coordinate care after youth receive CMH treatment. ‘Post-referral’ monitoring by family physicians (e.g., referral follow-up with a patient) has been shown to improve youth engagement with initial CMH treatment (Hacker et al., 2014). Family physicians’ involvement with youth patients’ care during *and after* CMH treatment might prevent youth from disengaging from needed future services.

### 4.6.4 Limitations

The current sample reflects only one province in Canada, and views captured in this study are those of youth, parents, and CMH providers from two CMH agencies in London, Ontario. The “agency culture” that emerged in this study might not reflect routine practices and care at all CMH agencies, especially given local initiatives on collaborative CMH models across the province (Collins et al., 2010). Few family physicians agreed to participate in the current study. Poor representation by these providers is an important finding that underscores a general lack of PHC involvement in CMH care. A different sampling approach, where youth are recruited from PHC practices rather than CMH agencies, might have led to different perspectives. However, the logistics of identifying and recruiting youth with ongoing or episodic mental health problems from PHC would have been extremely challenging; for example, an entire PHC practice would need to “buy-in” to the study (not just the individual physician) (Johnston et al., 2010). The current study did not examine perspectives of providers in other sectors of mental health care (e.g., education, child welfare). Compared to these providers, family physicians are in a unique position to monitor youth’s problems into adulthood. Gaining additional provider perspectives, however, would be useful for identifying barriers to collaboration across sectors beyond PHC and CMH.

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# Chapter 5

# 5 Transitioning to Adult Mental Health Care Amongst Young Adults Treated as Children and Youth

## 5.1 Abstract

Mental health problems experienced by youth often recur. Following Children's Mental Health (CMH) treatment, youth may require monitoring and follow-up possibly into young adulthood. For these youth, Primary Health Care is highly relevant. It is unknown how many individuals receive mental health care in the medical system (i.e., by a family physician, pediatrician, or psychiatrist) after CMH treatment (up to age 18), and into adulthood. The objectives of this study were to: (1) compare likelihood of having a mental health visit in the medical sector after age 18 (the outcome) between youth who received CMH treatment versus matched controls; (2) examine predictors of the outcome. This was a longitudinal, prospective, case-control cohort study which involved administrative data from CMH agencies in Ontario and the medical system (Ontario Health Insurance Plan; OHIP). The CMH sample was aged 7-14 years at their first CMH visit between 2006-2008 (N=2987); an age-, sex-, and region-matched control group was obtained from the general population (N=8961). Findings revealed that CMH youth were twice as likely than controls to have a mental health visit in the medical system after age 18; visits were primarily with family physicians. For CMH youth, the median survival time (when 50% experienced outcome) was 3.3 years. Significant predictors of having a mental health visit in the medical sector after age 18 were primarily related to higher service use in the CMH and medical system. The majority of youth treated for CMH problems will require some form of additional MH care. Family physicians can be part of this care, especially for youth transitioning into the adult system. Future research should continue to explore the current extent of family physicians' involvement for youth and families during and following CMH treatment.

## 5.2 Introduction

About three-quarters of adults with a mental illness recall that the onset of their problems occurred before 24 years of age (Kessler et al., 2005). Some of these adults would have received specialized Children's Mental Health (CMH) treatment during their childhood or adolescence. It has been argued that, at the age of transfer, our mental health care system "is weakest, where it should be strongest" (McGorry et al., 2013, p. 3). A lack of follow-up after CMH treatment and challenges with transitioning youth to adult care create significant barriers for youth who continue to need help in adulthood (Davidson et al., 2011; Mulvale et al., 2016). A better understanding of what happens with youth treated for CMH problems as young adults is needed to inform the development of new models of mental health care that can strengthen our system.

Exploring mental health service use amongst young adults within the medical sector is especially needed. Professionals in the medical sector play a major role in the identification, assessment, and referral of mental health problems amongst children and youth (Brugman, Reijneveld, Verhulst, & Verloove-Vanhorick, 2001; Rushton, Bruckman, & Kelleher, 2002; Sayal, 2006). Some medical providers are specialists in treating mental health issues (i.e., psychiatrists), while other providers, such as family physicians and pediatricians, provide both physical and mental health care (Gardner et al., 2010; Larson et al., 2015; Rushton et al., 2002; Sayal et al., 2010; Yeh et al., 2002). We know, based on self-report, that about two-thirds of youth and families involved with the CMH system are simultaneously involved with the medical sector (Reid, Cunningham, et al., 2011). It is unclear though how many individuals receive mental health services within the medical sector after receiving CMH treatment (i.e., up to age 18), and after the age of transfer. If those treated for CMH problems as children or youth are more likely than the general population to use mental health services in the medical system, then this would bolster a need to strengthen collaboration between CMH and our medical system for this group of youth.

We know that some youth will require mental health services as young adults, but very little research has followed youth treated for CMH problems after the age of transfer. The current study followed youth who had received CMH treatment in the province of Ontario, Canada, and examined whether they had received mental health services in the medical sector after age 18 (i.e., the age of transfer to adult services in Ontario). Two areas of research support the need for this work and are described below. First, studies that have assessed youth's access to specialized Adult Mental Health Services (AMHS) are presented. This will highlight a gap in our knowledge about access to other mental health services after the age of transfer, for example, by family physicians. Second, theoretical models of mental health service use are outlined to frame the choice of predictor variables used in the current study.

### 5.2.1 Transfer to Adult Mental Health Services (AMHS)

Only two studies to date have attempted to follow youth treated for CMH problems beyond the age of transfer (Cappelli et al., 2014; Singh et al., 2010). In both studies, the outcome of interest was transfer from CMH to specialized AMHS. The TRACK study, based in the United Kingdom (UK), was the first to identify a cohort of 16-21 year olds (N = 154) who had received CMH within the UK's National Health Services and assess their access to AMHS (Singh et al., 2010). AMHS included services provided by: physicians (i.e., adult psychiatrists), early intervention teams (e.g., for early psychosis), specialized clinics (e.g., Asperger syndrome services), adult inpatient units, as well as other community services. Of the total sample, 85% were considered "suitable" for AMHS by CMH providers, but only 49% of youth actually transferred to AMHS (i.e., attended AMHS appointment). Over a third (n = 52, 40%) of youth were not referred by CMH providers to AMHS, and some (6%) did not meet eligibility criteria (Singh et al., 2010). A common belief amongst CMH providers who did not refer youth to AMHS was that AMHS would not accept the referral or have the appropriate services. AMHS tends to treat individuals with severe and enduring mental illness (e.g., schizophrenia, psychoses). Many youth with other ongoing but less severe problems may not be suitable for AMHS.

A Canadian-based study (Cappelli et al., 2014) also assessed transfer to AMHS amongst a cohort of youth (N = 215), aged 16 to 20 years referred to a transitional program. All youth in this study were deemed eligible for AMHS, which included hospital services, community-based programs, specialized clinics (e.g., substance abuse treatment centers), and private psychologists. Criteria used to define eligibility were not made explicit by the authors; however, CMH providers of referred youth were required to be involved in the youth's transitional plan of care. Overall 59% of youth transferred to AMHS (i.e., seen by an AMHS provider). Youth who did not transfer were either wait-listed for AMHS (19%) or had cancelled services (22%; e.g., declined AMHS, moved away).

The above two studies focused on youth at the age of transfer and AMHS. However, some youth who will go on to require AMHS may not be receiving CMH services at the age of transfer (Schraeder & Reid, 2017). Youth who require adult care, but who do not access AMHS, might receive help from Primary Health Care (PHC) providers (i.e., family physicians in Canada). In a recent secondary data analysis of the TRACK study (Islam et al., 2016), over half of youth (56%) not referred to AMHS were discharged to their family physician [NB: discharge to family physicians was not reported by Cappelli et al., 2014]. The role of family physicians in caring for youth who have received CMH treatment has gained increasing attention. Indeed, recent guidelines from the National Institute for Health and Care Excellence (NICE) in the UK aimed at improving transition to adult care for youth indicate family physicians should be actively engaged in the transition planning process (Singh et al., 2016). It has also been recommended that youth be monitored by their family physician after receiving CMH treatment, particularly those at-risk of recurring mental health problems (Schraeder & Reid, 2017; Taylor et al., 2010). Yet, the proportion of youth who are seen by a family physician or other health professional (e.g., psychiatrist) following CMH treatment, and after the age of transfer, is virtually unknown.

### 5.2.2 Predicting Mental Health Service Use After Age 18

Our understanding of what predicts young adults who go on to receive AMHS after the age of transfer is very limited. In the TRACK study (Singh et al., 2010), transfer to AMHS was defined as at least one attended AMHS appointment and was, not surprisingly, more common amongst youth with a severe or enduring mental illness (i.e., schizophrenia, psychotic disorders, bipolar affective disorder, depression with psychosis) and those taking psychotropic medication at transfer. Predicting mental health service use within the medical sector after the age of transfer has not been studied. The outcome in the present study was therefore defined as a youth’s first office-based mental health visit in the medical sector after age 18.

A limitation of previous studies is the lack of conceptual framework. To address issues related to policy or social values, a framework is needed to organize the many individual, family, treatment system factors that might shape an individuals' service use. The following section outlines a theoretical framework for exploring predictor variables in this study.

### 5.2.3 The Revised-Network Episode Model (R-NEM)

Models of help-seeking behavior can be used to guide research on mental health service utilization in young adulthood. The *Revised-Network Episode Model* (R-NEM; revised for children and adolescents; Costello, Pescosolido, Angold, & Burns, 1998) builds on previous models of help-seeking (Aday & Andersen, 1974; Logan & King, 2001; Stiffman, Pescosolido, & Cabassa, 2004) by conceptualizing service utilization as a dynamic, social process embedded within a larger pattern of "networks". The model's emphasis on social "networks", rather than individual (youth or parent) decisions, is based on research suggesting that CMH service use cannot be fully explained by individual characteristics or predisposing factors (e.g., socio-economic status, illness severity). Rather, CMH service utilization is better predicted by considering a youth's service use within, and across, multiple sectors of care, and treatment system factors. Variables in the R-NEM are organized into: (1) *social content* or child and family-level factors (e.g., child's age, sex) and illness characteristics (e.g., problem severity); (2) *illness career*, a historical account of decisions resulting in "entrances" and "exits" (e.g., entry into CMH treatment, recovery); and (3) *social support/treatment systems* or the people and professionals involved with a youth's care; each of these factors are discussed below.

The R-NEM is the only theoretical model that has been empirically applied to research on service use amongst transition-age youth with mental health problems (Boydell et al., 2013). Boydell et al. (2013) used specific components of the R-NEM (i.e., family support system, community and school system, and treatment system) to guide qualitative interviews with youth at high risk of psychosis (aged 14 to 20). No quantitative studies to date have applied the R-NEM. The entire model includes 76 factors and cannot practically be tested in a single model (see Appendix 9 for a diagram of the full model). Further, the model does not prescribe how factors should be measured. For instance, an individual's "illness career" could theoretically be captured by their mental health service utilization within *both* CMH and medical systems. The current study selected some variables directly from the R-NEM (e.g., child's sex) and organized other variables (e.g., pattern of CMH care) within the R-NEM domains to predict the outcome.

#### 5.2.3.1 Social content

Previous research has shown that age of onset of CMH problems, such as anxiety and depression, does not consistently predict whether a child will experience recurrence or persistence of problems (Schraeder & Reid, 2017). It is therefore unclear how a child's age could be related to having a mental health visit in the medical sector after age 18. Specifically, age at first CMH visit was used in the current study. Female youth may be more likely to use services after age 18 compared to males, as females are consistently associated with higher mental health service use by physicians, particularly during young adulthood (Mackenzie, Gekoski, & Knox, 2006; Yu, Adams, Burns, Brindis, & Irwin, 2008). In Canada, where PHC is publicly-funded, research on area-level measures of socio-economic status has shown receipt of mental health care in PHC is more common amongst adults living in more deprived areas (e.g., more individuals living below low-income cut-off) compared to areas with higher socio-economic status (Durbin, Moineddin, Lin, Steele, & Glazier, 2015). In contrast, living in a rural area is often associated with poorer access to mental health care provided by family physicians [e.g., (Zayed et al., 2016)], and this might similarly influence access to care after age 18. In terms of illness characteristics, youth with more severe or comorbid CMH problems and those with poorer functioning tend to have longer-lasting problems (Birmaher et al., 2000; Lewinsohn et al., 1994). A higher impact of a child's illness on the family is also associated with illness severity (Zwaanswijk, Van Der Ende, Verhaak, Bensing, & Verhulst, 2003). Youth with these illness characteristics might therefore be expected to need ongoing care into adulthood.

### 5.2.4 Illness career

A youth's "illness career" begins with initial recognition of problems. Problems may be recognized by a parent or a professional in the CMH or medical system. For some youth, being recognized by a medical professional might be an indication of CMH problems that require ongoing care (e.g., medication monitoring). Youth who receive mental health care in the medical system prior to age 18 might therefore be more likely to be seen by a medical professional for mental health reasons after age 18. In the CMH system, several factors related to a youth's illness career might predict future service utilization. For example, youth with longer CMH treatment duration or higher frequency of visits might be more likely to have a mental health visit in the medical sector after age 18. Prior research conducted on the sample of

CMH youth used in the current study revealed distinct patterns of CMH care (Reid et al., 2015). The probability of having a CMH visit at the end of a 4-year study window was found to be highest for two pattern groups: “ongoing/intensive-episodic” and “brief-episodic”. We might expect that youth in these two pattern groups would be more likely to require ongoing care and thus have a mental health visit after age 18. Further, youth who have a shorter duration of time between their last CMH visit and transfer (18 years), and who are therefore closer to their 18th birthday, might also be expected to require additional treatment sooner as a young adult.

#### 5.2.4.1 Treatment system

The R-NEM posits that decisions about accessing and receiving care are influenced by *network ties*. The strength of a network tie reflects the patient-provider relationship. As such, frequent contact between a youth and their provider can strengthen a network tie. A youth with a higher number of general healthcare visits would be expected to have a stronger “tie” to the medical system, and therefore be more likely to have a mental health visit in the medical system after age 18. Research suggests individuals in the general population who receive mental health services as young adults are more likely to have received physical examinations in adolescence (Yu et al., 2008). Similarly, youth with a chronic physical health condition (e.g., diabetes) would not only be expected to have stronger ties to the medical system (e.g., scheduled follow-up visits in PHC) but also long-term care needs. As such, youth who have chronic health conditions might be more likely than youth without these disorders to have a mental health visit in the medical sector after age 18.

How a provider “functions” in the youth’s treatment system can also influence the strength of a network tie (Pescosolido, Boyer, & Medina, 2013). For example, a family physician might “function” differently than a pediatrician or psychiatrist. Family physicians follow their patients across the lifespan, while pediatricians and psychiatrists are viewed as specialists and tend to offer time- and age-limited services (i.e., pediatricians in Canada only see youth up to age 18). A youth who receives mental health care prior to age 18 by their family physician might be more likely to have a repeat visit after age 18, compared to youth who have not had a prior mental health visit or who have had a visit with a specialist physician.

### 5.2.5 The Current Study

This is the first longitudinal study to examine office-based mental health service utilization within the medical sector by youth who received CMH treatment. The sample captured children and youth who received care from CMH agencies funded by the Ministry of Children and Youth Services within the province of Ontario, Canada. In Canada, examining predictors of mental health service use between publically-funded child and adult systems has been hampered by the lack of a shared electronic health record database (or common patient identification number) across sectors of care. As such, studies in Canada have examined predictors of mental health service use amongst children and adolescents within the CMH system [e.g., (Schraeder & Reid, 2015)], or by providers (e.g., family physicians, psychiatrists) within the medical system [e.g., (Carlisle, Mamdani, Schachar, & To, 2012; Gandhi et al., 2016)], but not both. This study therefore involved a data linkage between CMH administrative data (Reid, Stewart, et al., 2011b) and population-based health datasets.

This study had two primary objectives: (1) to compare the likelihood of having a mental health visit within the medical sector after age 18 (the outcome) between youth who received CMH treatment (“CMH youth”) during childhood and adolescence and youth in the general population (i.e., age, sex, region-matched controls); and (2) to examine predictors of having a mental health visit within the medical system after age 18 for CMH youth and controls.

#### 5.2.5.1 Hypotheses

It was hypothesized that CMH youth would be more likely to experience the outcome (i.e., a mental health visit within the medical sector after age 18) than youth in the general population. In terms of predictors, the literature does not provide a strong basis for predicting the outcome based on some *social content* variables (i.e., child’s age at first CMH visit, sex); these variables were therefore exploratory in nature. The following factors were hypothesized to predict having a mental health visit within the medical sector after age 18: (A) *social content/ illness characteristic* variables: (i) living in a lower socio-economic status region, (ii) living in an urban region, (iii) higher levels of psychopathology, (iv) poorer functioning, (v) greater impact of child’s illness on family; (B) *illness career* variables: (vi) higher volume of CMH visits, (vii) longer duration of CMH treatment, (viii) greater number of episodes of care [i.e., 3 visits with 180 days between episodes, (Reid et al., 2014)], (ix) pattern of brief-episodic or ongoing/intensive-episodic patterns of CMH care, (x) higher volume of mental health service use within medical sector during and after CMH treatment; (C) *treatment system* predictors: (xi) higher volume of general health care visits in medical sector, (xii) presence of a chronic health disorder, (xiii) presence of a developmental disability, and (xiv) receiving mental health care from a family physician.

## 5.3 Methods

### 5.3.1 Study Design

Data for this longitudinal, prospective, case-control cohort study were obtained from two main data sources: (1) the Children's Mental Health Database (CMH-D; Reid et al., 2010) containing administrative records from 5 CMH agencies across Ontario, Canada; and (2) the Institute for Clinical Evaluative Sciences (ICES) databases containing population-based administrative health records in Ontario. Inclusion criteria for each data source are described below, followed by the process for data linkage between the CMH-D and ICES datasets. The variables and measures utilized in the current study are then presented. This study was approved by the research ethics boards at The University of Western Ontario and at ICES.

### 5.3.2 Data Sources

#### 5.3.2.1 Children's Mental Health Database (CMH-D)

Administrative data were obtained from five CMH agencies in Ontario that: (a) provided services for children and adolescents (5-18 years), and (b) were accredited by Children's Mental Health Ontario or a similar body. CMH agencies serving both rural and urban populations, and from Eastern, Central and Southwestern Ontario, were purposively sampled.

Data were obtained for children who met study criteria for 4 years from their first CMH visit. At each agency, eligible children: (a) were between the ages of 5 and 14 years at their first visit, (b) had their first visit between 2004 and 2006, and (c) had at least one in-person visit. The operational definition of the first CMH visit was a visit that had not been preceded by an earlier face-to-face visit for at least 18 months (although some children may have been seen at the agency at an earlier point in time, this criterion was felt to reasonably define "new clients").

Children who identified a developmental disorder (e.g., Autism, Down syndrome) at intake or received treatment in a program focused on developmental disorders within the agency were excluded. The long-term needs of these youth are already recognized by medical professionals.

#### 5.3.2.2 ICES Databases

ICES is Canada's largest health services research institute, and holds population-based health databases of the Ontario population. ICES is designated as a prescribed entity under Ontario's Personal Health Information Protection Act. This allows ICES researchers to link encoded population-based administrative databases for conducting approved research studies under strict privacy and security policies, procedures, and practices (see Data and Privacy at http://www.ices.on.ca) which are reviewed and approved by the Information and Privacy Commissioner of Ontario. Several ICES datasets were used in the current study (see Table 5.1).

### 5.3.3 Data Linkage

The Registered Person Database (RPDB) is the central database at ICES and provides demographic information (e.g., sex, date of birth, postal codes) for Ontario residents who are registered for provincial health insurance coverage, maintained by Ontario's Ministry of Health and Long-Term Care (MHLTC). Using probabilistic linkage (Howe, 1998; Jaro, 1995), the RPDB was linked to the CMH-D using the youth's date of birth, sex, postal code, and initials.

### 5.3.4 Measures

Variables in the current study (in italics) were obtained from the CMH-D and from ICES datasets and are described below. Table 5.1 summarizes the variables used in this study, based on the R-NEM domains, and the database each variable was collected from. Predictor variables captured various time windows prior to the age of transfer and are organized on a timeline (see Appendices 10 and 11).

**Table 5.1: Predictor variables used in study categorized by R-NEM domains**

| R-NEM Domain | Predictor Variables | Sample Used | Coding | Database Variable Collected From |
|---|---|---|---|---|
| “Social content” | | | | |
| Social content | Child’s sex | CMH & Controls | 0 = male<br>1 = female | CENSUS |
| | Child’s age at first CMH visit | CMH & Controls | 0 = < 11.3 years old<br>1 = ≥ 11.3 years old | CMH-D |
| | Neighbourhood income [a] | CMH & Controls | 1 = 1st quintile (lowest income)<br>2 = 2nd quintile<br>3 = 3rd quintile<br>4 = 4th quintile<br>5 = 5th quintile (highest income) | CENSUS |
| | Neighbourhood socio-economic status [a] | CMH & Controls | 1 = 1st quintile (least marginalized)<br>2 = 2nd quintile<br>3 = 3rd quintile<br>4 = 4th quintile<br>5 = 5th quintile (most marginalized) | ON-MARG |
| | Residence [a, b] | CMH & Controls | 0 = urban<br>1 = rural | CENSUS |
| Illness characteristics | Child psychopathology (i.e., internalizing, externalizing problems) [b] | CMH only | 0 = non-clinical significant problems (T score < 65)<br>1 = only clinically significant internalizing problems (T-score ≥65; 93rd percentile)<br>2 = only clinically significant externalizing problems<br>3 = both externalizing *and* internalizing problems significant problems | CMH-D |
| | Child’s functional impairment [c] | CMH only | 0 = non-clinical significant impairment (T score < 65)<br>1 = clinical impairment (T-score ≥ 65) | CMH-D |
| | Impact of child’s illness on family [c] | CMH only | 0 = non-clinical significant impact on family (T score < 65) | CMH-D |

| | | | | |
|---|---|---|---|---|
| | | | 1 = clinically significant impact (T-score ≥65) | |
| “Illness career” | | | | |
| CMH system | Total CMH visits[d] | CMH only | 0 = < 6 visits<br>1 = ≥ 6 visits | CMH-D |
| | Total number of episodes of care[d] | CMH only | 0 = No episodes of care<br>1 = only 1 episode of care<br>2 = ≥ 2 episodes of care | CMH-D |
| | Pattern of CMH service use (i.e., minimal, acute, brief-episodic, intensive, ongoing/intensive-episodic) [d, e] | CMH only | 0 = minimal<br>1 = acute<br>2 = intensive<br>3 = brief-episodic<br>4 = ongoing/ intensive episodic | CMH-D |
| | Duration of CMH involvement (i.e., time between first and last CMH visit) | CMH & controls | 0 = < 161 days<br>1 = ≥ 161 days | CMH-D |
| | Time between last CMH visit and age 18 | CMH & controls | 0 = < 2073 days<br>1 = ≥ 2073 days | CMH-D, CENSUS |
| Medical system | Total mental health visits during CMH involvement | CMH & controls | 0 = no visit<br>1 = ≥ 1 visit(s) | OHIP |
| | Total mental health visits between last CMH visit and age 18 | CMH & controls | 0 = < 2 visits<br>1 = ≥ 2 visits | OHIP |
| “Treatment system” | Presence of developmental disability (DD) prior to age 18 | CMH & controls | 0 = no DD<br>1 = presence of DD | CIHI-DAD, NACRS, OHIP |
| | Presence of chronic physical health disorder prior to age 18 | CMH & controls | 0 = no chronic health disorder<br>1 = presence of chronic health disorder | Disease registries: ODD, ASTHMA, ORAD, CCFDR, OCCC |
| | Total general health care visits during CMH involvement | CMH & controls | 0 = no visit<br>1 = ≥ 1 visit(s) | OHIP |
| | Total general health care visits between last CMH visit and age 18 | CMH & controls | 0 = < 10 visits<br>1 = ≥ 10 visits | OHIP |
| | OHIP-MH visit with family physician or specialist (i.e., psychiatrist, | CMH & Controls | 0 = no OHIP-MH visit between last CMH visit and age 18 | IPDB, OHIP |

| | | |
|---|---|---|
| | pediatrician), or both, between last CMH visit and age 18 | 1 = saw family physician only<br>2 = saw pediatrician or psychiatrist only<br>3 = generalized and specialist care (family physician & pediatrician or psychiatrist) |

*Note*. R-NEM= Revised-Network Episode Model. Databases: ASTHMA= the Ontario Asthma Database; CENSUS= Ontario Census; CCFDR= Canadian Cystic Fibrosis Data Registry; CIHI-DAD= Canadian Institute for Health Information Discharge Abstract Database; CMH-D= Children's Mental Health – Database; OHIP= Ontario Health Insurance Plan; ODD= Ontario Diabetes Database; ON-MARG= Ontario Marginalization Index; ORAD= Rheumatoid Arthritis Database; OCCC = Ontario Crohn's and Colitis Cohort Database. [a] At age 18. [b] Rural residence was defined according to Statistics Canada's recommended definition of ≤ 10,000 people (or Community Size = 5). [c] Of the CMH sample (N= 2987), only 1976 children have complete data. [d] Variable only for CMH sample. [e] Episode of care (Reid et al., 2014) was defined as a minimum of 3 CMH visits and a subsequent "free period" of 180 days without a visit.

#### 5.3.4.1 Demographics

Child's *age at their first CMH visit* and child's *sex* were obtained from the CMH-D. For the current analyses, postal codes were obtained for youth at their 18th birthday (the index date) to derive variables used for descriptive purposes and prediction models. Postal codes from the RPDB were linked to the 2006 Canadian Census to obtain neighbourhood community characteristics for each youth. *Neighbourhood income* quintiles were computed for each Dissemination Area (DA) and rural area (i.e., communities with less than 10,000 people) in the province; these were adjusted for both household and community size. DAs are geographical areas with small, relatively stable populations (i.e., between 400 to 700 persons) with similar economic and social conditions. The *neighbourhood income* quintile for each youth, based on their postal code, was entered as a predictor variable.

*Neighbourhood socioeconomic status* for a youth was obtained from the ON-MARG (Ontario Marginalization Index) database. The ON-MARG is a census- and geographically-based index derived to show differences in marginalization and to understand inequalities in health and social well-being between geographical areas. Specifically, the Material Deprivation (MD) dimension (Matheson et al., 2006; Matheson, Dunn, Smith, Moineddin, & Glazier, 2012) was used as a proxy for socioeconomic status, as has been done in other studies (Durbin et al., 2015; To et al., 2013). The MD is composed of six indicators from census data: (1) individuals aged 20 years and over without a high school graduation; (2) families who are lone parent families; (3) individuals who are receiving government transfer payments; (4) individuals 15 years old and over who are unemployed; (5) individuals living below the low-income cut-off (defined by Statistics Canada and adjusted for family and community size); and (6) households living in dwellings in need of major repair. DAs for the entire province were sorted and quintiles were created; Q1 being the least and Q5 the most deprived populations. Thus, the MD for each youth reflects the quintile for the DA in which they resided.

#### 5.3.4.2 Child Psychopathology and Functioning

The Brief Child and Family Phone Interview (BCFPI) was a measure used to collect data on child psychopathology and functioning of youth in the CMH-D. The BCFPI assesses *child psychopathology* and other factors known to influence treatment engagement (e.g., impact of illness on the family) and is used as an intake measure at CMH agencies in Ontario (Barwick, Boydell, Cunningham, & Ferguson, 2004). It is completed with a parent by an intake worker at a CMH agency; however, not all parents complete the BCPFI at intake for any number of reasons (e.g., staff workload demands). In the CMH-D, the BCPFI completed closest to the date of the child’s first CMH visit was collected.

Three composite scales from the BCFPI were captured in the CMH-D: a) *externalizing* (i.e., regulation of attention and activity; cooperation; conduct), b) *internalizing* (i.e., separation from parents, managing anxiety, and managing mood), and c) *child functioning/impairment* (i.e., social participation, quality of child’s social relationships, school participation, and achievement). Internal-consistency reliability (Cronbach's alpha) for the internalizing and externalizing composite scales are 0.87 and 0.85, respectively (Boyle et al., 2009).

The BCPFI internalizing and externalizing composite scales are significantly associated to related diagnoses (e.g., internalizing disorders related to separation and generalized anxiety disorders, and major depressive disorder) based on structured diagnostic interviews conducted in a clinic sample of children between the ages of 5 to 17 years (Boyle et al. 2009). Confirmatory factor analyses, in both community and clinic samples, support the underlying factor structure (Cunningham et al. 2009). T-scores were computed based on age and sex-based population norms. *Child psychopathology* was categorized as: clinically significant (i.e., T-score ≥ 65; 93rd percentile) externalizing and internalizing problems (3); only clinically significant internalizing problems (2); only clinically significant externalizing problems (1); or non-clinical significant problems (0). *Impairment of functioning* was categorized as: clinical impairment (i.e., T-score ≥ 65; 93rd percentile) (1) and non-clinical significant impairment (0) (i.e., T-score < 65).

*Impact on the family* was measured using a BCFPI subscale (i.e., global family situation) which assessed the extent to which the child's problems affected the family's external social supports and were a source of conflict within the family and provides an overall estimate of the impact of the problems on family functioning. Based on age and sex-based population norms, T-scores were computed and then categorized as: clinically significant impact on the family (i.e., T-score ≥65) (1) and non-clinical significant impact on the family (i.e., T-score < 65) (0).

#### 5.3.4.3 CMH System: Mental Health Service Use

Visit dates in the CMH-D were abstracted for a 4-year period for each individual; only face-to-face visits were included. Four variables captured a youth's mental health service use within CMH: (1) *total number of CMH visits*, (2) *duration of CMH involvement* (i.e., days between first and last visits) (3) *total number of episodes of care*, and (4) *pattern of CMH service use*. An episode of care (Reid et al., 2014) was defined as a minimum of 3 visits and a free period of 180 days without a visit signified before a new episode of care. Patterns of CMH service use were computed during prior analyses of the CMH dataset (Reid et al., 2015; Reid, Stewart, et al., 2011), which involved a multi-level latent class cluster analysis of visit data. Five distinct patterns of service use were identified and labelled as: Minimal (53% of children), Brief-Episodic (8%), Acute (20%), Intensive (13%), or Ongoing/ Intensive-Episodic (6%). Service use within each cluster was described in terms of number visits and duration of involvement within specific episodes of care (Appendix 12).

#### 5.3.4.4 Medical System: Mental Health and General Health Service Use

The number of mental health visits and general (or non-mental health related) visits in the medical sector prior to age 18 were calculated as predictor variables. Specifically, these visits captured concurrent service use during a youth's CMH involvement and then between their last CMH visit and age 18. For the control sample, parallel predictor variables were created based on the same index dates in the CMH sample (e.g., last visit in CMH).

Office-based mental health visits within the medical system were obtained from the Ontario Health Insurance Plan (OHIP) database, covering health care for all Ontario citizens. The majority (94%) of physicians' direct patient care is captured within OHIP (Rhodes, Bethell, & Schultz, 2006; Steele, Glazier, Lin, & Evans, 2004). Physicians are reimbursed by submitting claims to OHIP for medical services provided. For each visit, physicians submit two codes: a service fee code and a diagnostic code. Diagnostic codes represent the main "reason for the visit" and are coded using the 10th revision of the International Classification of Diseases (ICD). Service fee codes, also known as "billing codes", refer to insured procedures billed by a physician, which are then charged to the MHLTC.

For adult populations, select OHIP billing codes have been shown to have excellent specificity (97%) and adequate sensitivity (81%) for identifying mental health service utilization (L. S. Steele et al., 2004). However, OHIP billing codes used in prior studies could not be used in the current study as they do not capture mental health service use specific to children and youth. For example, certain childhood diagnoses (e.g., Attention Deficit-Hyperactivity Disorder) were not included. The current study, therefore, expanded on previous definitions of a "mental health visit" in the medical system to include diagnostic codes and service fee codes specific to CMH problems. Two family physicians (S.H., M.C) and a pediatrician (T.S) independently reviewed all OHIP diagnostic and service fee codes for their relevance to child and youth mental health problems; a consensus of codes was achieved via group discussion (see Appendices 13 and 14 for a complete list of these codes).

The operational definition for a mental health visit based on OHIP records (hereafter referred to as an "OHIP-MH visit") was: (i) any office-based visit with a mental health service fee code or general service fee code, *with* a mental health diagnostic code by a family physician or pediatrician, *or* (ii) any office-based visit by a psychiatrist. Non-office based visits (e.g., emergency department, inpatient visits) were excluded as these are primarily captured by other databases at ICES.

General health care visits ("OHIP-Health") were defined as any office-based visit by a family physician or pediatrician that did not meet criteria for an OHIP-MH visit.

### 5.3.4.5 Medical System: Type of Provider Seen

Physician specialty was used to describe OHIP-MH visits amongst youth. The ICES Physician Database (IPDB) was used to identify a physician's specialty (i.e., family medicine, pediatrics, psychiatry). The quality of data in the IPDB is routinely validated against the Ontario Physician Human Resource Data Centre database, which verifies this information through periodic telephone interviews with physicians.

### 5.3.4.6 Presence of Chronic Health Disorder

Chronic disease indicators were obtained from validated ICES-derived algorithms. Chronic disease registries included: the Ontario Diabetes Database (ODD; Hux, Flintoft, Ivis, & Bica, 2002), the Ontario Asthma Database (ASTHMA; Gershon et al., 2009), the Canadian Cystic Fibrosis Data Registry (CCFDR), the Ontario Rheumatoid Arthritis Database (ORAD; Widdifield et al., 2013), and the Ontario Crohn's and Colitis Cohort Database (OCCC; Benchimol et al., 2009). The presence of a chronic physical health illness was dichotomized into those without vs. with one of the following diagnoses prior to their 18th birthday: cystic fibrosis, sickle cell disease, asthma, Type 1 diabetes, rheumatoid arthritis, Crohn's and colitis, and congenital heart disease.

### 5.3.4.7 Presence of Developmental Disorder (DD)

The presence of a developmental disability, including genetic disorders (e.g., Downs syndrome), intellectual disability, and pervasive developmental disorder (e.g., autism), was recorded in billing diagnostic codes using the ICD-10 and Diagnostic and Statistical Manual of Mental Disorders, Text Revision (DSM-IV TR). Although youth were excluded from the CMH sample if they had a developmental disability (DD), it was possible that youth received a diagnosis for a DD from a professional in the medical system. The presence of a DD prior to age 18 based on codes in the medical system (see Appendix 15) was entered into the prediction model as a dichotomous variable.

### 5.3.5 Study Population

#### 5.3.5.1 CMH Youth

A sub-sample of youth from the entire CMH dataset was analyzed. As children in the CMH dataset could have been as young as 4 years old at their first visit, many children would not have yet reached age 18 by the end of 2015 (NB: ICES data holdings for OHIP data are lagged by one calendar year and at the time of these analyses they were available up to December 31, 2015). ICES data holdings for OHIP data are lagged by one calendar year). Thus, only youth with at least three quarters of a year (i.e., 273 days) of available health record data after the age of transfer (i.e., age 18) were included. About 70% (N = 3,967) of youth from the CMH dataset met this eligibility criterion.

#### 5.3.5.2 Control Cohort

A randomly selected matched control sample was obtained from the RPDB, and matched on: sex, age (year of birth), and Census division (Statistics Canada, 2011). A total of 3 controls were selected for every case in the CMH dataset (Hennessy, Bilker, Berlin, & Strom, 1999; Wacholder, Silverman, McLaughlin, & Mandel, 1992); see Appendix 16. Controls were assigned an “index date”, based on the matched case’s first CMH visit, and had to be eligible for OHIP until the end of the study window. As a result, cases and controls had the same follow-up time. A small percentage (5%, n = 34) of the CMH sample were found to have a visit in the medical system associated with a DD diagnosis *prior* to their first CMH visit. Matched controls with a DD within the same time frame were then assigned (NB: only DD diagnoses from the CMH sample were used). When 3 controls with a DD were not available within the Census Division, a healthy control was substituted.

## 5.4 Data Analyses

Analyses were performed using SAS Enterprise Guide 6.1 (SAS Institute Inc., Cary, North Carolina, USA).

### 5.4.1 Descriptive Analyses

Descriptive analyses for cases and controls were performed in relation to child’s sex, age at the start of the study window (i.e., age at first CMH visit for CMH youth), residence (e.g., rural), neighbourhood income quintile, socio-economic status (ON-MARG), and the presence of a chronic health disorder and DD. For the CMH sample, descriptive analyses were performed on a child's involvement with the CMH system (e.g., total CMH visits, pattern of CMH care, child psychopathology).

### 5.4.2 Survival Analyses

Time to first OHIP-MH visit (after age 18) was determined using survival analyses (Hosmer, Lemeshow, & May, 2008). Survival analysis is a collection of statistical procedures for analyzing data when the outcome variable of interest is time until an event occurs (Hosmer et al. 2008). Survival analysis is commonly used in the medical literature, and has been used less frequently in mental health research to investigate time to outcomes such as: youth's first contact with mental health services (Erath et al. 2009), subsequent help-seeking across CMH agencies by families (Schraeder & Reid, 2015); attendance at an initial psychiatric treatment appointment (Foreman and Hanna 2000), and CMH treatment drop-out (Harpaz-Rotem et al. 2004).

Data for survival analyses have 3 requirements: a) a clear time origin, b) a scale for measuring time, and c) an endpoint. For the current analyses, the time origin was the age of transfer (i.e., 18th birthday), coded as Day 0. Time to event was computed in days. The endpoint, or 'event', was coded as: youth who (1) had a mental health visit after turning 18 years old, or (0) did not.

Survival analysis is designed for time-to-event data where not all participants experience the "event" and participants have variable follow-up durations. Survival analysis therefore handles two unique aspects of the data. First, not all youth had a mental health visit after the age of transfer during the study period; it would not be expected that all youth would require mental health services as an adult, even if the follow-up period had been longer. Second, youth had variable lengths of maximum follow-up due to variation in participants' study entry times for the larger study (i.e., first visit at CMH agency). The duration of health record data available after the study's time origin (i.e., 18th birthday) varied from <1 year (minimum 273 days) to over 8 years. Survival analysis utilized participants' data up to the point of censoring or the outcome, whichever occurred first (Cleves, Gould, Gutierrez, & Marchenko, 2010; Hosmer et al., 2008); censoring refers to incomplete information on a participant's survival time.

In the current study, the Kaplan-Meier method was used to initially examine the relationship between categorical covariates and time to transfer, and to generate survival curves based on life table estimates. All predictor variables were examined through univariate and multivariate Cox proportional hazards (PH) regression analyses. The Cox PH model derives a Hazard Ratio (HR), comparing the likelihood (or risk) of the outcome between groups, or for each unit increase of a continuous variable, while adjusting for all other entered variables. An alpha level of $p < .05$ was used to test for statistical significance.

The analysis involved three steps. First, the main exposure variable (e.g., cases vs. controls) was entered separately into a Cox regression to assess whether time to first OHIP-MH visit differed between individuals who had received CMH treatment versus the matched control population. Second, each predictor was entered independently into a Cox regression to provide crude or unadjusted HRs. Third, predictor variables were then entered in three blocks, identified *a priori* based on the theoretical domains of the R-NEM (i.e., social content, illness career, treatment system). Each model is presented in the Appendices (e.g., Model 1 = social content variables; Model 2 = social content + illness career variables; Model 3 = social content + illness career + treatment system variables). Only the final adjusted model (Model 3) is shown in the results section. A complete-case analysis was conducted for predictor variables as missing data fell below 1% (Hancock & Mueller, 2010). Using list-wise deletion of all cases with missing values, the effective sample size for the Cox regression was 2959. As only 66% of the CMH sample had complete data on child psychopathology variables (i.e., BCFPI data), a separate blocked regression for this subsample was conducted.

To test the Proportional Hazards (PH) assumption, Schoenfeld residuals were calculated separately for each predictor variable and correlated with (ranked) survival time (Kleinbaum & Klein, 2005). Non-zero correlations were evidence against the PH assumption, indicating that the hazard was not constant over time. No variables in the current study violated the PH assumption.

#### 5.4.2.1 Exploratory Analyses

Based on the above prediction analyses, having an OHIP-MH visit prior to age 18 with a family physician emerged as a predictor of having an OHIP-MH visit after age 18. Descriptive analyses were therefore performed to further examine the involvement of family physicians for the CMH sample over time. A youth's involvement with a family physician for mental health care was therefore described across three time periods: (a) during CMH treatment, (b) after CMH treatment and prior to age 18, (c) after age 18.

## 5.5 Results

### 5.5.1 Matching the CMH-D and OHIP datasets

Of the entire CMH-D, 72% of youth (n = 3,967) were calculated to turn 18 years old by April 2, 2015 and have almost a year (i.e., 273 days) of available health record data. Of eligible youth, 77% (n = 3,051) were linked to the RPDB. A small percentage (2%) of youth were subsequently excluded because they: (a) died prior to their 18th birthday or shortly after (n = 7) or (b) became ineligible for OHIP before age 18 (i.e., moved out of the province; n = 57). A total of seven youth died after the age of transfer but contributed to survival times up to the point of censoring (*M* age at death= 20.2 years, SD= 1.1); some of these youth (n <= 5) had an OHIP-MH visit after age 18.

The current CMH sample consisted of 2,987 youth. Figure 5.1 depicts a flowchart of participant eligibility. A matched control sample consisted of 8,961 youth (Appendix 16). In the following sections, the clinical and demographic characteristics of the CMH sample will be described and compared to the control sample. Predictors of having an OHIP-MH visit after age 18 are then presented.

### 5.5.2 Descriptive Findings

#### 5.5.2.1 Demographic and Clinical Characteristics

The majority (60%) of CMH youth were male and on average 11.2 years old at their first CMH visit (SD = 1.70; Range = 7 to 14 years). The average length of follow-up was 3.9 years. The study window duration spanned a maximum of 8 years (i.e., 18 to 26 years old); on average, youth with a OHIP-MH visit were 20.9 years old (SD = 1.78) at their last OHIP visit.

Most youth (84%) resided in urban communities across the province. About 38% of the CMH sample had a comorbid chronic physical health condition, significantly more than the control sample (30%); in both samples, virtually all of the individuals with a chronic condition (95%) had asthma. A small percentage (5%) of CMH youth had a visit associated with a DD prior to age 18. Youth were relatively evenly distributed across neighbourhood income quintiles. Table 5.2 compares demographic and clinical characteristics between CMH and control samples. For the CMH sample, Table 5.3 summarizes characteristics of youth's CMH involvement. Of note, the majority (54%) of CMH youth had one episode of care and about 14% had two or more episodes.

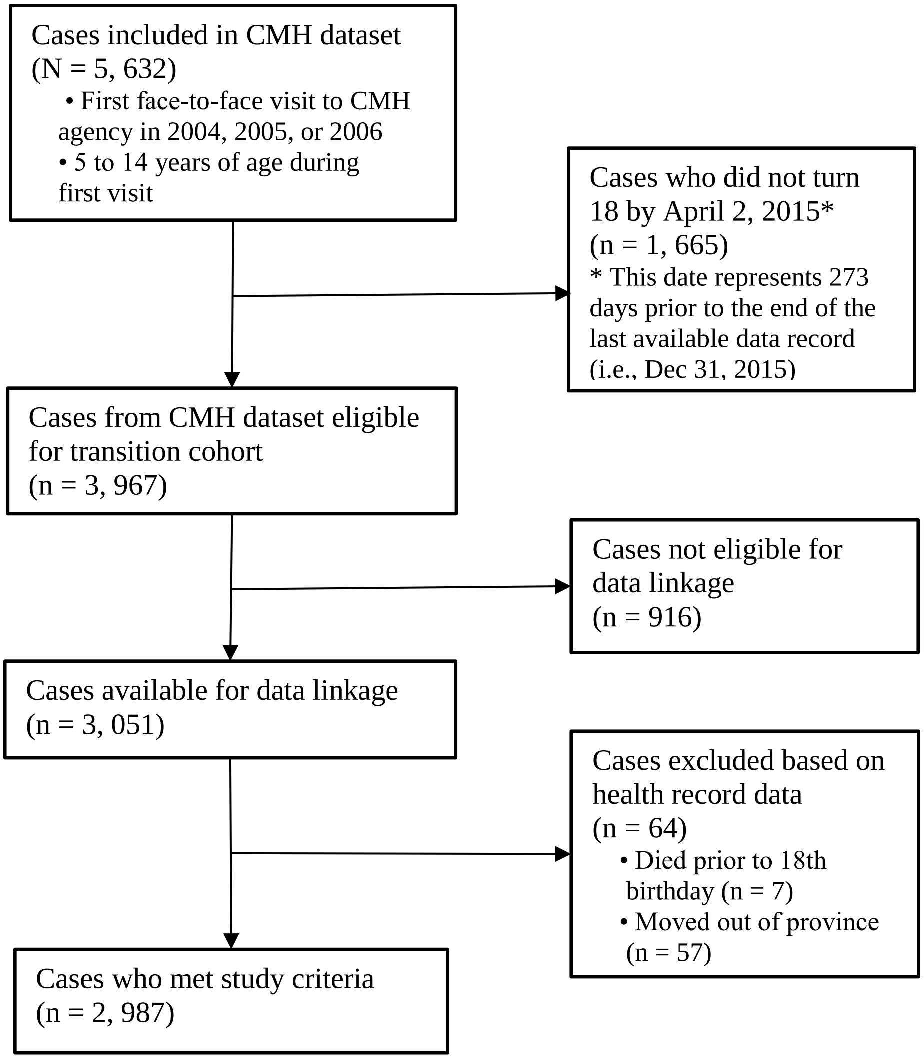

**Figure 5.1: Study cohort creation flowchart**

**Table 5.2: Comparison of demographics between CMH and control samples**

| Youth demographic characteristics | CMH sample<br>(*N* = 2987) | Control sample<br>(*N* = 8961) | $\chi^2$ |
|---|---|---|---|
| Age at start of study window[a] | 11.2 (1.7)<br>[Median = 11.3; Range = 7 -14] | 11.2 (1.7)<br>[Median = 11.2; Range = 7 – 14] | † |
| Sex (% female) | 39.6% | 39.6% | † |
| Residence | | | 0.04 |
| Rural | 16.2% | 16.4% | |
| Urban | 83.7% | 83.6% | |
| Neighbourhood income quintile[b] | | | 39.0*** |
| Q1 (lowest) | 21.6% | 17.8% | |
| Q2 | 22.9% | 20.6% | |
| Q3 | 21.7% | 23.1% | |
| Q4 | 19.7% | 22.1% | |
| Q5 (highest) | 14.0% | 16.4% | |
| ON-MARG – Material Deprivation[b] | | | 33.4*** |
| Q1 (least marginalized) | 19.1% | 22.2% | |
| Q2 | 22.6% | 24.5% | |
| Q3 | 22.2% | 22.5% | |
| Q4 | 16.5% | 14.8% | |
| Q5 (most marginalized) | 19.5% | 16.0% | |
| Presence of developmental disability (DD) in the year prior to first CMH visit | 0.8% | 0.7% | † |
| Presence of DD prior to age 18[c] | 5.5% | 0.7% | 283.0*** |
| Presence of chronic physical health illness[d] | 37.7%<br>95.2% | 30.0%<br>95.6% | 61.2*** |
| Asthma | 3.0% | 2.1% | |
| Type 1 diabetes | 5.0% | 3.8% | |
| Cystic fibrosis | 1.2% | <.1% | |
| Sickle cell disease | <.1% | <.1% | |
| Congenital heart disease | <.1% | <.1% | |
| Inflammatory bowel disease | <.1% | <.1% | |
| Rheumatoid arthritis | | | |

*Note.* Q = quintile. CMH = Children's Mental Health. ON-MARG = Ontario Marginalization Index. MV = matching variable. [a] For the CMH sample, this is their age at first CMH visit. [b] Discrepancies are a result of having to move beyond the dissemination area level in order to obtain matches for some of the age- and sex-matched controls. [c] Used in the prediction model. Control sample excluded youth with a developmental disability code *after* first CMH visit consistent with the eligibility criteria for the CMH sample. Some youth in the CMH sample had a developmental disability OHIP code after CMH involvement. [d] Percentages equal > 100%, as some youth had more than one chronic illness. † = $\chi^2$ not reported for matching variables.
*** $p < .0001$

**Table 5.3: Characteristics of involvement in Children's Mental Health (CMH) system: CMH sample only**

| Characteristics of CMH system involvement | | CMH sample (*N* = 2987) M (SD) or % |
|---|---|---|
| Age at first CMH visit | | 11.2 (1.7) [Median = 11.3; Range = 7 -14] |
| Total number of CMH visits | | 15.7 (32.4) [Median = 6; Range = 1–1066] |
| Duration of CMH involvement (in months) | | 12.7 (15.5) [Median = 5.4; Range = <1–49] |
| Total number of CMH episodes of care | | 0.83 (0.69) |
| | 0 episodes | 32.3% |
| | 1 episode | 54.1% |
| | 2+ episodes | 13.6% |
| Pattern of CMH service utilization | | |
| | Minimal | 53.3% |
| | Acute | 20.9% |
| | Intensive | 12.6% |
| | Brief-Episodic | 7.4% |
| | Ongoing/Intensive-Episodic | 5.8% |
| Time between last CMH visit and age 18 (in months) | | 70.2 (25.3) [Median = 69.1; Range = <1 –133.4] |
| Child psychopathology* | | |
| | Externalizing problems (T-scores) | 63.7 (14.3) |
| | Internalizing problems (T-scores) | 67.3 (13.5) |
| | Non-clinical significant problems (T score <65) | 27.5% |
| | Only clinically significant internalizing problems (T-score ≥65) | 12.9% |
| | Only clinically significant externalizing problems (T-score ≥65) | 27.1% |
| | Clinically significant internalizing *and* externalizing problems | 32.4% |
| Child functioning* [a] | | 65.9 (14.3) |
| | Non-clinical significant impairment (T score < 65) | 48.6% |
| | Clinical impairment (T-score ≥65) | 51.4% |
| Impact of child’s illness* [a] | | 73.3 (19.8) |
| | Non-clinical significant impact (T score < 65) | 36.4% |
| | Clinically significant impact (T-score ≥65) | 63.6% |

*Note.* CMH = Children’s Mental Health; * n = 1976, as only 66% of the CMH sample completed a Brief Child and Family Phone Interview (BCFPI).

### 5.5.3 OHIP-MH and Health Visits Before Age 18

Table 5.4 compares the CMH and control sample on OHIP-MH and OHIP-Health visits during: (1) CMH involvement and (2) between the last CMH visit and age 18. A higher proportion of CMH youth had at least one OHIP-MH visit during their CMH involvement (41.2%) and between their last CMH visit and age 18 (68.3%) than matched controls during those time periods (8.4% and 31.1%, respectively). In contrast, the proportion of youth who had at least one general health care (OHIP-Health) visit during those time periods was similar (~45% and >90%, respectively). The total number of OHIP-MH and -Health visits was highly skewed; the median value for each sample was therefore used to dichotomize visits for the prediction models.

**Table 5.4: Comparison of visits in medical system between CMH youth and control sample before age 18**

| Type of visit and time period | CMH sample (*N* = 2987) | | Control sample (*N* = 8961) | | $\chi^2$ |
|---|---|---|---|---|---|
| OHIP-MH visits | No visit | ≥ 1 visit | No visit | ≥ 1 visit | |
| During CMH Involvement | 58.8% | 41.2% | 91.6% | 8.4% | 1736.7*** |
| Between Last CMH Visit and Age 18 | 31.7% | 68.3% | 68.9% | 31.1% | 1288.8*** |
| OHIP-Health visits | | | | | |
| During CMH Involvement | 50.7% | 49.3% | 56.7% | 43.3% | 32.7*** |
| Between Last CMH Visit and Age 18 | 4.5% | 95.5% | 9.9% | 90.1% | 84.5*** |

*Note.* CMH = Children's Mental Health; OHIP = Ontario Health Insurance Plan; OHIP-MH = Mental health visit; OHIP-Health = General health care visit. Age of transfer is 18 years.

### 5.5.4 First OHIP-MH Visit After Age 18 (Outcome Variable)

About 52% of youth in the CMH sample had at least one OHIP-MH visit after the age of transfer; significantly more than the matched control sample (30%). Table 5.5 summarizes characteristics (e.g., diagnostic code) associated with the first OHIP-MH visit after a youth turned 18 years old. For the majority of youth, this visit was with a family physician (77% CMH; 88% controls) and the most common mental health problem for this visit was anxiety (53.2% CMH; 59.3% controls). An intermediate assessment (i.e., 20 minutes) was the most common service fee code; "psychotherapy" (i.e., ≥ 20 minutes) accounted for a very small (<5%) proportion of visits (see Appendix 23).

**Table 5.5: Comparing CMH and control samples on characteristics of the first OHIP-MH visit after age 18 (only individuals with at least one visit after age 18)**

| Characteristics of First OHIP-MH Visit After Age 18 | CMH Sample (*N* = 1549) | Control Sample (*N* = 2700) |
|---|---|---|
| Provider Type | | |
| Family physician | 77.4% | 88.3% |
| Pediatrician | 4.5% | 2.3% |
| Psychiatrist | 18.1% | 9.4% |
| Most Common Diagnostic Codes | | |
| Anxiety disorders | 53.2% | 59.3% |
| Behaviour disorders | 5.4% | 2.8% |
| Depressive disorder | 11.2% | 10.6% |
| Drug dependence | 3.6% | 2.4% |
| Other childhood mental health disorders (i.e., habit spasms, tics, stuttering, tension headaches, anorexia, sleep disorders) | 3.7% | 5.6% |
| Hyperkinetic syndrome of childhood (commonly ADHD) | 6.5% | 4.1% |

### 5.5.5 Predictors of an OHIP-MH visit after age 18

As hypothesized, youth who had received CMH treatment were twice as likely than controls to have an OHIP-MH visit after age 18 (HR = 2.15; 95% CI =2.02–2.29; *p* <.0001). Kaplan-Meier survival curves (Figure 5.2) show a gradual decline in youth ‘surviving’ (i.e., not having an OHIP-MH visit). Based on life table analyses, 25% of CMH youth were estimated to have had an OHIP-MH visit within 9 months after their 18th birthday and 50% did so by 39.5 months (3.3 years, the median survival time).

Table 5.6 presents the crude and adjusted HR from the Cox regression analyses for the final model (Model 3) for the CMH sample. Controlling for all predictor variables (i.e., adjusted HR) in the CMH sample, significant predictors of having an OHIP-MH visit after age 18 included: (A) Social content factors: being older (i.e., ≥ 11.3 years) at first CMH visit, being female; (B) Illness career factors: having an ongoing/intensive-episodic pattern of CMH service use, having ≥ 2 OHIP-MH visits between the last CMH visit and age 18, having a DD prior to age 18; and (C) Treatment system factors: having ≥ 1 OHIP-Health visit during CMH involvement, having ≥ 10 OHIP-Health visits between last CMH visit and age 18, having an OHIP-MH visit with a family physician only, or in combination with a specialist (i.e., psychiatrist, pediatrician), prior to age 18 (Appendix 17 presents the entire blocked regression model).

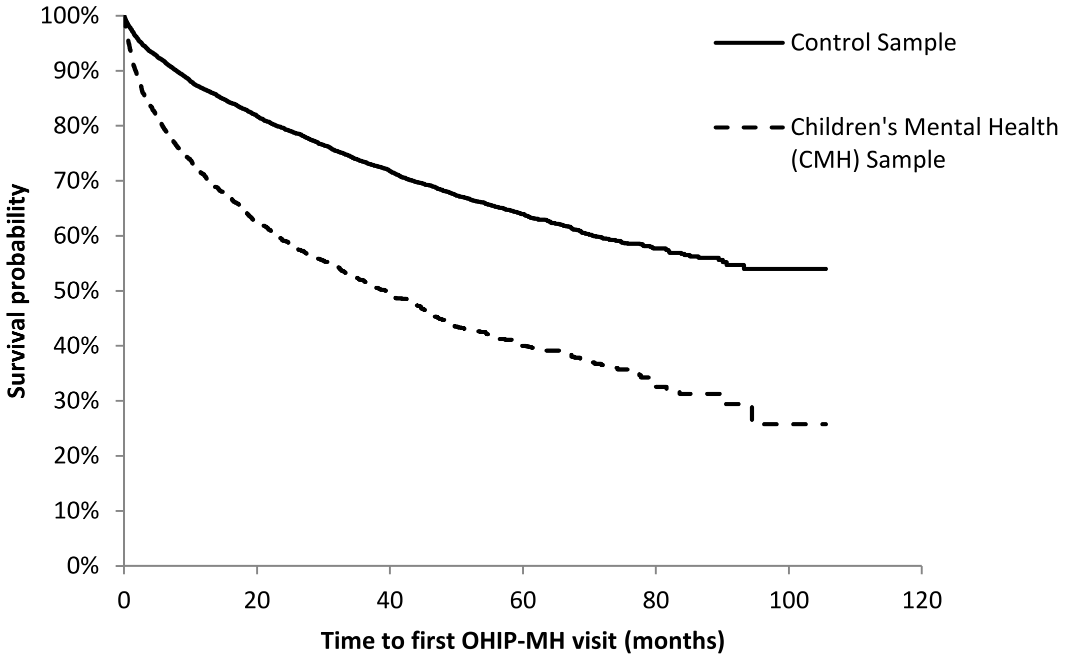

**Figure 5.2: The Kaplan-Meier survival curve shows the probability of not having an OHIP-MH visit (i.e., mental health visit in the medical sector) as a function of time in months since a youth's 18$^{th}$ birthday, or the age of transfer to adult care**

**Table 5.6: Univariate and multivariate Cox regression analyses for the CMH sample**

| Predictor Variables | N | Had a OHIP-MH visit post-18 | Hazard Ratio (HR) (95% CI) | |
|---|---|---|---|---|
| | | | Crude HR[a] | Adjusted HR[b] (Model 3) |
| Child's age at first CMH visit | | | | |
| <11.3 years (median age; ref) | 1493 | 43.8% | - | - |
| ≥ 11.3 years | 1494 | 59.8% | 1.04 (0.94-1.16) | 1.17 (1.02-1.35)* |
| Child's sex | | | | |
| Male (ref) | 1804 | 47.0% | - | - |
| Female | 1183 | 59.3% | 1.38 (1.24-1.51)** | 1.42 (1.28-1.58)*** |
| Neighbourhood income quintile | | | | |
| Q1 (ref) | 644 | 51.9% | - | - |
| Q2 | 684 | 49.6% | 0.95 (0.82-1.11) | 0.98 (0.82-1.16) |
| Q3 | 647 | 54.2% | 1.08 (0.93-1.25) | 1.03 (0.85-1.27) |
| Q4 | 587 | 50.8%) | 0.99 (0.84-1.15) | 1.01 (0.81-1.25) |
| Q5 | 417 | 54.0% | 1.11 (0.94-1.31) | 1.10 (0.81-1.25) |
| ON-MARG Material deprivation | | | | |
| Q5 (ref) | 577 | 53.8% | - | - |
| Q1 | 566 | 50.0% | 0.95 (0.81-1.11) | 0.99 (0.78-1.25) |
| Q2 | 669 | 55.0% | 1.04 (0.89-1.21) | 1.12 (0.91-1.40) |
| Q3 | 658 | 52.4% | 0.98 (0.84-1.14) | 0.97 (0.79-1.17) |
| Q4 | 489 | 47.8% | 0.86 (0.73-1.02) | 0.89 (0.74-1.07) |
| Residence | | | | |
| Urban (ref) | 2497 | 52.7% | - | - |
| Rural | 484 | 47.7% | 0.83 (0.72-0.96)* | 0.89 (0.76-1.03) |
| Duration of CMH involvement | | | | |
| < 161 days (ref) | 1488 | 48.1% | - | - |
| ≥ 161 days | 1499 | 55.6% | 1.32 (1.19-1.46)** | 1.04 (0.87-1.24) |
| Total CMH visits | | | | |
| < 6 visits (ref) | 1389 | 48.1% | - | - |
| ≥ 6 visits | 1598 | 55.1% | 1.34 (1.21-1.48)*** | 1.06 (0.87-1.30) |
| Episodes of care | | | | |
| No episode (ref) | 966 | 47.2% | - | - |
| Only 1 episode | 1616 | 53.4% | 1.27 (1.13-1.42)*** | 1.09 (0.92-1.29) |
| 2+ episodes | 405 | 56.8% | 1.47 (1.25-1.72)*** | 1.08 (0.84-1.40) |
| Pattern of CMH use | | | | |
| Minimal (ref) | 1593 | 47.8% | - | - |
| Acute | 625 | 54.2% | 1.22 (1.07-1.39)** | 0.97 (0.80-1.19) |
| Intensive | 376 | 56.7% | 1.45 (1.20-1.75)*** | 1.09 (0.86-1.34) |

| Predictor Variables | N | Had a OHIP-MH visit post-18 | Hazard Ratio (HR) (95% CI) | |
|---|---|---|---|---|
| | | | Crude HR[a] | Adjusted HR[b] (Model 3) |
| Brief-Episodic | 220 | 57.7% | 1.37 (1.18-1.60)*** | 1.11 (0.83-1.48) |
| Ongoing/ Intensive-Episodic | 173 | 64.2% | 1.81 (1.48-2.21)*** | 1.39 (1.05-1.84)* |
| Time from last CMH visit to age 18 | | | | |
| ≥ 2073 days | 1495 | 43.4% | - | - |
| < 2073 days (ref) | 1492 | 60.3% | 1.12 (1.01-1.24)* | 1.00 (0.86-1.15) |
| OHIP-MH visits during CMH involvement | | | | |
| <1 visit (ref) | 1755 | 45.9% | - | - |
| ≥ 1 visit | 1232 | 60.4% | 1.64 (1.48-1.81)*** | 1.12 (0.98-1.27) |
| OHIP-MH visits between last CMH visit and age 18 | | | | |
| < 2 visits (ref) | 1284 | 38.4% | - | - |
| ≥ 2 visits | 1703 | 62.0% | 2.40 (2.16-2.67)*** | 1.50 (1.24-1.82)*** |
| Developmental disability[c] | | | | |
| No | 2823 | 50.9% | - | - |
| Yes | 164 | 68.3% | 1.10 (0.99-1.22)*** | 1.60 (1.32-1.95)*** |
| Chronic physical health condition[c] | | | | |
| No (ref) | 1862 | 50.6% | - | - |
| Yes | 1125 | 53.9% | 1.10 (0.99-1.22) | 1.03 (0.93-1.14) |
| OHIP-Health visits during CMH involvement | | | | |
| No visit (ref) | 1513 | 46.4% | - | - |
| ≥ 1 visit | 1474 | 57.5% | 1.48 (1.33-1.63)*** | 1.16 (1.01-1.34)* |
| OHIP-Health visits between last CMH visit and 18 | | | | |
| < 10 visits (ref) | 1425 | 46.9% | - | - |
| ≥ 10 visits | 1562 | 56.3% | 1.46 (1.32-1.62)*** | 1.25 (1.12-1.40)*** |
| Provider seen between last CMH visit and age 18 | | | | |
| No visit (ref) | 947 | 35.9% | - | - |
| Family physician only | 634 | 54.6% | 1.92 (1.66-2.24)*** | 1.38 (1.13-1.68)** |
| Pediatrician or psychiatrist only | 428 | 50.5% | 1.89 (1.59-2.24)*** | 1.27 (0.99-1.61) |
| Combination | 978 | 66.2% | 3.15 (2.76-3.60)*** | 1.89 (1.49-2.39)*** |

| Predictor Variables | N | Had a OHIP-MH visit post-18 | Hazard Ratio (HR) (95% CI) | |
|---|---|---|---|---|
| | | | Crude HR[a] | Adjusted HR[b] (Model 3) |
| (FP & Pediatrician or Psychiatrist) | | | | |

*Note.* CI = Confidence intervals. CMH = Children's Mental Health; Episode of care = a minimum of 3 CMH visits with a subsequent free period (no visits) of 180 days; OHIP = Ontario Health Insurance Plan; OHIP-MH = mental health visit using OHIP records; OHIP-Health = general health care visit using OHIP records; ref = comparative reference category for calculated HRs. Age of transfer refers to 18 years old. BCFPI = Brief Child and Family Phone Interview.

[a] The sample size for crude HRs is the total sample (n = 2987), except for the following variables due to missing census-level data: residence (n =2981), neighbourhood income quintile (n =2979), and ON-MARG material deprivation index (n = 2959).

[b] For the adjusted model, N = 2957.

[c] Prior to age 18. * $p < .05$. ** $p = .01$. *** $p < .0001$. See Appendix for the same table for control sample.

A separate blocked regression model was run on a subset of CMH youth (n = 1976) with data on a child's psychopathology (e.g., internalizing problems; T score > 64), global functioning, and the impact of their illness on the family (Appendix 18). Crude HRs revealed significant predictors: having clinically significant externalizing problems only, or *both* internalizing and externalizing problems, high clinical impact on child's family, and clinical impairment in functioning (Appendix 19). However, none of these variables significantly predicted having an OHIP-MH visit after age 18 in the adjusted final model.

For the control sample, the prediction models (Appendix 20) included only those variables relevant to the general population (i.e., no CMH-specific variables) and revealed the same significant predictors of having an OHIP-MH visit after age 18 as in the CMH sample (Appendix 21 presents the results of the final prediction model with the CMH and control samples side-by-side for ease of comparison).

### 5.5.6 Family Physician Involvement in CMH Youth’s Mental Health Care

Table 5.7 shows the involvement of family physicians for CMH youth across three time periods: (a) during CMH treatment, (b) after CMH treatment and prior to age 18, and (c) after age 18 (Appendix 22 reports same for the control sample). One quarter of youth never had an OHIP-MH visit with a family physician during any of these time periods. Of youth who had at least one OHIP-MH visit with a family physician (n = 2,216), 14.5% saw a family physician at every time period.

**Table 5.7: Family physician involvement in mental health care across 3 time periods for CMH youth (N = 2987)**

| Family Physician Involvement for Mental Health Services | Time 1: During CMH Treatment | Time 2: After CMH Treatment (up to age 18) | Time 3: After Age 18 | Proportion of CMH Sample N = 2987 % (n) |
|---|---|---|---|---|
| No OHIP-MH visit with FP during any time period | ✘ | ✘ | ✘ | 25.8% (771) |
| Involvement during only 1 time period | | | | |
| OHIP-MH visit with FP during CMH treatment only | ✔ | ✘ | ✘ | 3.4% (100) |
| OHIP-MH visit with FP after CMH treatment only | ✘ | ✔ | ✘ | 16.3% (488) |
| OHIP-MH visit with FP after 18 treatment only | ✘ | ✘ | ✔ | 13.4% (400) |
| Involvement during 2 time periods | | | | |
| OHIP-MH visit with FP during and after CMH treatment | ✔ | ✔ | ✘ | 6.9% (206) |
| OHIP-MH visit with FP during CMH treatment and after 18 | ✔ | ✘ | ✔ | 3.5% (103) |
| OHIP-MH visit with FP after CMH treatment and after 18 | ✘ | ✔ | ✔ | 20.0% (598) |
| Involvement during 3 time periods | | | | |
| OHIP-MH visit with FP across all time periods | ✔ | ✔ | ✔ | 10.8% (321) |
| Totals % (n) | 24.4% (730) | 54.0% (1613) | 47.6% (1422) | |

*Note*. FP = family physician. ✔ = OHIP-MH visit with family physician; ✘ = no OHIP-MH visit with family physician.

## 5.6 Discussion

This study aimed to compare office-based mental health visits in Ontario's medical sector between youth who had received specialized CMH treatment (CMH youth) and youth in the general population (i.e., age, sex, and region-matched controls). CMH youth were more likely than the general population to have an OHIP-MH visit across all time periods: during CMH treatment, between the end of CMH treatment and age 18, and after age 18. Following CMH treatment, about 68% of CMH youth had at least one OHIP-MH visit prior to age 18; over half (52%) had an OHIP-MH visit after age 18. In comparison, about a third of the matched control sample had an OHIP-MH visit at those times. This finding is important as it suggests the majority of youth treated for CMH problems will require some form of additional mental health care and are much more likely than individuals in the general population to require such care. In this study, half of CMH youth were expected to have an OHIP-MH visit within 3.3 years from their 18th birthday (i.e., median survival time); this time ranged from one day to over 8 years. Thus, the need for additional care might occur months or years following CMH treatment.

High rates of recurrence and persistence exist amongst children and youth who receive evidence-based treatments for common CMH problems (e.g., depression, anxiety, ADHD) (Curry et al., 2011; Manassis et al., 2004; Nevo & Manassis, 2009; Vitiello et al., 2011). Whether a youth's OHIP-MH visit in the current study represented a recurrence of problems, their persistence, or the emergence of new problems is not known. Further research is needed to explore differences in CMH disorder trajectories into adulthood. Ultimately, the current findings provide evidence that CMH problems can be long-lasting and therefore developing new models of ongoing mental health care should be considered.

### 5.6.1 Predicting Mental Health Service Use in Young Adulthood

This study aimed to address the limited data that exists on predictors of mental health service utilization amongst young adults who were treated during childhood and/or adolescence. So, who was most likely to require mental health care after the age of transfer? Significant predictors of having an OHIP-MH visit *sooner* (after turning 18) are discussed below.

#### 5.6.1.1 Social Content Factors

At the individual-level, youth who were older ($\geq$ 11.3 years old) at their first CMH visit were more likely to have an OHIP-MH visit after age 18. It is possible that a higher proportion of youth with more severe problems were older in age at the start of treatment, and therefore more likely to require additional services. Being older at the start of CMH treatment might make it more likely for youth to receive care closer to the age of transfer. However, even for the oldest youth at the start of CMH treatment (13 and 14 year olds; n = 583), the average duration of CMH treatment was only 10.5 months; this means the majority of youth completed CMH treatment years before turning 18 years old.

Female youth in both samples were both 1.4 times more likely than males to have an OHIP-MH visit after age 18. This is consistent with research showing higher rates of mental health service utilization amongst females within the general medical sector (Drapeau, Boyer, & Lesage, 2009; A. E. Rhodes, Jaakkimainen, Bondy, & Fung, 2006). Some research suggests males are more likely to delay seeking mental health treatment (REF). This might eventually lead to requiring more intensive services (e.g., inpatient admission) which extend beyond PHC settings; such services and sectors of care were not captured in the current study.

#### 5.6.1.2 Illness Career Factors

Several factors related to a youth's mental health service use history, across both CMH and medical sectors, were predictive of youth having an OHIP-MH visit after age 18. As hypothesized, youth with an ongoing/intense-episodic pattern of CMH service use were more likely (64%) to have an OHIP-MH visit after age 18 than any of the other CMH service use groups. The characteristics of youth in this pattern group (long duration of CMH involvement and high number of visits) likely reflects a higher level of mental health need and, consequently, a greater need for both medical services (e.g., medication monitoring) and mental health treatment. It is noteworthy that almost half (47%) of youth in the "minimal" pattern of CMH service use (i.e., having only 3 CMH visits on average) also had an OHIP-MH visit after age 18. Some youth who receive even minimal CMH treatment might also require mental health care as a young adult; some youth may have received an inadequate amount, or type, of treatment as adolescents which might have contributed to a greater need for treatment as young adults. Thus, caution should be applied to establishing criteria for adult mental health services that is solely based on a youth's level of involvement with the CMH system.

#### 5.6.1.3 Treatment System Factors

A youth's "tie" to the medical system, prior to age 18, was also an important predictor of service use as a young adult. As suggested by the R-NEM, having strong, diverse ties to a large treatment system can influence service utilization. This is often the case for youth who require contact for other healthcare needs. In the current study, youth who had a developmental disability, but not a chronic health disorder, were more likely to have an OHIP-MH visit after age 18. One study (Ryan et al., 2011) has demonstrated a relationship between having chronic health disorder and family physician service utilization during early adolescence, but not young adulthood. It is possible that parental involvement with treatment appointments mediates this relationship. Ryan et al. (2011) found that a self-perceived "need" for health care amongst young adults was a better predictor of service use in PHC than presence of a chronic health disorder (Ryan et al., 2011).

Youth who had at least one general health care visit (OHIP-Health) during CMH treatment, and 10 or more of these visits following CMH treatment, were more likely to have an OHIP-MH visit after age 18. Seeing a family physician or pediatrician for a non-mental health related issue might reflect stronger connections to the medical system, as well as more positive help-seeking attitudes towards receiving help in the medical sector. It is also possible that OHIP-Health visits following CMH treatment were related to a youth's CMH problems. Somatic complaints (e.g., headaches, stomachaches) are frequently a manifestation of CMH problems that might result in problems being billed for a physical condition in the medical system. Thus, youth with a higher number of OHIP-Health visits after CMH treatment might reflect a persistence or recurrence of problems.

Receiving some mental health care (i.e., ≥ 2 OHIP-MH visits) after CMH treatment was predictive of having an OHIP-MH visit after age 18. Moreover, the type of physician who provided this care was important. After receiving CMH treatment, youth who were seen by a family physician prior to age 18 were 1.4 times more likely to have an OHIP-MH visit after age 18 than youth who did *not* have an OHIP-MH visit. Youth who were additionally seen by a specialist (i.e., psychiatrist or pediatrician) were 1.8 times more likely. Receipt of services from both a family physician and a specialist might reflect higher level of problem severity. Interestingly, having an OHIP-MH visit with a specialist *only* was not predictive of service use after age 18. This finding seems to underscore the importance of family physicians in providing ongoing care to youth treated for CMH problems. The implications of this are outlined below.

### 5.6.2 Implications for Mental Health Care for Young Adults

Family physicians provided most office-based OHIP-MH visits, followed by psychiatrists and pediatricians. The benefits of receiving mental health services from a family physician, and more generally within a Primary Health Care (PHC) setting, have long been recognized (Kelleher et al., 2006; Unutzer et al., 2006; van Orden et al., 2009; Woltmann et al., 2012). Receiving mental health services within PHC can be viewed as more accessible, less stigmatizing, and more comprehensive since it manages both physical and mental health problems (Campo et al., 2015; Kutcher et al., 2009; Rothman & Wagner, 2003). For youth at-risk of recurring CMH problems, having a family physician involved might be particularly beneficial (Schraeder & Reid, 2017; Taylor et al., 2010). Family physicians could provide ongoing monitoring and encourage re-engagement with specialized mental health services when necessary (e.g., significant deterioration in functioning) to maintain treatment gains. Family physicians could also provide continuity of care for youth who require services beyond the age of transfer.

Very little research exists, however, on the involvement of family physicians for youth following CMH treatment. Research suggests family physicians tend to be “out of the loop” or not directly involved in their youth patient’s mental health care (Schraeder, Brown & Reid, *In press).* Uncertainty about the role of family physicians for youth who have received CMH treatment has been expressed by youth and parents (Larson et al., 2015), CMH providers, and family physicians themselves (Schraeder, Brown & Reid, *In press*). In the current study, almost three quarters of youth had a mental health visit with their family physician either during or after CMH treatment, or after the age of transfer. This suggests family physicians *are* involved with youth who have received CMH treatment. However, the extent of this involvement remains unclear: Were family physicians aware of youth’s mental health treatment? Were they part of transition planning, or involved in a discussion about the potential need for their patient's long-term care?

### 5.6.3 Considerations for Future Research

This study was the first longitudinal, case-control cohort study to examine service utilization within Ontario's medical sector by youth who have received treatment from CMH agencies funded by the Ministry of Children and Youth Services. One of the major strengths of this study was our ability to conduct analyses using population-based data over a period ranging between 6.5 and over 12 years. Further, the linkage and integration of information from multiple databases allowed for a comprehensive understanding of mental health service utilization, specific to children and adolescents, across multiple sectors of care.

This study is not without limitations. First, the proportion of CMH youth who *should* have received mental health services after the age of transfer was unknown. Thus, it is not possible to know whether *not* having an OHIP-MH visit after age 18 reflects poor access to services or symptom improvement (e.g., problems remitted). Criteria to identify CMH youth who will require long-term services is in its infant stages (Purcell et al., 2014; Schraeder et al., 2016). Without a clear denominator of *who should* require mental health services in adulthood, however, rates of successful "transfer" cannot be reported.

In the current study, a youth's level of psychopathology and functioning did not predict whether they had an OHIP-MH visit after age 18. These data were only available at the start of a youth's CMH treatment, which limited any interpretation about the appropriateness of care received by youth after the age of transfer. It is likely that a youth's level of psychopathology and functioning closer to the age of transfer would be a better predictor of needing care after age 18. Future research would therefore benefit from obtaining multiple assessments of clinical variables (e.g., psychopathology, severity, functioning) at the end of CMH treatment and immediately prior to the age of transfer.

This study did not examine all mental health services covered by OHIP (e.g., inpatient stay, emergency department visits), and therefore is an underestimate of service utilization by youth within the medical sector. Recent work suggests mental health related emergency department visits and hospitalizations amongst children and youth have increased in Ontario (Gandhi et al., 2016); however, the population prevalence of children and youth with a mental-related ED visit is low (19.3 per 1000 population) (Gandhi et al., 2016). In addition, mental health care provided by nurses, social workers, and psychologists working within family health teams and paid for by the MHLTC was not captured. Thus, mental health care delivered by physicians is an underestimate of all mental health care provided. Research on concurrent mental health service use across acute, inpatient, and outpatient services and across all providers within the medical system is needed. Similarly, research on cross-sectoral mental health service utilization should consider linkage to other sectors of care, such as education and child welfare.

Finally, the current survival analysis provides a very basic understanding of service utilization after the age of transfer. A greater exploration of patterns of mental health service use after age 18 is needed to inform practice and policy recommendations. For example, understanding which specific services (e.g., type and location of service) are accessed by young adults following CMH treatment could inform the development of preferred and effective transition services. Several other important R-NEM factors impacting service utilization were not examined in the current study. For example, factors related to a youth's "social support systems" (e.g., family, peer groups) might be particularly influential on a young adult's decision to seek help. Within these social networks, attitudes and beliefs about, and experiences with, receiving help in the medical system shape a youth's pattern of care. Research shows that higher mental service utilization amongst children and youth is associated with parents' own experiences navigating the mental health system (Schraeder & Reid, 2015). Parent's own treatment history might result in greater knowledge of the service system and how (and when) to access it, which might facilitate a youth's ability to access services for themselves. Additional factors at the treatment-system level should also be considered, as factors related to access (e.g., wait-times) and practice "culture" (e.g., physician attitudes towards providing mental health care, incentives) might also influence youth perceptions about receiving mental health treatment within the medical sector. Finally, some cases may have received additional specialized treatment at CMH agencies in the years between the last CMH treatment visit captured in our data and age 18.

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# Chapter 6

## 6 General Discussion

Although many youth will require mental health services as young adults (Davidson et al., 2011; Paul et al., 2014; Singh, 2009), a growing body of research demonstrates that transitioning youth to adult care is poorly managed (Embrett et al., 2015; Mulvale et al., 2016; Singh et al., 2010). To improve transitions from Children's Mental Health (CMH) to adult care, we first need to know whether youth and their parents even consider adult care as a possibility. Much of our current understanding of transitions is based on research with young adults (i.e., aged 16 to 24) transferring to specialized Adult Mental Health Services (AMHS). This work has relied predominately on interviews with older youth, their parents, and their AMHS providers [e.g., (Hovish et al., 2012; Jivanjee & Kruzich, 2011; Swift et al., 2013)]. Perspectives from younger adolescents and their parents and CMH providers have not been examined. In terms of quantitative research, very few longitudinal studies (Cappelli et al., 2014; Singh et al., 2010) have actually followed youth across the age of transfer (i.e., 18 years old). We therefore know very little about how youth access mental health care after CMH treatment. Examining service utilization after the age of transfer amongst youth treated in CMH is needed.

The goal of this dissertation was to examine and report on key issues related to transitions from CMH to adult care. A mixed-methods approach was used to explore the challenges of caring for youth with ongoing mental health problems. A *qualitative* study consisted of interviews with youth (i.e., ages 12 to 15) treated in CMH, their parents, CMH providers, and family physicians. A complementary *quantitative* study examined the likelihood of receiving mental health services within the medical sector after the age of transfer amongst youth who had received CMH treatment. Together, these studies make a novel contribution to the literature by exploring the role of family physicians in caring for youth with mental health problems; an area that has been virtually ignored in CMH research. In line with a triangulation design model (Creswell et al., 2004), the integration of qualitative and quantitative findings presented across this dissertation are reviewed in this chapter. Implications and directions for future research are also discussed.

## 6.1 Summary of Findings and Common Themes

Analyses of the qualitative study in this dissertation focused on the views of: (a) youth and parents (Chapter 2); (b) CMH providers (Chapter 3); and (c) youth, parents, CMH providers, and family physicians (Chapter 4).

In Chapter 2, youth and parent perceptions about the *course* of CMH problems are revealed. The majority of youth and their parents viewed common CMH disorders as long-lasting, but not necessarily persistent, over time. Youth believed their problems "*didn't completely go away*" during treatment. Most parents believed their children would require additional treatment as young adults. Yet, a common theme of *"not having a plan"* to access this care emerged. Most youth had not considered where they would turn to for help if their problems recurred. Not surprisingly, parents feared their children would disengage from needed mental health services as young adults.

Chapter 3 focused on the challenges associated with caring for youth with ongoing mental health problems from the perspective of CMH providers. Participating providers responded to the needs of youth by "*stretching the boundaries*" or extending their involvement beyond the standard number of treatment sessions, and/or age when CMH should end. CMH providers also informally checked-in with youth post-treatment or in-between sessions. The cost associated with "*stretching the boundaries"*, in terms of staffing and resources, emerged as a significant theme. Notably, some CMH providers had "*no question*" their youth clients would require adult care. The possibility of transition to adult care, however, was not discussed. CMH providers raised important questions about this issue: How do I know if this youth will require transfer? When would this discussion be appropriate? What adult services would be available? Overall, Chapter 3 shed light on barriers for considering long-term treatment planning of youth in CMH. As stated by one CMH provider: *"We're not used to thinking beyond… into the gap that your study is looking at"*.

Chapter 4 focused on the role of family physicians. The consensus view of participating youth, parents, CMH providers, and family physicians themselves was that family physicians were *"out of the loop"* or not involved with youth patients' mental health care. A few reasons for this, from the perspective of youth, parents, and CMH providers, were: (1) inadequate time to discuss mental health problems in Primary Health Care (PHC), (2) a perceived focus on the medical model, and (3) a belief that family physicians lack the knowledge and expertise for providing mental health care. Youth, parents, and CMH providers expressed ambivalence about mental health care within PHC following CMH treatment. These views were contrary to participating family physicians who felt comfortable managing common CMH problems in PHC. Rather than perceiving a lack of time or focus on a medical model, family physicians perceived themselves to be "*out of the loop*" due to unique barriers in PHC for providing CMH. Poor coordination of care for youth and families treated in CMH was emphasized. For example, a lack of communication between family physicians and CMH providers meant that some family physicians were never involved in their youth patients' mental health care. Finally, there was also confusion from the family physician's perspective about their role in caring for youth when multiple other providers (e.g., psychiatrists, school counsellors) were already involved.

Finally, in Chapter 5, results from the quantitative study are presented. This study is the first longitudinal, case-control study in Canada to focus on the problem of transition to adult care in mental health using administrative data. A data linkage between visit data for children and youth involved with CMH agencies in Ontario and their health records is described for the first time. Analyses focused on the length of time to a youth's first mental health visit in the medical system after the age of transfer. Three key findings from this work were that: (1) these youth were twice as likely than those in the general population to have a mental health visit after age 18; (2) family physician involvement with these youth varied across time periods (24% during CMH treatment; 54% after treatment; and 48% after age 18); and (3) most factors that significantly predicted having a mental health visit after age 18 were related to service use histories in CMH (e.g., ongoing/intensive-episodic pattern of CMH service use) and the medical system (e.g., ≥ 2 mental health visits in the medical system between a youth's last CMH visit and age 18). Overall, this study provided evidence that children and youth treated in CMH continue to receive mental health services in the medical sector (i.e., by a family physician, pediatrician, or psychiatrist) as young adults.

The combined findings presented across this dissertation revealed two common themes. First, the *ongoing* mental health needs of children and youth are unlikely to be resolved solely within the CMH system. Perspectives from youth, parents, and CMH providers reinforced this view. Specifically, CMH providers identified barriers to having a discussion about the possible need for adult care; many *"didn't go there"* with their clients. Second, there is uncertainty about the role of family physicians in caring for youth with CMH problems. Below, I provide a greater discussion on both of these themes. Implications for improving mental health services for youth will also be addressed.

## 6.2 Who Should Transfer to Adult Care?

I first examined this question in my doctoral comprehensive exam review paper (Schraeder & Reid, 2017). I reviewed the existing longitudinal treatment outcome studies for common CMH problems, namely depression and anxiety, to identify risk factors for problem recurrence or persistence. Following CMH treatment, the course of these disorders appeared to vary depending on certain risk factors. For example, across treatment studies, depressed youth with high problem severity and poor family functioning were at an increased risk of recurrence (Schraeder & Reid, 2017). Although the findings from this review are beyond the scope of this discussion, of particular relevance is I proposed hypothetical disorder trajectories from childhood and adolescence into young adulthood to inform the possible need for adult care (see Appendix 24). This dissertation provides evidence to support these trajectories.

Three perceived disorder trajectories emerged from discussions with youth and parents (Chapter 2): (1) not chronic, (2) chronic and persistent, and (3) chronic and remitting. The majority of parents and CMH providers felt that youth's problems, although "chronic", would improve with CMH treatment. Yet, parents and CMH providers predicted youth to be "at-risk" for recurring problems. Accordingly, many youth appeared to fall within the chronic and remitting category. This is consistent with research showing that disorder recurrences, even after CMH treatment, are common amongst youth (Curry et al., 2011; Dunn & Goodyer, 2006; Vitiello et al., 2011). The longitudinal quantitative study in this dissertation also provided evidence to support these chronic disorder trajectories, especially since the majority of youth went on to receive mental health care as young adults. Taken together, the findings in this dissertation suggest CMH problems can be long-lasting.

If CMH problems are long-lasting, many youth would clearly require additional mental health care following CMH treatment. The longitudinal quantitative study followed youth after they had received CMH treatment. Prior to age 18, over two thirds (68%) of treated youth were seen in the medical system for a mental health related issue (i.e., by a family physician, pediatrician, or psychiatrist). We can assume that some of these youth already had the boundaries of service stretched when they were in the CMH system; for example, 13.6% of the CMH sample had at least two or more episodes of care (i.e., at least 3 CMH visits with a subsequent "free period" of 180 days) and involvement with CMH ranged up to 4 years. Based on interviews with youth, parents, and CMH providers, the qualitative study also suggested that many youth receive extended care in CMH. Specifically, CMH providers described working beyond the standard number of treatment sessions with their youth clients, informally checking-in with them between sessions, and "*leaving it open*" for families to re-engage post-discharge. Even after receiving this care in CMH, youth still went on to receive mental health care within the medical system.

One of the key unique features of the longitudinal study was its ability to capture youth's ongoing mental health needs over a long-term horizon. Specifically, the time between a youth's last CMH visit and the end of their study window ranged from 6.5 to over 12 years. As such, some youth were followed up to the age of 26 years old, well past when they would have become ineligible for CMH services. This study focused on youth who accessed mental health care after the age of transfer or 18 years old. Over half (52%) of youth treated in CMH were found to receive mental health services in the medical sector after age 18. By comparison, only 30% of young adults in the control sample received such care. Moreover, amongst youth who had an ongoing/intensive-episodic pattern of CMH service use, 64% went on to receive care as young adults and were 1.4 times more likely to do so than youth with other patterns of CMH care (e.g., minimal, acute).

Though we are still far from predicting who should transition to adult care with any certainty, many parents and CMH providers who were asked this question directly had already anticipated the need for future services for their child. Even so, CMH providers were unable to clearly identify any criteria upon which to base their opinion. Researchers have begun to explore the utility of applying clinical staging models to determine a youth's future mental health needs by establishing markers of illness progression (Hickie et al., 2013; Purcell et al., 2015). Very large sample longitudinal studies are required, however, before the long-term predictive value of such staging classifications can be determined. In the present longitudinal study, markers of illness (i.e., child psychopathology, global functioning, and impact of illness on family) were not predictive of receiving adult care. Rather, youth who had an ongoing/intensive-episodic pattern of CMH service use were significantly more likely to require adult care. At this time, youth with this pattern of CMH care are really the only group of individuals that we can confidently say should be engaged in any conversations about the possibility of adult care. Discussing the possible need for adult care, however, is only one piece of caring for youth with ongoing mental health problems. What does care in CMH look like for these youth? And what is the best way to care for them after CMH treatment? These issues are discussed below.

## 6.3 Caring for Youth with Ongoing Mental Health Problems

Youth who have ongoing and recurring mental health problems will require ongoing care. In this dissertation, no evidence of a system in place to provide this type of care to youth and families was found. Within the CMH system, providers reported *"stretching the boundaries"* as a way to cope with the needs of youth who required care beyond their initial CMH treatment. The general consensus by youth, parents, and CMH providers was that many youth do not "*fit the bill*" for the short-term nature of CMH treatments. When youth require treatment over an extended period of time, this can exacerbate problems related to a lack of coordination and continuity of care in CMH (Belling et al., 2014; Tobon et al., 2015; Tobon, Reid, & Goffin, 2014). This dissertation goes beyond previous research on these issues by highlighting the possible consequences of an uncoordinated CMH "system", not designed for youth with ongoing mental health problems: youth have "*no idea*" where to turn for help in the future; parents "*jump through hoops*" to access care or feel "*out of options*" after treatment; CMH providers *"bend the rules a bit"* to provide *"a revolving door service"* to clients over extended periods of time; and, within the medical system, family physicians are left wondering "*who is taking the lead?"*.

Findings from the present dissertation have key implications for improving CMH services for youth with ongoing mental health problems. First, the potential long-term treatment needs for youth who have had an ongoing/intensive-episodic history of CMH service use needs to be considered. Second, any discussion about transfer to adult care should consider that some parents and youth, who are only at increased risk for recurrence, may not have considered the possibility of adult care. Finally, steps for re-engaging with mental health services would have to be outlined at the end of treatment by CMH providers. Youth with ongoing mental health care needs would benefit from follow-up and routine monitoring. However, interviews with participating CMH providers indicated that this type of care is not feasible in our current CMH system due to a serious lack of treatment capacity and professional resources (Mental Health Commission of Canada, 2010; Schraeder & Reid, 2015; Waddell et al., 2002). The medical system, particularly PHC, has been largely ignored in terms of caring for youth treated in CMH. The present dissertation provides new insights about the role of family physicians for CMH.

## 6.4 The Role of Family Physicians for Youth in CMH

Why focus on the role of family physicians for youth with mental health problems? Family physicians are one of the only health professionals to care for their patients across the lifespan. Very few studies have examined the issue of integrating mental health care within PHC, specifically for children and youth (Kutcher, 2011; Kutcher et al., 2009; Tobon et al., 2015), and none have focused on transition to adult care. Though it has yet to be established *who* should be responsible for monitoring youth following CMH treatment, it has been recommended that family physicians must be involved (Schraeder & Reid, 2017; Taylor et al., 2010). The role of family physicians for youth who might require transfer to adult care was explored both qualitatively and quantitatively in this dissertation.

Interviews with participating family physicians revealed considerable doubt about how mental health care could be delivered in PHC. Issues related to collaboration between family physicians and youth patients' CMH providers contributed to this problem. For example, CMH providers require consent for sharing confidential patient information with providers outside their agency, including the youth's family physician. Obtaining this consent could be included as part of the intake process at the CMH agency in order to facilitate bringing family physicians within a youth's "circle of care" in CMH. However, CMH providers could encounter issues with obtaining this consent for two main reasons. First, not all youth and families will have access to a family physician (Reid, 2009); for example, one family relied on a walk-in clinic for their PHC needs in the qualitative study. Secondly, youth and families may not have a positive or ongoing relationship with their family physician and may therefore not want to share information about their CMH treatment with that provider. This would indicate a need for youth and families to be educated about the role of their family physicians at the outset of treatment, namely as a provider for physical health care *and* their mental health care needs. Overall, CMH agencies can take the lead in fostering relationships with their clients' family physicians at the outset of a youth's treatment. This relationship could be especially beneficial to efforts to improve transitions to adult care when youth are no longer eligible for CMH services.

Findings from this dissertation also support that family physicians are *"out of the loop"* of their youth patients' CMH treatment. Of the 10 families who participated in the qualitative study, 80% reported having a family physician, and most denied using their family physician for mental health care. Indeed, some parents expressed relying on a specialist physician (i.e., pediatrician, psychiatrist) for their child's "mental health needs" and viewed family physicians as completely separate. The quantitative findings are consistent with participants' views: only a quarter of CMH youth had a mental health related visit with a family physician during their CMH treatment. It is possible that even if CMH providers attempted to engage their client's family physician that some youth and families would not provide consent for information to be shared with their family physician. Some youth and families might view their family physician as separate from CMH or they may already have a medical specialist involved (e.g., pediatrician). It might not be until treatment is completed that youth and families are more likely to access the medical system. Indeed, although the longitudinal study showed that more youth had a visit with their family physician following CMH treatment, almost half had not. A lack of engagement with family physicians, both during and after a youth's CMH treatment, was a common theme across both studies.

Individuals who are involved with a family physician for their mental health care needs when they are younger could facilitate access to mental health care as young adults. Specifically, if youth see their family physician for ongoing visits *during* their CMH treatment, this could possibly influence youth and parents to view family physicians as part of their mental health care. The longitudinal study showed that a mental health visit with a family physician prior to age 18 predicted subsequent mental health service use in the medical system during young adulthood. Thus, youth treated in CMH who had been seen by a family physician were 1.4 times more likely to have a mental health visit in the medical sector after the age of transfer compared to youth who had not had a mental health visit during that time. Youth were *not* more likely to have a mental health visit after the age of transfer if they had *only* been seen by a specialist physician (i.e., psychiatrist, pediatrician) prior to age 18. This might be explained by considering that specialists offer time- and age-limited services (i.e., pediatricians in Canada only see youth up to age 18) compared to family physicians who follow their patients from childhood and adolescence into adulthood. It is worth emphasizing that if a youth has a mental health visit with a specialist during childhood and adolescence, this care would not be expected to continue after the age of transfer. It is therefore important to consider the reasons why a young adolescent might receive care by a family physician in general.

Research suggests some young adolescents might be more likely to receive care by a family physician during childhood and adolescence due to a number of factors. For example, young adolescents (aged 12 to 15 years old) who have access to a *regular* family physician are more likely to receive care from them (Ryan et al., 2011). Youth who have chronic physical health conditions are also more likely to receive care by family physicians (Ryan et al., 2011). This is likely due to the need for scheduled follow-up appointments in PHC or ongoing medication monitoring. Finally, some younger adolescents might be more likely to receive care from a family physician because they have established a trusting relationship with this provider (Malik, Oandasan, & Yang, 2002; Miller, Wickliffe, Jahnke, Linebarger, & Dowd, 2014).

It is possible that the above factors are also associated with a higher likelihood of receiving mental health care by a family physician during childhood and adolescence. For example, youth with mental health problems who require medication monitoring might be more likely to receive care by a family physician. In this dissertation, participating family physicians acknowledged that youth who were *not* being followed for medication might lack an incentive to attend follow-up appointments in PHC. This was perceived by family physicians as a major barrier for monitoring youth with ongoing CMH problems: *"It's very hard to get someone that's feeling good to keep coming back for follow-ups when they're not on medication, because they feel like there's no point of the visit"*. Youth who have an ongoing/intensive-episodic pattern of CMH service use might be expected to require ongoing medication monitoring due to their greater mental health needs. This would be another important reason for targeting this group, as it would be easier to have discussions about the possible need for adult care with youth in PHC who are already attending follow-up appointments with a family physician. Family physicians could then play an essential role facilitating re-engagement with specialized mental health services if necessary. In general, PHC offers valuable opportunities for improving mental health care and barriers to providing this care for all youth treated for CMH problems should be explored.

## 6.5 Relevance to Policy and Theory Development

This dissertation is relevant to current policy in the country. Canada's Mental Health Strategy, '*Changing Directions, Changing Lives'* (Strategy) (Mental Health Commission of Canada, 2012), has prioritized *"expand[ing] the role of primary health care in meeting mental health needs"* (Sec. 3.1., p. 56), and *"remov[ing] barriers to successful transitions between child, youth, adult, and senior mental health services*" (Sec. 3.3.5, p. 69). Its vision is a mental health system "*in which every door is the right door to meeting people's mental health needs*" (p. 58).

The Strategy has sparked system reform in CMH across provinces in the country. In 2013, Ontario's Ministry of Children and Youth Services (MCYS) released a draft service framework outlining minimum expectations for delivering mental health services at CMH agencies. This included specific expectations around "transitions to other services" and "follow-up after discharge". A recent audit of CMH agencies in Ontario was released in 2016 (Office of the Auditor General of Ontario, 2016) and produced outcomes that resonate with the findings of this dissertation. First, the audit found that CMH agencies did not always help in the transition of discharged youth to other service providers and this had the potential for serious negative consequences for youth. The results from this dissertation would add that helping discharged youth transition to their family physicians is especially lacking. Second, the audit revealed that CMH agencies failed to monitor and assess client outcomes to determine if clients benefitted from the services they received. This dissertation similarly found a lack of clear guidelines for monitoring clients in CMH, which is especially critical for understanding the needs of youth with ongoing CMH problems. The development of criteria for determining youth who will require adult care would benefit from the use of consistent, standardized assessment tools to monitor youth outcomes; this was also recommended by the CMH agencies that participated in the audit.

This dissertation is also relevant for theory development, which is a key part of addressing any issue related to policy or social values. A limitation of previous work on transitions to adult care has been the lack of conceptual framework. Without a framework, it becomes difficult to understand and prioritize the many individual, family, and treatment system factors that might shape an individual's service use and potential need for adult care.

The value of using a theoretical model, namely the Revised Episode Network Model [R-NEM; (Costello et al., 1998)], to guide research questions about mental health service use amongst youth was demonstrated in this dissertation. The model's emphasis on social "networks" underscores a need to consider a youth's experiences within, and across, multiple sectors of care. This network perspective is particularly useful for considering the issue of transition to adult care for several reasons. First, it encourages us to think about what happens when youth go for treatment and how their experiences in treatment can affect whether they stay in treatment and, if so, whether they consider a need for future care. Second, the network model encourages us to think about how a youth and family establish network contacts. Many different individuals within a youth's family, community, school, and treatment systems can become involved in their mental health care. Ultimately, the power of a youth's network, or how these individuals interact and work together, can shape a youth's "illness career" (Horwitz & Scheid, 1999). Transitioning from CMH to adult care is one part of this career that cannot be ignored. The issue of transition will likely require addressing unique factors in each part of a youth's network (e.g., family, school, CMH, PHC). Finally, although every society has some kind of treatment system, what that system looks like and who has access to it can vary substantially (Horwitz & Scheid, 1999). Research on transitions to adult care should be mindful that what might work in one system of care may not work in others. This could be due to a number of factors such as agency mandates, financial resources and supports, and practice cultures. Overall, the R-NEM raises important questions about how we study and collect data across, and within, the systems that care for youth with ongoing mental health problems. Future research should consider using a process model like the R-NEM to advance both policy and practice in the field.

## 6.6 Limitations and Considerations for Future Research

There are five key limitations of the studies conducted. First, the nature of the study samples should be addressed. All data were based on individuals residing in Ontario, and participants from the qualitative study were recruited from only two CMH agencies in the city of London. The issue of transition to adult care and the challenges associated with providing ongoing care has broad relevance for jurisdictions in other cities and provinces. Larger and more varied samples of youth, parents, and providers at other CMH agencies in Ontario should therefore be explored. This is especially important since “agency culture” emerged as an important influence on collaborative practices and how care was delivered by providers.

Second, as reflected by the qualitative sample, few family physicians agreed to participate in the qualitative study. Underrepresentation by these providers might actually support the finding of poor collaboration between PHC and CMH. This is consistent with the finding that the majority of CMH youth (75%) were *not* in contact with a family physician during their CMH treatment. A different sampling approach, targeting PHC practices rather than CMH agencies, may be necessary to gain more insights from family physicians and other PHC providers. Challenges should be anticipated with this approach, given the low base rates for patients with ongoing and complex mental health needs within any given family practice. As such, it would be extremely difficult to recruit these types of patients directly from PHC. An alternative approach might be to focus directly on understanding mental health care for children and youth within PHC, but not use a CMH patient or case-based approach.

Third, this dissertation was limited by a lack of criteria used to select youth treated in CMH that *should* receive mental health care in young adulthood. The proportion of CMH youth who *should* have received mental health services after the age of transfer is unknown, and it is not possible to know whether *not* having an OHIP-MH visit after age 18 reflects poor access to services or symptom improvement (e.g., problems remitted). Development of criteria to identify CMH youth who will require long-term services is still in its infancy (Rosemary Purcell et al., 2014; Schraeder & Reid, 2017). Without a clear denominator of *who should* require mental health services in adulthood, rates of successful “transfer” cannot be reported.

Fourth, this dissertation specifically focused on two sectors of care (CMH and the medical system). Views about the challenges of caring for youth with ongoing mental health problems might differ between providers in other sectors of care (e.g., education, child welfare, private and/or for-profit clinics). Research on cross-sectoral mental health service utilization should therefore involve linkage to other public sectors of care, such as education and child welfare. This dissertation represents a good first step in Ontario to link administrative mental health visit to better understand access and use of mental health services over time.

Finally, rates of mental health service utilization in the medical system (i.e., by a family physician, pediatrician, or psychiatrist) after CMH treatment and during young adulthood may be underestimated in the longitudinal study (Chapter 5). Not all mental health services covered by OHIP (e.g., inpatient stay, emergency department visits) were examined. Recent work suggests that mental health related Emergency Department (ED) visits and hospitalizations amongst children and youth (ages 10 to 24 years) have increased in Ontario (Gandhi et al., 2016). However, the reported population prevalence of ED visits for children and youth was very small (19.3 per 1000 population in 2011 fiscal year; Gandhi et al., 2016). Thus, estimates of mental health service use in the medical sector in this dissertation are likely very close to what would have been found if *all* mental health services within the medical sector had been included. It is possible that youth who received CMH treatment were more likely to access acute care mental health services (e.g., ED visits) than the general population due to the episodic and severe nature of some mental health problems. This should be examined in future research to better understand whether observed trends of increased mental health service use in acute care reflect challenges with access to outpatient care, a growing burden of CMH issues in Ontario, or issues related to transitions to adult care.

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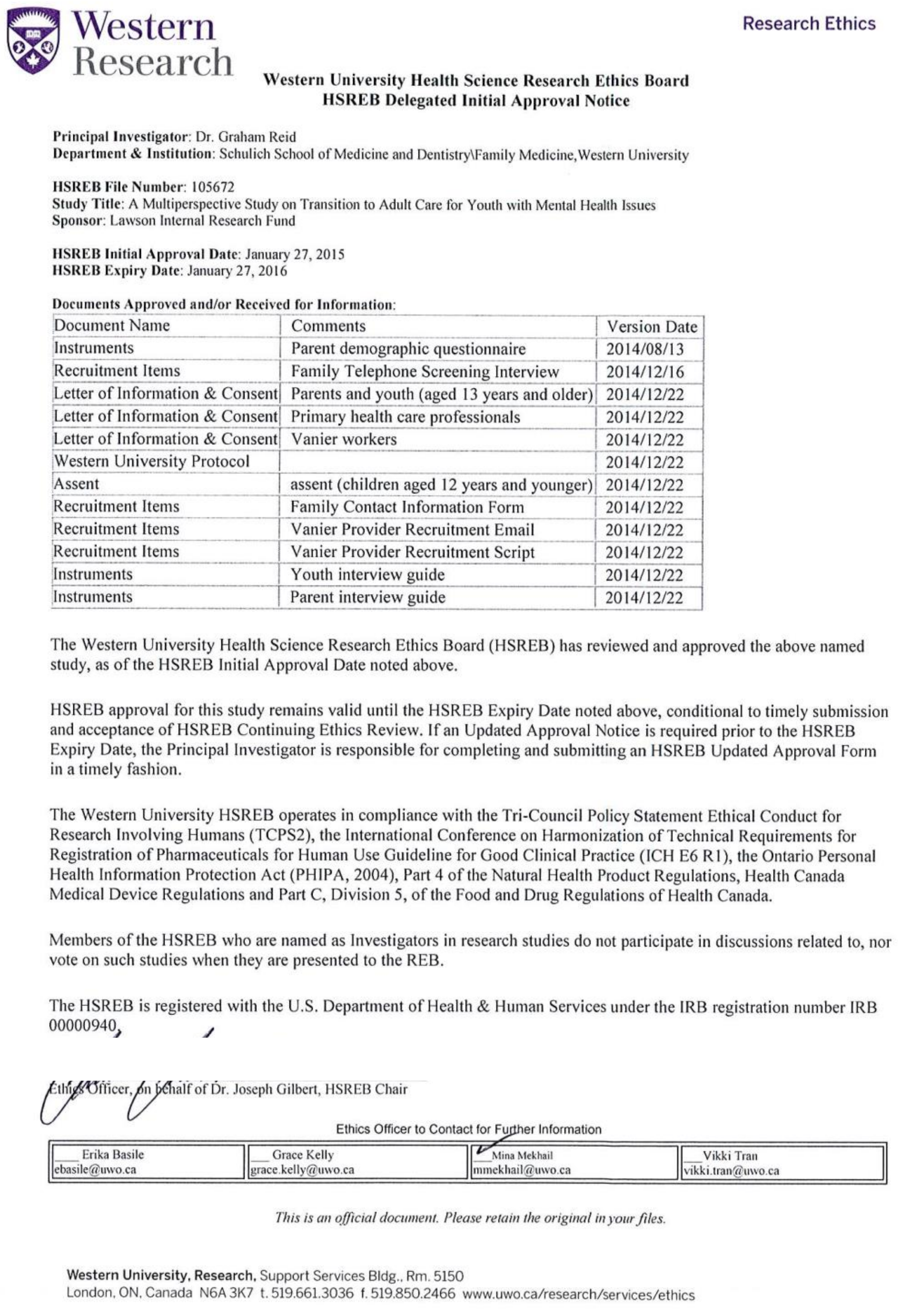
# Appendices

## Appendix 1: Qualitative study ethics approval documentation



Western Research

Research Ethics

**Western University Health Science Research Ethics Board**
**HSREB Delegated Initial Approval Notice**

**Principal Investigator**: Dr. Graham Reid
**Department & Institution**: Schulich School of Medicine and Dentistry\Family Medicine,Western University

**HSREB File Number**: 105672
**Study Title**: A Multiperspective Study on Transition to Adult Care for Youth with Mental Health Issues
**Sponsor**: Lawson Internal Research Fund

**HSREB Initial Approval Date**: January 27, 2015
**HSREB Expiry Date**: January 27, 2016

**Documents Approved and/or Received for Information**:

| Document Name | Comments | Version Date |
|---|---|---|
| Instruments | Parent demographic questionnaire | 2014/08/13 |
| Recruitment Items | Family Telephone Screening Interview | 2014/12/16 |
| Letter of Information & Consent | Parents and youth (aged 13 years and older) | 2014/12/22 |
| Letter of Information & Consent | Primary health care professionals | 2014/12/22 |
| Letter of Information & Consent | Vanier workers | 2014/12/22 |
| Western University Protocol | | 2014/12/22 |
| Assent | assent (children aged 12 years and younger) | 2014/12/22 |
| Recruitment Items | Family Contact Information Form | 2014/12/22 |
| Recruitment Items | Vanier Provider Recruitment Email | 2014/12/22 |
| Recruitment Items | Vanier Provider Recruitment Script | 2014/12/22 |
| Instruments | Youth interview guide | 2014/12/22 |
| Instruments | Parent interview guide | 2014/12/22 |

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review. If an Updated Approval Notice is required prior to the HSREB Expiry Date, the Principal Investigator is responsible for completing and submitting an HSREB Updated Approval Form in a timely fashion.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer to Contact for Further Information

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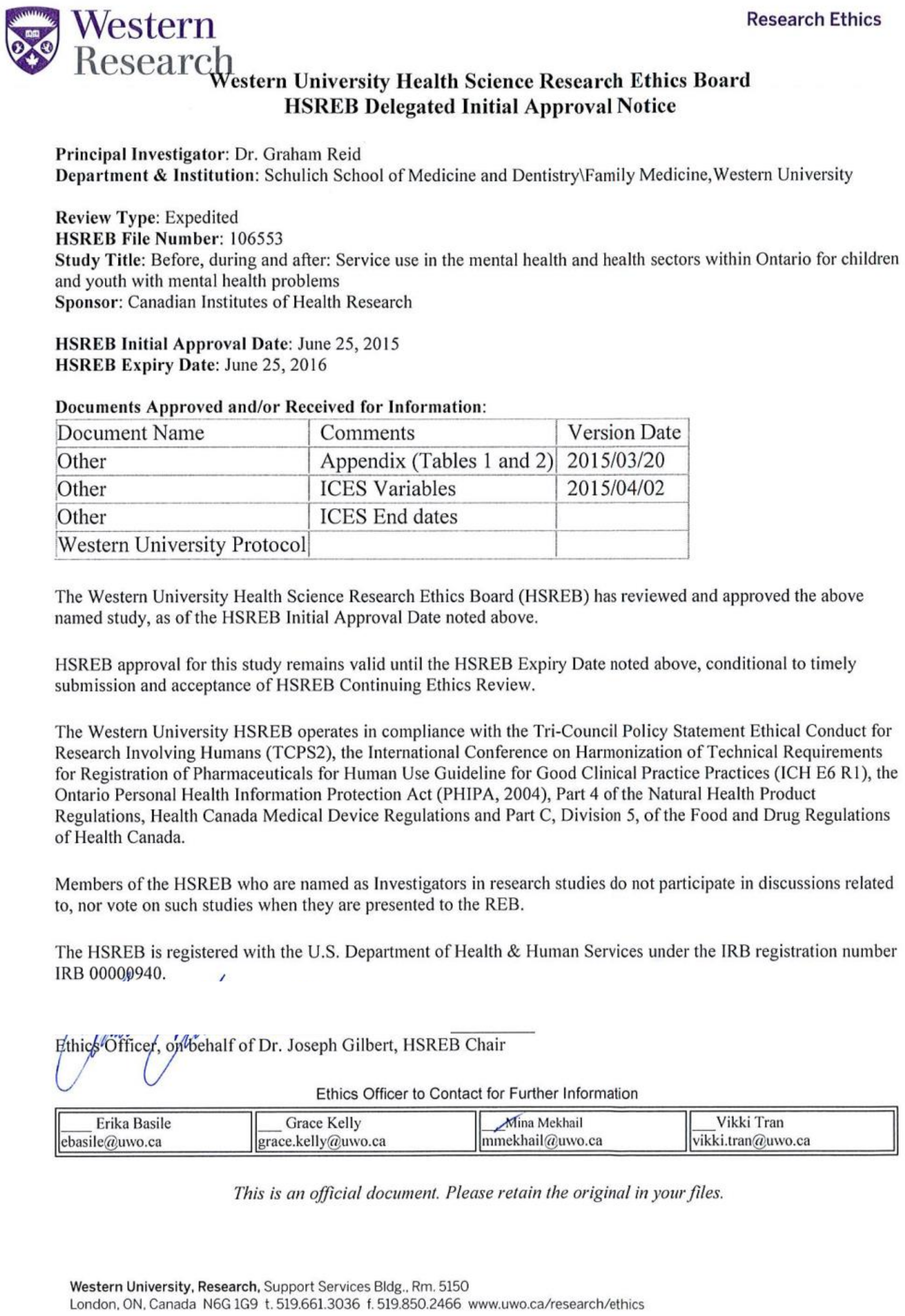
# Appendix 2: Quantitative study ethics approval documentation



Western Research

Research Ethics

## Western University Health Science Research Ethics Board
## HSREB Delegated Initial Approval Notice

**Principal Investigator**: Dr. Graham Reid
**Department & Institution**: Schulich School of Medicine and Dentistry\Family Medicine, Western University

**Review Type**: Expedited
**HSREB File Number**: 106553
**Study Title**: Before, during and after: Service use in the mental health and health sectors within Ontario for children and youth with mental health problems
**Sponsor**: Canadian Institutes of Health Research

**HSREB Initial Approval Date**: June 25, 2015
**HSREB Expiry Date**: June 25, 2016

**Documents Approved and/or Received for Information**:

| Document Name | Comments | Version Date |
|---|---|---|
| Other | Appendix (Tables 1 and 2) | 2015/03/20 |
| Other | ICES Variables | 2015/04/02 |
| Other | ICES End dates | |
| Western University Protocol | | |

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer to Contact for Further Information

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## Appendix 3: Qualitative Studies on Transitioning to Adult Care in Mental Health

| Authors | Objective(s) | Recruitment | Sample | Data Collection/ Analysis | Main Themes |
|---|---|---|---|---|---|
| Belling et al. (2014) | To investigate organizational factors that impede or facilitate transition of young people from CMH to AMHS | Health and social care professionals recruited from 4 NHS Mental Health Trusts in Greater London and the Midlands, including representatives of 4 local voluntary sector organizations | **<u>Professionals (n=34)</u>**<br>CAMHS: 5 nurses, 4 psychiatrists, 2 psychologists, 3 social workers;<br>AMHS: 3 nurses, 2 psychiatrists, 4 social workers; 7 managers; 4 voluntary sector | Semi-structured interviews/ Thematic analysis | ✓ Two core themes: eligibility issues and resources<br>✓ Lack of clarity on service availability and eligibility criteria<br>✓ Adult services not accepting patients until 17th or 18th birthday<br>✓ Variability in service cut-off ages<br>✓ Adult service workloads<br>✓ AMHS not meeting needs beyond severe and enduring mental illness (e.g., learning disability, ADHD) |
| Davis et al. (2005) | To focus attention on specific, structural, systemic impediments that exist and to stimulate discussion about how to minimize their impact on appropriate transition systems | Key informants recruited from organizations providing services in the Clark County Transition Network (e.g., case-management approaches, counseling and wrap-around services) | **<u>Professionals (n=103)</u>**<br>One from each organization providing services in the Clark County Transition Network to support young adults aged 14–25 years with serious MH problems | Key informant interviews/ Social Network Analysis [a] | ✓ Continuity of services<br>✓ Relationships between organizations<br>✓ Ratings of organizations and the system |
| Davis and Sondheimer (2005) | To describe transition services provided and efforts made by State mental | | **<u>Policy administrators (n = 50)</u>**<br>One member of the Children, Youth | Semi-structured interviews/ Descriptive analyses | ✓ Transition services provided and efforts made by the state's child MH system to serve youth with SED who were in the state child MH system; |

| Authors | Objective(s) | Recruitment | Sample | Data Collection/ Analysis | Main Themes |
|---|---|---|---|---|---|
| | health systems to serve youth with severe emotional and behavioural disorders | | and Families Division of the National Association of State Mental Health Program Directors per state | | ✓ Population policies that define eligibility criteria or definitions of target populations for child and adult MH services;<br>✓ Efforts to link child and adult MH systems for the purpose of transition support<br>✓ Interagency efforts to address transition needs that include the child MH system. |
| Dimitropulous, Tran, Agarwal, Sheffield, & Woodside (2012) | To conduct qualitative research on the perspectives of service providers regarding the transition process from pediatric to adult specialized eating disorder (ED) tertiary care programs | Service providers recruited from one Pediatric Eating Disorder Program (PEDP) and one Adult Eating Disorders Program (AEDP) – both are among the largest tertiary care programs for ED in Canada | **Professionals (n = NR)**<br>Service providers who had direct experience working with youth transition from PEDPs to AEDPs within last 12 months; professionals from community agencies (e.g., occupational therapists, social workers) and adolescent medicine pediatricians | Focus groups and qualitative interviews/ Constant comparison analysis | ✓ Illness-related factors (ambivalence and denial)<br>✓ The interruption of normative adolescent developmental processes by the illness<br>✓ The impact of decreased parental involvement in the adult compared to pediatric eating disorder programs |

| Authors | Objective(s) | Recruitment | Sample | Data Collection/ Analysis | Main Themes |
|---|---|---|---|---|---|
| | | | (specializing in TAY) | | |
| Gilmer, Ojeda, Leich, Heller, Garcia, & Palinkas (2012) | Assessed the needs for MH and other services among TAY who were receiving services in youth-specific programs in the US | Youths were sampled from geographically diverse programs to obtain a range of perspectives from San Diego County. Parents were recruited through two organizations focused on parents of children with mental illness. Providers recruited by word of mouth | **Youth (n = 75)**<br>TAY age 18 to 24 years who were receiving services in youth-specific programs<br>**Parents (n=14)**<br>Parents of TAY<br>**Professionals (n=14)**<br>Clinical therapists and social workers | Focus groups/ Constant comparison analysis | ✓ Youths expressed needs for improved scheduling of services, stronger patient-provider relationships, and group therapies that ad- dress past experiences of violence, loss, and sexual abuse and that pro- vide skills for developing and nurturing healthy relationships<br>✓ Parents and providers expressed needs for increased community-based and peer-led services<br>✓ All expressed needs for more housing options and for mentors with similar life experiences who could serve as role models, information brokers, and sources of social support for those pursuing education/employment |
| Jivanjee and Kruzich (2011) | To explore TAY and their parents' experiences and perceptions of receiving formal MH services and family/peer support | Local MH agencies, support groups, colleges, alternative schools, and youth employment organizations (youth); Family support organizations (parents) | **Youth (n=6)**<br>16 young people aged 17–23 years (mean 19.4 years), with range of MH problems<br>**Parents (n=18)** | Focus groups/NR | ✓ Positive experiences with mental health services and responsive service providers<br>✓ Challenges related to inappropriate or unavailable MH services<br>✓ Family/parental support<br>✓ Peer support |
| McLaren et al. (2013) | Identify organizational | Health and social care professionals | **Professionals (n = 34)** | Semi-structured | ✓ Service cultures (subthemes: individual vs. family |

| Authors | Objective(s) | Recruitment | Sample | Data Collection/ Analysis | Main Themes |
|---|---|---|---|---|---|
| | factors which facilitate or impede transition of young people from CMH to AMHS from perspectives of health professionals and representatives of the voluntary organizations in England | were recruited from 4 Mental Health Trusts in Greater London and the Midlands; staff each representing local voluntary sector organizations were also recruited | 16 CAMHS, 11 AMHS, 3 CMH & AMHS,<br>4 voluntary sector; included nurses, social workers, psychiatrists psychologists, service managers, voluntary sector | telephone interviews/ Structured thematic approach | perspectives; AMHS lack of confidence with young people; impact of transition on parents/carers)<br>✓ Communication and working practices (subthemes: two-way communication and feedback; early communication; joint working and liason; prior professional experience; inter-agency working practices and experiences; service use preparation for transition) |
| McNamara et al. (2013) | To compare best practice guidelines for transition with current process and experience in clinical practice in the Republic of Ireland | A national list of lead clinicians for CMH and AMHS teams was generated using information obtained from the Irish Health Services Executive website and telephoning individual clinics. Consultants from public and private services were recruited | **Professionals (n=57)**<br>32 from CMH teams and 25 from AMHS teams | Structured telephone interviews/ Descriptive analyses | ✓ Transfer numbers (number considered suitable vs. actual transfers)<br>✓ Lack of standardized practice nationwide regarding service transition boundary<br>✓ Age boundaries<br>✓ Determining suitability for transfer (criteria used by CMH)<br>✓ Transition process and guidelines<br>✓ Parental involvement<br>✓ Negotiations around timing and duration of transition<br>✓ Therapeutic relationship |
| Richards and | To establish themes of MH needs of young | MH, social care, education and voluntary agencies | **Professionals (n=39)** | Semi-structured face-to-face | ✓ Older adolescents have multi-faceted needs |

| Authors | Objective(s) | Recruitment | Sample | Data Collection/ Analysis | Main Themes |
|---|---|---|---|---|---|
| Vostanis (2004) | people aged 16–19 years, as perceived by professionals from all agencies involved in their care | across a district in the UK | 18 managers and 21 practitioners, including psychiatrists, nurses, MH workers, outreach worker, substance and alcohol misuse officer | interviews/ Thematic content analysis | ✓ Statutory mental health services are not geared towards this age group<br>✓ Communication between services is variable<br>✓ There are no formal transfer arrangements from child to adult services. |
| Singh et al., 2010 (“The TRACK study”) | To understand the experiences of service users, their parents and CAMHS/ AMHS clinicians of transition between CAMHS and AMHS | Youth and their parents and providers were recruited across 6 centers in the UK, previously included in a case-note review of transition outcomes (reported in Singh et al., 2010) by virtue of reaching the age of transfer between CAMHS and AMHS during a 12-month study period ending in September 2007 | **<u>Youth (n=11)</u>**<br>Youth who had received CMH, between the ages of 16 to 21 years.<br>**<u>Parents (n=6)</u>**<br>**<u>Professionals (n=9)</u>**<br>6 CMH clinicians and 3 in AMHS | Semi-structured face-to-face interviews [a]/ Constant comparative method within the Framework Approach, integrating a thematic analysis | ✓ Lack of preparation for transition<br>✓ Joint working<br>✓ Parental involvement<br>✓ Outcomes of transition (e.g., symptom improvement since transfer to AMHS)<br>✓ Other transitions (e.g., change of accommodation or educational status) |
| Styron et al. (2006) | To evaluate a Young Adult Service (YAS) in the US: a comprehensive | Randomly selected sample of youth recruited from a YAS in one state in the US | **<u>Youth (n= 12)</u>**<br>Young adults (18 years and above) with moderate/ severe mental | Structured face-to-face interviews [a]/ Thematic analysis | ✓ Living independently<br>✓ Support by staff and relationships with staff<br>✓ Planning for future (hopes and dreams) |

| Authors | Objective(s) | Recruitment | Sample | Data Collection/ Analysis | Main Themes |
|---|---|---|---|---|---|
| | service including clinical, residential, case-management and planned step-up/ step-down care into more/less intensive services. | | illness receiving services from the YAS; 3 groups (juvenile sex offenders, TAY with pervasive developmental disorders, TAY with behavioural needs) | using the constant comparative method | |
| Swift et al. (2013) | Explore the experiences of young people with ADHD during transition from CMH to AMHS in the UK | Patients identified and recruited through youth's CMH clinician at clinics in Nottinghamshire (UK) | **<u>Youth (n = 10)</u>**<br>Aged 17 to 18 years old with a diagnosis of ADHD. Many had co-morbid problems, including Autism, depression, and self-harm.<br>**<u>Parents (n=NR)</u>**<br>Some family members of youth were interviewed | Semi-structured interviews/ Thematic analysis | ✓ Clinician qualities and relationship<br>✓ Responsibility of care<br>✓ Nature and severity of problems<br>✓ Expectations of AMHS |
| Thomas, Pilgrim, Street, and Larsen (2012) | The primary aim was to understand participant perceptions of the Uthink project – an activity-based | Participants were recruited from their involvement with the Uthink project and included staff providing the service | **<u>Professionals (n=19)</u>**<br>19 professionals (referring and non-referring) and | Face-to-face or telephone interviews/ NR | Important mechanisms of the Uthink program included [a]:<br>✓ the voluntary attendance of the participants and the sense that they were agents, not passive recipients of a service |

| Authors | Objective(s) | Recruitment | Sample | Data Collection/ Analysis | Main Themes |
|---|---|---|---|---|---|
| | program to promote positive MH and recovery in young people aged 16-25 years across England. | at 3 sites in England, local professionals making choices about whether to refer to it, and service users who took part. | project staff (*n* not reported)<br>**<u>Youth (n=3)</u>**<br>Involved with Uthink program | | ✓ the regular structure of the programme which gave a sense of routine, and something to look forward to positively<br>✓ the explicit commitment to a strengths-based and recovery approach<br>✓ the emotional climate of positivity and fun, in contrast to provision focused on risk management and symptom surveillance |
| Williamson, Koro-Ljungberg, Bussing (2009) | To investigate the shared critical events related to help-seeking reported by teens with ADHD, their mothers, and their teachers, and how these events might explain teens' transitions in their illness | Recruitment through longitudinal cohort study that followed public school students at risk for and with ADHD since 1998 (Bussing et al., 2005) | **<u>Youth (n=8)</u>**<br>4 teenagers who received ADHD treatment and 4 teenagers who did not receive ADHD treatment during elementary school | Qualitative adaptation of the experience sampling method/ Critical incident analysis | Illness career transitions framed categories:<br>✓ Continuing treatment<br>✓ Transition from treated to untreated<br>✓ Transitioning from untreated to treated<br>✓ Remaining untreated |

*Note*. MH = Mental health. CMH = Children's Mental Health. AMHS = Adult Mental Health Services. TAY = Transition-aged youth. NR = Not reported. [a] Did not use a thematic analysis and therefore represents one aspect of the analysis. [b] Used a mixed-method study design, but only qualitative study details reported

## Appendix 4: Interview guide for parent or youth*

**Note to Interviewer**
This study is about caring for children with children's mental health problems.

By mental health problems, we mean problems in the areas of academic, behavioural, emotional, psychological, or social functioning that include virtually any type of mental health problem such as anxiety, depression, attention-hyperactivity deficit disorder, or behavior problems.

We are not focusing on developmental problems such as developmental disabilities or autism.

*****A slightly modified version of this guide (e.g., "your child" vs. "you") was used for youth.

### i) PREAMBLE

Thank you for participating in our research. Today's interview will last about one hour and can be broken down into three parts.

First, we will talk a bit about your experience getting help for [*child's name*] at [*Children's Mental Health Agency*] and the different people that have helped you.

Second, I would like to know your thoughts on your child's future mental health needs and possibly getting help as a young adult.

And finally, I would like to know how you think that help should be delivered.
You can think of this interview as more like a discussion. I have some questions I would like to cover, but the order is not as important as is hearing your thoughts and ideas. If you have any questions or something is not clear, please stop and ask me.

Do you have any questions before we get started?

## A) YOUTH'S MENTAL SERVICES BACKGROUND/CONTEXT

### A.1) History of mental health services received

- To start, please tell me about the reasons or problems that lead your child to be receiving help from [*Children's Mental Health Agency*].
- When did your child first experience problems with [*use parent's words to describe the mental health problems child is having]*?
- When did he/she first see a professional about these problems?
- What help has your child received since this time?

| | |
|---|---|
| *Probes* | ➔ Number and duration of episodes over time (episode defined as at least 3 visits with a 6 month "free period" between episodes].<br>➔ Have mental health problems stayed the same or changed over time? |

| | |
|---|---|
| | **If child has had more than one episode, probe for what parent thought about second episode:**<br>→ When your child's *[use parent's term]* came back, were you surprised? What was that like for you? For your child?<br>→ Can you remember what you were told about your child's [*parent's term]* possibly coming back again?<br>→ Looking back, how long did you think your child would have *[parent's term]* for?<br>→When your child first had [parent's term] what did you think the chances were that these problems would come back? |

### A.2) Current mental health services at agency

- I understand from when we first contacted your child was receiving services from [*Children's Mental Health Agency Name*].
- Tell me about the services or programs that your child is involved with there.

| | |
|---|---|
| *Probes* | ➔ How often does child meet with professional at agency?<br>➔ In what ways is parent involved in child's care? (Attending appointments? Parenting classes? Family therapy?) |

  - *If no* →Tell me about the services or programs that your child was involved with at [*Children's Mental Health Agency Name*].

| | |
|---|---|
| *Probes* | ➔ When did services end?<br>➔ Reasons no longer receiving services |

### A.3) Collaboration with other sectors

When children and youth have [*use parent's words to describe the mental health problems child is having]*, sometimes many people and professionals are involved with helping them. This might include physicians or guidance counselors at school.

- What other professionals are currently helping your child?

| | |
|---|---|
| *Probes* | ➔ Experience with the following sectors/individuals if not already mentioned:<br>✓ Family physicians<br>✓ Psychiatrists<br>✓ Nurses/Nurse practitioners<br>✓ Juvenile justice workers<br>✓ Child welfare workers<br>✓ Psychologists/social workers/counselors in private practice<br>✓ School/education professionals (e.g., guidance counselors)<br>➔ Probe for professionals that provided help concurrently with specialized mental health services |

[The following questions are related to each professional]:

- Tell me about the help they gave your child.
- In what ways does (*name of the professional; e.g. family physician*) connect with the people helping your child at [*Children's Mental Health Agency Name*]?

## B) VIEW ON FUTURE MENTAL HEALTH NEEDS

Some youth experience problems with mental health over many years, or they have problems that go away and then come back months or years later.

- When you think about the future for your child, do you think about his/her [*use parent's term]*?
- Have any of your child's providers [refer to A.3] talked to you or him/her about getting help as an adult or transition to adult care?
    - *If yes* → Who was this person?
        - When did they talk to you about this?
        - What do you remember from that talk?

Some youth with mental health problems continue to need help after they turn 18.

- If your child's problems came back when they were an adult, after they turned 18 years old, where do you think they would turn for help?

- What professional(s) do you think would be in the best position to provide this help?

| | |
|---|---|
| *Probes* | ➔ Who would they go to? [Note: if parent talks about connecting with a professional that they are currently seeing at the children's mental health agency, inform them about age cut-offs for service provision at agency] |

- In what ways do you think your involvement in your child's mental health care will change? Stay the same?

- What do you think about your child's ability to access mental health services as a young adult?

| | |
|---|---|
| *Probes* | ➔ Concerns about accessing appropriate services<br>➔ Different systems (child to adult mental health)<br>➔ Possibility of child moving away from home |

## C) PROVISION OF ONGOING MENTAL HEALTH CARE SERVICES

### C.1) Notion of "chronic" mental health problems

In caring for individuals with *chronic physical health problems*, like diabetes, ongoing monitoring/screening is often conducted on a routine basis with the goal of detecting problems before a crisis occurs.

Similar to these chronic physical problems, we know though that symptoms of mental health problems get better and then come back. Some people end up having mental health problems for many years, lasting into adulthood. We might even call these "*chronic mental health problems*".

- I'm interested in your thoughts about the idea of an adolescent having a "chronic mental health problem"
- What would it be like for you if a professional suggested that your child might have a "chronic mental health problem"?

### C.2) Regular mental health check-ups

We know that sometimes young people who have had mental health problems may be fine for a number of months or years but then have problems come back again. We are thinking that it might be helpful if people were able to have someone check in with them or see how they're doing on a regular basis when they are **not** having problems.

- What are your thoughts on something like a regular check-up for youth who might have mental health problems again in the future?

| | |
|---|---|
| *Probes* | ➔ In what ways do think these types of checkups might be helpful?<br>➔ In what ways do you think these types of checkups might be a hassle? |

- What do you think is the best of way of doing a regular checkup?

| | |
|---|---|
| *Probes* | ➔ Regular check-ups with whom? Where? (e.g., visits with a family physician) |

### C.3) Use of technology in monitoring

- What do you think about your child completing a checklist or questionnaire on a website, or on a smartphone or tablet app, to keep a record about how they are managing their [*use parent's words to describe mental health problems]*
- In what ways do you think your child completing a questionnaire or checklist every so often would be helpful? A hassle?
- What questions would you have before your child signed up to do a checklist like this?
- What would you think about the information from this being shared with the professionals at [*Children's Mental Health Agency Name*]? Your family physician?
- Would there be anyone else you would want to share this information with?

| | |
|---|---|
| *Probes* | ➔ Other concerns about doing a checklist or using technology |

**End of interview wrap-up procedures**

Ensure all major components of the interview have been covered
Obtain contact information for professionals (i.e., child's primary provider at the mental health agency and primary health care provider).
Ask interviewee if they have anything else they would like to add, or if they would like to return to any section to discuss further.

Ask participant if they would like to be sent a report of the findings from the study.
Thank the participant for their time and provide compensation.

## Appendix 5: Interview guide for professionals*

**Note to Interviewer**
This study is about caring for children with children’s mental health problems.

By mental health problems, we mean problems in the areas of academic, behavioural, emotional, psychological, or social functioning that include virtually any type of mental health problem such as anxiety, depression, attention-hyperactivity deficit disorder, or behavior problems.

We are not focusing on developmental problems such as developmental disabilities or autism.

*This guide was used with Children’s Mental Health providers, family physicians, and pediatricians. Some wording was accommodated for the specific professional (e.g., client vs. patient, agency vs. practice).

### i) PREAMBLE

Thank you for participating in our research. Today’s interview will last about one hour and can be broken down into three parts.

First, we will talk a bit about your role in [child’s] mental health care and any professional collaborations you have been involved with for this patient.

Second, I would like to know your thoughts on [child name]’s future mental health needs and possible transition to adult care.

And finally, I would to talk about some different ways for providing care to youth with ongoing or recurring mental health needs.

I have some questions I would like to cover, but the order is not as important as is hearing your thoughts and ideas. If you have any questions or something is not clear, please stop and ask me. Do you have any questions before we get started?

### A) SERVICES PROVIDED TO YOUTH PATIENT (BACKGROUND/CONTEXT)

#### A.1) Patient history and professional’s role in care

To start with, I would like to hear about your experiences in providing care for this child and their family. I understand from when we first contacted you that you were this child’s primary [*professional title - family physician, mental health provider*].

- Please tell me about how long you have cared for this patient and the types of care you have provided for this patient up until now.

| | |
|---|---|
| *Probes* | ➔ How often do you see this patient?<br>➔ When was their most recent visit?<br>➔ When was the child’s mental health problems first brought to your attention?<br>➔ What were the major concerns of the parents, and in what ways did you share these concerns? (or have differing views?) |

- Please describe this patient’s current mental health needs from your perspective.
- Please tell me about any kind of direct help or services that you have provided this child for their [*use professional’s words to describe the mental health problems child is having]*?

| | | |
|---|---|---|
| *Probes* | ➔ Types of services provided | |
| | **Child mental health care provider** | **Primary health care provider** |
| | ⇒ Initial assessment | ⇒ Initial assessment |
| | ⇒ Individual therapy | ⇒ Referral to specialized CMH services |
| | ⇒ Group therapy | ⇒ Therapy |
| | ⇒ Family therapy | ⇒ Parent counselling |
| | ⇒ Parent counselling | ⇒ Medication management |
| | ⇒ Comprehensive assessment | |
| | ⇒ Residential treatment | |

### A.2) Collaboration with other sectors

When children and youth, like [*child’s name*] have [*use professional’s words to describe the mental health problems child is having]*, sometimes many people and professionals are involved with helping them.

- In what ways have you/your agency collaborated with other professionals in other sectors to meet the needs of this specific patient?

| | |
|---|---|
| *Probes* | ➔ Experience with the following sectors/individuals if not already mentioned:<br>Family physicians<br>Psychiatrists<br>Nurses/Nurse practitioners<br>Juvenile justice workers<br>Child welfare workers<br>Psychologists/social workers/counselors in private practice<br>School/education professionals (e.g., guidance counselors) |

- In what ways does your [*practice or agency name*] direct or support your clinical staff in coordinating care across sectors for youth like [child’s name]?

## B) VIEWS ON YOUTH’S FUTURE MENTAL HEALTH NEEDS

Some youth experience problems with mental health over many years, or they have problems that go away and then re-emerge months or years later.

- Do you think [child’s name] will require mental health services in the future?

  We have been considering:
  A) *"ongoing care"* to be defined as: problems that would commonly last more than 2 years and/or be likely to reoccur,
  B) *"complex care"* to be defined as: children who are receiving services from 3 or more of the 5 provincial sectors involved in mental health care for children.
  By sectors, we mean primary healthcare, specialized mental health, education, juvenile

justice and child welfare.

- When you hear the terms "ongoing" or "complex mental health issues" applied to children and youth, how would you define or describe such problems?
- How would these definitions fit with the way you think about "ongoing" & "complex" mental health problems amongst children and youth?

Some youth with mental health problems continue to need help after they turn 18.

- If [*child's name*]'s problems came back a few years from now, where do you think they would turn for help?
- Has the topic of transition to adult care been discussed with [child's name] and their family?
    - *If yes* → How was this introduced?
      Who was involved in this discussion?
      When you introduced the discussion of plans for mental health services in young adulthood, how was it received?
    - *If no* → Would you, or have you, talked to your supervisor or peers about transition for this youth?
      At your agency/practice, when caring for a child or youth with ongoing/chronic mental health needs at what stage is the topic of when and how the transition will occur discussed?
      How is the topic introduced?
      Who is involved in these discussions?
      When you introduce the discussion of plans for ongoing mental health services, how are they received?
      How do you address the element of uncertainty about the child's future mental health in these discussions?
- Given the possibility of this child's need for mental health care in young adulthood, how would you describe your role with this patient over the long-term

| | |
|---|---|
| *Probes* | → In what ways do you think your involvement in this patient's mental health care might change? Stay the same? |

## C) PROVISION OF ONGOING MENTAL HEALTH CARE SERVICES

### C.1) Coordinator of care

Next, we would like to hear your ideas on how our service systems in general, should best care for children, like [child's name] with ongoing/complex mental health problems.
Who do you think should be the person (or agency?) coordinating care for children and youth with these types of mental health problems?

| | |
|---|---|
| *Probes* | → What specific roles/responsibilities of coordinating care should remain in the children's mental health system? |

### C.2) Screening/monitoring

We know that symptoms of mental health problems can wax and wane over time. In caring for individuals with *chronic* physical health problems, like diabetes or cystic fibrosis, ongoing monitoring/screening is often conducted on a routine basis with the goal of detecting problems before a crisis occurs.

- What are your thoughts on providing monitoring and/or regular follow-up visits for children with complex/ongoing mental health problems?

| | |
|---|---|
| *Probes* | ➔ How do you think monitoring could be accomplished within your agency/practice?<br>➔ What would the logistical and financial implications be for your agency/practice?<br>➔ Which professional or system do you think would be best situated to provide such ongoing monitoring? |

**C.3) Use of technology in monitoring**

- What do you think about having a youth or parent complete a checklist or questionnaire on a website or via a smart phone application?

| | |
|---|---|
| *Probes* | ➔ In what ways do think these types of checkups might be helpful?<br>➔ What concerns would you have about having clients complete an internet-based checklist like this? |

- How would you see the results of this being shared with the child's providers at your [*agency or practice*]?

**End of interview wrap-up procedures**
Ensure all major components of the interview have been covered
Ask interviewee if they have anything else they would like to add, or if they would like to return to any section to discuss further
Thank the participant for their time and provide compensation

## Appendix 6: Phases of Coding for Constructivist Grounded Theory (CGT)

| Phase of Coding | Description |
|---|---|
| Initial coding | The *first phase* of coding involved developing initial codes that emerged from the data. Two research investigators (KS, JBB) read a selection of transcripts to create a list of preliminary codes that represented recurring themes.<br>A line-by-line analysis of transcripts involved constructing initial coding templates for each group of participants (e.g., youth, parents).<br>Emphasis was placed on coding for ‘actions and processes’ in the data, a key strategy for fostering theoretical sensitivity (Charmaz, 2014) |
| Focused coding | The *second phase* of coding involved making decisions about which initial codes best represented the data. Codes were discarded, or refined if they were supported by the data.<br>The researchers attended to the “most useful” codes to facilitate sorting, synthesizing, and analyzing larger amounts of data. As the analysis matured and each new transcript was analyzed, data were compared with existing codes.<br>New questions were added to the interview guide to probe participants about emerging patterns. Focused coding also facilitated theoretical sampling of participants, whereby certain participants were purposefully recruited.<br>*Advanced focused coding* involved raising the ‘analytic level’ of certain codes. For each category, “properties and dimensions” were identified. Codes were compared with each other to form conceptual categories of similar codes.<br>Data collection ceased upon “theoretical saturation”, i.e., when new data did not provide new theoretical insights nor reveal new properties of categories. |
| Theoretical coding | The *third phase* of the constant comparison method essentially followed the codes selected during focused coding.<br>The goal was to specify possible relationships between categories developed through focused coding in order to move the ‘analytic story’ in a theoretical direction. Emphasis was placed on conceptualizing how categories might relate to each other in order to be integrated into the emerging theory.<br>A data matrix was created to represent a visual summary of common emerging themes, with exemplar quotes. Matrices were created to analyze categories and make comparisons between members of each participant group.<br>At each analytic phase, memo-writing and diagramming bridged the gap between coding and conceptual development. Sorting, comparing and integrating memos provided a logic for organizing the emergent analysis and helped to create and refine theoretical links. |

Charmaz, K. (2014). *Constructing grounded theory* (2nd Ed). Thousand Oaks, CA: Sage.

## Appendix 7: Additional participant exemplar quotes (Chapter 2)

| Emerging theme | Additional participant quotes |
|---|---|
| Family history of mental health problems | One parent felt her child's problems were not just "*a product of his environment*" and would therefore last into young adulthood.<br>*[They do come and go. From experience, severe depression for myself and postpartum depression… I totally understand that]* ***I know for myself there's been the cycle of how it goes, and different triggers of events*** (P3) |
| Not chronic | Another youth believed his problems would go away at some point in the future: *"Because they [bullies] will probably forget me…I look a lot different without my glasses on"* (Y3). **This youth later reconsidered and felt he might have problems in the future: "*because two of the people that bullied me live in my complex.*"** |
| Chronic and remitting (or recurring) | Youth in remission, who had improved with CMH treatment, still perceived their problems as chronic. Having multiple or comorbid problems was related to this. A youth anticipated his problems would "*probably stay"* because "*my anxiety affects my ADHD, like the more worried I am, the less I can pay attention*" (Y6).<br>Youth and their parents also considered how recurrence might be contingent on specific environmental stressors. One parent explained she was "*a hundred percent sure"* her child's specific phobia of the dentist would recur during his next appointment.<br>Even when problems had remitted and their child was discharged from treatment, parents described constantly seeking additional support: "*I'm on a lot of wait-lists for [CMH agency]. I'm always on at least five or six wait-lists at a time. You know, once I get off a few, then I have a couple more*" (P2). |
| Chronic and persistent<br>Help-hungry parents | *Nobody will formally diagnose him because he's not an adult, 18, beyond the anxiety and a general, general anxiety and the depression* – P3<br>Parents were doubtful that youth would re-access mental health treatment on their own P7. Part of this stemmed from feeling limited by their child's age to consent to treatment: *"We have no rights under the system because he has the right to consent. He should be in a group home right now. He shouldn't be living with us, not because we don't want him there but because we can't help him..."* (P7). |

## Appendix 8: Additional participant exemplar quotes (Chapter 4)

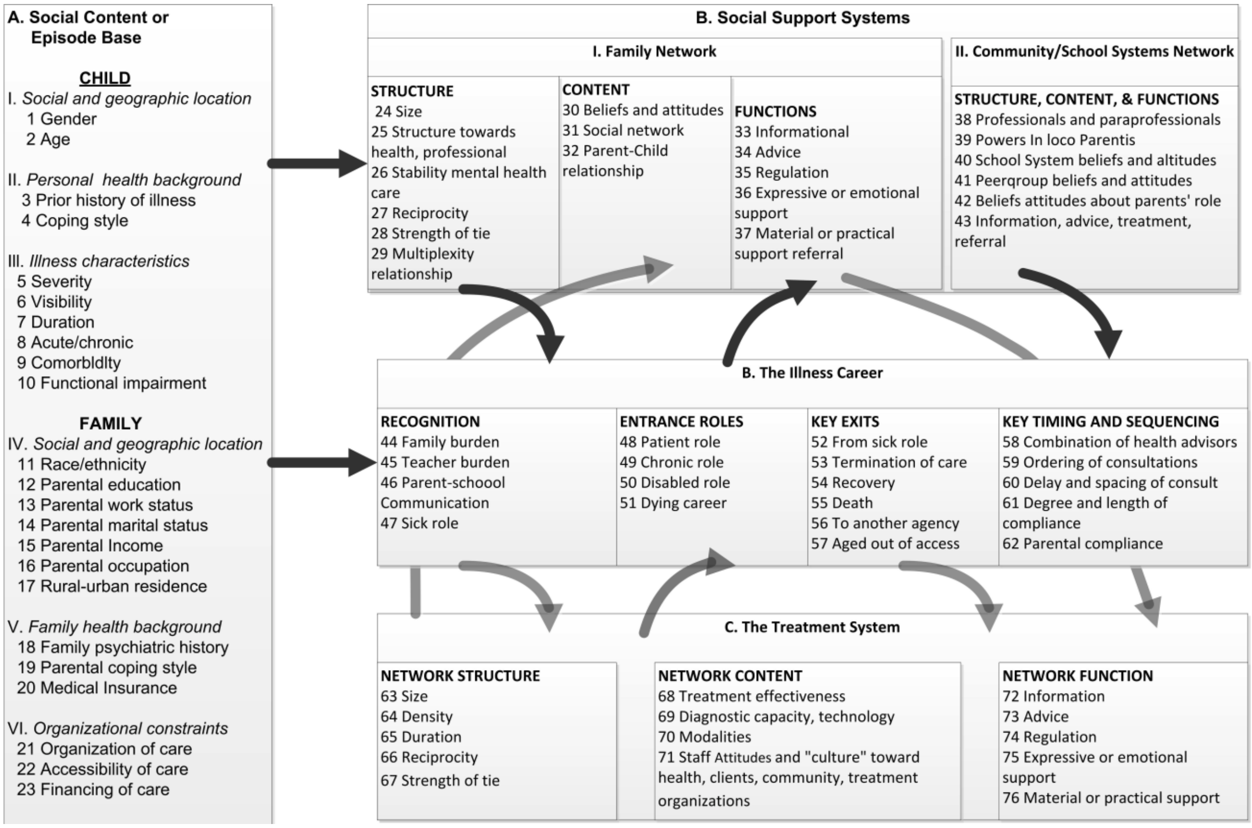
| Participant group | Additional participant quotes by emerging themes |
|---|---|
| Youth and their parents | Having inadequate time to discuss mental health within PHC<br>Rather than having time for a conversation about mental health problems, many parents felt their family physician was quick to refer their child elsewhere. *“When he was younger, [previous family physician] said, “You better get on the waiting list for [CMH agency]. You’ve got trouble.” And that’s pretty much [it] ... a couple [seconds] of conversation*” (P6).<br><br>Perceiving a focus on the medical model within PHC<br>A parent perceived medications to be a “*Band-Aid*” approach for treating her child’s mental health problems within PHC. *“They try to put a little Band-Aid on it and then after the third or fourth visit, then they’ll refer you to a specialist or pediatrician”* (P8).<br><br>Perceiving a lack of mental health expertise among family physicians<br>Youth and their parents often felt uncertain about whether family physicians were qualified or “*equipped*” to provide mental health care: *“Family doctors, I don’t think they are really equipped to like give out coping strategies. I think that’s more for like psychiatrists and counsellors”* (Y8).<br>Many youth and their parents felt their family physician did not have the knowledge or training to provide them with the ‘right’ mental health help. This perception contributed to disappointment with help provided by their family physician: “*We also had talked to [family physician] as to what was happening. He had pretended to be her psychiatrist ... but [youth] never really felt comfortable talking to him”* (P1).<br>Parents perceived the role of their family physicians as solely for *physical* health problems, rather than mental health problems: *He [family physician] is more of a general practitioner - colds, immunizations, height, weight checks - that kind of stuff”* (P3).<br><br>Views about the role of family physicians in monitoring<br>Youth and parents felt that monitoring after CMH treatment was “*needed*” and *“would probably make a huge difference”*. Perceived benefits of monitoring included the ability to track a youth’s progress or “*see patterns*” in their behaviour by way of *“keeping [youth] in the system”*. Another perceived benefit of monitoring was the potential to further de-stigmatize mental health by making monitoring check-ups “*the norm*”.<br>Parents felt their child would benefit from maintaining a “*constant connection”* with a provider through monitoring: *“I think the piece is that somebody who’s seeing [youth] regularly, then starts to see the picture, and can build it around what’s normal behaviour. If things are escalating, they would know”* (P7). |

| Participant group | Additional participant quotes by emerging themes |
|---|---|
| | Parents emphasized a need for monitoring during the *“I’m okay stage”,* or when problems were not severe, and not necessarily waiting for a crisis to bring them back into mental health services.<br>Most youth were confused about how monitoring would work within PHC: “*I never thought of it…in a doctor’s office, who is going to be the psychiatric person there? I’m not really sure”* (Y8). A statement like this emphasized the general perception that a *“normal doctor”* is separate from mental health care. This made it difficult for youth and their parents to imagine the role of their family physicians changing in the future. |
| CMH providers | A) Healthcare system culture<br>Having inadequate time to discuss mental health within PHC<br>Appointments within PHC that were *“one problem at a time, 15 minutes”* led CMH providers to wonder: *“where’s the time to really check in about mental health?”* (CMH1).<br>CMH providers perceived family physicians did not have time to build a relationship with patients, older youth in particular: *“A relationship is not a two-second face-to-face… And a teenager is one of the hardest individuals to get a trusting relationship with.”*<br><br>CMH providers anticipated youth would not feel comfortable discussing their mental health needs with their family physician. A CMH provider hoped this relationship would change in the future and imagined a youth saying*, “yeah I had an appointment the other day with the GP because that damn anxiety crept up again”* and *“it would just be as simple as that”* (CMH2). Unfortunately, there was consensus among CMH providers that mental health problems were not typically discussed within PHC due to a lack of time.<br><br>Perceiving a lack of mental health expertise among family physicians<br>It was suggested that family physicians who were not knowledgeable about mental health should *“connect themselves with others that do”* (CMH2).<br><br>B) CMH agency culture<br>Some CMH providers described routine practice of encouraging parents to *“share the report”* with their family physician. For this to happen, CMH providers recognized the need for parents to be involved with their child’s care and have an *“ability to self-advocate”.* There was a general assumption among some CMH providers that parents would keep their family physician “in the loop” of their child’s care: *“[parent]’s so good with communication and with everyone that’s involved… I’m assuming that it’s similar with the doctor”* (CMH4). CMH providers who did collaborate with family physicians noted variability in their experiences working with family physicians. As illustrated by one provider, collaboration was easier when family physicians were open to input about mental health: *“I’ve worked with* |

| Participant group | Additional participant quotes by emerging themes |
|---|---|
| | *family physicians who say "I'm a general practitioner. I don't understand the brain. I don't understand mental illness, it is far beyond my scope" and they are much easier to work with because they recognize their own limitations"* (CMH2).<br>Collaborating with family physicians was described as potentially helpful 'in theory', but not practical from the perspective of CMH providers: *"You know, theoretically, ethically, philosophically, yes, for sure. Practically, it hasn't worked out that way*" (CMH9). CMH providers generally felt collaboration between CMH and PHC was *"missing in our system"* (CMH2). |
| Family physicians | Lack of communication between mental health professionals and PHC<br>Family physicians felt "out of the loop" when they relied solely on parents for information. *"Obviously she was given directions from wherever to access these services, which she did on her own but I have no idea what transpired. I was just going by what the mom was saying"* (FP2). Challenges were identified when multiple physicians were involved: "*Let's say a specialist refers a patient of mine to another specialist, I don't often get a report because I wasn't the referral source; sometimes I'll end up having to track it down"* (FP2).<br><br>An uncoordinated mental health system<br>When multiple providers were involved, there was still uncertainty around whether the child was receiving adequate care, as articulated by one family physician: *"I'm trying to know, is this good enough?"* (FP7).<br><br>Providing mental health care to youth in PHC<br>Family physicians noted difficulties with gaining accurate information about youth's mental health problems, and suggested implementing standardized questions: *I think it's hard for us to get a great sense of what's happening at home, just in the office setting: "How are things going?" "Good." If we had some more standardized questions that were more specifically focused on mental health, then we can get a sense of trends and patterns going on.* (FP7)<br><br>Another family physician expressed: *"If it's been stable, I wouldn't necessarily make a jump to a psychiatry referral. There's no real need to have another doctor in their loop again just to add more complications and more appointments"* (FP7).<br><br>Implications and barriers of monitoring youth with mental health problems within PHC<br>One family physician encouraged youth patients to use PHC for their mental health needs but, in the absence of formalized monitoring practices, follow-up appointments were the youth's responsibility: *I sort of talk with patients* |

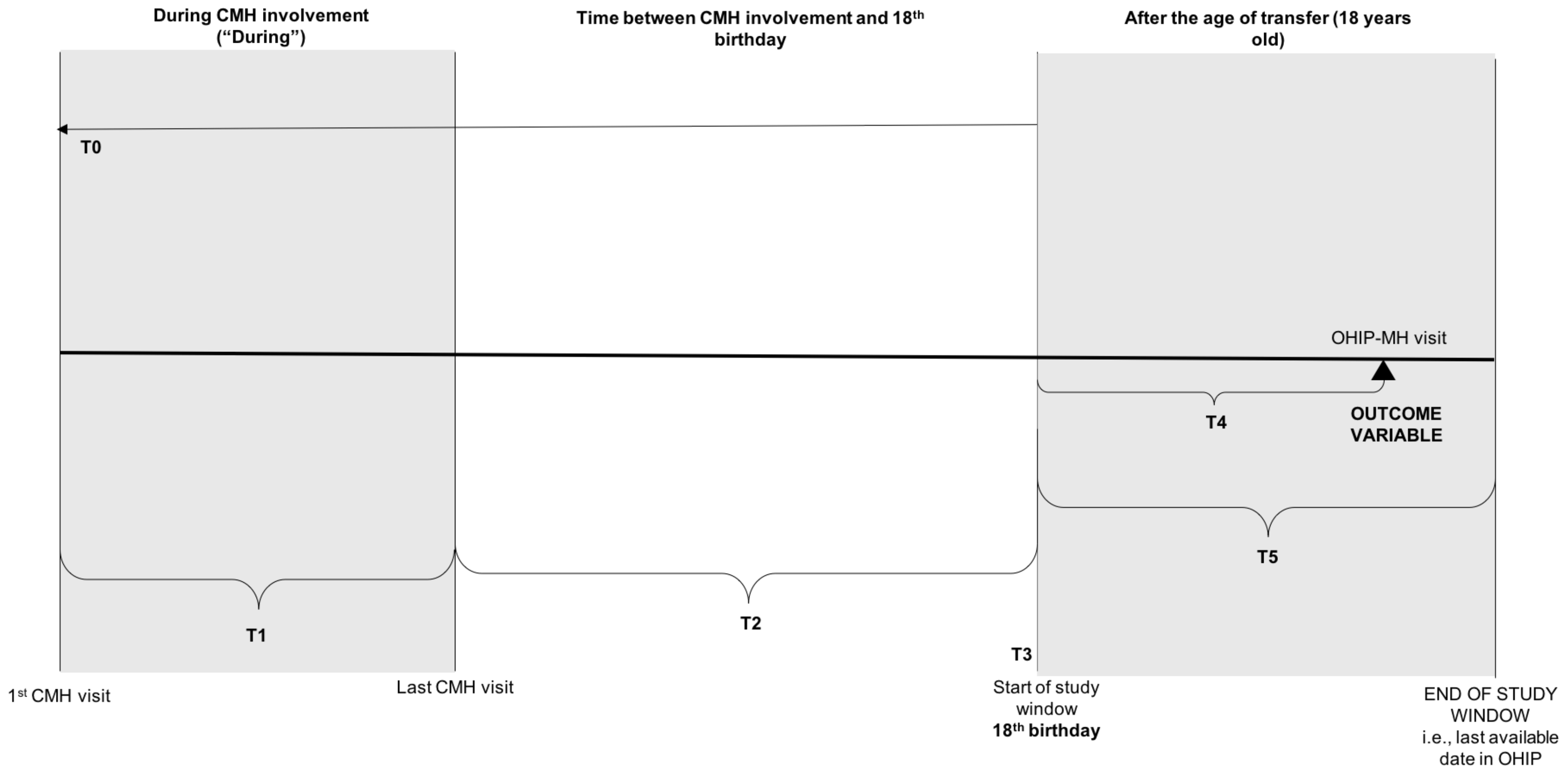
| Participant group | Additional participant quotes by emerging themes |
|---|---|
| | *about just how variable the course can be - so sometimes you'll feel good for a while and sometimes you'll not feel so good, and [I] encourage that if those times happen, they can come back and see me"… it's not like I can have these people come back every few months for years to keep tabs on them. So I have to leave the ball in their court.* – FP6 |

# Appendix 9: Revised Network Episode Model (R-NEM)



Based on: Costello, E. J., Pescosolido, B. A., Angold, A., & Burns, B. J. (1998). A Family Network-Based Model of Access to Child Mental Health Services. *Research Community and Mental Health*, *9*, 165–190

# Appendix 10: Timeline of predictor variables*



*See Appendix 11 for a legend of variables.

## Appendix 11: Predictors in current study grouped by time of data collection

| Time Window for Data Collection | Predictor Variables in Current Study |
|---|---|
| Time 0:<br>Birth to 18th birthday | • Child's sex<br>• Presence of developmental disability<br>• Presence of chronic physical health disorder |
| Time 1:<br>First CMH visit to last CMH visit | • Child psychopathology (i.e., internalizing, externalizing, global functioning)<br>• Length of time (i.e., duration of CMH involvement)<br>• Total number of CMH visits<br>• Total number Episodes of Care<br>• Pattern of CMH service use (i.e., ongoing/recurrent vs. not ongoing/recurrent)<br>• Total OHIP-MH visits<br>• Total OHIP-Health visits |
| Time 2:<br>Last CMH visit and 18th birthday | • Length of time (days)<br>• Total OHIP-MH visits<br>• Total OHIP-Health visits<br>• Provider seen (i.e., FP, pediatrician, psychiatrist) |
| Time 3:<br>Date of 18th birthday | • Neighbourhood income quintile<br>• Material Deprivation (proxy for socio-economic status)<br>• Rural/urban residence |
| Time 4:<br>18th birthday to first OHIP-MH visit (i.e., outcome) | • Time variable (*used for survival analyses*) |
| Time 5:<br>18th birthday to end of study window | • Time variable *(descriptive purposes only)* |

*Note*. CMH = Children's Mental Health; OHIP-MH = Mental health visit based on Ontario Health Insurance Plan. Age of transfer refers to 18 years old.

## Appendix 12: Summary of patterns of service use across 5 Children's Mental Health (CMH) agencies

| Pattern | N | % of all clients | Two or more episodes | Duration of involvement (years) | Mean visits (over 4 years) |
|---|---|---|---|---|---|
| Minimal | 2997 | 53% | 2% | 0.4 | 3 |
| Acute | 1131 | 20% | 4% | 0.8 | 16 |
| Intensive | 730 | 13% | 27% | 1.8 | 33 |
| Brief-Episodic | 447 | 8% | 71% | 3.5 | 29 |
| Intensive-Episodic/Ongoing | 327 | 6% | 46% | 3.3 | 87 |

*Note.* N = 5,632 (Reid et al., 2010)

## Appendix 13: OHIP diagnostic codes for children's mental health problems used in this study

**Mental Health Diagnostic Codes**

291 = Alcohol psychosis, delirium tremens, Korsakov’s psychosis**
292 = Drug psychosis**
296 = Manic-depressive psychoses, involutional melancholia
297 = Other paranoid states
298 = Other psychoses
299 = Childhood psychoses (e.g., autism)**
300 = Anxiety neurosis, hysteria, neuroasthenia, obsessive-compulsive neurosis
301 = Personality disorders
302 = Sexual deviations
303 = Alcoholism
304 = Drug dependence
305 = Tobacco use**
306 = Psychosomatic illness
307 = Habit spasms, tics, stuttering, tension headaches, anorexia, sleep disorders, enuresis**
309 = Adjustment reaction
311 = Depressive disorder
313 = Behaviour disorders of childhood and adolescence**
314 = Hyperkinetic syndrome of childhood (commonly used for ADHD)**
315 = Specific delays in development (e.g., dyslexia, dyslalia, motor retardation)**
319 = Mental retardation**
897 = Economic problems
898 = Marital difficulties
899 = Parent-child problems
900 = Problems with aged parents or in-laws
901 = Family disruption
902 = Education problems
904 = Social maladjustment
905 = Occupational problems
906 = Legal problems
909 = Other problems of social adjustment
977 = Of drugs and medications – including allergy, overdose, reactions**

*Note.* **Project-specific codes different from Steele algorithm.

## Appendix 14: OHIP service fee codes for children's mental health services by family physicians and pediatricians used in this study

**Mental Health Service Fee Codes**

K005 = Primary mental health care
K007 = Psychotherapy
K623 = Assessment for involuntary admission (Form 1)
K004 = Family psychotherapy**
K013 = Counselling – 1 or more people**
K033 = If K013 has already been used 3x in year**
K122 = Pediatric psychotherapy for individual**
K123 = Pediatric psychotherapy for family**

**General Service Fee Codes**

A001 = Minor assessment
A003 = Major assessment
A004 = General re-assessment
A005 = Consultation
A006 = Repeat consultation
A007 = Intermediate assessment
A008 = Mini assessment
A888 = Partial assessment
A901 = House call assessment
A905 = General/Family Practice-Limited consultation**
K002 = Interviews with relatives on behalf of patient**
K003 = Interviews on behalf of patient (CAS, leg.guard)**
K017 = Annual health exam – after child's 2$^{nd}$ birthday**
K032 = Neurocognitive assessment**
K008 = Diagnostic interview with child and/or parent**
K269 = Annual health exam - pediatrics**
A260 = Pediatrics – 75 min consultation**
A662 = Pediatrics – 90 min consultation**
A667 = Neurodevelopmental consultation**
A261 = Minor assessment**
A262 = Intermediate assessment**
A263 = Medical specific assessment**
A264 = Medical specific re-assessment**
A265 = Consultation**
A266 = Re-consultation**
C122 = Most responsible physician**
C123 = Most responsible physician**
C124 = Day of discharge – most responsible physician**
C260 = Pediatrics – 75 min consult**
C262 = Sub.vis. Up to 6 weeks – pediatrics - hospital**
C263 = Medical specific assessment – pediatrics**
C264 = Medical specific re-assessment**
C265 = Consult – pediatrics – hospital**

C266 = Repeat consultation – pediatrics – hospital**

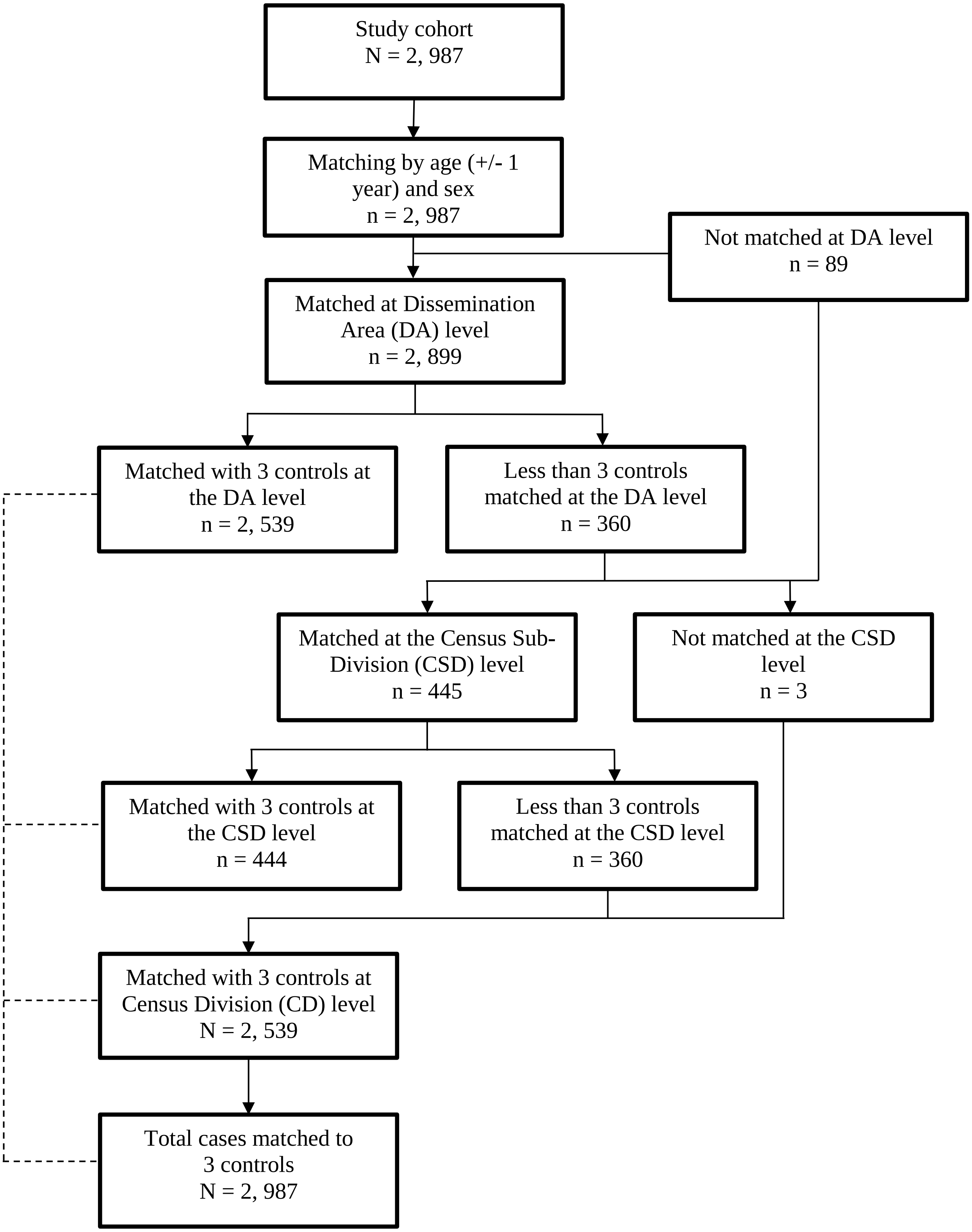
*Note*. **Project-specific codes different from Steele algorithm.

## Appendix 15: OHIP diagnostic codes for developmental disabilities

| Database | Diagnostic Codes |
|---|---|
| Ontario Mental Health Reporting System (OMHRS) | q3= 1 or q2d in: ('317','318','319') or q2a in: ('299') or q2b in: ('299') or q2c in: ('299') = Intellectual disability, not specified<br>**DSM-IV:** Q851 = Tuberous sclerosis<br>Q860 = Fetal alcohol syndrome<br>Q861 = Fetal hydantonin syndrome<br>Q871 = Congenital malformation syndromes<br>Q878 = Other specified congenital malformation syndromes, note elsewhere classified<br>Q90 = Down's syndrome<br>Q91 = Edward's syndrome and Patau's syndrome<br>Q920 = Whole chromose trisomy, meiotic nondisjunction<br>Q921 = Whole chromose trisomy, masicism<br>Q922 = Major partial trisomy<br>Q923 = Minor partial trisomy Q924 = Duplications seen only at prometaphase<br>Q925 = Duplications with complex rearrangements<br>Q927 = Triploidy and polypoidy<br>Q928 = Other specified trisomies and partial trisomies of autosomes<br>Q929 = Trisomy and partial trisomy of autosomes, unspecified<br>Q93 = Monosomies and deletions from the autosomes, not elsewhere classified<br>Q971 = Female with more than three X chromosomes<br>Q992 = Fragile X chromosome<br>Q998 = Other specified chromosome abnormalities |
| CIHI-DAD | **ICD-9:** 299 = Autism, 319 = Mental retardation<br>**ICD-10:** F845 = Asperger's syndrome,<br>Q851 = Tuberous sclerosis<br>Q998 = Other specified chromosome abnormalities |
| CIHI-NACRS | **ICD-10:** F845 = Asperger's syndrome<br>Q851 = Tuberous sclerosis<br>Q998 = Other chromosome abnormalities |
| Ontario Health Insurance Plan (OHIP) | 299 = Childhood psychoses (e.g., autism)<br>319 = Mental retardation |

*Note.* Only codes that appeared in CMH sample were used in the current study. These codes were from OHIP, NACRS, and CIHI-DAD databases.

## Appendix 16: Flowchart showing matching of study cohort with age-, sex-, and region-matched controls



**Appendix 17: Blocked Cox Regression analyses for CMH sample (N = 2959)**

| Predictor Variables | Hazard Ratios (HR) (Confidence Intervals) | | |
|---|---|---|---|
| | Model 1<br>*Social content* | Model 2<br>*Social content; illness career* | Model 3<br>*Social content; illness career; treatment system* |
| Child's age at first CMH visit | | | |
| <11.3 years (median age; ref) | - | - | - |
| ≥ 11.3 years | 0.94 (0.84-1.04) | 1.08 (0.94-1.24) | 1.17 (1.02-1.35)* |
| Child's sex | | | |
| Male (ref) | - | - | - |
| Female | 1.38 (1.25-1.53)*** | 1.49 (1.34-1.65)*** | 1.42 (1.28-1.58)*** |
| Neighbourhood income quintile | | | |
| Q1 (ref) | - | - | - |
| Q2 | 0.95 (0.80-1.13) | 0.94 (0.79-1.11) | 0.98 (0.82-1.16) |
| Q3 | 1.08 (0.88-1.32) | 1.03 (0.84-1.25) | 1.03 (0.85-1.27) |
| Q4 | 1.00 (0.80-1.24) | 1.00 (0.81-1.25) | 1.01 (0.81-1.25) |
| Q5 | 1.16 (0.91-1.47) | 1.11 (0.87-1.50) | 1.10 (0.81-1.25) |
| ON-MARG Material deprivation | | | |
| Q5 (ref) | - | - | - |
| Q1 | 0.86 (0.68-1.09) | 1.00 (0.79-1.26) | 0.99 (0.78-1.25) |
| Q2 | 1.00 (0.81-1.24) | 1.11 (0.89-1.38) | 1.12 (0.91-1.40) |
| Q3 | 0.97 (0.80-1.18) | 0.99 (0.81-1.21) | 0.97 (0.79-1.17) |
| Q4 | 0.86 (0.72-1.04) | 0.88 (0.73-1.06) | 0.89 (0.74-1.07) |
| Residence | | | |
| Urban (ref) | - | - | - |
| Rural | 0.82 (0.71-0.95)** | 0.82 (0.71-0.95)** | 0.89 (0.76-1.03) |
| Duration of CMH involvement | | | |
| < 161 days (ref) | | - | - |
| ≥ 161 days | | 1.06 (0.89-1.25) | 1.04 (0.87-1.24) |

| Predictor Variables | Hazard Ratios (HR) (Confidence Intervals) | | |
|---|---|---|---|
| | Model 1 *Social content* | Model 2 *Social content; illness career* | Model 3 *Social content; illness career; treatment system* |
| Total CMH visits | | | |
| < 6 visits (ref) | | - | - |
| ≥ 6 visits | | 1.00 (0.82-1.25) | 1.06 (0.87-1.30) |
| Episodes of care | | | |
| No episode (ref) | | - | - |
| Only 1 episode | | 1.13 (0.95-1.33) | 1.09 (0.92-1.29) |
| 2+ episodes | | 1.07 (0.84-1.38) | 1.08 (0.84-1.40) |
| Pattern of CMH use | | | |
| Minimal (ref) | | - | - |
| Acute | | 1.03 (0.84-1.26) | 0.97 (0.80-1.19) |
| Intensive | | 1.14 (0.90-1.45) | 1.09 (0.86-1.34) |
| Brief-Episodic | | 1.17 (0.88-1.56) | 1.11 (0.83-1.48) |
| Ongoing/ Intensive Episodic | | 1.45 (1.09-1.92)** | 1.39 (1.05-1.84)* |
| Time from last CMH visit to age 18 | | | |
| ≥ 2073 days | | - | - |
| < 2073 days (ref) | | 1.01 (0.89-1.16) | 1.00 (0.86-1.15) |
| OHIP-MH visits during CMH involvement | | - | - |
| <1 visit (ref) | | | |
| ≥ 1 visit | | 1.18 (1.04-1.35)** | 1.12 (0.98-1.27) |
| OHIP-MH visits between last CMH visit and age 18 | | - | - |
| < 2 visits (ref) | | | |
| ≥ 2 visits | | 2.34 (2.09-2.63)*** | 1.50 (1.24-1.82)*** |
| Developmental disability prior to age 18[b] | | | |
| No (ref) | | | - |
| Yes | | | 1.60 (1.32-1.95)*** |

| Predictor Variables | Hazard Ratios (HR)<br>(Confidence Intervals) | | |
|---|---|---|---|
| | Model 1<br>*Social content* | Model 2<br>*Social content; illness career* | Model 3<br>*Social content; illness career; treatment system* |
| Chronic physical health condition[b] | | | |
| No (ref) | | | - |
| Yes | | | 1.03 (0.93-1.14) |
| OHIP-Health visits during CMH involvement | | | |
| No visit (ref) | | | - |
| ≥ 1 visit | | | 1.16 (1.01-1.34)* |
| OHIP-Health visits between last CMH visit and 18 | | | |
| < 10 visits (ref) | | | - |
| ≥ 10 visits | | | 1.25 (1.12-1.40)*** |
| Provider seen between last CMH visit and age 18 | | | |
| No visit (ref) | | | - |
| Family physician only | | | 1.38 (1.13-1.68)** |
| Pediatrician or psychiatrist only | | | 1.27 (0.99-1.61) |
| Combination<br>(FP & Pediatrician or Psychiatrist) | | | 1.89 (1.49-2.39)*** |

*Note.* CMH = Children's Mental Health; Episode of care = a minimum of 3 CMH visits with a subsequent free period (no visits) of 180 days; OHIP = Ontario Health Insurance Plan; OHIP-MH = Mental health visit; OHIP-Health = General health care visit. Age of transfer refers to 18 years old. BCFPI = Brief Child and Family Phone Interview.

[a] CMH sample only. [b] Visit associated with this diagnostic code prior to age 18.

See appendix tables for control sample. OHIP-MH = mental health visit using OHIP records; OHIP-Health = general health care visit using OHIP records; ref = comparative reference category for calculated HRs. * $p < .05$. ** $p \leq .01$. *** $p \leq .0001$.

## Appendix 18: Blocked Cox Regression analyses for subset of CMH sample with Brief Child and Family Phone Interview (BCFPI) data (N = 1953)

| Predictor Variables | Hazard Ratios (HR) (Confidence Intervals) | | |
|---|---|---|---|
| | Model 1 *Social content + BCFPI data* | Model 2 *Social content + BCFPI data; illness career* | Model 3 *Social content + BCFPI data; illness career; treatment system* |
| Child's age at first CMH visit | | | |
| <11.3 years (median age; ref) | - | - | - |
| ≥ 11.3 years | 0.97 (0.85-1.10) | 1.13 (0.95-1.35) | 1.26 (1.05-1.50)* |
| Child's sex | | | |
| Male (ref) | - | - | - |
| Female | 1.35 (1.19-1.54)*** | 1.43 (1.26-1.63)*** | 1.36 (1.19-1.56)*** |
| Neighbourhood income quintile | | | |
| Q1 (ref) | - | - | - |
| Q2 | 1.01 (0.82-1.26) | 0.98 (0.79-1.22) | 1.02 (0.82-1.27) |
| Q3 | 1.20 (0.94-1.54) | 1.12 (0.87-1.43) | 1.10 (0.85-1.41) |
| Q4 | 1.18 (0.90-1.54) | 1.20 (0.92-1.57) | 1.16 (0.89-1.52) |
| Q5 | 1.31 (0.97-1.76) | 1.26 (0.94-1.70) | 1.22 (0.91-1.65) |
| ON-MARG Material deprivation | | | |
| Q5 (ref) | - | - | - |
| Q1 | 0.77 (0.58-1.04) | 0.88 (0.66-1.18) | 0.91 (0.68-1.22) |
| Q2 | 0.88 (0.67-1.14) | 0.97 (0.74-1.26) | 0.99 (0.76-1.30) |
| Q3 | 0.93 (0.73-1.18) | 0.98 (0.77-1.26) | 0.98 (0.76-1.25) |
| Q4 | 0.83 (0.66-1.05) | 0.87 (0.69-1.10) | 0.90 (0.71-1.13) |
| Residence | | | |
| Urban (ref) | - | - | - |
| Rural | 0.77 (0.65-0.93)** | 0.80 (0.67-0.96)* | 0.87 (0.72-1.05) |
| Child psychopathology | - | - | - |

| Predictor Variables | Hazard Ratios (HR) (Confidence Intervals) | | |
|---|---|---|---|
| | Model 1 *Social content + BCFPI data* | Model 2 *Social content + BCFPI data; illness career* | Model 3 *Social content + BCFPI data; illness career; treatment system* |
| Problems below clinical threshold (T score < 65; ref) | | | |
| Internalizing problems only (T score ≥ 65) | 0.91 (0.72-1.14) | 0.93 (0.74-1.17) | 0.88 (0.70-1.15) |
| Externalizing problems only (T score ≥ 65) | 1.14 (0.94-1.37) | 0.97 (0.80-1.17) | 0.92 (0.76-1.12) |
| Both internalizing and externalizing problems | 1.18 (0.98-1.42) | 1.00 (0.82-1.21) | 0.94 (0.77-1.14) |
| Child adjustment* [a] | | | |
| Below clinical threshold (T score < 65) | - | - | - |
| Clinical impairment in functioning | 1.14 (0.98-1.32) | 1.06 (0.91-1.22) | 1.06 (0.91-1.22) |
| Impact of child's illness* [a] | | | |
| Below clinical threshold (T score < 65) | - | - | - |
| High impact of child's illness | 1.14 (0.97-1.33) | 1.05 (0.90-1.23) | 1.06 (0.90-1.24) |
| Duration of CMH involvement | | | |
| < 161 days (ref) | | - | - |
| ≥ 161 days | | 1.12 (0.90-1.39) | 1.10 (0.87-1.38) |
| Total CMH visits | | | |
| < 6 visits (ref) | | - | - |
| ≥ 6 visits | | 1.07 (0.82-1.38) | 1.09 (0.84-1.42) |
| Episodes of care | | | |
| No episode (ref) | | - | - |
| Only 1 episode | | 1.06 (0.91-1.22) | 1.06 (0.85-1.32) |
| 2+ episodes | | 1.08 (0.79-1.48) | 1.10 (0.80-1.52) |
| Pattern of CMH use | | | |
| Minimal (ref) | | - | - |
| Acute | | 0.94 (0.72-1.23) | 0.91 (0.70-1.19) |
| Intensive | | 1.09 (0.80-1.48) | 1.07 (0.79-1.46) |
| Brief-Episodic | | 1.10 (0.76-1.60) | 1.11 (0.77-1.61) |
| Ongoing/ Intensive Episodic | | 1.27 (0.89-1.84) | 1.30 (0.90-1.87) |

| Predictor Variables | Hazard Ratios (HR)<br>(Confidence Intervals) | | |
|---|---|---|---|
| | Model 1<br>*Social content + BCFPI data* | Model 2<br>*Social content + BCFPI data; illness career* | Model 3<br>*Social content + BCFPI data; illness career; treatment system* |
| Time from last CMH visit to age 18 | | - | - |
| ≥ 2073 days | | | |
| < 2073 days (ref) | | 1.00 (0.83-1.20) | 0.98 (0.82-1.18) |
| OHIP-MH visits during CMH involvement | | - | - |
| <1 visit (ref) | | | |
| ≥ 1 visit | | 1.11 (0.94-1.32) | 1.05 (0.88-1.25) |
| OHIP-MH visits between last CMH visit and age 18 | | - | - |
| < 2 visits (ref) | | | |
| ≥ 2 visits | | 2.38 (2.05-2.76)*** | 1.65 (1.27-2.13)*** |
| Developmental disability prior to age 18[b] | | | - |
| No (ref) | | | |
| Yes | | | 1.70 (1.33-2.18)*** |
| Chronic physical health condition[b] | | | - |
| No (ref) | | | |
| Yes | | | 0.97 (0.85-1.10) |
| OHIP-Health visits during CMH involvement | | | - |
| No visit (ref) | | | |
| ≥ 1 visit | | | 1.17 (0.98-1.40) |
| OHIP-Health visits between last CMH visit and 18 | | | - |
| < 10 visits (ref) | | | |
| ≥ 10 visits | | | 1.25 (1.08-1.44)* |
| Provider seen between last CMH visit and age 18 | | | - |
| No visit (ref) | | | |

| Predictor Variables | Hazard Ratios (HR) (Confidence Intervals) | | |
|---|---|---|---|
| | Model 1 *Social content + BCFPI data* | Model 2 *Social content + BCFPI data; illness career* | Model 3 *Social content + BCFPI data; illness career; treatment system* |
| Family physician only | | | 1.25 (0.97-1.61) |
| Pediatrician or psychiatrist only | | | 1.07 (0.78-1.46) |
| Combination (FP & Pediatrician or Psychiatrist) | | | 1.78 (1.31-2.42)** |

*Note*. CMH = Children's Mental Health; Episode of care = a minimum of 3 CMH visits with a subsequent free period (no visits) of 180 days; OHIP = Ontario Health Insurance Plan; OHIP-MH = Mental health visit; OHIP-Health = General health care visit. Age of transfer refers to 18 years old. BCFPI = Brief Child and Family Phone Interview. [a] CMH sample only. [b] Visit associated with this diagnostic code prior to age 18.

See appendix tables for control sample. OHIP-MH = mental health visit using OHIP records; OHIP-Health = general health care visit using OHIP records; ref = comparative reference category for calculated HRs. * $p < .05$. ** $p \leq .01$. *** $p \leq .0001$.

### Appendix 19: Crude Hazard Ratios for Predictors from the Brief Child and Family Phone Interview (BCFPI) in the CMH Sample (N = 1976)

| Predictor Variable | N | Had a OHIP-MH visit post-18 | Crude Hazard Ratio (95% CI) |
|---|---|---|---|
| Child psychopathology | | | |
| Non-clinical significant problems (T score < 65; ref) | 544 | 46.7% | - |
| Only clinically significant internalizing problems (T score ≥ 65) | 255 | 43.5% | 0.93 (0.79-1.24) |
| Only clinically significant externalizing problems (T score ≥ 65) | 536 | 52.4% | 1.22 (1.03-1.45)* |
| Both internalizing and externalizing problems | 641 | 55.7% | 1.36 (1.16-1.60)** |
| Child adjustment* [a] | | | |
| Below clinical threshold (T score < 65; ref) | 961 | 45.7% | - |
| Clinical impairment in functioning | 1015 | 55.6% | 1.30 (1.15-1.47)*** |
| Impact of child's illness* [a] | | | |
| Below clinical threshold (T score < 65; ref) | 719 | 45.6% | - |
| High impact of child's illness | 1257 | 53.6% | 1.29 (1.13-1.47)*** |

*Note.* ref = comparative reference category for calculated HRs.

* $p < .05$. ** $p \leq .01$. *** $p \leq .0001$

**Appendix 20: Blocked Cox Regression analyses for the Control sample (N = 8803)**

| Predictor Variables | Hazard Ratios (HR) (Confidence Intervals) | | |
|---|---|---|---|
| | Model 1<br>*Social content* | Model 2<br>*Social content; illness career* | Model 3<br>*Social content; illness career; treatment system* |
| Child's age at start of study window | | | |
| <11.2 years (median age; ref) | - | - | - |
| ≥ 11.2 years | 0.96 (0.89-1.05) | 1.02 (0.92-1.13) | 1.10 (0.99-1.23) |
| Child's sex | | | |
| Male (ref) | - | - | - |
| Female | 1.51 (1.40-1.63)*** | 1.60 (1.48-1.73)*** | 1.55 (1.44-1.68)*** |
| Neighbourhood income quintile | | | |
| Q1 (ref) | - | - | - |
| Q2 | 1.13 (0.98-1.30) | 1.09 (0.95-1.26) | 1.06 (0.92-1.22) |
| Q3 | 1.11 (0.95-1.31) | 1.08 (0.92-1.27) | 1.08 (0.92-1.27) |
| Q4 | 1.10 (0.93-1.31) | 1.05 (0.89-1.25) | 1.04 (0.87-1.23) |
| Q5 | 1.25 (1.04-1.50)* | 1.18 (0.98-1.42) | 1.17 (0.97-1.41) |
| ON-MARG Material deprivation | | | |
| Q5 (ref) | - | - | - |
| Q1 | 0.80 (0.67-0.96)* | 0.88 (0.73-1.06)* | 0.84 (0.70-1.01) |
| Q2 | 0.91 (0.77-1.08) | 0.99 (0.84-1.18) | 0.99 (0.83-1.17) |
| Q3 | 0.89 (0.76-1.04) | 095 (0.81-1.12) | 0.93 (0.79-1.09) |
| Q4 | 0.92 (0.79-1.07) | 0.91 (0.78-1.06) | 0.92 (0.79-1.07) |
| Residence | | | |
| Urban (ref) | - | - | - |
| Rural | 0.93 (0.83-1.03) | 0.92 (0.83-1.02) | 1.01 (0.91-1.13) |
| Time from last CMH visit to age 18 | | | |
| ≥ 2073 days | | - | - |
| < 2073 days (ref) | | 1.05 (0.95-1.17) | 1.08 (0.97-1.20) |
| OHIP-MH visits during CMH involvement | | - | - |

| Predictor Variables | Hazard Ratios (HR) (Confidence Intervals) | | |
|---|---|---|---|
| | Model 1 *Social content* | Model 2 *Social content; illness career* | Model 3 *Social content; illness career; treatment system* |
| <1 visit (ref) | | | |
| ≥ 1 visit | | 1.75 (1.56-1.96)*** | 1.50 (1.32-1.69)*** |
| OHIP-MH visits between last CMH visit and age 18 | | - | - |
| < 1 visit (ref) | | | |
| ≥ 1 visits | | 2.79 (2.58-3.02)*** | 1.98 (1.67-2.35)*** |
| Developmental disability prior to age 18[b] | | | |
| No (ref) | | | - |
| Yes | | | 1.91 (1.41-2.59)*** |
| Chronic physical health condition[b] | | | |
| No (ref) | | | - |
| Yes | | | 1.03 (0.94-1.12) |
| OHIP-Health visits during CMH involvement | | | |
| No visit (ref) | | | - |
| ≥ 1 visit | | | 1.26 (1.16-1.37)* |
| OHIP-Health visits between last CMH visit and 18 | | | - |
| < 8 visits (ref) | | | |
| ≥ 8 visits | | | 1.44 (1.32-1.57)*** |
| Provider seen between last CMH visit and age 18 | | | |
| No visit (ref) | | | - |
| Family physician only | | | 1.07 (0.90-1.28) |
| Pediatrician or psychiatrist only | | | - |
| Combination (FP & Pediatrician or Psychiatrist) | | | 2.35 (1.96-2.82)*** |

*Note.* CMH = Children’s Mental Health; Episode of care = a minimum of 3 CMH visits with a subsequent free period (no visits) of 180 days; OHIP = Ontario Health Insurance Plan; OHIP-MH = Mental health visit; OHIP-Health = General health care visit. Age of transfer refers to 18 years old.  BCFPI = Brief Child and Family Phone Interview.
[a] CMH sample only. [b] Visit associated with this diagnostic code prior to age 18.
See appendix tables for control sample. OHIP-MH = mental health visit using OHIP records; OHIP-Health = general health care visit using OHIP records; ref = comparative reference category for calculated HRs. * $p < .05$. ** $p \leq .01$. *** $p \leq .0001$.

**Appendix 21: Comparison of CMH and Control samples for Model 3 prediction analyses**

| Predictor Variables | Model 3<br>Adjusted Hazard Ratio (HR)<br>(95% CI) | |
|---|---|---|
| | CMH Sample<br>(N = 2959) | Control Sample<br>(N = 8803) |
| Child's age at first CMH visit | | |
| <11.3 years (median age; ref) | - | - |
| ≥ 11.3 years | 1.17 (1.02-1.35)* | 1.10 (0.99-1.23) |
| Child's sex | | |
| Male (ref) | - | - |
| Female | 1.42 (1.28-1.58)*** | 1.55 (1.44-1.68)*** |
| Neighbourhood income quintile | | |
| Q1 (ref) | - | - |
| Q2 | 0.98 (0.82-1.16) | 1.06 (0.92-1.22) |
| Q3 | 1.03 (0.85-1.27) | 1.08 (0.92-1.27) |
| Q4 | 1.01 (0.81-1.25) | 1.04 (0.87-1.23) |
| Q5 | 1.10 (0.81-1.25) | 1.17 (0.97-1.41) |
| ON-MARG Material deprivation | | |
| Q5 (ref) | - | - |
| Q1 | 0.99 (0.78-1.25) | 0.84 (0.70-1.01) |
| Q2 | 1.12 (0.91-1.40) | 0.99 (0.83-1.17) |
| Q3 | 0.97 (0.79-1.17) | 0.93 (0.79-1.09) |
| Q4 | 0.89 (0.74-1.07) | 0.92 (0.79-1.07) |
| Residence | | |
| Urban (ref) | - | - |
| Rural | 0.89 (0.76-1.03) | 1.01 (0.91-1.13) |
| Duration of CMH involvement | | |
| < 161 days (ref) | - | NR |
| ≥ 161 days | 1.04 (0.87-1.24) | NR |
| Total CMH visits | | |
| < 6 visits (ref) | - | NR |
| ≥ 6 visits | 1.06 (0.87-1.30) | NR |
| Episodes of care | | |
| No episode (ref) | - | NR |
| Only 1 episode | 1.09 (0.92-1.29) | NR |
| 2+ episodes | 1.08 (0.84-1.40) | NR |
| Pattern of CMH use | | |
| Minimal (ref) | - | NR |
| Acute | 0.97 (0.80-1.19) | NR |
| Intensive | 1.09 (0.86-1.34) | NR |

| Predictor Variables | Model 3<br>Adjusted Hazard Ratio (HR)<br>(95% CI) | |
|---|---|---|
| | CMH Sample<br>(N = 2959) | Control Sample<br>(N = 8803) |
| Brief-Episodic | 1.11 (0.83-1.48) | NR |
| Ongoing/ Intensive Episodic | 1.39 (1.05-1.84)* | NR |
| Time from last CMH visit to age 18 | | |
| ≥ 2073 days | - | - |
| < 2073 days (ref) | 1.00 (0.86-1.15) | 1.08 (0.97-1.20) |
| OHIP-MH visits during CMH involvement | | |
| <1 visit (ref) | - | - |
| ≥ 1 visit | 1.12 (0.98-1.27) | 1.50 (1.32-1.69)*** |
| OHIP-MH visits between last CMH visit and age 18 | | |
| < 2 visits (ref) | - | - |
| ≥ 2 visits | 1.50 (1.24-1.82)*** | 1.98 (1.67-2.35)*** |
| Developmental disability[c] | | |
| No | - | - |
| Yes | 1.60 (1.32-1.95)*** | 1.91 (1.41-2.59)*** |
| Chronic physical health condition[c] | | |
| No (ref) | - | - |
| Yes | 1.03 (0.93-1.14) | 1.03 (0.94-1.12) |
| OHIP-Health visits during CMH involvement | | |
| No visit (ref) | - | - |
| ≥ 1 visit | 1.16 (1.01-1.34)* | 1.26 (1.16-1.37)* |
| OHIP-Health visits between last CMH visit and 18 | | |
| < 10 visits (ref) | - | - |
| ≥ 10 visits | 1.25 (1.12-1.40)*** | 1.44 (1.32-1.57)*** |
| Provider seen between last CMH visit and age 18 | | |
| No visit (ref) | - | - |
| Family physician only | 1.38 (1.13-1.68)** | 1.07 (0.90-1.28) |
| Pediatrician or psychiatrist only | 1.27 (0.99-1.61) | - |
| Combination (FP & Pediatrician or Psychiatrist) | 1.89 (1.49-2.39)*** | 2.35 (1.96-2.82)*** |

*Note.* CI = Confidence intervals. CMH = Children's Mental Health; Episode of care = a minimum of 3 CMH visits with a subsequent free period (no visits) of 180 days; OHIP = Ontario Health Insurance Plan; OHIP-MH = mental health visit using OHIP records; OHIP-Health = general health care visit using OHIP records; ref = comparative reference category for calculated HRs. Age of transfer refers to 18 years old. BCFPI = Brief Child and Family Phone Interview. [a] The sample size for crude HRs is the total sample (n = 2987), except for the following variables due to missing census-level data: residence (n =2981), neighbourhood income quintile (n =2979), and ON-MARG material deprivation index (n = 2959). [b] For the adjusted model, N =

2957. [c] Prior to age 18. * $p < .05$. ** $p = .01$. *** $p < .0001$. See Appendix for the same table for control sample.

**Appendix 22: Family Physician Involvement with Mental Health Care (OHIP-MH) Across 3 Time Periods for Control Sample**

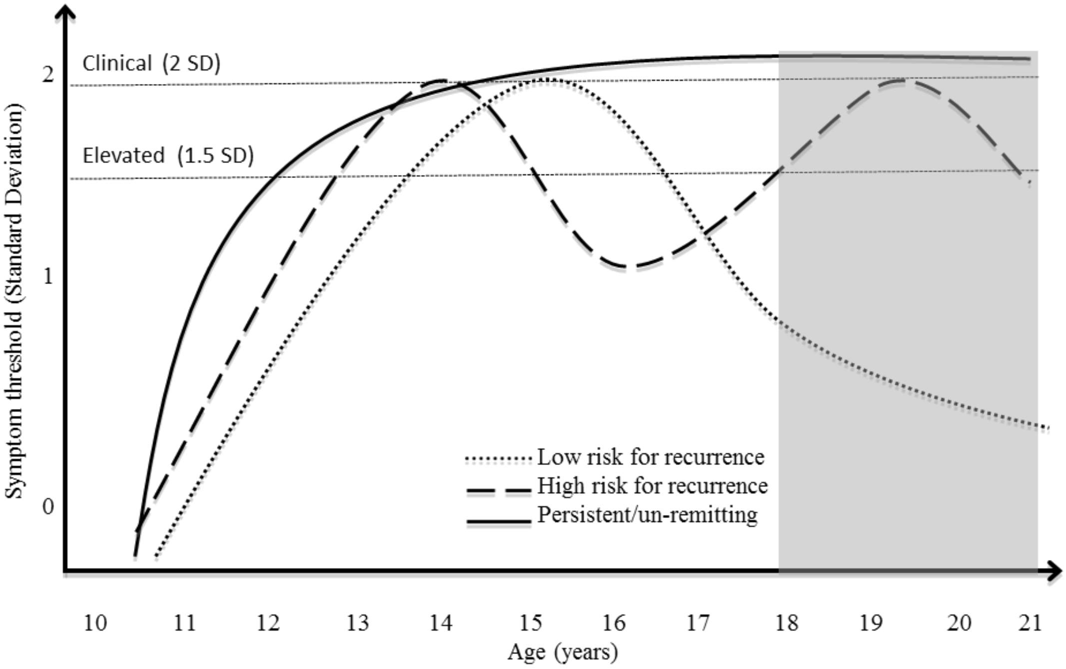
| Family Physician Involvement with Youth's Mental Health Care | Time 1: During CMH Treatment | Time 2: After CMH Treatment (up to age 18) | Time 3: After Age 18 | Proportion of Control Sample N = 8961 % (n) |
|---|---|---|---|---|
| No OHIP-MH visit with FP during any time period | ✘ | ✘ | ✘ | 55.2% (4947) |
| Only 1 Time Period | | | | |
| OHIP-MH visit with FP during CMH treatment only | ✔ | ✘ | ✘ | 1.4% (125) |
| OHIP-MH visit with FP after CMH treatment only | ✘ | ✔ | ✘ | 12.5% (1119) |
| OHIP-MH visit with FP after 18 treatment only | ✘ | ✘ | ✔ | 15.7% (1404) |
| 2 Time Periods | | | | |
| OHIP-MH visit with FP during and after CMH treatment | ✔ | ✔ | ✘ | 2.0% (175) |
| OHIP-MH visit with FP during CMH treatment and after 18 | ✔ | ✘ | ✔ | 1.0% (86) |
| OHIP-MH visit with FP after CMH treatment and after 18 | ✘ | ✔ | ✔ | 10.7% (954) |
| 3 Time Periods | | | | |
| OHIP-MH visit with FP across all time periods | ✔ | ✔ | ✔ | 1.7% (151) |

*Note*. ✔ = OHIP-MH visit with family physician; ✘ = no OHIP-MH visit with family physician

## Appendix 23: Comparison of first OHIP-MH service visits after age 18 between CMH and Control samples

| Most Common OHIP-MH Service Fee Codes | CMH Sample (*N* = 1549) | Control Sample (*N* = 2700) |
|---|---|---|
| Intermediate assessment | 40.3% | 44.3% |
| Major assessment | 3.5% | 3.7% |
| Minor assessment | 7.4% | 9.6% |
| Primary mental health care | 15.8% | 18.9% |
| Psychotherapy | 4.6% | 4.8% |
| Psychiatric care – outpatient | 4.5% | 2.3% |
| Consult – psychiatry | 5.3% | 2.9% |
| Counselling – 1 or more people | 3.9% | 4.3% |

# Appendix 24: Hypothetical courses of mental health disorders and the need for transfer to adult care



This graph illustrates hypothetical courses for mental disorders for transition-aged youth; age of transfer is 18 years old. The youth (solid line) that exhibits onset around 11 years of age, followed by a persistent or un-remitting course of the disorder, is likely to require transfer. The other two youth achieved remission [symptoms < 2 Standard Deviations (SD) above the mean on a standardized measure of psychopathology] from their first episode. The clinical (2 SD above mean) and sub-clinical or elevated (1.5 SD) symptom thresholds are indicated on the graph. While one youth does not experience a recurrence of the disorder, the other youth experiences a recurrence shortly after the age of transfer and should receive transition services.

From: Schraeder, K. E., & Reid, G. J. (2017). Who should transition? Defining a target population of youth with depression and anxiety that will require adult mental health care. *The Journal of Behavioral Health Services & Research*, *44*, 316-330.

# Curriculum Vitae

**KYLEIGH SCHRAEDER**
Department of Psychology
The University of Western Ontario

## EDUCATION

| | |
|---|---|
| 2016-2017 | **Pre-Doctoral Residency in Pediatric and Child Psychology**<br>Alberta Children's Hospital, Calgary, AB |
| 2012 - Present | **Doctor of Philosophy, Clinical Psychology**<br>The University of Western Ontario, London, ON<br>*Supervisor:* Dr. Graham Reid, Ph.D., C.Psych |
| 2012 | **Master of Science, Clinical Psychology**<br>The University of Western Ontario, London, ON<br>*Supervisor:* Dr. Graham Reid, Ph.D, C.Psych<br>*Thesis:* Why Wait? The Effects of Waiting Time on Subsequent Help-Seeking Among Families Looking for Children's Mental Health Services |
| 2010 | **Bachelor of Science, Honours Psychology with Distinction**<br>Queen's University, Kingston, ON<br>*Supervisors:* Drs. Valerie Kuhlmeier and Elizabeth Kelley, Ph.D<br>*Thesis:* How Do Typically Developing Adolescents and Adolescents with Autism Accurately Interpret Accidental Helping and Hindering? |
| 2009 | **International Full-Year Student Exchange Program, Psychology**<br>The University of Edinburgh, Scotland, UK |

## ACADEMIC AWARDS AND HONOURS

| **Date** | **Award and Organization** | **Value** |
|---|---|---|
| 2016 | Distinguished Trainee Research Award (2nd place)<br>North American Primary Care Research Group (NAPCRG) | $3000 |
| 2016 | Trainee Stipend Award<br>North American Primary Care Research Group (NAPCRG) | $1000 |
| 2016 | INSPIRE-PHC Travel Grant<br>Innovations Strengthening Primary Healthcare through Research (INSPIRE-PHC) | $175 |
| 2015 – 2016 | Ontario Graduate Scholarship (OGS)<br>Ontario Ministry of Training, Colleges and Universities | $15, 000 |

| | | |
|---|---|---|
| 2015 – 2016 | Western Graduate Research Scholarship (WGRS)<br>University of Western Ontario | $6, 000 |
| 2015 | POGO Student Bursary<br>Pediatric Oncology Group of Ontario (POGO) | $480 |
| 2015 | INSPIRE-PHC Travel Grant<br>Innovations Strengthening Primary Healthcare through Research (INSPIRE-PHC) | $175 |
| 2014 – 2015 | Transdisciplinary Understanding and Training on Research – Primary Health Care (TUTOR-PHC) Fellowship<br>Canadian Institutes for Health Research (CIHR) | $15, 000 |
| 2014 – 2015 | Quality of Life Initiative: Graduate Student Scholarship<br>Children's Health Research Institute (CHRI) | $10, 000 |
| 2014 – 2015 | Western Graduate Research Scholarship (WGRS)<br>University of Western Ontario | $7, 864 |
| 2014 | Student of the Year Award<br>London Regional Psychological Association (LRPA) | n/a |
| 2013 – 2014 | Western Graduate Research Scholarship (WGRS)<br>University of Western Ontario | $10,900 |
| 2012 – 2013 | Western Graduate Research Scholarship (WGRS)<br>University of Western Ontario | $11, 000 |
| 2013 | Marilyn (Pack) McClelland Graduate Award in Psychology<br>University of Western Ontario | $550 |
| 2012 | CIHR Health Professional Student Research Award (HPSRA)<br>Canadian Institutes of Health Research | $1308 |
| 2011 – 2012 | Western Graduate Research Scholarship (WGRS)<br>University of Western Ontario | $11, 000 |
| 2010 – 2011 | Western Graduate Research Scholarship (WGRS)<br>University of Western Ontario | $8,936 |
| 2009 | Dean's Special Award<br>Queen's University | $1, 000 |
| 2009 | Contribution to Health-Related Field Scholarship<br>St. Thomas Elgin General Hospital | $1, 000 |
| 2008 | Kathleen Ryan International Bursary<br>Queen's University | $1, 000 |

## FELLOWSHIPS

| | |
|---|---|
| 2015 - Present | ICES Student<br>Institute for Clinical Evaluative Sciences (ICES) |
| 2014 - 2015 | Research CIHR Fellow in Interdisciplinary Primary Health Care Research<br>Transdisciplinary Understanding and Training on Research – Primary Health Care (TUTOR-PHC) |

## GRANT FUNDING

---

Reid, G. J., **Schraeder, K.,** Brown, J.B., Stewart, S., Forchuk, C., Ryan, B., Wickett, J., Leschied, A., Carter, J. *A Multiperspective Study on Transition to Adult Care for Youth with Mental Health Issues.* Lawson Health Research Institute. March 2014 – February 2016. $14,678.

Reid, G. J., Barwick, M., Carter, J. R., Evans, B., Leschied, A. W., Kurdyak, P., Neufeld, R. W.J., **Schraeder, K**. E., St. Pierre, J., Stewart, S. L., Tobon, J. I., & Zaric, G. S. *Before, during, and after: Service use in the mental health and health sectors within Ontario for children and youth with mental health problems*. Canadian Institutes of Health Research (CIHR) Operating Grant. August 2014 – July 2017. $385,592.

## PUBLICATIONS & PRESENTATIONS

---

### ***Articles in Peer-Reviewed Journals***

**Schraeder, K**. & Reid, G. J. (2017). Who should transition? Defining a target population of youth with depression and anxiety that will need adult mental health care. *Journal of Behavioural Health Services and Research, 44*(2), 316-330. doi: 10.1007/s11414-015-9495-2

**Schraeder, K**., Vingilis, E., Osuch, E. (2016). Prevalence of substance use among adolescents in the First Episode Mood and Anxiety Program (FEMAP) versus adolescents in the general population. *Journal of Substance Abuse and Alcoholism, 4*(2), 1-5.

**Schraeder, K.** & Reid, G. J. (2015). Why wait? The effect of wait-times on subsequent help-seeking among families looking for children's mental health services. *The Journal of Abnormal Child Psychology, 43*(3), 553-565. doi: 10.1007/s10802-014-9928-z

**Schraeder, K.** (2012). The Wait-List Clinic at the Canadian-Mental Health Association – London-Middlesex. *Psynopsis (Fall Issue)*, 21-22.

### ***Manuscripts Currently Under Review***

**Schraeder, K**., Brown, J.B.B., & Reid, G.J. (in press). Perspectives on monitoring youth with ongoing mental health problems in Primary Health Care: Family physicians are "out of the loop". *Journal of Behavioural Health Services & Research*.

**Schraeder, K.,** Brown, J.B.B., & Reid, G.J. (in press). "I think he will have it throughout his whole life": Parent and youth perspectives about childhood mental health problems. *Qualitative Health Research*.

**Schraeder, K**., Reid, G.J., & Brown, J.B.B. (2017). *Stretching the boundaries: perspectives from children's mental health providers on caring for youth with ongoing mental health problems*. Manuscript submitted for publication.

### ***Invited Oral Presentations***

**Schraeder, K.,** Brown, J.B.B, & Reid, G.J. (November 13, 2016). Perspectives on monitoring youth with ongoing mental health problems: Family physicians are "out of the loop". Presented at the North American Primary Care Research Group (NAPCRG) 44th Annual Meeting: Distinguished Trainee Award Presentations. Colorado Springs, Colorado, US.

### ***Conference Presentations***

**Schraeder, K.,** Brown, J.B.B, & Reid, G.J. (November 13, 2016). Perspectives on monitoring youth with ongoing mental health problems: Family physicians are "out of the loop". Presented at the North American Primary Care Research Group (NAPCRG) 44th Annual Meeting. Colorado Springs, Colorado, US.

**Schraeder, K.** & Cataudella, D. (October 30, 2015). Impact of a Manualized Group Intervention for Bereaved Parents with Complicated Grief Symptoms: 3-Month Follow-up. Poster presented at the Multidisiplinary Symposium on Childhood Cancer, Toronto, ON.

**Schraeder, K.,** Reid, G.J., Brown, J.B., Carter, J., Forchuk, C., Leschied, A., Ryan, B.L., Stenason, L., Stewart, S., & Wickett, J. (June 4, 2015). Using an innovative multi-perspective sampling approach to explore issues in children's mental health care. Poster presented at the Trillium Primary Health Care Research Day, Toronto, ON.

Green, M.E., Jaakkimainen, L, Reid G.J, Hall-Barber, K., **Schraeder, K**, Dahrouge, S, Frymire, E. & Glazier, R.H. (June 4, 2015). Access to primary health care and utilization of walk in clinics and emergency rooms in Ontario. Poster presented at Trillium Primary Health Care Research Day: Toronto, ON.

Green, M., Hall-Barber, K., Reid, G.J., Jaakimainnen, L. & **Schraeder, K.** (May 27, 2015). Access to primary health care and utilization of walk in clinics and emergency rooms in Ontario. Paper presented at the Canadian Association for Health Services and Policy Research Annual Meeting: Montreal, Quebec.

**Schraeder, K.,** & Reid, G. (November 7, 2014). Who should transition? Defining a target population of youth in need of transfer from child mental health to adult care. Presented at the 2nd Annual Child and Adolescent Psychiatry Research Half-Day, Victoria Hospital: London, Ontario, Canada.

**Schraeder, K.,** & Reid, G. (June 4-6, 2014). Who should transition? Defining a target population of youth in need of transfer from child mental health to adult care. Presented at the 75th Canadian Psychological Association (CPA) Convention: Vancouver, Canada.

**Schraeder, K**., Otchet, F. & White, D. (June 14-17, 2013). A Comprehensive Program Evaluation of the Wait-List Clinic at the Canadian Mental Health Association (CMHA-LM). Presentation at the 74th Canadian Psychological Association (CPA) Convention: Quebec City, Canada.

**Schraeder, K.,** & Reid, G. (March 3-6, 2013). Why wait? The effects of waiting time on subsequent help-seeking among families looking for children's mental health services. Presented at the 26th Annual Children's Mental Research & Policy Conference: Tampa, Florida.

**Schraeder, K.,** Vingilis, E., Osuch, E., & Forster, C. (March 3-6, 2013). Prevalence of Substance Use Among Adolescents in the First Episode Mood and Anxiety Program (FEMAP) Versus Adolescents in General Ontario Population. Presented at the 26th Annual Children's Mental Research & Policy Conference: Tampa, Florida.

**Schraeder, K.,** & Otchet, F. (Feb 8-9, 2013). The Wait-List Clinic at the Canadian Mental Health Association London-Middlesex. Presented at the Ontario Psychological Association (OPA) Conference: Toronto, Ontario.

**Schraeder, K.,** Otchet, F. & White, D. (June 14-17, 2012). A Comprehensive Program Evaluation of the Wait-List Clinic at the Canadian Mental Health Association (CMHA-LM). Presented at the 73rd Canadian Psychological Association (CPA) Convention: Halifax, Canada.

## TEACHING AND SUPERVISION EXPERIENCE

### *Graduate Teaching*

2014-2016 Teaching Assistant
Clinical Psychology Initial Assessment Practicum PSYCH 9800
University of Western Ontario, London, Ontario

### *Undergraduate Teaching*

2015 Course Instructor
Introduction to Clinical Psychology, PSYCH 3301F-Summer Distance Studies
University of Western Ontario, London, Ontario

2010-2015 Teaching Assistant
Introduction to Psychology, PSYCH 1000
University of Western Ontario, London, Ontario

2011-2012 Teaching Assistant
Introduction to Clinical Psychology, PSYCH 2301
University of Western Ontario, London, Ontario

2011 Teaching Assistant
Psychology in Everyday Life, PSYCH 2301
University of Western Ontario, London, Ontario

### *Supervision Experience*

2014-2016 Supervision of Psychological Test Administation
Clinical Psychology Initial Assessment Practicum, PSYCH 9800
University of Western Ontario, London, Ontario

2013-2014 <u>Honours Thesis Research Advisor</u>
Student's Project Title: "Risk Behaviours and Service Use Intensity in Child Mental Health Care"
University of Western Ontario, London, Ontario

## ***<u>Other Professional Presentations</u>***

**Schraeder, K**. & Cataudella, D. (2015). *Behaviour basics: practical strategies for dealing with challenging behavior in medically ill children.* Presentation for Parent Group at Children's Hospital, London Health Sciences Centre, London, ON.

**Schraeder, K.,** & Reid, G.J. (2013, February). *Why Wait? The effects of waiting time on subsequent help-seeking among families looking for children's mental health services.* Presentation to the CPRI Regional Advisory Board Meeting, London, ON.

**Schraeder, K**. Responding to Difficult Child Behaviour, Thames Valley District School Board (TVDSB) Professional Development Day, March 7, 2014. Woodstock, ON.

**Schraeder, K**. & Hahn, C. Mental Health and Access to Care, "Finding Your Way" Series, London Public Library, February 23, 2014. London, ON.

**Schraeder, K**., Hahn, C, & Moliano, N. Mental Health and Access to Care, "Finding Your Way" Series, London Public Library, February 27, 2013. London, ON.

**Schraeder, K.**, & Reid, G.J. (2013, February). Why Wait? The effects of waiting time on subsequent help-seeking among families looking for children's mental health services. Presentation to the Child Parent Resource Institute (CPRI) Regional Advisory Board Meeting, London, ON.

**Schraeder, K.,** & Turnbull, K. Responding to Difficult Child Behaviour. "Finding Your Way" Series, London Public Library, February 16, 2012. London, ON.

**Schraeder, K.,** & Otchet, F. The Wait-List Clinic at CMHA-LM: A unique, collaborative, community mental health opportunity. London Regional Psychological Association, November 21, 2012. London, ON.

**Schraeder, K.,** Edwards, K., & Evraire, L. Why YOU should consider becoming a doctor in clinical psychology. Presented as part of the TD Discovery Day in Health Sciences at the University of Western Ontario, May 6, 2012. London, ON.

## ***<u>Media Interviews and Profiles</u>***

MacAuley, D. (November 14, 2016). Reflections on day one of #NAPCRG2016. *CMAJ (Canadian Medical Association Journal) blog.* http://cmajblogs.com/reflections-on-day-one-of-napcrg2016/#more-3664

Flynn, A. (November 19, 2013). Kyleigh Schraeder: Studying Access to Care and Transitions in Ontario's Child and Youth Mental Health System. *Evidence Exchange Network for Mental Health and Addictions (EENet).* http://eenet.ca/wp-content/uploads/2013/11/Kyleigh-Schraeder-Student-Spotlight.pdf

### ***Journal Reviewer (mentored by Dr. Graham Reid, PhD)***

Journal of Pediatric Sleep, January 2014.
Personality and Individual Differences, September 2014.
The Journal of Behavioural Health Sciences & Research, October 2014.
Journal of Abnormal Child Psychology, April 2014.
Journal of Personality and Individual Differences, May and July 2015.

## GRADUATE COURSEWORK

Clinical Assessment (Psych 9800)
Child Psychopathology and Diagnosis (Psych 9310)
Interventions with Children (Psych 9322)
Adult Psychopathology and Diagnosis (Psych 9311)
Professional Foundations of Clinical Psychology (Psych 9300)
Clinical Skills Pre-Practicum (Psych 9301)
Research Design (Psych 9540)
History and Systems of Psychology (Psych 9370)
Clinical Proseminar (Psych 9380)
Methods and Issues in Program and Policy Evaluation in Health Services (Epid 9531)
Psychological Perspectives on Immigration (Psych 9723)