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Paving the Way to Change for Youth at the Gap between Child and Adolescent and Adult Mental Health Services

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Abstract

By 2020 mental illness will be one of the 5 most common illnesses causing morbidity, mortality and disability among youth. At least 20% of Canadian youth have a psychiatric disorder the impact of which can dramatically alter their life trajectory. Focus on the factors contributing to this problem is crucial. Lack of coordination between child and adolescent mental health systems (CAMHS) and adult mental health systems (AMHS) and consequent disruption of care during this vulnerable time of transition is one such factor. Reasons for and the impact of this divide are multilayered, many of which are embedded in outdated, poorly informed approaches to care for this population in transition. This paper considers the etiology behind these reasons as potential foci for change. The paper also briefly outlines recent initiatives ongoing in Canada and internationally that reflect appreciation of these factors in the attempt to minimize the gap in service provision for youth in transition. The need to continue with research and program development endeavours for youth with mental illness whereby access to services and readiness for transition is no longer determined by age is strongly supported.

Currently, a quarter of the world's population comprises persons aged 10 to 24 years, the largest of this age group in history.[1] While definitions of age boundaries vary, it is clear that investment in the health of children and promoting physical and mental wellness in adolescents (ages 10-19 years)[2] and specifically youth (ages 15-24 years)[2] is a positive global strategy towards enhancing community wealth, human rights, and social change.[1,3] With improvement in morbidity and mortality of infancy and early childhood, there is now growing concern about youth in terms of their mental, sexual, and physical health.[1,2,4,5] In regards to mental health, more than 70% of psychiatric illnesses that carry significant morbidity risks in adulthood have their onset in childhood and adolescence.[6-8] In Canada, at least 20% of youth have at least one diagnosable psychiatric disorder with associated high rates of comorbidity such as homelessness, crime, and substance abuse.[4,7,9] By 2020, mental illness is projected to be one of the 5 most common causes of morbidity, mortality, and disability among young people worldwide,[10,11] drastically affecting youth's ability to lead productive lives. Consequently, youth mental health is thankfully a central focus of many emerging international health agendas, recognising that investing in identifying and addressing the mental health needs of this vulnerable group is a key strategy to enhancing health worldwide.[12]

Among the factors within health care systems that have been identified as potentially having a negative impact on mental health outcomes is the lack of coordination linking childhood to adult mental health systems and the consequent disruption of care for youth transitioning within this divide.[3,4] More specifically, driven by a historical, systems-driven bifurcation of child/adolescent and adult mental health services (CAMHS and AMHS, respectively) and during a time when young people are most vulnerable to mental ill-health impacts[13] and at highest risk for a decline in service utilisation,[14] adolescents who have reached an artificially determined transition age are no longer amenable to services because they have "aged out" of the CAMHS system. This health systems–related determinant of health has been identified as a significant shortcoming in Canada,[4,15-18] the United Kingdom,[19-21] Australia,[22] and the United States.[14] As a Canadian child/adolescent clinician working with youth with serious and persistent mental illness (SPMI) requiring mental health care across the life span who has witnessed the negative consequence of poor transition, an informed appreciation of the issues contributing to this divide is warranted.

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Research does demonstrate that most professionals, caregivers, and youth experience challenges with the transition process,[23,24] with many youth becoming lost to ongoing care in the course of transition and consequently at risk for heightened morbidity associated with their illness.[19,25] Commonly identified outcomes include disengagement, dropout, and consequent crisis-driven connection with AMHS at points of heightened illness severity, costly both to the young person and the system.[19,26] Many adolescents are not referred to AMHS or alternatively not accepted at AMHS despite having identified mental health needs and associated impairment.[19,26-28] It is suggested that contributing factors are manifold, leading to misperception on all parts of what services are available at AMHS and misunderstanding of the serious nature of early onset mental illness and the need for ongoing care across the life span.[19,24,26] Furthermore, the expectation that adolescents and their families can navigate the transition to AMHS in all its complexities without embedded supports and without coordination of care paths is poorly informed. Concerns expressed by adolescents with chronic medical and psychiatric illnesses include a lack of readiness, the experience of loss leaving pediatric services, feeling ill-prepared to navigate the AMHS, and lacking skills necessary to manage their own illness, let alone navigate transition.[17,24,29,30] Families have reported feeling isolated from the care of their loved one upon entering AMHS and helpless when denied access to information secondary to more stringent adherence to confidentiality parameters and privacy issues in AMHS.[4,30] Both CAMHS and AHMS clinicians, psychiatrists, and managers report anxiety and lack of confidence in their own skills and training as it pertains to caring for patients in the transition process.[24,30]

It appears the issues at the root of this problem are several and overlapping. One factor cited is the differing education and training and consequent culture and attitude between CAMHS and AMHS staff surrounding the construct of adolescence and related readiness as it applies to transition.[23,24] The relatively new child and adolescent psychiatry subspecialty has the adolescent phase of life as a focus.[22] However, the separation of training and resulting differing approaches to diagnosis and treatment for CAMHS and AMHS clinicians may serve to further the cultural divide among the specialties,[24] promoting the silo approach to care among the 2 services that exists in most developed countries.[4,19,31] CAMHS are perceived as more holistic in approach, including patient, family, and external supports in the circle of care, flexible in expectation[24,25,27] but also possibly too enabling of the patient and family, contributing to poor preparation for the transition process.[24] By contrast, AMHS are perceived as crisis and medication driven, focused only on the patient with a limited scope of external involvement.[24,27]

Research further supports the existence of differing attitudes and pervasive misperceptions among and between the 2 services specifically regarding the adolescent phase of life.[23,24,32] More specifically, the concept of readiness in adolescence in developed countries has been defined by societal expectations regarding role transitions and chronological age as opposed to the biological and social experiences specific to this life phase.[24] In truth, at the age of perceived readiness within health care and sometimes painfully evident to those who work with them, youth are in fact enduring transition not only from an institutional perspective but also from a developmental (gaining independence, resiliency of self), social (reaching age of maturity, freedom, heightened societal expectation), familial (separation-individuation), and psychological (gaining sense of identity and maturity) perspective.[2,3] The disparity between differing rates of brain development between the prefrontal cortex and the limbic system in adolescence[2,32] often manifests in the need for increased support, supervision, predictability, and consistency, particularly in times of stress and potential confusion. More important, this disparity can be magnified for those with childhood/adolescent-onset psychiatric illnesses whereby the symptoms of illness can further delay social, emotional, and cognitive development.[2,3,29] Potentially related to these factors is the outcome that help seeking is less common in youth aged 18 to 24 years requiring mental health care, including depressed or suicidal youth, compared to adults.[33] Given that suicide is the second leading cause of death in Canada in persons aged 15 to 24 years,[34] this age is a clear target for investigation regarding current expectations for health care delivery. Perhaps the age of readiness regarding transition should be more realistically considered as a fluid construct, subject to change depending on environmental, social, and biological stressors of the moment and measured on an individual rather than systems-driven basis.

Continuity of services is hindered also due to generally separated health systems with separate funding sources and mandates of care and a lack of leadership and prioritisation regarding transition between services.[35,36] There is an identified lack of clarity regarding policy and procedures for transition processes, differing referral criteria, and lack of communication between systems.[3,19,21,36] Given that predictors of dropout from mental health services in transition include barriers to accessing care, the perception of the relevance of treatment, and the connectedness or quality of the therapeutic relationship,[4,14,17,22] earnest attention to modifying such barriers is warranted.

Recent surveys of youth in transition from mental and medical health services suggest they are not ignorant of the issues related to this process.[17,23,24,35,37,38] Indeed, most youth have a positive attitude to health services transition.[38] Surveys demonstrate that youth are aware of some of the administrative issues such as lack of funding or extra resources required to support the transition process.[37] Youth reportedly request more collaborative approaches to enhance independence from pediatric care and prepare them for the perceived complexities of the adult system.[17,23] Youth report wanting to be actively included in the transition process and seek opportunities to develop their life skills with the support of familiar clinicians in the pediatric setting.[17,37,38] They favor a structured transition program with improved

coordination of services,[23] reduced wait times, and stronger patient-provider connection.[37] Identified suggestions by adolescents and families for improvement include (peer) mentorship through the process and case management, someone they can trust to help navigate the system,[37] and starting the transition process early.[17,35-39] Fortunately, identifying suggestions for improving the interface between CAMHS and AMHS is being promoted by policy makers and governments in the United Kingdom,[40] Australia,[22] the United States,[41] and Canada.[4,15,16,42,43] Moreover, the Mental Health Commission of Canada within its strategic plan has identified the need for improved access to services that cross the continuum of care with an emphasis on improving the experience of transitions as one of the primary objectives for the 2017 to 2022 framework for action. This includes working towards bridging the current policy-practice gap reflected in the lack of clearly delineated guidelines to support an improvement process for mental health transitions.[44]

Progress has been seen with and without governmental support in the development of unique and innovative platforms of care provision in the attempt to target the needs of youth in transition. Australian youth, for example, have access to Headspace, a large-scale government-funded, primary care clinic model targeting ages 12 to 25 years.[21,31] Service is multidisciplinary, spanning medical and psychiatric needs within a stigma-free environment. Clinics are intended to be youth friendly and highly accessible, with close links to external resources such as schools, providing a portal to more intensive care for those at high risk for severe and persistent psychiatric illness in a stepped-care model. Evaluation of Headspace, while initially positive, is ongoing. Access rates remain lower than expected, and outcomes for young adults with SPMI are under review with intent to redefine and adapt the model after further evaluation.[45]

Ireland established Headstrong, a National Centre for Youth Mental Health, supported by an autonomous charitable organisation funded through public-private partnership. Headstrong created Jigsaw, a new model of service delivery for youth with mental ill health.[31,45,46] Currently, 10 Jigsaw sites provide open-access, multidisciplinary care targeting young adults aged 12 to 25 years with mild to moderate mental health and addictions needs. Evaluation of this initiative is also under way.[46]

In Birmingham, England, Youthspace clinics were created for youth aged 16 to 25 years, supported by the mental health foundation trust in the area with a focus on improving transition from CAMHS.[47] Initiatives included improved communication and direct access between AMHS and CAMHS with youth-specific pathways for care in the AMHS system. Based on the success of this initiative and with widespread political support, a new 0- to 25-year service has been commissioned to offer youth a range of multidisciplinary expertise with emphasis on early identification of serious mental illness and reportedly a true life span approach to care.[31,45,47]

Closer to home, in Ontario, the first pilot of an innovative shared management model called the Youth Transition Project was evaluated.[18] In this model, CAMHS and AMHS providers worked together with the youth and family to develop individualised transition care plans to meet the needs of the patient. A transitions coordinator acted as a systems navigator through the process. Results were positive in regards to transition wait times, with 60% making a connection with AMHS.[18] More recently in Canada, we have seen the development of exciting strategic initiatives in adolescent mental health research. The Adolescent/young adult Connections to Community-driven Early Strengths-based and Stigma-free services network (ACCESS) and the Youth-Can IMPACT project are examples of elegantly designed research endeavours aimed at generating evidence for continuous service improvement upon unique and current models of care delivery for youth.[45] Objectives of the separate models are improved earlier access to care for youth and continued service delivery across the age spectrum. Both efforts are youth/family informed and will use randomised controlled designs (RCTs) to test the feasibility (clinical, economic, and practical) of the efforts to ultimately design a relevant and sustainable evidence-informed transformed youth mental health service.

Initiatives such as these are exciting in that they promote even incremental change parallel to and within current systems that is transparent and evaluated by stakeholders, including youth. Implementing changes without intent for early appraisal runs the risk of promoting poorly informed, costly (on many levels) endeavours. However, waiting for evidence for the ideal of "optimal transition" without a continuous improvement approach is unrealistic and untimely, and it risks years of poor outcomes for youth. The early psychosis program (EPP) movement, often heralded as pioneers in promoting seamless transitions for persons with chronic SPMI, achieved a philosophical shift in the conceptual framework of chronic early onset psychiatric disease over 2 decades of work. The gradual yet persistent approach adopted by EPP stakeholders has ultimately shaped the unrelenting acceptance of the positive impact of the provision of early and seamless care for youth with psychotic disorders. Certainly in this example, patience, diligence, and insidious implementation of even small ideological change proved useful and ultimately successful.

Success of this and any effort, however, requires clinicians and managers of both CAMHS and AMHS to adopt a shared responsibility for success of our youth requiring mental health care.[24] Without solid and unremitting dedication notwithstanding systems-level barriers, to eliminate the policy-practice gap in this area, even (perceived) "optimal" initiatives will fail. Recognition of the scope of the problem and potential positive impact of change and commitment on the part of all stakeholders (patient, family, psychiatrist, clinicians, manager, and government) is essential to effecting any difference. Education in this area in terms of adolescent brain development and psychiatric illness as it occurs across the life span must start earlier with a focus on inspiring desire and skill in *new* clinicians to lead

ongoing change in this area. Furthermore, adopting a transparent approach regarding the process of transition earlier will help to prepare the youth and family for transition as they age, promoting resilience to face the process as it occurs. Finally, continuous evaluation of and learning from new models in terms of strategies that do promote positive outcome for youth is essential.

Adolescent health is a young discipline, the current determinants of which are only recently being appreciated.[2] For adolescents with mental illness, the path to adulthood can be fraught with extra challenges that could contribute to further impairment over time. For those of us working with these youth, at the precipice of the gap, the realities outlined in this article are challenges that at times leave one feeling helpless. The systems-driven transition process from CAMHS to AMHS is one such challenge, poor navigation of which can lead to poor health outcomes.[2,4] The need for enhanced understanding and development of better models of transition within mental health care for youth is not debatable. Progress has been seen, but ongoing work is needed to delineate best practice leading to elimination of the current policy-practice gap. Ultimately, working towards a model of service delivery that supports the concept in all its facets (clinical, education, research, advocacy) whereby readiness for transition is no longer determined by age will undoubtedly best service this population, their families, and caregivers as we all prepare to navigate the transition to adulthood with resilience and confidence.

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