

Helping to Place Youth at the Centre: Reflection and Information Tool for Youth and Family Members[®]

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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. We hope it will help you understand what we learned in our research and help you think about how your views can be used in decisions about your care. We hope this information can help you to be better prepared to raise questions and have your opinions considered.

1. AGE AND LIFE STAGES:

Question: Do you feel that the service provided is right) for you given your age and what you are focusing on in your recovery (e.g., you are not placed in adult-based services before you are ready just because of your age)?

What we found from our research and what people told us:

- Youth may do better when services match their needs, regardless of how old they are.
- Some child services automatically end when youth turn 18. Others are more flexible and allow you to stay in child-based services longer. Other services may allow for an overlap where you get both child and adult services for a period of time.

Think about and ask: How long are your current services available? For example, *would it be better for you to move to adult services, or stay in child or transition services longer? Ask questions about what might be possible that would fit with your circumstances.*

2. ATTENTION TO MORE THAN JUST MEDICAL NEEDS:

Question: Do you feel all your needs are taken into account (e.g., appropriate housing, financial support, your relationships, training and work options, education)?

What we found from our research and what people told us:

- Programs that provide support for personal and social needs such as housing, employment and social relationships can be offered alongside programs that primarily focus on mental health needs.
- Peer support (support from others who have had similar experiences and may be the same age) can be a helpful addition to programs but has not been widely used.

Think about: *Are there any additional supports that can help your recovery? Ask questions about whether there are opportunities for more stable housing, relationship support, job training and peer support if you think these would help.*

3. PREPARING FOR DIFFERENT APPROACHES IN ADULT SERVICES:

Question: Do you feel that available services are youth-centred and help you and your family prepare for any differences in care when transitioning to adult services (e.g., a shift from child-focused and nurturing to adult-focused emphasizing independence)?

What we found from our research and what people told us:

- Moving from child-based services to adult-based services can be stressful because health care providers focus on different areas and may focus more on the youth than the family as a whole. Also, others in services may be older adults, and there is a greater expectation that you be independent.
- Youth that do not have enough support during the transition to adult-based services are more likely to stop attending services.

Think about and ask: *Are there ways you can be more comfortable about what to expect in adult services? Ask questions about the different approaches, how your family can be involved or what supports are there for them. Can I meet with adult providers ahead of the transition, spend some time in adult services and still be connected to my present services, or speak with peers who have made the transition successfully?*

4. COMMUNICATING WITH PROVIDERS:

Question: **Do you feel that you play an important role in planning your care** (e.g., How do service providers approach understanding what you need? Do we decide together what services I and my family will receive? Do I get a menu of options? Will my information be shared with my parents, school, or other service providers I work with?)

What we found from our research and what people told us:

- Programs have different policies about the amount of notice given before child services are stopped, and different processes regarding how much the youth and family are involved in decision-making.
- Sharing information and efforts to improve involvement among youth, their families, and health care providers can provide youth and families with a valuable sense of control over the transition process, which can make the transition go more smoothly.

Think about and ask: *How much input do you have to decisions about your care? Are there ways you can be comfortable sharing your opinions? Both prior to and following a transition, ask questions about whether time can be set aside at each appointment for you to share your preferences and whether your provider can let you know what might be discussed at the next meeting so you can prepare your thoughts ahead of time.*

5. PROVIDERS COMMUNICATING WITH EACH OTHER:

Question: **Do you feel that new health care providers know everything they need to about you** (e.g., do you need to repeat stories to different providers because they do not know enough about what has happened to you)?

What we found from our research and what people told us:

- It is helpful to have good communication when there is a transition from child to adult services, but not all organizations do a good job with this.
- Some organizations have created ways to improve communication, but this will be different at each organization, so knowing how they will share information can be helpful to smooth the transition process.

Think about and ask: *Are there things your new provider doesn't know about your situation, but they should? Are there easier ways for you to share this without retelling your story? For example, could you write about it and share that with your provider? Could you give permission for your previous provider to share what you told them?*

6. GETTING ACCESS TO SERVICES AND STAYING IN CARE:

Question: **Do you feel that services meet your needs** (e.g., appointments are available at convenient times, services are easy to get to, and services are geared toward your own age group?)

What we found from our research and what people told us:

- A common concern is not having enough services available and/or long wait lists.
- Family members having to take more time off from work during transitions.
- Greater financial costs as youth shift to adult services (e.g., costs for transportation to service locations, having to pay for privately-insured services).
- Greater likelihood of youth discontinuing services unless they have support during transitions.

Think about and ask: *What might be making it difficult for you to get to appointments or stay in services? Ask questions about whether services can be flexible to meet your needs, by helping with transportation, meeting in the community rather than in an office, evening or weekend appointments, offering a sliding payment scale, or other support during transitions.*

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

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