

# **TRANSITION TO ADULT HEALTH CARE**

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Shared Learning Forum

# Presenter & Authors



**Nice to  
Meet you**



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# **Disclosure of Financial Support & Presenter Disclosure**

- ▶ No external support
- ▶ No conflict of interest to declare
- ▶ No relationships to disclose

# Learning Outcomes

Participants will be able to:

- ▶ Discuss higher prevalence issues for Transition-Age Youth with IDD.
  
- ▶ Understand approaches and opportunities for promoting decision-making capabilities in supporting persons with intellectual/developmental disabilities' (IDD) transitioning from pediatric to adult health care.
  
- ▶ Consider examples of tools for optimizing transition support:
  - SHARE Transition Plan tool
  - My Hospital Form
  - New DD Primary Care Program Mental Health tools



# What words come to mind when thinking about transition concerns for youth with IDD?



focus. bold  
creative  
leader  
fast transpiration  
inspiration



# HEALTHCARE TRANSITION



## H·CARD D *snapshot*

**Study examines health and health service use of young adults with Autism and Developmental Disabilities**



### What you need to know

Young adults with developmental disabilities are more likely to have poorer overall health, have at least one psychiatric diagnosis and have higher health service use than young adults without developmental disabilities.

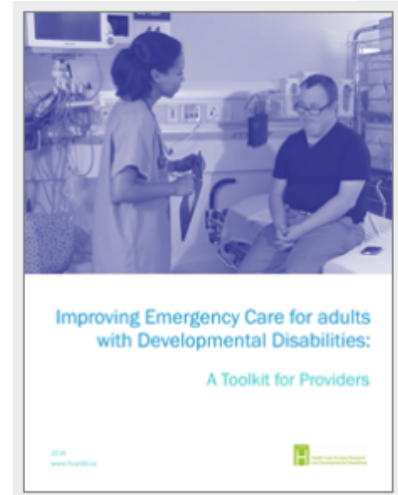
# Video H-CARDD Transition Age Youth Project



<https://www.youtube.com/watch?v=4Yki-9Wqlo&t=2s>

# Healthcare Transition Issues

- Mental health supports - challenging to access (HCARDD, 2018)
- Primary care (Family Physicians/NPs) – shortage in Ontario (OMA, 2024)
- Emergency Dept. experience – challenges with communication with providers, challenging environment (HCARDD, 2016)
- Transfer to adult health care subspecialists and coordination – one pediatric hospital versus fractured across multiple adult teams (CCKO, 2022)
- Reasonable accommodations – e.g., sedation for procedures, more time, etc., (DDPCP, 2018)



# Improving Healthcare Experiences

## Tools for People living with IDD

- ▶ [About Me\\*](#) ([Large Print](#)),
- ▶ [Exit Interview\\*](#) ([Large Print](#)),
- ▶ [Going to the ED: A Social Story](#),
- ▶ [Getting a Blood Test: A Social Story](#),
- ▶ [Getting More Money\\*](#) ([Large Print](#)),
- ▶ [Going to the ED: Videos for Patients](#),
- ▶ [Crisis Prevention and Management](#)

**About Me:**  
**My Health Information**

Health Care Access Research  
and Developmental Disabilities

**My Information:**

My name: \_\_\_\_\_

My birthday: Month \_\_\_\_\_ Day \_\_\_\_\_ Year \_\_\_\_\_

My address: \_\_\_\_\_

My phone number: \_\_\_\_\_

**Other Information:**

I receive ODSP: yes \_\_\_ no \_\_\_ *For Staff: If yes, list of medications available in Drug Profile Viewer*

I live (choose one): in my own house/apt \_\_\_ with family \_\_\_ group home \_\_\_

**Who to call for help:**

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

Relationship to me: \_\_\_\_\_

# Tools for Providers

## Examples:

- DDPCP Healthcare Transfer Tool – to identify and plan with respect to gaps in healthcare
- [CCKO Transition checklist and toolkit](https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/09/2.5-TAY-Transition-Transfer-Tool.pdf) – very comprehensive timeline, checklists, resource guide on planning transition.

**Healthcare Transfer Tool:**  
*Planning a transfer from paediatric to adult care for young people with intellectual and developmental disabilities*

Surrey Place Developmental Disabilities Primary Care Program

Patient Name: First: Last: DOB:

**A Review patients needs** Review sections below to help identify services and providers to be included in transfer plan and information relevant to include in referrals. Potential services and/or needed professionals are italicized.

**Intellectual and Developmental Disability**

**Confirmed diagnoses, psychological assessment available**

- Mild intellectual disability
- Moderate intellectual disability
- Severe intellectual disability

Profound intellectual disability

Autism spectrum disorder

Other: \_\_\_\_\_

**Psychological assessment needed**

- For eligibility for services
- To clarify diagnosis
- Other: \_\_\_\_\_

**Adaptive Functioning**

Patient is independent in ADLs and IADLs

Independent in ADLs but requires support for instrumental activities of daily living IADLS (eg, finances, scheduling, shopping)

Need help (prompting) for some ADLS

Needs help with all activities of daily living (ADLS) (dressing, bathing, eating, toileting)

**Need for community services/supports** (respite, home care, etc.):

**Notes:** \_\_\_\_\_

**Services, Supports and Funding**

Application for adult social services and income supports initiated (eg, in Ontario, Ontario Disability Support Program and Developmental Services Ontario)  Yes  No  Unsure

Notes (eligibility, intake, waitlists, service needed etc.): \_\_\_\_\_

**Communication**

Patient first language: \_\_\_\_\_  Uses a device, board or method other  **Translator needed**

<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/09/2.5-TAY-Transition-Transfer-Tool.pdf>

[https://  
ddprimarycare.surreyplace.ca/  
tools-2/mental-health](https://ddprimarycare.surreyplace.ca/tools-2/mental-health)

# New DD Primary Care Program Mental Health Toolkit

## My Coping Tool: How I Deal With Stress

Name: \_\_\_\_\_

Date: \_\_\_\_\_



### Part 1: About me when I am feeling good, like my usual self

Do this at home with someone who knows you well. Bring PART 1 to your doctor's office when you do PART 2 and 3.

You can attach pictures, draw or write your answers.

Things I like doing

People I like seeing

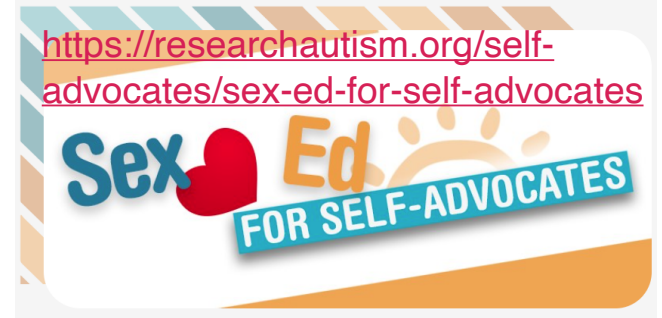
Places I like going

Things I say or do

Things that make me feel  
stressed, angry or upset



# Sexual Health



- ▶ Need for accessible, comprehensive sexual health education
- ▶ People living with IDD may experience:
  - Greater risk of sexually transmitted infections
  - Higher rates of sexual abuse
  - Decreased sexual health knowledge

(Schmidt et al., 2020)

## How to talk about sexuality

Sexuality is often associated with sexual activity, but parents and caregivers can have meaningful conversations with their children without focusing on sex. These conversations can enhance your child's confidence, self-awareness and personal safety.

**Talk about the body.** Teach your child the medical terms for their anatomy early on. Teach them the difference between public and private body parts and behaviours. This can help them understand what kind of touching is and is not appropriate, which can help them respect other people's boundaries and feel empowered to speak up if their own are crossed.

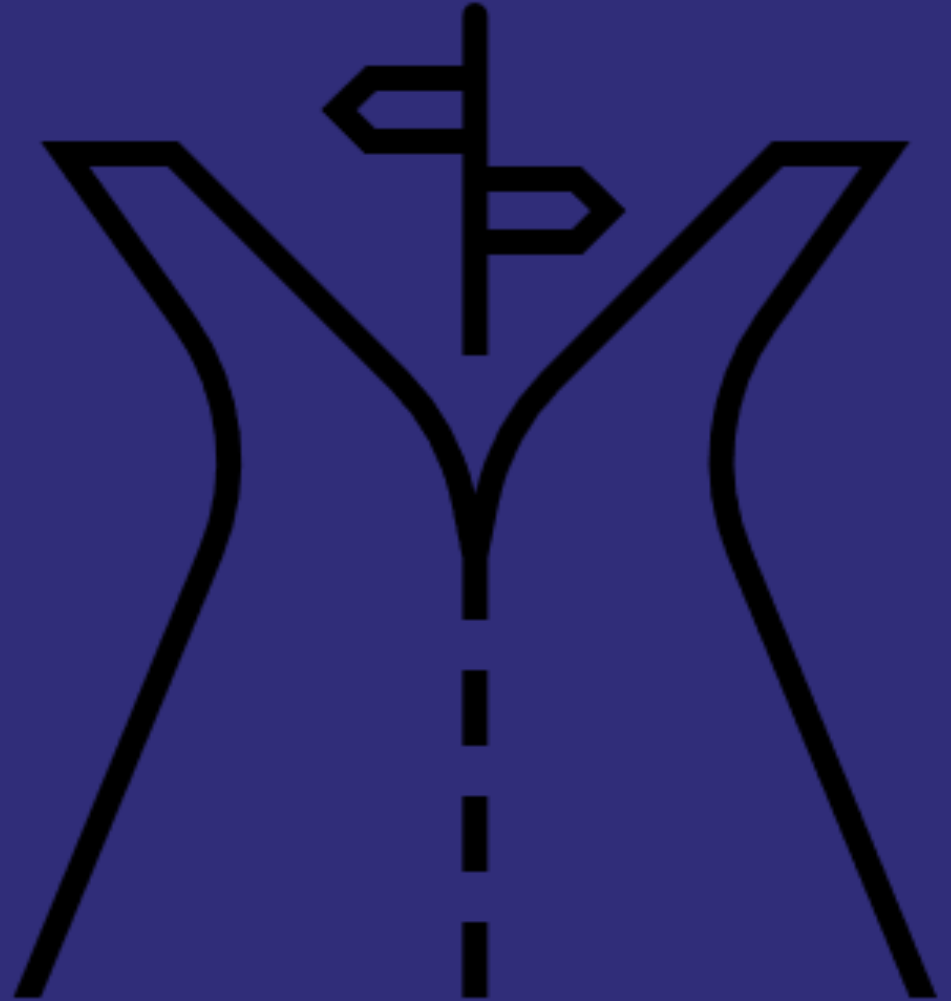
**Model consent.** Don't force your child to hug everyone and teach them to check in with people before touching them. At medical check-ups, involve your child by asking the doctor to explain what the appointment is about, and what parts of your child's body will be examined.

## Meet them where they're at

## Bridging to Adulthood Tips: Sexual Health Resources for Young Adults with Disabilities

- [About Health Teens](#) – Fact based sexual health information from Sick Kids hospital.
- [Disability Sexuality Consent](#) – Resources from Community Living Toronto. Includes a video recorded panel discussion about disability, sexuality and consent. Also, scroll to the bottom of the page for further practical resources and books.
- [Kerry's Place Sexuality Consultation](#) – consultation for parents and caregivers of people with autism who want to learn how to discuss sexuality with their child.
- [Let's Talk About Sex](#) – information and resources from Spinal Cord Injury
- [Let's Talk About Sex: A Resource for Parents](#) – published by Muscular Dystrophy Canada
- [Let's Talk Disability and Sex](#) – An event hosted by Bloorview Research Institute. Video recorded talks, transcripts and art projects are available online.
- [Pace Independent Living](#) – an example of an attendant service provider in Toronto where attendant staff have training in providing assistance with daily activities that can support a person's sexual expression (e.g. assistance with shopping for sexual materials, dressing, using

# DECISION MAKING CAPABILITIES



# Promoting Decision Making Capabilities

Legally capable	Substituted
<p><b>Independent</b> Capable themselves of making a decision</p>	<p><b>Interdependent</b> Capable with decision-maker's support/help</p> <p><b>Not Capable-</b> <b>Needs Substitute</b> <b>Decision Maker</b> <b>Unable, even with supports</b> <b>to make and communicate</b> <b>the decision</b></p>

# Questions Around Capacity

## Healthcare

- ▶ Who is the Substitute Decision Maker?
- ▶ Can a parent be 'kicked out' of an appointment?
- ▶ What if someone refuses a procedure or intervention?
- ▶ Do people need a power of attorney?

## Financial


- ▶ Who gets to control ODSP funding – parent or client?
- ▶ Who gets to control Passport Funding?
- ▶ Who do we call for suspected abuse neglect of finances?
- ▶ Do people need guardianship?

# Healthcare: Substitute Decision Making

## Key Points to Remember

- ▶ **Capacity** – Person understand nature of the decision and implications of treatment decision.
- ▶ **Privacy Vs Right to Support**
- ▶ **Role of developmental sector** – often help with communication of information, support of all parties. Paid supporters cannot be SDMs.

## Substitute Decision Maker



Court Appointed Guardian	Legally Appointed SDMs
Attorney for Personal Care	
Representative Appointed by Consent and Capacity Board	
Spouse or Partner	Automatic Family Member SDMs
Parents or Children	
Parent with right of access only	
Siblings	
Any other relatives	
Public Guardian and Trustee	SDM of last resort

Ontario's Health Care Consent Act, 1996



# Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities:

## *Promoting Capabilities*

### Introduction

This tool guides primary care providers in assessing and promoting the decision-making capabilities of adults with intellectual and developmental disabilities (IDD). It promotes health care decision-making capabilities in the context of the patient's relationships. The tool encourages those who are seeking patient consent to always accommodate patient needs and, if necessary, to involve decision-making supporters. Various formal supported decision-making arrangements are legally recognized in Canada, such as in British Columbia, Alberta, Manitoba, and The Yukon. Elsewhere, a supported decision-making approach can still be incorporated by the patient's substitute decision maker.

### How to use this tool

**KNOW YOUR PATIENT:** Prior to the health care visit, identify your patient's vulnerabilities and support needs as they relate to decision making. This could be based on information collected by office staff.<sup>[i,ii]</sup>

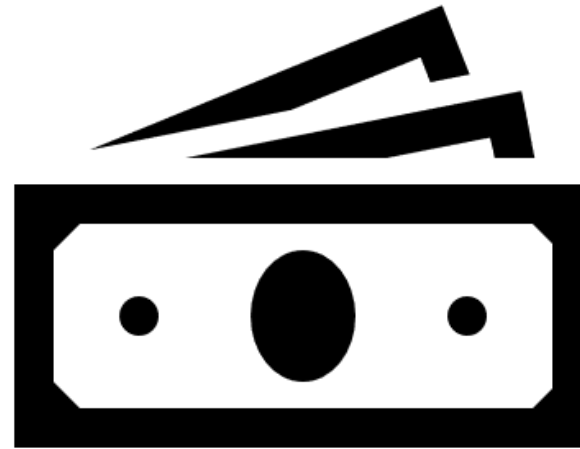
**ACCOMMODATE NEEDS:** Determine how best to accommodate your patient's needs at the beginning of each patient-provider encounter. These are changes to how services are normally delivered to be accessible for a person with a disability (e.g., more time, preferred ways of communicating, quiet environment).<sup>[iii]</sup>

**ASSESS WHETHER TO INVOLVE DECISION-MAKING SUPPORTERS:** This tool provides example questions to determine whether an independent, inter-dependent or dependent decision-making approach should be used with the patient for making the decision at hand (see table 1).



# Financial – Decision Making

- Setting up a bank account.
- ODSP – Trusteeship
- Passport Funding – Person Managing Funds
- Guardianship and Power of Attorney – what is the difference?



# Resources and Support

- ▶ [Partners for Planning](#)
- ▶ [Partners for Planning - Safe and Secure](#) - eBook
- ▶ Legal Aid Supports
  - [ARCH](#) – person must be able to direct, can assist with POA
  - ProBono Partnerships – through hospitals, CHCs and Family Health Teams
  - [Legal Clinics – Legal Aid Ontario](#)



# SHARE TRANSITION PLAN



# SHARE TRANSITION PLAN

## SHARE Transition Plan

Talking about transition with young people with IDD and their families

Surrey Place Developmental Disabilities Primary Care Program

<b>Patient Name</b>		<b>DOB:</b>
First	Last	
<b>Caregiver Name</b>		
First	Last	
<b>Transition visit</b>		
Visit 1:	Visit 2:	Visit 3:
<b>A Open conversation:</b> Ask the young person and their family what they feel are important topics to talk about in planning for adulthood (5 minutes). If they completed the SHARE Checklist®, review answers and highlight priorities.		
<b>Notes</b>		
<b>B Guided conversation:</b> Review the SHARE areas for planning the transition to adulthood. Explore SHARE items based on priorities and time available. You can come back to this list at any time. Use the check boxes to keep track of which items you discussed and which actions were taken.		

- ▶ Supports for Communication and Capability
- ▶ Healthcare Transition and Transfer
- ▶ Activities and Engagement
- ▶ Relationships and Wellbeing
- ▶ Exploring Services and Supports
  - DSO
  - ODSP
  - Local programs

# Relationships and Wellbeing

## Assessment Questions

- ▶ Who do you live with?
- ▶ Who are important people in your life?
- ▶ Are you lonely, bored? Privacy?
- ▶ Any issues with bullying or isolation?
- ▶ Any need for sexual health education or support in understanding sexuality?
- ▶ If a person has support needs, ask about mental health and physical health of the caregiver.

## Goals of Intervention

- ▶ Might identify goals such as:
  - Social skills training support
  - Need for more opportunities for social encounters
  - Caregiver support group/counselling
  - Crisis supports/crisis planning
  - Sexual health education support needs

# SHARE TRANSITION PLAN

- ▶ Start with open ended conversation with client, caregivers and providers.
- ▶ Overall vision for future – fears, hopes and dreams.
- ▶ Specific issues - decision making, healthcare, community participation, funding, etc.
- ▶ Helps identify priorities.



# Resources – How do you learn?

- ▶ **Direct Experience** – ask for tours, go and meet with intake workers, network with service providers, DSO fairs, etc.
- ▶ **Peers** – Phone a friend. DSO, Respite Services staff, colleagues.
- ▶ **Resource Lists:**
  - [Toronto Community Resource List \(pdpresources.blogspot.com\)](http://pdpresources.blogspot.com)
  - [MyCommunityHub - MyCommunityHub](#)
  - [respiteservices.com - Resources](http://respiteservices.com) - respite guide, camp guide, staffing agency list
- ▶ **Toolkits and Guides**
  - [CCKO-Youth-Transition-Caregiver\\_Youth-Checklist\\_-Final\\_Feb222022-Fillable.pdf \(pcmch.on.ca\)](#)

# Resources By Category

## ▶ **Healthcare**

- [HCARRD](#)
- [DDPCP \(surreyplace.ca\)](#)

## ▶ **Activities, Recreation and Respite**

- [Respiteservices.com](#)
- [Connectability](#)
- [Toronto Community Resource List \(pdpresources.blogspot.com\)](#)

## ▶ **Sexual Health and Education**

- [Toronto Public Health: Sexual Health Lesson Plans](#)
- [Relationship Group - Montage Support Services - Great 'grey' paper powerpoint,](#)
- [Sexuality and developmental disability: a guide for parents | Child and Parent Research Institute \(CPRI\) Sexual Behaviours Team recommended resources | ontario.ca](#)

## ▶ **Financial and Legal**

- [Partners for Planning - www.partnersforplanning.ca](#)
- [Identifying Your Substitute Decision-Maker \(SDM\) in Ontario | Advance Care Planning Ontario](#)
- [Office of the Public Guardian and Trustee | ontario.ca](#)

## ▶ **Government Funded Services and Supports**

- [Developmental Services Ontario](#)
- [Ontario Disability Support Program](#)





# Open Discussion

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