Helping to Place Youth at the Centre:
Reflection and Information Tool for Decision-Makers and Health Care Providers©
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This "tool" was developed by the *"Youth to Adult Transitions in Health Care – The Case of Mental Health Services in Ontario"* research team at McMaster University to help: (1) encourage greater reflection on youth-centredness; and (2) present some of our research findings in a way that is practical, concise, and easy to follow. Ask yourself the following questions, review the related study findings, and determine what you might be able to do differently to make care more youth-centred.

SECTION 1: HOLISTIC NEEDS (CONSIDERING THE BROAD NEEDS OF YOUTH)

a. DEVELOPMENTALLY APPROPRIATE CARE:

Question: **Are decisions about the youth's care restricted by administrative policies** (e.g., do you have flexibility in the application of age criteria to consider the youth's developmental age, when different from biological age, and are you able to address a variety of developmental factors, such as education and maturity)?

Findings:
- Interviews: Some organizations apply strict age criteria for services, while others adopt a more flexible approach where youth may be provided with an extended transition period to adult-based services.
- Literature: The integration of models and programs aimed at improving developmentally supportive aspects of care (e.g., vocational interventions and peer support programs) can improve outcomes.

b. ATTENTION TO PERSONAL/SOCIAL/CULTURAL/FINANCIAL NEEDS:

Question: **Are you able to fully consider the holistic needs of the youth as services change** (e.g., are you able to adequately consider his/her employment, social networks, the impact of a change in services, etc.)?

Findings:
- Interviews: Institutional policies around funding and availability of services (e.g., variations between child and adult services) can contribute to services being less youth-centred.
- Literature: (1) While many services focus on employment/vocational needs of youth, few address areas such as personal and interpersonal development (including sexuality); and, (2) there is limited use of peer support services to facilitate the transitions process, despite evidence in support of its value.

c. RECOGNIZING THE ROLE OF CARE PHILOSOPHY:

Question: **How might youth-centred care assist youth and families to be better prepared for shifts in approaches to care** (e.g., a shift from child-focused and nurturing to adult-focused emphasizing independence)?

Findings:
- Interviews: (1) There is variability across organizations, but care approaches seem to be entrenched within the culture of each organization; and, (2) being forced to adapt to the culture of an adult service contributes to stress and appears to be associated with an increased likelihood of the youth discontinuing service.
- Literature: (1) Child-based services often take into consideration biological, psychological and social factors within the youth's development context, while adult services more often focus on a diagnosis-based, pharmaceutical treatment; and, (2) child-based services tend to subscribe to a protective approach and more fully consider family and social context, while adult services tend to focus on the client as an individual.

SECTION 2: POLICIES AND ORGANIZATIONAL PROCESSES (CONSIDERING BARRIERS TO MEETING CARE NEEDS)

a. COMMUNICATING WITH YOUTH/FAMILIES:

Question: **Is information exchange accurate, timely, collaborative, adequately addresses privacy concerns, and includes ample opportunities for feedback** (e.g., are youth and family engaged in the planning of care and do they feel even more empowered following each communication interaction)?

Findings:
- Interviews: There is wide variability in: (1) the advance notice provided regarding the discontinuation of child-based services; and, (2) the extent to which youth and their families feel part of the decision process and whether their opinions/preferences are considered.
- Literature: Meaningful information-sharing and efforts to enhance engagement among youth, their families, and health care providers can provide youth and families with a valuable sense of control over the transition process.

b. COMMUNICATION ACROSS PROVIDERS AND SERVICES:

Question: **Is information exchange accurate, timely, collaborative, and collegial** (e.g., has the interaction helped to meet youth and family needs and enhance the quality of care)?

Findings:
- Interviews: (1) Some organizations have developed processes to enhance collaborative communication across organizations; and, (2) these processes are variable and tend to be driven by individuals.
- Literature: There is often very little communication and collaboration between child and adult services, which may be due to different administrative processes and approaches to treatment.

c. PROVISION OF SERVICES:

Question: **Are services adequately resourced and available, without financial barriers, and designed to meet the specific needs of a "youth" population** (e.g., easily accessible; service hours meet needs of the youth; services are provided in a comfortable and age appropriate environment; reasonable wait lists)?

Findings:
- Interviews: (1) A common concern is lack of available resources resulting in limited services and/or long wait lists; and (2) family members experience greater pressures to take time off employment during transitions.
- Literature: (1) Financial burdens typically increase as youth shift to adult services (e.g., transportation to service locations; a reduction in access to privately-insured services); and, (2) inadequate transition support may increase the likelihood of youth discontinuing services.

SECTION 3: OUTCOMES (CONSIDERING ORGANIZATIONAL LIMITATIONS AND SUCCESS AT MEETING NEEDS)

a. MAKING EVIDENCE-BASED DECISIONS:

Question: **Is there evidence available that may be used to support decisions about the youth, and if so, is it being used by decision-makers and providers** (e.g., are health care providers able to stay current with the latest evidence and are organizations willing to make changes based on that evidence)?

Findings:
- Interviews: (1) Providers feel stressed and overworked with little time available to stay up-to-date on the latest evidence; and, (2) despite best intentions, many providers did not fully appreciate the "youth-centred" care concept (e.g., they were delivering care plans the youth disagreed with; services hours were inconvenient).
- Literature: (1) Sex and gender are not adequately considered in the design of most studies; and, (2) some evidence-based activities (e.g., peer support) are not well implemented.

b. ENHANCING EFFICIENCY IN ALLOCATING RESOURCES:

Question: **Do decisions and services achieve the best possible use of resources** (e.g., alignment of service type and intensity with the youth's needs; avoiding duplication of assessments/services from other organizations)?

Findings:
- Interviews: (1) Some youth/families complained of having to repeat their stories as part of repeated initial assessments conducted by different agencies; and, (2) some youth, especially those with strong advocates, obtained overlapping services through multiple agencies, while other youth had minimal or no access to services.
- Literature: Very little is known about the financial impact of transitions (including the cost to youth and families and the system-wide costs of various approaches to addressing gaps in the care for youth).

c. FOCUSING ON THE LONG-TERM NEEDS OF THE YOUTH:

Question: **Does the care plan maximize the youth's ability to move toward independence and away from the need for services** (e.g., are the services adequate and sustainable with a focus on recovery and decreasing care)?

Findings:
- Interviews: Some organizations are focused on improving the child to adult transition process, while others are focused on meeting the needs of youth, largely independent of adult services.
- Literature: (1) Transition programs show some effectiveness in helping youth achieve more independence and control of their health, including greater independence in adulthood; and, (2) the change to adult services may be a culture shock for some young people, which discourages them from continuing to seek adult care services.

For more information about our findings and for full references see: http://youthtransitions.degroote.mcmaster.ca/