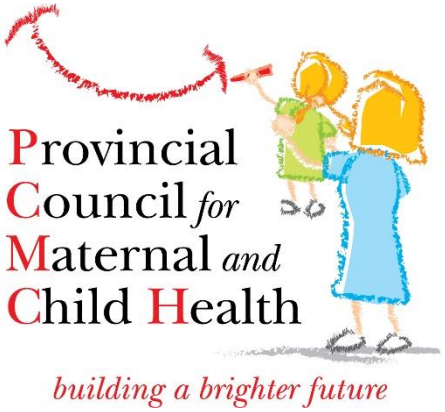
Caregiver
&Youth
Resource

Complex Care for Kids Ontario Youth Transition to Adult Care Toolkit

Caregiver and Youth Checklist & Transition Resource Guide

February 2022



Contents

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

ER – Emergency Room

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

YMC – Youth with Medical Complexity

About the Provincial Council for Maternal and Child Health

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 and 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. 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 population fall into five categories: high technology dependency, complexity, chronicity, fragility and geography (see Appendix A for Standard Operational Definition).

Purpose and Scope

This toolkit is focused on your youth with medical complexity (YMC) and you as their parent/caregiver supporting their transition journey in the Complex Care program to adult services.

This toolkit consists of:

- An age-based checklist for the healthcare providers (HCPs)/care team (separate document)
- An age-based checklist for the caregiver and youth with an accompanying *Transition Resource Guide* (attached below)
    - You can work alongside your youth's care team on the transition tasks and set up

relevant supports/services to ensure a smooth transition.

Who is this for?

This checklist and *Transition Resource Guide* (below) is developed to guide you (caregiver/parent) to support your child's transition to adult health services in partnership with your paediatric healthcare team to prioritize tasks throughout adolescence that will assist and improve the transition to adult care. Tasks are prioritized at each age to help guide you with some key resources (such as, funding services and supports) and how to access them. It is strongly recommended to begin the transition planning *early* to best support the success of the transition and allow time to learn about the differences between the paediatric and adult healthcare system.

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 this toolkit with you.

Source of Information

Members of this working group are 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 disproportionally 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 caregivers/parents when managing care for CYMC transitioning to the adult care system. When using this document, caregivers are reminded that Ontario is home to individuals from many diverse groups, including different ages, genders, gender identities, races, ethnicities, cultures and abilities living in a wide range of geographical locations. These factors can greatly influence a family's unique needs, expectations and responses to the care received, access to services and supports available and how it is managed. It is essential that parents and/or caregivers connect and collaborate with HCPs to ensure care and services are 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 the caregivers to consider consulting with organizations in their regions that specialize in supporting specific groups for assistance. Such organizations may be able to give advice on how to appropriately tailor the care being provided to an individual.

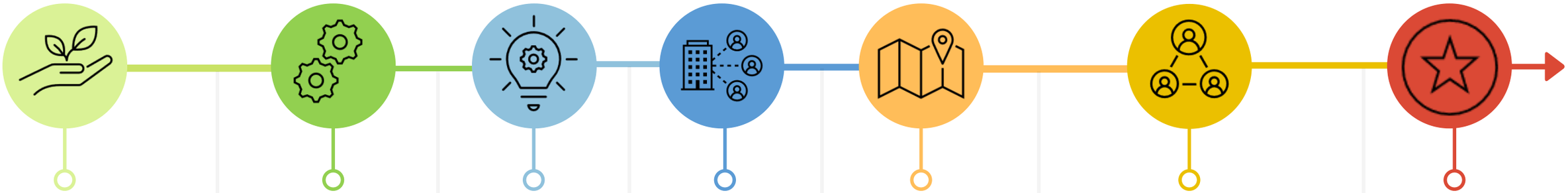
Using the Caregiver/Youth Checklist

Guiding Principles:

- To provide a **holistic approach** in guiding and supporting you with your CYMC through the process of transitioning to adult services;
- **To be proactive** in help mitigate any foreseen problems/crises during their transition journey and addressing concerns early on before your youth going into the adult care system;
- To use the age-based checklist **as anticipatory guidance, and tailor** to the individual circumstances in different organizations, and in response to the policies, practices of each region in the province of Ontario as necessary;
- To **communicate and collaborate** with PCP and/or adult care specialists to establish a smooth transition journey for your child/youth; and
- To **address core concerns** at each stage/milestone, create time frames and strategies in meeting deadlines and ensuring services/supports are not overlooked (e.g., focus on completing the tasks for the year, set reminders in your phone for key dates/appointments).

COMPLEX CARE FOR KIDS ONTARIO

Youth Transition to Adult Care Timeline



<AGE 12

- 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)

AGE 12-13

- 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*

AGE 14

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

AGE 15

- 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 Subsitute Decision-Maker (SDM)

AGE 16

- 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

AGE 17

- 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

AGE 18

- Last check-in with 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

Provincial Council for Maternal and Child Health
building a brighter future

COMPLEX CARE FOR KIDS ONTARIO (CCKO)
YOUTH TRANSITIONING TO ADULT CARE

My Youth's Transition Care Team Contact Information

- Identify **one or more person** who will help you and your child's transition to adult care
- Due to regional differences and based on your circumstances, you may not have a contact for all these services/providers and/or you may need additional members to support the transition to adult care services

Provider /Service	Name/Contact Information (Phone, Email)	Date Contacted	**Which part of the Transition Journey are they working on?** (e.g., psychological assessment, medical care plans, referrals, 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 Hospital Contact (e.g., Physiatrist) (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.

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

- When your youth is 16–17 years old, make connections to allow for one overlapping/joint appointment between the paediatric specialists and adult care specialists before they are transferred to adult care services at age 18.
- Note that in the paediatric care system many providers/specialists can be from the same organization/setting but in adult care system, specialists may be located at multiple settings or organizations.

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.		

Tasks and Dates in Your Youth's Transition Journey

Tasks to do before Age 12

- ☐ Apply for Social Insurance Number (SIN) and Canadian Citizen Passport for the child
  Additional items to obtain: Birth Certificate (long form), Status card registration (if applicable)
  To-Do Date: _____

- ☐ Open bank account for the child before age 6 (some banks will ask that the child be able to sign independently after age 12)
  To-Do Date: _____

- ☐ Apply for disability program/services: Assistance for Children with Severe Disabilities Program (ACSD); Disability Tax Credit (DTC) before setting up the Registered Disability Savings Plan (RDSP)
  To-Do Date: _____

- ☐ Apply for respite care services so child/youth can get familiarity

- ☐ Apply for funding for First Nations Children to access services and supports through Jordan's Principle and Inuit Child First Initiative (if applicable)
  To-Do Date: _____

- ☐ Explore funding opportunities through paediatric charities and organizations that make home modifications or vehicle accessibility for the youth (see *Transition Resource Guide*)

- ☐ Apply for accessible parking permits; explore accessible transportation options in youth's community (i.e., registering for para-transit services)
  To-Do Date: _____

- ☐ Sign up child for Access2card program that makes entertainment, cultural and recreational opportunities available and accessible to all (caregiver admission free or discounted)
  To-Do Date: _____

AGE 12-13

- [ ] **Find a Primary Care Provider (PCP) (e.g., Family Physician/NP) for youth** (follow links in the *Transition Resource Guide* by registering for Health Care Connect)
  To-do Date: _____
  - If this is not available, identify HCP that will help make referrals in youth's community and be the main provider for the youth at age 18

- [ ] Before starting high school, request a transition meeting at their current school to make appropriate educational placement decisions based on their needs
  Date of Appointment: _____
  - **During this meeting, request an *updated* psychological assessment report or letter if your youth is untestable (documentation request from a psychologist stating the person has an intellectual disability).** This assessment/letter will be required when applying for Developmental Services Ontario (DSO) or Ontario Disability Support Program (ODSP)
    To-Do Date: _____
  - Youth's care team may need to refer youth for this assessment/letter (e.g., developmental services, private assessment, alternative funding source, school)

- [ ] Recommend connecting with your HCCSS/local home care services to learn about the supports needed when transitioning into secondary school
  To-Do Date: _____

AGE 14

☐ Reminder to **ask for a referral from your care team to complete the psychological assessment or a letter by a psychologist**
To-Do Date: _____

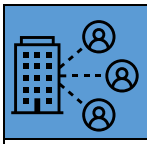
- Youth's care team may need to refer youth for this assessment/letter (e.g., developmental services, private assessment, alternative funding source, school)

☐ **With your care team, discuss goals and priorities about what your hopes and expectations are for your youth when they are an adult to learn what services and supports are available** (e.g., on-going support from a resident or day program, respite care, other social supports, etc.)
To-do Date: _____

☐ Discuss future caregiver planning with your care team regarding any concerns you may have about your own health that is going to impact on your ability to provide care to your youth in the future (if relevant and disclosed voluntarily)
To-do Date: _____

☐ Confirm completion of Individual Education Plan (IEP) for secondary school
To-do Date: _____

☐ Discuss healthy relationships and sexuality
To-do Date: _____
(YMC vary in their ability to have independent friendship/relationships. If your youth can interact with others on their own, it is normal and important to talk with them about healthy relationships and sexuality. As a caregiver, you may feel uncomfortable, however, your youth needs this information for their safety and well-being).



AGE 15

- [ ] **Schedule annual transition planning meeting with care team**
  Date of Appointment: _____

- [ ] **Share contact information of your youth's PCP with care team** (follow links in the *Transition Resource Guide* and register for Health Care Connect to find PCP)
  To-do Date: _____
  - If this is not available, identify HCP that will help make referrals in your community and be the main provider for the youth at age 18

- [ ] **Learn about DSO and ODSP (e.g., eligibility criteria, services/supports provided) with a member of your youth's care team.** Application for DSO can be started but not submitted before youth turns 16 (see *Transition Resource Guide* for more information)
  To-do Date: _____

- [ ] Work with HCCSS/home care service provider to identify any respite care/caregiver support needed and available in your community through the DSO Passport Program
  To-do Date: _____

- [ ] Discuss with your youth's care team how the care will be different when they transition into the adult healthcare system.

- [ ] Learn about consent, substitute decision-making (SDM) which is different in healthcare vs. financial sector after your youth turns 18 (see *Transition Resource Guide* for more information)
  To-do Date: _____

AGE 16

- [ ] **Schedule annual transition planning meeting with the care team**
  Date of Appointment: _____

- [ ] **Submit DSO application and provide documentation requested by DSO. Highlight medically complex needs on the application for earlier intake assessment as intake assessment can be a long process after DSO application submission. Maintain contact with DSO to provide and receive updates**
  To-do Date: _____
  - Obtain referral to Community Networks of Specialized Care by DSO contact

- [ ] **Schedule annual appointment with PCP from age 16 for the youth**
  Date of Appointment: _____

- [ ] **Request paediatric specialists to make referral to adult specialists. Monitor timeline for referrals to appropriate adult specialists and share information if available with your care team**
  Keep track of providers/specialists on page 10

- [ ] **Inquire with your care team if legal guardianship application is required prior to age 17** (see *Transition Resource Guide* for more information)
  To-do Date: _____

- [ ] Identify providers who will take over routine health screening services (e.g., dental care, vision) once your youth is 18 (providers may only see youth up to age 16), some coverage for these services will be available through ODSP
  To-do Date: _____

- [ ] Discuss with care team the level of support, complexity, frequency of care and specialized training that is needed at home and in school so they can ensure supports and services are in place in both settings (e.g., hours of care, including nighttime; discuss eligibility for nursing support at school or if your youth is being home-schooled, etc.)
  To-do Date: _____

- [ ] Explore Children's Wish organizations (Link to websites available in the *Transition Resource Guide*)

- [ ] Explore extra funding through paediatric charities for home modifications or vehicle accessibility in the paediatric sector that may be available before transferring to adult services
  To-do Date: _____

- [ ] Obtain a government issued basic photo ID for youth (if applicable)

AGE 17

☐ **Schedule final transition clinic meeting with the care team, PCP and/or HCCSS/ local home care services contact and discuss what the care will look like after your youth turns 18; be sure to understand how services and providers will change for your youth when entering the adult system**

Date of Appointment: _____

- **Obtain an updated final discharge care plan from your care team or a cumulative patient plan from your youth's PCP, which will be important for future follow-ups and keeping track of youth's heath status**
- Understand management of your youth's condition, how to get access to medical records and be aware of differences between paediatric and adult care

☐ **Ensure referrals have been received by the appropriate adult specialists and appointments have been booked.**

- Recommend having at least one overlapping/joint appointment between the paediatric specialists and adult care specialists to ensure smooth transfer of care
- Have last visits with the paediatric specialists to go over final transition needs to ensure supports/services are set-up with adult specialists/providers
- If possible, meet the adult care specialists with the PCP to review the complex care plan

Date of Appointments: _____ (consider setting booked appointments in your calendar promptly)

Keep track of providers/specialists on page 10

☐ **Schedule annual appointment with PCP for the youth**

Date of Appointment: _____

☐ **Create a crisis plan with a member from your youth's care team** (e.g., transition planner, HCCSS/local home care services coordinator) and share this with the PCP; keep a copy in case there is a caregiver emergency or urgent care needed

- Information to include: basic 24-hour care routine for the youth, any care providers that come during the day, family/friends that can help, local crisis resource contact, PCP contact, & pharmacy contact

To-do Date: _____

☐ **Apply for ODSP six months before youth turns 18. Complete paperwork with help from your youth's PCP and/or other medical professionals. Return completed application to ODSP by age 17.5**

To-do Date: _____

- Work with the HCCSS/local home care services contact to collect information on medical supplies; *track technology, equipment and supply needs for your youth as outlined on page 9* (e.g., G-tube supplies, incontinence supplies, oximeter, etc.); this information will be needed when filling out the ODSP form To-do Date: _____
- If eligible for ODSP, complete the Mandatory Special Necessities (MSN) form with PCP; bring the list prepared above To-do Date: _____

AGE 17 Continued:

- [ ] Ensure connection with a rehabilitation or physiatrist clinic (if available) to support ongoing care and management of disability care with physiotherapist (PT) / occupational therapist (OT); this includes equipment support, orthotics, seating and mobility clinic connections
  To-do Date: _____

- [ ] Determine if you or someone else will be a legal guardian for your youth
  To-do Date: _____
  - Contact the Office of the Public Guardian and Trustee (OPGT) to learn how to select a guardian, what is required if you choose to have legal guardianship, or when it may be necessary to have a legal guardian. For example, if you are enrolled in individualized funding models (such as, Family Managed Home Care) legal guardianship is necessary (see *Transition Resource Guide* for more information)

- [ ] Contact local HCCSS care coordinator/local home care services contact for referrals to set-up future home supports and case management transfers (if this applies for your region as in some regions, HCCSS will be the same until age 30)
  To-do Date: _____

- [ ] Learn about future respite opportunities/availability in your community

- [ ] Ensure prescriptions are up-to-date and have enough medication refills & enteral formula for at least six months after transition from care team
  To-do Date: _____

- [ ] Set up appointments for vision/dental cleaning/specialist check-ups with providers who will be assuming the care after age 18
  To-do Date: _____

- [ ] Explore accessible transportation and register for appropriate paratransit services within your city as needed
  To-do Date: _____

- [ ] Discuss future educational plans with school and care team (e.g., ability for your youth to stay in high school until age 21; post-secondary education plans and funding opportunities); connect with school's Access and Support Centre
  To-do Date: _____

AGE 18

- [ ] Your youth is formally discharged from paediatric centre/care team and their care is to be followed up by the PCP who will coordinate the care needs
- [ ] Schedule final check-in to review and learn how the process of transition to providers and services went and/or pending tasks
- [ ] Inform youth's care team of attendance to at least first appointment with PCP and adult specialists to ensure continuity
- [ ] Ensure that MSN form and special diet allowance are complete/submitted and verify that you will be receiving support from ODSP (including, dental and drug cards)
- [ ] Receive support from DSO and Passport Program or call to ensure that your youth is on the waitlist to receive the supports

TRANSITION RESOURCE GUIDE

Disclaimer: These are key services and resources to support YMC transitioning to adult care system based on *currently* available services. This is *not* a comprehensive list of resources and services as youth/caregiver may be eligible for additional supports based on your youth's region and need. Materials presented in this guide are for *information purposes* only. Caregivers and families are advised to seek legal advice regarding decision-making, capacity, Power of Attorney, and Legal Guardianship, or seek support from the appropriate service contact for more information.

Organization	What they do	What I need to do	More Information
Developmental Services Ontario (DSO) **Is my youth eligible for this?** **Yes___** **No ___** (tip: use the highlight tool above for 'Yes' or 'No')	Developmental Services Ontario helps adults with developmental disabilities find services and supports. It is the central access point to developmental services in the community, including: - residential supports - caregiver respite - Passport funding - day programs and community participation support (e.g., recreation, volunteering, employment or in-home supports) - professional and specialized services - person-directed planning Eligibility requirements include: - developmental disability (confirmed by a psychological assessment) - proof of age - proof of residence in Ontario The **Passport Program** is managed by DSO and provides funding for respite and support services. Speak with your DSO Case Coordinator for more details.	1) Review the DSO website to learn about the services available and eligibility criteria. Learn about this process when your child is 13 years old. 2) Contact your local DSO. It is best to **begin this process when youth is 15 and apply the day after the youth turns 16.** *Waitlists for intake assessment can be very long*. DSO requires documentation to confirm your child's eligibility. 3) If your youth has not already had one done, obtain a psychological assessment through your school board, hospital or privately. 4) If DSO determines you are eligible for services, they will book a Support Intensity Scale (SIS) assessment to determine your support needs. 5) Waitlists are prioritized by urgent needs. Contact DSO if there is a significant change in circumstances, such as a crisis or change in needs/illness, to ask for 'Urgent Response' service.	There are nine DSO agencies located across the province serving different counties and regions. Website to find your area local DSO: www.DSOntario.ca To contact by email or phone: https://www.dsontario.ca/about-us/contact-us

Organization	What they do	What I need to do	More Information
Ontario Disability Support Program (ODSP) **Is my youth eligible for this?** **Yes___** **No ___**	The Ontario Disability Support Program (ODSP) helps adults with disabilities who are in financial need pay for living expenses, such as food and housing. This is called Income Support. Those on Income Support may also qualify for extra funding for special diets, incontinence supplies, transportation to and from medical appointments, and some medical supplies. ODSP also has dental, vision and drug service benefits for eligible adults. ODSP may also assist with funding necessary items, such as commodes, bath chairs and ceiling lifts. Speak with an occupational therapist (you can get one through the HCCSS/local home care) and your ODSP worker for more information. ODSP also offers Employment Supports that help people with disabilities who can and want to work prepare for and find a job. **Please note:** If your youth is on Assistance for Children with Severe Disabilities Program (ACSD) they do not automatically qualify for ODSP. ACSD payments stop at age 18 and the ODSP application process must be complete to start receiving ODSP payments at age 18.	The ODSP application consists of two steps and should be initiated **six months <u>before</u> your youth's 18 birthday**: 1) Financial Assessment: start this application online or call your local ODSP office to book an appointment. 2) Disability Determination: If your youth is financially eligible, ODSP will provide you with a Disability Determination Package that must be filled out by a medical professional. Completed and signed forms must be received by the Disability Adjudication Unit (DAU) within 90 days of when you received them. The DAU reviews the application. This can take up to four months. The DAU's decision will be sent to you and the local ODSP office. If your youth is eligible, they will be assigned a case worker. You can go through an appeal process if they are deemed ineligible.	There are many ODSP offices throughout Ontario. To find your local office, go to: www.mcss.gov.on.ca/en/mcss/programs/social/odsp/contacts/index.aspx Website: www.mcss.gov.on.ca/en/mcss/programs/social/odsp/

Service	What they do	What I need to do	More Information
Health Care Connect **Will my youth need a new family doctor?** **Yes ___** **No ___**	Health Care Connect helps Ontarians find a family healthcare provider (family doctor or NP) who is accepting new patients. They can provide referrals to specialists, complete paperwork needed for 'proof of disability' and take care of basic healthcare needs (e.g., flu shots, regular checkups, etc.). It can also be used to change family healthcare providers. **Please Note:** If a family physician or NP is not available in your area/region, identify the most responsible healthcare provider/practitioner to assist with transition needs (e.g., in the Northern regions it may be nurses at the nursing station)	1) Make sure your youth has a valid health card, their address is up to date with Service Ontario and that they do not have a family doctor. If you are registered with a family doctor, you must call the doctor or Service Ontario to end your enrolment with them. 2) Join the program by registering online or by phone. You will be asked a short series of questions before being assigned a Care Connector, who will help you find a healthcare provider on your nearest Family Health Team or Community Health Team. 3) Speak with your healthcare team to determine future needs of medical professionals (such as, family doctor or NP at 18). **Begin this process when your youth is 13 years old.**	Register: by phone: 1-800-445-1822 Website: www.ontario.ca/healthcareconnect

Organization	What they do	What I need to do	More Information
Home and Community Care Support Services (HCCSS) **Will my youth require this?** **Yes ___** **No ___**	Home and Community Care Support Services (HCCSS) connects people with healthcare and support in their community. Professional case managers assess care needs and develop custom plans. Case managers will refer you to professional services to meet **at-home care needs, mainly nursing and personal support workers (PSWs).** Consultative services, such as physiotherapy, occupational therapy and social workers are also available. HCCSS coordinators manage the needs of children/youth and adults (age 18+) differently. If your youth is currently with HCCSS, they will be transferred to an adult case manager. *Family-Managed Home Care* is a self-directed program through HCCSS that provides eligible clients or their substitute decision maker to receive additional funding that they can use to purchase services or employ care providers. Your HCCSS care coordinator will remain responsible for developing care plans and monitoring outcomes. Connect with youth's team HCCSS care coordinator for more information.	1) Call your local HCCSS to make a referral for services. If a healthcare provider has already made the referral, the HCCSS Care Coordinator will call you once the referral is processed. **Begin this process when youth is 17 years old.** 2) You will be asked some questions to help the HCCSS better understand your needs. You will then either be connected with a Care Coordinator, and/or referred to the program or service that is right for you. If your child already receives HCCSS, contact your care coordinator to discuss services changes **before** the youth turns 18 and understand any differences if plan to receive both, HCCSS and Family-Managed Home Care (e.g., obtaining legal guardianship, etc.) .	HCCSS is available to eligible Ontario residents of any age and is funded by the Ministry of Health. Connect with your HCCSS Care Coordinator to begin the referral process before youth turns 18 years old or visit http://healthcareathome.ca/ to find local HCCSS (in some areas, young adult can be followed till age 30). **Note:** If HCCSS is not available in your region, identify local home care support services that is available in your community to begin this process.

	What it is	What I need to know	More Information
Substitute Decision-Maker **Will my youth require this?** **Yes__** **No __** ***Disclosure:*** *None of the information presented here is intended as legal advice and is for general education purposes. It is highly recommended that you consult with a lawyer to discuss decision making, capacity, legal guardianship or power of attorney conversations.*	The legal system in finance is different than in the healthcare system. As youth transition to the adult care system, it is important to have a good understanding of what is needed if you have to speak on their behalf and make decisions around their legal or financial matters. What is a *Substitute Decision-Maker (SDM)*? In Ontario, a SDM is someone who can make healthcare decisions on behalf of a patient when that patient is unable to make decisions for themselves (i.e., due to capacity). Everyone in Ontario has a SDM even if they have never prepared documentation appointing someone to act in that role (e.g., family members).	It is important to be aware that the *Substitute Decisions Act of Ontario* (SDA) states that if an adult person is found to be incapable and does not have powers of attorney or a legal guardianship appointment in place, the Ontario Public Guardian and Trustee (OPGT) then becomes the guardian of that disabled person. *Explore other options as OPGT does not apply to those whose permanent residence is on-reserve in Ontario (i.e., OPGT service will not be applicable).  Ontario's Health Care Consent Act, 1996	**Speak up Ontario** is a resource for learning about how the law works around healthcare decision-making, SDMs, healthcare consent, conversations and engaging in Advance Care Planning discussions: https://www.speakupontario.ca/resources-for-individuals-and-families/ **The Substitute Decision Maker Hierarchy** Healthcare providers must pick the highest ranked person (on the SDM Hierarchy chart at left). If you are a parent or relative, you are still able to make decisions on your adult child/youth's behalf in healthcare settings. https://www.speakupontario.ca/resource/the-substitute-decision-maker-hirearchy/

	What it is	What I need to know	More Information
Legal Guardianship **Will my youth require this?** **Yes__** **No __** ***Disclosure:*** *None of the information presented here is intended as legal advice and is for general education purposes. It is highly recommended that you consult with a lawyer to discuss decision making, capacity, legal guardianship or power of attorney.*	A guardian is an individual that is appointed by the court to make decisions concerning a disabled adult's: • medical concerns (guardianship of person); and/or • manage finances (guardianship of the estate) For example, Ontario Disability Support Program (ODSP) will allow a caregiver to act as a 'trustee' and Developmental Services Ontario (DSO) also *does not* require any formal legal paperwork to manage Passport Funding. **In many cases families do not need to pursue any kind of formal paperwork** (i.e., legal guardianship). They can use a joint bank account opened before the person turns 18 and manage funds through ODSP and DSO without any formal documentation. Other organizations or individualized funding programs (e.g., Family-Managed Home Care) *requires* legal guardianship for caregivers to manage finances on behalf of the person with disability/complexity. Signing a power of attorney form might not be an option for a young person with a significant intellectual disability. The person signing the forms must be considered 'mentally capable' of understanding the forms they are signing.	If you wish to be your youth's legal guardian after they turn 18 or if they are enrolled in individualized funding programs, **begin this process when the youth is 17.5 years old.** **Step 1:** At age 18, having OPGT appointed as a statutory guardian Family member asks a **qualified** capacity assessor to assess incapable person's capacity and see if OPGT would become statutory guardian of property. Find a list of capacity assessors here: https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacity/rosters/central.php The Capacity Assessment Office offers a Financial Assistance Program to cover the cost of an assessment in certain situations where an individual can't afford the fees. Applications for financial assistance can be obtained by contacting the Capacity Assessment Office at: 1-866-521-1033. **Step 2:** As a relative: apply as soon as possible to replace the OPGT as statutory guardian after the capacity assessment is completed by completing two forms: • Form 1: Application to replace the OPGT • Form 2: Management plan Information on how to apply is on the OPGT's website. https://www.ontario.ca/page/office-public-guardian-and-trustee	To find a lawyer: 1. Call toll-free number for Legal Aid at 1-800-668-8258. https://www.legalaid.on.ca/services/how-do-i-apply-for-legal-aid/ 2. You can also check with your local children's hospital for any pro-bono legal services or here: https://www.probonoontario.org/ 3. If your income is too high for Legal Aid, you can look on the 'professional services directory' of Partners for Planning (P4P), a non-profit organization that has lawyers recommended by other parents of children/youth with disabilities. https://www.planningnetwork.ca/en-ca/professional-services-directory

Service	What they do	What I need to do	More Information
Assistive Devices Program (ADP) **Will my youth require this?** **Yes___** **No ___**	ADP provides funding support to individuals with long-term physical disabilities who need equipment (e.g., mobility devices, orthotics; NOT bathroom equipment, home renovations, etc.). Equipment needs to be prescribed by an "ADP authorizer" (physiotherapist or occupational therapist). ADP may not cover the entire cost of equipment (typically up to 75% of the cost) and will only cover certain brands/types of equipment from authorized vendors.	1) Book an appointment with an authorizer for assessment. If you are not connected with an authorizer, ask your equipment vendor if they can help connect you. 2) Ask the authorizer about other funding sources. ODSP may assist with costs; check with your case worker to determine what is covered. You can also apply to charitable organizations for support. This can be completed when needed.	Website: for more information, and to see eligible items, visit: www.health.gov.on.ca/en/public/programs/adp/default.aspx Email: adp@ontario.ca
Disability Tax Credit **Is my youth eligible for this?** **Yes ___** **No __**	The Disability Tax Credit (DTC) is a non-refundable tax credit used to reduce the amount of income tax payable for eligible individuals. To be eligible, a person must have a "severe and prolonged mental or physical impairment". A qualified practitioner must fill out the paperwork. Visit the Canada Revenue Agency (CRA)'s website and click on the "Definition of Disability and List of Qualified Practitioners" to learn which practitioners qualify. A supporting person may be able to claim all or part of a dependent's Disability Tax Credit providing that both the supporting person and the dependent were residents of Canada during the tax year. This can be completed anytime online or mail.	1) Review eligibility criteria to determine if your youth qualifies. 2) Review the list of qualified practitioners. Book an appointment with a 'qualified practitioner' to have them fill out the Disability Tax Credit Application. 3) Download and print the Form T2201 for the qualified practitioner to fill out. Be sure to include any documentation about date of onset. If your youth had the disability in previous tax years, but you had not registered for DTC, you may be able to claim back money paid in taxes from these previous years. 4) Send the original signed form to CRA. Sending your form before you file your annual income tax and benefit return may help us assess your return faster.	Eligibility Criteria for Disability Tax Credit and more information websites: www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html canada.ca/disability-tax-credit or Call: 1-800-959-8281.

Service	What they do	What I need to do	More Information
Registered Disability Savings Plan (RDSP) **Do I want to do this?** **Yes ___** **No ___**	A Registered Disability Savings Plan (RDSP) is a federal tax-supported savings approach that encourages people to save for the future needs of a person with a disability. The Government may contribute Canada Disability Savings Grants of up to $3,500 a year, for up to 20 years, depending on the number of contributions made to the RDSP. The Government may also pay a Canada Disability Savings Bond of up to $1,000 a year, for up to 20 years, into the RDSPs of low-income and modest-income Canadians. No contributions are necessary to receive the bond. Earnings accumulate tax-free until money is taken out of the RDSP. People with disabilities must be 49 years old or younger to receive grants or bonds.	1) To be eligible for the Registered Disability Savings Plan, **your youth needs to first qualify for the Disability Tax Credit**. 2) Most banks provide RDSP programs. Ask at your local branch for more information. You may want to ask for a staff member who has had previous experience setting up an RDSP. Consult with other parents and/or adults with disabilities to find a financial advisor or bank employee with knowledge about RDSPs. This can be completed anytime. Setting this up *earlier* will be helpful even if youth may not reach retirement age. This allows families to access these funds penalty-free (e.g., for any equipment/home modifications, respite, etc.) for the youth/family if MD deems life expectancy to be limited.	Ministry of Children, Community and Social Services: www.mcss.gov.on.ca/en/mcss/programs/social/what/rdsp.asp x Canada Revenue Agency: - General summary*:* www.canada.ca/en/revenue-agency/services/tax/individuals/topics/registered-disability-savings-plan-rdsp.html Call the CRA's general enquiry line: 1-800-959-8281
Henson Trusts **Will my youth require this?** **Yes ___** **No ___**	A Henson Trust, also known as a discretionary trust, is structured to protect the assets of a person living with a disability, as well as their right to collect government benefits and entitlements such as those from ODSP.	It is important to consider the trustees you appoint. The Trustee is responsible for handling the assets that have been left in the trust for the youth. The Trustee(s) responsibilities can extend over a long period of time and end when the trust is terminated.	When setting up a Henson's Trust, you will want to consult a lawyer who has experience setting up this type of trust. Visit the Professional Services Directory for a list of lawyers at P4P - Planning Network. https://www.planningnetwork.ca/resources/henson-trust

Service	What they do	What I need to do	More Information
Respite Services **Will my youth require this?** **Yes __** **No __**	Respite is an occasional and temporary service providing support to families caring for a family member with a developmental and/or physical disability. It also provides support to the caregiver as the youth gets older. Respite Services links families and individuals to services in communities across Ontario. You may already have respite services before your youth turns 18 but it's important to consider what you and your youth will need once they have completed high school. For example, you may need to plan care for the hours that the youth was once in school. There are also opportunities to obtain some respite services through HCCSS.	1) Plan for your respite needs for when your youth is over 18. **Begin when your youth is 17 years old.** 2) Register by completing the "Online Family Registration" or print the forms and submit them by mail or fax. 3) Once your registration is received, the Respite Coordinator will contact you to confirm your request for in-home support. You can then use the Support Worker CHAP Program to select a Support Worker based on your family's needs and the worker's availability and skills.	Website: respiteservices.com Email: info@respiteservices.com **Please Note:** If respite services are not available in your region, explore respite options (e.g., with social worker or DSO contact) for this support as it will vary in remote communities (e.g., connect youth to day programs in DSO Passport Program).

	What it is	What I need to do	More Information
Transitioning into the School System and/or High School **Will my youth require this?** **Yes___** **No ___**	For a YMC, there are additional concerns about accessibility, having access to different therapies, or whether child will get the assistance they need to be successful in the classroom. Good transition planning and open communication are key to successful transition into school.	Consider discussing these questions with your local school or school board personnel when thinking about starting school or high school: ○ What are my child's needs and what supports they might need? • What resources or supports will my child get? • What can I do to get my child ready for a new school? • Is there a formal intake process when my child goes to school? • How much do I have to tell the school about my child's special needs? • Will my child have a full-time assistant to help in class? • What if my child is not toilet trained? • Who will I speak to if I have questions regarding my child's health concern? • Who do I go to for help with schooling? • Does the school have Health Support Services and how do I access it? • Who should I get to know to help advocate for my child at school? Ask questions if not familiar with the following terminology: 1. IPRC (Identification, Placement and Review Committee) 2. IEP (Individualized Educational Plan) 3. Psychological assessment 4. SEAC (Special Education Advisory Committee)	Therapies in school are accessed through Home and Community Care Support Services and Children's Treatment Centres or with private contact with Education Authorities. **Special Education Legislation Act and other information:** http://www.edu.gov.on.ca/eng/parents/speced.html

Organization	What they do	What I need to do	More Information
March of Dimes Home and Vehicle Modification Program **Will my youth require this?** **Yes___** **No ___**	The March of Dimes Home & Vehicle Modification Program provides funding for basic home and/or vehicle modifications. The program assists permanent Ontario residents with substantial impairments that are expected to last for a year or more. By reducing or addressing life safety risks, these modifications enable children, youth and adults with mobility restrictions to continue living in their homes, avoid job loss and participate in their communities. The applicant must have a substantial ongoing impairment that impedes mobility and participation in activities of daily living (e.g., personal care, community functioning). Applicants who meet program criteria can apply for grant funding: • Up to $15,000 lifetime maximum for home modifications; used before 18 years old then funds for home modifications are maxed out. • Up to $15,000 every ten years for vehicle modifications; you are responsible for purchase of the vehicle and ensuring it is relatively new and in good shape.	The application is a two-step process: 1) First part of application, the Applicant Assessment, can be found online and asks the applicant a variety of questions about their abilities and income to identify individuals in the greatest need. 2) If the stage one application is approved, you will be notified in writing and sent the stage two application – the Modification Proposal. You can appeal applications that are denied. 3) The stage two application requires supporting documentation, including two competitive vendor quotes, a completed Verification of Disability form, proof of residency and home or vehicle ownership, and proof of income. This is completed as needed.	Phone: 1-877-369-4867 Fax: 519-432-4923 Email: hvmp@marchofdimes.ca Website: www.marchofdimes.ca/EN/programs/hvmp/Pages/HomeandVehicle.aspx

Organization	What they do	What I need to do	More Information
March of Dimes Assistive Devices Program **Will my youth require this?** **Yes____** **No ____**	The March of Dimes Assistive Devices Program (different from the Ministry of Health Assistive Devices Program) can help you buy, repair and maintain a wide variety of mobility or assistive equipment (including wheelchairs). The program may also help you find alternate funding sources in your area. Funding is provided for devices that: • help adults live safely and independently in their homes; • allow for discharge from a hospital or rehabilitation center; • help avoid job loss; and • support opportunities for participation in educational, developmental and community activities.	1) To be eligible, the applicant must have an ongoing physical limitation that requires the use of an assistive device, be in financial need, be 19 years of age or older and be a permanent Ontario resident. 2) Complete and submit the application along with supporting documentation including: • A price quote from an equipment vendor • A letter of assessment/support from an Occupational Therapist • Income information (Notice of Assessment for the previous tax year) This is completed as needed.	Phone: 519-642-3700 or 1-866-765-7237 Fax for completed applications: 519-432-4923 Email: adp@marchofdimes.ca Website: www.marchofdimes.ca/EN/programs/adp/Pages/Adp.aspx

FAQ

1. Where can I get a psychological assessment completed for my youth?
   - Speak with your youth's school Principal or Special Education Resource Teacher (SERT) and request a referral to school board's Psychology Services.
   - Speak with a clinician at your tertiary hospital and request the assessment.
   - Private assessments are also available, and are usually faster, for approximately $2,000. These can be completed by a certified psychologist. (A member from complex care team can help find funding sources for psychological assessment).

2. How current does the psychological assessment have to be?
   - This depends on level of functioning and age of onset of health complexities; contact Developmental Services Ontario for guidance.

3. How do I know if my youth is eligible for Developmental Services Ontario?
   - You can review more information at https://www.dsotoronto.ca/access-services/eligibility-for- developmental-services-and-supports/

4. Will my youth continue to receive Special Services at Home (SSAH) respite funding after they turn 18 years old?
   - No. SSAH funding ends when your youth turns 18. If your youth is eligible for DSO, they may also be eligible for the Passport Program, which provides funding for respite and support for adults with developmental disabilities.

5. Will the funding for the Passport Program begin as soon as my youth turns 18?
   - Not necessarily. You may be on a waitlist to receive the funding. Be sure to emphasize your youth's needs to your DSO case coordinator to ensure they are aware.
   - Because the funding may not begin at 18 years of age, consider planning for the financial impact this could have. For example, if your youth is no longer attending school and will require support during the day, you may have to pay out-of-pocket for care until you start receiving Passport funding.

6. Is everyone eligible for funding with the Passport Program?
   - No. Only people who are eligible for DSO can receive this funding.

7. Will I continue to receive Assistance for Children with Severe Disabilities (ACSD) funding once my youth turns 18?
   - No. This funding ends at 18.
   - Your youth, or you on behalf of your youth, can apply to the **Ontario Disability Support Program (ODSP)** when they are 17.5 years old.

8. Do I still have to apply to ODSP if my youth is eligible for DSO?
    - Yes. They are two separate agencies.
    - If your youth is eligible for DSO, you can provide the letter of eligibility to ODSP, and this will decrease the amount of paperwork required.

9. When applying to ODSP, do they look at parents' income to determine eligibility?
    - No. They only consider your youth's income, assets, etc.

10. Would a Henson Trusts, RDSP and/or RESP, etc. for my youth make them ineligible for ODSP?
    - It's best to review the ODSP website or speak with a representative to determine which assets will impact eligibility. You can also speak with a financial planner to determine the best plan for saving for your youth's future.
    - It's a good idea to open a joint bank account with your youth in preparation of them receiving ODSP.
    - When saving money for your child's future, consider keeping accounts, trusts, etc. in your name if it will impact your youth's eligibility for ODSP.

11. Will my youth need to find a new family doctor once they turn 18?
    - If your youth sees a paediatrician, **they will need a family doctor for when they are an adult.** Speak with your care team to determine the need.
    - If youth also see specialists, speak with the specialists about what happens when your youth is over 18.

Source: Information in the *Transition Resource Guide* has been modified and adapted from the *Grandview Kids - Transition Guide to Adult Supports and Services*.

Following clinicians developed the *Grandview Kids - Transition Guide to Adult Supports and Services:*

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- Brittany Thordarson, MScOT, OT Reg. (Ont.) - now at Toronto Rehabilitation Institute Lyndhurst Centre
- Mandy Doherty, MSW RSW

Additional Resources

Community Support Services

211 Ontario
Free referral service to find information on community and social government services.
Certified Referral Specialists can link you to an appropriate provider if there is an immediate need
Phone: 2-1-1; *Email:* officeadmin@211ontario.ca; *website:* www.211ontario.ca

Community Networks of Specialized Care
Information on specialized service systems across healthcare sectors that support adults with developmental disabilities with high support and complex care needs (through DSO)
http://www.community-networks.ca/

Accessible and Specialized Transportation Services
https://aoda.ca/specialized-transportation-in-ontario/
http://www.mto.gov.on.ca/english/transit/municipal-transit-systems-in-ontario.shtml

Funding Support

Ceridian Cares
Provides financial assistance to families that require support
https://www.ceridiancares.ca/evaluation

Children's Wish Organizations
Helpful when looking to fulfil youth's/families' wishes (e.g., family portraits, re-doing rooms, etc.)
Websites: www.sunshine.ca; https://makeawish.ca; https://www.acvf.ca/;
https://starlightcovidsupport.org/

Easter Seals Ontario
Services and funding support for children/youth and their families
https://www.easterseals.org/

Jordan's Principle
Responds to unmet needs of First Nations children no matter where they live in Canada
https://www.sac-isc.gc.ca/eng/1568396042341/1568396159824
https://www.afn.ca/uploads/Social_Development/Jordan%27s%20Principle%20Handbook%202019_en.pdf

Muscular Dystrophy Canada
Helps clients obtain assistive devices to help with activities of daily living
www.muscle.ca

Non-Insured Health Benefits (NIHB)
Provides coverage for a wide variety of health benefits for eligible First Nations and Inuit clients
https://www.sac-isc.gc.ca/eng/1576790320164/1576790364553

Ontario Federation for Cerebral Palsy (OFCP)
Funding assistance for OFCP members
www.ofcp.ca/funding.php

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

Acknowledgements

The Provincial Council for Maternal and Child Health (PCMCH) would like to thank the CCKO Youth Transition to Adult Care Toolkit Working Group for their contributions and support in the development of this resource, as well as the CCKO Leadership Table, Clinical Institutes and Quality Programs Team at Ontario Health and other stakeholders for their review and feedback on this work.

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Appendix A: CCKO Standard Operational Definition

Standard Operational Definition for Children with Medical Complexity

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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	☐ 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 *For example:* *tracheostomy tube care, artificial airway, suctioning, oxygen support, or tube feeding*	☐ Child has prolonged dependence on medical devices to compensate for vital bodily functions, and requires daily/near daily nursing care *For example:* *cardiorespiratory monitors;* *renal dialysis due to kidney failure*	☐ Child has any chronic condition that requires great level of care such as: • 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	☐ The child has severe and/or life-threatening condition	☐ Lack of availability and/or failure of equipment, technology, or treatment places the child at immediate risk resulting in a negative health outcome	☐ Short-term changes in the child's health status puts them at immediate serious health risk *For example:* *an intercurrent illness*	☐ 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 ☐ Likely to experience exacerbation of chronic condition necessitating assessment by a healthcare provider in a timely manner
CHRONICITY	☐ The child's condition is expected to last at least six more months	☐ The child's life expectancy is less than six months		
COMPLEXITY	☐ Involvement of at least five healthcare practitioners/ teams and healthcare services are delivered in at least three of the following locations: • Home, School/ Nursing school • Hospital, • Children's Treatment Centre, • Community-based clinic (e.g. doctor's office) • Other (at clinician's discretion)	☐ The family circumstances impede their ability to provide day-to-day care or decision making for a child with medical complexity *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*		
GEOGRAPHY	☐ 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			

January 2019