SE LHIN – TRANSITIONAL AGED YOUTH (TAY) RESEARCH – FINAL REPORT

EXECUTIVE SUMMARY

Implemented through Youth Habilitation Quinte (Youthab), the youth transition research examined existing services to help improve the flow and access to care of youth aged 15 to 19 with mental health and/or addictions (MH&A) issues who are transitioning primarily from the children's to the adult MH&A system. Transition is defined as the process of change when youth move from one organizational system to another for service. Once the youth has been accepted by the new organization, their case is then closed by the referring organization. Through paper and on-line surveys, research interviews and focus groups with youth and service providers, the objectives were to determine service gaps and barriers for these youth who are transitioning. Funded by the South East Local Health Integration Network (SE LHIN), this study was conducted in the Counties of Hastings-Prince Edward (H-PE), Lennox & Addington (L & A), Frontenac, Leeds & Grenville (L & G) and Lanark. In addition to the research, the mapping of services for these areas has been undertaken and will be maintained.

Prevalence of Mental Illness among Youth

In the SE LHIN, at least 15% of children and youth have a mental illness[1] and it is estimated that the prevalence of mental illness between the ages of 15 and 24 is approximately 10,323 individuals.[1, 2] The prevalence of **serious** mental illness for youth between the ages of 15 to 24 is estimated at 5.4% or 3,716 individuals.[3] (Please refer to page 7.) Only 1 in 5 youth or 2,065 individuals aged 15 to 24 within our region who are in need of mental health services actually receive care.[3] By deduction, this would imply that 8,258 youth aged 15 to 24 within the SE LHIN who require mental health services do not receive care and need additional support. This may be due to the stigma of being labeled, the lack of information to access services, capacity limits, a lack of specialized services, disinclination to access services, lack of transportation or a lack of knowledge of potential services.

Research Methodology

There were two stages to the youth and service provider research:

1. Completion of a paper survey for youth and an on-line survey for MH&A agencies
2. Participation in a research interview/focus group

The research was conducted with:

- 9 - transitional aged youth (TAY)
- 14 - MH&A agencies and the Child and Adolescent Psychiatric Clinic
- 13 - community agencies/services (participated in the qualitative research only)

The research objectives were to identify, understand and assess:

- Barriers for youth who are transitioning;
- Services that are missing or needed for youth to transition seamlessly; and
- The scope of the problem with youth transitions.

[1] Waddell & Shepherd, 2002; Ministry of Children and Youth Services, 2006

[2] Statistics Canada estimates, July 1, 2011 and Ontario Ministry of Finance projections

[3] Improving Quality of Care and Patient Safety for Transitional Youth and Young Adults, submitted to the Champlain LHIN, 2010

Youth Demographic

Youth are transitioning into adulthood with a myriad of concerns around education, employment, relationships and striving to be independent. For youth with MH&A issues, coordinated services, support and engagement are required to facilitate their transition in accessing services and in becoming an adult. Youth can still be vulnerable as their adolescent brain continues to develop until the age of 25. Maturity varies for each youth. For these reasons, MH&A and community agencies view Transitional Aged Youth (TAY) as being 16 to 24 years old, with age-appropriate services corresponding to their developmental and life domain needs.

Transitional Aged Youth Research:

Over half (56%) of youth participants reported a transition or an attempted transition from one agency to another for service. Of these respondents, 20% or one young person did not follow through with the transition because the counsellor was perceived as being abrupt and did not engage the youth.

The key themes identified from the youth research are:

- Ensure youth feel comfortable accessing services and supports
- MH and supportive counselling are services most often accessed
- Youth are not aware that transitioning from Children's Mental Health (CMH) to Adult Mental Health (AMH) is an option
- Youth often do not know how to ask for help or what services they need
- Youth strive to acquire life skills to be successful

These themes will be described more fully in the Emergent Themes section below.

Perceived Demand

Most (87%) MH&A agencies perceived an increase in demand for services in the next few years. This is due to increased MH awareness, decrease in stigma, socio-economic factors and drug dependency.

EMERGENT THEMES

Analysis of the summary information from the surveys and the qualitative data informed the development of the emergent research themes. In providing context for the long-term improvement of client flow and appropriate access to care for TAY, the themes are grouped by access to care issues, requisites for building a solid foundation and the development of an effective transition process.

ACCESS TO CARE ISSUES:

Access to care is hindered by:

- Limited capacity
- Systemic barriers
- Cultural differences
- Lack of specialized, intensive services
- Lack of appropriate programming for TAY
- Lack of resources

There is limited capacity to community clinical counselling for those with a mid-range of mental health issues over the age of 18. Youth under the age of 18, can still access services from CMH. Youth over 18, who do not qualify for AMH or are not diagnosed have limited access to free clinical counselling. Even when clinical counselling is available, some CMH and community agencies perceive that those with moderate MH issues are not adequately served. This is critical as youth respondents highlighted that MH and supportive counselling are services most often accessed.

There are simply not enough psychiatrists, especially for adolescents in the adult system. Wait times are lengthiest in Lanark at 3 months. Access to public psychiatric and psychological assessments is limited. Depending on the school board, each school is only allotted 2 to 5 psychological assessments per year.

Systemic barriers and differences in ministerial culture prohibit the access to programs, services and information resources. Systems were not set-up originally as being client-centred. Although CMH accepts anyone who has mental health issues and needs help, AMH agencies were established historically as requiring a diagnosis and as such, there are potential clients who would not receive services. Most AMH agencies accept referrals without a diagnosis but some may still request a diagnosis and will assist the client to access a psychiatrist to obtain an assessment. This practice presents an additional hurdle and has created confusion for clients, and referring CMH and community agencies.

Part-time psychiatrists with an AMH&A service cannot consult with clients under 18. Some justice-related prevention programs are only available for those who have committed a crime, not for those who are at risk. Case files cannot be transferred between Youth and Adult Probation.

The adult MH&A system lacks specialized, intensive services and appropriate programming for TAY. Specialized services and counselling for eating, mood, complex behavioural and Autism Spectrum disorders are needed. Youth who have been severely abused or traumatized, but do not have a diagnosis often require more specialized, intensive services and support. For youth transitioning from CMH, AMH is a culture shock. There is no wraparound service; group sessions and supported housing can include 40 to 50 year olds. Youth are expected to be forthcoming and advocate for the services that they need. Youth addictions programming does not exist in most areas. There are no residential treatment facilities between Toronto and Ottawa for youth with addictions.

The lack of resources and time constraints is a barrier for community agencies/services as well as MH&A agencies. Hospitals lack psychiatric resources and indigenous services do not have sufficient resources to meet their demand. Adult Probation need more time for psychological and sexual risk assessments, while schools need more time to support students who are not attending classes regularly. Additional AMH&A counsellors are needed to reduce lengthy wait lists. To transition youth properly, extra resources and time are required for meetings and to transport and accompany youth. For indigenous services, the lack of cross-cultural training and indigenous staff is perceived as a barrier in accessing mainstream community MH&A services. Having indigenous workers would provide an improved cultural understanding and perspective of this youth population.

REQUISITES TO BUILDING A SOLID FOUNDATION:

Identified as a barrier, a service gap or both, the following components if improved would provide the core requisites in building a strong infrastructure for youth transitioning and can lead to successful outcomes for TAY.

- Communication, awareness, and the sharing of information
- Comprehensive youth services, supports and engagement
- Affordable, supported and emergency housing for youth
- Accessible public transportation
- Prevention and early intervention strategies

Identified as a key barrier, agencies and ministries lack information and understanding of one another's services. Different ministries (Child and Youth, Health and Long-Term Care, Education and Community and Social Services, Community Safety and Correctional Services) need to better understand each other's roles and differences. The differences make connections difficult. Better communication is needed between agencies, schools, hospitals, and justice services to understand each other's services and how resources can be available for each agency and to avoid duplication of services. Some MH frontline staff are unaware that clinical counselling services are available at Family Health Teams (FHTs) and Community Health Centres (CHCs).

Perceived as a gap, TAY require comprehensive, coordinated services, support and engagement. Youth feel most comfortable when counsellors are youth-friendly, helpful and flexible. Appropriate, enhanced services and supports including holistic case management, counselling, recreational activities, vocational and educational programs, and housing can help youth succeed. But ultimately, youth strive to acquire practical skills as in life, social, coping, employment readiness, and supports that build their confidence and self-esteem so that they can be independent and successful.

Youth may not know what services are available, how to access them and often do not know how to ask for help. From the youth research, they were not aware that transitioning from CMH to AMH is an option. Engagement is required to inform and assist youth to access services and advocate for themselves. Texting is the preferred means of accessing help among youth as it can be anonymous. Some agencies expressed the need to meet youth's reliance on technology by engaging them differently yet providing them with the support that they require.

Age appropriate, supportive and emergency housing was indicated as a gap and barrier. Stable and affordable housing is a key foundation of support. Without it, youth have a difficult time accessing MH counselling and /or pursuing employment needs. More semi-independent living programs like the Transition Home (Youthab) and supportive housing in rural centres are required. For youth who have criminal records or have high needs, a significant gap exists in supported housing and supported emergency housing.

There is a lack of public transportation particularly in rural areas. Identified as a barrier and gap, counsellors would often drive select clients to appointments and meetings. This places a challenge on limited resources needed for counselling.

Education, prevention and early intervention strategies are needed. Youth and their families, service and care providers would be more knowledgeable, be able to better manage MH&A issues and prevent

escalating destructive behaviours if these strategies are in place. Identified educational and intervention topics would include: suicide prevention and intervention for TAY, primary care and in-school staff awareness of MH&A services, concurrent disorder education for non-MH&A service providers, psycho-education on substance use to avert potential criminal offences, and creative early intervention or prevention programs or services.

DEVELOPMENT OF EFFECTIVE TRANSITION PROCESSES IS NEEDED:

Current transitions are not tracked and can be improved. Youth transitions in L&G, L&A, Lanark, and addictions in Frontenac are informal to semiformal with good collaboration among agencies. For the Youth and Adolescent Psychiatric Clinic, transitions are seamless for First Episode Psychosis and Personality Disorder services. In H-PE, youth services are better coordinated and integrated as Youthab provides MH counselling, housing and employment services. However, agency referrals for transitioning into AMH are infrequent as the need for a diagnosis and the lack of clinical counselling services limits access. In Frontenac, there are communication and perception issues. CMH do not know who to contact at AMH in transitioning youth and are not aware that AMH offers clinical counselling and can assist clients to obtain a diagnosis. Addictions services in H-PE, L&G and Lanark can coordinate services but do not transition youth.

Overall, some transition processes are working well; however, others are working less well. Solutions have been suggested for their improvement. If the developmental processes are adapted, they would contribute to a more effective youth transition process.

Transition services and supports working well:

- Good collaborative relationships
- Practices that are client-centred and facilitate the transition process

Transition services and supports working less well:

- Lack of information and communication processes
- Less than optimal coordination
- Lack of transition planning
- Limited sharing of information and collaborative decision-making at the operational level
- Lack of cultural understanding
- Lack of resources

Collaborative relationships enable a positive flow and facilitate a successful transition. Good communication and support enhances the overlap bridging of clients. Practices that are client-centred in facilitating introductions and sharing information, increase youth's willingness to engage, make their lives easier and improve the client flow.

Transition processes can be improved through better planning, communication, coordination, collaboration, additional resources, flexibility and supports. Proposed solutions by the respondents include:

- Protocols to outline the transition process from initial referral to follow-up
- Enhance frontline staff's knowledge regarding transition processes, agencies' roles and of workers at other agencies

- Initiate better coordination with other agencies and services to facilitate client flow and follow-up
- Improve the sharing of information and collaborative decision-making at the operational manager level
- Additional resources and flexibility to bridge services between CMH and AMH

Framework Ideas

The ideas generated ranged from the practical, the expected and an innovative alternative. The options were aggregated from MH&A and community agencies/services.

The most frequently cited idea is to have dedicated transition workers. Some MH&A agencies preferred to have one dedicated worker at each agency to work collaboratively with each other and the client to facilitate the transition. Among community agencies/services, it was suggested that a Transition Worker/System Navigator would bridge the two systems, with dedicated workers in each system.

Extend current children's mental health services to age 24. TAY need wraparound services including youth services under one roof. It was also suggested that the youth offender system be extended to age 24.

Provide a quality, comprehensive youth service. Proposed by some MH&A agencies, services would incorporate best practices for youth services programming and engagement, making transitions invisible.

Incorporate MH&A into primary care teams. Suggested by some community agencies/services, primary care becomes the entry point. This would minimize the stigma and normalize the treatment of mental health.

Building capacity, improved communication, engaging youth and frontline staff, and developing an effective transition framework are required to facilitate the flow and access to care for TAY. Enhanced services and TAY programming within AMH&A, and prevention and early intervention strategies would address some of the service gaps. The sharing of information and the flexibility to coordinate resources across ministries and community services can resolve some of the cultural barriers but would require a dedicated collaborative effort. Likewise, systemic barriers and gaps such as, affordable housing and public transportation would require collective advocacy and commitment from appropriate levels of government.

In conclusion, it is aspired that some of the recommendations summarized above will be implemented to assist TAY to acquire the appropriate services, skills and supports to build their confidence and self-esteem. Clarifying and streamlining the referral and diagnosis process can make life easier for youth and their families. Engagement, early intervention, age appropriate services and supports can help TAY manage issues and overcome difficulties. Practical transition processes and dedicated transition workers can ensure transitional aged youth are comfortable and supported during the bridging of services.