Quality
Standards

Transitions From Youth to Adult Health Care Services

Care for Young People Aged 15 to 24 Years

Provincial
Council for
Maternal and
Child Health
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Health

Scope of This Quality Standard

This quality standard addresses **care for young people aged 15 to 24 years[1,2] who are transitioning from youth to adult health care services.** A *transition* is defined as the purposeful, planned movement of adolescents and young adults requiring a change from child- and youth-oriented services to adult-oriented services, with or without a transfer to a new provider.[3,4] A *transfer* of care is a one-time event that occurs when a young person is transferred out of the child health system. It is important to note that preparation for the transition should be started as early as possible, as described in quality statement 1.

There are different models by which young people will transition from a pediatric health care service or provider, and some may transition to any combination of these models. At a minimum, all young people will need a primary care provider. For those young people who see a pediatric provider for primary care, they will need to transition to a primary care provider who offers an adult approach to care. In addition, some young people may also transition:

- To one or more adult (specialist) care services and/or
- Through services for young people (aged 15 to 24 years) that bridge pediatric and adult care, commonly called "adolescent and young adult clinics," "transition to adulthood clinics," or "transitional aged youth services"

We use *adult service or another provider* throughout the quality standard to mean any new service or health care provider who will take a role in the young person's future care or who will transition them to an adult approach to care. Although we use *transition to adult services* throughout the quality standard, the term includes any transfer out of youth-oriented services at age 18[5,*] and into an adult approach to care.

The scope of this quality standard includes all clinical populations, including young people with disabilities or special health care needs such as those with chronic and/or complex physical, intellectual, or developmental conditions and/or with mental illness and substance use. Where appropriate, it also includes parents and caregivers or other substitute decision-makers (see Appendix 3, Glossary). The scope of this quality standard includes all pediatric and adult health care settings and providers relevant to the transition to adult health care services.

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[*] There may be exceptions to this age of transfer, both for specific patient populations and for individual young people.

What Is a Quality Standard?

Quality standards outline what high-quality care looks like for conditions or processes where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They:

- Help patients, families, and caregivers know what to ask for in their care
- Help health care professionals know what care they should be offering, based on evidence and expert consensus
- Help health care organizations measure, assess, and improve their performance in caring for patients

Quality standards and their accompanying patient guides are developed by Ontario Health, in collaboration with health care professionals, patients, and caregivers across Ontario.

For more information, contact QualityStandards@OntarioHealth.ca.

Quality Statements to Improve Care: Summary

These quality statements describe what high-quality care looks like for young people aged 15 to 24 years transitioning from youth to adult health care services.

Quality Statement 1: Early Identification and Transition Readiness

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).

Quality Statement 2: Information-Sharing and Support

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.

Quality Statement 3: Transition Plan

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

Quality Statement 4: Coordinated Transition

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.

Quality Statement 5: Introduction to Adult Services

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.

Quality Statement 6: Transfer Completion

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).

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Why This Quality Standard Is Needed

About 15% to 18% of young people in North America have a chronic health condition.[6,7] Nearly all of these young people (more than 98%) are expected to reach age 20 and will therefore transition from youth to adult health care services. Mental illness and substance use are also common in children and young people, with about 20% having at least one challenge before they are 18 years old,[8-10] and up to 70% of these young people needing adult services for problems that persist beyond that age.[11] Further, with advances in medical technology and treatments, more than 90% of young people with complex disabilities are living into adulthood and transitioning from child- and youth-oriented to adult-oriented services.[12]

The transfer to adult care is a critical and vulnerable time for young people and for their parents and caregivers. While learning to manage their own health care, many young people must also change health care providers and adapt to new services, people, and processes. In addition, this period coincides with their transition to adulthood, a challenging time of physical, psychological, and social changes when they may be leaving home for postsecondary school or starting to work.[13,14] Some young people may feel psychosocial difficulties or disorders such as anxiety and depression during this time,[15] and parents and caregivers may experience distress and uncertainty from their changing roles in their child's life.[16]

Too often, transition planning revolves around systems and providers, rather than the young person. Young people (and their parents and caregivers, where appropriate) bring important expertise to the discussion, and their involvement in co-designing the transition plan is essential.[17]

The transition process is further complicated by health system barriers, including poor communication and coordination between youth and adult health care providers, a lack of person- and family-centred social supports and resources, and gaps in funding at the age of transition.[18,19] As a result, transitions to adult health care services are often disorganized and can disrupt the continuity of care. This may lead to poor health outcomes due to preventable lapses in adherence to appropriate care, and a lack of follow-up after missed or delayed care.[3,20] Either can result in avoidable hospital admissions, emergency department visits, and increased health system costs.[21]

Young people with complex medical conditions, developmental disabilities, and/or intellectual disabilities[4] are particularly vulnerable and at increased risk of worsening health. They often experience multiple transitions in services, have difficulty accessing appropriately trained adult health care providers, and have limited information and resources to support them and their caregivers.[12,18]

Interviews conducted at six children's treatment centres in Ontario found that young people with complex physical disabilities, and their parents and caregivers, reported ongoing challenges and negative impacts of the transition to adult services.[12] Among these were a lack of access to health services (physician specialists and other health care professionals), a lack of knowledge by health care professionals, a lack of information provided, and uncertainty regarding the transition process.[12,18] Respondents suggested that more extensive information, support, and collaboration were needed throughout the transition process.[12]

Many young people with mental health care needs or substance use, and their caregivers, have also reported negative experiences transitioning from child and youth mental health services to community or adult mental health and addictions services. Among these challenges are limited information about care in the community or about the adult mental health and addictions system, being left out of the transition discussions, not feeling prepared for the transition, and receiving care that was poorly planned and executed.[22-24] In addition, service gaps are a common problem for young people transitioning to adult mental health services.[25,‡] Currently, community-based child and youth mental health treatment centres in Ontario are only funded to provide services for young people up to the age of 18.[‡] Adult mental health systems often function separately from services for children and youth, and with marked differences in their funding and approach to care.[26] As a result, up to 50% of young people disengage from mental health and addictions care during the transition to adult care,[24] leading to potentially avoidable negative health and social outcomes, poor use of health care resources, and unnecessary costs to the system.[22,24,26]

Young people living in rural, remote, and Northern communities may face additional challenges to accessing appropriate care when transitioning to adult health services compared with their urban peers.[25,‡] These geographical barriers—which include the need to travel to large urban health care centres and hospitals, the time and financial resources required to do so, and a lack of culturally relevant services—can further worsen continuity of care.

Living in stressful social and economic conditions can also impact a young person's overall health and well-being as they transition from youth-oriented to adult services.[27] Such stresses include social stigma, discrimination, and a lack of access to post-secondary education, employment, income, and housing.[28] This is especially important for Indigenous, Black and racialized, and newcomer children and young people who may have experienced intergenerational or present-day traumas and continue to experience systemic racism.[29] A lack of trauma-informed

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[‡] Advisory committee consensus.

practices (see Appendix 4, Guiding Principles) has been identified as a main barrier for young people in establishing supportive long-term relationships with caregivers and front-line service providers.[30]

Young people in care in the child welfare system who have reached the age of majority (age 18 or 19, depending on where they live) face additional barriers in accessing the transition supports and services they need.[31] These young people experience higher rates of homelessness, unemployment, poverty, mental illness, post-traumatic stress, and substance use, and lower levels of education, compared with their peers who were not in care.[30-32] These systemic inequities result in harm to young people and lead to negative outcomes. Some groups—including Indigenous, Black and racialized, and 2SLGBTQ+ youth, and young people with disabilities—are overrepresented in the child welfare system and therefore are at a higher risk of experiencing challenges and poorer health outcomes as they transition into adulthood.[31,33]

In consulting with young people with lived experience in care to inform Ontario's Child Welfare Redesign Strategy, the Ministry of Children, Community and Social Services learned of the many challenges they face navigating the health system as they transition to adulthood. Important to these young people was having access to a primary care provider and mental health care, as well as strong advocacy skills to seek help and support.[33] Young people leaving care have also reported that developing and nurturing meaningful, supportive long-term relationships, including with service providers such as social workers, can act as a bridge during these difficult times of transition.[30,32]

Successful transitions in health care for young people are critical for their lifelong well-being. Enhancing the transition process from child- and youth-oriented services to adult-oriented services has the potential to positively impact[5]:

- Health outcomes and quality of life
- The experience for young people and their parents and caregivers
- The quality of health care provided
- Financial and other costs to young people, parents and caregivers, and the health care system

This quality standard includes six quality statements that address areas identified by the Transitions From Youth to Adult Health Care Services Quality Standard Advisory Committee as having high potential to improve transitions in care for young people in Ontario.

Measuring the Success of This Quality Standard

The Transitions From Youth to Adult Health Care Services Quality Standard Advisory Committee identified seven overarching indicators to measure the success of this quality standard. These indicators will be considered as a set to measure overall success. Measurement for some indicators can be supported by existing provincial data sources. However, data collection and measurement for this topic area are currently limited, so measurement will require the use of locally sourced data.

Indicators That Can Be Measured Using Provincial Data

- Percentage of young people who have transitioned out of youth-oriented services who have their first visit with an adult service or another provider after transfer of care
  - Notes:
    - This indicator is applicable to young people with health care needs that require regular follow-up with a provider
    - For measurement purposes, this could be a visit within 12 months after transfer. However, the time period can be tailored based on health care needs
    - Provincial data sources capture physician visits. Local data collection may be required, depending on the health care need and to track visits to nonphysician services
    - This indicator does not capture continuity of care in adult services beyond the first visit
- Percentage of young people who have transitioned out of youth-oriented services

Indicators That Can Be Measured Locally

- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services who had a designated most responsible provider for the transition

- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who completed a transition readiness assessment prior to transfer of care
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being satisfied with the transition
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Percentage of young people who have transitioned out of youth-oriented services who report that they maintained their quality of life around the period of transfer of care

Quality Statements to Improve Care

01

Early Identification and Transition Readiness

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).

Sources: Canadian Association of Pediatric Health Centres, 2016[34] | CanChild Centre for Childhood Disability Research, 2009[35] | National Institute for Health and Care Excellence, 2016[16]

Definitions

Identification: This is the process of identifying and tracking who will be transitioning out of child- and youth-oriented services and when the transfer will happen.

As early as possible: No specific age is recommended, as the optimal timing to start transition planning will depend on the young person's circumstances. Transition planning may start as early as young childhood, 10 or more years before age 18. It can begin whenever the young person, their provider, and/or parents or caregivers identify that a transition to adult care will likely be necessary due to the nature of their health condition or disability.

Regular collaborative reviews of transition readiness: This involves separate assessments for the young person, and for their parents and caregivers, and includes[34]:

- Regular assessments of self-care skills and knowledge needed for functioning in the adult health care system
- Regular assessments to determine if the young person is at risk of experiencing difficulties and may need additional support

- Identification of the young person's needs, tasks, and goals (and those of their parents and caregivers)

These reviews are collaborative, involving the young person, parents and caregivers, and providers. In some instances, young people may want or need their assessment to be done independently of their parents and caregivers. Reviews start as early as possible and are updated regularly (i.e., once a year at minimum, or more frequently if needed).[16,34,36,37]

Examples of validated transition readiness assessment tools:

- Transition Readiness Assessment Questionnaire (TRAQ)[38]
- Transition Questionnaire (TRANSITION-Q)[39,40] in conjunction with MyTransitionApp[41]
- Am I ON TRAC? for Adult Care Questionnaire for youth and for parents[42]

Examples of other commonly used transition readiness resources:

- Got Transition for youth and for parents and caregivers[37]
- Well On Your Way Transition Readiness Checklists for youth,[43] parents of independent youth,[44] and parents of dependent youth[45]

Ongoing preparation needs for transition: This process is started as early as possible, involves the young person and their parents and caregivers, is developmentally appropriate, and evolves over time.[5,16,46] Components include but are not limited to[5,16,36,37]:

- Addressing needs, tasks, and goals identified through *regular collaborative reviews of transition readiness* (see definition)
- Discussing needs for self-care and how to use health care services
- Connecting the young person to other services and sources of support, including peer support, and, where appropriate, caregiver support for the young person's parents and caregivers (see quality statement 2)
- Identifying an appropriate adult service or another provider and starting to plan for linking with them
- Confirming which adult services are publicly funded versus those requiring private insurance or out-of-pocket costs (e.g., pharmacare, dental, nonmedical health services)
- Checking for any changes in funding and eligibility for funding supports or programs

- Reviewing and updating their medical summary and emergency care plan and, if needed, legal documents
- Preparing the young person (and their parents and caregivers, where appropriate) for an adult approach to care, including self-advocacy, access to information, and legal changes in decision-making, privacy, and consent
- Having an annual meeting or regular review of transition planning, if appropriate and needed, to ensure the young person's changing needs (and the needs of parents and caregivers) are taken into account.[16] Frequency and timing are based on their individual needs

Rationale

Transitioning from youth to adult health care services can be overwhelming and difficult for young people and their parents and caregivers, and it is often started too late. The process should be started as early as possible, with a life-course approach to development and transition (see Appendix 4, Guiding Principles, *Life-Course Approach*). It should recognize the chronic nature of childhood illness and disability and prepare the young person for an adult approach to care.[5] For young people, this includes learning new skills and taking on more responsibility for their health care. All health care providers should support the preparation for transition and fully involve the young person and, where appropriate, their parents and caregivers.

Early identification and preparation of young people who will be transitioning out of youth-oriented services allows for a more gradual transition process. Young people (and their parents and caregivers) need time to be involved in decisions, and adjust to changes to their future care.[16] Without this preparation, young people sometimes lose confidence and disengage from health services.[16] Regular assessment of transition readiness can help to identify ongoing needs as people get ready for the transition and to see who is at risk of difficulties and may need additional support.[34]

There are also critical milestones related to a young person's age that affect their eligibility for specific services and supports. Often young people and their parents and caregivers find out about these programs late in the transition process, which can lead to service delays.[ǂ]

For young people aging out of the child welfare system, the transition to adult health services often means leaving youth providers and services that have

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[ǂ] Advisory committee consensus.

supported them throughout their time in care (stakeholder consultation). Health care providers should be aware of the additional challenges this group faces and work together, before the young person reaches age 18, to connect them with primary care and mental health care providers who will continue into adulthood.[33] For example, community health centres and family health teams have social work and other supports that do not have an age cut-off.[‡] Health care providers should also be aware that moving frequently is another challenge faced by young people in care, as it can disrupt transition planning and continuity of care.[‡]

What This Quality Statement Means

For Young People, Parents, and Caregivers

Your health care providers should work with you to help you prepare for your transition, or move, to adult care. If you want, your parents and caregivers can be involved too. Your health care providers should start helping you prepare as early as possible, and they should support you during this whole move.

For Clinicians

Identify young people who will be transitioning out of child- and youth-oriented services as early as possible and keep track of when they will transition.

Conduct regular collaborative reviews of transition readiness to support the young person's ongoing preparation needs for transition (and the needs of their parents and caregivers). Start these reviews as early as possible and update the reviews regularly (i.e., once a year at minimum, or more frequently if needed).

For Organizations and Health Services Planners

Ensure systems, processes, and resources are in place to identify and track young people who will transition out of child- and youth-oriented services and when the transfer will happen.

Ensure that child- and youth-oriented services have systems, processes, and resources in place to conduct regular collaborative transition readiness reviews that are started as early as possible and updated regularly. These reviews should support the young person's ongoing preparation needs for transition (and the needs of their parents and caregivers).

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of young people who will transition out of child- and youth-oriented services (and their parents or caregivers, where appropriate) who have discussions about their ongoing preparation needs for transition
- Percentage of young people who will transition out of child- and youth-oriented services (and their parents or caregivers, where appropriate) who receive regular reviews of transition readiness at least once within 12 months

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

02

Information-Sharing and Support

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.

Sources: Canadian Association of Pediatric Health Centres, 2016[34] | CanChild Centre for Childhood Disability Research, 2009[35] | National Institute for Health and Care Excellence, 2016[16]

Definitions

Information-sharing and support: The appropriate information and support from health care providers are identified and provided through regular collaborative reviews of transition readiness. (See definition of *regular collaborative reviews of transition readiness* in quality statement 1.) This includes developmentally appropriate information and support tailored to the individual needs, tasks, and goals of the young person (and their parents and caregivers, where appropriate), to help them make informed decisions about their care. Examples include[16,34,35]:

- Explaining what the transition process involves, why it is important to begin preparing early, and what to expect from child- and youth-oriented services and adult services
- Helping them understand their health care needs, treatment plan, and needs for self-care

- Developing advocacy, self-management, and other skills for the transition
- Informing them what services and supports are available (before, during, and after transition), and how child- and youth-oriented services and supports differ from adult services and supports
- Facilitating connections to peer support, if the young person wants it. This may involve individual or group peer support, coaching and mentoring, and/or advocacy to support the young person in planning for the transition and navigating the systems and available resources.[35] This may be through voluntary- and community-sector organizations, such as specific support groups or charities
- Facilitating connections to caregiver support (e.g., family and caregiver support services or groups), if parents and caregivers want this support
- Informing them where they can get information about supports and services that they may be eligible for or entitled to and when to apply (e.g., adult developmental services accessed through Developmental Services Ontario and financial benefits such as the Ontario Disability Support Program)

Information and support may be provided in a variety of formats including verbal (in-person or video meetings or phone calls), written, electronic, computer-based reading programs, audio, or braille.[16] Ideally, these materials are co-designed with young people and their caregivers.

The information and support provided are culturally appropriate, trauma-informed, and accessible to all involved, for example by assisting people with physical, sensory, developmental, or learning disabilities or by providing translations. When needed, an interpreter or advocate is provided.

Developmentally appropriate: This considers the young person as a whole, addressing their biological, psychological, and social development broadly.[16] This approach ensures the young person is informed about, and helped to play an active role in, their care and support, within the full extent of their capability.

Throughout the transition process: This involves all phases of the young person's transition—before, during, and after the transition—from youth-oriented services to an adult approach to care, with or without a transfer to an adult service or another provider.

Collaborative information-sharing: This involves the mutual sharing and exchange of information between the young person (and their parents and caregivers, where appropriate) and health care providers and allows the young person time to reflect on and discuss the information.[35] For example, this may involve asking the young person (and their parents and caregivers, where appropriate) what information and support they want to receive.

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: This includes recognizing and respecting the unique knowledge and valuable experience that parents, caregivers, and the young people themselves possess and bring to the conversation.[17] For example, they likely have developed an extensive knowledge of their (or their child's) health over time that can help inform their care; understand their (or their child's) needs and concerns; already take an active role in managing their (or their child's) health care; and know when emergency or specialist consultation and/or other supports are needed.

Rationale

When young people and their parents and caregivers do not have enough information and knowledge of available supports and services, this can make the transition more challenging and less successful.[16] They need to feel involved, respected, and empowered to make informed decisions. Providing information and support throughout the transition process can improve their experience of the transition and help ensure their needs and goals are met.[47]

Parents, caregivers, and the young people themselves possess unique knowledge and valuable experience (see definitions in this quality statement). It's important for health care providers to seek their expertise and input in all decision-making about their care.[17]

It's also important to recognize that some young people may lack support and involvement from parents and caregivers. Young people who live in care (such as group homes, foster homes, or youth justice facilities) may be disconnected from their family or community.[29] With limited support networks, these young people may require additional supports and resources to meet their unique needs.[29,30,48]

What This Quality Statement Means

For Young People, Parents, and Caregivers

Your health care providers should offer information and support to meet your 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 health and your treatment plan
- How you can be more comfortable managing your care
- Any services and supports available to you
- How services and supports for young people are different from those for adults
- Where to go for peer support and mentoring, if you want it
- Where parents and caregivers can go for support, if they want it
- Any benefits and financial support you 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 about this information and write it down for you.

Your care team should ask you questions about your health condition and experiences. They should learn from you and your parents, just like you learn from them, and they should put information from everyone involved into your transition plan (see quality statement 3).

For Clinicians

Offer developmentally appropriate information and support to meet the young person's identified needs throughout the transition process. Tailor the information and support to the young person's perception of their health and their stage of transition readiness. If appropriate, also offer tailored information and support to meet the needs of parents and caregivers.

Ensure that information and support are culturally appropriate, trauma-informed, and accessible to all involved, for example, by accommodating physical, sensory, developmental, or learning disabilities or by providing translations. When needed, ensure an interpreter or advocate is provided.

Remember that the young person (and their parents and caregivers, where appropriate) is a valuable member of the team and has expertise to offer. Make sure there is a collaborative flow of information between all members of the team, so that everyone has the information and support they need and want to facilitate a successful transition to adult services.

For Organizations and Health Services Planners

Ensure that youth-oriented services and adult services have systems, processes, and resources in place to offer information and support to meet the young person's needs (and those of their parents and caregivers, where appropriate) throughout the transition process.

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who receive developmentally appropriate information to meet their needs
- Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who feel that they were asked for their experience and expertise during transition planning and shared goal-setting

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

03

Transition Plan

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

Sources: Canadian Association of Pediatric Health Centres, 2016[34] | National Institute for Health and Care Excellence, 2016[16]

Definitions

Transition plan: A written document (printed or ideally digital) summarizing decisions about the young person's transition, detailing their plan of care, timelines, and who will support them (and their parents and caregivers, where appropriate) as they transition out of youth-oriented services.[16] The plan is individualized, based on the young person's developmental and ongoing care needs, culturally appropriate, and linked to other plans they have with respect to care and support, such as education, employment, and housing.[16,23,34]

The transition plan is a working document for the health care teams involved in the young person's care, and includes these details, where available and relevant[5,37]:

- Transfer package for an adult service or another provider, including:
  - Final transition readiness assessment
  - Plan of care, including needs, tasks, goals, and prioritized actions of the young person
  - Medical summary and emergency care plan
  - Legal documents (e.g., do-not-resuscitate directive; legal changes in decision-making, privacy, and consent)
  - Condition fact sheet, if needed
  - Additional clinical records

  - Date the transfer package was sent and any communication with the adult service or another provider (including whether the transfer is accepted and date of the first appointment/visit)
- Documentation of anticipatory guidance on the transition plan (e.g., the timing of first appointment/visit with an adult service or another provider, frequency of follow-up, natural history of the young person's condition, how they will manage their care while away from home for post-secondary education, how their needs and challenges may change over time)
- Contact information and language of communication for:
  - Parents and caregivers
  - Youth and adult providers, primary care providers, and home and community care providers

The transition plan also includes a personal folder, created and held by the young person (and their parents and caregivers, where appropriate) and shared with adult services.[49] The personal folder may include but is not limited to[16,50]:

- A one-page profile or communication passport (written record of the young person's skills and personality, what's important to them, and how to best support their involvement in their care)
- Information about their health, education, community and social service needs, and communication needs
- Information about other plans (e.g., developmental services plan, individual education plan)
- Other pertinent health information (e.g., safety protocols, medical directives, assistive devices such as a wheelchair or communication aid)
- Other details the young person may want to convey (e.g., past trauma, mental illness, substance use, or foster care)
- History of unplanned admissions
- Preferences about parent and caregiver involvement, taking the young person's capacity into account
- Emergency care plans
- Strengths, achievements, goals, and hopes for the future
- Name of any substitute decision-makers appointed under a "Power of Attorney for Personal Care"

Examples of transition planning resources:

- Youth Transitions to Adult Health Services: Transition Discharge Planning Tool[51]
- Complex Care for Kids: Ontario Youth Transition to Adult Care Toolkit—Caregiver Checklist & Resource Guide and Healthcare Provider Checklist[52]
- **mind**your**mind** Service Transition Plan: Moving to Adult Mental Health and Addiction Services[53]
- Youth Transitioning in KFL&A: Protocol for Youth Transitioning into Adult Mental Health and Addictions Services[54]
- MyTransitionApp[41]
- SHARE Transition Plan: Talking About Transition With Young People With Developmental Disabilities and Their Families[55]
- Transition Tracker[56]

The transition plan should be shared at a collaborative transition meeting (see definition of *meeting* in quality statement 5) or within 1 month before the last visit with youth-oriented services.[5] The plan should be shared with the young person (or substitute decision-makers) and each adult service or other provider they are transitioning to. If the young person consents, the plan should also be shared with parents and caregivers.

Co-created: Young people (and their parents and caregivers, where appropriate) work collaboratively with their health care providers to develop the transition plan together.

Circle of care: A term commonly used to mean the group of health care providers involved in a person's care who need to share information to provide that care. Consent to share information within the circle of care is generally implied—for example, when a patient accepts a referral to another health care provider.[57,58] However, it is important to explicitly ask the young person (if capable) who they consent to share their information with. If the young person consents to sharing with their parents and caregivers, or if the parents and caregivers are the substitute decision-makers appointed under a "Power of Attorney for Personal Care," the transition plan is also shared with them.[58]

Rationale

Young people, parents, and caregivers have described the transition to adult care as "falling off a cliff"[59] or "being on the edge of a canyon."[60] A transition plan that documents what care will be continued, by whom, and with a clear discussion of any gaps in care and how to address these gaps, can help young people and their parents and caregivers know what to expect and feel confident in the process.[§] The young person's transition plan helps ensure that their transition from youth-oriented to adult services is well coordinated and meets their care needs.

Too often, transition plans revolve around the providers and services, rather than the young person (and their parents and caregivers, where appropriate), and frequently primary care providers are not included.[§] Transition planning that revolves around the needs of the young person (and of the parents and caregivers, where appropriate)—and that includes the primary care provider—is essential to prevent problematic gaps in the young person's care.[§]

What This Quality Statement Means

For Young People, Parents, and Caregivers

Your health care providers should involve you in planning your transition out of services for young people. If you want, your parents and caregivers can be involved too. Your care team (which includes your youth *and* adult providers) should write a transition plan with you. It should describe your care and who will support you when you transition to adult services. This plan should be easy to read and understand.

Your health care providers should work with you (and your parents and caregivers, if you like) to create a personal folder. You can review and update it over time. The information in this folder will help you understand your care and help you share information with an adult service or another provider. It could include, for example:

- One page that talks about your skills and personality, what's important to you, and how you would like to be supported
- Your strengths, achievements, goals, and hopes for the future
- Information about your education, health, community and social support service needs, and any devices you use to help you communicate
- Other details you want to convey (such as details of past trauma, mental illness, substance use, foster care)
- Emergency care plans

[§] Advisory committee consensus.

For Clinicians

If you are a youth provider transferring care to an adult service or another provider, prepare a documented, individualized transition plan for young people who will transition out of youth-oriented services. Develop this plan with the young person (and their parents and caregivers, where appropriate) and the health care teams involved in the person's care (including youth-oriented and adult services, primary care, and home and community care providers). Give the young person (and their parents and caregivers, where appropriate) a written copy (printed or ideally digital) of their transition plan before they transfer out of youth-oriented services.

Prepare a transfer package that includes the information listed under the definition of *transition plan* in this quality statement. Obtain consent from the young person or their substitute decision-makers to share this information (e.g., via electronic portal, printed) within their circle of care.

In the transfer package include a letter to the adult provider for the same or similar type of service you provide, asking them to confirm that they have received the transfer package, whether they will accept the transfer, and the timing of the first appointment or visit. Communicate with them about the pending transfer of care as early as possible. There should be an opportunity for the two (or more) providers to have a conversation about the transfer if the complexity of the young person's health warrants more detail than can be readily shared in a transfer package. The youth provider remains responsible until the adult service or provider assumes care.

Ensure the young person's primary care provider is involved and receives a copy of the transition plan. If primary care is also being transitioned, then both primary care providers need to be involved.

Use standardized documentation tools to ensure a succinct, clear, and timely exchange of the transition plan at a collaborative transition meeting (see definition of *meeting* in quality statement 5) or within 1 month before the last visit with youth-oriented services.[5]

For Organizations and Health Services Planners

Ensure that youth-oriented and adult services have systems, processes, and resources in place to:

- Give young people transitioning from youth-oriented to adult services (and their parents and caregivers, where appropriate) a written copy (printed or

ideally digital) of their transition plan before they transfer out of youth-oriented services
- Enable standardized documentation and communication strategies (e.g., electronic portal) to allow for clear and timely communication of the transition plan with an adult service or another provider and with primary care and home and community care providers (*timely* meaning at a collaborative transition meeting [see quality statement 5] or within 1 month before the last visit with youth-oriented services)

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of young people who will transition out of youth-oriented services who have a documented transition plan
- Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

04

Coordinated Transition

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 process is complete.

Sources: Canadian Association of Pediatric Health Centres, 2016[34] | CanChild Centre for Childhood Disability Research, 2009[35] | National Institute for Health and Care Excellence, 2016[16]

Definitions

Designated most responsible provider: This is one person, from among the health care team providing care and support to the young person (and their parents and caregivers, where appropriate), who agrees to take the role of coordinating the transition to adult services.[16] This provider is identified early on and may change over time, given that the transition process is often prolonged. The young person (and their parents and caregivers, where appropriate) helps decide who this provider will be. In some instances, it may be a nurse, social worker, youth worker, or primary care provider. In other instances, this provider may have a job title such as “transition navigator,” “transition lead,” “transition coordinator,” “transition worker,” or “case manager.”

Although the health care team has a shared responsibility for the transition (see definition of *health care team* in Appendix 3, Glossary), the designated most responsible provider oversees, coordinates, and provides transition support.[16] They are the main link with other providers, particularly if a young person receives care from more than one service or provider. They arrange appointments for the young person, act as their support person and as an advocate, and guide them to other services and sources of support. They also provide support to the young person's parents and caregivers, where appropriate. Overall, they ensure there are no gaps in the transition process.

The designated most responsible provider is involved throughout the transition, supporting the young person until a time agreed on with the young person (and their parents and caregivers, where appropriate). When the young person (and/or their parents and caregivers, where appropriate) agrees that the transition is complete, this provider (if they are based in youth-oriented services) hands over responsibilities to an adult service or another provider.[16]

Throughout the transition process: This involves all phases of the young person's transition—before, during, and after the transition—from youth-oriented services to an adult approach to care, with or without a transfer to an adult service or another provider.

Rationale

The transition to adult services can be a stressful time for young people and their caregivers because it is a lengthy process and may involve various providers and services.[46] Having a designated most responsible provider who the young person (and their parents and caregivers, where appropriate) knows and trusts to oversee the transition planning and coordination can lead to a more positive experience, better attendance in adult services, and better outcomes.[16,46]

For young people with complex needs, identifying a designated most responsible provider is particularly important because, without this support, the responsibility for finalizing the transition process can often fall to a parent or caregiver (advisory committee consensus).

What This Quality Statement Means

For Young People, Parents, and Caregivers

If you are transitioning out of services for young people, you will help choose a single provider to be the "designated most responsible provider" for your transition. This will be someone you know and trust. This person will work with you (and, if you want, your parents and caregivers) to coordinate your care. They will help arrange appointments and provide support until you feel your transition is complete. Your designated most responsible provider will be named early on in your transition process, and the person who does this job may change over time.

For Clinicians

Work with the young person (and their parents and caregivers, where appropriate) to identify a designated most responsible provider. Then act as or work with this provider to coordinate care and provide support throughout the transition process and until the young person (and their parents and caregivers, where appropriate) considers the transition is complete.

For Organizations and Health Services Planners

Ensure systems, processes, and resources are in place for young people who are transitioning out of youth-oriented services to have a designated most responsible provider to coordinate care and provide support throughout the transition process and until the transition is complete.

QUALITY INDICATORS:
HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of young people who are transitioning out of youth-oriented services who have a designated most responsible provider for the transition
- Percentage of young people who are transitioning out of youth-oriented services (and their parents or caregivers, where appropriate) who feel supported with care coordination by their designated most responsible provider

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

05

Introduction to Adult Services

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.

Source: National Institute for Health and Care Excellence, 2016[16]

Definitions

Meeting: A collaborative transitions meeting (sometimes called a joint working meeting or joint discharge/transfer meeting) includes the young person, their youth providers, and key adult health care providers. Parents and caregivers may attend some or all of the meetings, where appropriate.

This may be one meeting (with key providers together with the young person) or multiple meetings that pair providers from youth-oriented and adult services (e.g., physician to physician, social worker to social worker). These meetings may also involve the designated most responsible provider for the transition (see definition of *designated most responsible provider* in quality statement 4).

Sometimes the transfer of care is to the young person's current primary care provider. If not, the primary care provider is also included as a collaborative and consistent source of support for the young person and their parents and caregivers.

The meeting or meetings may be in-person or virtual (teleconference, videoconference). In some situations, a formal transitions meeting may not be necessary, and the young person and their youth-oriented service providers can decide whether a collaborative transitions meeting is needed. The adult service provider may request a meeting if they feel they need more information than was provided in the transition plan (see definition of *transition plan* in quality statement 3) to support a successful transition.

Adult services or other providers: This includes any new service or health care provider who will take a role in the young person's future care (or when they transfer to an adult approach to care).

Transfer: The actual point at which the responsibility for providing a person's care and support moves from youth-oriented to adult services or another provider.[16]

Rationale

Young people and their caregivers may feel anxious about transitioning to adult services or another provider, especially if they have been with child- and youth-oriented services for a long time.[16,47] Meeting and engaging with each provider who will take a role in their future care can help reduce concerns about the transfer and increase their confidence about transitioning to an adult service or another provider.[16,47] Being part of the communication between current and future health care providers creates a collaborative transition—a transfer of care where the patient is present and involved in the conversation.[61]

The meeting also facilitates and maintains continuity of care, and it provides an important opportunity for the young person (and their parents and caregivers, where appropriate) to ask questions about the transfer, share their needs and preferences, and clarify next steps or details for their first visit (e.g., appointment time, location). This can lead to a better experience for the young person and their parents and caregivers, improved attendance in adult services, and better outcomes.[16]

It is important to include the primary care provider in these meetings, especially for a young person with complex care needs, as the primary care provider can play a crucial role as a consistent source of support and resources for the young person (and their parents and caregivers, where appropriate) in navigating a complex health care system.[17]

What This Quality Statement Means

For Young People, Parents, and Caregivers

Before you transition from services for young people to services for adults, you will meet with key health care providers from the services you are transitioning to. If you want, your parents or caregivers can join you for these meetings. These meetings may involve your youth and adult providers meeting with you together, or perhaps your "designated most responsible provider" will go with you to meet a provider from your adult service. These meetings might take place in person, or they might be over video or by phone.

For Clinicians

If you are a new provider taking a role in a young person's care, meet with the young person (and their parents and caregivers, where appropriate) before they transfer. This process may involve attending a collaborative transition meeting with the young person and their provider(s) from youth-oriented services. This may also involve their designated most responsible provider for the transition. These meetings may be in person or virtual (teleconference, videoconference).

For Organizations and Health Services Planners

Ensure that youth-oriented and adult services have systems, processes, and resources in place for young people (and their parents and caregivers, where appropriate) to meet with key adult services or other health care providers they will transition to before they transfer from youth-oriented to adult services. This may be one meeting (with key providers together) or multiple meetings that pair providers from youth-oriented and adult services. These meetings may involve the designated most responsible provider for the transition. Meetings may be in-person or virtual (teleconference, videoconference).

QUALITY INDICATOR: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who have a meeting with the key adult service or another provider before the transfer of care
    - If multiple providers are involved in care, collect and measure data separately for each key adult service or other provider that the young person will transition to

Measurement details for this indicator, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

06

Transfer Completion

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).

Sources: Canadian Association of Pediatric Health Centres, 2016[34] | National Institute for Health and Care Excellence, 2016[16]

Definitions

Remain connected: This involves the designated most responsible provider continuing to follow the young person by checking in with them (e.g., by phone, secure text messages, email) and with their parents and caregivers, where appropriate, until they have had their first visit with each adult service or other provider they are transitioning to. In some instances, this may require a call or meeting with a youth-oriented health care provider (who is responsible until the transfer is complete) to assist the young person (and their parents and caregivers, where appropriate) in addressing needs that come up (e.g., medication management, a change in health status) while they wait for adult care to be established and/or to achieve closure with the transition.

Designated most responsible provider: See the definition in quality statement 4.

Supported until health care service transitions are complete and confirmed: The designated most responsible provider monitors the transition and provides any support needed while the young person (and their parents and caregivers, where appropriate) waits to be seen by each adult service or other provider. This support continues until the young person has established care with each adult service or other provider and the young person (and their parents and caregivers, where appropriate) has confirmed that health care service transitions are complete. If there is no equivalent adult service or other provider, or if there is a long wait to establish care with the adult service, then an appropriate care provider must be identified to address any health care needs. In most cases, the primary care provider takes on this role.

Rationale

A gap sometimes occurs between discharge from youth-oriented services and a first appointment with an adult service or another provider. During this time, it is important that young people (and their parents and caregivers, where appropriate) remain connected with the designated most responsible provider, who can offer support while they wait to be seen by their new providers.[46]

Closing the loop between youth-oriented and adult services is also an essential part of transfer completion. This means confirming that the young person has established care with each adult service or other provider.[37] Many adult services and other providers do not have processes in place to follow up when people do not attend appointments and may not understand why it is important to do so (advisory committee consensus). For young people transitioning to adult services, missed first appointments and loss of contact can mean they do not engage with adult services and get lost from the system.[16] In turn, this can affect their physical health, mental health, and social care needs.

What This Quality Statement Means

For Young People, Parents, and Caregivers

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

For Clinicians

If you are the designated most responsible provider for the transition:

- Monitor the young person’s transition to each adult service or other provider by regularly checking in with the young person (and their parents and caregivers, where appropriate)
- Offer support, as needed, while the young person waits to be seen by each adult service or other provider

- If the young person has medical needs, direct them (and their parents and caregivers, where appropriate) to the most appropriate person or place with medical expertise to address their needs
- Confirm that the young person has attended their first appointment with each adult service or other provider and that they (and their parents and caregivers, where appropriate) agree their health care service transitions are complete

For Organizations and Health Services Planners

Ensure that youth-oriented and adult services have systems, processes, and resources in place for the designated most responsible provider to complete the transition.

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who feel that their designated most responsible provider supported them until they confirmed their health care service transitions were complete
- Percentage of young people who have transitioned out of youth-oriented services who have their first visit with the adult service or another provider after transfer of care
    - If multiple providers are involved in care, collect and measure data separately for each adult service or other provider that the young person will transition to

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Appendices

Appendix 1. About This Quality Standard

How to Use This Quality Standard

Quality standards inform patients, clinicians, and organizations about what high-quality care looks like for health conditions or processes deemed a priority for quality improvement in Ontario. They are based on the best evidence.

Guidance on how to use quality standards and their associated resources is included below.

For Young People Transitioning From Youth to Adult Health Care Services

This quality standard consists of quality statements. These describe what high-quality care looks like for young people who are transitioning from youth to adult health care services.

Within each quality statement, we've included information on what these statements mean for you, as a patient, and for your parents and caregivers, if you want them to be involved.

In addition, you may want to download this accompanying patient guide on transitioning from youth to adult health care services, to help you and your family have informed conversations with your health care providers. Inside, you will find information and questions you may want to ask as you work together to make a plan for your care.

For Clinicians and Organizations

The quality statements within this quality standard describe what high-quality care looks like for young people aged 15 to 24 years as they transition from youth to adult health care services. They are based on the best evidence and designed to help you know what to do to reduce gaps and variations in care.

Many clinicians and organizations are already providing high-quality evidence-based care. However, there may be elements of your care that can be improved. This quality standard can serve as a resource to help you prioritize and measure improvement efforts.

Tools and resources to support you in your quality improvement efforts accompany each quality standard. These resources include indicators and their definitions (Appendix 2). Measurement is key to quality improvement. Collecting and using data when implementing a quality standard can help you assess the quality of care you are delivering and identify gaps in care and areas for improvement.

There are also a number of resources online to help you, including:

- Our patient guide on transitions from youth-oriented to adult health care services, which you can share with patients and families to help them have conversations with you and their other health care providers. Please make the patient guide available where you provide care
- Our measurement resources, which include our measurement guide of technical specifications for the indicators in this quality standard, and our "case for improvement" slide deck to help you to share why this standard was created and the data behind it
- Our placemat, which summarizes the quality standard and includes links to helpful resources and tools
- Our *Getting Started Guide*, which includes links to templates and tools to help you put quality standards into practice. This guide shows you how to plan for, implement, and sustain changes in your practice
- Quorum, an online community dedicated to improving the quality of care across Ontario. This is a place where health care providers can share information and support each other, and it includes tools and resources to help you implement the quality statements within each standard
- The Health Equity Impact Assessment tool, which can help your organization consider how programs and policies impact population groups differently. This tool can help maximize positive impacts and reduce negative impacts, with an aim of reducing health inequities between population groups

How the Health Care System Can Support Implementation

As you work to implement this quality standard, there may be times when you find it challenging to provide the care outlined due to system-level barriers or gaps. These challenges have been identified and documented as part of the development of the quality standard, which included extensive consultation with health care professionals and lived experience advisors and a careful review of available evidence and existing programs. Many of the levers for system change fall within the purview of Ontario Health, and as such we will continue to work to address these barriers to support the implementation of quality standards. We will also engage and support other provincial partners, including the Ministry of

Health or other relevant ministries, on policy-level initiatives to help bridge system-level gaps.

In the meantime, there are many actions you can take on your own, so please read the standard and act where you can.

Appendix 2. Measurement to Support Improvement

The Transitions From Youth to Adult Health Care Services Quality Standard Advisory Committee identified seven indicators for this quality standard. These indicators can be used to monitor the progress being made to improve care for young people aged 15 to 24 years in Ontario. Measurement for some indicators can be supported by existing provincial data sources. However, data collection and measurement for this topic area are currently limited, so measurement will require the use of locally sourced data.

Using data from these indicators will help you assess the quality of care you are delivering and the effectiveness of your quality improvement efforts. We realize this standard includes a lengthy list of statement-specific indicators. These indicators are provided as examples; you may wish to create your own quality improvement indicators based on the needs of your population. We recommend you identify areas to focus on in the quality standard and then use one or more of the associated indicators to guide and evaluate your quality improvement efforts.

Consider collecting data and measuring indicators by various equity stratifications that are relevant and appropriate for your population, such as patient socioeconomic and demographic characteristics. These may include age, family income, region/geography, education, language, race, and sex. Please refer to Appendix 4, Guiding Principles, *Social Determinants of Health*, for additional equity considerations.

Our measurement guide provides more information and concrete steps on how to incorporate measurement into your planning and quality improvement work.

Measuring the Success of This Quality Standard

Indicators That Can Be Measured Using Provincial Data

Percentage of young people who have transitioned out of youth-oriented services who have their first visit with an adult service or another provider after transfer of care

- Denominator: total number of young people who have transitioned out of youth-oriented services
- Numerator: number of people in the denominator who have their first visit with an adult service or another provider after transfer of care

- Notes:
    - This indicator is applicable to young people with health care needs that require a regular follow-up with a provider
    - For measurement purposes, this could be a visit within 12 months after transfer (at age 18, as a proxy for age of transfer). However, the time period can be tailored based on health care needs
    - Provincial data sources capture physician visits. Local data collection may be required, depending on the health care need and to track visits to nonphysician services
    - If multiple providers are involved in care, collect and measure data separately for each adult service or other provider that the young person will transition to
    - This indicator does not capture continuity of care in adult services beyond the first visit
    - This indicator is also included in quality statement 6
    - Please refer to the measurement guide for more information
- Data sources:
    - Administrative databases (e.g., Discharge Abstract Database [DAD] or using a validated algorithm, if available) to identify young people with certain health care needs
    - Ontario Health Insurance Plan (OHIP) Claims Database to identify physician visits with an adult service or another provider after transfer of care
    - Note: local data collection may be required depending on the health care need and to track visits to nonphysician services

Percentage of young people who have transitioned out of youth-oriented services who have an unscheduled emergency department visit in the first year after transfer of care

- Denominator: total number of young people who have transitioned out of youth-oriented services
- Numerator: number of people in the denominator who have an unscheduled emergency department visit in the first year after transfer of care
- Notes:
    - Age of transfer may depend on the health care needs of the young person and/or setting
    - An emergency department visit may be due to the lack of follow-up with an adult service or another provider, or a worsening condition. Risk adjustment can be considered

- Data sources:
  - Administrative databases (e.g., DAD or using a validated algorithm, if available) to identify young people with certain health care needs
  - National Ambulatory Care Reporting System (NACRS) to identify emergency department visits
  - Note: local data collection may be required depending on the health care need

Indicators That Can Be Measured Locally

Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan

- Denominator: total number of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate)
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Numerator: number of people in the denominator who report being involved as much as they want to be in co-creating the transition plan
- Notes:
  - Please see quality statement 3 for definitions of *co-created* and *transition plan*
  - This question is adapted from the Health Care Experience Survey (Ministry of Health),[62] which has a validated survey question that can be used to inform your local data collection: "When you see your provider or someone else in their office, how often do they involve you as much as you want to be in decisions about your care and treatment?" (Response options: always, often, sometimes, rarely, never, don't know, refused)
  - This indicator is also included in quality statement 3
- Data sources: local data collection via patient and/or parent/caregiver survey

Percentage of young people who have transitioned out of youth-oriented services who had a designated most responsible provider for the transition

- Denominator: total number of young people who have transitioned out of youth-oriented services
- Numerator: number of people in the denominator who had a designated most responsible provider for the transition

- Notes:
  - Please see quality statement 4 for the definition of *designated most responsible provider*
  - This indicator is also included in quality statement 4
- Data source: local data collection

Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who completed a transition readiness assessment prior to transfer of care

- Denominator: total number of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate)
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Numerator: number of people in the denominator who completed a transition readiness assessment prior to transfer of care
- Note: Please refer to the measurement guide for examples of transition readiness tools that can be used to measure this indicator for young people and parents/caregivers
- Data sources: local data collection via patient and/or parent/caregiver survey

Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who report being satisfied with the transition

- Denominator: total number of young people who have transitioned out of youth-oriented services
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Numerator: number of people in the denominator who report being satisfied with the transition
- Note: Please refer to the measurement guide for examples of tools that can be used to measure this indicator for youth and parents/caregivers
- Data sources: local data collection via patient and/or parent/caregiver survey

Percentage of young people who have transitioned out of youth-oriented services who report that they maintained their quality of life around the period of transfer of care

- Denominator: total number of young people who have transitioned out of youth-oriented services
- Numerator: number of people in the denominator who report that they maintained their quality life around the period of transfer of care
- Notes:
    - Please refer to the measurement guide for examples of surveys that can be used to measure this indicator for young people
    - Consider using the time period for measuring maintained quality of life as the time from discharge from youth-oriented services to follow-up with an adult service or another provider
- Data source: local data collection via patient survey

How to Measure Improvement for Specific Statements

Quality Statement 1: Early Identification and Transition Readiness

Percentage of young people who will transition out of child- and youth-oriented services (and their parents or caregivers, where appropriate) who have discussions about their ongoing preparation needs for transition

- Denominator: total number of young people who will transition out of child- and youth-oriented services (and their parents or caregivers, where appropriate)
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Numerator: number of people in the denominator who have discussions about their ongoing preparation needs for transition
- Notes:
    - Please see quality statement 1 for the definition of *ongoing preparation needs for transition*
    - Consider defining the age at which this indicator is measured based on the needs of your population or tracking at multiple time points prior to the transfer of care. Refer to quality statement 1 for the definition of *as early as possible* for guidance on timing for transition planning
- Data source: local data collection

Percentage of young people who will transition out of child- and youth-oriented services (and their parents or caregivers, where appropriate) who receive regular reviews of transition readiness at least once within 12 months

- Denominator: total number of young people who will transition out of child- and youth-oriented services (and their parents or caregivers, where appropriate)
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Numerator: number of people in the denominator who receive regular reviews of transition readiness at least once within 12 months
- Notes:
    - Please see quality statement 1 for the definition of *regular collaborative reviews of transition readiness* and for examples of transition readiness tools that can be used to measure this indicator for young people and parents/caregivers
    - Consider tracking whether the review of transition readiness was a collaborative process (as described in quality statement 1)
- Data source: local data collection

Quality Statement 2: Information-Sharing and Support

Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who receive developmentally appropriate information to meet their needs

- Denominator: total number of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate)
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Numerator: number of people in the denominator who receive developmentally appropriate information to meet their needs
- Notes:
    - Please see quality statement 2 for definitions of information-sharing and support and developmentally appropriate
    - Quality statement 2 notes that information-sharing and support should occur throughout the transition—before, during, and after transition. Consider tracking this indicator at one or more of these time points for the purpose of measurement
- Data source: local data collection

Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who feel that they were asked for their experience and expertise during transition planning and shared goal-setting

- Denominator: total number of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate)
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Numerator: number of people in the denominator who feel that they were asked for their experience and expertise during transition planning and shared goal-setting
- Note: Please see quality statement 2 for the definition of a*ctively 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*
- Data sources: local data collection via patient and/or parent/caregiver survey

Quality Statement 3: Transition Plan

Percentage of young people who will transition out of youth-oriented services who have a documented, individualized transition plan

- Denominator: total number of young people who will transition out of youth-oriented services
- Numerator: number of people in the denominator who have a documented, individualized transition plan
- Note: Please see quality statement 3 for the definition of *transition plan*
- Data source: local data collection

Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who report being involved as much as they want to be in co-creating the transition plan

- Denominator: total number of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate)
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Numerator: number of people in the denominator who report being involved as much as they want to be in co-creating the transition plan

- Notes:
    - Please see quality statement 3 for definitions of *co-created* and *transition plan*
    - This question is adapted from the Health Care Experience Survey (Ministry of Health),[62] which has a validated survey question that can be used to inform your local data collection: "When you see your provider or someone else in their office, how often do they involve you as much as you want to be in decisions about your care and treatment?" (Response options: always, often, sometimes, rarely, never, don't know, refused)
    - Exclusion: people who reply "don't know" or "refused"
    - This indicator is also included in the section "Measuring the Success of This Quality Standard"
- Data source: local data collection via patient survey

Quality Statement 4: Coordinated Transition

Percentage of young people who are transitioning out of youth-oriented services who have a designated most responsible provider for the transition

- Denominator: total number of young people who are transitioning out of youth-oriented services
- Numerator: number of people in the denominator who have a designated most responsible provider for the transition
- Notes:
    - Please see quality statement 4 for the definition of *designated most responsible provider*
    - This indicator is also included in the section "Measuring the Success of This Quality Standard"
- Data source: local data collection

Percentage of young people who are transitioning out of youth-oriented services (and their parents or caregivers, where appropriate) who feel supported with care coordination by their designated most responsible provider

- Denominator: total number of young people who are transitioning out of youth-oriented services (and their parents or caregivers, where appropriate)
    - Data collected and measured separately for each subgroup:
        - Young people
        - Parents or caregivers
- Numerator: number of people in the denominator who feel supported with care coordination by their designated most responsible provider
- Notes:
    - Please see quality statement 4 for the definition of *designated most responsible provider*

  - Quality statement 4 notes that the designated most responsible provider should coordinate care and provide support throughout the transition process—before, during, and after transition—and until the transition is complete. Consider tracking this indicator at one or more of these time points for the purpose of measurement
- Data sources: local data collection via patient and/or parent/caregiver survey

Quality Statement 5: Introduction to Adult Services

Percentage of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate) who have a meeting with the key adult service or another provider before the transfer of care

- Denominator: total number of young people who will transition out of youth-oriented services (and their parents or caregivers, where appropriate)
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers
- Numerator: number of people in the denominator who have a meeting with the key adult service or another provider before the transfer of care
- Notes:
  - Please see quality statement 5 for the definition of *meeting*, *adult services or other providers*, and *transfer*
  - If multiple providers are involved in care, collect and measure data separately for each key adult service or other provider that the young person will transition to
- Data sources: OHIP Claims Database (to determine if a case conference took place) or local data collection

Quality Statement 6: Transfer Completion

Percentage of young people who have transitioned out of youth-oriented services (and their parents or caregivers, where appropriate) who feel that their designated most responsible provider supported them until they confirmed their health care service transitions were complete

- Denominator: total number of young people (and their parents or caregivers, where appropriate) who have transitioned out of youth-oriented services
  - Data collected and measured separately for each subgroup:
    - Young people
    - Parents or caregivers

- Numerator: number of people in the denominator who feel that their designated most responsible provider supported them until their health care service transitions were complete and confirmed
- Note: Please see quality statement 6 for definitions of designated most responsible provider and supported until health care service transitions are complete and confirmed
- Data sources: local data collection via patient survey and/or parent/caregiver survey

Percentage of young people who have transitioned out of youth-oriented services who have their first visit with the adult service or another provider after transfer of care

- Denominator: total number of people who have transitioned out of youth-oriented services
- Numerator: number of people in the denominator who have their first visit with the adult service or another provider after transfer of care
- Notes:
  - This indicator is applicable to young people with health care needs that require a regular follow-up with a provider
  - For measurement purposes, this could be a visit within 12 months after transfer. However, the time period can be tailored based on health care needs
  - If multiple providers are involved in care, collect and measure data separately for each adult service or other provider that the young person will transition to
  - This indicator does not capture continuity of care in adult services beyond the first visit
  - This indicator is also included in the section “Measuring the Success of this Quality Standard”
  - Please refer to the measurement guide for more information
- Data sources:
  - Administrative databases (e.g., DAD or using a validated algorithm, if available) to identify young people with certain health care needs
  - OHIP Claims Database to identify physician visits with an adult service or another provider after transfer of care
  - Note: local data collection may be required depending on the health care need, and to track visits to nonphysician services

Appendix 3. Glossary

Culturally appropriate care: Care that incorporates cultural or faith traditions, values, and beliefs; is delivered in the person's preferred language; adapts culture-specific advice; and incorporates the person's wishes to involve family or community members.[63]

Health care professionals: Regulated professionals, such as nurses, nurse practitioners, occupational therapists, pharmacists, physicians (family doctors, specialists), physiotherapists, psychologists, respiratory therapists, social workers, and speech-language pathologists.

Health care providers: Regulated professionals and also people in unregulated professions, such as administrative staff, behavioural support workers, personal support workers, child life specialists, recreational staff, spiritual care staff, and volunteers.

Health care team: All youth and adult providers, primary care providers, home and community care providers, as well as any other health care providers who give care and support to the young person (and their parents and caregivers, where appropriate).

Parents and caregivers, where appropriate: Those individuals who provide care and/or legal guardianship or whom the young person deems important in supporting their health.[34] In some instances, this may be a substitute decision-maker (see definition, below). There are varying degrees of involvement of parents and caregivers throughout the transition, including when a young person has transitioned to adult services or another provider. Young people should be asked regularly how they would like their parents and caregivers involved. Involvement of parents and caregivers will vary depending on the young person's age and capacity to participate.

Primary care provider: A family physician (also called a primary care physician), nurse practitioner, or community pediatrician.

Substitute decision-maker: A person appointed to make decisions on behalf of another under a "Power of Attorney for Personal Care."

Young person: A person aged 15 to 24 years.[1,2] Some prefer to be referred to as a "youth" or "young adult" (advisory committee consensus).

Appendix 4. Values and Guiding Principles

Values That Are the Foundation of This Quality Standard

This quality standard was created, and should be implemented, according to the Patient, Family and Caregiver Declaration of Values for Ontario. This declaration "is a vision that articulates a path toward patient partnership across the health care system in Ontario. It describes a set of foundational principles that are considered from the perspective of Ontario patients, and serves as a guidance document for those involved in our health care system."

These values are:

- Respect and dignity
- Empathy and compassion
- Accountability
- Transparency
- Equity and engagement

A quality health system is one that provides good access, experience, and outcomes for all people in Ontario, no matter where they live, what they have, or who they are.

Guiding Principles

In addition to the above values, this quality standard is guided by the principles outlined below.

Acknowledging the Impact of Colonization

Health care providers should acknowledge and work toward addressing the historical and present-day impacts of colonization in the context of the lives of Indigenous Peoples throughout Canada. This work involves being sensitive to the impacts of intergenerational and present-day traumas and the physical, mental, emotional, and social harms experienced by Indigenous people, families, and communities, as well as recognizing their strength and resilience. This quality standard uses existing clinical practice guideline sources that may not include culturally relevant care or acknowledge traditional Indigenous beliefs, practices, and models of care.

Developmentally Appropriate Care and Support

Developmentally appropriate care and support considers the young person as a whole, addressing their biological, psychological, and social development broadly.[16] This approach ensures the young person is informed about, and helped to play an active role in, their care and support.

French Language Services

In Ontario, the *French Language Services Act* guarantees an individual's right to receive services in French from Government of Ontario ministries and agencies in 26 designated areas and at government head offices.[64]

Integrated Care

Health care providers and community and support service providers in youth-oriented and adult-oriented services, and primary care providers, work together in an integrated way to promote shared accountability, effective communication, and care coordination to facilitate a smooth and gradual transition for young people (and their parents and caregivers, where appropriate).[16] This may involve a joint vision or statement for transitions, and mutually agreed upon and shared transition protocols or policies, information-sharing protocols, and approaches to practice.

Life-Course Approach

The life-course approach to care looks at the individual over time and considers their broad environment. For young people with disabilities or health care needs, this may include different contexts such as social (e.g., opportunities to participate in meaningful activities); physical (e.g., accessibility); and public policy (e.g., funding supports, such as attendant care or job coach, to help build capacity to participate in adult communities). It is important to recognize the interaction between the people and their environments: the environment can have an effect on the person and the person can also influence the environment.[35]

Recognition and Support of the Role of Parents, Family, and Caregivers

Recognition and support of the role of parents, family, and caregivers means creating the conditions and culture where they are respected for their expertise and welcomed as partners in the young person's care.[65,66] This begins with acknowledging the positive impact they have on health outcomes at an individual and system level. Other key components in developing collaborative relationships among the young person, their family/caregivers, and health care providers include consistent involvement, mutual trust, and attending to the needs of parents, family, and caregivers.[17]

Social Determinants of Health

Poverty and social isolation are two examples of economic and social conditions that influence people's health, known as social determinants of health. Other social determinants of health include employment status and working conditions, ethnicity, food security and nutrition, gender, housing, immigration status, social exclusion, and residing in a rural or urban area. Social determinants of health can have strong effects on individual and population health; they play an important role in understanding the root causes of poorer health. Young people with health care needs requiring a transition from youth-oriented to adult services often live in stressful social and economic conditions that may worsen their overall health and well-being,[27] including social stigma, discrimination, and a lack of access to education, employment, income, and housing.[28]

Strengths-Based Practice

Strengths-based practice actively involves the young person and their care providers who support them in working together to achieve the young person's intended outcomes, in a way that draws on the young person's strengths.[16] The young person is recognized and acknowledged as the expert of their own lived experience, while the clinician is recognized as an expert in their discipline and in facilitating a conversation that reinforces the young person's strengths and resources.

Trauma-Informed Care

Trauma-informed care is health care that reflects an understanding of trauma and the impact that traumatic experiences can have on human beings.[29,32] In this approach, it is not necessary for the young person to disclose their trauma; rather, the approach acknowledges how common trauma is among disadvantaged children and young adults, especially those involved in the child welfare system, and seeks to connect those interested in treatment with appropriate trauma services.[30,32]

Youth-Centred (Person-Centred) Care

Youth-centred (or person-centred) means recognizing and acknowledging the young person as the expert of their own lived experience and as an equal partner in the transition process, and taking account of their views and needs about their own care and support.[16] All of a young person's needs are supported as they emerge and change over time, including those related to their wider context (e.g., education and employment, meaningful participation, health and wellness including mental health, and community integration).

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About Us

Ontario Health is an agency of the Government of Ontario. Our mandate is to connect and coordinate our province's health care system in ways that have not been done before to help ensure that Ontarians receive the best possible care. We work to support better health outcomes, patient experiences, provider experiences and value for money spent.

Equity, Inclusion, Diversity, and Anti-Racism

Ontario Health is committed to advancing equity, inclusion and diversity and addressing racism in the health care system. As part of this work, Ontario Health has developed an Equity, Inclusion, Diversity and Anti-Racism Framework, which builds on existing legislated commitments and relationships and recognizes the need for an intersectional approach.

Unlike the notion of equality, equity is not about sameness of treatment. It denotes fairness and justice in process and in results. Equitable outcomes often require differential treatment and resource redistribution to achieve a level playing field among all individuals and communities. This requires recognizing and addressing barriers to opportunities for all to thrive in our society.

For more information: ontariohealth.ca/our-team

About the Provincial Council for Maternal and Child Health

The mandate of the Provincial Council for Maternal and Child Health (PCMCH) is to provide evidence-based and strategic leadership for reproductive, neonatal and paediatric health services in Ontario. PCMCH fulfils this mandate by collaborating with provincial government agencies and organizations, regional maternal and child health networks, care providers, and patients and families. Our goal is to foster a healthcare system that provides timely, accessible, equitable and high-quality care for perinatal patients, children, youth and their families, and that supports life-long health for all Ontarians.

For more information: https://www.pcmch.on.ca/

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