

"WE SUFFER FROM BEING LOST" *

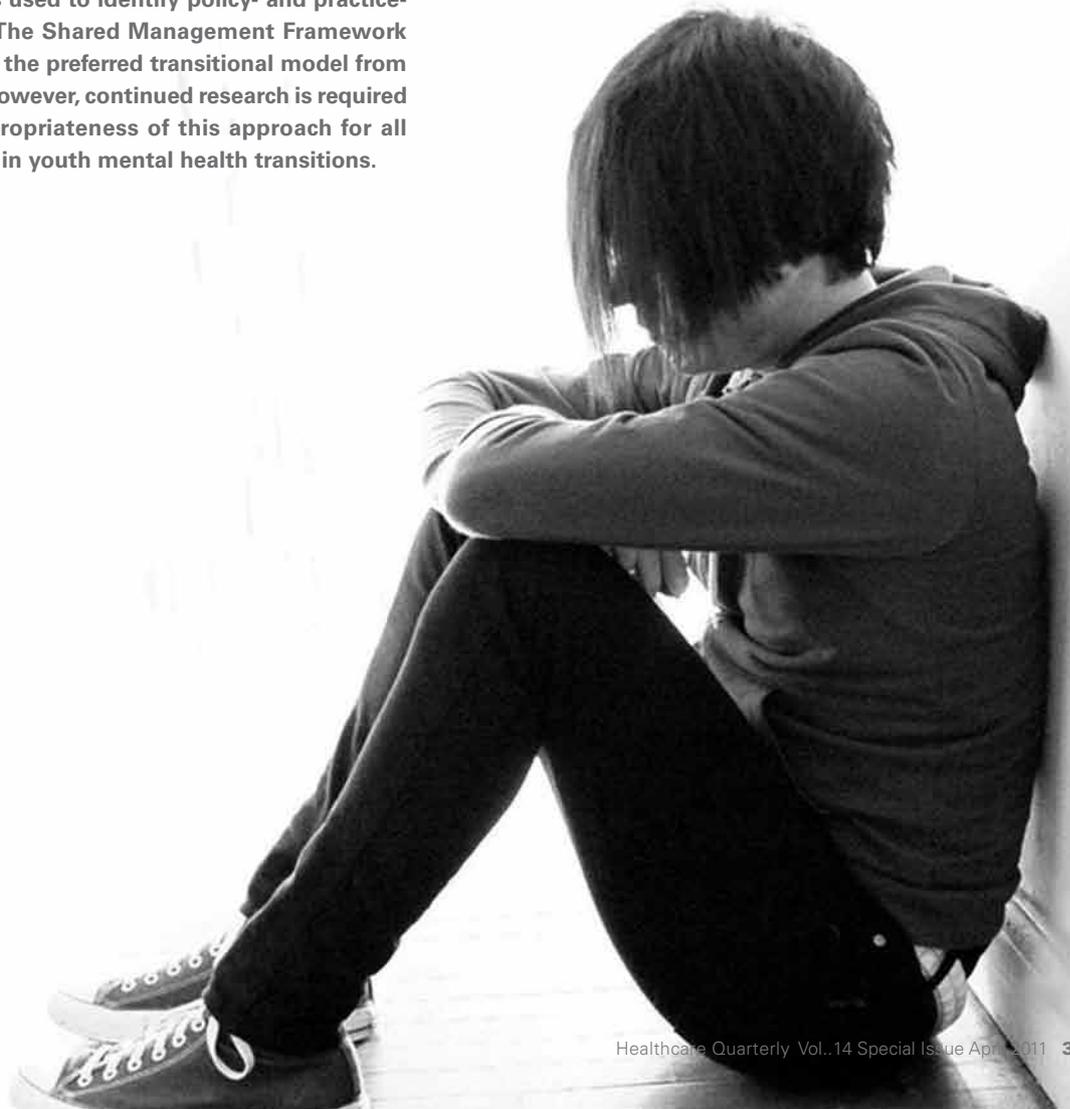
Formulating Policies to Reclaim Youth in Mental Health Transitions

Melissa A. Vloet, Simon Davidson and Mario Cappelli

* This quotation is from an 18-year-old woman currently transitioning between child and adolescent mental health services and adult mental health services who consented to participate in transitional work conducted by our research group.

Abstract

The greatest financial and institutional weaknesses in mental health services affect individuals between the ages of 16 and 25. The current project sought to identify bodies of evidence supporting effective transitional pathways and to engage policy leaders in a discussion of youth mental health transitions to highlight stakeholder perspectives. Three efficacious pathways from youth health service environments to adult health service structures were identified in the literature: the Protocol/Reciprocal Agreement Structure, the Transition Program Model and the Shared Management Framework. Evidence was presented to a panel of policy officials occupying various roles, up to the position of assistant deputy minister, from the provincial ministries of health, education, child and youth services and training, colleges and universities in Ontario. The panel was then engaged in a discussion regarding youth mental health transitions, and thematic analysis was used to identify policy- and practice-level considerations. The Shared Management Framework was recommended as the preferred transitional model from a policy perspective; however, continued research is required to determine the appropriateness of this approach for all stakeholders involved in youth mental health transitions.



Despite remarkable advancements in the medical management of chronic illness, little attention has been directed toward the psychosocial implications of negotiating the interface between youth and adult services for populations growing up with such conditions. The paucity of existing literature indicates that the development of a coordinated transition system linking pediatric services to adult systems of care will pose one of the most significant challenges to the healthcare system this century (Viner and Keane 1998). This is particularly evident in the area of mental health, where achieving continuous care is considered the most demanding transition area from a systems perspective since it requires the highest degree of interpersonal contact between service users and healthcare providers (Haggerty et al. 2003).

Approximately 70% of all psychiatric disorders have an onset occurring in childhood or adolescence/early adulthood (Kessler et al. 2005; Kim-Cohen et al. 2003). Affected youth are often diagnosed with conditions that prove to be chronic and require care throughout the developmental spectrum. The available outcome data uniformly demonstrate that in the absence of appropriate treatment, youth with mental health concerns become "more vulnerable and less resilient" with time (Wattie 2003). Feedback from multiple stakeholders involved in the transition between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) in Canada suggests that, overall, CAMHS appears siloed from AMHS (Government of Ontario 2009; Mental Health Commission of Canada [MHCC] 2009). This lack of integration results in significant barriers at a point where effective transition of services is necessary to achieve the recovery-oriented reform described by MHCC (2009).

Research in the United Kingdom, Australia and the United States has identified similar fragilities at the interface between CAMHS and AMHS, with the greatest financial and institutional weaknesses in mental health services being reported during the transition between CAMHS and AMHS, affecting individuals between the ages of 16 and 25 (McGorry 2007; Pottick et al. 2008; Singh et al. 2005). Patrick McGorry, one of the world's leading experts in youth mental health and the 2010 Australian of the Year, explains: "Public specialist mental health services have followed a paediatric-adult split in service delivery, mirroring general and acute healthcare. The pattern of peak onset and the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest" (2007: S53). The discontinuity between CAMHS and AMHS "jeopardize(s) the life chances of transition-age youth (ages 16–25 years) who need to be supported to successfully adopt adult roles and responsibilities" (Pottick et al. 2008: 374) and is counterintuitive given the research identifying adolescence and young adulthood as developmental periods associated with higher rates of psychological morbidity. Young people with psychiatric problems are character-

ized as a vulnerable population due to several factors, including increased risk-taking behaviours, lower rates of school completion and difficulties negotiating role transitions to adult-oriented social and occupational responsibilities (Davis et al. 2004; Health Canada 2002; Roberts et al. 1998).

Intervening at the level of the CAMHS-AMHS transition represents one of the most important ways that we can facilitate mental health promotion, mental illness prevention and recovery (MHCC 2009). The importance of this policy target was recently highlighted by both the Select Committee on Mental Health and Addictions (2010) and the Ministry of Child and Youth Services (2006) in Ontario, which recommended adopting a continuous/collaborative transitional system of care for youth with mental health concerns. In order to bridge the policy-practice gap, the identification and implementation of an appropriate model of care for youth navigating mental health transitions in Ontario is required.

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Methods and Objectives

The current project sought to (1) identify bodies of evidence supporting effective transitional pathways and (2) engage policy leaders in a discussion of CAMHS-AMHS transitions to highlight stakeholder perspectives. By including multiple sources of evidence (i.e., scientific literature, best practices and policy-level experience), the research team was able to conduct a thematic analysis that led to the identification of policy- and practice-level considerations for policy leaders.

Results

Objective One: Identify Bodies of Evidence

The literature scan identified three bodies of evidence supporting efficacious pathways from youth health service environments to adult health service structures: the Protocol/Reciprocal Agreement Structure, the Transition Program Model and the Shared Management Framework.

Protocol and Reciprocal Agreement Structure

Government and policy leaders in the United Kingdom developed and disseminated National Service Framework tools including protocol and reciprocal agreement templates. These tools were intended to act as cost-effective service contracts between healthcare settings, to facilitate in the clarification of

roles and responsibilities of service providers at both ends of the transition and to provide a foundation for the continuous care of transitioning youth (Health and Social Care Advisory Service 2006). However, the efficacy of the protocol/reciprocal agreement approach has proved suboptimal largely due to a pervasive policy-practice gap. Evidence indicates that less than a quarter of mental health service providers in the United Kingdom identified specific CAMHS-AMHS transition agreements (Singh et al. 2010; UK Department of Health 2006). When available, CAMHS-AMHS protocols are typically directed by institutional factors rather than evidence from best practice (Singh et al. 2010). This structure, although feasible within the Canadian healthcare context, is significantly constrained by antiquated chronological age demarcations directing service eligibility for youth, arbitrary service boundaries that continue to direct systems of care and a lack of interface with community care (Singh et al. 2010).

Transition Program Model

Globally, the best-known transition program for CAMHS-AMHS is called headspace. This program evolved as a community-based model of care to complement Australia's Orygen and address gaps in service delivery while providing integrated, holistic care for youth. It is funded by the government of Australia as part of its commitment to the Youth Mental Health Initiative and was designed to promote and facilitate improvements in the mental health, social well-being and economic participation of Australian youth aged 12–25 years. This transition model is composed of service delivery sites (communities of youth services), staffed by a full complement of healthcare providers (e.g., general practitioners, psychiatrists, psychologists, addictions counsellors, social workers and administrative personnel). In contrast to the protocol structure described above, headspace explicitly considers developmental age and interfaces with the community in an effort to deconstruct eligibility constraints and service boundaries. However, despite the preliminary evaluation data supporting the efficacy of headspace as a transition program (e.g., Muir et al. 2009), the funding model for this structure is not feasible in the Canadian public healthcare context.

Shared Management Framework

The Shared Management Framework has previously been applied in several healthcare contexts to direct the transitions of youth with chronic conditions from child service environments to adult service environments. Recently, the application of this framework by Holland Bloorview Kids Rehabilitation Hospital and the Toronto Rehabilitation Institute was recognized as a leading practice by Accreditation Canada (2008). The model is typically composed of (1) a transition team to facilitate the movement of youth and (2) a transitions coordinator (this could be a nurse or social worker) who is hired by both organizations and helps direct the "development of a transition program while also assisting

with training, evaluation, and even management of a transition clinic, among other tasks" (Provincial Council of Maternal Child Health 2009: 14). In most cases, separate clinics continue to operate out of both youth and adult locations; however, in some cases, dedicated transitions clinics have been erected. This model bridges community- and hospital-based care; however, it requires a high level of stakeholder investment. Despite this, it appears to be the most feasible model of service delivery and one that could easily translate to mental health care in Canada.

Objective Two: Engage Provincial Policy Leaders

With the collaborative spirit of provincial contacts in Ontario, our research team was able to conduct a meeting with a panel of policy officials occupying various roles, up to the position of assistant deputy minister, from the provincial ministries of health, education, child and youth services and training, colleges and universities in Ontario. The research evidence was presented and policy officials provided their informed perspectives on transitions. Several key policy- and practice-level considerations emerged from the discussion.

Policy-Level Considerations

The first theme in policy-level considerations was accountability to the mental health strategies. Policy leaders agreed that the transition from CAMHS to AMHS must reflect valued targets that have been documented in the Ministry of Child and Youth Services framework (2006), the Select Committee on Mental Health and Addictions' final report (2010), the Romanow report (2002) and the MHCC framework (2009). They suggested that selecting a model to facilitate the CAMHS-AMHS transition would target key goals including (1) developing a coordinated system of care with clearly delineated service plans that are appropriate to the service user, (2) involving families in the process and (3) reducing stigma of mental health.

Theme two documented the **risks and consequences of policy imposition**. There was a reluctance to mandate professional practice in CAMHS-AMHS transitions since policy imposition has proved unsuccessful in the past. Indeed, the work of Singh and colleagues (2010) supports the notion that simply advocating for a protocol structure does not translate into a better system of care. Before any action can be taken at the policy level to select an appropriate healthcare model for CAMHS transition, ministries need to have information about best practices for transitions and evaluations of the financial incentives and disincentives to determine feasibility and course of implementation. In order for policy recommendations to be useful, they must also be informed by stakeholder (i.e., policy leaders, service managers, care providers, youth and families) perspectives.

The final theme was **funding and accountability**. At this point there exists some uncertainty around how the implementation of a transitional model might be funded. Options

explored included (1) shifting the funding envelope locally and (2) having directed funds that follow the client/patient. However, a pilot project to help determine feasibility of the desired transitional model is considered the best first step at this stage. In order for any proposed transitional model to exist in the long term, it would have to be supported by outcome data. Some conversation about how this data could be obtained and tracked occurred. The consensus was that in order to fund a permanent transitional model of care, a systematic evaluation combined with an interdisciplinary and cross-ministerial data convergence of mental health-related outcomes would be necessary, and longitudinal outcomes would have to be tracked.

Practice-Level Considerations

Theme one in practice-level considerations was **roles and responsibilities**. Communication lapses and role confusion often accumulate at the interface between CAMHS and AMHS. When this occurs, youth transitioning from CAMHS to AMHS may be perceived as a risk transfer rather than a shared responsibility. The panel of policy leaders was primarily of a CAMHS orientation and expressed significant concerns over the lack of representation of AMHS perspectives. In order to promote a shared care approach, it will be necessary to engage leaders in AMHS.

Theme two involved **acknowledging developmental needs and special populations**. Concerns were expressed about the lack of flexibility in terms of funding youth in transition given the chronological age demarcations that currently act as barriers within the system. An acute awareness about the impracticality of these types of arbitrary age restrictions was identified, and other programs and community-level agencies that recognize the importance of the developmental model of care were noted. Applying developmental age as a context for the transition was discussed, and evidence from international groups, particularly in Australia, was convincing enough to encourage some thought about modifications to the current system. It appeared that applying developmental age as a context for the transition is a valued target for future policy development in this area.

The policy leaders also acknowledged that most youth who make contact with the system are treated similarly despite their differing developmental needs. This approach lacks a best fit for the client/patient and may result in care or treatment plans that are not well-suited to the concerns of the youth or the families involved. The lack of fit is especially compromised during the CAMHS-AMHS transition and represents a systematic weakness in the mental health system that needs to be targeted.

The third theme was *transitional planning*. Concerns were identified about delays in the planning for CAMHS-AMHS transitions and the lack of coordination between interfacing institutions including hospitals, colleges, universities, housing services and employment. A more proactive approach is considered a necessary element to improve CAMHS-AMHS transi-

tions. Improvements to transitional planning were highlighted at both the service level and policy level. In particular, closer communication between transitional planning groups at the ministerial level was identified as a desired goal.

The fourth and final theme was the **rights and needs of youth**. Despite the costly nature of crisis-driven reconnection in the system, some youth desire a "fresh start" as they move forward to AMHS. This can create a number of barriers to access in social, occupational and community domains for the youth involved. Discussion occurred surrounding ongoing projects aimed at bridging connections between education and healthcare to support young people who are transitioning. Policy leaders suggested that, at the present time, more information from youth is required to determine how they can best be supported in their mental health journey.

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Summary of Results

By combining the evidence in the literature with the policy leaders' perspectives, we generated a list of key recommendations. These are presented in Table 1.

Discussion

In consultation with the policy leaders, the Shared Management Framework was selected as the most appropriate approach for CAMHS-AMHS transitions. However, the literature unequivocally supports the use of core public funding in order to apply a CAMHS-AMHS transitional model in a public service context such as that in Canada (Muir et al. 2009). This will require a significant shift in perspective and will necessitate that the rigidity of funding boundaries be reassessed for this population. Nonetheless, given that the shared management model is informed by best practice guidelines, empirical research in the field and stakeholder contributions from other healthcare settings, this framework has excellent potential for translation to mental health.

In an effort to ensure the shared management model will be a good fit for all stakeholders involved in the CAMHS-AMHS transition, the policy leaders suggested that more research on stakeholder perspectives is needed. Combining the literature scan and policy perspectives collated in this study with the views of stakeholders directly involved in CAMHS and AMHS will inform adaptations that may be required to promote effective transitions using the Shared Management Framework. At the present time, our group is conducting research with youth, parents and mental health providers involved in the CAMHS-

TABLE 1.
Policy and practice recommendations

Policy-Level Recommendations

1. The development of a CAMHS-AMHS transitional model reflects current policy goals for mental health care in Canada.
2. Policy makers should be involved in the shaping of clinical practice rather than simply imposing standards. In order to select the most appropriate transitional model, policy makers require both information about the best-supported models for CAMHS-AMHS transitions and stakeholder perspectives.
3. Transitional planning needs to be viewed as a shared responsibility rather than a risk transfer.
4. AMHS perspectives need to be engaged at both the policy and service levels in order to support a successful model of transition for youth.
5. The current model of funding needs to be adapted to reflect the shared role of CAMHS and AMHS in the transition.
6. Longitudinal outcome data are required to evaluate future transitional programs/models of care.

Practice-Level Recommendations

1. Developmental considerations should play a major role in helping to direct the transitional process for youth.
2. A developmental model for youth transitioning from CAMHS to AMHS should be considered.
3. Transitional plans need to be flexible to adapt to the individual needs of service users and their families in different service environments.
4. Transition plans must be initiated earlier than they currently are.
5. Families are important stakeholders and need to be engaged in the transition process while still respecting the burgeoning autonomy of the youth in transition.

AMHS transition. Preliminary data support the use of this framework, and investigations are currently ongoing. Applying the Shared Management Framework to establish transition team programs in mental health care currently holds significant promise in terms of positioning Canada as an international leader in the mental health care of young people and their families. A policy-ready paper on CAMHS-AMHS transitions is being prepared by our group for the Ontario Centre of Excellence for Child and Youth Mental Health. The paper will be released in 2011 and will be accessible through the centre's website (www.onthepoint.ca). **HQ**

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