



Specialist Services Committee

QUALITY INITIATIVE PROJECT

SYSTEM GAPS AND BARRIERS TO TRANSITION AND CARE:

FINDINGS FROM THE BCPS TRANSITION AND MENTAL HEALTH TRANSITION PROJECTS

January 2020

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Other Reports in this Series:

Pathways to Support Community Pediatricians Transferring Patients with Mental Health Challenges to Adult Care – Final Report to Doctors of BC Specialist Services Committee

Pathways to Support Community Pediatricians Transferring Patients with Mental Health Challenges to Adult Care – Progress Report Compilation



TRANSITION OF YOUTH
WITH MENTAL HEALTH DISORDERS
FROM
PEDIATRIC TO ADULT SYSTEMS OF
CARE:
System Gaps and Barriers
to Transition and Care

Findings from the BCPS Transition and Mental Health Transition
Projects

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Background

BC's pediatricians serve children and youth from birth to age 19, often as a support to a primary care physician, but also as the most responsible physician for patients with complex health needs. BC pediatricians are committed to improving access to care and quality of care for their patients. The BC Pediatric Society has been a long-time advocate for improvements to mental health care for children and youth, and pediatricians have actively participated in local, regional and provincial efforts to that end, including the Child and Youth Mental Health and Substance Use (CYMHSU) Collaborative and the CYMHSU Community of Practice. In addition, the BCPS in collaboration with the BC Children's Hospital Department of Neuropsychiatry, has established the Neuropsychiatry Community of Practice.

The challenges of transitioning youth from pediatric to adult health services are well documented, as are the negative impacts associated with poor transitions and loss of continuity of care (MHCC 2015, Toulany 2019). Beginning in 2015, the BC Pediatric Society undertook projects to support pediatricians working in community settings in the transition of their patients from pediatric to adult systems of care. Initial work focused on supporting overall transition, while the subsequent focus was on the transition of patients with mental health disorders¹. While these projects did not incorporate formal gaps analyses, the findings pointed to significant gaps in access to care and appropriateness of care.

Throughout, pediatricians and family physicians expressed concerns regarding access to services for their patients with diagnosed mental health disorders: they reported challenges and frustrations when attempting to secure care for children and youth in the pediatric system (prior to age 19), and when attempting to transition patients to adult mental health services as they approached age 19. Physicians are particularly concerned with the impact of these challenges on the quality of care available to transitioning youth, and the system barriers that delay or do not accommodate care and treatment to youth with mental health disorders. It is important to note that many of these challenges and concerns were also identified by individuals working within local, regional and provincial mental health services.

The consistency of these challenges, and the significant impacts on patients and physicians led to the development of this document. It begins with a description of mental health disorders in youth and the transition process, a brief description of BC systems of care for youth and adults, and examples of gaps and barriers to care, grounded in the experiences of BC pediatricians and family physicians as reported in the projects. It ends with recommendations to improve the care of for youth with mental health disorders in British Columbia.

¹These projects, funded by Doctors of BC Specialist Services Committee were *Transitioning Patients from Community Pediatricians into Adult Care* (2015) and *Pathways to Support Community Pediatricians Transferring Patients with Mental Health Challenges to Adult Care* (2018).

About Youth Mental Health

Approximately 14% of BC children and youth will experience a mental illness (Waddell 2014; CMHA 2014). The majority (up to 70%) of mental health problems have their onset during childhood or adolescence, and young people aged 15 to 24 are more likely to experience mental illness and/or substance use disorders than any other age group (Canada 2006, Pearson et al, 2014).

Children and youth who experience mental illness are at risk of profound negative impacts in almost every facet of their lives, including ability to form healthy relationships and academic success. Issues such as leaving school early, youth unemployment, youth justice involvement, bullying, and traumatic release from care are amplified for young adults with mental illnesses. Unaddressed mental health and substance use issues lead to underemployment or lack of workforce participation, and they increase the human and economic burden of mental health problems and illnesses. Most alarmingly, suicide is the second leading cause of death for Canadian youth and one in five of all deaths among young adults age 15–24 are due to suicide. (Mental Health Commission of Canada, 2015, p5). While early diagnosis and treatment can mitigate the impacts of mental illness, it is estimated that less than 20% of Canadian children and youth will receive appropriate treatment. (Leitch 2007, Mental Health Commission of Canada, 2014).

About Transition

Transition has been defined as the “purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care”. There is a growing body of research documenting the challenges patients and families face at the time of transition, and the need for supports during this process. (Paone and Whitehouse 2011, Hart et al 2019, Alderman et al, 2019).

The BC Pediatric Society supports the Canadian Pediatric Society recommendations for transition to adult care for youth with special needs(Kaufman et al, 2007), and the complementary work of the BC Children’s Hospital ON TRAC program². In this model, early engagement and active collaboration between the patient, family, pediatric and adult care providers are key components of success.

The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound before and throughout the transfer of youth into the adult system. (Kaufman et al, 2007).

² These tools were developed under the leadership of Dr. Sandy Whitehouse and her Youth Health Transition BC Team. See <http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care>

About Transitioning Youth with Mental Health Disorders in BC

- Youth receiving care from community pediatricians at the age of transition generally have complex mental and/or physical health needs that are not met by other service providers in that community, including youth who have been unsuccessful in securing primary care attachment. Youth with less severe or less complex health issues have generally transitioned their care to family physicians at an earlier age: however, in some cases alternate care providers cannot be engaged and youth remain in the care of pediatricians beyond the usual age of transition.
- Family physicians provide care along the life continuum. As youth in their care reach age 19³, their specialist care and support services must be transitioned to adult service providers.
- Youth with diagnosed mental health issues can be in a variety of mental health care situations as they approach transition age, including:
 - Receiving care from Child and Youth Mental Health/Aboriginal Child and Youth Mental Health (CYMH/ACYMH) services;
 - Receiving care through Developmental Disabilities Mental Health (DDMH) Services;
 - On wait lists for assessment or treatment for CYMH/ACYMH/DDMH services;
 - Receiving care from community or private mental health service providers (psychiatrists, psychologists, mental health counsellors, community agencies);
 - Receiving mental health care from pediatricians and family physicians with or without the support of mental health specialists. This includes youth who do not meet eligibility criteria for CYMH/ACYMH/DDMH mental health services and who are unable to access community mental health service providers;
 - Not receiving care, due to lack of treatment capacity in the community, or personal choice; and
 - Youth with new onset symptoms suggestive of a mental health disorder who have not yet been assessed or linked to care.

Why is Transition Important?

The Mental Health Commission of Canada describes the challenge of transition for youth with mental health disorders as follows:

Emerging adults (EA⁴) who are engaged in child and adolescent mental health services must transition into adult services at a prescribed age. EA are not adequately supported during this transition, despite evidence that interventions at this stage will positively impact an individual's lifetime trajectory of mental health. Additionally, EA requiring services for the first time are often not able to find, access, or recover within the adult mental health and addiction service sector. (Mental Health Commission of Canada, 2015).

³ Youth and adult health services have different age-based eligibility criteria; however age 19 is the most common age when transition is required.

⁴ The Mental Health Commission of Canada uses the term “emerging adult” to describe youth and young adults (age 16-25)

In addition to adverse health and quality of life impacts for youth, lack of transition planning combined with ad hoc systems for patient transfer can lead to inappropriate use of emergency services and expensive use of the adult health care system (Whitehouse, 2015).

Recent Canadian research on the association of primary care continuity on outcomes following transition to adult care has shown decreasing use of mental health service access among young adults with childhood-onset severe mental illness change during transition. The authors note the potential for improved outcomes with timely and appropriate access to effective primary care during this period. (Toulany et al, 2019).

Large declines in mental health service use have been described after the transition from youth to adult services for youth with mental illness. This decrease is likely due to pediatric and adult mental health systems generally functioning as separate entities with marked differences in approach, eligibility, and care philosophies. (Toulany et al, 2019).

Mental Health Services in BC - Systems Change

In most if not all regions of BC, services to persons with mental health and substance use services are engaged in processes of change intended to improve access to care and care outcomes. These include:

- Recent release of the *A Pathway to Hope* policy document from the Ministry of Mental Health and Addictions, and associated increased funding for mental health
- A process to review and renew the service framework for Children and Youth with Special Needs that includes consultation with service recipients, families and service providers
- Building primary care capacity for management of mental health and substance use disorders
- The launch of *Compass*, a clinical consultation service providing expert advice to pediatricians, family physicians and other care providers treating patients with mental health and substance use issues
- Improving access to care for transition-aged youth through programs such as the Foundry, and specific programs through some health authority Adult Mental Health and Substance Use (AMHSU) services
- Child and Youth Mental Health and Substance Use (CYMHSU) Collaborative activities have united some communities in recognition of local mental health and substance use care needs, and have addressed some system barriers to care
- Changes to access and configuration of adult mental health and substance use services in communities served by regional health authorities
- Enhancement of on-line service-finding resources (e.g. Foundry Community Services web feature, HealthLink BC)
- The newly formed Adult Mental Health and Substance Use Network
- Established transition protocols for some youth receiving mental health services through specific programs (e.g. Child and Youth Mental Health [CYMH] and Developmental Disabilities Mental Health [DDMH]) at the time of transition.

While these changes are expected to have positive medium to longer term impacts on overall system capacity, in many communities the changes are in early stages of planning and implementation and have not yet made a substantial impact on front-line service access. In addition, many experts believe these welcome recent investments are insufficient to address service demand in a system that has been “starved of resources for many years”. An additional challenge lies in recruiting and retaining qualified staff to fill positions. Feedback from practicing clinicians suggest that the backlog of unserved and underserved clients in some communities is overwhelming new services, and that the existing transition protocols are ineffective in some communities due to limited service capacity.

Barriers to Care

Pre-Transition Barriers to Care

It is well known that early identification and intervention on mental health disorders leads to better outcomes. Yet there are considerable barriers to access for assessment and early intervention services for infants, children and youth, particularly those with developmental or intellectual disorders, complex behavioural disorders and less severe mental health disorders.

There is a need for early identification and treatment of mental health issues in all age groups beginning with infants to mitigate the impact/change the trajectory of disorders that are responsive to treatment at the mild to moderate stage, escalate care for those with potentially serious and persistent disease, and ease the burden at age of transition.

- While most lasting mental health disorders become evident during childhood or adolescence, there is limited capacity for assessment and diagnosis, and as a result some youth enter transition experiencing mental health disorders that have not been diagnosed or treated.
- Lack of capacity in the CYMH system has left children and youth on long wait lists for care while their mental health deteriorates and creates the need for more intensive service provision at a later date, including transition age.
- Specific assessments are required for children with neurodevelopmental and intellectual disorders to access specialized care and funding for that care. As of September 10, 2019, the overall wait time for autism assessment with the BC Autism Assessment Network was 59.4 weeks, and wait times were known to vary across the province⁵.
- There is a lack of appropriate service capacity for certain children and youth including those with developmental and intellectual disabilities and Autism Spectrum or Fetal Alcohol Spectrum disorders. The unmet mental health needs of these youth can be magnified at the time of transition. (Ono et al, 2019).

⁵ Source: BC Autism Assessment Network website <http://www.phsa.ca/our-services/programs-services/bc-autism-assessment-network>

- Effective evidence-based programs exist for children with Oppositional Defiant Disorder (Waddell et al, 2018)⁶. However, a lack of early diagnosis and intervention often leads to difficulties across the lifespan and involvement with the youth and adult justice systems. Some youth are able to access treatment through the justice systems.

Barriers at the Time of Transition

At the time of transition, pediatricians and family physicians are supporting youth age 16-19 to transfer their care to appropriate service providers in the adult systems of care. We identified multiple gaps and challenges in relation to mental health services. Simply put, youth in need are not receiving needed mental health services.

- There are few youth-appropriate mental health and addictions services in British Columbia, which poses a barrier to care at a time when mental health and substance use disorders begin to appear.
- Lack of overall capacity for AMHSU services for youth and adults in BC
 - While tools such as transition protocols are helpful, clinicians in the field report that there are often too few available resources for successful implementation.
- There remains an overall lack of capacity for provision of mental health and substance use treatment for youth and adults in general. Eligibility criteria and wait lists for Child and Youth Mental Health (CYMH) and Adult Mental Health and Substance Use (AMHSU) services continue to result in youth with mental health and/or substance use disorders not receiving needed services.
- Complex eligibility requirements (based on age, diagnosis, geography or program) continue to delay or restrict access to services for patients and families in need.
- Age-related service criteria create a “grey zone” for transition-aged youth who at around age 17 are deemed too old to enter child and youth service streams and too young to enter adult service streams. This issue is further complicated by waiting lists which delay access to treatment while the youth continues to age.
- Lack of capacity for youth-focused or youth-friendly mental health and substance use services in AMHSU systems continue to pose barriers for youth entering treatment in many communities. A recent research publication from the Children’s Health Policy Centre reviews the evidence on effective prevention and treatment programs for youth with substance use disorders (Schwartz et al, 2019).

The mismatch between institutional and developmental transitions is a central barrier to the uninterrupted provision of services to [emerging adults]. This lack of fit is characteristic of a provider-led system, where care is determined by institutional factors rather than client needs. (Singh et al., 2010 in MHCC 2015).

⁶ For example, *Confident Parents Thriving Kids*

- Inadequate capacity for specific mental health and substance use programming for Aboriginal youth, who continue to experience multiple barriers to mental wellness (multiple traumas, overrepresented among youth in government care and among youth involved with the criminal justice system).
- Inadequate supports for youth transitioning out of foster care, who are known to have a greater incidence of mental health challenges than youth in the general population. (BC Coroners Service, 2018; CMHABC 2019).
- In many cases, public-facing information (e.g. website content) may not be current with changes on-the-ground, and often does not include information that is important to community pediatricians and family physicians seeking to transition their patient to appropriate mental health and substance use services (e.g. age and eligibility criteria, access pathway, capacity to accept patients into care, waiting list information).
- The legacy of the CYMHSU collaborative has been short-lived in some communities, as resources developed to assist in navigation and access to services are becoming outdated, and there is no provision for sustainable upkeep
- While efforts are apparent to improve navigation to service access portals, more is needed. In addition, navigation does not guarantee service availability.
- Internationally, many jurisdictions are implementing programs to serve youth to age 25⁷. In BC, Foundry services are being established to meet the needs of youth age 12-25. However, they currently exist in a limited number of locations, and the walk-in model of care is not suited to longitudinal care needed for treatment of mental health disorders.

In British Columbia the current system of care for children with neurodevelopmental disorders does not appear to recognize there are two distinct patient populations: in one the children have few comorbidities and need limited specialized intervention and support, while in the other the children have significant mental health comorbidities and sometimes extremely challenging behaviors that require intervention for which funding is not readily available. Where this second population is concerned, vigorous family advocacy is required to access services and family breakdown can result. (Ono et al, 2019)

Youth with Special Needs Fall through the Gaps

There is considerable evidence that services to meet the needs of children and youth with special needs are inadequate to meet the demands in British Columbia, and this intensifies service need at the time of transition. The *Children and Youth with Special Needs Service Framework Development Summary of Engagement and Research Findings* identified multiple barriers to care, and concluded “the complement of services is generally right, but more is needed.” However, the findings from this project highlight

⁷ See for example Abidi, 2017.

multiple gaps in care for children with complex, chronic conditions and/or multiple comorbidities, whose health needs do not align with service access and eligibility criteria.

- AMHSU services lack the capacity to deal with the population of youth with intellectual disabilities; youth have been refused treatment from both DDMH and adult mental health service programs in some communities.
- Agency gatekeeping and eligibility requirements such as Intelligence Quotient (IQ score), particularly in regard to mental health services for youth with developmental or intellectual disabilities and mental health disorders poses a barrier for physicians and families attempting to connect patients to needed mental health services.
- Psychoeducational assessments are often not readily available to children and youth experiencing difficulties, delaying access to needed supports from programs and agencies such as MCFD Children and Youth with Special Needs, Community Living BC and Services to Adults with Developmental Disabilities (STADD).
- System fragmentation, bureaucratic processes, lack of respite, out-of-home service obstacles and limited specialized training for care result in children and youth with neurodevelopmental disorder and mental illness fall through the cracks.

Pediatrician and Family Physician Perspectives on Transition

- Health and mental health systems demand a transition from pediatric to adult systems of care at by age 19. This abrupt cut-off creates challenges for transition timelines, and can create a “dead zone” for patients requiring mental health and other services as they approach age 19.
- Some patients are refused pediatric mental health service as they approach transition age and referred to adult services (for which they are age-ineligible). This is challenging in all cases, but particularly for patients with new onset disease.
- Patients with complex/multiple health conditions who do not have a family physician are the most difficult to transition due to challenges with primary care attachment. In some cases there is no primary care practice willing to accept the patient, and the patient turns to walk-in-type clinical arrangements or hospital emergency departments for needed care.
- Adult systems of care are complex, fragmented and difficult to navigate for those who have only occasional contact with them. This includes pediatricians, and families.
- There are few youth-friendly mental health services, which leads some youth with mental health disorders to refuse or drop out of treatment services they do not feel are relevant to them.
- Youth ageing out of government care are a particular concern to pediatricians and family physicians. The abrupt transition of care and loss of support contributes to mental health challenges and difficulties establishing a stable lifestyle.

Implications for Pediatricians and Family Physicians Transitioning Youth from Pediatric to Adult Systems of Care

- Maintaining continuity of mental health care during transition and facilitating entry into care for those who are not receiving services are fundamental challenges that are faced by pediatricians, family physicians, patients and families on an ongoing basis.
- Many youth with mental health disorders experience treatment gaps during transition due to system capacity, confusing transition processes and treatment services that are focused on older populations.
- Established transition pathways for youth who are receiving services from MCFD programs (A/CYMH and DDMH) are often ineffective due to lack of service capacity.
- Community pediatricians and family physicians must continue to develop one-off solutions for transitioning these youth to adult mental health and substance use services/service providers.
- Funding based on diagnosis vs functional need contributes to a complex and confusing pathway to service access and transition.

Recommendations for Action

Improve access to appropriate evidence-based care for mental health and substance use within pediatric systems of care in BC communities.

1. Increase access to evidence-based **early identification and treatment** resources for infants, children and youth (pre transition) to ensure impactful and effective supports that can alter the trajectory of future mental health needs.
2. **Increase access to appropriate evidence-based care for children and youth with special needs**, particularly those with concurrent physical or developmental/intellectual disabilities who currently face considerable challenges in accessing appropriate care.
3. Improve access **to psychoeducational assessment** for children and youth experiencing developmental, intellectual or learning difficulties who may need specialized services. BCPS also recommends that greater consideration be given to functional abilities in these assessments for service.
4. The BC Pediatric Society endorses the 16 recommendations of the BC Legislature Select Standing Committee on Children and Youth Report on *Children and Youth with Neuro-Diverse Special Needs* to improve identification and assessment, eligibility and services, coordination and transitions and child and family-centred support.

Improve access to appropriate evidence-based care for mental health and substance use for transition-aged youth in BC communities.

5. Increase **access to evidence-based youth-friendly mental health and substance use treatment options** in BC communities. Involvement of youth in planning and delivery of services may increase attachment to needed care.
6. Increase access to **navigation services** for youth transitioning to adult systems of care, particularly for those experiencing mental health disorders and developmental disabilities where gatekeeping and limited service capacity pose particular barriers to access.
7. Provide outreach services to vulnerable and hard-to-reach youth experiencing mental health disorders and/or substance use challenges. These youth are often most in need of care and least able to navigate or attach to traditional services.
8. Increase access to evidence-based **services for youth and young adults experiencing neurodevelopmental disorders**, including those experiencing attention-deficit/hyperactivity disorder (ADHD), autism, learning disabilities, and intellectual disability. Youth and young adults with neurodevelopmental disabilities often *fall between the cracks* of service eligibility criteria and thus do not have access to the care they need.
9. Re-examine **access criteria** for services such as Community Living BC and Services to Adults with Developmental Disabilities (STADD) to give greater consideration to functional ability.
10. Ensure that all eligible individuals in all BC communities have access to STADD navigation services.
11. Ease restrictions on age of youth transition to adult services (and the age 19 cut off for patients to be followed by a pediatrician) to allow a more graduated transfer of care for patients who require a slower transition or longer period of time before they are ready to function in adult systems of care.
12. Enhance primary care attachment options for transition-aged youth to help ensure continuity of care and improved mental health and life outcomes.

Improve access to information on child and youth and mental health and substance use services in BC.

13. Improve communication of up-to-date information for physicians, patients and families on how to access treatment and support resources in BC communities. Current information processes often provide incorrect or out of date information that poses an additional barrier to care.

Improve access to life skills and community supports for youth in need.

14. Improve access to life-skills training and community supports for youth with mental health disorders, particularly those without a stable living environment and youth ageing out of government care.
15. Consider raising the age at which youth age out of care from age 19 to 25, and continue supports to assist them with transition to adulthood.

Provide greater support to pediatricians and family physicians caring for transition-aged youth.

16. Ease billing code restrictions to allow pediatricians to bill MSP for care to patients through the transitioning age group (i.e. to age 25 years).
17. Facilitate the integration of pediatric and primary care to ensure greater continuity of care and ease of transition.

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