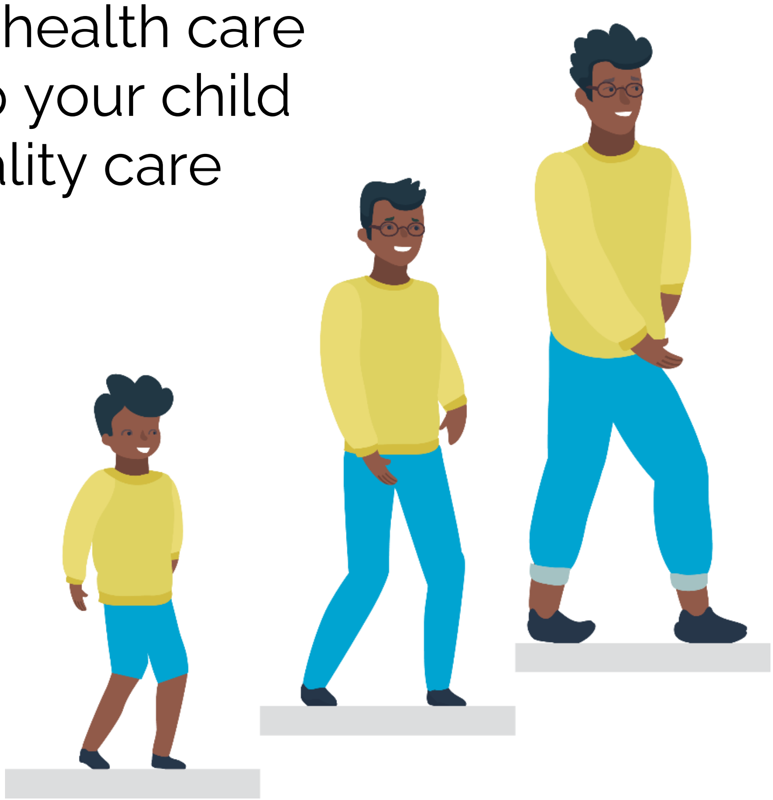
Quality Standards

Moving From Youth to Adult Health Care Services

Suggestions on what to discuss with your child's health care providers to help your child receive high-quality care



Provincial Council for Maternal and Child Health
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Ontario Health

Ontario Health is committed to improving the quality of health care in the province in partnership with patients, health care professionals, and other organizations.

To do that, Ontario Health develops quality standards. These are documents that outline what high-quality care looks like for conditions or processes where there are large differences in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. These quality standards set out important steps to improve care. They are based on current evidence and input from an expert committee that includes patients, health care professionals, and researchers.

This caregiver guide accompanies the quality standard on transitioning (moving) from youth to adult health care services. It outlines the top six areas where providers can take steps to improve care for people moving from youth to adult health care services. The patient guide also includes suggestions on what to discuss with your child's health care providers, as well as a link to helpful resources.

This caregiver guide is for you if:

- Your child wants you to be involved in their care and treatment decisions *or*
- You are your child's substitute decision-maker. This means you have been legally appointed to make care and treatment decisions for your child because your child can't make these decisions for themself

Below is a summary of the top six areas to improve care for young people moving from youth to adult health care services.

Quality Statement 1: Early Identification and Transition Readiness

What the standard says
Young people who will transition out of child- and youth-oriented services are identified as early as possible and have regular collaborative reviews of transition readiness to support their ongoing preparation needs for transition (and the needs of their parents and/or caregivers).

What this means for you
Your child's health care providers should work with you and your child to help them prepare for their transition, or move, to adult care. Their health care providers should start helping them prepare as early as possible, and they should support your child during this whole move.

Your child's health care team should involve you in preparing for your child's transition.

☐ Share your knowledge and expertise about your child's condition and needs
☐ Ask any questions about your child's care
☐ Ask them about what support groups or other resources are available
☐ Let the health care team know if you need help

Quality Statement 2: Information-Sharing and Support

What the standard says

Young people (and their parents and caregivers, where appropriate) are offered developmentally appropriate information and support to meet their needs throughout the transition process. Information-sharing is collaborative, and health care providers actively seek the experience and expertise of the young person (and their parents and caregivers, where appropriate) and incorporate it into the transition planning and shared goal-setting.

What this means for you

- Your child's health care providers should offer information and support to meet your needs and your child's needs throughout the transition process. This might include information and support on:
    - What will happen during this process and why it is important to begin preparing early
    - Your child's health and their treatment plan
    - How you both can become more comfortable managing their care
    - Any services and supports available to your child
    - How services and supports for young people are different from those for adults
    - Where your child can go for peer support and mentoring, if they want it
    - Where you can go for support, if you want it
    - Any benefits and financial support your child might be able to get and how to apply for them
    - Where to go for more information or resources to support you
- Your care team can talk with you and your child about this information and also write it down for you.
- Your care team should ask you and your child questions about their health condition and experiences. They should learn from you both, just like you learn from them, and they should put information from everyone involved into your transition plan (see page 5).

Quality Statement 3: Transition Plan

What the standard says

Young people have an individualized transition plan that is co-created, documented, and shared within their circle of care.

What this means for you

- Your child's health care providers should involve you and your child in planning their move out of services for young people.
- Your child's care team (which includes their youth *and* adult providers) should write a transition plan with you both. It should describe your child's care and who will support them when they move to adult services.
- This plan should be easy to read and understand, and it should include:
    - A transfer summary for an adult service or another person who will now be providing their care
    - Details about their first appointment with the adult service or another provider, including how often your child might see them
    - How to contact your child's youth and adult providers, family doctor or nurse practitioner, and home and community support service providers
- Your child's health care providers should work with you both to create a personal folder for your child. You can review and update it together over time. The information in this folder will help you both understand your child's care and share information with an adult service or another provider.

> Your child's *circle of care* is the group of health care providers involved in their care. With consent from you and your child, they will share information with each other to help them provide your child with good care.

Quality Statement 4: Coordinated Transition

What the standard says

Young people have a designated most responsible provider for the transition process. This provider works with the young person (and their parents and caregivers, where appropriate) to coordinate their care and provide support throughout the transition process and until the young person (and their parents and caregivers, where appropriate) confirms that the transition is complete.

What this means for you

- Your health care team should involve you and your child in choosing a single provider to be the "designated most responsible provider" for this move. This should be someone your child knows and trusts.
- This person should work with you and your child to coordinate their care.
- They should help arrange appointments and provide support until you and your child feel their transition is complete.

> Your child's *designated most responsible provider* is one person on their health care team who agrees to coordinate your child's move to adult services. You and your child can help decide who this provider is. If this move takes a long while, over time your child might have more than one designated most responsible provider.

Quality Statement 5: Introduction to Adult Services

What the standard says

Young people (and their parents and caregivers, where appropriate) have a meeting with key adult services or other providers before the transfer, to facilitate and maintain continuity of care.

What this means for you

- Before your child moves from services for young people to services for adults, they should be offered a meeting with key health care providers from the services they are moving to.
- These meetings might happen in a variety of ways:
    - Your child's youth and adult providers might meet with you both together
    - Your child's designated most responsible provider might go with you both to meet a provider from your child's adult service
    - The meetings might take place in person, or they might be over video or by phone

Quality Statement 6: Transfer Completion

What the standard says

Young people remain connected to the designated most responsible provider for their transition and are supported until health care service transitions are complete and confirmed by the young person (and their parents and caregivers, where appropriate).

What this means for you

- After your child's last visit to services for young people, their designated most responsible provider should stay in contact with you both.
- They should monitor your child's transition.
- They should provide any support your child needs while they wait for their first appointment with each adult service or other care provider who is taking a role in their care.
- This support should continue until your child has had their first appointment with each adult service or other provider and you both have confirmed that their health care service transitions are complete.

Need more information?

We have put together a list of resources that might be helpful for you. You can download it here.

If you have any questions or feedback about this guide, please contact us at QualityStandards@OntarioHealth.ca or 1-877-280-8538 (TTY: 1-800-855-0511).

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