Mind the Gap:

A Study of the Youths' Experiences During the Transition from Child and Adolescent Mental Health Services to Adult Mental Health Services in the Champlain LHIN

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Introduction

Mental health problems experienced by children, youth and young adults are increasing dramatically, and epidemiologists estimate increases in incidence rates of at least 50% by 2020.^{1,2} In Canada, at least 70% of mental health problems have an age of onset occurring in childhood, adolescence or young adulthood.³

Available evidence indicates that youth who are engaged in child and adolescent mental health services (CAMHS) and require continued services in the adult mental health system (AMHS) are not well supported as they prepare to transition. ⁴⁻⁷ A lack of integration and effective collaboration between systems has been noted in Canada, the US, the UK, and Australia. ^{6,8-10} Moreover, research evidence clearly demonstrates that the period of transition from youth to adulthood offers a unique opportunity to impact on the lifetime trajectory of mental illness. ^{8,11}

As transition aged youth (aged 16-25 inclusive) move into adulthood, those with serious mental health conditions often have poor functioning and high rates of homelessness (30%), arrests (60%), school dropout (42%), and unemployment. At present, the most common outcomes for youth transitioning from CAMHS to AMHS include disengagement from services and crisis-driven reconnection in the future. Unfortunately, youth who disengage from service during this transition are at significantly higher risk of developing more enduring mental health problems. 13-16

A *shared management model*¹⁷ was implemented in our region to address the service gap. It is characterized by a flexible, collaborative approach whereby youth and adult providers from hospitals and communities work together with youth and families to develop individualized transitional care plans that promote coordination and continuity of care between CAMHS and

AMHS. This model of transitional care involves three key components: (1) collaboration and contributions of partner providers through an advisory committee composed of hospitals and agencies; (2) a transition coordinator who acts as system navigator to help prepare youth and families for transition, follows through with care plans by coordinating referrals, and ensures that youth are seen in a timely manner and remain engaged in the clinical services that meet their mental health needs; and (3) a research team to monitor and assess the implementation of the model.¹⁸

The objective of this study is to fill a gap in the current literature by explaining the challenges youth encounter during the transition from CAMHS and AMHS in the Champlain LHIN²⁵. In order to achieve this objective, our study surveyed the qualitative experiences of youth who both disengaged and remained engaged in care during the transition from CAMHS to AMHS. This study also captured the demographic, illness, developmental and access factors of youth who both disengage and remain engaged during the transition from CAMHS to AMHS.

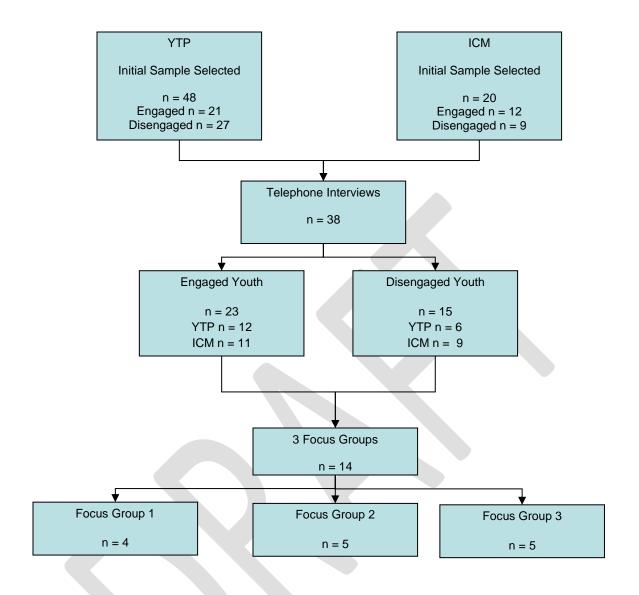
Participants

Participants were recruited from two sources: 1) Youth transitioned to AMHS by the Ottawa-Carleton Transitional Mental Health Services for Youth Program (n = 47) and 2) Youth seen in an Intensive Case Management (ICM) program (n = 20). In total, 38 Youth were interviewed, 23 of which were engaged in services after the transition period and 15 of which had disengaged from services during the transition period. From this group of 38 interviewees, 9 participated in a Focus group session.

Figure 1: Participants

Stages of the Transition & Interview Process

Distribution of youth at different stages of transitions program who successfully transitioned, disengaged from services during the transfer, participated in interviews, and participated in focus groups.



Methods

Sample

A sample was selected from the current clientele of the Youth Services Bureau of Ottawa's (YSB) Intensive Case Management (ICM) program and current and former clients of the Ottawa-Carleton Transitional Mental Health Services for Youth Program (YTP). Of the initial sample, a total of 38 respondents were interviewed, of which an additional 14 participated in focus groups. A flow chart outlining how respondents were selected is available as (see Figure 1).

Data collection

A 15-minute telephone interview was conducted with respondents. Participants were asked a series of questions (**see survey appendix**) on the key questions below, and were invited to participate in one of three 45-minute focus groups held in an accessible downtown location.

Outcomes

The primary outcome of this study was to capture the experiences of both engaged and disengaged respondents concerning their transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). Other outcomes included capturing and comparing the demographics, illness data, developmental data, and access data of both the engaged and disengaged youth. This data was collected and measured qualitatively using an open-ended questionnaire on the respondents' experiences during this transition period, as well as questions about the nature of the transition program, and respondent's impressions and

experiences of AMHS. These were measured both during the telephone interview, and additionally during focus groups to further explore respondents' experiences.

Covariates

Quantitative and qualitative data was collected from participants during the telephone interview to further describe the study sample. Information collected focused on four key areas: demographic data, such as age, etc., illness data, including primary and secondary diagnoses, developmental data outlining progression along developmental pathways such as education, employment, housing, etc. and access to health services and systems.

Analysis

Descriptive statistics were generated to describe the sample of the telephone interview. Qualitative telephone and focus group answers were grouped into key themes as expressed by participants. Results are presented in tables or as descriptive paragraphs, where appropriate.

Results

Sample Demographics

Table 1 outlines selected sample statistics. The sample was predominantly female (60.5%), with a mean age of 19.5 years. 60.5% of respondents were successfully engaged with AMHS at the time of their transition. Half (50.0%) of respondents were currently enrolled in schooling, with 81.6% having completed high school or equivalent. 13.2% of respondents had not yet completed high school or equivalent. 76.3% of respondents were not employed at all. 39.5% of respondents were living on their own, with 26.3% still living in a parental home.

52.7% of respondents reported fair or poor physical health, with 78.9% having access to a family doctor. 47.4% of respondents currently had a mental health professional.

Transition Experiences

Respondents answered a series of questions about their transition experiences. Their satisfaction over the transition experience ranged from the generally positive to the overwhelmingly negative, with a diversity of experiences in between. Key themes around which participants raised issues were as follows: i) Communication during pre and post-transition, ii) TYP program satisfaction, iii) Availability of and access to AMHS services, and iv) Experience with AMHS services.

Communication during Pre and Post-transition

Most respondents reported being informed several months prior to transition that a transition was to occur. This conversation was often initiated by the CAMHS service provider. In some cases of youth accessing services later in their adolescence (age 16-17), they were informed upon intake that their length of stay with the CAMHS service would be short and that a transition would take place imminently. However, some respondents reported not being informed that they would "age-out" of services at all. Of this, a female respondent (disengaged, ICM) said, "Well I realized [that I had aged out] when I turned 18 and had no services at all." Another female respondent (disengaged, TYP) indicated that "[Program staff] didn't say anything, they just called in one day, and they're just 'We can't help you any more, you need to go into the adult services."

Many respondents had very positive things to say about the transition program staff. The staff involved in transitions were reported by many respondents as being engaged and very helpful. For example a respondent (engaged, TYP) reported that, "[the transition staff] was such a sweetie [they] even brought [my doctor's] papers to me at the Young Women's Shelter. [They] didn't even tell me to come back to [their] office to get them; [they] brought them to me with brownies." Additionally, another respondent (engaged, TYP) reported, "I have had good experiences with [them] and [they] got my ODSP up and rolling. [They] got me in touch with a social worker and [they set up a meeting] with the psychiatrist. That part of what [they] did was great. CHEO held their end..."

Some respondents indicated difficulties in contacting transition-involved staff. For example, one respondent (disengaged, ICM) had the following to say: "It's very long process though, and [transition staff] never called me back, and I had to harass [them]. I literally called [them] every single day for two weeks, and then I got a reply, so, that's pretty bad." Another respondent (engaged, TYP) indicated that for him, "...the biggest thing was actually being contacted like everyone else. They called me once, set up an appointment and they told me pretty much 'you don't need this you have had a psychiatrist for this many years' and I haven't heard from them since. I have been trying to contact them but they just do not contact people unless it's like a year after or like not at all which is kind of terrible"

In addition, some youth reported difficulties with nursing staff providing negative messaging about the adult mental health system during the transition. For example a respondent (engaged, ICM) indicated "I found it really kind of annoying when a lot of the nurses, especially the older ones at CHEO were like, 'Oh, well, you really need to get it together.' That's not what you need to tell me, that's not helpful in any way, what I need to do or what it's going to be like.

Help me better prepare for it, instead of just being like, 'You're not going to like it.'"Some helpful suggestions did arise from the discussion, including a desire for the availability of a telephone number to contact post-transition if adult services weren't working out, or to provide additional support during the transition age. Additionally, respondents indicated that they would have preferred a greater degree of follow-up once the connection to adult services had been made.

Additionally, some participants were aware that the difficulties they had in reaching program staff may be due to workload issues. Said one respondent (engaged, TYP): "[The transition staff person] was really hard to reach. I don't know if [they are] in charge of everyone but [they have] a lot of patients so maybe if there were more than one person it would help to be more personalized instead of just a number."

Respondents at the focus groups were unanimous in supporting having the availability of some literature like a pamphlet, explaining what the transition process was going to be like, outlining key resources available, contact information in case of emergencies, etc. They indicated that having something like that would have at least given them some agency in the process and kept them better informed. A respondent (engaged, ICM) suggested: "... maybe a better understanding of what's offered and how to access it, like if they could provide a pamphlet, that would be very good." Another respondent (disengaged, ICM) echoed those comments: "That there needs to be a better kind of understanding of how, [things are] different. They tell you it's different, but I kind of wish they'd been like, 'This is how it's different. This is what you should be expecting, so if you need this, this is how it's going to be different,' because they're just throwing you out there. Well, [they're] going to set you up with some people, but [they're] just going to kind of, [dropping you]."

Transition Program/ICM Satisfaction

There were a diversity of opinion regarding the general experience with the transition program (TYP or ICM). While most people reported generally positive experiences, other respondents reported that the transition program was not helpful for them at all, or that there was a lack of preparedness for the transition.

One respondent (engaged, ICM) indicated that having their parent's support improved the process: "Well, my experience was pretty good, I can't say any bad things. But mostly because of my parents advocating for me, helped ... focus [their] attention more sort of have him remember that I was there, and that I needed resources, whatever, so... But, in my opinion, they should have more than one person leading a transitional team."

One respondent (engaged, TYP) indicated, "Preparing for [the transition, the TYP team] did a great job letting you know this is going to happen, [...] you are going to see this person and he is going to try to do this. They don't prepare you for the fact that [adult services] are not going to call you back."

Another respondent (engaged, TYP) indicated that the personalized attention that they received from the transition staff was "very helpful" but mentioned that the program itself was too short. Other respondents indicated feeling prepared for the transition. However, some respondents felt that the transition program did not meet their needs going through the transition into AMHS. Many respondents who transitioned either successfully or not reported anxiety about the transition. For example a respondent (engaged, ICM) said: "It was really really scary and I didn't want to change." Another respondent (disengaged, ICM) reported that great preparation would have been very helpful: "I would have liked someone to tell me, you know,

you gotta start working on transitioning and stuff, or someone to help me, instead of just being like, "What do I do?" instead of just randomly calling people, before I aged out. Like when I was 17, they could have been, "Yeah, I'm going to send you here".

A respondent (disengaged, ICM) also suggested that the transition period was valuable in moving forward with their life: "Changing from youth to adult [services ...] affected me in a good way to know I am growing up. It's scary to know I am growing up but it gives me more goals and new goals."

In addition, there was a perception in many respondents that program staff were illprepared to handle their needs and that the program itself was hampered by a lack of staff (as
noted above). For example, one respondent (engaged, ICM) noted that transition staff were
"always hard to get a hold of, [they] didn't seem to know what [they] was talking about, and
you'd go in, and [they'd] be like, "Well, what are you looking for after this?" Well, I don't
know, everyone's telling me it's really different, so I have no idea what there is, it's kind of your
job, isn't it?"

Many respondents indicated that there was no real transition and that they were simply dropped. One respondent (disengaged, TYP) reports: "It would have been helpful if they would have told me that once I turned 18, all services stopped, that they would have helped me set things up. I went a whole year and a half without any help, a doctor, anything. And I was stuck with my pediatrician for that whole year and a half, and she didn't know what to do, because all she could do was prescribe me my medication."

Availability of and Access to AMHS services

The availability of AMHS services and access to them was a noted concern for many participants. Many participants were waitlisted for services and for some, reported waits of upwards of a year to two years to access services, with no services for them in the interim. A respondent (disengaged, TYP) indicated, "I went a whole year and a half without any help, a doctor, anything. And I was stuck with my pediatrician for that whole year and a half, and she didn't know what to do, because all she could do was prescribe me my medication."

Some respondents during the telephone interviews indicated not having been referred to any adult services due to a lack of specific programming suited to their needs. In addition, many reported that they would have preferred being offered a choice of services or service providers, instead of a single provider, as some respondents indicated a poor relationship or experience with the referred service (see section below). However, some respondents also experienced a smooth transition into their adult service, especially when appropriate services were found in a timely manner and a good relationship was quickly established. Some respondents indicated that having access to the CAMHS service provider during an overlap period was very helpful as their CAMHS provider was able to provide coaching to transition, in addition to what was received in the TYP.

Geographic location of services was noted as a difficulty for some, especially those in outlying areas. For example, some participants living in distant satellite towns and exurbs reported difficulty in finding transportation to services, especially when bus services were not available. Additionally, even when respondents had access to bus services, some reported bus times of over an hour to reach their adult services. One respondent (engaged, TYP) indicated that adult services were more geared towards "you come to us, not we come to you" and would have preferred some flexibility from the AMHS service provider with that regard.

One respondent (disengaged, TYP) had experience engaging in transfers from the child and adolescent medical system into the adult medical system, and reported the following: "My medical doctors between the transfers were like 'okay the papers are transferred', the adult place has called me and set up an appointment and the doctor from CHEO will see me [...] after I have seen the new [adult medical doctors] to make sure [I] saw them [...]. The mental health services did none of that."

Experience with AMHS Services

Generally, youth experienced unfavorable interactions with the adult mental health system. Many reported that their AMHS care providers were not familiar with how to handle transition-aged youth, and simply treated them like fully fledged adults. This was seen as problematic because as one respondent (engaged, ICM) said, "you are supposed to be treated like an adult because you are 18. You are not in the same place when you are 18 as you are when you are 60. You don't have the same train of thought and you don't have the same life experience and I think that one day you are 17 and the next day you are 18."

However, some saw this sudden transition as an opportunity for personal growth. Some said that having to wait extended periods of time for services helped them become more independent and gave them a "push" towards self-growth. However, during this extended time period, many people reported worsening conditions including increased instances of self-harm and suicidal ideation and attempts.

Some respondents noted a lack of compassion and difficulty finding AMHS practitioners that understood the difficult transition period and demonstrated compassion. One respondent (disengaged, TYP) reports, "It's basically like you are playing a guessing game with which

doctor is going to be compassionate enough to go 'okay actually you got screwed, you need help and I am going to give you a bit of a hand." Another respondent (disengaged, ICM) indicated that they felt the key difference between AMHS and CAMHS was that "[CAMHS] put more time and effort into you. [CAMHS] take the time to actually help you."

With regards to in-patient services, some youth reported being admitted to in-patient wards in the AMHS, and reported it very negatively. On respondent (engaged, TYP) reports: "My first stay [at an adult facility] was hell. They put me in the part where there are people yelling and it was this old lady that was yelling, throwing herself on the ground and asking for hot water. They didn't have any groups. When you had to take your meds they called your name over the intercom and the nurses never talk to you." Youth reported that having a section dedicated to transition-aged youth would be more appropriate. For example, one respondent (engaged, TYP) indicated that in one facility, there was another transition aged youth admitted and found that was helpful in making the stay less unpleasant. However, some respondents indicated that some transition aged services were available and they were very happy with them. For example, one respondent (engaged, TYP), said: "I think it would be helpful if there were services geared towards adults and then services for 18-25 year olds. I did a DBT group at [an adult facility] and it was for 18-25 years olds and its' very good. It's with people who are transitioning also and people around your age so you can kind of talk. Until you are fully transitioned and used to the adult hospitals and programs it would be helpful."

One common complaint was that adult services did not seem prepared for their arrival.

Many felt that they were repeating their same story multiple times to their new care providers, and that if they had "just read my file", adult service providers would have been better prepared.

For example, one respondent (engaged, TYP) indicated, "one thing I noticed is that there was a

lot of miscommunication between the adult services and youth services. When I was transitioned into the adult they were like 'well we don't have your file yet.' It got to the point that 6 weeks into the program they still didn't know what was wrong with me. That's definitely one thing I want to change is communication."

Finally, some preferred the way adult services were structured compared to CAMHS services. A respondent indicated that adult services were more issue-focused, and attention was set towards achieving particular goals decided on by the patient and the care provider, compared to CAMHS services which are often simply geared towards getting patients to simply talk. This more direct and goal-oriented approach was seen as favorable by some respondents, and they enjoyed the flexibility and freedom it offered them.

Discussion

The primary goal of this study was to examine the transition experiences of participants in the YTP and ICM.

The demographic questions conducted during this study revealed that only 50% of these youth are currently attending school. 76.3% of these youth are unemployed. None of the youth surveyed (n = 38) self-report their physical health as excellent, while 52.7% report their physical health as only being fair or poor. 21.1% of these youth surveyed do not have access to a Family Practitioner and a staggering 52.6% do not have access to a mental health professional. It is clear that youth transitioning from CAMHS to AMHS are not having their basic employment and education needs met. Furthermore, their self-reported health, and level of access to a Family Practitioner and Mental Health Specialist is deplorably low. Improving youth access to employment, education, and health services should become a priority.

The communication questions conducted during this study revealed that during the Pre and Post-transition periods, youth felt that they were not given ample warning about the impending transition from CAMHS to AMHS. Some of those who were claim that the descriptions provided of AMHS on behalf of CAMHS employees were neither constructive nor conducive to a successful transition. Many youth noted that the transition process is a long one and that it is very difficult to contact anyone on the transitions team which suggests the shared management model may be understaffed and that this understaffing may be leading to the alienation and disengagement of youth from the shared management model of mental health and addictions services during the transition from CAMHS to AMHS. Constructive criticism from youth included the creation of a telephone contact number for youth who feel their needs are not being met, the personalization of services, and a support such as a pamphlet which could i) explain the transitions process while ii) providing a list of resources and emergency contact information. It is clear that for the shared management model to meet the needs of youth it's staffing must be increased.

The satisfaction questions conducted during our study revealed that there was a diversity of opinion concerning youth satisfaction with the *shared management model*¹⁷. Here too, criticisms included that the transitions program appears to be under-staffed and that while the program was "very helpful", it was "too short." After this transition through the *shared management model*¹⁷the Availability and Access to AMHS was a concern to many participants as many reported lengthy (12 months and more) waits for services. Aside from the waiting period, some respondents felt that there was a lack of specific programming suited to their needs. Youth who lived outside of the Greenbelt also reported access and transport issues. A feature

which youth enjoyed was the continued access to CAMHS until space in AMHS became available. It is evident that not only do youth have difficulty accessing the current shared management model, they also found that services were too short, and difficult to access if you do not live outside of the City of Ottawa.

The questions concerning youth "Experience with AMHS Services" revealed that many youth perceived AMHS as not being prepared for their arrival as they were under the impression that file had not been reviewed by the staff. Youth also found that the AMHS programming was inappropriate for their needs and that there was a lack of programming available. Some youth even reported a worsening of symptoms including instances of self-harm, suicidal ideation and attempts. Constructive youth criticism included the recommendation of "having a section dedicated to transition-aged youth" as they did not believe that the existing programs were geared towards them – a recommendation which has been implemented in other Nations. 8,9,11 Despite the criticism of AMHS, some youth enjoyed the flexibility, freedom and goal-oriented nature of AMHS. It is clear that while some youth enjoyed the goal-oriented nature of AMHS, many others believe that AMHS is often unprepared for their arrival and that it does not provide programming which meets their needs. A possible long-term solution to this challenge could be adding new funding to create a transitional youth program which would review the files of youth transitioning from CAMHS to AMHS and create age-appropriate programming and groups that would meet their needs.

Recommendations PENDING



Table 1 – Selected Sample Demographics

	Total		Engaged		Disengaged	
	%	n	%	n	%	n
Total	100%	38	60.5	23	39.5	15
Gender						
Male	39.5%	15	43.5%	10	33.3%	5
Female	60.5%	23	56.5%	13	66.7%	10
Age	Mean:19.4		Mean:19.4		Mean:19.5	
Currently Enrolled in School						
Yes	50.0%	19	47.8%	11	53.3%	8
No	50.0%	19	52.2%	12	46.7%	7
Highest Level of Schooling Completed						

Elementary	13.2%	5	21.7%	5	0.0%	0
High School/GED	81.6%	31	78.3%	18	86.7%	13
University	5.3%	2	0.0%	0	13.3%	2
Currently Employed						
Yes	23.7%	9	30.4%	7	13.3%	2
No	76.3%	29	69.6%	16	86.7%	13
Current Housing Status						
On Own	39.5%	15	45.3%	10	33.3%	5
Parental Home	26.3%	10	17.4%	4	40.0%	6
Shared Accomodation	18.4%	7	17.4%	4	20.0%	3
Other	15.8%	6	21.7%	5	6.7%	1
Current Self- Reported Physical Health						

Excellent	0%	0	0%	0	0%	0
Very Good	18.4%	7	13.0%	3	26.7%	4
Good	28.9%	11	30.4%	7	26.7%	4
Fair	31.6%	12	34.8%	8	26.7%	4
Poor	21.1%	8	21.7%	5	20.0%	3
Access to Family Doctor						
Yes	78.9%	30	87.0%	20	66.7%	10
No	21.1%	8	13.0%	3	33.3%	5
Currently has a MH Professioanl						
Yes	47.4%	18	56.5%	13	33.3%	5
No	52.6%	20	43.5%	10	66.7%	10

References

- The Health Status of the European Union: Narrowing the Health Gap. Luxemburg: European Commission, 2003.
- Report of the Surgeon General's Conference on Children's Mental Health: A National
 Action Agenda, Washington, DC: U.S. Department of Health and Human Services,
 2000.
- 3. Canadian Community Health Survey: Mental Health and Well-Being, Ottawa, ON: Statistics Canada, 2002a.
- 4. Freeland A. We've Got Growing Up to Do: Youth Mental Health Transitions. An International Focus on Youth in Transition: Development and Evaluation of a Mental Health Transition Service Model, 2012.
- 5. Paul, M., Ford, T., Kramer, T., Islam, Z., Harley, K., & Singh, S. P. (2013). Transfers and transitions between child and adult mental health services. *The British Journal of Psychiatry*. Supplement, 54, s36–40.
- 6. Pottick KJ, Bilder S, Vander Stoep A, et al. US Patterns of Mental Health Service Utilization for Transition-Age Youth and Young Adults. *The Journal of Behavioral Health Services and Research* 2008; 35(4): 373-389.
- 7. Singh SP, Paul M, Islam Z, et al. Transition from CAMHS to adult mental health services (TRACK): A study of service organisation, policies, process and user and carer perspectives: Report for the National Institute for Health Research Service Delivery and Organisation Programme, 2010.
- 8. Davidson S, Cappelli M, Vloet MA. We've Got Growing Up to Do: Policy and Practice in Youth Mental Health Transitions. Ottawa, Ontario Centre of Excellence for Child and Youth Mental Health, 2011.

- 9. McGorry PD. The specialist youth mental health model: Strengthening the weakest link in the public mental health system. *Medical Journal of Australia* 2007; 187(7): s53-s56.
- 10. Singh S, Evans N, Sirelin L, et al. Mind the gap: The interface between child and adult mental health services. *Psychiatric Bulletin* 2005; (29): 292–294.
- 11. McGorry P, Bates T, Birchwood M. (2013). Designing youth mental health services for the 21st century: Examples from Australia, Ireland and the UK. *The British Journal of Psychiatry* 2013; 54: s30–5.
- 12. Edlund MJ, Wang PS, Berglund PA, et al. Dropping out of mental health treatment: patterns and predictors among epidemiological survey respondents in the United States and Ontario. *The American Journal of Psychiatry* 2002; 159(5): 845–51.
- 13. Davis M, Banks S, Fisher W, et al. Longitudinal patterns of offending during the transition to adulthood in youth from the mental health system. *The Journal of Behavioral Health Services & Research* 2004; 31(4): 351–366.
- 14. O'Brien A, Fahmy R, Singh SP. Disengagement from mental health services: A literature review. *Social Psychiatry and Psychiatric Epidemiology* 2009; 44(7): 558–68.
- 15. Richards M, Vostanis P. Interprofessional perspectives on transitional mental health services for young people aged 16–19 years. *Journal of Interprofessional Care* 2004a; 18(2): 115–128.
- 16. Youth Advisory Committee of the Mental Health Commission of Canada: Evergreen: A Child and Youth Mental Health Framework for Canada A project of the Child and Youth Advisory Committee of the Mental Health Commission of Canada, 2010.
- Kieckhefer GM, Trahms CM. Supporting development of children with chronic conditions: from compliance toward shared management. *Pediatric Nursing* 2000; 26(4): 354–363.
- 18. Cappelli M, Davidson S, Vloet M, et al. Evaluation of the Ottawa-Carleton Transitional Youth Program: Transitional Program Based on a Shared Care Management Model.

- Paper presented at the 26th Annual Children's Mental Health Research and Policy Conference, Tampa, FL, March 4, 2013.
- Dall K, Lefebvre M, Pacey M, Sahai V. Champlain LHIN: Socio-Economic Indicators Atlas. Government of Ontario, Ottawa, ON, 2006.
- 20. Community Mental Health Common Assessment Project: Ontario Common Assessment of Need: OCAN User Guide: Community Care Information Management, 2010.
- 21. Issakidis C, Teesson M. (1999). Measurement of need for care: A trial of the Camberwell Assessment of Need and the Health of the National Outcome Scales. Australian and New Zealand Journal of Psychiatry 1999; 33: 754–759.
- 22. Dennis ML, Chan YF, Funk RR. Development and validation of the GAIN short screener (GSS) for internalizing, externalizing and substance use disorders and crime/violence problems among adolescents and adults. *The American Journal of Addictions* 2006; 15: s80-s91.
- 23. Lyons, JS. Communimetrics: A Communication Theory for Measurement in Human Services. New York: Springer, 2009.
- 24. Cappelli, M., Davidson, S., Racek, J., Leon, S, Vloet, M., Tataryn, K, Gillis, K., Freeland, A., Carver, J., Thatte, S., Lowe, J. Transitioning Youth into Adult Mental Health and Addiction Services: An Outcomes Evaluation of the Youth Transition Project.
- 25. Singh, Swaran P. Transition of care from child to adult mental health services: the great divide. University of Warwick,2009. Retrieved from:

http://wrap.warwick.ac.uk/3758/1/WRAP_Singh_current_opinions5.pdf, 20 March 2014.

26. Clark, Hewitt B. Transition to Independence Process (TIP) System: A Community-Based Model for Improving the Outcomes of Youth and Young Adults with EBD. Retrieved from: http://tipstars.org/Portals/0/pdf/TIP%20Model%20Overview.pdf 20 March 2014.

Survey Appendix

Introduction

Thank you for agreeing to be interviewed today. My name is _____ and I am part of the team looking at the barriers to transition. We are doing a project that looks at what happens when young people move from child and adolescent mental health services to adult mental health services. We'd like to hear about your experiences going through this process. This will help us understand what the transition was like for you, the role of the transition team in that process and ways that we can improve our services to better meet the needs of young people.

Everything you say here is private. The only situation where this would not apply is if you told me something that made me concerned that there was a risk of serious harm to either yourself or to another person.

All the information collected from today will be stored on a computer and your name will not be recorded on the computer so that your answers stay private. Only the people doing the evaluation will be able to view the information. Members of the transition team and other care providers do not have access to the information.

Are you willing for me to record our conversation so that I don't have to write while we are talking? Nobody outside the research team will hear the tapes and they will be kept in a locked filing cabinet.

Interest to Participate in Focus Group

Before we begin, we are interested in hosting some focus groups, that's where five or six people get together, hosted by a facilitator, to talk about their experiences in transitions and getting the services they need.

- FOC1: If the timing worked for you, would you be interested in participating in the focus group?
 - Yes
 - o No
- IF YES: FOC1A: Great, thank you. We're currently looking at hosting the focus groups on DATE1. Would this work for you?
 - Yes
 - o No
- FOC1B: What about DATE2. Would this work for you?
 - Yes
 - o No

• FOC10	: What about DATE3. Would this work for you?
0	Yes
0	No
Demographics	
Now I'd like to	get some information about you.
• AGE1:	What is your year, month and Date of birth? YEAR: Month: Date:
• SCH1:	Are you currently enrolled in school?
0	Yes
0	No
• SCH2:	What's the highest level of school you've completed?
0	Elementary
0	High School
0	GED
0	College
0	University
	Are you currently employed?
0	Yes
	EMP2: Full time?
	■ EMP2: Part time?
	■ EMP2: Other?
	EMP2A: Specify:
0	No
 EMP3: 	How much do you make a year, roughly?

 HOU1: 	What's your current housing situation? By this, we mean, where are your living?
0	On own
0	Parental Home
0	Maternal Home
0	Paternal Home
0	Foster Caregiver's Home
0	Shared Accomodation (not family)
0	Community Housing
0	Street
0	Couch Surfing
0	Other
	■ HOU1A: Specify:
Health and Me	ntal
explained in the	d just like to remind you that all the information provided here is confidential, as e beginning. n general, would you say your health is: (excellent, very good, good, fair, or poor)? Excellent
0	Very Good
0	Good
0	Fair
0	Poor
<u> </u>	
• SMH1:	What is your primary mental health diagnosis?
• SMH1A	A: When were you first diagnosed with (above)?
	A: Do you have a secondary mental health diagnosis?
0	Yes
	• Specify:
	SMH2A: When were you diagnosed for (above)?
0	No

When was the last time that...

psychiatrist, etc.

SMH3A: you used alcohol or other drugs weekly or more often? o Past Month (3) 2 to 12 months ago (2) 1+ years ago (1) Never (0) SMH3B: you spent a lot of time either getting alcohol or other drugs, using alcohol or other drugs, or feeling the effects of alcohol or other drugs? o Past Month (3) 2 to 12 months ago (2) 1+ years ago (1) Never (0) SMH3C: you kept using alcohol or other drugs even though it was causing social problems, leading to fights, or getting you into trouble with other people? o Past Month (3) o 2 to 12 months ago (2) 1+ years ago (1) Never (0) SMH3D: your use of alcohol or other drugs caused you to give up, reduce or have problems at important activities at work, school, home, or social events? Past Month (3) 2 to 12 months ago (2) 1+ years ago (1) o Never (0) SMH3E: you had withdrawal problems from alcohol or other drugs like shaky hands, throwing up, having trouble sitting still or sleeping, or that you used any alcohol or other drugs to stop being sick or avoid withdrawal problems? o Past Month (3) 2 to 12 months ago (2) 1+ years ago (1) Never (0) ACC1: Do you have a family doctor? Yes No 0

ACC2: Do you have a mental health professional? This can mean a psychologist, counsellor,

	o Yes
	ACC2A: What type?
	o No
•	ACC6: Who follows your current mental health care?
	o Type:
•	ACC3: How many times have you visited the emergency department at a hospital for a mental health condition in the past year?
	 ACC3A: When was the date of your last emergency room visit? M:D:Y:
•	ACC4: How many times have you been admitted to hospital for your primary mental health
	diagnosis in the last year? O ACC4A: When was the date of your last admission in the last year?
	M:D:Y:
	<u></u>
•	ACC5: Are you currently taking any medication for your mental health?
	o Yes
	ACC5B: Who prescribed you this medication?
	Family Doctor
	Psychiatrist
	Emergency Room Physician
	• Other
	ACC5C: Who's monitoring this medication with you?
	Family Doctor
	 Psychiatrist
	Emergency Room Physician

Thank you for all that information. I know that's a lot of questions, but now we're getting to the last section. Here, we're going to talk about your experiences with the transition program.

Other

TRNQ: Before we start, what are you doing now? (college/working/hobbies, etc)	
TRNC: How did you realize that you would have to move from the Child and Adolescent Me	ental Health
Services to the Adult service?	

TRND: Was there anything that helped or was unhelpful in preparing you for this move?
TRNE: Thinking back, is there anything that would have been more helpful in preparing you for the
move, or anything that you would change?

TRN	TRNF: How would you describe your transition experience?										
									nd 10 equals		
l .			you wer	e for the	e transit	ion? (Pro	ompts: I	How coul	d you have	been bette	r prepared
for t	he transi	tion?)									
1	2	3	4	5	6	7	8	9	10		
_	_	J	·	J					10		

	H: On a see you wit				_	satisfied	d at all a	nd 10 be	ing very satis	sfied, how s	atisfied
1	2	3	4	5	6	7	8	9	10		

TRNG: How would you describe your experience working with the transition team?

		ale of 1 t atisfactio					d and 10) is very	satisfied, how would you rate
1	2	3	4	5	6	7	8	9	10

TRNI: What are the strengths of the transition program?

TRNR: Thinking back, is there anything that was not helpful or acted as a barrier in making the
transition? (Prompts: transportation, availability and timing of appointments, etc.)
TONIL How and the transition are seen by improved 12
TRNJ: How could the transition program be improved?
TRNK: Have you been to the adult service you were referred to? If no, why not?

TRNL: What has it been like going there?
TRNM: What are the main differences between CAMHS and AMHS?

TRNO: What do you like best/least about AMHS?
TRNP: Has the process of changing from CAMHS to AMHS had any effect on you?
Trive. has the process of changing from Calvins to Alvins had any effect on you!