

LOST IN TRANSITION? HEALTH SERVICE UTILIZATION OF IWK
MENTAL HEALTH AND ADDICTIONS PATIENTS ON TRANSITION
TO ADULT SERVICES.

by

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DEDICATION

*For my Grandparents, George and Barbara Foster, and my musical muses, Anne Murray
and Dolly Parton.*

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ABSTRACT

The objective of this thesis was to improve our understanding of transition aged youth accessing public Mental Health & Addictions (MHA) services in Nova Scotia and identify potential inequities using routinely collected health administrative data. Specifically, we aimed to: 1) describe transition aged youths' demographics and service use patterns; 2) estimate the associations between clinical, demographic, and socioeconomic factors with attendance to adult MHA services; 3) assess the associations' sensitivity using a two-visit definition of attendance. We created a retrospective cohort of youth known to IWK MHA services from 2016-2019 and linked them with Nova Scotia Health MHA data. Using multi-level logistic regression, we measured the unadjusted associations of the selected factors with adult MHA attendance. Across both definitions of attendance, MHA-related Emergency Department use, community-level proportion of single parent households, and presenting concern categories were associated with attendance to adult MHA services. Certain associations may be indicative of inequities.

LIST OF ABBREVIATIONS USED

ADA	Aggregate Dissemination Area
ADHD	Attention Deficit Hyperactivity Disorder
CCI	Canadian Classification for Interventions
CIHI	Canadian Institute for Health Information
CAPA	Choice and Partnership Approach
CMHA	Community Mental Health & Addictions
DSM	Diagnostic & Statistical Manual of Mental Disorders
DA	Dissemination Area
ED	Emergency Department
HRM	Halifax Regional Municipality
HCN	Health Card Number
IOM	Institute of Medicine
ICD	International Classification of Diseases
IWK	IWK Health
MHA	Mental Health & Addictions
NS	Nova Scotia
PCCF	Postal Code Conversion File
REB	Research Ethics Board
SES	Socioeconomic Status
UK	United Kingdom
USA	United States of America

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In the words of the great Canadian icon, Nova Scotia's most valuable export, and my most revered writing companion, Anne Murray, it's time to “spread [my] tiny wings and fly away” but I hope I have helped make a positive difference in the experience of transitioning youth thanks to those mentioned above (and more) that I will continue throughout my clinical career.

CHAPTER 1: INTRODUCTION

Adolescence is full of transitions. This developmental stage comes with a host of biological, social, and developmental changes as individuals transition into adult roles. For those who access child and adolescent mental health services, many must also navigate a transition between services, as they age out of pediatric services and enter the adult mental health system. In Canada, most tertiary public healthcare is divided between pediatric and adult services; mental health and addictions (MHA) care is no exception. In the Halifax Regional Municipality (HRM), youth health is managed by IWK Health up until age 16 for most physical illnesses and conditions, and up to age 19 for MHA care, at which point Nova Scotia Health assumes adult specialist care.¹ Ideally, care would be expected to be continuous from youth to adult MHA care. However, over half of youth, in jurisdictions such as the United Kingdom (UK) and United States of America (USA), in need of a transition fail to successfully make their transition to adult services due to difficulties at both the individual and system level.² There are currently no such Canadian estimates.

The transition from youth to adult MHA care is considered one of the most difficult problems this century's mental health policymakers have to reconcile with.^{3,4} Despite its importance, very little is known about MHA service use patterns during the transition between youth to adult MHA services in Canada, and MHA service use patterns during the transition have not yet been quantitatively evaluated in Nova Scotia.⁵ Transitions between child and adolescent (youth) and adult MHA services have often been evaluated qualitatively.⁶⁻⁹ While these findings provide rich insights into youths' experiences, they are difficult to implement across health systems and in continuous quality improvement. Qualitative studies have also identified that non-clinical factors, such as household income, may contribute to difficulties in transitioning across youth and adult MHA services, providing opportunities to investigate inequities.¹⁰ The transition period is a unique and complex period to investigate inequities, as many transition-aged youth are stuck between two very different paradigms of MHA service delivery, while also transitioning to a more independent role as a health service user. The developmental and social changes of adolescence and the transition between MHA systems may indeed exacerbate known inequities in mental health services, disproportionately affecting already vulnerable youth.

The next chapter presents a review of the academic literature about the transition from MHA services. This review confirmed that transitions represent a complex process that has not been widely researched in the Canadian context nor with health administrative data. While clinical, demographic, and socioeconomic factors have been found to be associated with successfully transitioning to adult MHA services^{11,12}, they have not been interpreted in the context of inequities and it is unclear whether the same assumptions apply in the Canadian MHA system. Our review also identified that attendance to a single outpatient adult MHA appointment is typically used as an indicator of a successful transition, despite widespread recognition that attendance declines after this first visit. Thus, longitudinal follow up is required to assess whether a transition was in fact successful and equitable across episodes of care, not only at the first visit.

The objective of this thesis was to improve our understanding of transition aged youth accessing publicly funded MHA services in Nova Scotia and identify potential inequities using routinely collected health administrative data. Specifically, we aimed to: 1) describe the demographics and service use patterns of transition aged youth; 2) measure the associations between clinical, demographic, and socioeconomic factors with attendance to adult MHA services; and 3) assess the sensitivity of these associations using a two-visit definition of attendance.

To meet these objectives, we conducted a retrospective cohort study by conducting a unique linkage of paediatric and adult health administrative databases. The third chapter of this thesis presents the study design, methodology, empirical findings and conclusions from our analysis of a cohort of transition aged youth attending youth MHA services at the IWK Health Centre in Halifax, Nova Scotia. Lastly, the concluding chapter highlights the strengths and limitations of our work, as well as identifies future directions and recommendations for transition aged MHA care and research in Nova Scotia.

This investigation of the health service use of transition aged youth in receipt of youth MHA services at IWK Health was necessary to identify how health systems can use routinely collected data to identify where they can better support youth, and what considerations must be made to help those most vulnerable to poor transitional outcomes. To our knowledge, this was the first

analysis of health service outcomes of transition aged youth known to Nova Scotia's MHA services, and one of few Canadian studies employing administrative data sources to describe patterns of care across the transition age.

CHAPTER 2: LITERATURE REVIEW

2.1 CHILD & ADOLESCENT MENTAL HEALTH

Mental illness is a highly prevalent health concern in Canada, with an estimated 1 in 5 Canadians experiencing mental health problems in any given year.¹³ Mental illness is often a chronic condition, with upwards of 70% of cases beginning before the age of 25, and 50% of cases emerging before the age of 14.¹⁴⁻¹⁶ Early detection and treatment of emerging mental illness is associated with improved outcomes at any age, but particularly so as youth develop into adulthood.¹⁷ Unfortunately, fewer than 25% of Canadians aged 4-17 in need of specialized mental health services actually receive them.^{18,19} In the background of a host of developmental changes, youth with chronic disease, including mental illness, must reconcile a shift in healthcare service delivery that is difficult to manage without proper planning and preparation. The transition boundary between youth and adult health systems often contributes to unmet need by compounding challenges in access to care.¹⁹

2.2 THE TRANSITION FROM YOUTH TO ADULT MENTAL HEALTH & ADDICTIONS SERVICES

Although many mental health services are offered privately, in most publicly-funded health systems, healthcare is divided between paediatric and adult services. The care philosophies and organizational structure of these two systems are often different and have historically operated independently of one another.²⁰ Youth between the ages of 16-25 are often considered to be “in transition” between youth and adult mental health services. Without proper planning and care, they are at high-risk for adverse mental health outcomes as they transition to adult services.²¹⁻²³

A medical transition is the “purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centered to adult-oriented healthcare systems.”^{24(p570)} It is estimated that 25-49% of all youth MHA patients attending at any point (i.e., birth to adulthood) in their youth will require a transition to adult services.²⁵ Despite these high estimates of ongoing need, up to 60% of youth in need of continuing mental health care at transition age are estimated to drop out at this boundary.² A recent systematic review found that

only 24% of youth in need of transition made contact with the adult MHA system.²⁶ Of the minority of patients who made some form of contact with the adult MHA system, the TRACK study, conducted in the UK, found that fewer than 5% of patients reported a seamless transition.²⁷ Once a patient gets their “foot in the door” of adult MHA care, 16% are clinically discharged after their first appointment.²⁷ Administrative discharges, due to consistent no-shows or cancellations, are likely to be even higher. Evidently, the divided delivery of mental health services in adolescence leaves many lost in transition.²⁸

2.3 THE DIFFERENCES BETWEEN YOUTH AND ADULT MENTAL HEALTH & ADDICTIONS SERVICES

There are often policies in place to navigate this inevitable divide of services at such a critical juncture of life; however, seamless transition is rare, with differences between youth and adult systems seemingly overriding consideration of what is best for the individual.^{29,30} For example, youth MHA care is often perceived as more patient- and family-oriented, holistic, and inclusive compared to adult MHA.³¹ Youth services often consider health bio-psychosocially by taking into account social determinants, developmental milestones, and trajectories of maturing adolescents while providing services as needed, rather than traditional standardized assessments and treatment plans.²⁹ In Nova Scotia, the IWK has implemented the Choice and Partnership Approach (CAPA).³² Unlike traditional models of care which focus on diagnostically-driven treatment pathways, CAPA takes a more holistic approach to service delivery.³² Although individuals may receive a formalized diagnosis at some point in their treatment, it is not the focus of their care. The focuses of care revolve around “engagement, therapeutic alliance, choice, strengths, goals, and care planning.”³² The CAPA approach is contrasted with the biomedical approach, and Diagnostic and Statistical Manual (DSM)-driven adult MHA system, which is often perceived by users as individualistic, diagnosis-based, crisis-driven, and focused on pharmaceutical intervention.^{9,20} While these differences in approaches are compatible with the social development of adolescents and the importance of early intervention, they nonetheless represent different paradigms of care which can be difficult to navigate without proper preparation and planning.

Beyond seeing different age groups and having different care philosophies, youth and adult MHA systems tend to differ in terms of what qualifies as a need for service, including within Nova Scotia. While private MHA services can be delivered more flexibly irrespective of acuity or complexity of the concern, although offered on a fee-for-service basis, the public mental health system is different: publicly funded MHA services provide care to those with symptoms or impairment of function warranting specialized services. Thus, mental health concerns that do not meet diagnostic criteria, or have not yet been classified and assessed using diagnostic criteria, are not accepted by the Nova Scotia Health adult MHA system due to their specific mandates.⁵

In keeping with an early intervention approach, the Nova Scotia IWK-NS Health MHA service mandate for youth outlines a wider range of eligibility criteria than NS Health's adult mandate. For example, the youth mandate places an emphasis on developmentally-appropriate, family-based treatment of "moderate to severe symptoms of mental disorder and/or harmful substance abuse."³³ In contrast, the adult mandate offers services for "confirmed or suspected moderate to severe mental disorders (including addictions), based on the most up to date DSM diagnostic criteria."^{34(p6)} In other countries with similar processes (i.e. UK), youth patients and their parents have described narratively that they were told they were "not ill enough" for adult services, even if they had a mental health crisis only a few months prior to their transition.⁹ While youth MHA treats sub-syndromal symptoms that have the potential to worsen, adult MHA may not without a suspected diagnosis, further leaving at-risk youth vulnerable to unmet service needs.

In addition to these mandated differences in service eligibility, longstanding biases from clinicians means patients may not be referred from youth MHA because youth clinicians anticipate some will not meet adult criteria, or believe the adult system will not have the necessary expertise to treat their condition.²⁷ These concerns are not unfounded; referrals for Autism Spectrum Disorders, learning disabilities, and Attention Deficit/Hyperactivity Disorder (ADHD) are often rejected by the adult system for not meeting diagnostic criteria, despite receiving youth services.³⁵ There are known biases and criticisms of many neurodevelopmental disorders being perceived as child-specific by adult MHA providers, particularly ADHD.¹¹ In research from both the UK and USA, confirmed DSM psychiatric diagnoses, formal risk

assessments, pharmacotherapy, a history of childhood inpatient hospitalizations, and psychotic disorders all increased the likelihood of transitioning, while neurodevelopmental disorders are often discharged to primary care or remain in youth MHA past the transition boundary.^{11,26,27,36} These known differences in transitional health service utilization based on clinical factors highlight how the lack of coordination between youth and adult systems creates additional challenges for youth transitioning to adult services, and how some youth may be more vulnerable than others to these transition-specific challenges.

2.4 INEQUITIES IN TRANSITION SUCCESS

2.4.1 WHAT IS INEQUITY?

The fact that some youth are more vulnerable to unsuccessful transitions than others under Canada's universal healthcare system prompts consideration of whether such differences are inequitable. Timely access to medically necessary health services, regardless of factors like socioeconomic status (SES), is a pinnacle of universal healthcare; yet those most in need of MHA services are often the least likely to access them.^{37,38} This is particularly true in the transition period.³⁶ Differences in healthcare access, utilization, and/or quality between individuals who need care may be indicative of health system inequities and are likely to be exacerbated by the difficulties associated with transitioning between youth and adult MHA systems.

In a perfectly equitable health system, we expect individuals who bear the larger burden of mental illness, or have a higher clinical need, to use more resources. After standardizing for different levels of need we can analyze horizontal equity, which is "equal treatment for equal medical need, irrespective of other characteristics such as income, race, place of residence, etc."³⁹ These "other characteristics" are termed non-need factors. While past literature can guide the classification of factors into need versus non-need for investigations of inequities in access to primary care or mental health care, such work has not yet been applied to MHA transitions.

2.4.2 INEQUITY IN THE CONTEXT OF TRANSITIONS

Typically, clinical need can be inferred through variables such as age, sex, comorbidities, and health status. Biological sex, for example, plays an important role in the age of onset,

severity, and pattern of many mental illnesses.⁴⁰ While it is historically difficult to select specific variables to identify need, Nova Scotia’s tiered delivery of mental healthcare (*Figure 1.1*) gives an indication of what level of services an individual needs; higher tiers are reserved for increasing need reflected by the intensity of services required, or complexity of clinical presentation.⁵ Tier 3 is where the outpatient MHA services of the IWK and NS Health focus on treatment of mental health concerns that cannot be managed via community services or in primary care. About 50% of those with non-affective psychotic disorders and/or bipolar disorders, depression, anxiety, substance abuse, and most patients with psychoses and comorbid mental illness qualify for Tier 3 services; an estimated 5% of the general adult population requires this level of care.⁴¹ While factors like age, diagnosis, and comorbidities may be used to differentiate need between these tiers, within tiers it is much more difficult, and even more so in the context of transitions.

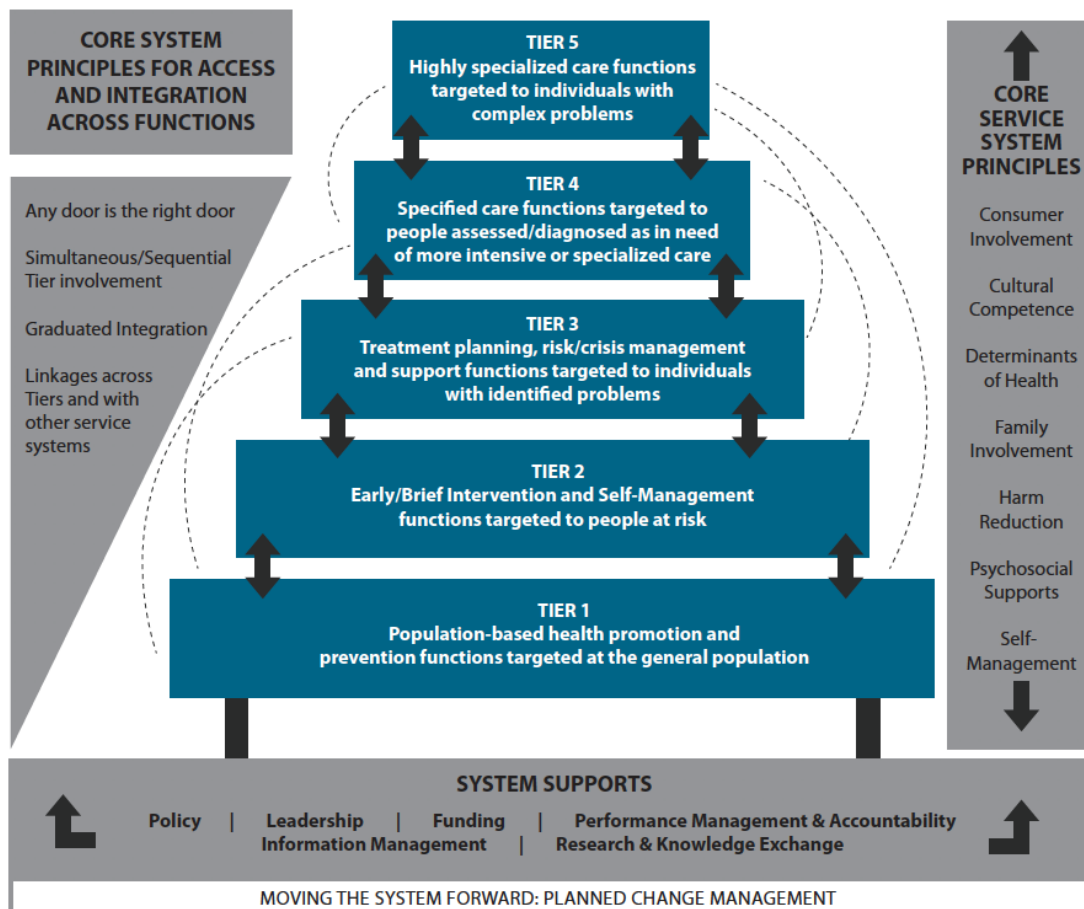


Figure 1.1: Tiers of Mental Health Service in Nova Scotia³⁶

Tier 3 (and up) MHA services in Nova Scotia are divided at 19 years old, thus any youth in IWK Tier 3 services at age 19 may need to transition to adult MHA services. Past cross-sectional work has shown that up to 80% of youth attending services at the transition boundary are eligible to transition, and only 6% are no longer in need of care, thus not all youth would be expected to attend adult services.¹¹ As youth move through services at the IWK, their clinicians may assign a priority designation to their care based on a patient's presenting concern or diagnostic category. However, this priority designation may differ between youth and adult systems. Such differences are not uncommon; in a European review, 36% of interviewed youth MHA clinicians reported differences in eligibility criteria between youth and adult MHA systems negatively impacting the transition process.²⁵ The differing eligibility criteria and measurement of clinical need between youth and adult MHA systems is one example of uncertainty that exists in defining need factors.

The Institute of Medicine (IOM) in the USA has created a widely used equity framework for investigating inequities in healthcare at the patient-, provider-, and system- level.⁴² According to the framework, non-need factors stem from “discrimination, biases, stereotyping, uncertainty, the operation of the healthcare system, or the legal and regulatory climate.”⁴²

As the framework outlines, uncertainties arise whenever a care provider must make a judgement based on their clinical experience and the facts they can ascertain regarding a patient. These judgements are often aided by cognitive shortcuts, or heuristics, which have been ingrained from their training and experience. While the IOM report outlines the contribution of heuristics related to race, ethnicity, age, and socioeconomic status to inequities, we must also consider how the philosophic differences in care and professional training between youth and adult MHA services can contribute as well. As mentioned above, clinician biases of certain neurodevelopmental disorders being child-specific can play a role in shaping a provider's decision to accept or reject a transition referral, despite a youth clinician deeming it necessary. This is just one example of how uncertainties can contribute to inequities in transition success.

Even for those who are accepted into adult services, diagnostic stereotypes or uncertainty around the appropriateness of treatment may further contribute to inequities in care. In the

context of transitions, the above-mentioned biases and hesitations around neurodevelopmental disorders being child-specific is another example of how uncertainty can contribute to transition period inequities. While investigations of youth or adult mental health services individually may not identify diagnosis as a source of inequities, this is evidently not the case throughout the transition period. These considerations highlight the need to move beyond the traditional understanding of what factors constitute “need” versus “non need” and consider more holistically how a variety of factors can contribute to inequitable differences in service utilization across the transition.

Of the literature that does exist on mental health service inequities, typically, race/ethnicity^{43,44} and SES indicators^{10,45} are analyzed as non-need factors. Of note, household income is the most commonly used SES indicator in inequality investigations of youth mental health.⁴⁶ Children and youth from lower income households are up to three times more likely to develop a mental illness⁴⁶, and the degree of unmet mental health care need in adolescence is strongly associated with economic disadvantage; this likely reflects difficulties in accessing and/or navigating the healthcare system.⁴⁷ These difficulties negatively impact one’s vulnerability to illness, willingness and ability to attend appointments, and are likely to interact with other factors throughout the transition period.

In a similar way, coming from a single-parent family is a uniquely important SES indicator when assessing inequities in transition.⁴⁸ While coming from a single-parent household can have a direct impact on material circumstances, similar to household income, it can also create additional barriers for communication and treatment adherence. For example, a single parent may be less available to consistently attend appointments with youth due to work or other commitments, leading to different guardians attending each visit, or cancelled appointments. Given that parental involvement in transition decisions is often highly valued by transitioning youth, those from single-parent homes may be particularly vulnerable to disengagement by not having a consistent, informed guardian to advocate for them throughout the transition process.^{9,49,50} Such familial support is crucial throughout any mental health treatment, but particularly so in the transition period as families are less often directly involved in a patient’s care due to the increased need for self-advocacy in the adult system.²⁹ Without the appropriate

supports in place, youth may not be prepared or be willing to advocate and actively seek help for their conditions.^{27,51} Youth of lower SES and/or single-parent households may be particularly vulnerable to the challenges of self-advocacy and health education and thus, poor transitions.

This increased autonomy in adult MHA relative to youth MHA points towards the need for careful consideration of patient preferences as youth transition across systems. Differences due to patient preferences are not typically indicative of inequities, but this is a complicated issue in the context of transitioning youth. When patients turn 19 years of age, they are expected to make informed treatment decisions in the adult system; however, many are not prepared or able to do so. In a UK study, the most common reason a referral was not made to adult MHA services was refusal by the patient and/or their carer, despite only 17% of those refusing deemed to have no clinical need for ongoing treatment.²⁷ These choices are made while coming to terms with diagnoses of often chronic illnesses and accepting that one's mental health concerns are an ongoing issue with often life-long implications.⁵² Accepting this and engaging in health promotion can be difficult at these ages; not only can this disproportionately affect those of lower SES, but special considerations must also be made for individuals with neurodevelopmental delays. While some may argue that refusal of a referral reflects a patient preference, we must consider that those with neurodevelopmental disorders may not be at a developmental stage where they are capable of making well-informed treatment decisions, despite being of a chronological age to do so.²⁹ While the youth MHA system is often well experienced in adjusting care based on developmental milestones, the adult system often fails to recognize the diversity of developmental/cognitive trajectories for many youth with mental illness.³⁵ This represents a characteristic of the healthcare system that can contribute to inequities. While investigations of inequity often consider clinical factors, such as diagnosis, as strictly indicative of clinical need within individual services (e.g. youth MHA alone), this is clearly not the case in the context of MHA transitions.

During the transition from youth to adult MHA, need and non-need factors are not only complex themselves, but also interact in a complex manner. For example, we know youth and adult MHA services are fundamentally different in their areas of expertise. While youth MHA is often well equipped to deal with neurodevelopmental disorders like ADHD or Autism Spectrum

Disorder, they are often hesitant to definitively label mental illnesses with an onset in adolescence or early adulthood (i.e. emerging personality disorders).²⁵ In contrast, adult MHA care is well equipped to deal with mental illnesses with an onset in adolescence, but report not feeling comfortable or having the necessary training to manage neurodevelopmental disorders.²⁵ In a review of 28 European youth MHA systems, 64% of youth MHA clinicians reported that transitions were complicated by a lack of adolescent-specific competencies on either side of the transition boundary.²⁵ Consequently, individuals with later onset illnesses may be more likely to be referred to and/or accepted by adult MHA, and thus have successful transitions. These clinician biases regarding mental illnesses such as ADHD or ASD may affect perceptions of need on either side of the transition boundary, in addition to those known to exist by SES, race, and ethnicity.¹¹

These factors that contribute to inequities do not work in isolation. Whenever multiple factors can contribute to inequities, they can interact multiplicatively to widen gaps in care. The idea of intersectionality and inequity is often applied in the context of race, gender, sexual orientation, and class.^{53,54} Intersectionality theory recognizes that people have multiple identities and there can be multiplicative (positive or negative) effects from identifying with more than one social group, particularly if they are a minority.⁵⁵ For example, a youth MHA patient may be of low income, which is associated with both increased risk of mental illness and challenges in accessing care, but they may also be a racial minority, and feel mistrustful of the medical system or receive substandard care due to stereotyping and biases.⁴⁴ This individual's lived experience being both low-income and a minority race, shape their interactions with the health system and can create unique differences in care. Historically, applying intersectionality paradigms in health research has been difficult, as administrative databases do not often capture race, gender, or class, resulting in one-dimensional investigations of inequities.⁵⁶ Thus, more holistic interpretations incorporating qualitative experiences, and/or better capturing of these factors in routinely collected administrative data are needed to appropriately interpret differences in care. Evidently, qualitative literature investigating youths' unique transition experiences should guide the selection of independent variables and interpretation using the IOM framework in empirical studies.^{7,9,29}

2.4.3 CONSIDERATIONS FOR ANALYZING INEQUITY

Inequities in access to services can appear well before the transition period begins. Socioeconomic status,¹⁰ race,⁴⁴ or place of residence⁵⁷ can preclude youth from accessing needed care before even accessing MHA services for the first time. Youth who are in receipt of youth MHA services have overcome the first hurdle of entering and accessing these services and are likely different from those who do not. Much of the mental health-related literature on inequities has focused on describing differences between those with and without initial access to services; studies looking at continued use of services, or across an episode of care, particularly in the transition period, are likely to produce unique findings.

In addition to the many unknowns regarding transition-specific inequities, there are still challenges that are common to many inequity analyses. For example, neither individual-level SES indicators nor treatment preferences are routinely captured in health administrative databases and need to be supplemented through linkages with other data sources. For example, Census data at the dissemination area-level has been used to obtain information on SES at the community level.⁵⁸

Looking at community itself as a covariate may capture the complex interplay between socioeconomic, racial, ethnic, and cultural factors on health service utilization. Communities reflect a variety of factors, beyond SES indicators, which can play a role in health and health service use.⁵⁹ Community dynamics have also been implicated in mental health inequities.⁵⁷ A variable representing geographic community can capture these factors and their relationships and can be more informative in clinical practice than individual SES indicators like income. There are evidently still many unknowns when it comes to inequities in transition success; to fully appreciate these, we must understand the impacts of poor transitions.

2.5 THE IMPACTS OF AN UNSUCCESSFUL TRANSITION

Youth who do not successfully transition to adult services, despite being in need to do so, are likely to have increased difficulties later in life. While few studies have specifically compared the outcomes of a transitioned subgroup versus a non-transitioned subgroup within a cohort, qualitative literature has given us insight into some of these difficulties and there are

known consequences of disengagement from needed MHA services. Of the literature that does exist, unmet need in the transition age range has been associated with increased mental health-related ED usage, confusion regarding medications, contact with the criminal justice system, and interruptions in employment/educational attainment.^{9,60,61} Improving transitional mental health care is agreed to be one of the most effective ways of preventing exacerbation of existing or emerging mental and physical illness by ensuring continuity of care.^{8,29,62} Continuity of care throughout an episode of mental illness is associated with lower rates of crisis-driven mental health service utilization, particularly the frequency and length of inpatient hospitalizations and ED visits in both children and adults, and higher levels of self-reported patient satisfaction.^{11,63,64} Additionally, the known interruptions in youth educational and occupational attainment from an exacerbation of mental illness results in lost productivity and prevents youth from achieving their full potential, though these are difficult to measure.^{60,61} Given the difficulties in measuring the impact on individuals, much of the transition literature has investigated impacts via service utilization.

Beyond the potential worsening of an individual's symptoms, a poor transition can lead to distrust in the mental health system and deter adolescents from accessing services in the future.⁶⁵ Some youth report feeling abandoned when their youth MHA services end and they are not supported throughout their transition process, which deters them from accessing further care.⁹ In 2017-2018, Nova Scotian adolescents aged 18-24 years old accounted for 67% of all child and adolescent mental health inpatient hospitalizations, which reflects the peak onset of mental illness.¹⁴ We would similarly expect that outpatient mental health screening and treatment would increase across this same age range as youth reach the peak onset of mental illness, yet transition aged youth show a 45% decline in outpatient visits in 18-19 year old youth relative to 16-17 year olds.⁶⁶ While outpatient MHA visits tend to decline across the transition period, transition aged youth tend to make up the majority of MHA inpatient hospitalizations and MHA-related ED use.

Mental health-related ED visits and inpatient hospitalizations in Canada are increasingly occurring among adolescents and young adults relative to other age groups, and are known to be inequitably distributed in children from low income families.^{14,67-69} These mental health-related

ED visits in the absence of routine outpatient care are unlikely to lead to continued engagement with the outpatient mental health system.⁷⁰ While this increase cannot be directly attributed to difficulties in transitioning between systems, youth engagement work in the IWK ED identified that some youth and their families utilize the ED for mental health concerns when they have “fallen through the cracks” of outpatient care.⁷¹ While some youth may prefer to utilize the ED, or use it appropriately in a time of crisis, repeated mental health-related ED visits typically reflect gaps in outpatient care; 39% of youth mental health-related ED users had three or more visits in 2013-2014.¹⁴ Given that the transition to adult MHA services often creates gaps in care, some of these visits are likely attributable to poor transitions.

Evidently, longitudinal research on the negative impact of poor transitions into adulthood is lacking, with no consensus on the consequences of an unsuccessful transition.⁷² Given the short observation period commonly used in transition studies, it is difficult to investigate the longstanding impacts. Several longitudinal studies are currently underway in both Europe and Ontario, which hope to address this gap in the literature by better understanding long-term outcomes post-transition to adult services.^{62,73} Nonetheless, researchers, clinicians, patients, and policymakers agree that the transition from youth to adult MHA is a problem, yet little is known beyond setting-specific descriptions, and a few intervention evaluations.^{26,36,72}

2.6 THE CHALLENGES IN RESEARCHING TRANSITION SUCCESS

Beyond not knowing whether transition success is inequitably distributed nor the impacts of poor transitions, within what we know regarding MHA transitions, there are often inconsistencies in the definitions and approach. There is little standardization in the measurement of symptoms, functioning, or engagement/alliance in MHA services in general. Consequently, nearly every study of MHA transitions has different criteria to define who should transition, what a successful transition is, and what outcomes should be measured.⁷² With the episodic nature of many chronic mental illnesses, clinicians themselves must grapple with identifying patients without having a standard to identify what constitutes a need to transition to adult MHA services.⁷⁴ Only 11% of European youth MHA systems reported conducting a standardized need assessment of youth approaching the transition boundary, which further complicates defining the population in need of continuing services and examining their outcomes.²⁵

2.6.1 THE MEASUREMENT OF TRANSITION SUCCESS

While the construct of what constitutes a successful transition has been widely agreed upon, disagreements remain regarding what is a valid measure of transition success. Most studies use attendance to a single outpatient adult MHA appointment as a measure of transition success.^{11,26} However, using this short observation period to evaluate transition success has the potential for misclassification, given that attendance drops off steeply after the first visit due to discharges, cancellations, or no-shows.^{11,26} Given this, the use of one visit to evaluate successful transitions likely overestimates transition success; the true goal of the transition process is for youth to remain engaged with adult services, as needed, rather than only one visit. Additionally, such a definition may also be less sensitive to inequities in transition, as factors like SES are likely to have increasing influence over an episode of treatment. While there is strong rationale for looking at a longer observation period, there is no empirical evidence in the current literature to guide the decision of what constitutes *enough* attendance with adult services to be considered a successful transition.

2.6.2 THE IMPORTANCE OF CONTEXT IN MHA TRANSITIONS

Much of the current literature has focused on regional MHA service policies via observational studies or qualitative interviews rather than implementing interventions or examining the impact of transitions from a health system perspective.⁷⁵ No known randomized-control trials have been conducted on transition interventions.⁴ While individualized accounts of the barriers and experiences of transitioning youth have been documented qualitatively, there is a lack of research on how mental health care systems impact transition success.⁸ Thus, generalizability is limited. Ultimately, the sheer complexity and differing organization of MHA services between regions, and even health authorities, makes transition evaluations difficult to accomplish and compare across settings, further justifying the need for setting-specific evaluations.

2.7 THE TRANSITION FROM YOUTH TO ADULT MHA SERVICES IN NOVA SCOTIA

Given the heterogeneity of mental health systems and populations throughout Canada, if we are interested in the transition from youth to adult MHA services in Nova Scotia, we must consider the context of Nova Scotians. For youth residing in the NS Health Central Zone, MHA

services are offered at the IWK, where outpatient MHA care is referred to as Community Mental Health & Addictions (CMHA). Within CMHA there are specific care clinics for specific diagnoses such as early psychosis, eating disorders, obsessive compulsive disorder, concurrent disorder, and ASD. The transition experience for those involved in specific care clinics, namely early psychosis, are often much more cohesive than those who do not have an exact match in the adult system or remain in the provision of (non-specific) CMHA care. To address some of these concerns, in 2015 NS Health and IWK developed a set of transition guidelines aimed at improving the cohesiveness of the transition to adult services.⁷⁶

2.7.1 GOVERNMENT & COMMUNITY RESPONSE TO MHA TRANSITIONS

There has also been considerable interest in recent years to improve and investigate the transition to adult MHA services from the Mental Health Commission of Canada, the federal and provincial governments, and local organizations.^{5,77} Locally, the Stay Connected Mental Health Project began in 2013, with the aim to “culturally shift how youth and their families transition from pediatric to adult-based services.”⁷⁸ Stay Connected has spearheaded several initiatives to improve MHA transitions in the HRM. Despite these initiatives, there is still concern around the transition to adult MHA services; the 2017 Auditor General of Nova Scotia’s report explicitly critiqued the gap created in the transition between youth and adult MHA care, recommending that “there should be a defined process for transitioning between youth and adult mental health care.”⁷⁹ More recently, adult MHA services have been critiqued by the Nova Scotia College of Social Workers for the disconnect between the biomedical/DSM-based model of service delivery, characteristic of most adult MHA services, and need for a more biopsychosocial and social justice based approach that takes into account social determinants of health.⁸⁰ The report also acknowledges that barriers and inequities may be created and/or maintained through the current approach to service delivery here in Nova Scotia. Evidently, transitional MHA care and research still has room for improvement and requires further investigation.

2.8 SUMMARY OF THE CURRENT GAPS

The literature review presented in this chapter points to several common gaps. First, few studies have been conducted using routinely collected health administrative data. While qualitative studies have provided valuable insights into the experiences of transitioning youth,

these results are difficult to implement at the health system level and may not be representative. Secondly, despite several studies investigating the association of clinical and demographic factors, the role of inequities and community-level factors have been overlooked. This is evidently an important and complicated issue that requires multiple data sources to address. Lastly, most studies have used attendance to only one visit in adult services to ascertain transition success, despite recognition of some of its limitations, and the need for more longitudinal follow up in adult services. Transitions to adult services are complicated and represent a unique period for investigating inequities across an episode of care but require longitudinal definitions that look beyond the first visit in adult services to assess this. From a quality assurance perspective, it is also important to pilot methods for conducting these assessments of transitional health service use outcomes using routinely collected data. While transitions are consistently identified as an important area for intervention and improvement, there continues to be a lack of published literature in the Canadian context. Thus, there is a need to investigate the use of novel definitions of transition success, look more longitudinally along an individual's episode of care, and interpret associations of demographic, clinical, and socioeconomic factors with attendance to adult services with an equity lens to guide future work and ultimately improve the transition experience of vulnerable youth.

CHAPTER 3: MENTAL HEALTH AND ADDICTIONS SERVICE USE IN A COHORT OF TRANSITION AGED YOUTH ACROSS PAEDIATRIC AND ADULT SERVICES

3.1 ABSTRACT

The peak onset of mental illness coincides with a transition from youth to adult mental health and addictions (MHA) services. However, over half of youth who need to transition do not do so, which can negatively impact the management of mental illness. While qualitative literature has identified common themes, these have been difficult to implement in health systems research. Thus, the objective of this study was to improve our understanding of transition-aged youth accessing publicly funded MHA services and identify potential inequities using routinely collected health administrative data. We created a retrospective cohort of transition-aged youth known to youth MHA services, and linked them with adult MHA service data. We measured the unadjusted associations of previously reported factors with attendance to adult MHA services, and conducted a sensitivity analysis using a two-visit definition of attendance. We found that less than a third of transition-aged youth known to youth MHA services attend adult MHA services in the first six months following the transition boundary. Youth and adult MHA-related ED usage, receiving specific-care services, and presenting with serious and enduring mental illness in youth services were associated with increased odds of attendance to adult services across both definitions of attendance. Having a moderate area-level proportion of single-parent families was also associated with higher odds of attendance compared to high single-parent family areas. Overall, these low rates of attendance in adult services may reflect that only few individuals require a transition, or that there are logistical challenges which contribute to potentially inequitable transitions.

3.2 INTRODUCTION:

Early and appropriate interventions for mental health concerns in youth are imperative to avoid negative outcomes,¹⁻³ yet many Canadian youth in need of specialized mental health and addictions (MHA) services do not receive adequate care.⁴⁻⁶ Adolescence is a particularly critical period for diagnosis and intervention, as upwards of 70% of mental illness has an onset before the age of 25.¹⁻³ For a majority of youth accessing child and adolescent MHA services in adolescence, they will require a transition to adult services when reaching the transition boundary.^{7,8} These transitions should be smooth and continuous, however studies from the United States (USA) and United Kingdom (UK) estimate that over 60% of youth disengage from services during the transition period, widening the gap between those in need and accessing MHA services.^{7,9,10} There are currently no comprehensive estimates of disengagement across youth and adult MHA services in Canada.

Youth and adult MHA services differ both philosophically and structurally.¹¹ Eligibility criteria for MHA services often differ, which can leave youth ineligible or without direct service equivalents when transitioning to the adult system.⁸ For those who maintain service eligibility, service delivery is often more individual focused, rather than family oriented, and centered more on diagnosis and pharmaceutical intervention relative to youth MHA.^{11,12} Additionally, there are currently no evidence-based guidelines regarding who should transition to adult MHA services,¹³ and clinician biases regarding diagnosis and treatment are known to influence decisions to send or accept referrals, which may exacerbate known inequities in MHA care.^{7,14-17}

Qualitative studies have provided rich insight into individual experiences and identified potential inequities during transitions.¹⁷⁻¹⁹ For example, qualitative indicators of successful transitions have been proposed and validated, including information transfer, parallel care between youth and adult MHA, and transition planning.^{7,20,21} Such research has also revealed that patients' preferences for treatment play a role in transitions, where youth may refuse a referral to adult MHA services regardless of the clinicians' recommendation.⁷ While valuable in better understanding the priorities of transitioning youth, these findings are difficult to translate into in health system-wide continuous quality improvement and policy development. Of the quantitative literature, most have used referral acceptance, or attendance to a single outpatient adult MHA

appointment to ascertain transition success. However, referrals may not be routinely tracked, and there is often a sharp decline in attendance after the first adult MHA visit, which calls into question the validity of this indicator.^{7,10,14} Additionally, past research has identified that non-clinical factors (e.g., race/ethnicity) affect attendance not only at first contact with MHA services, but also across episodes of care.²² Thus, looking more longitudinally may provide a more comprehensive picture of transition-aged health service use and potential inequities. Given the importance of the transition age for lifelong mental wellbeing, there is a need to address the paucity of literature on transitions in the Canadian context.^{23,24}

3.2.1 OBJECTIVE

The objective of this study was to improve our understanding of transition-aged youth accessing publicly funded MHA services in Nova Scotia and identify potential inequities using routinely collected health administrative data. Specifically, we aimed to: 1) describe demographics and service use patterns of transition-aged youth; 2) estimate the associations between clinical, demographic, and socioeconomic characteristics and health service use with attendance to adult MHA services; and 3) assess the sensitivity of these associations using a two-visit definition of attendance.

3.3 METHODS:

3.3.1 PEDIATRIC MHA COHORT

A retrospective cohort of transition-aged (18.5-19.5 years) youth was created using data housed at the IWK Health Centre, a paediatric health centre in Halifax, Nova Scotia (NS) providing child and adolescent MHA services for youth up to their 19th birthday. To be eligible, youth were required to have lived within the NS Health Central Zone, which encompasses Halifax and surrounding areas, and attended at least one outpatient youth MHA appointment between April 2016 to August 2019 at the transition age of 18.5-19.5 years (n=664). The lower bound of 18.5 years reflects the earliest age a transition to adult MHA services can be initiated, with age 19 years being the formal paediatric age cut off within the NS MHA system. Youth must have held a valid health card from any Canadian province/territory at the time of their IWK appointment.

Demographic and clinical characteristics (sex, age, presenting concern, priority status, clinic type) were collected from youths' last IWK MHA visit. Presenting concern was coded as yes/no for each of the following types: serious and enduring mental disorders (schizophrenia, Axis II disorders, bipolar disorders); emotional/neurotic disorders (anxiety and/or depressive disorders); eating disorders; neurodevelopmental disorders (autism spectrum disorders, conduct disorders, attention deficit and hyperactivity disorder (ADHD)); to be determined. We differentiated between specific care clinics (e.g., NS Early Psychosis Program) and Community MHA (non-specific) clinics, as specific care clinics have more streamlined transition processes to adult MHA services than Community MHA. We also collected any (yes/no) IWK or Nova Scotia Health MHA-related ED use in the year prior to one's 19th birthday, as ascertained from *International Classification of Diseases (ICD-10)*²⁵ diagnostic and assessment codes and Canadian Classification for Interventions²⁶ counselling codes (*Supplement*). Census data on geography (aggregate dissemination area (ADA)) and dissemination-area (DA) level socioeconomic factors (median household income, percentage of single parent families) from the 2016 Canadian Census of Population were linked to each youth's home DA via six-digit postal code using the Postal Code Conversion File[®].²⁷

3.3.2 LINKAGE WITH ADULT MHA SERVICES

IWK records for the cohort were linked by health card number with Central Zone outpatient adult MHA appointment and MHA-related Emergency Department (ED) visit data housed at Nova Scotia Health, which provides MHA services for adults across the province. Adult MHA-related ED visits within six months following the 19th birthday were identified by presenting concern or *International Classification of Diseases (ICD-10)*²⁵ discharge diagnoses (detailed information in *Supplement*). We defined repeat ED users as youth who attended the ED for a MHA-related concern at least three times within the six month observation period, as this may reflect challenges and gaps in community care.¹ The study observation window ended in March 2020 to allow for sufficient follow-up time in adult services and avoid introducing confounding from the COVID-19 pandemic.

3.3.3 IDENTIFICATION OF ATTENDANCE IN OUTPATIENT ADULT MHA SERVICES

Our outcome of interest was attendance to outpatient adult MHA services, which was defined as attendance to at least one adult outpatient MHA appointment within six months following the 19th birthday (**one-visit definition**). We also conducted a sensitivity analysis of the definition, considering attendance to at least two adult outpatient MHA appointments within this same time frame (**two-visit definition**).

3.3.4 REFERRALS MADE THROUGH STAY CONNECTED

For a subset of youth (n=54), we could identify whether a referral from IWK to Nova Scotia Health MHA services was made through the Stay Connected Mental Health Project, which provides additional support and evaluation of transitioning youth; as a sensitivity analysis, these individuals were further analyzed as a subset of the main cohort, as they likely had improved transitions to adult services and we were able to confidently identify this group as needing to transition.

3.3.5 STATISTICAL ANALYSIS

To meet objective 1, we summarized the demographic, clinical, and socioeconomic characteristics of the full IWK MHA cohort along with their health service use (frequencies of their adult MHA outpatient use and ED service use). To meet objective 2, we first described the demographic, clinical, and socioeconomic characteristics as well as the health service use by transition success measured by adult MHA service attendance using the one-visit definition. We then estimated the unadjusted associations between attending adult MHA services and each of the independent variables, sex, presenting concern (yes/no for each category), clinic type, priority status, youth ED use, adult ED use, DA-level median household income, and DA-level proportion of single parent household (quartiles) using multi-level logistic regression models with ADA as a random intercept to account for community clustering. These independent variables were selected based on their hypothesized role in the transition period and reported irrespective of statistical significance. If there were fewer than five youth in an ADA, we replaced their ADA with the most socioeconomically similar neighbouring ADA. From the null model (including only the random intercept), we included each independent variable individually to measure unadjusted associations with attendance to adult MHA services. We did not run

adjusted models due to low power. To investigate if the association between attendance to adult MHA services and each of the presenting concerns differed by sex, we also ran sex-stratified analyses. To address objective 3, we repeated all analyses using the two-visit definition of attendance to adult MHA services.

Lastly, as a sensitivity analysis, we repeated all analyses for the Stay Connected sub-cohort. Due to small sample size, it was not feasible to create multi-level nor stratified models in this sub-cohort. Instead, we created a logistic regression model with robust standard errors to provide a conservative estimate of confidence intervals given potential small magnitude clustering.

This study was approved by the IWK Health (*REB#1026393*) and NS Health (*REB#1026611*) Research Ethics Boards. All analyses were conducted using Stata version 16 (StataCorp, College Station, TX).

3.4 RESULTS

Figure 2.1 summarizes the inclusion and exclusion for the study. We identified 843 youth seen by IWK MHA services over the age of 18.5 years between April 2016 to August 2019. After excluding youth beyond the upper age range and outside the geographic area, the full cohort of transition-aged youth known to IWK MHA services consisted of 664 youth (281 males and 383 females), with a mean age of 18.9 years (Range: 18.5-19.5 years) (Table 1).

Table 1 presents the demographic, clinical, socioeconomic and health service use characteristics of the full cohort (n=664). With respect to the clinical characteristics of the full cohort, emotional/neurotic disorders were the most common presenting concern (n=305 (45.9%)). A small proportion (n=81 (12.2%)) of the full cohort were identified as priority patients in youth MHA services, meaning that due to the severity, acuity, and/or impact on daily functioning of their presenting concern, they required IWK MHA services within one week of referral/last visit. Approximately 28% (n=185) of the full cohort received care in specific care clinics, which provide specialized care for certain diagnoses (e.g., concurrent disorders, autism spectrum disorder, psychotic disorders). In terms of socioeconomic characteristics, the DA-level median household income in the full cohort was \$39,701 (IQR: \$31,653-\$46,818). With respect to health

service use, 19.3% (n=128) of the full cohort had MHA-related ED use between the ages of age 18-19 years, while 7.7% (n=51) had adult MHA-related ED use (age 19-19.5 years).

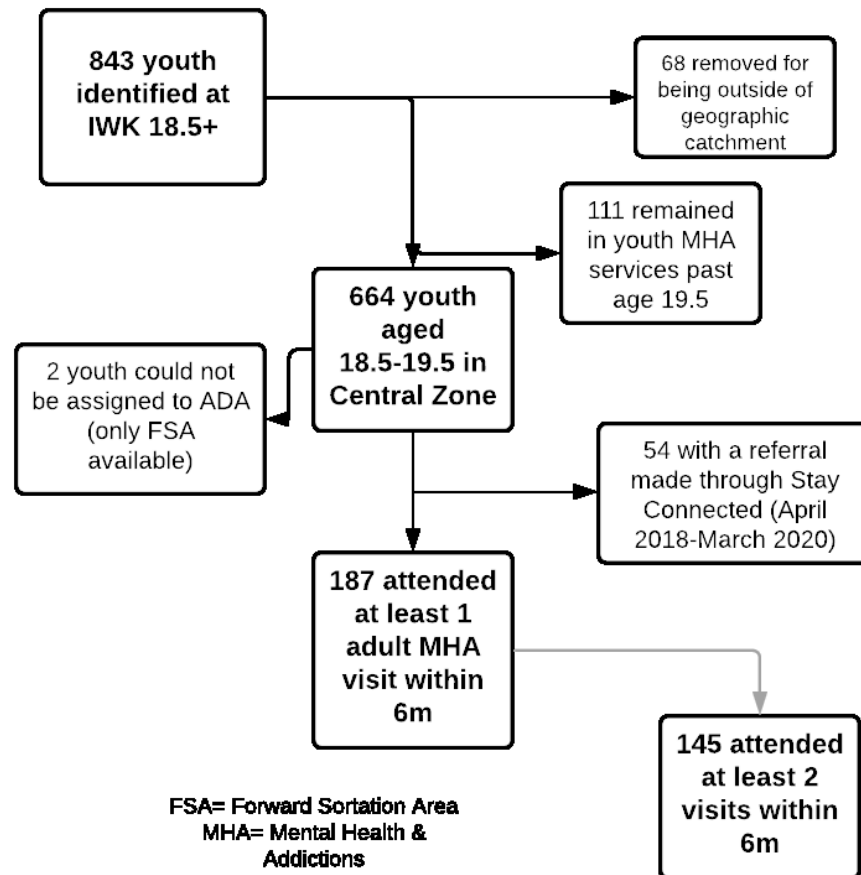


Figure 2.1: Flow diagram outlining the inclusion and exclusion criteria for the cohort across youth and adult services.

3.4.1 CHARACTERISTICS AND HEALTH SERVICE USE BY ONE-VISIT DEFINITION OF ATTENDANCE

Table 2 summarizes the demographic, clinical, and socioeconomic characteristics, and health service use by attendance to adult MHA services using the one-visit definition (≥ 1 visit within six months following the 19th birthday). From the full cohort, 28.2% (n=187) attended at least one visit in adult MHA services within six months of their 19th birthday. The demographic, clinical, and socioeconomic factors, and health service use of those attending at least one visit are found in the third column of Table 2; for those who did not attend any visits within six

months following their 19th birthday, descriptions are found in the second column of Table 2. The demographic, clinical, and socioeconomic characteristics of those attending and not attending at least one visit were not tested for statistically significant differences (i.e., t-tests) to avoid inflation of the type I error rate from redundant comparisons and are only for descriptive purposes.

Table 1: Descriptive Statistics of the Full Cohort

	Full Cohort n=664 (100%)
Demographic Characteristics	
Age at last IWK visit, mean (Min-Max)	18.9 (18.5-19.5)
Male	281 (42.3%)
Clinical Characteristics	
Presenting Concern	
Serious & Enduring Mental Disorders	43 (6.5%)
Emotional/Neurotic Disorders	305 (45.9%)
Eating Disorders	15 (2.2%)
Neurodevelopmental Disorders	60 (9.0%)
Substance Use Disorders	87 (13.1%)
To Be Determined	43 (6.5%)
Missing	111 (16.7%)
Priority Stream	81 (12.2%)
Specific Care @ IWK	185 (27.9%)
Socioeconomic Characteristics	
DA-Level Median Household Income/year (IQR)	\$39,701 (31,653-46,818)
DA-Level Percentage of Single-Parent Households	
<25 th centile (Low)	155 (23.4%)
25 th – 75 th centile (Moderate)	331 (51.5%)
>75 th centile (High)	166 (25.1%)
Health Service Use	
Any Youth ED use	128 (19.3%)
Any Adult ED use	51 (7.7%)
Repeated Adult ED Use (3+)	13 (2.0%)
Median number of adult mental health-related ED visits in 6 months (IQR)	1 (1-3)

In terms of health service use, youth who attended at least one visit within six months had a median of four (IQR: 2-7) adult outpatient MHA visits. In addition, 22.4% (n=42) of youth who attended at least one visit in adult MHA services attended both youth and adult MHA services

simultaneously, meaning their first adult MHA visit preceded their last youth MHA visit. Those who attended their first adult MHA appointment after leaving youth MHA services (n=143) had a median wait time of 81.5 days to first adult MHA visit (IQR: 36-129.5).

When looking at MHA-related ED service patterns, among those who did not attend any outpatient adult MHA services within six months (Table 2, second column), very few youth (n=17 (3.6%)) utilized the adult ED, and fewer than five were repeat (3+ visits) ED users. Among those who attended adult outpatient services at least once (Table 2, third column), 18.2% (n=34) used the adult ED, and very few 6.4% (n=12) were repeat ED users (Range: 0-7) within six months.

3.4.2 CHARACTERISTICS ASSOCIATED WITH ATTENDANCE IN ADULT MHA SERVICES

Table 2 also summarizes the unadjusted associations between clinical, demographic, and socioeconomic characteristics as well as youth and adult ED use with attendance to adult MHA services (4th column), accounting for community clustering. Among clinical characteristics, youth with serious and enduring presenting concerns had 2.17 times higher odds (95% CI: 1.11-4.25) of attending adult MHA services; however, stratified analysis showed significance only among males (Supplemental Table 3). Youth in specific care clinics at their last IWK visit also had higher odds (OR: 1.53 (95% CI: 1.04-2.23)) of attending adult MHA services. Among the socioeconomic characteristics, those living in an area with a moderate percentage of single parent households (25th to 75th percentile) had higher odds (OR: 1.61 (95% CI: 1.03-2.52)) of attending adult services than those living in areas with a high (>75th centile) percentage of single parent households; attendance among those living in areas with a low (<25th centile) proportion of single parent households was not significantly different than those living in areas with a high proportion. In terms of health service use, both youth and adult ED use had strong associations with attending adult MHA services; having at least one youth MHA ED visit was associated with 2.60 times (95% CI:1.72-3.93) higher odds, and having at least one adult MHA ED visit was associated with 6.66 times (95% CI:3.52-12.61) higher odds of attending adult MHA services. Differences between communities explained 4.2% (95% CI: 1.0%-16.3%) of the variance in the probability of attending at least one adult MHA visit, unadjusted for other factors (data not shown).

Table 2: Descriptive Characteristics of Youth Meeting the One-Visit Definition of Attendance and Unadjusted Associations Modelling Attendance to At Least One Visit.

	Attended 0 Visits within 6 Months n=477 (71.8%)	Attended at least 1 visit within 6 months n=187 (28.2%)	Unadjusted Odds Ratios*
Demographic Characteristics			
Age at last IWK visit, mean	18.8	19.0	-
Male	210 (44.0%)	71 (38.0%)	0.76 (0.53-1.09)
Clinical Characteristics			
Presenting Concern			
Serious & Enduring Mental Disorders	25 (5.2%)	18 (9.6%)	2.17 (1.11-4.25)
Emotional/Neurotic Disorders	218 (45.7%)	87 (46.5%)	0.98 (0.69-1.41)
Eating Disorders	11 (2.3%)	0	0.96 (0.29-3.15)
Neurodevelopmental Disorders	43 (9.0%)	17 (9.1%)	0.99 (0.54-1.81)
Substance Use Disorders	59 (12.4%)	28 (15.0%)	1.26 (0.76-2.07)
To Be Determined	36 (7.5%)	7 (3.7%)	0.50 (0.21-1.17)
Missing	85 (17.8%)	26 (13.9%)	-
Priority Stream, Yes	58 (12.1%)	23 (12.3%)	1.02 (0.60-1.72)
Specific Care @ IWK, Yes	122 (25.6%)	63 (33.7%)	1.53 (1.04-2.23)
Socioeconomic Characteristics			
DA-Level Median Household Income/year, (IQR)	\$39,183 (31,361- 46,794)	\$40,605 (33,160- 46,818)	1.00 (0.99-1.01)
DA-Level Percentage of Single-Parent Households			
<25 th centile (Low)	117 (24.6%)	38 (20.4%)	1.10 (0.63-1.89)
25 th – 75 th centile (Moderate)	231 (48.5%)	110 (59.1%)	1.61 (1.03-2.52)
>75 th centile (High)	128 (26.9%)	38 (20.4%)	Reference
Health Service Use			
Median number of adult outpatient visits in 6-months (IQR)	0	4 (2-7)	-
Median time to first adult outpatient MHA visit, days (IQR)	-	81.5 (36-129.5)	-
Last Youth MHA appointment after first adult appointment	-	42 (22.4%)	-
Any Youth ED use	71 (14.9%)	57 (30.5%)	2.60 (1.72-3.93)
Any Adult ED use	17 (3.6%)	34 (18.2%)	6.66 (3.52-12.61)
Repeated Adult ED Use (3+)	<5	12 (6.4%)	-
Median number of adult mental health- related ED visits in 6 months (IQR)	1 (1-1)	1 (1-3)	-

*All models included a random intercept by ADA and were unadjusted for other factors. 95% confidence interval is presented in brackets.

Bold indicates statistically significant association (p<0.05)

Presenting concerns were coded as yes/no for each category independently.

- indicates the association was not modelled

Cell sizes <5 were suppressed for confidentiality

3.4.3 SENSITIVITY ANALYSIS: ATTENDANCE IN ADULT SERVICES (TWO-VISIT DEFINITION)

Table 3 summarizes the descriptive characteristics and health service use patterns of the full cohort divided by the two-visit definition of transition success (<2 visits within six months, ≥ 2 visits within six months), as well as the unadjusted associations between clinical, demographic, socioeconomic and health service use factors with attendance to adult MHA services (4th column), accounting for community clustering. A small proportion (21.8% (n=145)) of the full cohort attended at least two visits within six months following their 19th birthday, which is 6.3% fewer than the one-visit definition. The results of the unadjusted associations were similar between the analyses using the one-visit and two-visit definitions (4th columns in Table 2 and Table 3). The magnitudes of these associations, apart from adult MHA-related ED use, were greater in the two-visit definition compared to the one-visit definition. Unique to those attending at least two adult MHA visits, females with substance use presenting concerns had statistically significant higher odds of attending adult MHA appointments (Supplemental Table 3).

3.4.4 SENSITIVITY ANALYSIS REFERRED THROUGH STAY CONNECTED

Few youth (54 (15.5%) out of 664 youth in the full cohort) were identified as referred to adult MHA services through Stay Connected (Figure 2.1). However, this is an underestimate as these data were only collected from April 2018 and did not capture all referrals within that timeframe. Most youth in this Stay Connected sub-cohort (n=34 (63%)) attended at least one adult outpatient MHA appointment within six months of their 19th birthday (Supplemental Table 5), and 55.5% (n=30) attended at least two visits (Supplemental Table 6). There were a few notable differences between the full cohort and the Stay Connected sub-cohort: compared to the full cohort, males (43.6% in full cohort vs. 25.9% in Stay Connected sub-cohort) and youth with neurodevelopmental disorders (9.0% in full cohort vs. <5% in Stay Connected sub-cohort) appeared to be underrepresented in these referrals through Stay Connected. Additionally, compared to the full cohort, a larger proportion of youth referred through Stay Connected used the ED in both youth and adult MHA services (Supplemental Table 4).

Table 3: Descriptive Characteristics of Youth Meeting the Two-Visit Definition of Attendance and Unadjusted Associations Modelling Attendance to At Least Two Visits

	Attended <2 visits within 6 months n=519 (78.2%)	Attended at least 2 visits within 6 months n=145 (21.8%)	Unadjusted Odds Ratios*
Demographic Characteristics			
Age at last IWK visit, mean	18.8	19.0	-
Male	224 (43.1%)	57 (39.3%)	0.83 (0.57-1.23)
Clinical Characteristics			
Presenting Concern			
Serious & Enduring Mental Disorders	26 (5.0%)	17 (11.7%)	2.97 (1.48-5.94)
Emotional/Neurotic Disorders	237 (45.7%)	68 (46.9%)	0.98 (0.66-1.45)
Eating Disorders	11 (2.1%)	<10	1.40 (0.42-4.68)
Neurodevelopmental Disorders	49 (9.4%)	11 (7.6%)	0.76 (0.38-1.53)
Substance Use Disorders	64 (12.3%)	23 (15.9%)	1.35 (0.79-2.32)
To Be Determined	38 (7.3%)	<10	0.47 (0.18-1.25)
Missing	94 (18.1%)	17 (11.7%)	-
Priority Stream, Yes	64 (12.3%)	17 (11.7%)	0.93 (0.52-1.68)
Specific Care @ IWK, Yes	132 (25.4%)	53 (36.5%)	1.77 (1.18-2.68)
Socioeconomic Characteristics			
DA-Level Median Household Income/year (IQR)	\$39,183 (31,515-46,611)	\$40,644 (32,778-47,471)	1.00 (0.99-1.00)
DA-Level Percentage of Single-Parent Households			
<25 th centile	124 (24.0%)	31 (21.4%)	1.35 (0.73-2.49)
25 th – 75 th centile	254 (49.1%)	87 (60.0%)	1.76 (1.06-2.91)
>75 th centile	139 (26.9%)	27 (18.6%)	Reference
Health Service Use			
Median number of adult outpatient visits in 6-months (IQR)	0	5 (3-8)	-
Median time to first adult outpatient MHA visit, days (IQR)	-	62 (31-117)	-
Last Youth MHA appointment after first adult appointment	-	38 (26.2%)	-
Any Youth ED use	81 (15.6%)	47 (32.4%)	2.75 (1.77-4.27)
Any Adult ED use	24 (4.6%)	27 (18.6%)	5.14 (2.78-9.51)
Repeated ED Use (3+)	<5	11 (7.6%)	-
Median number of adult mental health-related ED visits in 6 months (IQR)	1 (1-1)	1 (1-4)	-

*All models included a random intercept by ADA, and were unadjusted for other factors. 95% confidence interval is presented in brackets.

Bold indicates statistically significant association (p<0.05)

Presenting concerns were coded as yes/no for each category independently.

- indicates the association was not modelled

Cell sizes <5 were suppressed for confidentiality

In terms of the unadjusted associations between clinical, demographic, and socioeconomic characteristics and health service use with attendance to adult MHA services, either using the one- and two-visit definitions of attendance, no characteristic was statistically significant, except DA-level median percentage of single-parent households (Supplemental Tables 5 & 6).

Those known to have been referred through Stay Connected had 5.67 times (95% CI: 3.06-10.51) higher odds of attending adult services than those who did not have record of a referral (n=349), within the timeframe where referral data were collected (April 2018-March 2020) (Supplemental Table 4)

3.5 DISCUSSION

Overall, we aimed to improve our understanding of transition aged youth attending IWK MHA services. In the current study, fewer than a third of transition aged youth known to IWK MHA services attended adult MHA services within six months of the transition boundary. These low rates of attendance may reflect logistical challenges between youth and adult MHA services, including wait times, referral delays, and/or differences in service provision between youth and adult MHA services which are difficult to capture in health administrative data. It may also reflect that few individuals require or are eligible to transition to adult services. Nonetheless, the data reflect lower than expected rates of transition to adult services based on the literature.⁷ Based on the results from the unadjusted regression analyses, it appears that there are certain clinical factors, such as MHA-related ED use and presenting concern, which are associated with attending adult services. Additionally, it appears that of those who attend any outpatient adult MHA services, nearly 25% do not attend more than one visit, highlighting the need for more longitudinal follow up of transition aged youth past the transition boundary. Our findings ultimately highlight the challenges in utilizing health administrative data to measure transition success but also identify opportunities for improving continuous quality improvement across the transition from youth to adult MHA services.

3.5.1 ATTENDANCE TO ADULT SERVICES

While not every patient known to IWK MHA services is expected to attend adult MHA services, past literature has estimated that up to 80% of youth attending youth MHA services at the transition boundary in the UK are suitable to transition to adult MHA services.⁷ While there are no equivalent estimates in Canada, we know that all individuals in our sub-cohort of known referrals to adult MHA through Stay Connected, were deemed suitable to transition by youth MHA clinicians. Still, only 63% in this sub-cohort attended adult MHA services within six months following their 19th birthday. While it is reassuring that those identified as being referred to adult MHA through Stay Connected are more likely to attend adult services, these rates still fall nearly 20% below what we would expect.

While we would have expected a larger proportion to subsequently attend adult MHA services based on eligibility, the proportion of this cohort who attended adult MHA services (28.2%) is slightly larger than what has been found in existing literature, reflecting just how difficult transitions are across the globe.¹⁰ In a systematic review of youth eligible to transition to adult MHA services across Europe, Australia, and North America, 24% were found to have “completed their transition” to adult MHA services.¹⁰ However, studies have used different definitions of transition success,^{7,28} and used shorter observation windows,²⁹ which may explain why our point estimate was slightly higher and makes these difficult to compare. While it is difficult to directly compare transition rates between countries and even health systems, all of these transitions rates are lower than what would be expected based on the population’s need for care directly before the transition boundary.

3.5.2 FACTORS ASSOCIATED WITH ATTENDANCE TO ADULT MHA SERVICES

Our unadjusted regression analyses indicate that there are certain presenting concern categories of adolescents in youth MHA which are more likely to subsequently attend adult MHA services. These associations are consistent with known differences in service mandates between youth and adult MHA services. For example, it is consistent with both service delivery and prognosis for these illnesses that youth with serious and enduring presenting concerns are more likely to transition to adult MHA services than other presenting concerns. In terms of service delivery in Nova Scotia, individuals with serious and enduring disorders are also more likely to receive care

in specific care clinics, such as the Nova Scotia Early Psychosis Program, which have developed streamlined transition guidelines separate from Community MHA and span both youth and adult MHA services. While we could not objectively assess need for services or diagnostic assessment, we did see that individuals in specific care clinics had higher odds of attending adult MHA. Similarly, individuals with serious and enduring concerns may be more likely to require more intensive services (i.e., from a specialist) and thus meet the stringent criteria for adult MHA services.³⁰ Given that adult MHA in North America and Europe has been characterized as being biomedically and diagnostically driven relative to youth MHA,^{12,18} those who fit into DSM-V diagnostic classes requiring specialist management, such as those with serious manifestations of mental illness such as psychoses, may be more likely to be accepted by adult MHA than someone receiving early intervention for MHA concerns that could worsen over time, as is common in youth MHA services. While these individuals are likely still significantly impaired, they appear to be less likely to subsequently attend adult services within the first six months of becoming eligible. It is reassuring that those likely to be most in need of specialist services are subsequently attending adult services. Further assessing the qualitative differences in transition guidelines between specific care clinics and community MHA may identify efficacious transition policies for wider adoption.

While we also expected that those with neurodevelopmental disorders would be less likely to attend adult services, given that past literature from the UK and USA has found that disorders such as ASD or ADHD are less likely to be referred and/or accepted by adult MHA due to clinician biases,^{7,8,18} we did not find a significant association. These conditions (namely ADHD) have recently been recognized to be lifespan conditions,³¹ thus, adult services may have adapted and begun offering expanded and appropriate services into adulthood, which subsequently has increased adult MHA attendance in those with these concerns. We did however notice that males and youth with neurodevelopmental disorders were underrepresented in those referred through Stay Connected relative to the full cohort but, acknowledge that this subset of referrals identifiable in the data is non-random, and thus may reflect selection bias relative to all referrals made to adult MHA services.

In terms of health service use, those with youth or adult ED use were more likely to attend adult services, which may reflect increased need for or access to MHA services. It is also likely that those with MHA-related ED visits are involved in more proactive care-seeking behaviours, and/or aware of worsening symptoms and thus are more likely to attend adult MHA services.^{32,33} This finding is novel, as past work has found that transitioning youth who remain on the waitlist for adult MHA services report more ED visits than those who transitioned immediately after crossing the age boundary.³⁴ However in the Cappelli et al. study,³⁴ their cohort consisted of only individuals referred to adult MHA services, which is not true for our cohort. We might expect that if a gap in care resulting in unmet need for services and progression of illness across the transition period was created, ED utilization would be higher in those who did not attend adult services. While this does not appear to be the case, at least in the short term, it may be confounded by need if those who did not attend outpatient MHA services did not need any MHA care. Longer periods of observation of MHA-related service use, including ED usage, may also reveal different trends.

3.5.3 LOOKING BEYOND ONE VISIT

Based on our results, using a longer observation (i.e., at least two visits) period to measure attendance and potential inequities across an episode of care is particularly informative in the context of transitions. Even after accessing youth MHA services once, many non-clinical factors such as race²², geography³⁵, education¹⁶, and socioeconomic status³⁶ may affect an individual's ability to continue accessing MHA services. Indeed, when looking more longitudinally, we saw that nearly 25% of those who attended a single visit in adult MHA services did not attend a second visit within the six-month observation period, which may reflect that these individuals only required one visit in which their needs were met or may be related to discharges and/or inequities in access to care. While most transition studies end observation at the first outpatient adult MHA visit, this is higher than the 16% found in a previous study.⁷ We cannot however, differentiate between youth whose needs were met in their first visit or in the wait time between youth and adult MHA services, and those who did not attend multiple visits due to inequities or barriers in care. Without an indication of clinical discharge, we cannot differentiate these pathways. Additionally, the magnitude of the associations using the two-visit definition appeared larger than the one-visit definition, which may indicate that factors that influence attendance to

the first visit have an increasing influence over repeated visits. Further work specifically investigating the subgroup of individuals who attend only one visit in adult MHA services, looking more longitudinally, incorporating clinical discharges, wait times, and patient experiences, would help understand why youth do not attend multiple adult MHA visits, and more precisely identify how factors affecting attendance to the first adult MHA visit may reflect the need (or lack thereof) for subsequent visits.

In terms of socioeconomic factors, we found that geography explains a small proportion (<10%) of the variance in the probability of attending adult services. This may reflect that there was little heterogeneity in the cohort, or that most of the variability in the probability of attending adult services is due to individual-level factors. We were underpowered to create adjusted models to examine how the explained variability changes when adjusting for individual- and area- level factors, however doing so in future studies would help further assess this hypothesis.

While we did not find a significant relationship with median income, our cohort's median income was below the Halifax poverty line across the observation period,³⁷ which likely reflects the overrepresentation of mental illness and/or increased need for these services in those of low income. This finding confirms that transition-aged youth known to IWK MHA services are a vulnerable subset of the population in terms of both their developmental stage and socioeconomic characteristics. While we did not have individual-level data, it is known that those of lower socioeconomic status (SES) are more likely to need,³⁸ and more likely to have difficulties in accessing MHA services.³⁶ Further work should ensure that the appropriate supports are in place for these individuals to continue accessing needed MHA services across the transition boundary, and further address unmet need in those who have not accessed services at all, which was outside of the scope of this study. Additionally, we did find that those living in areas with a high ($\geq 75^{\text{th}}$ centile) proportion of single parent families were less likely to attend adult MHA services than those in areas with a moderate ($25^{\text{th}} - 75^{\text{th}}$) proportion. This association with single parent families is opposite to what we would expect epidemiologically in terms of need for MHA services, thus likely reflects difficulties in access. While clinician biases regarding what constitutes a need for services or what the appropriate management is for a certain patient must be recognized, we would be able to better differentiate between need and

access by routinely collecting indicators of ongoing need for services (i.e., referrals), adjusting for these indicators, and looking more longitudinally to assess the influence of these factors across an episode of care. Even with better data collection of those who are accessing services, there is still the need to educate and recognize the potential for inequities across the transition to adult MHA services by better understanding the gap between population-based expectations of need, and who is actually accessing or requesting care across the transition period.

3.5.4 LIMITATIONS

We must also acknowledge some limitations. In our data sources, we could not classify individuals according to their referral/eligibility to transition to adult MHA services. While this information was available for some of our cohort, it was not collected comprehensively. Thus, for the 71.8% of the cohort who did not attend adult MHA services within the first 6 months past the transition boundary, we cannot classify them as “unsuccessfully transitioned” as they may not have met eligibility criteria for adult MHA services or importantly, did not need/want adult MHA services offered at Nova Scotia Health (i.e., their treatment was complete) or preferred to access them elsewhere (i.e., privately). Next, we were limited by our sample size in exploring both multi-level and stratified analyses, particularly in the sub-cohort with known referrals through Stay Connected. We also could not create adjusted models, which means our statistically significant univariable associations may be confounded by other factors. We could not extend our overall observation period to increase power, as substantial changes to the transition process, including the transition guidelines and Stay Connected Mental Health Project, were implemented in June 2015. Including youth in attendance to services prior to this would undermine the internal validity of our study. We also found that wait times for adult MHA services were highly variable over the observation period. While we used a six-month observation period to capture episodes of care spanning the transition boundary, based on wait time trends some individuals may have attended a ‘transition’ appointment more than six months past their 19th birthday, and thus were misclassified as not attending adult MHA services. In terms of our inequity analyses, important indicators such as income³⁶, family status²⁹, race,²² and gender,³⁹ which are known to play a role in inequities, are not routinely collected in health administrative data. Thus, we could not investigate these associations at the individual level. We also acknowledge that over 15% of our

cohort had missing data on presenting concern, which may non-differentially bias the presented associations of presenting concern categories with attendance to adult MHA services.

3.5.5 RECOMMENDATIONS

Challenges in transitions between pediatric and adult services are common in MHA^{7,8} and have repeatedly been identified as a priority for improvement,^{23,24} including within Nova Scotia.⁴⁰ Yet there is a dearth of information on the transition between youth and adult MHA services, and a significant gap in data collection; our results have highlighted some of these gaps. Without accurately identifying and tracking transitioning youth, the data required to plan, implement, and evaluate the transition from youth to adult MHA services will continue to be uncertain. To address these identified problems and assess the efficacy of any future interventions, we must ensure we can accurately capture who needs and who completes successful transitions to adult MHA services. On the youth MHA side, having a routinely collected indicator of youth's disposition (i.e., discharged to primary care, referred to adult MHA, concerns resolved) or file closure would improve the specificity of transition evaluations and enable continuous quality improvement for this potentially vulnerable group. On the adult MHA side, routinely tracking referrals received, the decisions for these referrals, clinical discharges, and no-shows /cancellations would add a richness to the assessment of service use in transition aged youth by being able to differentiate different service pathways, particularly when attendance drops substantially after the first visit.^{7,10,14} Similarly, there is a need in both systems to capture youths' preferences or shared decisions made during treatment to help more accurately assess inequities. Beyond tertiary youth and adult MHA services, there may also be opportunities outside of the formal health system to collect data from community-based programs or primary care to supplement future analyses.

3.5.6 CONCLUSION

Overall, care teams within and between health authorities must work together across youth and adult services to improve information capture and transfer to allow quality monitoring and improvement. We have found important associations between clinical factors, such as MHA ED use and presenting concern categories, and identified that longer observation periods may provide further insights. Our results also highlight the need for data solutions at the health system

level to improve the capture of those transitioning between youth and adult MHA services. Routinely tracking referrals between services and implementing newly developed standardized assessments, such as the Transition Readiness and Appropriateness Measure,⁴¹ or the Adult Needs and Strengths Assessment for Transition to Adulthood (ANSA-T),⁴² will help better identify transition suitable youth, reinforce quality improvement initiatives, and improve information sharing and parallel care. There are also opportunities to incorporate youths' self-reported need assessments, such as the Camberwell Assessment of Need,⁴³ in youth MHA services close to the transition boundary to identify met and unmet need and plan interventions accordingly. As it exists currently, health administrative data is not ideally suited to answer these important questions about transition aged health service outcomes and potential inequities. Further quantitative findings from robust data sources will complement qualitative findings of the perceived gaps in care, improve certainty regarding transition eligibility, and enable identification of vulnerable youth to ensure the health system prevents future youth from becoming lost in transition.

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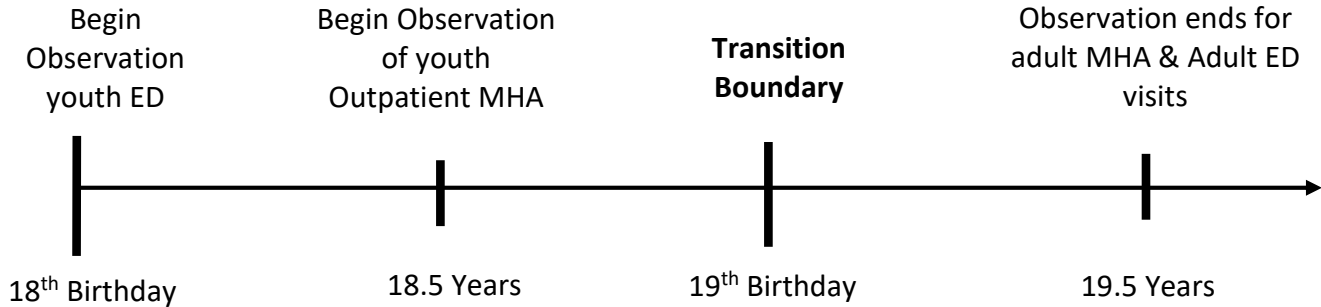
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3.7 ONLINE SUPPLEMENT TO MANUSCRIPT



Supplemental Figure 1: Individual Transition Timeline & Observation Windows

Supplemental Table 1: ICD-9, ICD-10 Codes & Canadian Classification for Intervention Codes Used to Ascertain Mental Health & Addictions Related Emergency Department Usage

IWK	Mental Health-Related ED Use	<p>The codes include: Substance Use: ICD-10 F1-19, F55</p> <p>Mental Health: ICD-10 F00-09, F53.1, G30, R41.3, F20-29, R41.0, F30-33, F34.0, F32.1, F34.8, F34.9, F38, F39, F53.0, F40-F42, F93.0-93.2, F32.0, F43.1, F43.8, F43.9, F60-62, F68-69, F43.2, F44, F45, F48.0, F48.1, F48.8-48.9, F53.8-53.9, F50-52, F54, F59, F63-F66, F70-73, F78-92, F93.0, F93.3, F93.8, F93.9, F94, F95, F98-99, O99.3</p> <p>Assessment: ICD-10 Z03.2</p> <p>Counselling: CCI 6.AA.10.xx</p>
Nova Scotia Health	Mental Health-Related ED Use	<p>The codes include: Substance Use: ICD-9 303-306</p> <p>Mental Health: ICD-9 290-319 E90-959</p> <p>Assessment: ICD-9 V7189</p>

Supplemental Table 2: Descriptive Statistics for Cohort Stratified by Sex

	Males N=281	Females N= 383
Demographic Characteristics		
Age at last IWK visit, mean (SD)	18.9 (0.27)	18.9 (0.26)
Clinical Characteristics		
Presenting Concern		
Serious & Enduring Mental Disorders	26 (9.2)	17 (4.4)
Emotional/Neurotic Disorders	108 (38.4)	197 (51.4)
Eating Disorders	0	15 (3.9)
Neurodevelopmental Disorders	46 (16.4)	14 (3.6)
Substance Use Disorders	54 (19.2)	33 (8.6)
To Be Determined (TBD)	14 (5.0)	29 (7.6)
Missing	33 (11.7)	78 (20.4)
Specific Care Clinics @ IWK	110 (39.1%)	75 (19.6%)
Specific Care Clinic @ 1 st NSH	25 (35.1%)	14 (12.0%)
Priority Stream	25 (8.9%)	56 (14.6%)
Socioeconomic Characteristics		
DA-Level Adjusted Yearly Median Household Income (IQR)	\$40,966 (33,018-47,830)	\$38,527 (31,221-46,426)
DA-Level Median Percentage of Single-Parent Households		
<25 th centile (Low)	70 (24.9%)	85 (22.3%)
25 th – 75 th centile (Moderate)	147 (52.3%)	194 (50.9%)
>75 th centile (High)	64 (22.8%)	102 (26.8%)
Health Service Use		
Known to Stay Connected? (April 2018-March 2020)	14 (9.7%)	40 (19.5%)
Median number of adult outpatient visits in 6-months post-19 th birthday (IQR)	4 (2-9)	3 (2-6)
Median time to first adult outpatient MHA visit, days (IQR)	74 (36-129)	85 (38-130)
Any Youth ED Use	48 (17.1%)	80 (20.9%)
Any Adult ED Use	14 (5.0%)	37 (9.7%)
Repeated (3+) Adult ED Use	6 (2.1%)	7 (1.8%)
Median number of adult ED visits in 6-months (IQR)	1 (1-3)	1 (1-2)

Bold indicates significant *t*-test or non-parametric equivalent ($p < 0.05$)

Presenting concerns were coded as yes/no for each category independently.

- indicates the association was not modelled

Supplemental Table 3: Univariable stratified analysis of presenting concern by sex

	1-Visit		2-Visit	
	Males n=281	Females n=381	Males n=281	Females n=381
Presenting Concerns				
Serious & Enduring, Yes	3.40 (1.49-7.73)	1.00 (0.33-2.99)	4.79 (2.08-11.04)	1.10 (0.33-3.61)
Emotional/Neurotic, Yes	0.76 (0.43-1.35)	1.13 (0.71-1.81)	0.76 (0.41-1.40)	1.15 (0.69-1.92)
Eating Disorders, Yes	-	0.84 (0.25-2.79)	-	1.30 (0.38-4.40)
Neurodevelopmental, Yes	0.92 (0.44-1.92)	1.75 (0.57-5.38)	0.80 (0.35-1.82)	0.84 (0.22-3.25)
Substance Use, Yes	1.04 (0.53-2.06)	1.87 (0.88-3.96)	0.75 (0.34-1.63)	2.86 (1.32-6.19)
To Be Determined, Yes	1.19 (0.36-3.93)	0.25 (0.07-0.87)	1.07 (0.29-3.99)	0.24 (0.55-1.06)

Bold indicates statistically significant association (p<0.05)

Presenting concerns were coded as yes/no for each category independently.

- indicates the association was not modelled

Supplemental Table 4: Descriptive Statistics of Sub-Cohort Referred Through Stay Connected

	Stay Connected Referral Sub-Cohort n=54	No Stay Connected (April 2018-March 2020) n=295
Demographic Characteristics		
Age at last IWK visit, mean (SD)	19.0 (0.22)	18.9
Male	14 (25.9%)	(44.1%)
Clinical Characteristics		
Presenting Concern		
Serious & Enduring Mental Disorders	5 (9.2%)	21 (7.1%)
Emotional/Neurotic Disorders	30 (55.5%)	131 (44.4%)
Eating Disorders	<5	6 (2.0%)
Neurodevelopmental Disorders	<5	27 (9.1%)
Substance Use Disorders	6 (11.1%)	39 (13.2%)
To Be Determined	<5	7 (2.4%)
Missing	8 (14.8%)	64 (21.7%)
Specific Care @ IWK, Yes	14 (25.9%)	80 (27.1%)
Specific Care @ 1 st NSH, Yes	6 (14.3%)	16 (22.2%)
Priority Stream, Yes	10 (18.5%)	36 (12.2%)
Socioeconomic Characteristics		
DA-Level Yearly Median Household Income (IQR)	\$38,048 (28,091- 45,099)	\$39,312 (31,515- 46,752)
DA-Level Median Percentage of Single-Parent Households		
<25 th centile (Low)	13 (24.1%)	64 (21.8%)
25 th – 75 th centile (Moderate)	27 (50.0%)	152 (51.9%)
>75 th centile (High)	14 (25.9%)	77 (26.3%)
Health Service Use		
Median number of adult outpatient visits in 6-months (IQR)	5 (3-8)	3 (1-5)
Median time to first adult outpatient MHA visit, days (IQR)	57 (38-102.5)	49.5 (1-128)
Any Youth MHA ED use	20 (37.0%)	57 (19.3%)
Any Adult MHA ED Use	10 (18.5%)	21 (7.1%)
Median number of adult mental health- related ED visits in 6 months (IQR)	1 (1-2)	1 (1-3)

Cell sizes <5 suppressed for confidentiality

Supplemental Table 5: Characteristics of Youth Referred Through Stay Connected meeting the 1-visit Definition of Attendance

	Attended 0 Visits within 6-Months n=20 (37.0%)	Attended at least 1- visit within 6-months n=34 (63.0%)	Unadjusted Odds Ratios*
Demographic Characteristics			
Age at last IWK visit, mean	18.9 (0.24)	19.1 (0.19)	-
Male	(30.0%)	8 (23.0%)	0.72 (0.20-2.51)
Clinical Characteristics			
Presenting Concern			
Serious & Enduring Mental Disorders	<5	<5	2.53 (0.26-24.93)
Emotional/Neurotic Disorders	9 (45.0%)	18 (52.9%)	1.97 (0.64-6.11)
Eating Disorders	<5	<5	-
Neurodevelopmental Disorders	<5	<5	-
Substance Use Disorders	<5	<5	0.25 (0.04-1.54)
To Be Determined	<5	<5	0.57 (0.03-10.0)
Missing	<5	<5	-
Priority Stream, Yes	5 (25.0%)	5 (14.7%)	0.52 (0.13-2.10)
Specific Care @ IWK, Yes	5 (25.0%)	9 (26.5%)	1.08 (0.30-3.88)
Socioeconomic Characteristics			
DA-Level Median Household Income/year (IQR)	\$33,273 (24,640-45,705)	\$40,981 (34,203-45,099)	1.00 (0.99-1.00)
DA-Level Median Percentage of Single-Parent Households			
<25 th centile (Low)	5 (25.0%)	8 (23.5%)	4.0 (0.79-20.3)
25 th – 75 th centile (Moderate)	5 (25.0%)	22 (64.7%)	11.0 (2.39-50.6)
>75 th centile (High)	10 (50.0%)	4 (11.8%)	Reference
Health Service Use			
Any Youth MHA ED use	5 (25%)	15 (43.3%)	2.37 (0.69-8.09)
Any Adult MHAED Use	<5	9 (26.5%)	6.84 (0.78-59.9)
Median number of adult outpatient visits in 6-months (IQR)	0	5.5 (4-9)	-
Median adult mental health-related ED visits in 6 months (IQR)	1 (1-1)	1 (1-2)	-
Median time to first adult outpatient MHA visit, days (IQR)	-	57 (38-102.5)	-

Bold indicates statistically significant association (p<0.05)

Presenting concerns were coded as yes/no for each category independently.

- indicates the association was not modelled

Cell sizes <5 were suppressed for confidentiality

Supplemental Table 6: Characteristics of Youth Known to Stay Connected meeting the 2-visit Definition of Attendance

	Attended less than 2 visits within 6- Months n=24 (37.0%)	Attended at least 2-visits within 6- months n=30 (63.0%)	Unadjusted Odds Ratios*
Demographic Characteristics			
Age at last IWK visit, mean (SD)	18.9 (0.22)	19.1 (0.19)	-
Male	(25.0%)	8 (26.7%)	1.09 (0.31-3.77)
Clinical Characteristics			
Presenting Concern			
Serious & Enduring Mental Disorders	<5	<5	3.54 (0.36-34.71)
Emotional/Neurotic Disorders	12 (50.0%)	18 (60.0%)	1.5 (0.50-4.48)
Eating Disorders	<5	<5	-
Neurodevelopmental Disorders	<5	<5	-
Substance Use Disorders	<5	<5	0.36 (0.06-2.18)
To Be Determined	<5	<5	0.79 (0.04-13.74)
Missing	<5	<5	-
Priority Stream, Yes	5 (20.8%)	5 (16.7%)	0.76 (0.04-13.74)
Specific Care @ IWK, Yes	(20.8%)	9 (30.0%)	1.63 (0.46-5.79)
Socioeconomic Characteristics			
DA-Level Median Household Income/year (IQR)	\$37,340 (27,969-43,563)	\$39,061 (33,730-46,818)	1.00 (0.99-1.00)
DA-Level Median Percentage of Single-Parent Households			
<25 th centile (Low)	5 (20.8%)	<10	3.32 (0.79-20.3)
25 th – 75 th centile (Moderate)	9 (37.5%)	18 (60.0%)	5.0 (1.21-20.72)
>75 th centile (High)	10 (41.7%)	<5	Reference
Health Service Use			
Median number of adult outpatient visits in 6-months (IQR)	0	5.5 (4-9)	-
Median time to first adult outpatient MHA visit, days (IQR)	-	51.5 (33.5-89)	-
Any Youth MHA ED use	7 (29.2%)	13 (43.3%)	1.86 (0.59-5.86)
Any Adult MHA ED Use	<5	8 (26.7%)	3.99 (0.75-21.33)
Median number of adult MHA related ED visits in 6 months (IQR)	1 (1-1)	1 (1-2)	-

Bold indicates statistically significant association (p<0.05)

Presenting concerns were coded as yes/no for each category independently.

- indicates the association was not modelled

Cell sizes <5 were suppressed for confidentiality

CHAPTER 4: CONCLUSION

4.1 OVERVIEW OF RESULTS

The overarching objective of this master's thesis was to improve our understanding of transition aged youth accessing publicly funded MHA services in Nova Scotia and identify potential inequities using routinely collected health administrative data. Specifically, we aimed to: 1) describe the demographics and service use patterns of transition aged youth; 2) measure the associations between clinical, demographic, and socioeconomic factors with attendance to adult MHA services; 3) assess the sensitivity of these associations using a novel two-visit definition of attendance. These objectives were achieved through both a review of the literature and an empirical analysis.

First, the literature review identified several common gaps in the current transitions literature, which we used to inform our analyses in Chapter 3. While few studies have been conducted using routinely collected administrative data, they are often limited in the variables that have been investigated, their interpretations in the context of inequities, and in the length of observation period used to observe adult MHA use. While qualitative literature has provided rich insight into individual level experiences, it has thus far been limited in providing a system-wide view of transitioning youth, which is often more feasible using routinely collected health administrative data. However, without incorporating the findings of qualitative literature into quantitative health services research studies using routinely collected data, it will be difficult to fully address these gaps. We have deliberately used these limitations and perspectives found in qualitative literature to inform the analyses presented in Chapter 3.

Although the main results are quantitative, they are heavily informed by qualitative literature to help us better understand transition aged youth. The literature review and empirical chapters have not only improved our understanding of transition aged youth but have also identified where gaps in current data collection lie, and how these can be addressed in the future to provide deeper understandings of transition aged youth. More specifically, we have also addressed the following objectives through the empirical paper:

4.1.1 OBJECTIVE 1

For objective 1, our results indicated that most youth attending IWK MHA services aged 18.5 years and above do not subsequently attend adult MHA services at Nova Scotia Health between the ages of 19-19.5 years. Those who did not attend may not have done so for a host of possible reasons including that: they did not require a transition to adult services; they accessed private MHA services; they accessed NS Health MHA services outside of the Central Zone; or they required a transition but did not successfully complete this transition. We could not differentiate between these different outcomes with the current data. Of note, there were variables we intended to capture which would have provided further insights into these possibilities, but they were not available or were poor quality. These included clinical discharges, administrative discharges, cancellations, and no shows, which would have greatly improved the specificity of service pathways identified and helped minimize misclassification. The descriptive analysis also identified the difficulties in identifying a need to transition using routinely collected data, and the need to better track youths' disposition at time of transfer to adult MHA services. Nonetheless, describing the clinical, demographic, and socioeconomic characteristics of this vulnerable group, as well as their service use pathways has helped provide an overall picture of transition aged youth in the Nova Scotia Health Central Zone, which was not previously available.

4.1.2 OBJECTIVE 2

For objective 2, we found significant associations of both youth and adult ED use, certain presenting concern categories (serious and enduring mental disorders, to be determined, and addictions) consistent with known differences in service mandates between youth and adult services, and DA-level proportion of single parent families with attendance to outpatient adult MHA services. While we were not able to assess adjusted associations as originally intended, which would have allowed us to adjust for need and more accurately assess inequities, these unadjusted analyses have provided insight into areas for further investigation in future studies.

4.1.3 OBJECTIVE 3

For objective 3, we found that the associations with attendance to adult MHA services often increased in magnitude when using a two-visit definition versus a one-visit definition of attendance, which may be indicative of the increasing influence of inequities over an episode of care. We also found that a sizeable proportion (nearly 25%) of those who attended one visit did

not attend further visits, highlighting the need for more longitudinal follow up in measuring transitional health service outcomes, and the limitations of using only one visit to measure transition success, which is commonly used in existing literature. These high rates of disengagement after the first visit further support the need for improved capture of clinical and administrative discharges in adult MHA services and more longitudinal follow up of transitioning youth.

To conclude this thesis, I will elaborate on the strengths and limitations of the present work, as well as address recommendations for future quality improvement and research initiatives for youth transitioning between youth and adult MHA services.

4.2 STRENGTHS & LIMITATIONS

This research has several major strengths. It has also deliberately addressed major gaps identified in the literature. First, to our knowledge, this is the first study to be conducted in Nova Scotia investigating MHA transitions. Although there have been calls to action from clinicians, the Federal and Provincial government, and local organizations^{5,77} to investigate the transition between youth and adult MHA services, this is the first time a cohort of IWK youth at transition age have been investigated across the transition boundary. There is also substantial value in understanding what variables need to be captured to enable continuous quality assurance across the transition boundary with routinely collected administrative data.

Additionally, this is the first study, to our knowledge, to explicitly compare definitions of attendance to adult MHA services. It is well known that attendance to appointments alone may not indicate engagement, and attendance to one visit may not indicate a successful transition.²⁶ By looking further along a patient's trajectory in adult care, we have identified that factors are likely to have increasing influence over an episode of care, which is consistent with other work not specific to transitions.⁴⁴ While this study did not aim, nor have the capacity to validate this new definition, it is an important consideration when investigating transition success at the system level. Future work should further target the definition of transition success at the health system level, and work with patients and clinicians, to create a validated definition, and understand the potential implications of misclassification without looking more longitudinally in

adult services or having indicators of whether individuals were clinically or administratively discharged after their first visit.

Our use of Census of Population geography (ADA) as a cluster variable also provides unique insights for planning the provision of services. From a policy perspective, community interventions designed to support youth who fall through the cracks of the transition from youth to adult MHA services, offered in high-risk communities, may help mitigate some of the negative consequences of unsuccessful transitions, and help youth navigate the complex transition process. While identifying proactive interventions for patients in clinic based on clinical and/or demographic characteristics (e.g., high MHA-ED use) is likely to be the most efficacious point of intervention, community supports in vulnerable areas can help fill gaps in care across the transition boundary and help support those outside of the formal mental health system. Geographic approaches such as those used in the current study may help identify areas where these extra supports are most needed.

While the identification of our cohort captured all transition aged youth known to MHA services, there is currently no comprehensive indicator of a need to transition nor referral to adult services in routinely collected data. Thus, we cannot be certain what proportion of our cohort had unsuccessful transitions versus those who did not need or want to attend adult MHA services at transition age. We also ran into several obstacles, particularly with data quality, which forced us to deviate from the original protocol. First, we were unable to obtain data on clinical and administrative discharges due to inadequate recording in the administrative databases used. These two aspects represent very different clinical outcomes; clinical discharges may be seen as an optimal outcome, given that the care provider has deemed the patient no longer in need of services, while administrative discharges are more concerning, and reflect repeated cancellations or no-shows. While patient preferences for treatment should be considered when defining optimal transitions, and cancellations do not necessarily indicate an individual has transitioned to adult services, it would greatly improve the classification of youth if we had an indicator of an individuals need for continuing services.

Since we did not have these indicators, we further limited the age range of our cohort after identifying that those below the age of 18.5 years or above 19.5 years had much lower attendance in adult service than those between the ages of 18.5-19.5 years. After discussion with clinical experts, we realized that those who attended youth MHA services before the age of 18.5 years would not have yet been eligible to initiate a transition to adult services, thus would not have undergone a formal transition between youth and adult MHA care. For those over the age of 19.5 years at last IWK visit, we would not have observed them in adult services. If we had indicators of referrals, including the dates, we would be able to better specify observation windows for each individual, rather than relying on the 19th birthday as the index date. We also attempted to incorporate wait times for entry into adult MHA services in our definitions of attendance to improve our specificity. However, we found that these were highly variable across the study observation period; thus, setting a definitive cut-off (i.e., visit within three months of 19th birthday) would have introduced substantial misclassification bias. Keeping these highly variable, and often long, wait times in mind, even our six-month observation period may have been too short to identify trends in service usage for both outpatient and ED MHA service usage. Longer observation periods should be used in future investigations.

Lastly, we did not have information on individual-level indicators for socioeconomic status. While our area-level variables are informative, they must not be interpreted at the individual level. In many instances, individual- and area-level socioeconomic status may be discordant with one another. Routinely collecting these indicators would facilitate answering novel questions regarding inequities across an episode of care in those accessing services at the individual level.

4.3 IMPLICATIONS

Ultimately, there is a need for a well-documented, accountable, and intentional transitional process to ensure that youth are supported across their transition from youth to adult MHA services and subsequently improve their outcomes. A transition is not merely an administrative event, and there must be a clear and collaborative process implemented which involves youth and their families, as well as youth and adult MHA services. While there are system-wide transition guidelines, we need to ensure that these guidelines are upheld and implemented across the entire system to ensure youths' needs are being met, which currently is not feasible using

routinely collected data. The Stay Connected Mental Health Project is one example of a more formalized and specialized transition process spanning youth and adult MHA services. They also collect some of the important indicators of successful transitions which can be used to implement continuous quality improvement and ensure that youth who need a transition have a successful one. It is clear from our results that individuals in specific care clinics or known to Stay Connected are more likely to subsequently attend adult services. While this may be related to increased need, these services are known to implement intentional, planned, transitions that span youth and adult MHA services. Using the policies implemented by Stay Connected or specific care clinics as a guide to inform policies in the wider Community MHA system, and ensuring that services can be held accountable for upholding these policies through routinely collected indicators will help facilitate successful transitions. This will ultimately help ensure youth achieve their full potential by successfully transitioning to adult services when such a transition is needed.

We cannot address what we cannot measure, thus there is a need for improved data collection to facilitate quality improvement, research, and ultimately improve patient care across the transition period. Given that improvements to the transition between youth and adult MHA care have been identified as a priority by the Provincial Auditor General,⁷⁹ solutions to these gaps should be of interest to decision makers, to ensure that any intervention in the future that is implemented can be meaningfully assessed. As the province of Nova Scotia works towards implementing One Person One Record, there is great potential for addressing gaps in data collection, and better tracking individuals across their transition to adult MHA services, but we must ensure that meaningful variables are captured accurately and easy to access.^{8,11} From a clinical perspective, gaps in data collection only serve to limit clinicians' ability to help youth achieve a seamless transition,^{8,11} while from a research perspective, these gaps mask the complexity of the problem and hinder our ability to target and investigate interventions. Using clinician and patient perspectives to inform data systems is likely to subsequently improve patient outcomes, particularly in the transition period.

From an education perspective, it is important to further educate clinicians about the transition process and ensure that they are involved in the development of intentional transition processes

from the early stages. There is clearly a need for youth and adult MHA services to share their experiences, as well as further understand what supports youth require on both sides of the transition boundary to create a meaningful process for transitioning. Ensuring that clinicians are involved will help ensure that any formalized transition processes that are implemented are actually feasible, and that all individuals understand the need for additional supports across this vulnerable period. Supporting clinicians through these changes will help ensure that the processes are actually followed. Taking on a multi-disciplinary approach involving clinicians, youth and their families that emphasizes the current state of understanding of transitions, the importance of these transitions, and where the gaps in implementation and data collection lie will ultimately help develop a needs-based intentional process for transitioning between youth and adult MHA services.

4.5 FUTURE DIRECTIONS

To address these data gaps, novel study designs and collaboration from community partners may provide much needed answers. For example, conducting a mixed methods study which incorporates qualitative experiences of transitioning youth with quantitative data regarding their health service utilization may better define clusters of individuals and their subsequent patterns of care across the transition boundary. Similarly, incorporating clinician perspectives more formally would help identify if the perceived gaps in care identified in other jurisdictions are also relevant in the Canadian context. There are also opportunities for primary care or community-based services to be involved in this research to broaden the scope outside of formal Tier 3 services. Significant headway is being made in the European Union with the MILESTONE study, incorporating mixed methods techniques to understand MHA transitions at the system- and individual-level, in its final phase.⁶² Similar collaboration from patient-, government- and clinician-partners should be explored and prioritized in the Canadian context to address this significant gap in knowledge.

Beyond the data implications, the results also highlight the need to address the socioeconomic vulnerability of transition-aged youth. While we cannot assess the causality, the median household income of the cohort was below the Halifax poverty line. It is well established that low-income individuals are particularly vulnerable to the emergence of mental illness and are

more likely to have difficulties in attending services. Early interventions in low-income communities and in low-income families are likely to have positive downstream effects both within and outside of the transition to youth to adult MHA services. It is imperative that any future intervention or policy surrounding transition aged youth involve these individuals in consultation to better understand the unique barriers they face in accessing care, and how we can meaningfully address these barriers both within and outside of the formal health system.

Overall, the presented evidence confirms that the transition from youth to adult MHA services occurs at a critical period in one's development. Thus, transition processes for those in need should not introduce additional barriers for youth living with mental illness. While our results must be interpreted cautiously, they indicate a gap in the collection of routine indicators across the transition from youth to adult MHA services, which are likely similar in other specialties. This thesis has provided a necessary baseline for planning future research involving the transition from youth to adult MHA care, and confirmed the feasibility of conducting linkages between the IWK and Nova Scotia Health to answer new health system problems. Conducting further linkages with Statistics Canada (e.g., multiple deprivation index, Canadian Community Health Survey) or other more specific survey data, such as individual needs assessments, may also be beneficial in addressing these gaps in data collection while more long-term solutions at the health system level are developed. Further work should also compare trends in MHA-related ED use and inpatient hospitalizations to capture all health system use more comprehensively. Having routinely collected data available to map and understand the transition from youth to adult MHA services will help provide evidence-based guidelines for transitioning youth and avoid further youth from becoming lost in transition.

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Appendix 1: Variable Dictionary

Source Dataset	Variable	Description	Measurement	Why are we using it?
IWK	Sex	Male/Female	Binary	Individual Level Covariate
IWK	Age	At time of registration for last recorded outpatient CMHA appointment in IWK.	Continuous	Individual Level Covariate,
IWK	Visit Date	Date of last known IWK MHA appointment	Date	Identify the start of the transition
IWK	Presenting Concern	Categorization of presenting concern from DSS.	Categorical	Individual Level Covariate
IWK	Priority Code Flag	On initial intake to IWK services, given priority or regular code. Priority = 7 day timeline, Regular = 28 day timeline.	Binary	Individual Level Covariate
IWK	Postal Code	Postal code at last known visit to outpatient IWK MHA care.	Categorical	For linkage with Census data via PCCF for sociodemographic variables.
IWK	Mental Health-Related ED Use	The codes include: Substance Use: ICD-10 F1-19, F55 Mental Health: ICD-10 F00-09, F53.1, G30, R41.3, F20-29, R41.0, F30-33, F34.0, F32.1, F34.8, F34.9, F38, F39, F53.0, F40-F42, F93.0-93.2, F32.0, F43.1, F43.8, F43.9, F60-62, F68-69, F43.2, F44, F45, F48.0, F48.1, F48.8-48.9, F53.8-53.9, F50-52, F54, F59, F63-F66, F70-73, F78-92, F93.0, F93.3, F93.8, F93.9, F94, F95, F98-99, O99.3 Assessment: ICD-10 Z03.2 Counselling: CCI 6.AA.10.xx	Binary	Confounder
Census	Family Structure (CHASS code: v168/(v168+v184))	% of single parent households. Derived from the total lone parent census families in private households/total families with children.	Continuous (%)	Area-Level Covariate

Source Dataset	Variable	Description	Measurement	Why are we using it?
Census	Median Household Income (CHASS code: v1933)	Median annual household income after tax.	Continuous	Area-Level Covariate
NS HEALTH	Visit Date	Date of First outpatient MHA visit	Date	To identify the length of the transition.
NS HEALTH	Transition Success	Attendance to 1 appointment in NS HEALTH CMHA within 2 months of 19 th birthday, as well as 1 additional attendance within 5-7 th month after initial visit.	Binary	Analytic & Descriptive Outcome
NS HEALTH	MH-related ED Visits	The codes include: Substance Use: ICD-9 303-306 Mental Health: ICD-9 290-319 E90-959 Assessment: ICD 9 V7189 Counseling: CCI 6.AA.10.xx	Count	Descriptive Outcome
NS HEALTH	No-Show	No attendance to appointment without notice.	Binary	Descriptive outcome
NS HEALTH	Stay Connected Participation	HCN is known to SCMHP. Ideal “gold standard” of transitions.	Binary	Potential covariate in regression analyses. Only collected from March 2018.
NS HEALTH	Special Care Clinic Patient Flag	IWK and NS HEALTH have several specialty care clinics. These clinics often have well developed transition guidelines and processes relative to Community MHA.	Binary	Sensitivity analyses including these patients and excluding them.

Appendix 2: Transition Pathway Map

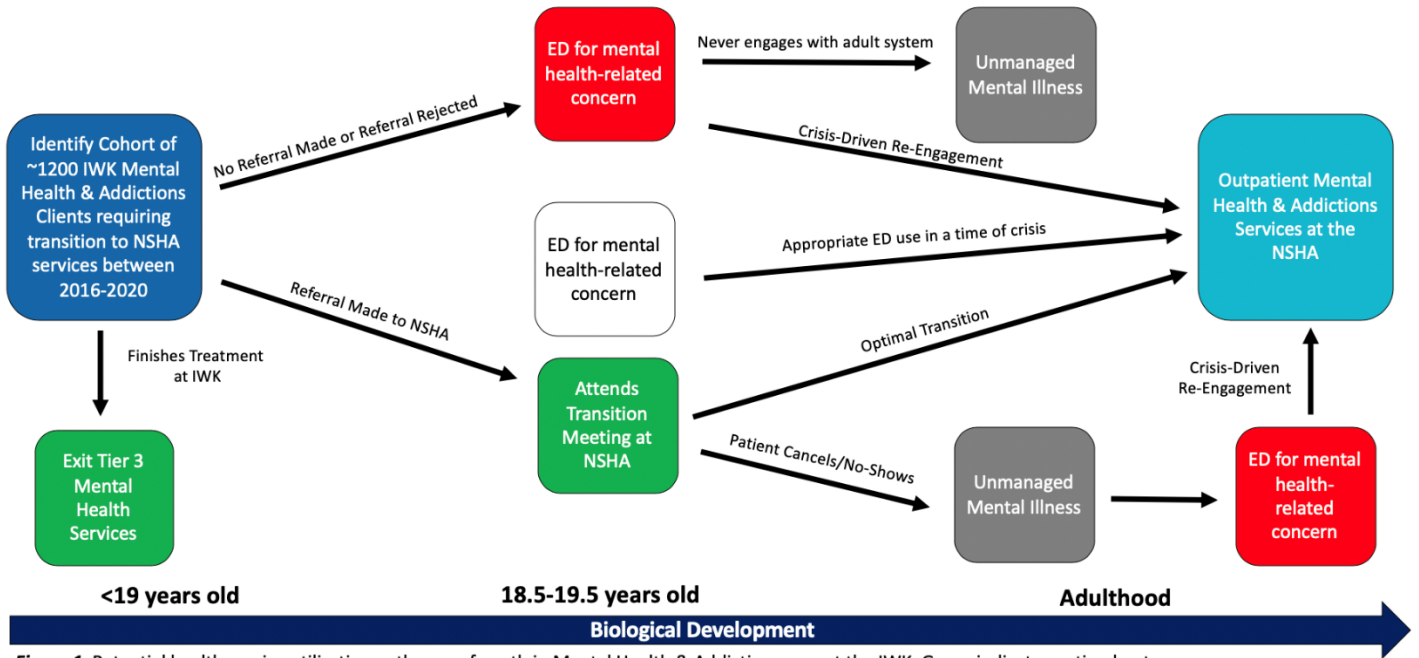


Figure 1. Potential health service utilization pathways of youth in Mental Health & Addictions care at the IWK. Green indicates optimal outcomes, red sub-optimal, and grey unmeasurable with the current design.

Appendix 3: IWK-NS Health Transition Guidelines

In 2015 NS Health and the IWK developed a set of transition guidelines outlining how care is to be delivered over the course of the transition period. At the age of 18.5, individuals receiving care at the IWK are to be referred to the NS Health MHA program. A single transition coordinator (nurse) receives the referral, and using the NS Health Tier 3 mandate makes a determination of need, which may or may not be the same as that determination made from the IWK. The transition coordinator then matches the patient with the most appropriate provider, with the first adult appointment being booked close to the patient's 19th birthday. Although care may continue at the IWK past one's 19th birthday, the transition of MHA care at NS Health cannot begin before turning 19 years old. Ideally the transition should include a period of shared management, or hand over hand care where the transitioning individual and their family are working with both youth and adult providers. Youth and their families are expected to be fully involved in the transition planning to achieve the best outcomes.