

DDPCI Transition readiness checklist and transition toolkit

Developmental Disabilities Primary Care Initiative (DDPCI)
Transition Working Group

Dr. Ullanda Niel, Family Physician Practicing in Developmental Disabilities
Jessica Wood, PhD student, Surrey Place Centre
Maureen Kelly, Nursing, Surrey Place Centre
Dr. William F. Sullivan, Family Physician, Clinical Director & Chair of DDPCI

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Transition vs Transfer

Transition	Transfer
<ul style="list-style-type: none"> Occurs over time Purposeful planned movement of youth from child-centered to adult-centered care 	<ul style="list-style-type: none"> One-time event Responsibility of care moves from child-centered to adult –centered provider

Transition Readiness Checklist

- A questionnaire that assesses the health care skills of the youth with developmental disabilities (DD) and their caregivers.
- The youth and primary caregiver should complete the questionnaire together.
- The tool looks at four different health skill areas:
 - Knowledge of Health Condition(s), Medication and Treatment
 - Taking Charge of Health Condition(s), Medication and Treatment
 - Taking Charge at the Doctor's Office
 - Daily Living Skills and Thinking About the Future

Transition Readiness Checklist

DDPCI – Transition Readiness Checklist

Name: _____ DOB: (dd/mm/yyyy): _____

	Yes, I do this	I am learning how to do this	I need to learn how	I need someone to help me do this – who?	Does not apply to me
Knowledge of Health Condition(s), Medication and Treatment					
1. I can explain my health problems/ disability					
2. I can name my medications and treatments and I can tell others what they are for.					
<i>Health Knowledge: Discussion and plan (consider both the youth and their caregiver).</i>					

DDPCI – Transition Readiness Checklist

Name: _____ DOB: (dd/mm/yyyy): _____

	Yes, I do this	I am learning how to do this	I need to learn how	I need someone to help me do this – who?	Does not apply to me
Taking Charge of Health Condition(s), Medication and Treatment					
3. I am ready to make decisions about my health.					
4. If I get sick, I know who to call or how to get help.					
5. I know what to do if I have a medical emergency.					
6. I keep track of my doctor and dental appointments					
7. I keep my important health information.					
8. I take my own medications.					
9. I know how much I should take of each medication.					
10. I know what to do if I miss a dose of medication.					
11. I know the side effects of my medication(s) and what to do if I have these side effects.					
12. I call in my medication refills					
13. I know how my medications and treatments are paid for.					
14. I take care of my treatments (asthma treatments, C-rube care, CPAP machine, catheterization).					
15. I take care of my medical equipment and supplies (e.g. wheelchair).					
<i>Taking Charge of Health: Discussion and Plan (consider both the youth and their caregiver).</i>					

Transition Readiness Checklist

DDPCI – Transition Readiness Checklist

Name: _____ DOB: (dd/mm/yyyy): _____

	Yes, I do this	I am learning how to do this	I need to learn how	I need someone to help me do this – who?	Does not apply to me
Taking Charge at the Doctor's Office					
16. I carry my health card in my wallet and bring important health information with me to doctor's appointments/the emergency department (e.g., Health Passport or Emergency Record).			X		
17. I know the names of my doctors and other health care providers.		X			
18. I call to book my own health care appointments.		X			
19. Before each doctor's appointment, I make a list of questions I want to ask.		X			
20. I can tell my doctor what I need during health care visits.		X			
21. I spend time alone with my doctor at each visit.	X				
22. I know I can talk to my doctor about sex and relationships.		X			
Taking Charge: Doctor's Office: Discussion and Plan					
Mum carries all the patient's health information- They are considering putting in is backpack, Medic Alert Bracelet (or equivalent), Portable Patient Profile					
Mum knows all the specialist doctor's names but doesn't have a list. Pt knows a few of the doctor's names - Complete Health Providers and Specialist List					
Pt has never called to book a doctor's appointment- Appointment Scheduler Tool					

Transition Toolkit

- Builds on the Transition Readiness Checklist
- Explains the skills needed in each area of readiness
- Suggests tools that will help the person with DD and their caregivers to achieve each skill.

Creating The Transition Toolkit

Using the Transition Readiness Checklist

DDPCI – Transition Readiness Checklist

	Yes, I do this	I am learning how to do this	I need to learn how	I need someone to help me do this – who?	Does not apply to me
Taking Charge at the Doctor's Office					
16. I carry my health card in my wallet and bring important health information with me to doctor's appointments/the emergency department (e.g., Health Passport or Emergency Record).			X		
17. I know the names of my doctors and other health care providers.		X			
18. I call to book my own health care appointments.			X		
19. Before each doctor's appointment, I make a list of questions I want to ask.			X		
20. I can tell my doctor what I need during health care visits.		X			
21. I spend time alone with my doctor at each visit.		X			
22. I know I can talk to my doctor about sex and relationships.		X			

Taking Charge-Doctor's Office: Discussion and Plan
Mum carries all the patient's health information- They are considering putting in is backpack, Medic Alert Bracelet (or equivalent), Portable Patient Profile

Using The Transition Toolkit

Tools marked are designed for youth with developmental disabilities (and are useful for caregivers, too!)
 Tools marked are designed for caregivers.

The Transition Skills and Resources Toolkit

<p>16. I carry my health card in my wallet and bring important health information with me to doctor's appointments/the emergency department (e.g., Portable Health Record, Health Passport or Emergency Information Form).</p>	<ul style="list-style-type: none"> Keeps a portable health record and brings this to health care appointments and emergency department and shares it with health care team members. Recognizes that a health card is required and brings it to clinical appointments. If appropriate, has a Medic-Alert bracelet or necklace. 	<p>Available online:</p> <ul style="list-style-type: none"> Portable Patient Profile, Sunny Place Centre, DDPCI www.sunnyplace.ca/Primary-Care/Pages/Tools-for-caregivers.aspx My Health Passport, Hospital for Sick Children, www.sickkids.ca/GoodFor/Transition-Interventions-Tools/MyHealth-Passport/index.html Emergency Information Form, American Academy of Pediatrics, http://www.2asp.org/af/ocacyblankform.pdf Medic-Alert – bracelet or necklace, www.medic-alert.ca/en/index.asp
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Examples of Tools

Portable Patient Profile – My Health Information

I will fill out this form and carry it with me to health care appointments. I will keep this form up to date, with help from my doctor and family or caregiver, and will make sure the information is correct. Information completed (add new/xxx):

Name: _____ DOB: (dd/mm/yyyy) _____
 Address: _____ City/Town: _____
 Postal Code: _____ Home Phone: _____ Cell/Work Phone: _____
 Other Health Insurance: _____

Main Health Problems or Diagnoses: _____

Developmental Disability: Cause, if known: _____
Level of adaptive functioning: Mild Moderate Severe Profound
 _____ health and medical information with my doctor.

Major Surgeries and Hospitalizations:

Where?	Why?	Year:
_____	_____	_____
Where?	Why?	Year:
_____	_____	_____
Where?	Why?	Year:
_____	_____	_____

Allergies (include medicine, food, environment, contact or other. Also describe what happens.):

- _____ What happens: _____ Year: _____
- _____ What happens: _____ Year: _____
- _____ What happens: _____ Year: _____

What I am attaching to this form:

<input type="checkbox"/> List of my current medications	<input type="checkbox"/> Latest lab results
<input type="checkbox"/> List of latest immunizations	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Other: _____	<input type="checkbox"/> Latest lab results
<input type="checkbox"/> Other: _____	<input type="checkbox"/> Other: _____

Special Care Needs

My main language is: _____
 If not English, do I understand English? Yes No Speak English? Yes No
 I communicate with: words sentences gestures sign language pictures other: _____
 I understand and learn best by: simple explanations written words pictures
 sign language other: _____

I have problems with:

- vision
- hearing
- movement/mobility

I use the following medical equipment and/or mobility equipment:

Things that may make me anxious or upset me in medical appointments (e.g., medical exams, blood work, needles, noise, lighting, smells, colours, textures, crowds, waiting): _____

Things that help when I get anxious or upset:

Health care plans or protocols that I/my caregivers use (e.g., for bowels, seizures, crisis) – please attach a copy: _____

My doctor should have the following information/contacts:

Phone: _____ (e-mail): _____
 P/E like to add: _____

Adapted from New York State Department of Health, 07/2002 www.health.ny.gov/forms/072002.pdf

the Readiness Checklist and Toolkit

<h3 style="text-align: center;">Strengths</h3> <ul style="list-style-type: none"> • Provides a method of assessment of skills AND the tools to build the skills • Brief listing of 1-2 tools per skill • Tools are available and accessible (many online, free) • Many tools are designed specifically for the youth or adults with DD to complete themselves • Some tools are designed for caregivers of people with DD • Many tools are Canadian • Tools are evidence based or based on best clinical practice 	<h3 style="text-align: center;">Limitations</h3> <ul style="list-style-type: none"> • Very health oriented • Not exhaustive • Has not yet been evaluated in a primary health care setting
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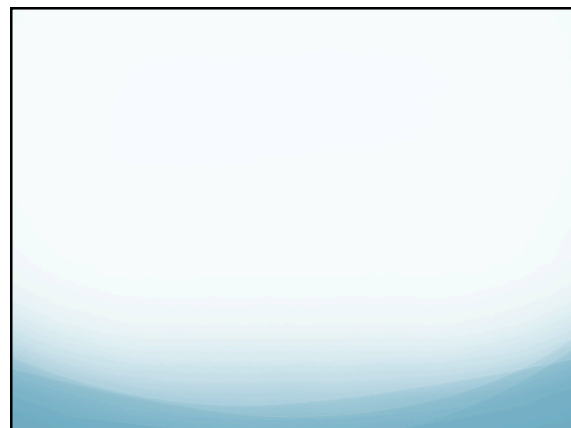
and Transition Toolkit Created by:

- Developmental Disabilities Primary Care Initiative (DDPCI) Transition Working Group
 - **Dr. Uilanda Niel**, Family physician practicing in developmental disabilities (mdtransition@gmail.com)
 - **Jessica Wood**, PhD student, Surrey Place Centre
 - **Maureen Kelly**, Nursing Surrey, Place Centre

Dr. William F. Sullivan, Family physician, clinical director and chair of DDPCI

Readiness Checklist and Toolkit are Available at:

- FMF website
- Surrey Place Website: www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- mdtransition@gmail.com



Other Examples of Tools

Suggested Sections for Family/Caregiver Health Care Binder

Health Issues and Diagnoses

- Portable Patient Profile
www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- My Health – 3-Sentence Summary
www.sickkids.ca/Good2Go/Transition-Interventions-Tools/Easy-interventions/32716-Three-Sentence%20Summary%20BOOKMARK%20format%20for%20website.pdf
- MyHealth 3-Sentence Summary with DD-specific examples
www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- Caregiver Health Assessment
www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- Medic-Alert information – www.medicalert.ca

and Procedures

- Genetic assessment
- Psychological assessment (needed for access to adult services in Ontario for people with DD)
- Functional assessments
- Copy of MRI or CT scan results, if ever done
- Copy of any blood tests and urine tests done in the past year, or the most recent, if none done in the past year
- Copy of reports of any X-rays or any other tests, procedures and assessments

Medications and Treatments

- Current medications person is taking (pharmacy can print)
- List of other medications taken in the past and why they were discontinued
- Background and supplies needed (name of form, address information, e.g., supplier's name and contact person, catalogue number, quantity, cost, forms to submit for reimbursement, if covered by health benefits)

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MyHealth 3-Sentence Summary

Sentences

Sentence 1: My age, diagnosis and brief medical history
Sentence 2: My treatment plan
Sentence 3: My questions/concerns to talk about during this visit

Examples

Introduction: Hi, My name is Alexander Smith.
Sentence 1: I am 16 years old. I have Down syndrome. I have had asthma since I was little.
Sentence 2: I have been taking Xanax and Elavital since I was three.
Sentence 3: I am here today because I can't run anymore. I adjust the mesh and can't breathe.
What I brought with me: Here is my Today's Visit form, a copy of my Portable Patient Profile, and all the current medication I take.

Introduction: Hi, My name is Maria Santos.
Sentence 1: I am 22 years old. I have epilepsy and a mild developmental disability.
Sentence 2: I take three medications (give doctor the bag with your medicines). I haven't had any seizures lately.
Sentence 3: I am here today because I am sleepy all the time. My mother worries if the medicines are making me sleepy.
What I brought with me: Here is my Today's Visit form, a copy of my Portable Patient Profile, and all the current medication I take.

Introduction: Hi, My name is Sandhu Singh.
Sentence 1: I am 19 years old. I have Fragile X syndrome.
Sentence 2: I haven't seen a doctor since I saw my pediatrician Dr. King two years ago.
Sentence 3: I am here today because I took a form filled out by a doctor for a program I want to go to.
What I brought with me: Here is my Today's Visit form, a copy of my Portable Patient Profile, and all the current medication I take.

Now it's your turn
What would be most important for you to tell any doctor or health care professional you are seeing?

Introduction: Hi, My name is _____
Sentence 1: I am _____ years old. I have (briefly name your diagnosis and/or health problem). _____
Sentence 2: I usually see my doctor every _____ months for _____ (if not, why you usually see your doctor) and take medication for _____
Sentence 3: I have a problem with _____ and that's why I'm here today.
What I brought with me: Here is my Today's Visit form, a copy of my Portable Patient Profile, and all the current medication I take.

Adapted for Persons with Developmental Disabilities from MyHealth 3-Sentence Summary
www.health.ny.gov/health_care/transportation_services/transportation_services/32116-1.htm
https://www.health.ny.gov/health_care/transportation_services/transportation_services/32116-1.htm

Transportation Scheduler

Completed by: _____ Date: _____

How will you get to your appointment?

Family/Friend Support Worker Taxi/WheelTrans*

When you are phoning the person who is driving you, have these things ready:

Phone number of the person who is driving you
 Name and address of the doctor
 Date and time of your appointment
 Your address and telephone number
 Calendar

When you phone the person who is driving you, say the following:

Hello, this is (say your name).
 I need a ride to get to my doctor's appointment on (say date and time).
 I am going to (give name and address of the doctor).
 I will need a ride back to (give your address).
 Can you do this? (If not, call _____).
 What time will you pick me up? (Write down the time).
 Who do I call if there is a problem? (Write down the phone number).
 * If you are taking a taxi or WheelTrans, don't forget to bring money to pay for the trip.

Mark on your calendar:

Location of doctor's appointment.
 Date and time for transportation pick up.
 Phone number to call if there is a problem.

Modified from www.HealthTransitionNY.org
 New York State Institute for Transition Training