ON TRAC is a Provincial Transition Initiative to support the preparation, planning and transfer of youth (12-24 years of age) with chronic health conditions and/or disabilities (CHC/Ds) to adult care and ensure that transfer is successful with youth engagement and attachment to primary care and adult specialist services.

**Background:** The transition of youth from pediatric to adult care is a process and requires facilitation to ensure coordinated, continuous care to optimize their health and fullest potential.\(^1\) The increasing number of youth with CHC/Ds requiring continuous care after transition to adult care requires organized systems of care to address the significant health and social issues this vulnerable population experiences including:

1. Measurable adverse outcomes including increased mortality, morbidity, and poor long-term prognosis and quality of life.\(^2\),\(^3\),\(^4\)
2. Increased risk factors including a decline or cessation of medical care leading to secondary disease or illness.\(^5\),\(^6\) Several studies have shown follow-up rates in adult clinics after transfer to be less than 50% for several chronic conditions, including congenital heart disease, diabetes and spina bifida. Renal transplant patients who have not been engaged in transition planning have exhibited unexpected poorer outcomes and unexplained increased mortality after transfer compared to those who were in a transition program.\(^7\)
3. Inappropriate use of emergency service and expensive use of the adult health care system.\(^8\)

The Transition Clinical Practice Guideline (CPG) recommendations and clinical tools have been developed with and for youth, parents, and health care providers from pediatric, adult, rehabilitation and community settings. The purpose of this guideline is to standardize the transitional care of youth (12 to 24 years) with a CHC/D’s and their families requiring ongoing health care and surveillance beyond pediatric care into adult services. This guideline is a synthesis of pre-existing learning from ON TRAC,\(^9\) current contemporary knowledge (400+ research articles), international guidelines,\(^10\),\(^11\),\(^12\),\(^13\),\(^14\),\(^15\),\(^16\),\(^17\) and stakeholder engagement and testing. The seven recommendations outline standards of care to address:

1) Identification and assessment of youth with CHC/Ds ages 12-24 requiring transition preparation and support;
2) Documentation of the preparation and transfer to adult specialists and community-based family practitioners;
3) Access to education, resources and services for youth, families and health care providers; and
4) Data collection, monitoring and evaluation of measureable outcomes.

### Transition Clinical Practice Guideline: Summary of Recommendations

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\(^1\) The increasing number of youth with CHC/Ds requiring continuous care after transition to adult care requires organized systems of care to address the significant health and social issues this vulnerable population experiences including:

1. Measurable adverse outcomes including increased mortality, morbidity, and poor long-term prognosis and quality of life.\(^2\),\(^3\),\(^4\)
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3. Inappropriate use of emergency service and expensive use of the adult health care system.\(^8\)
All patients with chronic health conditions and/or disabilities (CHC/Ds), 12 - 24 years of age requiring clinic visits > 2x per year should have access to regular, developmentally-appropriate, transition planning and preparation. Beginning during early adolescence (age 12) with increasing personal responsibility for their care (as they are able), through to transfer at 18 years of age, until they are securely integrated into the adult system (by 24 years of age). Through annual assessments, care should be responsive to individual differences of development, cognitive and physical abilities, cultural & family dynamics and the trajectory of the young person’s illness.

### Recommendation II  Youth & Family Engagement

Youth and family engagement and interaction are central to the success of all transitions. For youth with CHC/Ds with cognitive/learning impairments and/or special needs, a family member or health advocate/guardian should be identified. All youth and or family/guardians should be active participants engaged through annual readiness assessments (quiz or checklist), education, counselling, and when available, workshops.

### Recommendation III  Attachment to Community and Adult Services

All youth with CHC/Ds requiring ongoing medical care and support should be attached to a family practitioner (physician and/or nurse practitioner) by 14 years of age, and an adult specialist(s) and services should be identified within one year before leaving pediatric care (16-17 years of age). Visits to the adult specialist should be within 6 months of transfer. Transfer to adult care providers will require the development of functioning referral networks to facilitate coordination, communication and follow-up between pediatric and adult providers.

### Recommendation IV  Documentation

The transfer from pediatric to adult care is a time of increased clinical risk which requires particular attention to the transfer of current and relevant documentation. This includes using standardized clinical transition tools; the transition clinical pathway (simple or complex) and a medical transfer summary, supported by appropriate reports and assessments, sent to the adult specialist(s), family practitioner and the youth at the time of transfer.

### Recommendation V  Education, Skill Support and Resources for all Stakeholders

A requirement for transition within health care is education, online resources and skill support for all stakeholders (youth, young adults, families and health care providers) to address the comprehensive care needs of transitioning youth, including condition-specific care requirements, anticipatory health and medical information, emergency planning, long-term care requirements, psychosocial and emotional concerns, privacy and consent, community supports, sexual health, educational/vocational and financial planning, living arrangements and access to services and resources.

### Recommendation VI  Roles and Care Coordination

Successful transition requires an understanding of the roles and responsibilities amongst all stakeholders in the process. The youth/young adult, family, community-based family practitioner and specialized pediatric and adult care physicians and allied health providers are the core stakeholders in transition. For youth with more complex needs, government and community-based care providers are also integral to the process. A most responsible practitioner should be identified for each patient throughout the process. Specialized care coordination and navigation may be necessary for more complex, individual patient situations.

### Recommendation VII  Evaluation

Use ongoing data collection methods including patient identification (clinic lists or registries), youth and family assessments, continuous process and tool testing, feedback and satisfaction of all stakeholders, and youth health outcomes and quality of life measures as part of quality improvement and accreditation standards for transition.

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2 UK Department of Health Transition (2006) Getting it right for young people. Improving transition of young people with long-term conditions from children’s to adult health services.


6 Kipps, S., Bahu, T., Ong, K., Ackland, F.M., Brown, R.S., Fox, C.T. et al (2002). Current methods of transfer of young people with Type 1 diabetes to adult services. Diabetics Medicine, 19, 649-54.


8 Rianthavorn, McDonagh, Southwood & Shaw. (2008). Transition of care from paediatric to adult services: one part of improved health services for adolescents. Archives of Disease in Childhood, 93(2):160-163.

9 In 1998, Children’s and Women’s Health Centre of BC under the title ON TRAC (Taking Responsibly for adolescent to Adult Care) developed a framework, clinical pathway and tools for youth, families and health care providers. Adapted into transition practice by UK Royal College of Nursing; Sick Kids Toronto; UK Department of Health; Cincinnati Children’s Hospital.


