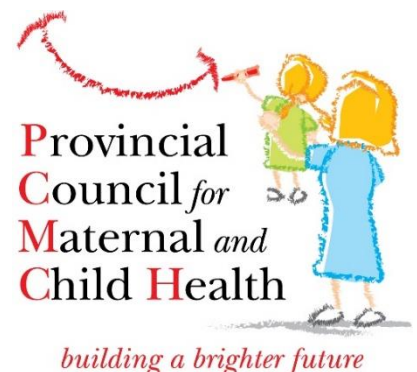




Healthcare
Provider
Resource

Complex Care for Kids Ontario Youth Transition to Adult Care Toolkit Healthcare Provider Checklist

February 2022



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About the Provincial Council for Maternal and Child Health

The Provincial Council for Maternal and Child Health (PCMCH) provides 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.

About Complex Care for Kids Ontario and Population Definition

Complex Care for Kids Ontario (CCKO) is a provincial program led by PCMCH that improves service delivery, health and quality of life in meeting the needs and requirements of children/youth with medical complexity (CYMC) and their families. CCKO coordinates care across health and social support services and strengthens community services to improve access and enable care closer to home. It also advances the integration and coordination of care for children and youth whose complex healthcare needs persistently generate high healthcare utilization and costs. The CCKO program is implemented in four paediatric tertiary hospitals in Ontario: The Hospital for Sick Children, Children's Hospital of Eastern Ontario, McMaster Children's Hospital, and Children's Hospital at London Health Sciences Centre through ambulatory complex care clinics and in partnerships with community-based clinics across Ontario. Features of this unique paediatric subpopulation fall into five domains: high technology dependency, complexity, chronicity, fragility and geography (see Appendix A for Standard Operational Definition).

Background: The Need for this Toolkit

Studies show that through advancements in lifesaving and life-sustaining technologies, an estimated 90 per cent of paediatric patients with complex chronic illnesses are living longer [1]. Such advancements in medical treatment and technological support have also increased the life expectancy for children with medical complexity (CMC) who are medically fragile and/or technology dependent (MFTD) as many are living well into adulthood [2,3]. In

2019-2020, there were on average 13 per cent of youth who were >14 years of age that were preparing to transition to adult care services (CCKO program metrics). Moreover, the transition practices and approaches across CCKO program vary, with gaps in how healthcare providers (HCPs) are supporting this unique population with their transition needs [4].

Consequences of ineffective transition strategies have been well-documented [4,5,6]. Young people with medical complexities and/or intellectual disabilities are particularly vulnerable due to the various healthcare providers and community contacts they require. This adds to the confusion and difficulties navigating and accessing multiple layers within the healthcare and social services' systems [4,7,11]. Losing multiple providers and acquiring new ones can result in loss of familiar settings, staff and routine making the transition period especially difficult for the families [4]. Additional barriers also include lack of knowledge/capacity or limited access to expertise by adult care providers to manage paediatric conditions [6]. Hence, these challenges can lead to deterioration of the youth's health status, avoidable hospital admissions, emergency department visits and increased health system costs [5,8].

Disease-specific transition research tends to focus on transitioning from a paediatric specialty to an equivalent adult specialty; however, there is no comparable to paediatric complex care program in the adult services [4]. Consequently, the management falls to the adult primary care provider (PCP). Additionally, a large majority of youth with medical complexity (YMC) have limited capacity for independence and self-management; therefore, the current tools and recommendations focusing on transition readiness or self-management do not adequately address unique issues faced by YMC and their families [4; working group consensus].

Starting the transition planning *early* in childhood is recommended as this will provide time for the youth and caregiver to minimize disruptions between paediatric to adult services and allow time to build capacity for the family to learn about the adult oriented healthcare and social services system [2,7]. This entails an approach that is holistic and collaborative with youth, caregiver and youth's care team as outlined in this toolkit. Although the toolkit focuses on youth and/or their parents/caregivers, who are transitioning from the CCKO program to adult-oriented services, it may also have applicability to youth and caregivers who are not in the program adapted to their circumstances and region.

Purpose and Scope

The toolkit aims to streamline the transition process and support YMC and caregivers in their transition journey from the Complex Care program to adult services.

This toolkit consists of:

- An age-based checklist for the healthcare providers/care team (attached)
- An age-based checklist for the caregiver and youth with an accompanying *Transition Resource Guide* (separate document)

Note: the term “caregiver” includes a broad spectrum of potential caregivers for children/youth, including parents, grandparents and/or legal guardian(s). Through this work, both the HCPs and youth/caregiver supporting the transition needs of this unique population can work collaboratively and proactively to navigate supports into adult healthcare and social services.

Importance of Youth Engagement

While there are many differences in a complex care youth’s ability to take part in their care or care decisions, it is critical that they be offered opportunities, and encouraged, to participate in any way they can to develop independence and autonomy. It is encouraged that youth are given every opportunity to participate to the best of their capacity in the application of this toolkit.

Source of Information

Members of this working group are healthcare providers (HCPs) from children’s hospitals in Ontario with complex care clinic programs, rehabilitation services and primary care, along with family representatives with lived experience. Decisions were made by working group achieving agreement on tasks (see Acknowledgements for working group membership).

A Note on Health Equity

Advancing health equity across the reproductive and child healthcare system in Ontario is a priority at PCMCH. Social determinants of health, and their intersections, affect the health of individuals, groups and communities in many different ways. Health equity is achieved by removing unfair and avoidable barriers that compromise health and well-being. Although health inequity often impacts people from racial and ethnic minority groups, it is critical to note that people are socially disadvantaged for many reasons aside from race and ethnicity. Addressing anti-Indigenous and anti-Black racism, and other forms of systemic oppression that disproportionately affect the health of equity-seeking groups, is an important step in ensuring health equity.

This document, and the outlined tasks, are meant to be applied by HCPs when managing care for CYMC transitioning to the adult care system. When using this document, HCPs are reminded that Ontario is home to many diverse groups, including people of different ages, genders, gender identities, races, ethnicities, cultures and abilities living in a wide range of geographical locations. These factors can greatly influence a person's unique needs, expectations and responses to the care received, access to services and supports available and how care is managed. It is essential that the care provided by HCPs is culturally safe and sensitive, considers the individual and/or family's unique circumstances, and recognizes that what may be suitable for one person may not be appropriate for another, even if they have the same medical condition. In some situations, it may be appropriate for HCPs to consider consulting with organizations that specialize in supporting specific groups. Such organizations may be able to give advice on how to appropriately tailor the care being provided to an individual.

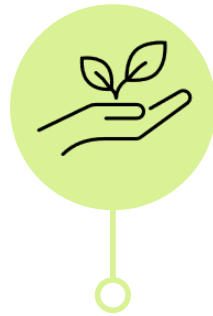
Using the HCP Checklist

Guiding Principles:

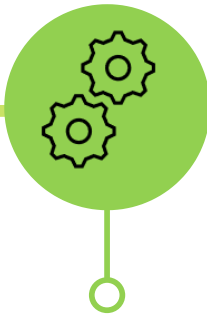
- To provide a **holistic approach** in guiding and supporting parent/caregiver and the CYMC through the process of transitioning to adult services;
- **To be proactive** in mitigating any foreseen problems/crises during their transition journey and addressing concerns early on before going into the adult care system;
- To use the age-based checklist (below) **as anticipatory guidance, and tailor** to the individual and family's circumstances in different organizations, and in response to the policies and practices of each region in Ontario as necessary;
- **To communicate and collaborate** with PCP and/or adult care specialists, along with the caregivers and youth to establish a smooth transition journey for the YMC; and
- To **address core concerns** for youth/caregiver at each stage/milestone, create time frames and strategies in meeting deadlines and ensuring services/supports are not overlooked.

COMPLEX CARE FOR KIDS ONTARIO

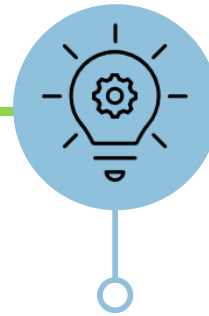
Youth Transition to Adult Care Timeline



<AGE 12



AGE 12-13



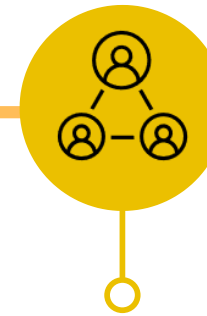
AGE 14



AGE 15



AGE 16



AGE 17



AGE 18

- Obtain [Social Insurance Number](#) (SIN), [passport](#), birth certificate, Status card (if applicable)
- Set up bank account
- Apply for:
 - [Assistance for Children with Severe Disabilities Program](#) (ACSD)
 - [Disability tax credit](#) (DTC)
 - [Registered disability savings plan](#) (RDSP)
 - [Accessible parking permits](#)
 - [Respite services](#)
- Review [entertainment/recreational opportunities](#)
- [Jordan's Principle](#) and
- [Inuit Child First Initiative](#) (if applicable)

- Identify/connect with [adult primary care provider](#) (PCP)
- Request a transition meeting at youth's school to make appropriate educational decision on youth's needs for high school
- Request updated psychological assessment or letter if youth is untestable from psychologist*

- Review transition tasks with care team/family
- Discuss goals & priorities for future planning, including Goals of Care
- Confirm IEP completion
- Discuss healthy relationships/sexuality

- Annual transition planning meeting with care team/family
- Begin [Developmental Services Ontario](#) (DSO) application to be submitted at age 16
- Learn about the adult care system
- Learn about [Substitute Decision-Maker \(SDM\)](#)

- Continue annual transition planning meeting with care team/family
- Submit [DSO](#) application*
- Annual appointment (appt.) with PCP from here
- Discuss referral to adult specialists with all paediatric specialists
- Discuss legal guardianship
- Explore providers for dental & vision care

- Periodic check-ins and final transition clinic meeting with care team/family
- Ensure appt. with all paediatric specialists to transfer care
- Overlapping/joint appt. with adult and paediatric specialists
- Develop a crisis plan of youth's daily routine
- Make a list of technology, equipment, supplies
- Submit [Ontario Disability Support Program](#) (ODSP) application at age 17.5*
- Transfer of home care services
- Determine future respite needs
- Request prescription refill for medications & enteral formula for 6 months
- Caregiver to have copies of care plan/key reports

- Last check-in with the paediatric team/family
- Adult care providers to have care plan/last consultation note/relevant medical records
- Confirm 1st or 2nd appts. with PCP and all adult care specialists
- Receiving DSO and Passport funding, and ODSP after age 18

* = Time-sensitive tasks

This timeline presents some key tasks. Please see the full checklists and *Transition Resource Guide* for further details. Each age lists new tasks to do *in addition* to the items in the previous age as some tasks build on tasks listed in the preceding age.



Your feedback is important! The Provincial Council for Maternal and Child Health is dedicated to improving the usability of this toolkit. We encourage healthcare providers and caregivers using this toolkit to submit feedback via an online survey by scanning the QR code or [clicking here](#).

v02 May 2022

Youth's Transition Care Team Contact Information

- Identify **one or more person** in the care team who will facilitate the transition planning of the YMC and their caregiver to the adult care system (e.g., NP, RN, SW, HCCSS CC, etc).
- Due to regional differences, and based on youth's circumstances, some youths/families may not have a contact for the services/providers listed below and/or some may need additional members to support the transition to adult care services.

Provider/Service	Name/Contact Information (Phone, Email)	Date Contacted	Roles and Responsibilities (e.g., psychological assessment, referrals from paed to adults, forms, etc)
1. Complex Care Paediatrician			
2. Nurse Practitioner			
3. Most Responsible Adult Primary Care Provider/ Family Physician			
4. Social Worker			
5. Home Care Contact			

6. Coordinated Service Planner Coordinator/Case Manager			
7. Developmental Services Ontario (DSO) Contact			
8. Ontario Disability Support Program (ODSP) Caseworker			
9. School Contact			
10. Transition Planner/ Community Treatment Centre Contact (if available)			
11. Adult Rehabilitation Contact (e.g., Psychiatrist) (if available)			
12.			
13.			
14.			
15.			
16.			

Technology, Equipment and Supplies

- Identify/list the youth's technology, equipment and/or supply needs when transitioning to adult services (such as, seating & mobility clinic, G-tube change support, respiratory, positioning, orthotics, home equipment, etc.).
- At age 18, they will not be eligible for paediatric rehabilitation services or children's treatment centre services for these supports. This will also be helpful when completing the ODSP form at age 17.

Patient Addressograph

Technology, Equipment and Supplies	Future Contact/Vendors for the Adult Care System (if available)
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
11.	
12.	

Current Paediatric Providers and Adult Care Service Providers

Make connections **when youth is 16 – 17 years old** to allow for at least one overlapping/joint appointment between the paediatric specialists and adult care specialists.

Patient Addressograph

Paediatric to Adult Care Specialists		Transfer Plan
Paediatric Specialists (Service, Name, Contact) Current paediatric specialist patient has in place and/or receiving care from (e.g., Neurologist)	Adult Specialists (Service, Name, Contact) Adult specialists responsible for that service when youth is age 18+	Identify who will be doing this transfer to the specialists (e.g., NP, MD, SW, etc.)
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		

Healthcare Provider Transition Checklist from Paediatric Complex Care to Adult Care Services

- Continue updating *Youth's Transition Care Team Contact Information* (pages 7-8) as providers in the transition planning process are identified.



Tasks to do before Age 12

- ☐ Discuss if caregiver has obtained [Social Insurance Number](#) (SIN) and [Canadian Citizen Passport](#), birth certificate (long form), Status card (if applicable) for the child/youth
- ☐ Discuss if a bank account is set up for the child/youth, preferably before age 6. Some banks will ask that the child/youth be able to sign independently after age 12
- ☐ Discuss to set up and apply for the following services with caregiver:
 - [Assistance for Children with Severe Disabilities Program](#) (ACSD)
 - [Disability Tax Credit](#) (DTC); this is required to set-up before a Registered Disability Saving Plan (RDSP)
 - [Registered Disability Saving Plan](#) (RDSP)
- ☐ Discuss applying for [respite care services](#) with caregiver so child/youth can get familiarity/gain trust
- ☐ Discuss funding for First Nations children to access supports through [Jordan's Principle](#) and [Inuit Child First Initiative](#) (if applicable)
- ☐ Discuss applying for [accessible parking permits](#). Explore accessible transportation options and encourage caregiver to register for the appropriate paratransit services for their region (if needed)
- ☐ Prompt caregiver to explore funding opportunities through paediatric charities and organizations that make home modifications or vehicle accessibility for the youth (see *Transition Resource Guide* for more information)
- ☐ Encourage caregiver to sign up for [Access2card](#) program that provides entertainment, cultural and recreational opportunities available and accessible to all (caregiver admission free or at a discounted price)



AGE 12-13

- ☐ **Encourage caregiver to find a Primary Care Provider (PCP) (e.g., Family Physician/NP) for youth**
 - Caregiver can register for [Health Care Connect](#).
If this is not available (in some rural communities), identify an HCP that will help caregiver make referrals/supporting transition planning process for the youth/caregiver
- ☐ Before starting high school, caregiver should request a transition meeting at youth's current school to make appropriate [educational placement decisions](#) based on youth's needs for secondary school.
 - **During this meeting, caregiver is to request an *updated* psychological assessment or a letter if youth is untestable (documentation from a psychologist stating the person has an intellectual disability)** as needed for Developmental Services Ontario (DSO) and Ontario Disability Support Program (ODSP).
 - HCP may need to refer youth/caregiver for this assessment/letter (e.g., developmental services, private assessment, alternative funding source, school)
- ☐ Recommend that caregiver and youth to connect with HCCSS/local home care services to learn about the supports needed when transitioning into secondary school
- ☐ Consider asking youth/caregiver about hopes for the youth's life after age 18 for the youth (overall vision; specific fears and concerns during transition)



AGE 14

- ☐ **Review transition planning items with youth and caregiver**

- ☐ Remind caregiver that an **updated psychological assessment or letter if youth is untestable (documentation from a psychologist stating the person has an intellectual disability)** to be completed from youth's school as needed for DSO and ODSP.
 - HCP may need to refer youth for this assessment/letter (e.g., developmental services, private assessment, alternative funding source, school)

- ☐ **Liaise with youth's care team to guide conversations based on youth and caregiver's goals and priorities**
 - Consider what caregiver wants for their child as an adult (e.g., on-going support from a resident or day program, respite care, other social supports, etc.)
 - This may include conversation around Goals of Care (which is different in the adult care system)

- ☐ Discuss future caregiver planning (if relevant and disclosed voluntarily; these discussions can occur any time during the transition planning process).
 - *Conversation prompt.* Is there anything about your own health, disability status or finances that is going to impact on your ability to provide care to your youth in the future?
 - If you identify that the needs exceed the caregiver's capacity or anticipate that this will happen in the future, consider contacting developmental services (e.g., social worker, coordinated service planners, etc.) to inquire about additional services for the caregiver.

- ☐ Confirm if Individual Education Plan (IEP) was completed for secondary school

- ☐ Inquire if caregiver is interested in discussing healthy relationships and sexuality for the youth (YMC vary in their ability to have independent friendship/relationships. If youth can interact with others on their own, it is normal and important to talk with them about healthy relationships and sexuality. Provide support if caregivers feel uncomfortable; however, their youth needs this information for their safety and well-being)



AGE 15

- ☐ **Schedule annual transition planning meeting with the youth and caregiver, along with key HCPs**
- ☐ **Check that caregiver has found and identified a PCP for youth** (e.g., family physician/NP). If not, register for [Health Care Connect](#).
 - If this is not available (in some rural communities), identify an HCP that will help caregiver make referrals/support transition planning for the youth
- ☐ The [DSO application](#) can be started at age 15 but not be submitted before 16th birthday. **Remind caregiver to gather eligibility documents**
 - Depending on family's circumstance, factor in funding support/hours of respite needed for caregiver's health and review DSO Urgent Response/crisis supports
- ☐ Identify what [respite support](#) is available; this information can also be found on DSO's Passport Program
- ☐ Initiate conversation about substitute decision-maker (SDM), consent, and legal guardianship with caregiver (see *Transition Resource Guide* for more information)
 - Obtain healthcare decision-making history:
 - Patient requires substitute decision maker (SDM):
Name, Relation: _____
 - Legal assistance is needed to identify a SDM or clarify SDM role: YES NO
(tip: use the highlight tool above for 'Yes' or 'No')

Conversation prompt: What accommodations have been needed to make healthcare successful for youth? Do you feel comfortable asking for these in the adult system or would you like to have paediatric providers advocate and help explain when they refer?
- ☐ Encourage independence and autonomy for the youth and caregiver to raise their confidence for self-advocacy and understand the differences in adult care system



AGE 16

- ☐ **Schedule annual transition planning meeting with family and key HCPs**
- ☐ **Support caregiver or team completing youth's [DSO application](#).**
 - After application submission, DSO will schedule an intake assessment – there can be a long wait for this so submitting a complete application early is essential
 - Send the youth's care report, with consent from the caregiver to DSO once the family is eligible
 - **Highlight medically complex needs** on the application for earlier intake assessment by DSO and obtain referral to [Community Networks of Specialized Care](#) by DSO contact
- ☐ **Encourage caregiver to schedule annual appointments for youth with PCP, starting at age 16**
- ☐ **Prompt paediatric specialists to provide referrals to appropriate adult specialists**
 - Team to monitor timeline of referral acceptance to ensure a smooth transition to end of paediatric services
Keep track of paediatric and corresponding adult specialists and list them on page 10
- ☐ **Discuss with other HCPs and caregiver if legal guardianship is necessary in youth's situation**
 - It is not needed for ODSP, DSO, bank account set-up or for healthcare decision-making but it is required for Family Managed Home Care or other special circumstances
(see *Transition Resource Guide* for more information)
- ☐ Discuss importance of routine health screening (e.g., dental care, vision) and confirm providers who will assume this care at age 18 (provider may only see youth until age 16), some coverage will be available through ODSP
 - This may include exploration/trial that will fit youth's needs and circumstances (e.g., clinics that are wheelchair accessible for the youth, etc.)
- ☐ Discuss and document answers to these questions to learn the level of support, complexity, frequency, and intensity of care needed for home and community services:
 - Does the youth need help with all activities of daily living (e.g., dressing, bathing, eating, toileting)?
YES NO
 - How many hours of care a week do they need, and at what hours?
 - Does that include nighttime care? YES NO
 - Does the healthcare provider need specialized training to provide care? YES NO
 - Discuss eligibility for nursing support at school/homeschool with nursing support, if applicable
- ☐ Explore Children's Wish organizations before transitioning to adult services (link to websites in the *Transition Resource Guide*)
- ☐ Reminder for caregiver to explore funding opportunities through paediatric charities/organizations that make home modifications or vehicle accessibility for the youth (see *Transition Resource Guide* for more information)
- ☐ Ensure that youth obtain [government issued](#) basic photo ID card (if applicable)



AGE 17

- ☐ **Conduct periodic check-ins with HCPs in care team to discuss transition items** (e.g., who is doing what to ensure tasks are not duplicated or missed)
- ☐ **Schedule final transition clinic meeting with care team, PCP and HCCSS/local home care service provider to go over any transition needs and navigation support.**
 - Provide an updated final discharge care plan to caregiver or cumulative patient plan from youth's PCP
 - Ensure families have good understanding of management of the condition and are aware of differences between paediatric and adult care; provide space to ask questions (e.g., differences in ER and in-patient hospital stay options in paediatric vs. adult settings; goals of care)
- ☐ **Confirm with caregiver if paediatric specialists have made referrals to appropriate adult specialists.** Care management should be handed over to the PCP and adult specialists.
 - Recommend caregiver having at least one overlapping/ joint appointment between the paediatric specialists and adult care specialists before youth is transferred to adult care services
Keep track of providers/specialists on page 10
- ☐ **Confirm that PCP has received all relevant and most up-to-date medical documents, reports, care plan**
 - Encourage caregiver to have at least two appointments with PCP for the youth by age 17.
- ☐ **Create crisis plan of youth's daily routine and compile a list of technology, equipment and/or supplies needed in case of caregiver emergency or urgent care** (with a transition planner or HCCSS/local home care service provider). Information to include:
 - Youth's basic 24-hour care routine
 - Any care providers that come during the day
 - Name of family/friends who can help
 - Local crisis resource contact
 - PCP contact and pharmacy contact
- ☐ **Provide support to caregiver for submitting the [ODSP](#) application (six months before youth turns 18)**
 - Identify HCP who will assist family completing the ODSP forms to be submitted by age 17.5
- ☐ In collaboration with HCCSS/local home care service provider and caregiver, **collect information for medical supplies to track technology/equipment needs to maintain daily care** (e.g., G-tube supplies, incontinence supplies, oximeter needs, etc.) which will be important to know when filling the Mandatory Special Necessities (MSN) form for ODSP application
Keep track of this on page 9
- ☐ Ensure connection with a rehabilitation or physiatrist clinic (if available) to determine youth's physiotherapist (PT) / occupational therapist (OT) needs; this includes equipment support, orthotics, seating and mobility clinic connections
- ☐ Determine if caregiver needs to apply to be a legal guardian for the youth
 - If enrolled in individualized funding models (e.g., Family-Managed Home Care) legal guardianship is necessary (see *Transition Resource Guide* for more information)

AGE 17 continued:

- ☐ Make referral and/or transfer services for HCCSS/local home care services in the adult healthcare system (if this applies for your region as in some regions, HCCSS can be until age 30)
- ☐ Encourage caregiver to determine future [respite](#) needs for themselves/family in youth's community
- ☐ Ensure refill prescriptions are up-to-date, and youth/caregiver has enough medications & enteral formula for at least six months after transition for the youth from paediatric care team
- ☐ Encourage caregiver to set-up first appointments for vision/dental cleaning/specialist check-ups with providers who will be assuming care after age 18
- ☐ Remind caregiver to explore accessible transportation and register for appropriate paratransit services for the youth within their city, as needed
- ☐ Engage with HCCSS/local home care service provider to have discussion regarding future educational plans for youth (e.g., eligible for secondary school until age 21, post-secondary education plans and [funding opportunities](#))



AGE 18

- ☐ Conduct a final check-in to identify if applications to funding agencies and/or process of transferring to adult specialists went smoothly; address anything pending
- ☐ Ensure PCP has received updated care plan and all documents (i.e., last consultation notes, goals of care, medical records, etc.)
- ☐ Confirm family attends first/second appointments with the PCP and other adult specialists
- ☐ Discharge youth from paediatric centre; family continue to follow-up with PCP. Points to mention to caregiver/family:
 - Youth to be cared for in adult healthcare system
 - PCP in the community will coordinate the needs between the caregiver, adult specialists and hospital visits
 - Paediatric providers may still be contacted by families or PCP with regards to navigating care process in the new environment
- ☐ Confirm with caregiver if MSN form and special diet allowance was completed/submitted and that youth/caregiver will be receiving funding support from ODSP, such as ODSP income, drug and dental cards for the youth
- ☐ Check to ensure youth is receiving support from DSO Passport Program or prompt caregiver to call to ensure that youth is on the waitlist to receive support as now 18 years old

Additional Resources



Resources for youth who *can* seek employment/ post-secondary education

Government of Canada: Employment Resources for Person with Disability

https://www.canada.ca/en/employment-social-development/campaigns/hiring-persons-disabilities.html?utm_campaign=esdc-edsc-inclusiveworkplacesem-21-22&utm_medium=sem&utm_source=ggl&utm_content=ad-text-en&utm_term=hiring%20individuals%20with%20disabilities&adv=2122-179701&id_campaign=15384962116&id_source=135879993571&id_content=564622197351&qclid=EAlaQobChMlvKb9wMn19QIVL8qUCR2s1QY0EAAAYASAAEgJoyfDBwE&qclsrc=aw.ds

Ministry of Transportation

Driving assessments

<http://www.mto.gov.on.ca/english/safety/functional-assessment-centres.shtml>

National Educational Association of Disabled Students (NEADS)

<https://www.neads.ca/>

Ontario Disability Support Program: Employment Supports service providers

https://www.mcass.gov.on.ca/en/mcass/programs/social/odsp/employment_support/EmploymentServiceProviders.aspx

Scholarships/Bursaries for Post-Secondary Education

<https://www.disabilityawards.ca/>

Seeking support at Post-Secondary Institutions

- Consult with the institution's Access and Support Centre for students
- Provide Support Centre with IEP information prior to beginning post-secondary institution
- Discuss your educational needs prior to and throughout youth's school year



General Guidelines and Resources for Youth Transitioning from Paediatric to Adult Care Services

Canadian Association of Paediatric Health Centres

A Guideline for Transition From Paediatric to Adult Health Care for Youth with Special Health Care Needs: CAPHC Transitions Community of Practice – A National Approach (2016)

<https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care>

Got Transition

<http://www.gottransition.org>

Provincial Council for Maternal and Child Health

Report of the Transition to Adult Healthcare Services Work Group (2013)

<https://www.pcmch.on.ca/health-care-providers/paediatric-care/pcmch-strategies-and-initiatives/transition-to-adult-healthcare-services/>

Ontario Health/Provincial Council for Maternal and Child Health Transitions from Youth to Adult Health Care Services Quality Standard Advisory Committee.

Transitions from Youth to Adult Health Care Services: Care for Young People Aged 15 to 24 Years (2022)

<https://www.hqontario.ca/Portals/0/documents/evidence/quality-standards/qs-transitions-from-youth-to-adult-health-care-services-quality-standard-en.pdf>

Transition Hub

<http://www.transitionhub.ca>

Acronyms and Definitions

ACSD – Assistance for Children with Severe Disabilities Program

CCKO – Complex Care for Kids Ontario

CMC – Child with Medical Complexity

CYMC – Children and Youth with medical complexity

Caregiver – includes broad spectrum of potential caregivers for children/youth,
including parents, grandparents and/or legal guardian(s)

DSO – Developmental Services Ontario

DTC – Disability Tax Credit

HCCSS – Home and Community Care Support Services

HCP – Healthcare Provider

IEP – Individual Education Plan

MD – Doctor of Medicine

MSN – Mandatory Special Necessities

MFTD – Medically Fragile and/or Technology Dependent

NP – Nurse Practitioner

ODSP – Ontario Disability Support Program

OPGT – Ontario Public and Guardian Trustee

PCP – Primary Care Provider

PCMCH – Provincial Council for Maternal and Child Health

RDSP – Registered Disability Savings Plan

SDM – Substitute Decision Maker

SW – Social Worker

Transfer – a one-time event of stopping services in one system and re-establishing in
another

Transition – a purposeful, planned movement of adapting to become ready for the
handing over of services from child-oriented to adult-oriented care [12] YMC

– Youth with Medical Complexity

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Appendix A: CCKO Standard Operational Definition



Standard Operational Definition for Children with Medical Complexity

To be eligible for Complex Care for Kids Ontario, the child must:

- ☐ Be under 18 years of age.
- ☐ Meets one criterion (indicated by a check box) from four of the five categories below.
- ☐ Medically complex child/youth not currently being followed by a multi-disciplinary team (e.g., diabetes team, cystic fibrosis, or neuromuscular clinics).

Rather, child/youth should continue to be followed in their current team rather than (individual exceptions aside) referred to the Complex Care for Kids Ontario.

TECHNOLOGY DEPENDENT AND/OR USERS OF HIGH INTENSITY CARE	<input type="checkbox"/> Child is dependent on mechanical ventilators, and/or requires prolonged IV administration of nutritional substances or drugs and/or is expected to have prolonged dependence on other device-based support <i>For example: tracheostomy tube care, artificial airway, suctioning, oxygen support, or tube feeding</i>		<input type="checkbox"/> Child has prolonged dependence on medical devices to compensate for vital bodily functions, and requires daily/near daily nursing care <i>For example: cardiorespiratory monitors; renal dialysis due to kidney failure</i>		<input type="checkbox"/> Child has any chronic condition that requires great level of care such as: <ul style="list-style-type: none">• Child is completely physically dependent on others for activities of daily living (at an age when they would not otherwise be so dependent)• Child requires constant medical or nursing supervision or monitoring, medication administration and/or the quantity of medication and therapy they receive
FRAGILITY	<input type="checkbox"/> The child has severe and/or life-threatening condition	<input type="checkbox"/> Lack of availability and/or failure of equipment, technology, or treatment places the child at immediate risk resulting in a negative health outcome	<input type="checkbox"/> Short-term changes in the child's health status puts them at immediate serious health risk <i>For example: an intercurrent illness</i>	<input type="checkbox"/> As a consequence of the child's illness, the child remains at significant risk of unpredictable life-threatening deterioration, necessitating round-the-clock monitoring by a knowledgeable caregiver	<input type="checkbox"/> Likely to experience exacerbation of chronic condition necessitating assessment by a healthcare provider in a timely manner
CHRONICITY	<input type="checkbox"/> The child's condition is expected to last at least six more months			<input type="checkbox"/> The child's life expectancy is less than six months	
COMPLEXITY	<input type="checkbox"/> Involvement of at least five healthcare practitioners/ teams and healthcare services are delivered in at least three of the following locations: <ul style="list-style-type: none">• Home, School/ Nursing school• Hospital,• Children's Treatment Centre,• Community-based clinic (e.g. doctor's office)• Other (at clinician's discretion)			<input type="checkbox"/> The family circumstances impede their ability to provide day-to-day care or decision making for a child with medical complexity <i>For example, the primary caregiver and/or the primary income source are at risk of not being able to complete their day-to-day responsibilities</i>	
GEOGRAPHY	<input type="checkbox"/> Child meets criteria for at least three of the four previous categories, and has significant challenges to seek appropriate medical services based on rurality or access				

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