

## Position Statement

# A call for action: Recommendations to improve transition to adult care for youth with complex health care needs

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### ABSTRACT

Youth with complex health care needs, defined as those requiring specialized health care and services for physical, developmental, and/or mental health conditions, are often cared for by paediatricians and paediatric specialists. In Canada, the age at which provincial/territorial funders mandate the transfer of paediatric care to adult services varies, ranging between 16 and 19 years. The current configuration of distinct paediatric and adult care service boundaries is fragmentary, raising barriers to continuity of care during an already vulnerable developmental period. For youth, the lack of care integration across sectors can negatively impact health engagement and jeopardize health outcomes into adulthood. To address these barriers and improve transition outcomes, paediatric and adult care providers, as well as family physicians and other community partners, must collaborate in meaningful ways to develop system-based strategies that streamline and safeguard care for youth transitioning to adult services across tertiary, community, and primary care settings. Flexible age cut-offs for transfer to adult care are recommended, along with considering each youth's developmental stage and capacity as well as patient and family needs and circumstances. Specialized training and education in transitional care issues are needed to build capacity and ensure that health care providers across diverse disciplines and settings are better equipped to accept and care for young people with complex health care needs.

**Keywords:** Adolescent; Adult Care; Chronic Illness; Medical Complexity; Transfer; Transition; Young Adult; Youth

### KEY CONCEPTS

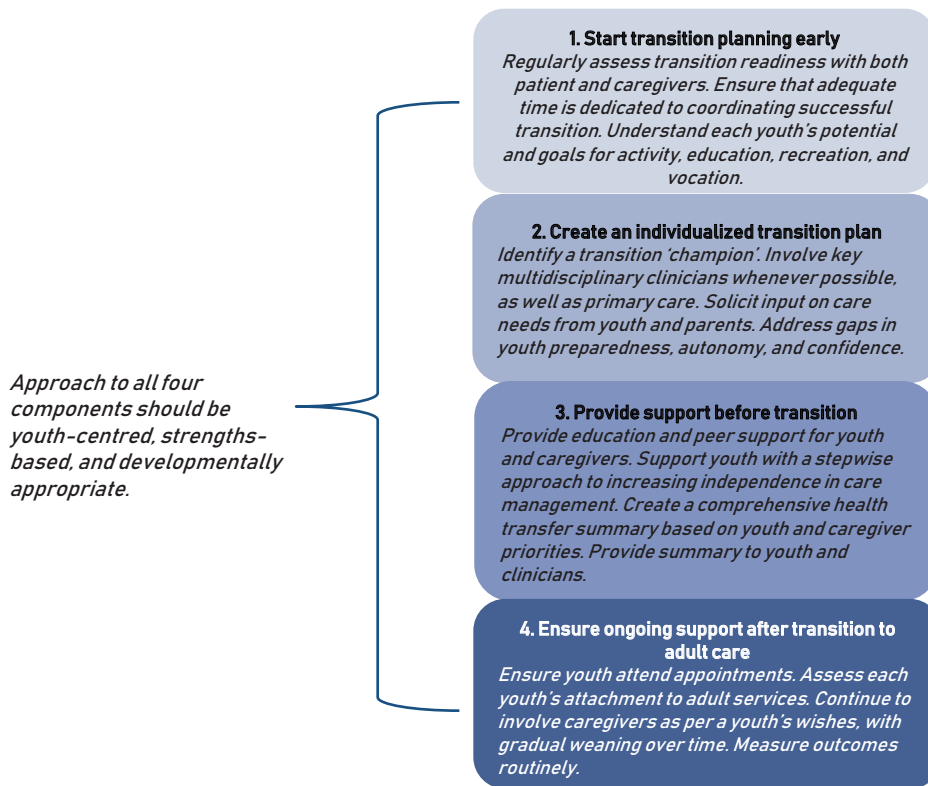
Transition refers to the purposeful and planned process of moving from paediatric to adult care services beginning in adolescence and continuing into early adulthood (1). Transfer represents a one-time event during the process of transition when the responsibility for care shifts officially from a paediatric to an adult care provider or team. The core principles of transition planning are summarized in Figure 1 and include the following components: (1) start transition planning early; (2) create an individualized transition plan; (3) provide support before transition; and (4) ensure ongoing support after the transition to adult care. Identifying a designated transition “champion”—a clinician who takes responsibility for facilitating and coordinating the health care providers (HCPs) involved in a young person's care, including primary care, and ensuring effective communication throughout the process—is beneficial (2). The overarching care goals of transition are to increase the

youth's level of responsibility for their own health care management, enhance understanding of the condition(s) they are living with, and build skills needed to navigate the adult health care system (3). The age at which transfer from paediatric to adult care services is mandated in Canada ranges between 16 and 19 years.

Youth with complex health care needs include those with physical, developmental, and/or mental health conditions as well as those with medical complexity (4). The complexity, care needs, and the number of children with complex health care needs are increasing in Canada, largely as a result of medical advances in the treatment of many childhood conditions (5,6). Children and adolescents with medical complexity share several characteristics, including chronic and often severe conditions, functional limitations with frequent reliance on technology, and high health care service utilization (6). Youth with complex health care needs often require ongoing

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**Figure 1.** Four core components of successful transition.

health surveillance and care to maintain optimal health into their adult years (7).

## CHALLENGES WHEN TRANSITIONING TO ADULT CARE

Transitioning youth with complex health care needs goes far beyond the medical transfer itself, posing unique challenges for youth, caregivers, and clinicians involved in their care (8–13). Poor health outcomes following transition have been described in the literature for several populations with complex health care needs. Specific conditions that “lead the field” in transition research include diabetes mellitus (13–16), cystic fibrosis (17–19), congenital heart disease (20,21), and kidney or other organ transplantation (22,23). For example, in population-based Ontario studies, the rate of diabetes-related hospital admissions increased significantly, from 7.6 to 9.5 per 100 patient-years, in the 2 years after transfer to adult care (24), and nearly one-half of Ontario youth had a gap longer than 12 months in diabetes care while transitioning to adult care (25).

Declines in health status may also be complicated by the many complex physical, psychosocial, and developmental changes that accompany adolescence and young adulthood. Youth frequently require support for building self-management skills, navigating new systems of care and relationships, and adapting to shifts in housing, vocation, education, and personal circumstances. Youth may not rank health as highly as other areas of transition in their lives. Furthermore, chronic physical health conditions are associated with increased depressive symptoms in emerging adults (26). Altogether,

these challenges may contribute to patient disengagement, poor treatment adherence, increases in hospitalization or emergency room visits, and detrimental health outcomes overall (27–31). In addition, the negative transition of care experiences contributes to caregiver or family burden and distress (32,33). Many youths with medical complexity and developmental disability continue to need family or other caregivers to retain key supportive roles during and following transition to adult care, especially if they lack the capacity to consent to or make health care decisions (34). Despite all these challenges, few jurisdictions in Canada have adequately addressed transitional care issues in health or broader social policies (35).

There is limited evidence in support of any single effective transition intervention for youth with a chronic illness or disability, or for those with multiple morbidities (e.g., a physical and mental illness). Interventions are often disease- or organ-specific, focus on specialist-to-specialist provider transition, fail to focus on medically complex or technology-dependent patients, and lack clarity on which specific approaches are the most effective for successful transition (36–38). Commonly used strategies include patient/caregiver education, resources to support information delivery, care navigators/coordinators, and joint paediatric-adult clinics (39–44). Broader psychosocial models that can help guide transition processes across various health care contexts are also lacking. Moreover, very little is known about the impact and role of primary care providers in supporting the transition of youth with complex health care needs (45–47). The lack of evidence to guide clinical practice and policy around the role of primary care providers in the transition of youth with complex health care needs, including

mental illness, is problematic. In part, this evidentiary gap reflects the fragmented nature of the primary-to-specialty care interface as well as historic priorities for transition within the paediatric community. Transition interventions need to be carefully tailored, timed, and integrated into the broader health care system to have a meaningful and positive impact on outcomes.

### FLEXIBILITY IN TRANSITION CARE IS ESSENTIAL

Adolescence comprises significant biological change and growth as well as major role transitions. How this formative period is conceptualized and defined influences the scope and focus of laws, policies, and programs intended to protect and empower adolescents (48). The age range for adolescence is not well defined (49), for example, and is characterized by significant individual variations in development. Some experts argue that adolescence should be redefined to include 10- to 24-year-olds, to better align with current adolescent growth patterns, and improved understanding of neurodevelopment, and timing of role transitions (48). Indeed, more flexible age cut-offs for transition to adult care would better reflect developmental age and readiness than chronological age or other definitions of adolescence (48–50). In this model, youth would be given increasing levels of responsibility and information as they move through the developmental stages of adolescence at their own pace.

In Canada, there is no universal legally defined age of consent for health care decision-making (51). HCPs are required to make assessments based on their patient's emerging self-awareness, developing values and beliefs, and maturing cognitive skills. In effect, the capacity of each paediatric patient to consent to a proposed treatment can vary with age and circumstances and is determined on a case-by-case basis (further legal variations may exist across jurisdictions). This approach aligns with the notion of evolving capacities articulated in the United Nations Convention on the Rights of the Child, which recognized that children from different environments and cultures, faced with diverse life experiences, would acquire competencies at different ages (52). The contributions of children to society, and the capacities they bring to it, must be reflected in law, policy, and practice.

Health care system leaders should adopt a comparable approach for decisions related to age of transition to adult care. Youth and families identified as “high risk” due to medical or psychosocial complexity should be individually recognized as needing more extensive multidisciplinary transition support (53). At the same time, equitable access to health care services that optimize transition care is not assured for children and youth. Specific high-risk groups include children and youth with complex health care needs who live in communities disadvantaged by rural or remote settings, or by economic, educational, or cultural marginalization. These disparities increase significantly around the point of transition to adult care.

To optimize outcomes, transfer of care should occur when an individual's health is relatively stable. To ensure quality,

continuous care to patients and families during transition, flexible funding and reimbursement models are needed to support HCPs on both sides of the paediatric–adult divide. Mechanisms could include extending the age cut-off for which paediatricians are reimbursed and transfers are mandated and increasing resources for paediatric settings and care providers when patients are transferring later or developing illnesses more commonly seen in adults.

HCPs should regularly assess transition readiness in the young people they see, with specific focus on self-management skills in health and life. Whenever possible, care teams should identify a transition “champion”: a clinician who takes a leading role in transition planning and coordination. While this level of attention is not always possible in community settings, the youth's primary care clinician (family physician, paediatrician, or nurse practitioner) may need to assume a greater role in transition planning and coordination. Clinicians must recognize youth as experts in their own health care, and proactively seek their input, as appropriate, regarding the timing, manner, and duration of transition care needed. Youth should have access to key information in their medical records during the transition process, and be supported in acquiring health literacy (54). Achieving health literacy is an important developmental milestone, characterized by increasing autonomy and learning to navigate the health care system. There is a subset of youth, however, for whom this process is not a reality. In these circumstances, parents or other capable caregivers will need to maintain key roles and responsibilities for care following the transition. For these youth and caregivers, transition should still be thoughtfully approached because they will need to adjust to adult-oriented health care and may have unique considerations (e.g., guardianship or substitute decision maker status).

### INVOLVING PRIMARY CARE PROVIDERS IN TRANSITION

Paediatric specialists should involve an adolescent's primary care provider early in the transition process to ensure continuity of care, facilitate better communication and handover on health and social issues, and increase opportunities for education regarding specific care needs. Collaborating early is particularly important because there is often no adult care equivalent to a paediatric care provider who has been involved in meeting a youth's complex or chronic care needs before transition. Such ‘missing links’ could include a general paediatrician, developmental paediatrician, complex care paediatrician, adolescent medicine specialist, or behavioural medicine specialist. Forging new relationships with primary care and adult HCPs, who might include internal medicine specialists and community agencies (to determine expectations and services in the area), must be an ongoing process (3).

While primary care providers are well positioned to assist and support patients and families transitioning from paediatric specialty care, they may feel ill equipped to manage the level of care required for youth with complex needs. This gap deepens when the primary care provider has not been deliberately engaged while the patient is still being managed in the paediatric subspecialty system. Other ‘transitional’ gaps

related to training, health policy, and education, as well as in specific health areas of concern, have been identified in primary care and other settings (55–57). Therefore, specialized transition education, training, and capacity-building among primary care providers is critical. At the same time, opportunities for paediatricians and paediatric specialists to continue supportive care following transition, through ongoing consultations or a period of shared care, should be supported. A youth or caregiver may not understand the exact role of primary care during transition. Strengthening their engagement with and attachment to a primary care “home-base,” while fostering health literacy skills during and after transfer to adult care, will help ensure successful transition (58). Future research and policy-making should focus on interventions that integrate primary and specialist care for specific populations with higher chronic health care needs (45).

Although many youth with complex health care needs do not see their primary care provider regularly, their involvement during transition is particularly important (58,59) and has been associated with positive patient outcomes (25,60). Connecting routinely with primary care providers should become established practice and be prioritized for youth with complex health care needs well before the transfer process begins. Primary care is the most opportune setting for routine care and screening and early intervention, and can optimize continuity at a time when specialist care may be more fragmented than before transition (61,62). Targeted efforts should be made to ensure that youth with complex health care needs have access to, and connect regularly with, their primary care provider, and to encourage this relationship as early as possible.

Little guidance is provided in the literature (45–47) concerning the role of primary care during transition, but providing continuous, equitable access to comprehensive, family-centred, developmentally appropriate, coordinated health care, is an achievable goal (47). The literature does support taking a holistic approach to optimize health outcomes during transition to adult care (63–67). Community services and primary care teams tend to provide more holistic care than other health settings and are effective for integrating social determinants of health—such as housing, school, employment, and social services—to meet needs of youth “where they live”.

### DEFINING AND EVALUATING SUCCESSFUL TRANSITION

A successful transition ensures care that is continuous, coordinated, and adapted to each youth’s development and maturity, while improving (or at least maintaining) disease control, patient satisfaction, quality of life, and social participation throughout young adulthood. Improvements in transition care have been limited by a lack of quality indicators as well as standardized, evidence-based, easy-to-administer methods for measuring or tracking such indicators (18,67). Both are needed to highlight areas for improvement, track changes over time, evaluate programs, benchmark across jurisdictions, and to focus further study. Collaboration among stakeholders is key to ensuring that complex health care needs are met during and beyond transition, enabling every youth to reach their full potential.

### RECOMMENDATIONS

The following principles of successful transition practice should be reflected upon and integrated into clinical service, research, and advocacy on behalf of youth and their families.

1. Effective transition ensures care that is continuous, comprehensive, coordinated, developmentally appropriate, and that meets the needs of all participants: patients, families, and health care providers (HCPs). For optimal outcomes, transition services for youth with complex care needs should be integrated into clinical care and performed by multidisciplinary teams.
2. Preparing youth for transition must include a stepwise plan that increases their autonomy and recognizes changing parent and caregiver roles. Flexible age cut-offs between paediatric and adult care services are needed. Decisions on the timing of transition should consider each individual’s development and capacity.
3. Paediatric and adult care providers need to collaboratively develop health care system-based strategies that streamline and safeguard care for youth transitioning to adult care. They should advocate in support of integrated care models across tertiary, community, and primary care settings, taking youth-centred approaches. Individualized care includes conversations with youth about how they would like to involve parents or caregivers in future health care, in specific circumstances. When a youth’s autonomy is not assured, this approach should involve support from caregivers. A short period of overlapping care between paediatricians or specialists and primary care providers may be needed. During this overlap, primary care clinicians should consider more frequent visits with transition-aged youth to build rapport and optimize continuity of care.
4. The increasing population of youth with complex health care needs who are transitioning to adult care should drive the redefinition of quality indicators used to measure improvement in health outcomes and care delivery for this vulnerable population, and to help them navigate developmental and other life-course changes.
5. New educational initiatives are needed to increase capacity of care for youth with complex care needs in diverse clinical settings. A collaborative, national approach to education is imperative, involving youth, families, and both paediatric, adult, and primary health care providers.
6. Adaptable program funding and physician compensation systems that support continuous, shared, and integrated care during the transition period are essential. Funding and payment models should be flexible regarding age cut-offs and shared care among paediatric and adult health services.

### RECOMMENDED RESOURCE

Children’s Healthcare Canada’s (CHC) Child Health Hub in Transition to Adult Healthcare: <https://www.transitionhub.ca>.

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## POTENTIAL CONFLICTS OF INTEREST

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